

Ankle-Foot Orthoses for Young Children with Cerebral Palsy

by

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## **Abstract**

Cerebral palsy occurs due to brain injury during the fetal period or after birth resulting in movement and posture impairments that affect the individual's functional ability in daily life. Ankle Foot Orthoses are often prescribed, in combination with other interventions, for children with cerebral palsy before the age of six years to prevent gastrocnemius-soleus muscle shortening, tendo-achilles contracture, and improve walking performance. Despite routine use in clinical practice, there is a low level of evidence about how AFOs affect children's functional abilities and limited information about parents' experiences with early AFO use. Prescription practices would be informed by a more in-depth understanding of how parents experience their young children's AFO use so that clinicians can be more knowledgeable about the barriers and challenges faced by families.

This thesis aimed to provide evidence-based, family-centered clinical practice recommendations for prescribing and monitoring AFOs for young children with cerebral palsy. This objective was addressed in three separate studies: 1) a scoping review to describe research on outcomes associated with early AFO use, AFO use patterns, and parent and clinician perspectives on AFO use among young children with cerebral palsy, 2) a qualitative study to understand parent experience with AFO use by their young children, and 3) a Delphi study to develop core clinical considerations for AFO prescription and monitoring. Although improving participation outcomes is a primary goal of rehabilitation, the scoping review revealed that activity and participation outcomes are often ignored in pediatric orthotics research. In the second study, I interviewed parents of young children with cerebral palsy who used AFOs to explore their experiences with their children's early AFO use. Parents reflected on their challenges with the adjustment period to AFOs, the perceived stigma of using AFOs in public,

the perceived benefits of wearing AFOs, and the need to work collaboratively with clinicians to determine optimal AFO dosage and wear recommendations. The final study combined the data from the scoping review and qualitative study with an expanded search of the literature to integrate research, clinicians' views, and family perspectives into a consensus-based list of core considerations for AFO prescription and monitoring for young children with cerebral palsy. The core considerations for AFO (timing of initial prescription, selection of type and construction, communication with families, frequency and duration of use, outcomes associated with AFO use, and clinical team functioning) are intended to support clinicians in aligning their practices with the priorities of families to optimize AFO use.

## Preface

This dissertation is an original work completed by Pegah Firouzeh, under the supervision of Dr. Lesley Pritchard, Associate Professor at the Department of Physical Therapy, Faculty of Rehabilitation Medicine, College of Health Sciences, University of Alberta. I have received guidance from my supervisory committee, Drs. Patricia Manns, Christopher Morris, and Lyn Sonnenberg while completing this work.

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I was the primary researcher in this study and was involved in the design, data extraction, synthesis of the findings, and writing the manuscript. All co-authors were involved in the research design and reviewing the manuscript.

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I was also the primary researcher in the design, data collection, analysis, and writing the manuscript. All co-authors were involved in the research design and reviewing the data analysis and manuscript.

Chapter four will be revised for submission to a peer-reviewed journal. The manuscript will be co-authored with Drs. Lesley Pritchard, Christopher Morris, Lyn Sonneberg, and Patricia Manns. I designed the study, recruited participants, collected and analyzed the data, and wrote the manuscript with the guidance of co-authors.

The research projects in Chapters three and four received research ethics approval from the University of Alberta Health Research Ethics Board:

- Ankle Foot Orthoses for Young Children with Cerebral Palsy, Pro00095225
- Clinical Practice Considerations for AFO Prescription and Monitoring, Pro00111701

## **Dedication**

To Lucas

wishing you a happy childhood full of love

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## Table of Contents

<b>CHAPTER ONE: INTRODUCTION.....</b>	<b>1</b>
Cerebral Palsy .....	1
Epidemiology .....	3
Classification.....	4
Rehabilitation Interventions for Children with Cerebral Palsy.....	7
Ankle Foot Orthoses for Children with Cerebral Palsy .....	8
Effects of AFOs on Gait and Function.....	11
Controversies about AFO Use and Areas for Future Research.....	13
Problem Statement .....	16
Dissertation Purpose.....	17
Researcher Positionality.....	19
<b>CHAPTER TWO .....</b>	<b>33</b>
<b>Ankle Foot Orthoses for Young Children with Cerebral Palsy: A Scoping Review .....</b>	<b>33</b>
Introduction .....	36
Methods.....	37
Stage 1: identification of research questions .....	38
Stage 2: identification of relevant studies.....	38
Stage 3: study selection .....	38
Stage 4: charting the data.....	39
Stage 5: summarizing and reporting the results.....	40
Discussion .....	53
Limitation and Future Research Directions .....	57

Appendix A. Search strategy for Medline (Ovid) database .....	58
<b>CHAPTER THREE .....</b>	<b>65</b>
<b>Parent Experience with Ankle-Foot Orthoses for their Young Children with Cerebral Palsy: A Qualitative Study .....</b>	<b>65</b>
Introduction .....	68
Materials and Methods .....	69
Results .....	74
Discussion .....	83
Limitations .....	87
Conclusion.....	88
<b>CHAPTER FOUR.....</b>	<b>94</b>
<b>Clinical Practice Considerations for Ankle-Foot Orthosis Prescription and Monitoring in Young Children with Cerebral Palsy: A Delphi Study .....</b>	<b>94</b>
Introduction .....	95
Methods.....	96
Results.....	105
Discussion .....	129
Limitations .....	134
Conclusions .....	135
Appendix A. Search Strategy .....	137
Appendix B. Included Articles in the Literature Review.....	140
Appendix C. Results of Secondary Analysis of Interviews .....	152
Appendix D. Preliminary Delphi Items with Reference Coding .....	155
<b>CHAPTER FIVE: GENERAL DISCUSSION.....</b>	<b>165</b>
Clinical Implications .....	167
Implementation of Findings .....	171



Strengths & Limitations .....	174
Future Research Directions .....	175
Conclusions .....	176
<b>Bibliography .....</b>	<b>181</b>

## List of Tables

Table 2.1. Quantitative Study Description.....	42
Table 2.2. Qualitative Study Description.....	45
Table 2.3. Group Design Studies Conduct Rating Summary .....	47
Table 2.4. Single Subject Design Conduct Rating Summary .....	47
Table 2.5. Critical Appraisal Checklist for Qualitative Research.....	48
Table 2.6. ICF Classification of Outcome Measures .....	50
Table 3.1. Participants' Demographic Characteristics.....	71
Table 4.1. Items used in R1& R2 of the Delphi survey .....	107
Table 4.2. Participants' Demographic Characteristics.....	110
Table 4.3. New Items Suggested in Round 1 and Included in R2 .....	110
Table 4.4. Results of R1 & R2.....	113
Table 4.5. Ratification Meeting Results .....	125
Table 4.6. Final Core Clinical Considerations.....	127

## List of Figures

Figure 2.1. PRISMA Flow Chart .....	41
Figure 4.1. Example of an R2 Result Shared During the Ratification Meeting .....	103
Figure 4.2. Study Process.....	103
Figure 4.3. PRISMA Flowchart (Updated Scoping Review) .....	106
Figure 4.4. PRISMA Flowchart (Rapid Literature Review).....	107

## **Abbreviations**

**AACPDM:** American Academy for Cerebral Palsy and Developmental Medicine

**AFO:** Ankle Foot Orthosis

**AFOs:** Ankle Foot Orthoses

**BoNT:** botulinum toxin

**CFCS:** Communication Function Classification System

**CP:** Cerebral Palsy

**EDACS:** Eating and Drinking Ability Classification System

**EMG:** Electromyography

**FRAFOs:** Floor Reaction Ankle Foot Orthoses

**GMFCS:** Gross Motor Function Classification System

**GMFM:** Gross Motor Function Measure

**HAFOs:** Hinged Ankle Foot Orthoses

**ICF:** International Classification of Functioning, Disability, and Health

**IOS:** International Organization for Standardization

**JB:** Joanna Briggs Institute

**MACS:** Manual Ability Classification System

**PEDI:** Pediatric Evaluation of Disability Inventory

**PLS:** Posterior Leaf Spring

**PRISMA-ScR:** Preferred Reporting Items for Systematic Reviews and Meta-Analysis Extension for Scoping Reviews

**REDCap:** Research Electronic Data Capture

**SAFOs:** Solid Ankle Foot Orthoses

**SCPE:** Surveillance of Cerebral Palsy in Europe

**VFCS:** Visual Function Classification System

## CHAPTER ONE: INTRODUCTION

### Cerebral Palsy

The most frequently cited definition of cerebral palsy describes the condition as “a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior, by epilepsy, and by secondary musculoskeletal problems” (1). Damage or lesions to the central nervous system cause primary impairments, including muscle weakness (2), loss of selective motor control, and atypical muscle tone (1). Spasticity is described as velocity-dependent increased muscle tone resistant to passive stretch and is present in most children with cerebral palsy (3). Spasticity is one of the underlying causes of abnormal joint reaction forces in the developing child. Therefore, bony alignment during growth is affected, which leads to deformities, most commonly in the feet or hips (4). Atypical muscle growth is also observed in individuals with cerebral palsy. The neurologic and muscular pathophysiology in cerebral palsy causes increased muscle stiffness (5), decreased movement through a full joint range of motion, and poor selective motor control, leading to decreased movement frequency. As a result of all of these factors, muscles often undergo contracture (4, 6), resulting in decreased range of motion (7). Children with cerebral palsy also have reduced muscle strength (5), causing joint imbalances, mostly in the ankle and hip, impacting postural stability (8), gait, and other gross motor abilities (9). Postural stability is a prerequisite for maintaining balance in static and dynamic positions and contributes to motor performance (10). Lower postural stability has been observed in young children with cerebral

palsy (younger than 31 months) compared to older children (11), affecting gait and daily activities that require navigating and controlling body position in the desired direction. These secondary impairments, such as gait deviations (12, 13), decreased range of motion (13), musculotendinous contracture, and bone and joint deformities (12) are variable for each child.

Children with cerebral palsy also often experience reduced gross motor function and physical activity levels. Gross motor function refers to the ability to walk, run, and jump using large muscle groups (14). Children with cerebral palsy vary in their motor abilities, ranging from minor restrictions for higher-level motor skills, such as running and jumping, to requiring assistance with most movements (14, 15). Ambulatory children with cerebral palsy often present with reduced endurance in walking (16), leading to lower physical activity levels (17) compared to typically developing children of the same age.

All factors discussed above can interact with social and physical environments, resulting in participation restrictions (18). Participation is a multidimensional concept (19) and is defined as “involvement in life situations” (18), for example, social interaction, engagement in school activities and play in various environments for children (20). Participation in physical play is believed to be affected by the level of motor function ability, age, and gender (21). It has been reported that low physical activity levels in children with cerebral palsy affect their participation in home and communities (22). In addition, barriers to self-directed mobility, including environmental factors, significantly affect participation in children with cerebral palsy (23). Adapting activities or environments based on the needs of children with motor impairments likely enhances attendance and engagement in play and social participation.

## **Epidemiology**

Cerebral palsy is one of the most common childhood-onset physical disabilities (24), with a global prevalence rate of approximately 2.1 in 1000 live births (25). Epidemiological studies have reported that prenatal risk factors account for 75% of cerebral palsy diagnoses, while risk factors during the neonatal period contribute to 10% to 18% of cases (24). Premature birth, infertility treatment, hypoxia, multiple pregnancies and gestations (24, 26), infection (24, 27), and genetics (28) are a few of the many reported risk factors. While, traditionally, cerebral palsy was typically diagnosed between 12-24 months (29, 30) due to lack of accurate diagnostic tools, the possibility of early diagnosis has changed in recent years. A growing body of evidence supports diagnosis as early as six months of age through evaluation of child and family medical history and risk factors, standardized neurological examinations and imaging, and standardized motor assessments (31). Early diagnosis is crucial to accessing early intervention programs that have the potential to prevent or minimize the progression of primary and secondary impairments (1, 32).

Preventative treatments for known risk factors of cerebral palsy include, but are not restricted to, regular screening of fetal growth, management of infections during pregnancy, reduction of preterm birth, and prenatal administration of magnesium sulphate and corticosteroids (33). These treatments have decreased the prevalence in high-income countries (34, 35). However, there is still a higher prevalence in low and middle-income countries due to limited access to obstetric and prenatal intensive care (33).

## Classification

The clinical presentation of cerebral palsy is heterogeneous (24) and is primarily described using established classification systems. Classification systems allow for a common and systematic approach to documentation of changes throughout the lifespan (1). The original classification system developed by Balf & Ingram in 1955 (36) used muscle tone (spasticity, ataxia, dyskinesia, and mixed types), topographical distribution (diplegia, hemiplegia, quadriplegia, and triplegia), and severity (mild, moderate, and severe) to describe clinical presentation. Poor reliability of this classification has been reported due to the subjectivity of differentiating between the severity of motor impairments and the overlap between topographical categories. For example, what level of upper extremity involvement differentiates spastic diplegia from spastic quadriplegia? Therefore, more standardized descriptions and classification systems have been proposed and are now used routinely in clinical practice and research (37).

The Surveillance of Cerebral Palsy in Europe (SCPE) (38) recommended categorizing cerebral palsy based on the clinical presentation of motor (movement) pattern and posture using three groups, spastic (unilateral or bilateral spastic), dyskinetic (dystonic or choreathetotic), or ataxic. Spastic cerebral palsy, caused by white matter lesions, is the most common type (39) and is characterized by velocity-dependent, increased resistance to passive stretch (3), which may become more apparent over time (38). Dyskinetic cerebral palsy is caused by lesions to the basal ganglia and results in involuntary movement. In non-spastic cerebral palsy, muscle tone is increased during movement and decreases during sleep or rest. Ataxic cerebral palsy results in difficulties in balance and coordination due to damage to the cerebellum (38).



Although the classification proposed by SCPE has been widely used for capturing and registering data for surveillance (38), Rosenbaum and colleagues (1) recommended a more comprehensive approach to classification to capture the accompanying impairments and reduce variation in reporting. The authors suggested considering four dimensions when describing cerebral palsy: 1) the nature and typology of motor disorders and functional motor abilities; 2) accompanying impairments, such as sensory and musculoskeletal impairments and seizures; 3) anatomical distribution and neuroimaging findings; and 4) causation and timing of the injury (1). A comprehensive description that includes information on these four components overcomes the significant limitations of traditional classification, notably the lack of information on functional motor abilities.

The Gross Motor Function Classification System (GMFCS) (40) is the standard and universally understood classification system for functional motor abilities in children with cerebral palsy. The GMFCS has been used extensively in clinical practice and research as a valid and reliable tool to describe children's functional performance (41). The GMFCS includes five distinct levels. Differences between the levels vary between age groups and are based on children's gross motor abilities, preferred mobility methods, and their need for assistance to perform a task. For example, children between four to six years of age in level I are able to sit in a chair without hand support, walk independently, climb up and down the stairs, and have emerging running and jumping skills. Children in level II experience some difficulties with running, particularly on uneven surfaces, and use handrails to ascend and descend stairs. Children classified as GMFCS level III use mobility devices, such as walkers, and can independently sit and transfer to standing using a stable surface. Children in level IV use wheelchairs, have limited self-mobility, and move in and out of sitting positions with assistance.

Children in level V use wheelchairs for mobility and to support their trunk, head, and neck (40). Other functional classifications of cerebral palsy include the Manual Ability Classification System (MACS) (42), the Communication Function Classification System (CFCS) (43), the Eating and Drinking Ability Classification System (EDACS) (44), and the Visual Function Classification System (VFCS) (45). These classifications describe fine motor skills, communication, eating and drinking, and visual abilities, respectively. These classifications, along with the GMFCS, provide a comprehensive description of the functional abilities of an individual with cerebral palsy and can be used to predict developmental trajectories through adolescence (46, 47).

The definition of cerebral palsy proposed by Rosenbaum et al. (1) and their comprehensive approach to classification is compatible with the International Classification of Functioning, Disability, and Health (ICF) (18). The ICF is a conceptual biopsychosocial framework and describes functioning as the outcome of dynamic interactions between its components (body functions and structures, activity, and participation) and contextual (environmental and personal) factors (18). Body functions and structures indicate functioning from a physiological and anatomical perspective, respectively, while activity and participation indicate functioning from an individual and social perspective. Environmental factors address the physical, social, and attitudinal environment in which people live (18). The ICF describes disability as an outcome of an interaction between the individual with a health condition and environmental factors, indicating that human functioning is influenced by facilitators promoting an individual's activity and participation or barriers leading to restrictions and limitations (18). The ICF has been used in clinical practice and research universally as a framework to define human functioning (18).

## **Rehabilitation Interventions for Children with Cerebral Palsy**

The introduction of the ICF encouraged a shift from focusing on impairments to improving functional tasks, activities, and meaningful participation in different contexts of a person's life in pediatric rehabilitation (48). Interventions for children with cerebral palsy are multidimensional and variable, likely due to the heterogeneity of the condition, varying clinical presentation, and the diversity of the goals that children and families set with clinical teams. Collaborative goal-setting is a key principle of family-centered approaches in pediatric rehabilitation (49). Tailoring the intervention plans based on child and family preferences and values is a cornerstone of family-centered service as it aims to involve the child and family in treatment decision-making and enhance partnership with clinical teams (49). Applying family-centered care models in pediatric rehabilitation is associated with higher rates of child and family satisfaction and improved outcomes (50). Cerebral palsy is a lifelong condition, and therefore, management should be individualized according to the continuous changes in environments and child and family goals and values (51).

Standard lower extremity interventions for children with cerebral palsy depend on the child's GMFCS level and treatment goals (52). However, cerebral palsy management usually addresses spasticity, ankle range of motion, monitoring of hip integrity (53), functional motor abilities, and muscle weakness (13) to ultimately promote activity and participation while allowing for growth and development (53). Novak et al. (34) conducted a systematic review to evaluate the efficacy of interventions for managing cerebral palsy and suggested that using multiple treatment options to address a specific goal is optimal. Some of the evidence-based interventions that authors indicated to be effective include botulinum toxin (BoNT), intrathecal baclofen, diazepam, and selective dorsal rhizotomy for reducing muscle tone and spasticity;

bimanual training, constraint-induced movement therapy, goal-directed training, mobility and treadmill training, occupational therapy post botulinum toxin for improving functional abilities and task performance, casting for improving and maintaining ankle range of motion, and active strengthening and goal-directed training following casting to maintain joint range of motion.

### **Ankle Foot Orthoses for Children with Cerebral Palsy**

In addition to the interventions noted above, one of the most common interventions for children and young adolescents with cerebral palsy is the Ankle Foot Orthosis (AFO) (54), which was classified as a ‘probably effective’ intervention (34). AFOs are often custom-made from thermoplastic and are used to improve gait performance, control foot and ankle positioning and movement, maintain ankle range of motion, and enhance overall functioning (12, 55). Prescribing AFOs in conjunction with botulinum toxin injections has contributed to improved outcomes, including delaying the need for orthopedic surgery until the child is older (56). Orthotic prescription is an interdisciplinary approach that, ideally, should be conducted in collaboration with families (12, 57). Decision-making about orthotic design is based on physical examination of the child and their biomechanical and functional needs. Clinicians aim to ensure a balance between movement restriction to facilitate stability and support during standing and allowing for enough joint range of motion to facilitate walking and other functional mobility (12) with the aim of enhancing overall child function and development.

The International Organization for Standardization (IOS) defines an orthosis as an “externally applied device used to modify the structural and functional characteristics of the neuromuscular and skeletal systems” (58). Orthotic treatments are usually prescribed in combination with other interventions, such as physical therapy, oral medication, botulinum toxin,

or surgery to prevent deformities, provide a solid base of support, facilitate functional motor skills, and improve gait efficiency (59). Generally, the aim of orthotic treatment for ambulatory children is to improve gait and maintain ankle range of motion (GMFCS levels I-III). The objective of orthotic provision for children classified as GMFCS levels IV-V is to prevent contracture and improve or maintain an upright posture and weight bearing (60).

Ankle function plays a major role in walking, and interventions addressing ankle impairments in children with cerebral palsy affect their gait (61). Some of the gait characteristics in children with cerebral palsy include instability in stance, lack of clearance during swing phase, lack of heel strike during initial contact, short step length, and high energy consumption (12, 62). These attributes manifest variably depending on the type and severity of cerebral palsy. Four types of gait patterns have been introduced for children with unilateral cerebral palsy (63, 64). Type 1 and 2 represent a foot drop in the swing phase due to the weakness of ankle dorsiflexors. Type 2 is differentiated from Type 1 by the presence of ankle plantar flexor contracture, leading to ankle dorsiflexion restriction in the stance phase of gait. Type 3 includes contracture of knee flexors, which, in addition to the characteristics of type 2 gait, causes increased knee flexion in stance and delayed knee flexion during the swing phase. Type 4 presents the characteristics of all three types plus involvement of hips, requiring more complex management (63). Common gait patterns for children with bilateral cerebral palsy include true equinus, jump gait, apparent equinus, and crouch gait (65). It is reported that the prevalence of crouch gait increases with age, while equinus gait may decrease (66). Gait characteristics of children with cerebral palsy are multifactorial and occur due to primary and secondary impairments combined with the use of strategies to compensate for impairments (4). For example, children with spastic unilateral cerebral palsy present with drop foot due to weakness in ankle dorsiflexors, causing insufficient

clearance during the swing phase of gait. They usually initiate plantarflexion in stance early and longer on the non-affected side to compensate for this deviation, causing vaulting (62).

Therefore, interventions to maintain walking function are complex and include a combination of physical therapy, AFOs, spasticity management, and surgery (53). Different types of AFOs are prescribed clinically to address gait impairments in children with cerebral palsy by providing stability during stance and clearance in swing and allowing enough flexibility for push-off (12).

There are many AFOs available for clinicians to choose from, and terminology is inconsistent in the literature; therefore, only the most common pediatric AFOs for the cerebral palsy population are described here. Solid AFOs (SAFOs) are frequently prescribed to restrict motions in all planes, allowing correct foot positioning during the initial contact in gait and controlling equinus positioning of the foot in the swing phase (12, 62). SAFOs are mostly indicated for children with genu recurvatum, apparent equinus, and crouch gait patterns (67). Hinged AFOs (HAFOs) allow plantar and dorsiflexion at the ankle and adjustments can be made to control and restrict the amount of plantar flexion. Hinged AFOs allow for more ankle mobility and functional activities (e.g., transitional movements). Some children with cerebral palsy develop crouch gait using HAFOs, so they should be monitored carefully (12, 62). Floor Reaction AFOs (FRAFOs) control motion in the stance phase and are indicated for children with crouch gait (68) to help them to improve knee extension during walking and standing, which can decrease pain and improve walking function (69). Posterior Leaf Spring (PLS) orthosis, a one-piece plastic shell trimmed narrowly from the distal part of tibia to the proximal part of hind foot, restricts excessive plantar flexion during the swing phase of gait, accommodating more ankle dorsiflexion compared to the SAFO (68).

## **Effects of AFOs on Gait and Function**

There is some evidence suggesting that AFOs increase step length (54, 70-76) and walking speed (54, 71-74), decrease cadence (73-76) and optimize energy expenditure (74-77), all of which contribute to enhancing gait efficiency among children and young adolescents with cerebral palsy. Furthermore, AFOs enhance ankle dorsiflexion angle during both stance (progression of the body to forward) and swing (toe clearance) phases to optimize gait patterns (78). PLS and HAFOs are suggested to be effective for improving push-off in children with unilateral cerebral palsy, while SAFOs reduce peak power generation at push-off (73, 74). SAFOs effectively promote positioning of the ankle in the swing phase and initial contact, provide more stability during the stance phase, stabilize proximal joints, and facilitate hip and knee extension (67).

AFOs facilitate ankle positioning and greater knee flexion during the swing phase of gait in children with drop foot (67). Those with a genu recurvatum have shown improvement in ankle positioning during the swing phase using AFOs, and those with jump gait have presented with more efficient ankle kinematics in the stance phase of the gait (67). Children with crouch gait have demonstrated improved heel strike with AFOs (67). Those with the apparent equinus gait pattern have shown decreased knee flexion in the stance phase, reduced push-off power, and better ankle positioning during the swing phase using AFOs (67). A study evaluating the effects of SAFOs and FRAFOs did not identify a difference between the two types for decreasing knee flexion for crouch gait (79). The authors concluded that the effects of AFOs on gait were not due to AFO type but rather based on the ankle angle. That is, a more plantarflexed AFO predicted greater reduction of knee flexion during gait (79). Other determining factors identified in predicting the positive performance of AFOs during crouch gait were child-related and included

the level of dorsiflexion in stance, the amount of knee flexion contracture, age, and severity of crouch. Gait in older children and those with more severe contracture did not improve with AFOs as much as in younger children with less joint range of motion restrictions (79). Moreover, a cross-sectional study explored the effects of AFOs on maintaining or improving ankle dorsiflexion range of motion and reported that children across all GMFCS levels benefited from using AFOs to maintain or improve joint range of motion (80).

While some studies have not identified significant effects of AFOs on the gross motor skills of children and adolescents (54, 75, 76), a few systematic reviews have reported improvement of gross motor function assessed by the Gross Motor Function Measure (GMFM) (81), (73, 74) and the Pediatric Evaluation of Disability Inventory (PEDI) (82), (73). There are contradictory findings about the effects of AFOs on standing postural control, with some studies claiming no effects (73, 83) and a few studies with small sample sizes presenting improvements using FRAFOs (84) and HAFOs (85). The effects of AFOs on daily step counts and intensity have been studied previously, and no significant changes in the daily step counts or intensity with using AFOs were reported (86). Only one study has explored the experience of clinicians related to clinical aspects of AFO use (87), and very few studies have explored child or parent experience with AFO use. Since the majority of the current body of knowledge is derived from assessing AFOs in clinical and research settings, more research is required to highlight how children and families experience AFO use and how AFOs affect daily activities in different environments.

A substantial body of research is focused on AFO use in older children and young adolescents with cerebral palsy; therefore, there are gaps in the process of AFO provision and effectiveness for improving outcomes for young children (88). AFOs are usually prescribed



before the age of six years (80) when young children are in their developmental and growth phase (89). Therefore, it is important to ensure that AFOs do not interfere with joint motion necessary for optimal motor functioning at this age, such as floor mobility and transitioning from sitting to standing. Family perception affects adherence to AFO use (72), and therefore lack of consideration for their perspectives may ultimately adversely affect treatment outcomes. Since parents and caregivers are advocates for their young children, understanding their vision, values and experience related to AFO use could inform clinical practice about what is meaningful to families. Optimizing clinical practice requires consideration of the outcomes that matter most to children and families, as well as understanding how families make meaning of their experiences with AFOs. Hence, understanding family experiences would enable integration of child and family values with the current body of knowledge. Collaborative decision-making that values both clinical and parental perspectives would likely contribute to a family-centered approach in pediatric orthotics that aligns with family values, goals, and needs.

### **Controversies about AFO Use and Areas for Future Research**

Despite the positive reports of the effects of AFOs, there are some concerns that AFOs may negatively impact a child's functional abilities (90). For example, restricting ankle range of motion with AFOs may limit the ability of young children to move up and down from the floor independently (81). In community early childhood settings, it is possible that a reduction in floor mobility could result in decreased level of activity and participation in play. Therefore, promoting activity and meaningful participation must be considered when making recommendations about optimal AFO dosage. There have also been concerns about the use of AFOs related to potential for weakness of gastrocnemius and soleus muscles over the long term (91); however, evidence is insufficient to confirm or refute this claim. Furthermore, the efficacy

of AFOs for improving gait quality has been questioned. For example, Ries and colleagues (92) reported that only 37% of prescribed AFOs promoted gait quality in children with cerebral palsy. The same authors reported increased step length as the only outcome associated with AFO use for children (72). By contrast, a systematic review reported strong evidence of gait improvement in children with cerebral palsy using different types of AFOs, with HAFOs contributing significantly to gait speed in unilateral cerebral palsy (73). Another systematic review reported that stride length and gait speed were increased with SAFOs and HAFOs, with the effects of SAFO demonstrating a more significant effect on gait speed for children with bilateral cerebral palsy (74). The same authors suggested that PLS use is associated with increased gait speed for children with unilateral cerebral palsy, while children with bilateral cerebral palsy experienced increased stride length, cadence, and gait speed with FRAFO use (74). There are also controversies about the effects of AFOs on balance. A systematic review by Lintanf and colleagues (73) suggested small to moderate effects of different types of AFOs on balance. A randomized trial identified a significant improvement in balance following the use of individualized AFO and footwear combinations (93). The inconsistency in the findings of systematic reviews and randomized trials creates some challenges with the interpretation of the findings. The equivocal nature of the evidence is likely due to poor reporting of participant demographics, clinical presentation (i.e., type of gait and biomechanical characteristics), and AFO types, construction, materials, and designs (94). Low level of quality of the study designs also contributes to the equivocal nature of the body of evidence regarding the effectiveness of AFOs published in systematic reviews (74).

Although systematic reviews, meta-analyses, and randomized controlled trials are considered to be the gold standards for evaluating and summarizing evidence about the

effectiveness of interventions, it has been argued that using the mean of group studies to make decisions about the best interventions for an individual diagnosed with cerebral palsy may not provide the most useful evidence (95). Cerebral palsy is a heterogeneous condition with diverse clinical presentations. By relying on heterogeneous group studies, the effects of different AFOs for specific subgroups of children can be difficult to identify. With the advancement of personalized medicine, which focuses on a patient's biological characteristics, clinical history, and environmental factors in prescribing treatments, treatment plans have been shifting from the "one size fits all" concept to personalized care to address each patient's need and improve health outcomes based on their medical background and preferences (96, 97). Therefore, more rigorous research designs with homogenous groups of cerebral palsy as sample participants that decrease variability should be designed to enhance personalized medicine in research and practice (95). With the shift of care plans to empowering individuals' preferences and needs, researchers and clinicians should explore the benefits of AFOs and the optimal dosage, particularly with young children, to inform clinical practice by shifting the focus to personalized care.

Surprisingly, there are insufficient data from family and child perspectives on AFO use in home and community environments, causing more ambiguities about AFO provision for young children. Involving families in developing treatment plans may enhance quality of care since tailoring the interventions according to the young children and family preferences and needs is associated with family satisfactory service delivery, empowerment, and better treatment outcomes (49). The family-centered approach has been introduced as one of the most successful service delivery models in early intervention for children with disabilities (98). However, this approach may not be fully realized in pediatric orthotics. For example, although previous studies have focused on the importance of collaborative goal-setting for AFO provision (57, 87), goal-

setting tools are often not used with children with cerebral palsy in clinical practice related to orthotics (99). Child and family values and preferences could be incorporated into clinical decision-making to a greater extent by involving families in goal-setting for their young children's orthotics treatment plan.

## **Problem Statement**

Children with cerebral palsy experience motor impairments affecting their movement and posture, which may lead to activity limitations and participation restrictions (1). Meaningful activity and participation are considered to be the desired outcomes in rehabilitation disciplines (18) and are important to families and children with conditions such as cerebral palsy (100). Rehabilitation is focused on improving functional abilities and participation outcomes (101) with the recognition that every child has the right to participate in society and activities that are meaningful to them (102). AFOs may affect participation positively by increasing walking levels (103) or negatively due to social stigma (92), or by restricting functional movements that may affect the young child's ability to attend and engage in floor play. Clinicians and researchers are unlikely to fully grasp the extent to which AFOs influence young children's daily activities without involving their primary caregivers in research and practice to understand their experience. There is a gap between service delivery in rehabilitation services and what children and families value for their therapeutic treatment (104). This gap likely exists in pediatric orthotics due to scant literature on parent perspectives about orthotic devices, including AFOs (105). Parents and primary caregivers of children with cerebral palsy carry sources of information that are not available to healthcare professionals, such as experiences with service delivery (106). Therefore, engaging families in research and understanding their perspective on AFO use would inform clinical decision-making and could modify clinical views on

individualized intervention plans tailored to family values and child preferences. In addition, parents observe their children in home and community settings, while clinicians assess children briefly in clinical settings. The challenges and benefits of AFO use may not be evident to clinicians in short assessments, and family feedback provides valuable insight into their child's daily function with AFOs. Knowledge about parents' values, goals, and expectations related to AFOs would inform clinical decision-making about AFO prescription and monitoring practices.

Although AFOs are prescribed for young children with cerebral palsy, prescription and monitoring practices for young children with cerebral palsy are variable, and standardized practice guidelines and protocols are lacking (87). This lack of standardization leads to diverse and potentially less rigorous practices, which may impede clinicians from developing the required confidence in their decision-making about selecting the appropriate AFO type (87) and making AFO dosage recommendations. With the limited body of evidence for AFO prescription and monitoring practices for young children, clinical practice could be improved by synthesizing current evidence and integrating it with family experiences to ensure that clinical practice is more consistent and family-centered. Developing clinical considerations for AFO prescription and monitoring for young children with cerebral palsy that embeds the perspectives of families and clinicians would be a valuable contribution to clinical practice and a closer step to developing standardized clinical guidelines in pediatric orthotics.

## **Dissertation Purpose**

This thesis aims to generate evidence-based, family-centered clinical practice recommendations for prescribing and monitoring AFOs for young, ambulatory children (GMFCS levels I-III) with cerebral palsy aged 2-5 years. This research aims to incorporate the

existing clinical evidence and the experience of parents, clinicians, and researchers to identify critically important areas in research and practice related to AFO prescription and monitoring with young children with cerebral palsy. Three separate but interrelated studies were conducted to address the overarching aim:

### **Study 1**

A scoping review to describe research on outcomes associated with early AFO use, AFO use patterns, and parent and clinician perspectives on AFO use among young children with cerebral palsy.

### **Study 2**

A qualitative study to gain insight into parent experience with AFO use by their young children to inform prescription and monitoring practices.

### **Study 3**

A Delphi study to develop core clinical considerations for practice related to AFO prescription and monitoring for young children.

These studies are described separately in chapters two, three, and four. The thesis culminates in a final chapter that summarizes the findings and includes a discussion of the important implications for research and clinical practice in the field of pediatric orthotics. References are provided after each chapter, and a general bibliography for all chapters is provided in the final section of this dissertation.

## **Researcher Positionality**

I received professional training (BSc. Orthotics & Prosthetics) in Iran and worked as an orthotist for a few years. Throughout my graduate program, I became familiar with different research paradigms (i.e., quantitative, qualitative, and mixed-methods) and their epistemological views that influence the choice of methodology and interpretation of data. During my PhD training, I was not involved in clinical practice; however, my clinical background influenced research questions and likely affected the conclusion I drew from the findings of this research. Although I am the lead researcher for this thesis, multiple perspectives are guaranteed in this dissertation through the guidance of my supervisory committee. Their experiences in conducting pediatric research and clinical lenses have assisted me in developing research questions that are practical for clinicians and meaningful for families and children with cerebral palsy.

This thesis includes both qualitative and quantitative research paradigms. Qualitative research requires an active engagement of the researcher with participants, data collection, and analysis, while quantitative research takes a post-positivist approach with minimum researcher influence on the data (107). In Chapter 3, I used Interpretive Description as the methodological approach to reflect participants' voices and describe their experiences and perceptions of AFO use with their children to provide high-level interpretation meaningful in a clinical context through my clinical lens.

Each individual has unique characteristics based on their beliefs and perceptions, which affect and shape how they understand and experience the world (108). Reflexivity is described as “acknowledging the existence of researcher bias and explicitly locating the researcher within the research process. At a more active level, it involves a more wholesale embracing of subjectivity,

for example, by exploiting researcher's/co-researcher's reflective insights and by engaging in explicit, self-aware meta-analysis throughout the research process" (109). As a researcher with a clinical background, I need to acknowledge how my experiences and knowledge affected my engagement with this research. My clinical experience and the gaps I encountered as a clinician at an early career stage motivated me to develop this research project to enhance the foundational knowledge about AFO prescription and monitoring in young children with cerebral palsy.

I engaged in reflexive practices throughout my research in several different ways. My field notes that I completed during and after data collection in Chapter 3 helped me to reflect on my understanding of families' personal stories as a clinician and integrate them with the knowledge I received from families in this research. I remained aware of how I used my clinical lens in analyzing the data and interpreting the findings by using Interpretive Description, with its focus on clinical implications, to reflect on my clinical knowledge and experiences. I used peer debriefing during data collection and analysis with my multi-disciplinary supervisory committee, which challenged some of my assumptions, and encouraged further reflection about my positionality.

I believe in the importance of prioritizing the needs of families. By taking a family-oriented approach in conducting this thesis and using the ICF as the main conceptual framework, I aimed to focus on the gaps associated with AFO use in young children. Consistent with the ICF, I believe in the importance of studying functioning beyond the conventional way of "fixing impairments" and taking a more holistic approach across an individual's lifespan, considering their activity, participation, and the environments they engage in. By using ICF as the conceptual framework, I aimed to highlight the existing gaps in functioning associated with AFO use and emphasize the role of social and environmental factors affecting children's daily functioning and



how families perceive them. In Chapter 4, I took a pragmatic approach to synthesize different sources of information and triangulate data to develop considerations from the perspectives of different stakeholder groups. Through this thesis, I have tried to address underexplored areas of pediatric orthotics with the help of families, clinicians, and researchers to improve the process of AFO prescription and monitoring for young children with cerebral palsy.

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## **CHAPTER TWO**

### **Ankle Foot Orthoses for Young Children with Cerebral Palsy: A Scoping Review**

This study has been published as:

Firouzeh P, Sonnenberg LK, Morris C, Pritchard-Wiart L. Ankle foot orthoses for young children with cerebral palsy: a scoping review. *Disability and Rehabilitation*. 2021;43(5):726-38.

## **Abstract**

**Aim:** To describe research on outcomes associated with early Ankle Foot Orthosis (AFO) use, AFO use patterns, and parent and clinician perspectives on AFO use among young children with cerebral palsy.

**Method:** Arksey and O'Malley's five-stage method was used to conduct a scoping review. MEDLINE (Ovid), PubMed, CINAHL, Cochrane Database of Systematic Reviews, EMBASE, PEDro, Web of Science and Scopus were searched for studies evaluating AFO use with children under the age of six years. Descriptive information was extracted and outcomes were categorized according to the International Classification of Functioning, Disability, and Health (ICF). Quality assessments were conducted to evaluate methodological rigor.

**Results:** Nineteen articles were included in the review; 14 focused on body functions and structures, seven on activity level outcomes and no studies addressed participation outcomes. Evaluations of the effects of AFOs on gross motor skills other than gait were limited. Overall, the body of evidence is comprised of methodologically weak studies with common threats to validity, including inadequate descriptions of study protocols, AFO construction, and comparison interventions.

**Conclusion:** Research evaluating the effects of AFOs on age-appropriate, functional outcomes, including transitional movements, floor mobility, and participation in early childhood settings, is needed to inform practice regarding early orthotic prescription.

## **Implications for Rehabilitation**

- Lack of rigorous evidence about the effects of AFOs in young children limits the ability of research to guide practice in pediatric rehabilitation.
- More rigorous research that evaluates a broader range of age-appropriate outcomes, including those focused on participation in meaningful activities, could further inform clinical practice.
- While clinicians often discuss expectations and goals with individual families, qualitative research that provides more insight into the experiences of families could guide AFO prescription and monitoring practices.

## Introduction

Cerebral Palsy (CP) affects the development of movement and posture (1) and is characterized by primary impairments, including muscle tone abnormalities, muscle weakness, disturbed coordination, and decreased selective motor control, all of which can lead to secondary impairments such as muscle and joint contractures, bony deformities, and gait deviations (2). These impairments can cause activity limitations throughout the lifespan (1), and while CP is a non-progressive condition, secondary impairments can progress over time, resulting in significant changes to motor function. Healthcare professionals aim to enhance functional abilities and participation of individuals with CP through a variety of strategies, including some focused on the prevention of development of secondary impairments and optimizing efficiency of functional movement (3).

Ankle Foot Orthoses (4) are frequently used with children with CP to prevent musculoskeletal deformities and to provide support and stability during standing and walking (5). They are considered a mainstream treatment option and are often used in combination with other interventions to improve biomechanical alignment during gait. It is assumed that improved biomechanical alignment increases gait efficiency (6) and gait control (7-9). For example, children with CP often present with spasticity in the gastrocnemius-soleus muscles and AFOs are used to control equinus positioning of the foot by limiting excessive ankle plantarflexion during gait (6, 10). In addition to the biomechanical advantage of decreasing plantar flexion, AFOs may delay or prevent the alteration of the gastrocnemius musculotendinous unit architecture (11). Multiple studies have suggested other positive, gait-related, biomechanical effects of AFOs with older children (10, 12, 13), including increased stride length (10, 12, 14-17), velocity (8, 14-18), and reduced energy expenditure (18-20). The potential for adverse effects of long-term AFO use,



particularly those related to decreased gastrocnemius and soleus muscle strength have also been proposed (6). While gait-related outcomes associated with AFO use are important, the effects of AFOs on other gross motor skills, such as running, stair climbing, floor mobility (21), and participation in meaningful activities, also require evaluation. A broad consideration of outcomes is particularly important for young children since orthoses are often prescribed before the age of six years (11), when they may prevent joint motion necessary for floor mobility and transitioning between positions on and off the floor. Since many young children with CP are still developing their motor skills (22), any devices perceived by parents to adversely affect movement, cause skin irritation, disuse atrophy, or movement limitations may offset suggested advantages of AFOs (23). Therefore, in addition to understanding the effects of AFOs on outcomes, it is also imperative to have insight into the factors that influence AFO use in young children. Several reviews have addressed AFO use in children and youth with CP (7, 9, 13, 24, 25); however, none have focused on children under the age of six years. The overall aim of this scoping review was to describe the body of literature evaluating AFO use with young children with cerebral palsy.

## **Methods**

Arksey and O'Malley's five-stage process for scoping review studies (26) was used to conduct this review. While systematic reviews typically focus on articles with high levels of evidence and quality to determine evidence to support specific outcomes of interest (26), scoping reviews describe existing research literature and highlight evidence gaps, thus representing a better fit with the review objectives. Although quality appraisal is not discussed in the framework presented by Arksey and O'Malley (26), incorporating the quality analysis for scoping studies has been recommended as a strategy for identifying methodological gaps (27, 28). In keeping with these more recent recommendations, we also conducted a quality analysis to

describe the level of evidence and quality of existing research. We adhered to the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Extension for Scoping Reviews (PRISMA-ScR) reporting guidelines (29).

### **Stage 1: identification of research questions**

The three research questions were: 1) what outcomes associated with early AFO use in young children with cerebral palsy have been evaluated? 2) What research has been conducted to describe AFO use patterns in young children with cerebral palsy? 3) What studies have explored parent and clinician perspectives on AFO use among young children with cerebral palsy?

### **Stage 2: identification of relevant studies**

Search strategies were developed in collaboration with a medical librarian, using the keywords “cerebral palsy” and “ankle foot orthosis.” The following eight databases were searched for relevant articles published until March 2018: MEDLINE (Ovid), PubMed, CINAHL, Cochrane Database of Systematic Reviews, EMBASE, PEDro, Web of Science and Scopus using database-specific search queries. In addition, references in the selected articles were hand searched to ensure all relevant studies were identified. An example search strategy conducted in February 2018 is provided in Appendix A.

### **Stage 3: study selection**

Inclusion criteria were original studies written in English that described outcomes associated with AFO use, AFO use patterns, or family and clinician experiences with AFO use with children with cerebral palsy under six years of age. Studies with a portion of participants six years and older were included if data for children under six years of age were extractable (e.g.,

case studies), or if the sample included at least 50% of children younger than six years. Where it was not possible to determine the proportion of children under six years of age, studies with a mean age of less than six were included. Conference abstracts, reviews and study protocols were excluded but were used to search for additional, relevant articles. Studies that evaluated AFOs in conjunction with other rehabilitation interventions were also excluded. Study selection was conducted in two phases according to the protocol outlined by Arksey and O'Malley (26): 1) Titles and abstracts were reviewed and screened for relevance by one reviewer (PF). 2) Articles selected for full-text review were assessed independently by two reviewers (PF and LPW). The reviewers met to discuss discrepancies and to reach consensus on the articles to be included. The selection process is summarized in Figure 2.1.

#### **Stage 4: charting the data**

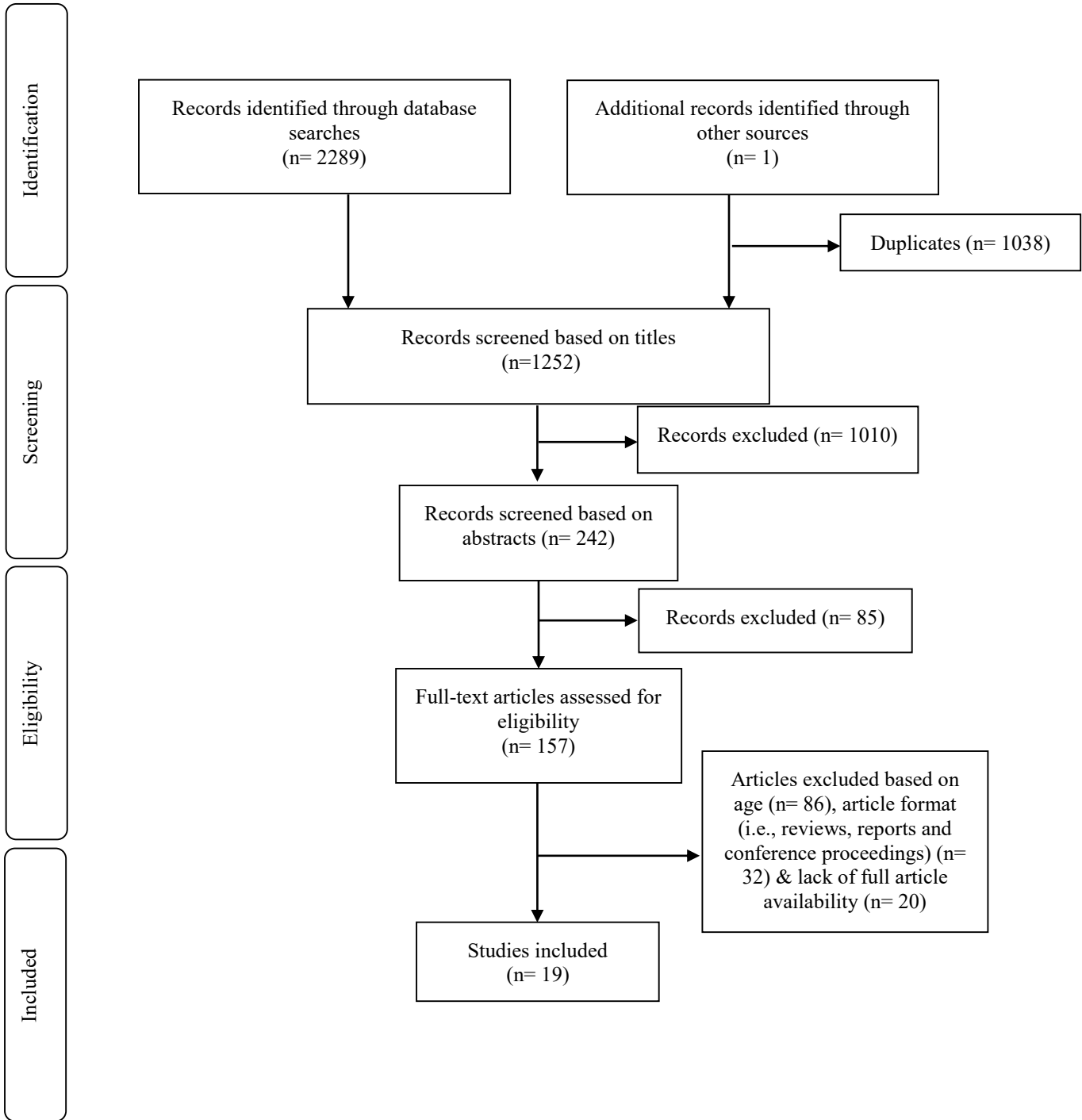
The authors developed a data charting form to facilitate documentation. The form was pilot tested by two reviewers (PF and LPW) and modified to ensure relevant information was included. Data from the studies were charted independently by the same two reviewers and then discussed for the purpose of reaching consensus. General descriptive information about the study, including authors, year and country of publication, study design, research objectives, participant information (i.e., age, CP sub-type, and Gross Motor Function Classification System (GMFCS) levels), interventions, and results were charted and tabulated. Outcomes evaluated were then classified using the conceptual framework of the International Classification of Functioning, Disability, and Health (ICF) (30). In order to consider methodological rigor of this body of research, level of evidence and quality of quantitative studies were assessed using the American Academy for Cerebral Palsy and Developmental Medicine (AACPD) methodology for systematic reviews study conduct rating tool (31). Consistent with the AACPD

methodology for systematic reviews, only group and single-subject design studies with a level of evidence I–III were considered for quality appraisal (31). The AACPDm group study conduct evaluation tool includes seven questions designed to detect threats to internal validity, including adherence to inclusion/exclusion criteria and group assignment, assessor’s awareness of group assignment and adequate control for confounding variables. Group studies are classified as strong with a score of six or seven, moderate with a score of four or five, and weak if the score is three or less. Single-subject design studies with a score of 11–14 out of 14 questions are considered strong, seven to ten as moderate, and less than seven as weak quality (31). Critical appraisal of qualitative research was conducted using the Joanna Briggs Institute (32) checklist for qualitative studies (32). This tool is a ten-item checklist intended to evaluate rigor with an emphasis on methodological cohesiveness. A score of ten indicates high quality. Independent raters (PF and LPW) completed ratings for all included studies and then met to compare responses and reach consensus. Discrepancies (n=2 levels of evidence) were resolved by a third rater (LS).

### **Stage 5: summarizing and reporting the results**

Results are provided in Table 2.1. The 19 included studies were published between 1986 and 2018; the number of publications remained relatively consistent over time. The largest proportion of studies (n=8) was authored by researchers in the USA (33-40), followed by the UK (n=2) (41, 42), Canada (n=2) (43, 44), China (n=2) (12, 45), South Korea (n=2) (46, 47), Egypt (n=1) (48), Iran (n=1) (49), and Belgium (n=1) (50) (Tables 2.1 and 2.2).

Figure 2.1. PRISMA Flow Chart



**Table 2.1. Quantitative Study Description**

<b>Author</b>	<b>Country</b>	<b>Participants*</b>	<b>Study Design, &amp; Level-Quality**</b>	<b>Aim/Purpose of Study</b>	<b>Intervention(s)</b>	<b>Key findings</b>
Bjornson et al. (2006) (33)	USA	n=23, 1 year 9 months - 7 years 3 months, spastic, GMFCS I (n=6), II (n=3) & III (n=14)	Randomized cross-over design, II- S (6/7)	To examine the immediate effect of bilateral dynamic AFOs on crawling, kneeling, standing, walking, running and jumping skills.	Dynamic AFOs	Dynamic AFOs improved gross motor skills in a clinical setting.
Bjornson et al. (2016) (34)	USA	n=11, 3 - 6 years old, bilateral CP, GMFCS I (n=1), II (n=9) & III (n=1)	Randomized cross-over design, II- M (4/7)	To examine the effects of AFOs on walking activity in the community	All participants wore prescribed orthoses (supramalleolar orthosis, non-articulated, hinged & solid AFOs) or no orthoses for two weeks in random order	AFO/footwear did not affect number steps/day, % time walking, number of strides/day >30 strides/min & peak activity index.
Butler et al. (1992) (41)	UK	n=6, 3 years 7 months - 6 years 5 months, hemiplegia (n=1), diplegia (n=5), GMFCS NR	Case series, IV	To examine the effects of adjusted, solid AFO use and balance training with children with CP	Solid AFOs with passive stretching of ankle dorsiflexion, balance training of 10-15 minutes for 4-6 months	Decreased magnitude of knee-extension moment arm toward normal occurred when barefoot. Improvement was noted for knee-extension moments, foot/ground contact and stance phase posture. Improvements were not related to range of motion or speed.
Carmick (1995) (35)	USA	n=1, 18 months, spastic diplegia, GMFCS NR; the participant was ambulatory	Case report, V	NR	Solid and then hinged AFOs with physical therapy once a week to increase ankle range of motion	Hinged AFOs allowed more ankle and forefoot mobility which led to biomechanical gait changes. They also were associated with improved balance, strong heel strike and less internal rotation of legs.
Carmick (2012) (36)	USA	n=4, Case 3: 4 years, spastic diplegia Case 4: 3 years 5 months, ataxia & hypotonia Both GMFCS III (Cases 1 & 2 excluded based on age)	Case report, V	To illustrate the importance of subtalar joint alignment during casting for an orthotic device.	Solid AFO & supramalleolar orthosis	Molding orthosis in a position other than the neutral position of the subtalar joint had detrimental impacts on lower limb joints alignment which contributed to gait deviation, pressure sores and inability to walk.

Carmick (2013) (37)	USA	n=3, Case 1: 4 years, spastic diplegia, GMFCS II Case 2: 6 years, spastic quadriplegia, GMFCS II Case 3: 4 years 11 months, spastic diplegia GMFCS III	Case report, V	To illustrate compensation strategies while wearing AFOs	Hinged AFO & supramalleolar orthosis with electrical stimulation	Internal hip rotation and toe walking occurred when orthoses blocked digit extension.
Dalvand et al. (2013) (49)	Iran	I: n=20, C: n=10, 4 - 8 years old, spastic diplegia, GMFCS I (n=12), II (n=13) & III (n=5)	Randomized controlled trial, II- W (2/7)	To examine the effects of hinged and solid AFOs on standing and walking abilities	NDT for 3 months (3, 1-hour sessions/week) with hinged or solid AFOs for the intervention groups and barefoot for the control group	Hinged AFOs improved standing and walking.
Desloovere et al. (2006) (50)	Belgium	I: n=15, 4 - 10 years, spastic hemiplegia, GMFCS NR C: n=51 (historical TD controls), 3 to 11 years	Case-control study, IV	To evaluate the effects of two types of orthoses on gait in a homogeneous group of children, using both barefoot and shoe walking as a control condition.	Posterior leaf spring & dual carbon fiber spring AFOs combined with shoes for the intervention group.	Both AFOs improved gait patterns; however, push-off at the ankle improved significantly with the carbon fiber spring AFO. Combination of both orthoses and shoes were necessary for improving spatiotemporal parameters of gait.
Embrey et al. (1990) (38)	USA	n=1, 2 years 8 months, spastic diplegia, GMFCS NR; the participant ambulated independently	Single subject design (A-B-A-BC-A), IV	To examine the effectiveness of inhibitive ankle-height orthoses used in conjunction with NDT and effectiveness of NDT in isolation to decrease excessive knee flexion during gait.	Bilateral inhibitive AFOs with NDT (30-minute session, 3 times per week for 3 months)	The use of NDT alone was more effective than the combination of NDT and AFOs. However, the combination had a more immediate effect on excessive knee flexion during gait.
Hainsworth et al. (1997) (42)	UK	n=12, 3 years 11 months - 7 years 5 months, spastic diplegia (n=8) & spastic hemiplegia (n=4), GMFCS NR; all children were ambulatory	Single subject design (ABAB), IV	To examine the effects of AFOs on walking patterns	Hinged & solid AFOs with routine physiotherapy	AFOs improved joint range of movement and gait (mediolateral shear force).
Harris & Riffle (1986) (39)	USA	n=1, 4 years 5 months, spastic quadriplegia, GMFCS NR; the participant could sit, knee-walk, pull-to-stand by half-kneeling over the right foot and stand	Single subject design (alternating treatment), I-M (9/14)	To examine the effects of inhibitive AFOs on independent standing	Inhibitive AFOs	AFOs improved the duration and maintenance of standing balance as well as standing pattern symmetry.

		independently for 10 seconds without orthoses				
Lam et al. (2005) (12)	China	I: n= 13, 3 years 3 months - 9 years 7 months, spastic diplegia with moderate dynamic equinus, GMFCS NR C: n=18 , age: NR	Case-control study, IV	To examine the effects of different orthotics on gait	Conventional (solid) & dynamic AFOs for the Intervention group. Control group was assessed barefoot	Both AFOs were associated with increased stride length, better control of equinus and limited plantarflexion at push-off. However, plantar flexion limitation at push-off was lesser with dynamic AFOs. Conventional AFOs reduced the median frequency of muscle firing, which may result in improved walking endurance. Ankle movement was less restricted with dynamic AFOs.
Middleton et al. (1988) (43)	Canada	n=1, 4 years 5 months, spastic diplegia, GMFCS NR	Case report, V	To evaluate the effects of rigid & hinged AFOs on gait by using quantitative biomechanical techniques.	Hinged & rigid AFOs	More natural ankle motion, lower knee moment during stance phase and enhanced lower limb symmetry occurred with hinged AFOs compared to rigid AFOs.
Olama et al. (2013) (48)	Egypt	I: n=15 Mean age (SD)= 4.8 years, spastic diplegia, GMFCS NR; all subjects could stand with support C: n= 15, Mean age (SD)= 4.4 years, spastic diplegia, GMFCS NR; all subjects could stand with support	Randomized controlled trial, II- W (3/7)	To evaluate the effects of three-side support AFOs on standing balance	Three-side support AFOs (30-min sessions, three times weekly, for 6 months) with therapeutic exercise for the intervention group. Control group received a therapeutic program only.	Practicing with three side support AFO for 6 months, had positive effects on balance control and postural reactions.
Park et al. (2004) (46)	South Korea	I: n=19, 2 - 6 years, spastic diplegia, GMFCS NR; all participants could stand up from a chair independently C: n=21 (historical TD controls), 3-5 years	Cohort study without a concurrent control group, IV	To investigate the effects of hinged AFOs on sit-to-stand transfers	Hinged AFOs	Hinged AFOs improved temporal, kinetic and kinematic parameters of sit-to-stand transfers.
Rha et al. (2010) (47)	South Korea	I: n=21 Mean age (SD)= 6.10 (1.09) years,	Cohort study with a concurrent	To compare postural stability and control mechanisms during quiet side by side standing	Hinged AFO for the intervention group. Control group was assessed barefoot.	Hinged AFO did not improve postural stability in quiet side-by-side standing. They were assisted with postural control.



		all with spastic bilateral CP, GMFCS I (n=4), II (n=13) & III (n=4) C: n= 22, Mean age (SD)= 5.64 years, TD controls	control group, III- M (5/7)	between typically developing children and bilateral CP and to determine if hinged AFOs have any effects on improving the postural stability and control mechanisms in children with CP		
Wilson et al. (1997) (40)	USA	I: n=15 2 -5 years, spastic diplegia with dynamic equinus, GMFCS NR; children could sit on a bench or stand up from a bench unsupported or by using a pole. C: n=20 age: NR	Case-control Study, IV	To evaluate the effects of solid and articulated AFOs on sit-to-stand.	Articulated AFOs in locked and unlocked positions (intervention group) compared to barefoot (control).	Articulated AFOs in the unlocked position improved control of equinus and efficiency of sit-to-stand transfers.
Zhao et al. (2013) (45)	China	Day group: n=56, Day-Night group: n=56, 13 months - 4 years, spastic diplegia, GMFCS I (n=48) & II (n=64)	Randomized controlled trial, I- M (5/7)	To compare day vs day and night wear of hinged AFOs	Hinged AFOs with conventional physiotherapy including NDT, hydrotherapy and NES for quadriceps 5 times/week.	No difference between groups

\***Participant:** number, age, groups; control & intervention, CP sub-type and GMFCS levels.

\*\*Strong (S) = a score of 6 or 7, Moderate (M) = a score of 4 or 5, Weak (W) = a score of ≤ 3

**Abbreviations:** I= Intervention group, C= Control group, GMFCS= Gross Motor Function Classification System, NR= Not Reported, AFO= Ankle Foot Orthoses, CP= Cerebral Palsy, NDT= Neuro Developmental Treatment, TD= Typically Developing, SD= Standard Deviation, NES= Neuromuscular Electrical Stimulation.

**Table 2.2. Qualitative Study Description**

Author	Methodology	Method	Phenomena of Interest	Setting	Participants	Data Analysis	Themes
Kane et al. (2018) (44)	Interpretive description	Semi-structured, in-person focus groups	AFO prescription and clinical decision-making practices of clinicians	Five rehabilitation centers in four Canadian provinces	Four physiatrists, 17 physiotherapists, 10 orthotists and one kinesiologist (experience ranging from 1-39 years)	Comparative analysis	AFO prescription is a collaborative, iterative and individualized process.

## **Study design, level of evidence, and quality assessment**

Of the 19 included articles, five were randomized controlled trials (33, 34, 45, 48, 49), including two randomized cross-over design studies (33, 34). In addition, there were three single-subject design studies (38, 39, 42), three case-control studies (12, 40, 50), four case reports (35-37, 43), two cohort studies; one with a concurrent control group (47) and one with a non-concurrent control group (47), and a case series (41). Only one qualitative study, an interpretive description, was identified and included (44). The AACPDm level of evidence and quality assessment ratings for group and single-subject design studies (31), are presented in Tables 2.1, 2.3, and 2.4. Of the 15 group design studies, one was level I (45), four were level II (33, 34, 48, 49), and one was level III (47). The remaining nine studies were identified as level IV (12, 40, 41, 46, 50) and V (35-37, 43). Of the three single-subject design studies, only one was level I (39), and the other two were classified as level IV (38, 42).

In our assessment of group studies, only the small randomized cross-over design study (Level II) received a strong score (33). Three studies were assessed as moderate (34, 45, 47), and two as weak quality (48, 49). The only eligible single-subject design for quality appraisal, the alternating treatment design, was determined to be of moderate quality (39). The one included qualitative study (44) received a score of eight out of 10 (Table 2.5). A description of interventions, outcomes evaluated, and key findings are presented according to the three study objectives below.

**Table 2.3. Group Design Studies Conduct Rating Summary**

Author	Study Design	Level/Quality*	Inclusion/Exclusion Criteria	Intervention Description	Reliable Outcome Measures	Blinded Assessors	Power Calculation	Dropout/Loss to Follow-up	Controlling Bias
Bjornson et al. (2006) (33)	Randomized Cross-Over Design	II- S (6/7)	Yes	Yes	Yes	Yes	No	Yes	Yes
Bjornson et al. (2016) (34)	Randomized Cross-Over Design	II- M (4/7)	Yes	Yes	Yes	No	No	Yes	No
Dalvand et al. (2013) (49)	Randomized Controlled Trial (small RCT, n <100)	II- W (2/7)	No	No	Yes	Yes	No	No	No
Olama et al. (2013) (48)	Randomized Controlled Trial (small RCT, n <100)	II- W (3/7)	No	Yes	Yes	No	No	No	Yes
Rha et al. (2010) (47)	Cohort Study with Concurrent Control Group	III- M (5/7)	Yes	Yes	Yes	No	No	Yes	Yes
Zhao et al. (2013) (45)	Randomized Controlled Trial (large RCT, n >100 )	I- M (5/7)	Yes	No	No	Yes	Yes	Yes	Yes

\*Strong (S) = a score of 6 or 7, Moderate (M) = a score of 4 or 5, Weak (W) = a score of ≤ 3.

**Table 2.4. Single Subject Design Conduct Rating Summary**

Author	Study Design	Level/Quality	Participants' characteristics	Independent Variable	Intervention Description	Dependent Variable	Inter/Intra-rater Reliability	Blinded Assessor	Stability of Data	Type of Single Subject Design	Adequate Number of Data Points > 3	Replication of Intervention across	Visual Analysis	Graph for Visual Analysis	Report of Statistical Analysis	Criteria for Statistical Analysis
Harris & Riffle (1986) (39)	Alternating Treatment Design	I-M (9/14)	Yes	No	No	Yes	Yes	No	Yes	Yes	No	Yes	Yes	No	No	Yes

\*Strong (S) = a score of 11-14, Moderate (M) = a score of 7-10, Weak (W) = a score of < 7.

**Table 2.5. Critical Appraisal Checklist for Qualitative Research**

Author	Congruity between philosophical perspective & research methodology	Congruity between research methodology & objectives	Congruity between research methodology & methods	Congruity between research methodology & data analysis	Congruity between research methodology & interpretation of results	Statement to locate the researcher culturally or theoretically	Influence of researcher on the research & vice-versa	Representation of participants & their voices	Evidence of ethical approval by an appropriate body	Flow of conclusions from the analysis or interpretation of the data
Kane et al. (2018) (44)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes

**Outcomes associated with AFO use**

Seventeen studies evaluated outcomes associated with AFO use. These outcomes are reviewed and summarized according to the ICF dimensions (Table 2.6).

**Body functions and structures:** Gait parameters including kinetics, kinematics, and gait patterns (n=8) (12, 35, 36, 38, 41-43), balance and stability (n=4) (39, 46-48), range of motion (n=8) (12, 35, 36, 38, 40, 42, 45, 50), and muscle activity with electromyography (EMG) (n=3) (12, 45, 50), were the outcomes evaluated in the ICF Body Functions and Structures dimension. Only three of these studies were identified as level I-III of evidence (39, 47, 48) and the quality of these studies ranged from weak (48) to moderate (39, 47). These three studies evaluated the effects of AFOs on standing balance (48), independent standing (39), postural

stability, and postural control mechanisms (47). Positive effects of AFOs on independent standing (39), standing balance (48), and postural control mechanisms were reported (47).

**Activity and participation:** Outcomes evaluated in the ICF Activity domain included gross motor function as measured by the Gross Motor Function Measure (51) (n=5) (33, 36, 37, 45, 49), active time walking (n=1) (34), and motor strategies for sit-to-stand transition (n=1) (40). One of these studies was level I (moderate quality) (45) and three were assessed as level II evidence, with quality ratings of weak (49), moderate (34), and strong (33). The study classified as level I evidence suggested daytime AFO resulted in greater changes to GMFM scores compared to day and night use. Two level II studies reported positive effects of AFOs on gross motor skills (crawling, kneeling, etc.) (33) and standing and walking abilities (49), while the authors of the moderate quality study did not report any improvement in community walking activity (34). No studies included evaluations of participation. Outcomes and outcome measures used in the included studies are classified by ICF dimensions and summarized in Table 2.6.

**Table 2.6. ICF Classification of Outcome Measures**

ICF Dimensions	Outcomes	Outcome Measures	Author(s)
Body Functions & Structures	Balance & Stability	Dynamic balance & biodex stability evaluation	Olama et al. (2013) (48)
		Pressure data, anteroposterior (AP) & mediolateral (ML) displacement, transverse body rotation strategies	Rha et al. (2010) (47)
		Duration of standing balance and independent standing	Harris & Riffle (1986) (39)
		Temporal, kinetic and kinematic data during sit-to-stand transfer	Park et al. (2004) (46)
	Gait Parameters	Gait kinematics and kinetics	Lam et al. (2005) (12), Embrey et al. (38), Butler et al. (1992) (41), Middleton et al. (1988) (43), Desloovere et al. (2006) (50)
		Gait pattern	Hainsworth et al. (1997)
		Gait description	Carmick (1995) (35), Carmick (2012) (36)
	Muscle Activity	Electromyography	Lam et al. (2005) (12), Zhao et al. (2013) (45), Desloovere et al. (2006) (50)
	Lower Extremities Range of Motion	Active ankle dorsiflexion	Lam et al. (2005) (12), Carmick (1995) (35), Desloovere et al. (2006) (50)
		Active knee flexion	Embrey et al. (38)
		Passive ankle dorsiflexion	Wilson et al. (1997) (40), Hainsworth et al. (1997) (42), Zhao et al. (2013) (45)
		Passive knee and hip range of motion	Wilson et al. (1997) (40)
		Active knee and hip range of motion	Lam et al. (2005) (12), Desloovere et al. (2006) (50)
		Anatomical description of lower extremities	Carmick (2012) (36)
	Activity	Gross Motor Function	GMFM-88
GMFM-66			Bjornson et al. (2006) (33), Carmick (2012) (36), Carmick (2013) (37), Zhao et al. (2013) (45)
Total daily steps & active walking time			Bjornson et al. (2016) (34)
Documentation of sit-to-stand strategies, sit-to-stand duration			Wilson et al. (1997) (40)
Participation	No studies that evaluated outcomes in the participation dimension were identified.		

**Abbreviation:** ICF= International Classification of Functioning, Disability & Health, GMFM= Gross Motor Function Measurement.

**AFO characteristics:** Six studies compared the effects of two different types of AFOs (12, 35, 40, 43, 49, 50). Three of these studies compared solid (rigid) with hinged AFOs (35, 43, 49). All three studies reported improvements in gait and standing with hinged AFOs. However, the methodological quality varied among these studies; one was a level II with weak quality (49), and the other two were level V (35, 43). Lam et al. (12) compared the effects of conventional (solid) and dynamic AFOs on gait and concluded that they have unique short-term effects; conventional (solid) AFOs increased the function of calf muscles and improved walking endurance, while dynamic AFOs caused less ankle restriction and better management of equinus positioning of the foot. Wilson et al. (40) evaluated articulated AFOs in locked and unlocked positions to determine the effect on sit-to-stand transfer time. The unlocked position decreased sit-to-stand time compared to the locked position (40). The study that compared the effects of posterior leaf spring and dual carbon fiber spring AFOs on gait patterns demonstrated a greater improvement of ankle push-off with the latter AFO type (50). However, all three studies were classified as level IV evidence (12, 40, 50).

Four studies compared the effects of different AFO types on walking activity in community-based settings (34), walking patterns (42), subtalar joint alignment during molding of AFOs (36), and compensatory gait strategies due to orthoses induced restrictions in joint movement (37). One of these studies was identified as level II (34) and three were classified as level IV and V evidence (36, 37, 42). While the studies with lower levels of evidence reported positive effects of supramalleolar orthoses (36, 37), hinged (37, 42) and solid AFOs (36, 42), the study classified as level II evidence did not find any difference in either walking activity level (number steps/day and proportion of time walking) or intensity (number of strides/day and peak activity index) between supramalleolar orthosis, non-articulated, hinged, and solid AFOs (34).

Seven articles focused on one type of AFO (33, 39, 41, 45-48), either dynamic (33), inhibitive (39), three-side support (48), solid (41) or hinged (45-47). These studies included evaluations of the effects of day vs. day-night use (45), sit-to-stand transfer time (46), and postural stability and control mechanisms (47) using hinged AFOs, and the effects of solid AFOs on gait (41). In addition, one study evaluated the effects of dynamic AFOs on gross motor skills (33), and the effects of inhibitive AFOs (39) or three-side support AFOs (48) on standing balance. Two of the seven studies were identified as level I (moderate quality) (39, 45), two as level II (one strong (33) and one weak quality (48)) and one study as level III evidence (moderate quality) (47). The remaining two studies were identified as level IV evidence (41, 46). All studies reported positive effects associated with AFO use.

One study (level IV evidence) evaluated the effect of Neurodevelopmental Treatment (NDT) in isolation and in combination with inhibitive AFOs (38). It was reported that NDT was more effective in isolation for decreasing knee flexion over time, but the combined method had better immediate effects on decreasing excessive knee flexion (38). However, since the study was a non-randomized single-subject design (low level of evidence) and was not replicated across more than one subject, inferences about effectiveness are limited. No long-term longitudinal studies were included in the review. A description of the AFOs evaluated in each study and key findings are presented in Table 2.1.

### **AFO use patterns in young children with CP**

Only one study addressed outcomes associated with AFO use patterns, a large RCT (level I, moderate quality) (45). Zhao et al. (45) examined the effects of day vs. day-night use of hinged AFOs among young children with CP on gross motor skills, muscle activation (EMG), and passive ankle range of motion. There was an improvement in range of motion and GMFDM scores



after using AFOs for both day and day-night groups, but there was no difference in range of motion between the two groups. Also, GMFM scores were higher for the day wear group compared to the night and day wear group (45). No studies describing actual AFO use patterns of young children were identified for inclusion in this review.

### **Parent and clinician experience with AFO use**

Only one study explored clinician experience with prescribing AFOs for children with CP. This qualitative study suggested that orthotic prescription is a dynamic process based on clinician assessment and collaboration of the rehabilitation team (44). No studies about parents' perspective and experience associated with their children's AFO use were identified.

### **Discussion**

This review confirmed a predominant focus on gait-related outcomes in research evaluating AFOs with young children with CP and revealed some gaps related to evaluating the effects on other age-appropriate gross motor skills. While a previous review suggested that wearing AFOs might create challenges for daily routines and floor mobility of young children who have less developed motor skills (21), the effects of AFOs on these outcomes have not been evaluated. Clinicians often recommend limiting AFO wear time to certain hours when children wear shoes. This strategy could overcome movement restrictions caused by AFOs that affect floor mobility when children are not wearing shoes. However, shoe removal may not be appropriate for some community settings, such as preschools and daycares. In addition, adherence to limiting AFO wear time when shoes are on might not be an ideal strategy for younger children who spend a significant amount of time on the floor. Thus, additional research is required to evaluate the effects of AFOs on a broader range of age-appropriate gross motor

skills and other meaningful outcomes, including activities specific to young children who use different movement strategies, such as crawling and bottom shuffling, to explore their environment. Furthermore, the effects of AFO-footwear combination tuning with younger children need to be evaluated. While one level IV study evaluated the effects of AFOs with shoes on/off in young children (50), none of the studies included evaluation of the effects of AFO-footwear combination tuning on functional outcomes with younger-age groups. The effects of optimal AFO-footwear combination tuning on participation outcomes also requires attention since the main reason for providing AFOs is to improve walking function so that children can participate in the activities that are meaningful to them (52). We conducted a quality appraisal to allow a description of the methodological quality of this body of literature. The level of evidence and quality evaluations revealed a weak evidence base, with few studies using rigorous research designs and strategies to avoid threats to validity. Absence of power calculation (33, 34, 47-49), unmasked assessors (34, 47, 48), lack of clear descriptions of interventions (45, 49), and inclusion/exclusion criteria (48, 49) were common sources of potential biases among the level I-III studies evaluated. This finding is consistent with systematic reviews on AFO use by older children (7, 25). While case studies can be valuable for highlighting novel approaches and previously unreported findings, lack of randomized, controlled trials or rigorous single-subject designs limits the ability to make inferences about effectiveness and inform practice. Single-subject and randomized, cross-over designs may be feasible in clinical settings as these designs allow for smaller sample sizes while still allowing for rigorous evaluations of the effects of AFOs.

This review also revealed a lack of standard terminology about AFO types, which makes comparison across studies challenging; a limitation identified in previous reviews (7, 21, 25, 53).

Ambiguity creates challenges with generalizability of the findings and valid comparisons across studies. Ridgewell et al. (13) suggested use of reporting guidelines for AFO interventions for children with CP, and emphasized the importance of reporting AFO design and material details to facilitate comparison of different types of AFOs and to facilitate study replication. Despite these recommendations, a recent literature review by Eddison et al. (53) confirmed that studies evaluating AFOs for children with CP still lack adequate descriptions of AFO construction. Adherence to reporting guidelines would provide consistency, facilitate comparison of findings across studies, and enable the conduct of meta-analyses. The small number of articles included in our scoping review also highlighted the lack of studies focused on AFO use in children under the age of six. Assessing the effects of AFOs in natural environments, such as child care and community settings, may be an effective way to expand the evaluation of outcomes with this group of children and families. Evaluation of children's functioning in their homes, schools, and communities would provide valuable contextual information relevant to participation; daily challenges that may not be apparent in controlled, clinical settings. While research with this younger age group can be more challenging (40, 54), the different position transitions, variety of mobility methods, and potential for unique parent's perspective on AFO use necessitate evaluations specific to this age group.

We identified only one study exploring clinicians' perspectives about AFO prescription for children with CP (44), and we found an absence of studies about parent experience. Kane et al. (44), aimed to identify underlying patterns associated with clinical AFO prescription. Collaboration of rehabilitation team members and evaluation of AFO outcomes were presented as influential factors in decision making in regard to AFO prescription. However, these factors could be affected by inexperienced individual clinicians, possibly resulting in children not

receiving the optimal orthoses type. This insight into clinical practice highlights the value of qualitative research that elucidates the subjective experiences of clinicians that affect how they approach AFO prescription and consultation with families. AFO use often declines after the age of five (11), and therefore, longitudinal research to explore use patterns and challenges associated with AFO use is also warranted. A qualitative study conducted with parents of children between 4–18 years (not included in this review) suggested that parents perceived dynamic AFOs had positive effects on posture and alignment and psycho-social factors such as participation in play and peer activities (55). Research exploring parent perspectives would also be valuable for informing clinical practice as parent and child experience with AFO use in daily life will likely affect how much and where they decide to use them. Qualitative research with parents has the potential to inform prescription guidelines for younger children, as setting meaningful goals for AFO use is an important consideration during the prescription process (24). Gaining insight into parents' perspective and experience may also assist with the development of family-centered guidelines for wear time recommendations, ideal age or stage of development for prescription, as well as providing the basis for discussion about the activities that may be affected by AFOs. Finally, there were no longitudinal studies included in our review. While we were likely to exclude those that evaluated older children or adults, this gap has been noted previously (9, 21). Longitudinal study designs would provide additional information about the long-term effects of AFO use, including possible contributions to muscle weakness, effects on the development of contractures, and associated long-term effects on activity and participation level outcomes.

## **Limitation and Future Research Directions**

Since we limited the search to children under six years, we may have excluded longitudinal studies that included some data for younger children. Findings of this scoping review highlight the need for more rigorous research evaluating the effects of AFOs on activity and participation level outcomes for children with CP. In particular, the evidence base would benefit from studies with more rigorous methodologies, more detailed information about AFO design and parallel interventions, and additional qualitative studies to explore the perspectives of parents regarding AFO prescription and use. A broader perspective on outcomes, in addition to evaluating the effects of AFOs on gait, would be beneficial. For example, studies with young children could include the effects of AFOs on floor mobility, transitional movements, and participation in age-appropriate play. Addressing these evidence gaps could inform evidence-based protocols for prescribing AFOs for young children with CP.

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## Declaration of Interest

The authors report no conflict of interest.

## Appendix A. Search strategy for Medline (Ovid) database

1. exp Foot Orthoses/
2. ((ankle-foot) adj2 (orthos\$ or orthotic\$ or brace\$ or splint\$ or support\$)).mp
3. ((ankle or foot) adj2 (orthos\$ or orthotic\$ or brace\$ or splint\$ or support\$)).mp
4. ((lower-limb\$) adj2 (orthos\$ or orthotic\$ or brace\$ or splint\$ or support\$)).mp.
5. ((lower extremity\$) adj2 (Orthos\$ or Orthotic\$ or Splint\$ or brace\$ or support\$))
6. exp Orthotic Devices/
7. exp Braces/
8. 6 OR 7
9. exp Ankle Joint/ or exp Ankle/
10. exp Foot/ or exp Foot Joints/
11. 9 OR 10
12. 8 AND 11
13. exp Lower Extremity/
14. 13 AND 8
15. 1 OR 2 OR 3 OR 4 OR 5 OR 12 OR 14
16. exp Cerebral Palsy/
17. (Cerebral Pals\$).mp.
18. 16 OR 17
19. 15 AND 18

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## **CHAPTER THREE**

### **Parent Experience with Ankle-Foot Orthoses for their Young Children with Cerebral Palsy: A Qualitative Study**

This study has been published as:

Firouzeh P, Morris C, Sonnenberg LK, Manns P, Pritchard L. Parent experience with ankle-foot orthoses for their young children with cerebral palsy: a qualitative study. *Disability and Rehabilitation*. 2023:1-8.

## **Abstract**

**Purpose:** This study explored the experiences of parents of young children with cerebral palsy who used Ankle-Foot Orthoses (AFOs).

**Materials/Methods:** Parents of children with cerebral palsy (n=11; age range 2-6 years) who used solid or hinged AFOs participated. Interpretive Description, a qualitative methodological approach focused on the application of findings to clinical practice, was used. Semi-structured interviews were conducted, and themes were developed using thematic analysis.

**Results:** Four themes described parent experience with their children's AFOs: 1) "Hear what I am saying": Collaborative decision-making with families, 2) "Is my child going to be excluded because of AFOs?": Parent and child adjustment was a journey, 3) AFOs created financial and practical challenges, 4) The perceived benefits of AFO use.

**Conclusions:** Adjusting to AFOs was a challenging and time-consuming process for parents and children, which may have resulted in lower frequency and duration of use than anticipated by clinicians. Clinicians must be aware of the physical and psychosocial adjustment process as children and families adapt over time and work with families to ensure AFO use is optimized and individualized.

## **Implications for Rehabilitation:**

- Clinical practice will be enhanced by understanding parent experience with their children's receipt and use of Ankle-Foot Orthoses (AFOs).
- Clinicians should work with families to establish and monitor individualized wear-time schedules that align with family routines.
- Information about AFOs, including appearance and alternative clothing requirements, should be provided to families in advance of receiving AFOs.

## Introduction

Ankle-Foot Orthoses (AFOs) are common interventions for children with cerebral palsy for improving gait quality, enhancing stability during standing and walking, maintaining ankle range of motion, preventing deformities (1, 2), and facilitating gross motor function (3). Currently, clinical decision-making about AFO prescription and monitoring practices is often driven by clinical assessments of muscle tone, joint range of motion, and gait pattern (4), all of which are classified as the Body Functions and Structures component of the International Classification of Functioning, Disability and Health (ICF) (5). It has been argued, however, that decisions about AFO prescription and monitoring should be a dynamic process focused on functional outcomes that requires perpetual evaluation by clinical teams and families to meet clinical and family goals (4, 6). Owen (7) suggested that AFO prescription and dosage should be driven by the desired goals for AFO use across all components of the ICF, including participation in activities that children find engaging. This perspective aligns with the shift toward promoting daily function, inclusion, and meaningful participation seen more broadly in pediatric rehabilitation (8).

Incorporating family goals in decision-making pertaining to AFO prescription is recommended to optimize treatment outcomes (4). Maximizing child involvement in the process by ensuring they have a voice in their treatment plans may further enhance their motivation to participate (9). Understanding how AFOs impact daily function, participation, and children's routines in their home and community settings will facilitate the alignment of clinical prescription and monitoring practices with parent and child goals. For example, while there are many reports of the positive effects of AFOs (2, 10), there are also some concerns that use of AFOs may limit floor mobility and transitional movements for young children, negatively



affecting their daily function (11). Furthermore, adherence to AFO use by older children may be influenced by the aesthetics of the orthotic device (12), child acceptance, and family perceptions of AFOs (13). Positive family experience with interventions is a key factor in successful AFO management for children (4); however, research exploring the experiences of families is limited (14). In addition, there is a dearth of research evaluating the effects of AFOs on participation for young children with cerebral palsy (14); research exploring parent experience may explain functional and participation-focused outcomes that are meaningful to families. This study aimed to gain insight into parent experience with AFO use by their young children with cerebral palsy to inform prescription and monitoring practices.

## **Materials and Methods**

### **Study Design**

Interpretive Description, a qualitative approach developed for gaining practical knowledge in applied health disciplines to inform clinical understanding of the phenomenon under study (15), was the methodological framework used for this study. Interpretive Description enables researchers to provide rich descriptions and high-level interpretations of participants' lived experience through a clinical lens (15). This study received ethics approval from the Health Research Ethics Board at the University of Alberta (Ethics ID: Pro00095225). All participants provided verbal consent at the beginning of the interviews. Identifying information was removed from the transcripts prior to extracting any of the quotes for inclusion in publications and presentations.

## **Participant Recruitment**

Invitations were distributed among clinician-researchers known to have interest in pediatric orthotics and rehabilitation across Canada to be shared with families of children with cerebral palsy and also via social media platforms. Parents and caregivers were eligible to participate if they spoke English and were parents/guardians or caregivers of a child with: 1) cerebral palsy, Gross Motor Function Classification System (GMFCS) (16) Level I-III, 2) aged 2-6 years, 3) who was currently using AFO(s) for at least one month, and 4) living in Canada.

Twenty-one parents indicated interest in participating in the study from June 2020 to April 2022. In total, six families were deemed ineligible because their child had a diagnosis other than cerebral palsy (n=1), they were older than six years of age (n=2), or they were classified as GMFCS level IV or V (n=3); four eligible families declined to participate in the interviews due to time constraints. Some of the children wore one AFO (n=4), and the others used them bilaterally.

Eleven parents (ten mothers and one father) participated in individual interviews. A follow-up interview was conducted with one of the parents to clarify some aspects of the first interview. Their children ranged in age from two to six years, and at the time of the interview, they had been wearing AFOs for at least four months. Additional participant information is provided in Table 3.1.

**Table 3.1. Participants' Demographic Characteristics**

Participant	Relationship to child	Child sex	Child age	GMFCS level	Distribution of CP	Type of AFO(s) used currently	Months since receipt of AFO(s)	Province
P1	M	m	5y	II	BL	Hinged	36	AB
P2	F	m	6y, 1m*	II	BL	Hinged	24	AB
P3	M	m	2y, 2m	III	BL	Solid	15	AB
P4	M	f	4y, 11m	I	UL	Hinged	41	AB
P5	M	m	4y	II	BL	Solid	24	NB
P6	M	m	5y, 9m	I	BL	Hinged	4	ON
P7	M	m	3y, 5m	III	BL	Solid	17	AB
P8	M	f	2y, 3m	II	UL	Solid	4	AB
P9	M	m	2y, 9m	I	UL	Hinged	12	ON
P10	M	m	5y, 6m	III	BL	Solid	48	AB
P11	M	m	3y	I	UL	Solid	18	SK

M= mother; F= father; m=male; f= female; y=years; m\*= month(s); BL= bilateral; UL= unilateral; AB= Alberta; NB= New Brunswick; ON= Ontario; SK= Saskatchewan.

## Data Collection

Interviewing enables researchers to co-construct knowledge by giving voice to participants as they explain the subjective meaning they ascribe to their experiences (17). The initial interview topic guide was pilot tested with a parent of a child with cerebral palsy to verify question clarity and alignment with the study objective. Minor modifications were made to the guide after the pilot interview. Individual interviews (45-60 minutes) were conducted by the first author (PF) using a semi-structured guide (box 3.1) and the automated transcription feature of Zoom (San Jose, CA: Zoom Video Communications Inc.) (18). At the beginning of the interviews, the interviewer informed families that she solely focused on research at the time of conducting this study and although trained as an orthotist, she was not currently actively involved in clinical practice. Thus, families were reassured that the interview was

a safe space for communication to share their experiences and insights. Questions were designed to explore parent experience and perception of AFO use, including the benefits and challenges and the process of adjusting to AFOs. A follow-up interview was conducted when more in-depth information was required from the interviewee.

**Box 3.1. Interview Guide**

1. Can you tell me about what it was like when (child) received his/her AFOs?
2. What was it like when (child) first started wearing the AFOs? At the time, how did you feel about (child) using AFOs?
3. Is there anything that would have been helpful to know before your child received AFOs?
4. What were your expectations for AFOs for (child)?
5. You mentioned that you hoped the AFOs would (their expectations). Did that happen? Please explain.
6. What are the negatives associated with using AFOs, if any?
7. What are the positives associated with using AFOs, if any?
8. Are there any activities that your child finds more difficult because of the AFOs? Please explain.
9. Are there any activities that your child finds easier because of the AFOs? Please explain.
10. What was the recommended wear time for AFO use (i.e., hours per day and types of activities)? Did your child wear the AFOs (insert recommended parameters)? If not, why?
11. How did you feel about the recommendation to wear the AFOs (insert recommended parameters)?
12. If parents mentioned that their child experienced challenges: You mentioned that your child (insert any descriptions of barriers to AFO use). What do you think was going on when your child responded this way? How did you feel about it?
13. If there was a discrepancy between actual and recommended wear time: What is it like for you when there is a difference between the wear time expectations from clinicians and your reality?
14. How do you feel about giving your child breaks from AFOs?
15. What would be helpful in regard to wear time recommendations from clinicians?

**Data Analysis**

Following each interview, the first author compared the recordings and Zoom-generated transcripts and edited discrepancies. The six-step inductive thematic analysis process described by Braun and Clark (19) was used to analyze the data. Comments were used to identify relevant text and assign codes within Microsoft Word: Two researchers (PF and LP) 1) familiarized themselves with the data, 2) identified codes in the transcripts independently, and 3) developed themes. The researchers then discussed their coding and preliminary themes to further refine them, ensuring they were aligned with the aim of this study (Step 4). Researchers discussed the

higher-level concepts within each theme, collaboratively defined the themes, and generated short descriptions (Step 5). Finally, themes were expanded and edited during manuscript preparation, and relevant quotes from participants were extracted to substantiate the themes (Step 6).

## **Rigor**

Strategies described by Sally Thorne to enhance credibility, such as epistemological integrity, appropriate sampling, and providing a thick description of the data were used to inform study design and data collection, analysis, and reporting (15). In addition, verification strategies described by Morse et al. (20), including methodological coherence and collecting and analyzing data iteratively, were also used to enhance study rigor. Methodological coherence (20) was ensured by aligning the research aim and the study methods with the methodological framework, Interpretive Description. Purposive sampling (15) was used to recruit participants who had experience as parents or primary caregivers of children who wore AFOs and who were willing to share their experiences. To engage with the data and ensure that data collection and analysis was conducted iteratively (20), data were analyzed after each data collection session, and the interview guide was modified as needed to ensure exploration of relevant aspects of parent experience.

In addition to the strategies outlined above, peer debriefing (21) was used to enhance the credibility of interpretation of the data. The multi-disciplinary research team was knowledgeable about cerebral palsy, clinical interventions for children with neurodevelopmental conditions, and qualitative methodology. All co-authors reviewed the study protocol and, after the analysis, reviewed the themes and description and the results to assist with the interpretation of data from their various disciplinary perspectives. The researchers primarily involved in the analysis (PF & LP) had clinical experience as an orthotist and a pediatric physical therapist, respectively. While

the first author was mindful of her perspective, personal beliefs, and clinical experience during the interviews, peer debriefing encouraged the author to become more aware of how her own perspectives affected the collection and interpretation of data and ensured a focus on participant's voice with the aim to inform clinical practice. Therefore, the first author attempted to create knowledge that was reflective of the study participants' voice and experience rather than imposing her beliefs about the topic. Reflexivity was facilitated through discussions throughout data collection and analysis and by acknowledging how previous clinical and research experience affected engagement with data and interpretation of the results in clinical practice. In addition, the author remained focused on the issues that mattered to families and then interpreted them through a clinical practice lens. This process contributed to ensuring epistemological integrity, an important element of rigor in Interpretive Description research (15).

## **Results**

The analysis resulted in four themes that described parent experience and perception of young children's AFO use: 1) "Hear what I am saying": Collaborative decision-making with families, 2) "Is my child going to be excluded because of AFOs?": Parent and child adjustment was a journey, 3) AFOs created financial and practical challenges, and 4) The perceived benefits of AFO use. The themes are described in more detail below.

### ***1. "Hear what I am saying": Collaborative decision-making with families.***

While each parent described a unique journey toward accepting AFOs as part of their daily routine, they often perceived that AFOs were uncomfortable for their children and that they needed time and more breaks in their wear-time schedule to adjust to AFOs. One parent was

concerned about her child's mental health as the parent perceived AFO use as another therapy that required dedication and effort:

“I think it's important for him [child], and for all of us, to not only stay physically healthy but also mentally healthy ... to have the recreation time to let his body and his mind rest ... instead of constantly having therapy.” (P7)

To facilitate adjustment to AFOs, parents believed that clinical teams should recognize and consider children's tolerance of AFOs when making wear-time schedule recommendations as “it's a whole kid, it's not just an ankle that we are treating.” (P8). Some parents discussed a discrepancy the AFO dosage recommended by clinicians, which was variable among study participants, and the feasible wear time in their children's daily routines. Although parents valued clinicians' opinions and attempted to follow their recommendations, they perceived instructions “wear AFOs full-time” or “as much as possible” as vague and disconnected from their children's tolerance and abilities. For example, one parent described her experience with her child wearing AFOs for the recommended amount of time:

“... It's easy for them [clinicians] to say that –‘wear it all the time, just do it’... But they're not the ones that have to deal with it [AFO], and have to fight with it ... I do listen to the doctors. We do put them on as much as we can, but they don't have to see him in pain ....” (P1)

The discrepancy between the prescribed AFO dosage and actual wear time became a source of shame, guilt, and internal struggle for some parents. A parent of a 3-year-old child described her experience with her child's lack of tolerance for wearing AFOs for the recommended time:

“... we should be doing it, why can't we do it ... which is, you know, like guilty and shameful, but at the same time, I'm trying to be sympathetic too - he's a little boy.” (P7)

Another parent who described her child as having a cognitive impairment stated that she was unable to explain the reason for wearing AFOs to her child. She also experienced internal conflict between putting the AFOs on her child, as directed, and observing her pain:

“It's hard to explain [to the child], this [AFO] is for your benefit ... because our daughter is delayed ... and there's a lot of guilt with it. Even now, when we put it on, it hurts ... you don't want your kids to hurt, and you don't want to be the cause of the pain either, right?” (P8)

Some parents questioned their parenting skills because of their inability to keep AFOs on their child for the recommended amount of time and assumed they were to blame for adverse outcomes associated with not wearing the AFOs. For example, a mother of a three-year-old boy described her fear about risking her child's future: “If he doesn't wear them [AFOs] now, his legs will be messed up forever. He's never going to walk” (P7). Parents acknowledged that working toward a collaborative and supportive relationship with their clinical teams so that adjustment strategies and barriers to AFO use can be discussed is essential for optimizing AFO outcomes:

“I think kid's clinical success is really dependent on how effectively you [clinicians] can partner with parents.” (P6)

Parents perceived that an individualized schedule that gradually increased daily AFO wear time was necessary to facilitate adjustment to AFOs. A parent of a 4-year-old child (P5) described how reassurance from the clinical team that allowed for some flexibility in the wear



schedule would have been helpful in adapting to AFOs: "... it was good to know by this date he should be wearing them [AFOs] all the time, but also kind of let you know that there is going to be a transition period, and it kind of does depend on the kid and their personality." Another parent emphasized the need for professional input into optimizing dosage for the AFOs: "I wanted to hear how long they [clinical team] wanted us to wear it, and then we figured it out within our lifestyle" (P3).

Parents recognized that there was a need for enhanced and open communication between families and clinical teams, as it was not always convenient for families to share their observations and experiences about AFO use with the team. Some parents found approaching the clinical team to discuss AFO modifications or changes in the wear-time schedule challenging and sometimes felt that they were questioning clinicians' recommendations:

"... it is that part that how do I question without telling you [clinicians] that I think you are wrong, right? So there is that challenge that I have got to balance there ... that uncomfortableness of having some of these conversations ...." (P8)

Most families did not have general knowledge about AFOs to prepare children for AFO use. Therefore, lack of knowledge emerged as a barrier to communicating effectively with their children and led to inaccurate assumptions about AFOs: "I didn't realize that it was something that you wear all the time." (P7). Parents believed that with adequate and reliable information to explain the purpose of wearing AFOs to their children, they would be more successful in convincing children to wear them:

"I think providers really need to highlight the benefits of an AFO, what the overall goal of an AFO is, and what it is helping to prevent as children develop ... so that they can

have that [information] in their toolkit when they [parents] are trying to explain to a toddler and, like in a topic-friendly manner.” (P11)

Receipt of contradictory opinions about AFO use and wear-time recommendations from different clinicians was confusing for families:

“I think the biggest challenge that we face is just going from one provider to the next, one will say this is really beneficial and the next person say ... ‘I can’t believe you have her [wear] AFO because don’t you know how much muscle weakness that is going to cause her.’ So we’re kind of constantly thrown between those two mindsets.” (P4)

Conflicting opinions from the clinical team forced some families to independently decide about wear-time routines. For example, a mother of a 2-year-old boy (P9) described, “... because we got different opinions, we just kind of have used our judgment.” While parents articulated many challenges related to their children’s AFO use, they identified collaborative decision-making as a practical approach to mitigating these challenges.

## ***2. “Is my child going to be excluded because of AFOs?”: Parent and child adjustment was a journey.***

Parents were fearful of the perceived stigma associated with wearing AFOs, which resulted in an initial resistance to AFO use. The internalization of social pressure to look “normal” made the process of accepting AFOs overwhelming for some parents. Initially, some parents expressed embarrassment when people saw their children wearing AFOs:

“[I feel] embarrassed, and I don’t want them [people] to judge him or see that there’s something wrong with him for having them [AFOs] ....” (P10)

“... so there is some embarrassment, unfortunately, or some fear that people are going to think that we’ve hurt her, and we worry about that ...” (P8)

Parents were also concerned about their children looking different from their peers and the potential exclusion that could result from this difference. A parent of a 5-year-old boy (P6) described how she felt a “shock” because she was not ready to see her child in AFOs: “... I knew when you look at a kid like that [with AFOs], one of the first things that you register is...that they have a deficit of some kind.” One parent explained that her husband assumed that AFOs would inhibit their child’s participation because the child would be excluded from group activities by his peers:

“... he [dad] doesn’t want people to treat him [child] differently because ... he doesn’t want people to say, oh you’re wearing AFO, so maybe it’s not safe for you to play the sport with us ....” (P9)

The participants acknowledged that their concerns about stigma and the effects of others’ perceptions on their child’s participation and inclusion appeared to be primarily a parental struggle; their children were accepted in communities and were included in group activities by their peers. As one parent described, “three and four-year-olds are such sponges” (P3). Some parents also focused on how they could impact society by viewing parental advocacy about cerebral palsy and AFOs as an opportunity to enhance awareness about children’s use of assistive devices and normalize differences:

“I want her to grow up in a society where she’s accepted, even though she’s going to be different, right? We know she’s going to need help, we know she’s going to be different, but I don’t want her to be judged negatively for something that’s not her fault.” (P8)

The perceived stigma shifted over time once parents recognized the positive outcomes associated with AFO use. The parent of a 3-year-old boy (P7) explained that the journey of accepting and dealing with AFOs was challenging due to the discomfort accompanied by using AFOs, the effort required to adapt to AFO use, and the need to adhere to the recommended number of hours. However, she felt positive about the process when she reflected on how much the child and family had achieved:

“You think about where he was at, like a year and a half ago, or whenever he got them [AFOs], it was a struggle, it was tough to get through, and now I’m happy and proud of him ....” (P7).

Parents described the path to AFO acceptance and adjustment as a symbol of success, as they overcame the difficulties of the journey and adapted to the new device. However, this success was not achieved easily and required patience and practice:

“... it is kind of like a demonstration of something that he’s really worked on with his body, that he’s proud of. I think as much as they [AFOs] are pain and they are in place as a result of a deficit, they are also like a symbol of success, that he went through a really painful procedure.” (P6)

### ***3. AFOs created financial and practical challenges.***

Parents experienced similar challenges with AFO use, regardless of where they lived. Although the majority of AFO costs are publicly funded in Canada, the cost-share portion was unexpected for some families. They had to manage their finances accordingly and ensure that they had appropriate insurance coverage.

“... it was figuring out where we were going to find the money. Because that is an extra expense on top of us that we have to come up with every year, we have to pay an expense for AFOs ... we have to pay a \$500 deductible every year. So now we have it figured out. We budget for it. But that first round was kind of like, oh crap.” (P3)

Parents expressed challenges in finding footwear and clothes that fit AFOs. They were concerned about finding good quality footwear within their budget, and their children often needed two different pairs for use with and without AFOs:

“... because the AFOs make his foot two times bigger. So the shoes that he has is two times bigger. So if you just put the shoes on, then they are huge shoes; he is tripping everywhere. So we have to buy another pair of shoes, so it gets a little expensive.” (P1)

As children outgrow their clothes and footwear frequently, this imposes costs for adapted clothing and shoes. Parents believed that some practical challenges, including their lack of knowledge about where to buy suitable footwear and pants, types, and brands of footwear, could have been mitigated by suggestions from the clinical team:

“I think like a couple of well-chosen blogs and some better pamphlets, a little bit of like peer support availability, would go a huge way. So the feelings were like incredible frustration on the day that I basically had to carry him around a shopping mall, to find socks, I was definitely near tears.” (P6)

Some families expressed difficulties in keeping the AFOs on when their children learned how to take them off. For example, a parent (P8) described that “she [child] learned how to rip the straps ... so we usually put a sock over it, we also use medical tape ..., and it’s bought us some extra time to keep it on her foot longer.” Parents perceived that their children were often

uncomfortable in their AFOs, particularly in warmer temperatures. Furthermore, wearing long socks and running shoes was inconvenient for them during warm weather. Some children were able to vocalize their concerns about wearing AFOs; however, in the absence of redness or skin issues, parents felt it was unnecessary to remove them:

“... I do find that more stressful having him vocalize that he doesn't want to wear his brace, but there is no redness when we assess his foot, so we know it is not hurting him; it is just more, I think, an independent seeking sort of thing for him right now. And that we just say it helps your foot, and you have to wear it, that's the end of the story, so that one is a very solid non-negotiable ....” (P11)

#### ***4. The perceived benefits of AFO use.***

Parents perceived that AFOs provided stability, improved their children's gait pattern and daily function, and played an important role in building their confidence and willingness to try new activities. As such, children were physically active for a longer period of time during play when wearing AFOs. For example, the parent of a four-year-old boy (P5) mentioned that “it has given him enough support that he is able to try things, and his confidence has kind of built from there.” Parents believed that children felt safer and more secure when wearing AFOs because of the increased stability and improved balance:

“... he was falling so much, he was getting a little bit scared of running, so that was a worry for me. So, I would say the AFO was definitely helping with that because he has no fear of anything now ... the first time he wore it [AFO], he was like, 'I'm so excited, I'm having so much fun,' it was really nice to see ... the tripping is gone, and he can still run like, he can keep up with other kids of his age.” (P9)

Parents recognized that children explored more activities while using AFOs, and they were able to keep up with peers more easily.

## **Discussion**

The families in this qualitative study reported several perceived benefits of AFO use, such as improved gait pattern, balance, and stability, which have been evaluated and reported in previous studies (22-26). However, some of the positive outcomes reported by the parents in this study were beyond the Body Functions and Structures outcomes typically evaluated in young children (14). For example, parents noted increased child confidence and motivation to try new activities, such as running, which is consistent with a previous study (27). Naslund et al. (27) reported that parents of children (4-18 years of age) who used dynamic AFOs experienced improved security and safety, which resulted in increased confidence in some daily activities, such as riding a bike. Confidence and motivation are two important precursors to outcomes that could affect children's participation in multiple environments and are rarely evaluated. The ICF defines participation as involvement in a life situation at a social level (5). Future research could explore how AFOs affect confidence, motivation, and participation. Research evaluating participation as an outcome is limited (14), and the parent focus on participation outcomes in this study suggests that research needs to expand beyond evaluation of outcomes in the Body Functions and Structures component of the ICF. Participation in situations that are enjoyable for children is an important facilitator of child development (28). Therefore, studying if and how AFOs promote children's engagement in situations that are meaningful to them would make an important contribution to the existing literature.

The parents in this study expressed that they deviated from recommended AFO usage parameters because they did not align with family routines, priorities, and their children's tolerance of AFOs. Schwarze et al. (29) reported a significant difference between the recommended dosage of AFO use and the measured wear time among young AFO users, emphasizing a misalignment between clinical expectations and the realities of families. The authors also identified a difference in children's AFO use between weekdays and weekends, which may be attributed to environmental factors and children's engagement in different activities at home and school (29). Optimal wear time and schedules should be individualized to meet child and family goals and routines and incorporate family perceptions about feasibility (30). Establishing wear-time routines that consider family goals, the clinical objectives of AFO provision, child tolerance, functional mobility, and activity engagement is also more likely to optimize AFO use. Kane et al. (4) highlighted the importance of individualized AFO prescription in collaboration with families to ensure families are partners in decision-making. This approach to AFO prescription and monitoring may increase the likelihood that families feel comfortable discussing any challenges they may experience with AFO use. Collaborative planning with families, a cornerstone of family-centered care, is associated with a higher rate of user satisfaction (31). Collaborative, goal-focused planning is also warranted since there are currently no consistent, evidence-based guidelines on optimal AFO wear time (29), and optimal dosage may be variable, depending on the goals of AFO use. Current practice is largely based on a study conducted by Tardieu et al. (32) in 1988 that recommended wearing AFOs for a minimum of 6 hours a day to prevent contracture of the gastrocnemius musculotendinous unit. Future research should explore optimal AFO use parameters that are aligned with outcomes that are meaningful to children and families. Parents in our study expressed that optimal adjustment to AFO use



required an initial low dosage that could be increased over time, emphasizing the importance of incorporating parent and child input and experience into the development of wear-time schedules.

Clinical expectations about AFO use that misalign with the capacity of families to adhere to them may result in parental stress and guilt. Parents assigned self-blame for not being able to follow the wear-time expectations, which was sometimes interpreted as bad parenting. This experience may be related to a recent diagnosis of cerebral palsy, which may have initial adverse effects on the well-being of families (33). Although disability is widely considered to be a social construct resulting from the existing gap between family and child needs and resources, services, and supports (33), families may struggle with the diagnosis and feel unsure about their child's future (34). It is important for clinical teams to recognize that individual beliefs about disability and cultural values and views on disability may shape parents' experience and initial willingness to use AFOs or any other visible assistive device in public settings.

Conflicting advice from members of multi-disciplinary clinical teams created challenges for some of the families of this study. Parents noted that they often identified inconsistencies in the information provided by different clinical team members, which they found confusing. Clinical teams should make efforts to communicate regularly with each other (35) and deliver comprehensive and consistent information, working as an interdisciplinary team, to implement and practice effective interactions with families. Use of a key contact for families may also be an effective strategy to improve communication. Families indicated that they often had more regular contact with certain clinicians, often physical therapists, allowing for a more comfortable environment for open discussion and problem-solving.

Parents struggled with the perceived stigma that they believed AFOs would have effects on the inclusion of their children. Parrette and Scherer (36) reported an association between using assistive devices and stigma. Stigma stems from the social symbolism of assistive devices representing incapability and exclusion (37), which some parents highlighted in their interviews. Parents' perspectives shifted as they observed improvements in their children's function when using AFOs, and most parents reported that their concerns about exclusion were not realized as their children did not experience social isolation at daycare/school and in communities. Clinicians should be aware that perceived stigma may initially affect parents' willingness to use AFOs in their communities, and parents may require additional time to adjust. Clinician awareness of family concerns in this regard will facilitate individualized treatment plans that consider family readiness and acceptance of assistive devices. Despite the extensive research on the benefits of using orthoses continuously to maintain biomechanical properties (38), it is crucial to consider how the aesthetics of devices influence children and families and what it means to them personally (37) when discussing the AFO use plans. Clinician understanding of parental concerns and practical implications of AFO use with young children on an individual and societal level may lead to improved alignment of clinical expectations and actual AFO use.

Successful use of an assistive device requires education and guidance to users about the mechanism, clinical objectives of use, dosage, and associated short and long-term goals set collaboratively by clinicians and families (7, 35). In this study, families expressed they had little to no knowledge of what AFOs would look like prior to receiving them, how they would limit their choice of footwear and clothes, the expected dosage of wear time, and the role of AFOs in children's functioning when the device was introduced to them. Similar findings were reported by Zaino et al. (35), who studied the experiences of AFO users with cerebral palsy and their

caregivers in the United States and reported a knowledge gap among users about AFO provision, such as the rationale for prescribing a specific type of AFO. Their findings also emphasized the importance of educating families about AFOs to address their challenges and concerns, a perspective also supported by other research (38). Clinical teams can assist parents with navigating practical challenges, such as providing advice regarding clothing/footwear brands that have worked for other families or financial resources to support extraordinary expenses. Also, a written individualized document with details about the AFO hygiene and maintenance, types of footwear and adapted clothing, wear-time instructions, and eligible activities with AFOs could be useful for families. Clearly, ensuring good AFO fit and parental knowledge of how to monitor skin integrity would also facilitate children's adjustment to the device.

This study highlighted the perceived benefits of AFO use in multiple environments from parents' perspectives, challenges with AFO adjustment that were exacerbated by expectations from clinical teams regarding high frequency and duration of wear time, and parental concerns about stigma that could potentially affect children's inclusion. Future research should focus on the contribution of factors, including cultural values and views about orthotic devices and associated psychosocial concerns in shaping children and families' adjustment to AFO use in public settings. Also, engaging young children in future research studies to address their voices about orthotic devices would provide more insight into practicing collaborative decision-making with families and children about AFO provision and monitoring.

## **Limitations**

One limitation of this study was that we did not collect information about family ethnicity and socio-economic status, which could influence families' access to resources and shape their

perception of AFO use by their children. Also, we only received responses from families in four provinces of Canada; therefore, voices of parents from other provinces were not included. Only one father participated in the interviews, and including more fathers may have affected the results. Furthermore, children used different types of AFOs for variable amounts of time, which may have affected parent experience.

## **Conclusion**

This study explored parents' experiences of their young children with cerebral palsy using AFOs and provided insight into family challenges and experience. Parents observe their children in home, school, and community environments and have insights that might not be evident during short clinical visits. The findings of this study suggest that interactions with families related to AFO prescription and monitoring may be improved with increased collaborative decision-making with families and the development of individualized AFO use plans that consider family context. Insight into parents' values, goals, and preferences related to AFOs for their young children may contribute to the development of treatment plans that support families' goals and priorities.

Parent perception of AFOs affects children's adherence to AFO use and acceptability of the device. The influence of psychosocial factors associated with AFO use in children and families was prominent in this study, and clinicians should be mindful of psychosocial factors that may affect AFO wear time. Ensuring open communication with families that acknowledges their individual contexts is important for the development of effective therapeutic relationships.

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## **Declaration of Interest**

The authors report there are no competing interests to declare.

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## **CHAPTER FOUR**

### **Clinical Practice Considerations for Ankle-Foot Orthosis Prescription and Monitoring in Young Children with Cerebral Palsy: A Delphi Study**

## **Introduction**

Ankle Foot Orthoses (AFO) are used clinically in combination with physical therapy, botulinum toxin, or surgery in the physical management of children with cerebral palsy (1). They are often prescribed before six years of age to improve gait patterns (2) and functional mobility and to maintain ankle range of motion (3). These goals are achieved by facilitating foot positioning on initial contact, stability and forward progression of the body during stance, and toe clearance in the swing phase of gait (4, 5).

Despite the widespread clinical use of AFOs for children with cerebral palsy, evidence to support their efficacy in home and communities is limited, and prescription and monitoring guidelines for use are lacking (6). A paucity of rigorous research on the effectiveness of AFOs with young children and insight into family and child experience with AFO use has hindered the development of standardized AFO prescription guidelines (7). As a result, clinicians base AFO prescription and monitoring decisions primarily on the presence of gait impairments, gastrocnemius and soleus spasticity, their clinical knowledge of different types of AFOs, and accepted practices in their institutions (6). Also, by considering assessments of ankle range of motion, muscle tone, and gait pattern as determining factors for timing of AFO prescription and selection of the AFO type (8), clinical practice decision-making is largely based on factors described as body functions and structures component of the International Classification of Functioning, Disability and Health (ICF) (9). However, it has been suggested that decision-making about AFO provision should also consider the ability of AFOs to affect activities and participation (10). A broader perspective beyond gait-related outcomes is needed in clinical practice and research to improve understanding of the effects of AFOs for younger ages in their home and community environments (7). Recent research suggests that taking a family-centered

approach in decision-making about AFO prescription, such as incorporating family values and goals in adjusting the dosage, may promote treatment outcomes for young children (11).

A synthesis of the existing body of knowledge regarding best practices related to AFO prescription and monitoring that incorporates family and clinical perspectives is needed to guide clinical practice. Development of evidence-based, family-centered considerations for AFO prescription and monitoring and identification of a core set of outcomes for evaluating AFOs would enhance clinical practice. Family input into the process of identifying clinical practice considerations is key due to their role as primary support for their children and depth of insight into their children's needs. Consensus on core considerations for AFO prescription and monitoring from parents' and clinicians' perspectives could mitigate some of the uncertainties with AFO clinical decision-making and ensure a focus on enhancing child and family satisfaction, successful use, and positive outcomes. The aim of this study was to develop consensus-based clinical practice considerations for AFO prescription and monitoring for young children with ambulatory cerebral palsy, aged 2-5 years, Gross Motor Function Classification System (GMFCS) (12) levels I-III.

## **Methods**

### **Study Design**

The Delphi technique is an iterative and efficient method of establishing consensus among experts (13, 14), particularly when there is a lack of definitive evidence (15, 16). The Delphi technique was, therefore, appropriate for developing clinical practice considerations because of the lack of evidence and guidelines that embed family experience with AFO use. The Delphi technique in this study was informed by Sinha et al. (13) and Williamson et al. (14):

involving clinical experts and patients (families in this study), incorporating open-ended questions, minimizing attrition by receiving confirmation from potential panelists for participating in the survey in advance and setting consensus criteria before initiating the survey rounds. Four steps were used to conduct the Delphi survey study: 1) survey development, 2) survey administration (two rounds), 3) ratification of the results with a sub-group of panelists in an online meeting, and 4) finalization of core clinical considerations.

### **Ethics Approval**

This study received approval from the Health Research Ethics Board at the University of Alberta (Ethics ID: Pro00111701). All participants were informed that submission of the responses implied their consent to participate.

### **Survey Development**

Three sources of information were used to identify candidate clinical considerations for the first survey for prescribing and monitoring AFOs for young children with cerebral palsy: a scoping review, a literature review, and a qualitative study. All three sources are described below.

***Scoping review:*** We conducted a scoping review in 2019 to summarize the outcomes evaluated in studies on the effects of AFOs on young children with cerebral palsy, AFO use patterns, and clinician and parent experiences with early AFO use among young children (2-5 years old) with cerebral palsy (7). The search was updated in June 2021 to identify any recently published literature and extract relevant information. Key findings from this review were used as the basis for candidate Delphi survey items.

**Literature review:** Rapid reviews are simplified and less structured forms of knowledge synthesis compared to systematic or scoping reviews (17). A rapid pragmatic review aimed to expand on the scoping review to include studies that would not meet the scoping review inclusion criteria, specifically AFO prescription guidelines and studies exploring clinician or family experiences with AFO use with children older than six years of age. Studies were included if they were full-text articles that 1) addressed clinicians' or families' experiences with prescribing and monitoring AFOs for children with neurodevelopmental conditions up to 18 years of age and 2) included protocols or guidelines for prescribing and monitoring AFOs. The search was conducted in four databases, Medline (Ovid), CINAHL (EBSCOhost), Scopus, and EMBASE (Ovid), with the assistance of a medical librarian in the Faculty of Rehabilitation Medicine, University of Alberta, in July 2021 (Appendix. A). The search was limited to English publications from 2000 to 2021, and studies were excluded if they evaluated AFOs in children or young adolescents with progressive conditions. One researcher (PF) screened the abstracts and selected the studies based on the inclusion criteria for full-text review. After a full-text review and extracting relevant information, two researchers (PF & LP) analyzed the extracted data and used the data as the basis for developing candidate Delphi survey items.

**Qualitative study:** Our original qualitative study, described elsewhere (11), explored parent experience with their young children's AFO use. This study was the primary source of information for parent experience in the survey development as no other studies explored parent experience with AFO use in young children with cerebral palsy (7). We conducted a secondary analysis of those qualitative data to specifically identify challenges with AFOs described by parents, family expectations of service delivery, and meaningful and functional outcomes

associated with AFO use. Relevant information was extracted and added to the preliminary data in the Word document.

**Data Aggregation:** Data from all three sources were synthesized, similar items were aggregated, and relevant, meaningful considerations were created as the draft survey items. Two researchers (PF & LP) developed general themes related to the items of the survey in agreement with the objective of the study inductively, which were used as section headings of the survey. Items were organized into seven sections: timing of initial AFO prescription, selection of AFO type and AFO construction, communication with families, frequency and duration of AFO use, AFO monitoring, outcomes associated with AFO use, and clinical team functioning. Each item was referenced to the extraction source (scoping review, qualitative study, or literature review) to provide an audit trail when moving items between sections iteratively while indexing the sources of information. This step ensured items were meaningful in the clinical context and compatible with the scope of each section. The draft of the survey was reviewed by all co-authors and edited accordingly.

**Rating Scale:** A 9-point scale (from 1 to 9) was used as a scoring system as follows: ratings of 1-3 indicated “less important” and should not be included in the core clinical considerations, ratings of 4-6 indicated “important but not critical,” and may be included in the core clinical considerations, and ratings 7-9 indicated “critical,” and should be included in the core clinical considerations. The option of “unable to comment” was added to the rating scale to provide flexibility to those who felt they did not have enough expertise or background knowledge about the item and to waive their opinion about the level of importance of considerations.

**Consensus Criteria:** The definition of consensus described by Williamson et al. 2012 (18) was used in the Delphi study. That is, if 70% or more of participants in all three stakeholder groups scored critical (7-9) and less than 15% scored less important (1-3), we considered there to be consensus for including the item in the core clinical considerations. If 70% or more of the participants scored less important (1-3), and only 15% or less in all three groups considered the item critical, there was a consensus that the item would be excluded. Any other percentage indicated a lack of consensus on an item for inclusion (18) and was considered for rerating in R2.

**Pilot Survey:** The draft survey was inserted into Research Electronic Data Capture (REDCap) (19, 20). The survey was first tested with the co-authors and then with a small group of stakeholders, including three clinicians (an orthotist, a physical therapist, and a physiatry resident) and two parents of children with cerebral palsy using cognitive interviewing (21). The first author conducted individual interviews over Zoom (San Jose, CA: Zoom Video Communications Inc.) (22) with the pilot panelists, so they could rate the importance of the items while thinking out loud and sharing their perception of the items within each section. This technique provided the authors with the respondents' instant feedback on language, clarity, and cohesiveness, as well as their perspectives about the appropriateness of the items within each section of the survey. The interviews were recorded to give the authors the opportunity to review the feedback received if needed. Interview transcripts and responses to the survey items were used as data. The data were analyzed after each cognitive interview, and the first author (PF) extracted comments from the transcripts and added the new suggestions to the final draft. Two researchers (PF & LP) discussed the feedback from pilot interviews, and relevant items that aligned with the study objective were added to the survey.



## Survey Administration

**Participants:** Panelists were recruited from three Canadian expert stakeholder groups: 1) pediatric clinicians who were involved in the process of prescribing, constructing, or monitoring AFOs for young children with cerebral palsy, 2) researchers knowledgeable about AFOs for children with cerebral palsy, and 3) parents of children with cerebral palsy (GMFCS level I-III), 2-5 years of age, who used any type of AFOs for at least a month. Parents (n=6) who participated in the interviews for the previously conducted qualitative study (11) were contacted if their children met the age requirement for this study. The study was also advertised throughout cerebral palsy organizations' social media platforms and among known pediatric researchers in Canada whose focus is on AFOs for children with cerebral palsy.

**Delphi Survey Data Collection:** An invitation email was sent to potential panelists two weeks prior to launching the survey with detailed information on the Delphi study process. The Delphi survey link was sent to the panelists who indicated their interest in participating in the study over two rounds (R1 and R2). A maximum of three reminders were sent to the participants in each round. Each round remained open for eight weeks. After the completion of each round, participant responses were downloaded. Demographic characteristics and ratings were described using frequency distributions for each item across all three stakeholder groups using StataIC 15 (23).

**R1:** Participants were asked to rate the importance of each item in the Delphi survey using a 9-point scale, which is commonly used in Delphi surveys (14). A 9-point rating scale was used in the first round to provide panelists greater flexibility for rating within the categories. Participants were able to suggest additional items in R1, which were reviewed by the co-authors

for inclusion in R2 if they represented a new consideration that was not included in the existing items.

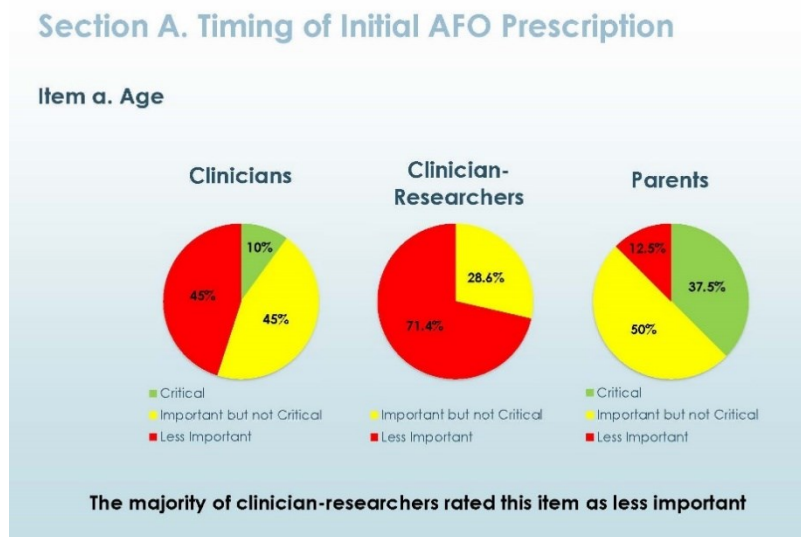
**R2:** In R2, participants were presented with the items that met the inclusion criteria for inclusion in the core clinical considerations and were provided with the opportunity to comment on them if they disagreed. In addition, the distribution of critical rating (score 7-9) for all three stakeholder groups from R1 were provided to them. Participants were asked to reflect on the ratings of the items included in R1 and then to rerate the items that did not reach consensus in the first round. In R2, the rating scale was collapsed to a three-point scale (1, 2, and 3) but with the same description of categories: “less important”, “important but not critical” and “critical” for inclusion in the core considerations, respectively. A 3-point rating scale was used in the second round of the Delphi to provide participants with more definitive options compared to the first round and to simplify the cognitive process.

### **Ratification Meeting with a Sub-group of Panelists**

An invitation to participate in an online stakeholder meeting was embedded as a question in the survey in R2. A sub-group of panelists from R2 participated in an online meeting using Zoom (22) to ratify the items that did not reach consensus in R2. The first author facilitated the meeting. At the beginning of the meeting, the items that had already met the consensus criteria were presented, and the participants were asked if they had any objections to including them in the core clinical considerations. The results of the second survey for each item that had not yet reached consensus for inclusion or exclusion were presented using pie charts (Figure 4.1) and discussed among the participants to give them the opportunity to reflect on their perspectives. The ratification meeting discussion highlighted redundant items and clarified panelists’ perspectives that seemed ambiguous prior to the meeting. Following the discussion for each

item, voting was conducted on each item individually. The poll feature of Zoom was used to vote on the items as yes-include or no-exclude. The item was included in the core clinical considerations if more than two-thirds of the panelists voted yes-include, consistent with the  $\geq 70\%$  consensus criterion for inclusion in R1 & R2. The poll results were presented to the panelists after voting for each item.

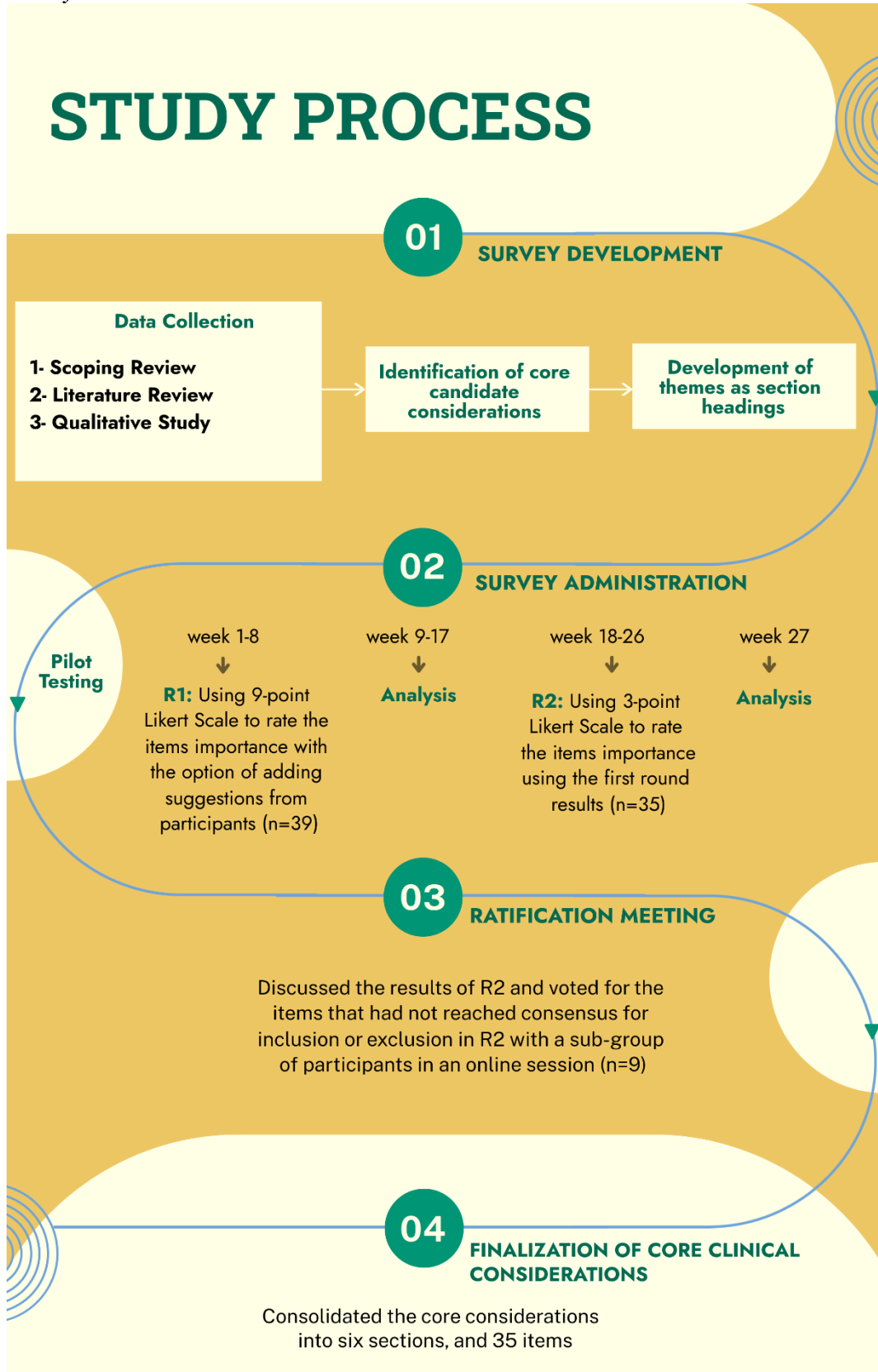
*Figure 4.1. Example of an R2 Result Shared During the Ratification Meeting*



## Finalization of Core Clinical Considerations

Results of R2, ratification voting results, and panelist comments were used to consolidate the considerations in each section and, where appropriate, merged sections to avoid duplication. Two researchers (PF & LP) aggregated some of the considerations in each section to make them more applicable to clinical practice and to reduce the overall number of items (e.g., running, walking, and jumping were categorized under one consideration, gross motor function, for measuring outcomes in association with AFO use). The final list of clinical considerations was reviewed with the co-authors, and the considerations were further refined based on their input. The study process is illustrated in Figure 4.2.

Figure 4.2. Study Process



## Results

### Survey Development

The updated search strategy for the scoping review resulted in seven new studies for data extraction published between 2018-2021 (Figure 4.3). This scoping review highlighted the current emphasis of literature on biomechanical properties and gait-related outcomes associated with AFO use (7). The outcomes identified in this scoping review were categorized according to the ICF, highlighting the absence of research evaluating the effects of AFOs on age-appropriate, functional outcomes in activity and participation domains. Furthermore, there was a noticeable lack of evidence on AFO use patterns, such as frequency and duration of AFO use in young children and family perspectives about early AFO use. Limited information about clinicians' perspectives and considerations was identified in regard to prescribing, monitoring, and evaluating AFOs for young children with cerebral palsy.

Sixteen articles were included in the rapid literature review (Figure 4.4). One study was identified by searching the bibliography, resulting in 17 studies. The characteristic of each study is presented in Appendix B. Meaningful statements from the secondary analysis of the qualitative study are presented in Appendix C. The extracted and refined data from three sources resulted in 70 items and were categorized under seven sections with relevant reference coding, presented in Appendix D: 1- Timing of initial AFO prescription, 2- AFO construction and selection of AFO type, 3- Communication with families, 4- Frequency and duration of AFO use, 5- Monitoring AFOs, 6- Outcomes associated with AFO use, and 7- Clinical team functioning. Fourteen items were added after pilot administration of the survey and discussions with co-authors. A total of 84 items were developed for R1 and are presented in Table 4.1.

Figure 4.3. PRISMA Flowchart (Updated Scoping Review)

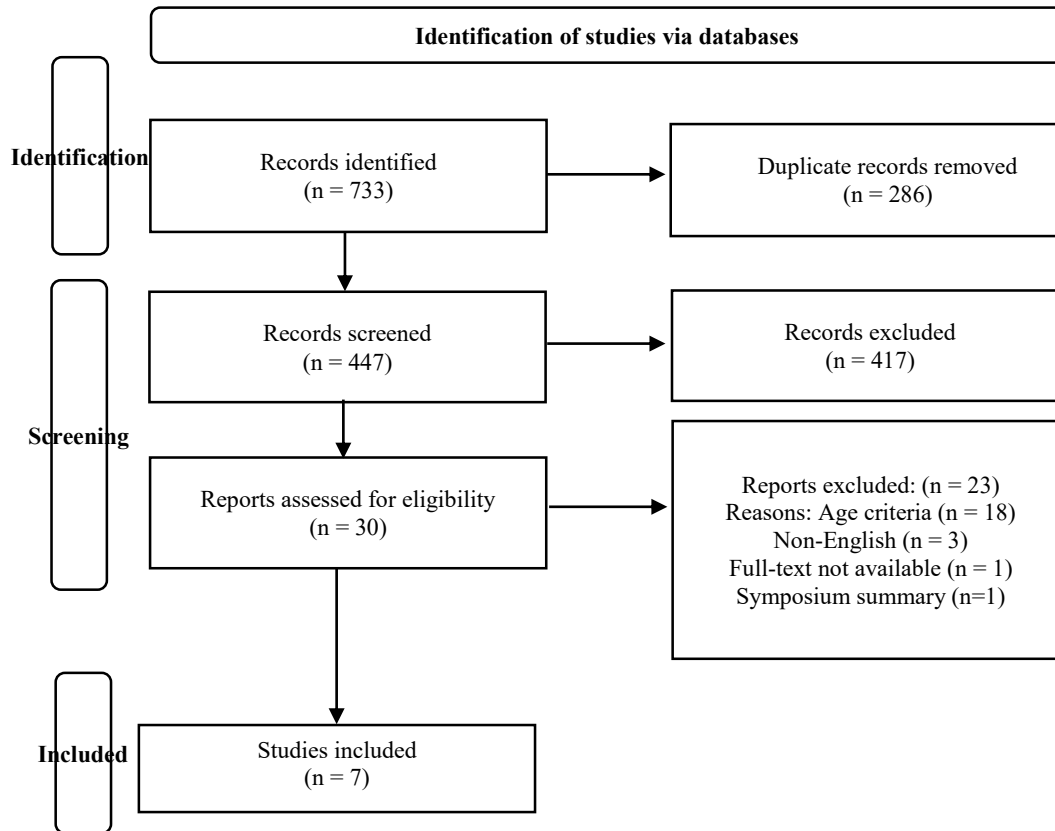


Figure 4.4. PRISMA Flowchart (Rapid Literature Review)

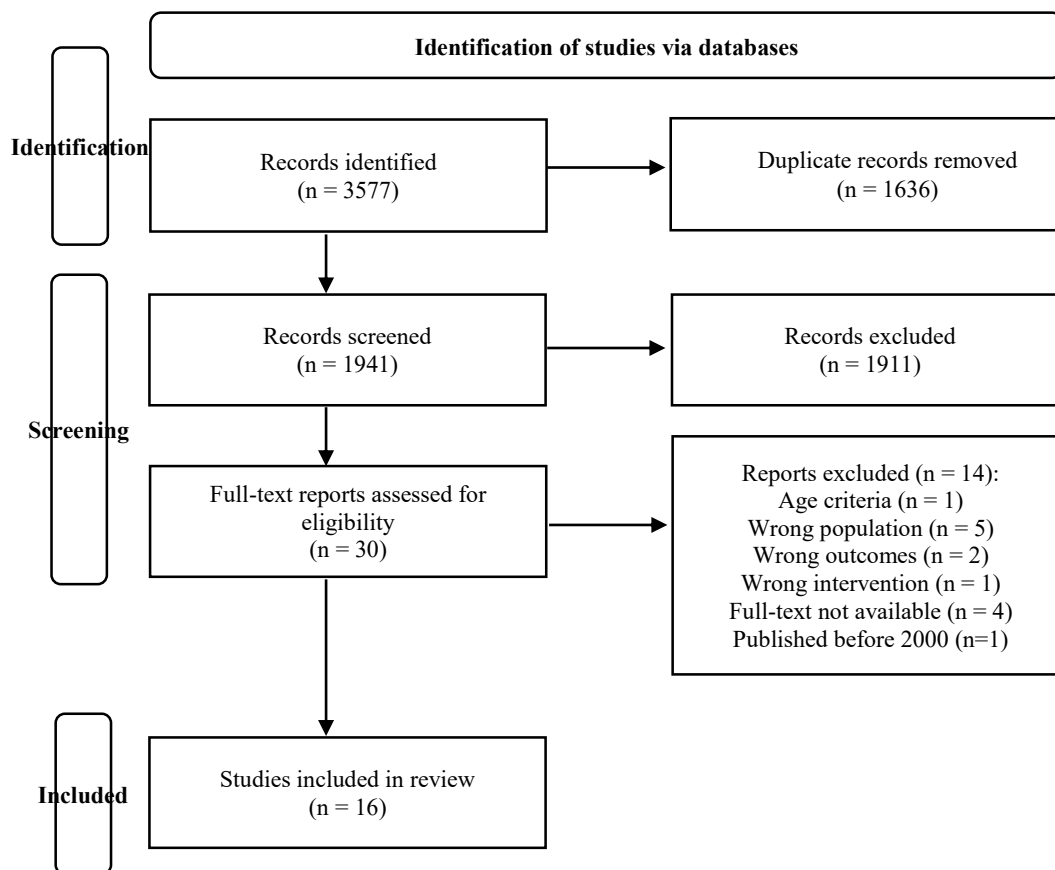


Table 4.1. Items used in R1 & R2 of the Delphi survey

Section A. Timing of Initial Prescription	
a.	Age
b.	Gross motor function (e.g., crawling, sitting, standing, walking, running, climbing up and down the stairs)
c.	Gross motor function level (i.e., Gross Motor Function Classification System level)
d.	Gait pattern (e.g., the emergence of equinus gait)
e.	The amount of plantar flexor spasticity
f.	Dorsiflexion range of motion
g.	Family ability to travel to and attend appointments (e.g., time off work, costs associated with travel)
h.	Family ability to afford AFOs
i.	The ability of AFOs to address family priorities, preferences, and goals
j.	Clinical goals of AFO use
k.	Timing of any other treatments (e.g., botox or serial casting)
l.	Presence of pain that could be relieved by AFOs
Section B. 1. Selection of AFO Type	
a.	Visual analysis of gait pattern
b.	Gait analysis using video recording (non-instrumented)
c.	Instrumented gait analysis (e.g., gait laboratory)
d.	Child's daily functional mobility routine (e.g., getting up and down from the floor, moving on the floor, going up the stairs, walking, using mobility aids, etc.)
e.	Gross motor function level (i.e., Gross Motor Function Classification System level)

f.	Child and family priorities, preferences, and goals
g.	Muscle strength assessment
h.	Spasticity assessment (e.g., Modified Tardieu)
i.	Ankle joint range of motion assessment
j.	Bone deformity of the foot (e.g., midfoot break)
k.	Any other ongoing or recent treatments that could modify the child's muscle tone (e.g., medication for spasticity management)
<b>Section B.2. AFO Construction</b>	
a.	Child preferences for design (e.g., color, pattern)
b.	Options of alternate materials/construction (e.g., air holes) that are more conducive to excessive temperatures
c.	Options for thinner materials that allow more flexibility for movement
d.	Modifications for comfort (e.g., padding over ankles, strap options)
e.	Child and family's previous experience with orthoses.
<b>Section C. Communication with Families</b>	
a.	Ensure families understand why AFOs have been recommended for their young children.
b.	Discuss the advantages and disadvantages of different types of AFOs (e.g., hinged, solid) with families.
c.	Discuss possible adverse effects of AFOs (e.g., floor mobility restrictions, skin issues) with families.
d.	Maximize child involvement in AFO decision-making.
e.	Inform families about how to monitor AFOs (e.g., skin integrity and AFO fit).
f.	Ensure families are aware of safety issues (e.g., risk of falling when AFOs are worn without shoes).
g.	Ensure families know about AFO size and appearance and the implications for appropriate clothes and footwear (e.g., footwear, pants, and socks to wear with AFOs).
h.	h. Advise families where they can purchase specific footwear and clothing brands to fit AFOs within their budget.
i.	Ensure families are aware of the cost of AFOs and adapted clothes.
j.	Schedule regular follow-up sessions with families (e.g., need for adjustments/maintenance and replacement and to address families' questions/concerns).
k.	Ensure families are aware of the available support resources for attending appointments to receive AFOs (e.g., financial aid, transportation compensation, etc.).
l.	Ensure families are aware of the time commitment for appointments for AFO construction.
m.	Inform families about the adjustment period required to increase children's tolerance for AFOs.
n.	Discuss family concerns related to emotional adjustment to AFOs (e.g., stress associated with child's resistance to wearing AFOs or parent concern about the child looking different because of AFOs).
o.	Ensure families have information about peer groups in the community (e.g., support groups, children's playgroups), so they can learn from the lived experience of other families.
p.	Ensure ongoing communication with families to obtain information about children's abilities to function in multiple environments such as home, school, child care, and community.
q.	Ensure ongoing communication with families to obtain information about their goals and the children's needs in multiple environments such as home, school, child care, and community.
<b>Section D. 1. Frequency &amp; Duration of AFO Use (Factors)</b>	
a.	Family and child preferences, priorities, and routines (e.g., fit with family schedule)
b.	Goals of AFO use
c.	Effects of AFOs on functional mobility (e.g., if AFOs inhibit play time on the floor in daycare, they could be removed)
d.	Environments that are best suited to AFO use (e.g., AFOs/shoes are not worn at home).
e.	Child's acceptance of AFOs (e.g., child routinely objects to AFO use)
f.	Child's physical tolerance for AFOs
<b>Section D. 2. Frequency &amp; Duration of AFO Use</b>	
a.	Provide families with tools to support the adjustment period (e.g., schedule for gradually increasing wear time).
b.	Ensure families have opportunities to share concerns about AFO frequency and duration based on the child's function and daily challenges in different environments (e.g., activity restrictions with AFOs such as limitations moving around on the floor at daycare).
c.	Plan the frequency and duration of AFO use, including wear-time breaks, collaboratively with families.
d.	Provide families with general guidelines for AFO wear-time and encourage families to decide on the details based on their daily routines.
<b>Section E. Monitoring AFOs</b>	
a.	Monitoring of AFO size as the child grows.



b.	Monitoring of pain or discomfort.
c.	Monitoring of the presence of skin redness or pressure points.
d.	Monitoring of frequency and duration of AFO use.
e.	Monitoring of child's tolerance and acceptability of AFOs.
f.	Monitoring ease of putting on and taking off AFOs.
g.	Obtaining input from the child and family on AFO effectiveness.
h.	Determining if AFOs are contributing to achieving current rehabilitation goals
<b>Section F. Outcomes associated with AFO Use</b>	
a.	Joint range of motion (e.g., ankle dorsiflexion)
b.	Prevention of joint/bone deformity
c.	Pain reduction
d.	Gross motor function (e.g., standing, walking, running, kicking, crawling, standing up from the floor)
e.	Movement agility (i.e., moving and changing directions quickly)
f.	Gait parameters (e.g., walking speed, gait pattern, trunk control, or posture)
g.	Walking efficiency (energy consumption)
h.	Balance
i.	Fatigue
j.	Safety (e.g., fall frequency)
k.	Psychosocial factors (e.g., child's sense of well-being, body image, confidence, self-esteem, perceived stigma)
l.	Attainment of goals identified by the child and/or family.
m.	Attainment of goals identified by clinical teams.
n.	Participation and inclusion
o.	Functional independence
p.	Child satisfaction with AFOs
q.	Parent satisfaction with AFOs
<b>Section G. Clinical Team Functioning</b>	
a.	Clinical team members communicate regularly with each other to ensure families are provided with consistent information.
b.	Clinical visits are structured to optimize team collaboration (e.g., multidisciplinary clinics).
c.	Clinical teams ensure collaboration with members of children's communities (e.g., teachers, coaches, and school therapists) to obtain information about children's needs and function across environments.
d.	Ensure that clinical team members have the same treatment goals related to AFO use for each child.

## Delphi Survey

Data from REDCap was downloaded into a Microsoft Excel version 2016 after each survey round. After de-identifying the panelists, descriptive statistics were used to describe the demographic characteristics of each stakeholder group in both rounds. The demographic characteristics of participants are presented in Table 4.2.

**Table 4.2. Participants' Demographic Characteristics**

R1			R2		
Role (n)	n (%)	Provinces, n (%)	Role (n)	n (%)	Provinces, n (%)
<b>Clinicians:</b> Orthotist (11) Physical Therapist (8) Physiatrist (2) Pediatrician (1)	22	AB, 5 (22.73) BC, 3 (13.64) MB, 2 (9.09) NL, 1 (4.55) NS, 2 (9.09) ON, 6 (27.27) QC, 1 (4.55) SK, 2 (9.09)	<b>Clinicians:</b> Orthotist (10) Physical Therapist (8) Physiatrist (1) Pediatrician (1)	20 (57.1)	AB, 4 (20) BC, 3 (15) MB, 1 (5) NL, 1 (5) NS, 2 (10) ON, 6 (30) QC, 1 (5) SK, 2 (10)
<b>Clinician-Researchers:</b> Developmental Pediatrician (1) Physical Therapist (4) Orthopaedic Surgeon (1) Kinesiologist (1)	7 (18.0)	AB, 3 (42.86) ON, 3 (42.86) SK, 1 (14.29)	<b>Clinician-Researchers:</b> Developmental Pediatrician (1) Physical Therapist (4) Orthopaedic Surgeon (1) Kinesiologist (1)	7 (20)	AB, 3 (42.86) ON, 3 (42.86) SK, 1 (14.29)
<b>Parents</b>	10 (25.6)	AB, 7 (70) NB, 1 (10) ON, 1 (10) SK, 1 (10)	<b>Parents</b>	8 (22.9)	AB, 5 (62.5) NB, 1 (12.5) ON, 1 (12.5) SK, 1 (12.5)
<b>Total</b>	<b>39 (100)</b>			<b>35 (100)</b>	

AB: Alberta, BC: British Columbia, MB: Manitoba, NL: New Brunswick, NL: Newfoundland and Labrador, NS: Nova Scotia, ON: Ontario, QC: Quebec, SK: Saskatchewan

**RI:** Thirteen parents indicated interest in participating; three were ineligible due to being on the waiting list for receiving AFOs at the time of the study. Thirty-five healthcare professionals (clinicians and researchers) and ten parents of children with cerebral palsy from eight Canadian provinces agreed to participate in the Delphi study. Three healthcare professionals did not complete the survey, and three completed partially, therefore, excluded from the analysis. Of 45 potential panelists, 22 clinicians, seven clinician-researchers, and ten parents (total n=39) completed R1 (response rate=86.7%). Seven of the 12 items in timing of initial AFO prescription, six of the 11 items in selection of the AFO type, one of the five items in AFO construction, and 13 of the 17 items in communication with families were rated critical across all three stakeholder groups. Six of the ten items in frequency and duration of AFO use, all items (n=8) in AFO monitoring, 13 of the 17 items in outcomes associated with the AFO use and all four items in the clinical team functioning section were rated critical by three groups of

panelists. In total, fifty-eight items met the consensus criteria to be included in the core clinical consideration in the first round and are highlighted in green in Table 4.4. The remaining items (n=26) did not reach consensus to be included in or excluded from the core clinical considerations and were considered for rerating in R2. New items were suggested by participants in R1, which were reviewed and discussed by the co-authors, resulting in 15 new items that were added to the second round of the Delphi survey. The new items from R1 are presented in Table 4.3.

**Table 4.3. New Items Suggested in Round 1 and Included in R2**

<b>Section A. Timing of Initial Prescription</b>	
1.	Family readiness for receiving AFOs for their child (e.g., time commitment to adjust to AFO use, emotional readiness, etc.).
2.	Presence of foot/ankle deformity
3.	Accompanying medical conditions that might affect child's tolerance of wearing AFOs (e.g., autism).
<b>Section B. 1. Selection of AFO Type</b>	
4.	Shank to vertical angle alignment of tuned AFO-footwear combinations during gait
5.	Dynamic pedobarography (i.e., foot pressure measurement)
6.	Static alignment of joints
<b>Section B.2. AFO Construction</b>	
7.	Ease of donning and doffing AFOs
8.	Use of durable materials so that AFOs can be worn until the child outgrows them.
9.	Modification of AFO heel height in combination with footwear (i.e., tuning)
10.	Ease of adjustment for growth (e.g., extending the proximal trimline, or footplate)
11.	Thinner materials (e.g., copolymer plastic) to make AFOs and fit them in shoes more easily.
<b>Section C. Communication with Families</b>	
12.	Ensure that families are provided with necessary information about AFOs in multiple formats (verbal, written, web-based, video), at different reading levels and languages.
<b>Section D. Frequency &amp; Duration of AFO Use</b>	
---	No new item was suggested.
<b>Section E. Monitoring AFOs</b>	
13.	Monitoring the need for AFO repair (e.g., Velcro/straps are worn out)
<b>Section F. Outcomes associated with AFO Use</b>	
---	No new item was suggested.
<b>Section G. Clinical Team Functioning</b>	
14.	Ensure that there is a main contact person for families.
15.	Ensure the systems of care enable the time required for communication with families.

**R2:** Three panelists (one physiatrist and two parents) did not respond to the R2 invitation and one clinician completed the survey partially in the second round, therefore, was removed from the analysis. In total, 20 clinicians, seven clinician-researchers, and eight parents completed the survey in R2 (n=35, response rate=89.7%). The attrition rate between R1 and R2 was 10.3%.

The only item that met the consensus criteria to be excluded from the core clinical considerations was “instrumented gait analysis” in “selection of the AFO type” section and is highlighted in red in Table 4.4. Three items (highlighted in green in Table 4.4.) in the categories of initial timing of AFO prescription, selection of AFO type and frequency and duration of AFO use met the inclusion criteria and were added to the core clinical considerations. The remaining items were discussed in an online ratification meeting with a sub-group of panelists. The distribution of rating across all three stakeholder groups for each item in R 1 & R2 is presented in Table 4.4.

**Table 4.4. Results of R1 & R2**

Section A. Initial Timing of AFO Prescription	R1 Scoring	R1						R2 Scoring	R2					
		Clinicians		Clinician-researchers		Parents			Clinicians		Clinician-researchers		Parents	
		n	%	n	%	n	%		n	%	n	%	n	%
a. Age	7-9 <sup>a</sup>	8	36.4	3	42.9	3	33.3	3 <sup>e</sup>	2	10	0	0	3	37.5
	4-6b	11	50	2	28.6	3	33.3	2 <sup>f</sup>	9	45	2	28.6	4	50
	1-3 <sup>c</sup>	3	13.6	2	28.6	3	33.3	1 <sup>g</sup>	9	45	5	71.4	1	12.5
	U to C <sup>d</sup>	--	--	--	--	1	--	U to C	--	--	--	--	--	--
b. Gross motor function (e.g., crawling, sitting, standing, walking, running, climbing up and down the stairs)	7-9	21	95.5	4	57.1	8	88.9	3	15	75	5	71.4	7	87.5
	4-6	1	4.5	3	42.9	0	0	2	4	20	2	28.6	1	12.5
	1-3	0	0	0	0	1	11.1	1	1	5	0	0	0	0
	U to C	--	--	--	--	1	--	U to C	--	--	--	--	--	--
c. Gross motor function level (i.e., Gross Motor Function Classification System level)	7-9	10	47.6	2	28.6	8	80	3	1	5	0	0	2	25
	4-6	8	38.1	4	57.1	1	10	2	12	60	2	33.3	5	62.5
	1-3	3	14.3	1	14.3	1	10	1	8	35	4	66.7	1	12.5
	U to C	1	--	0	--	0	--	U to C	--	--	1	--	--	--
d. Gait pattern (e.g., the emergence of equinus gait)	7-9	21	95.5	6	85.7	5	71.4	3						
	4-6	1	4.5	1	14.3	1	14.3	2						
	1-3	0	0	0	0	1	14.3	1						
	U to C	--	--	--	--	3	--	U to C						
e. The amount of plantar flexor spasticity	7-9	19	86.4	5	71.4	6	75	3						
	4-6	2	9.1	2	28.6	1	12.5	2						
	1-3	1	4.5	0	0	1	12.5	1						
	U to C	--	--	--	--	--	--	U to C						
f. Dorsiflexion range of motion	7-9	21	95.5	6	85.7	6	85.7	3						
	4-6	1	4.5	1	14.3	1	14.3	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	3	--	U to C						
g. Family ability to travel to and attend appointments (e.g., time off work, costs associated with travel)	7-9	4	18.2	2	28.6	3	30	3	2	10	0	0	2	25
	4-6	15	68.2	3	42.9	4	40	2	5	25	3	42.9	0	0
	1-3	3	13.6	2	28.6	3	30	1	13	65	4	57.1	6	75
	U to C	--	--	--	--	--	--	U to C	--	--	--	--	--	--
h. Family ability to afford AFOs	7-9	8	40	2	28.6	4	40	3	2	10	0	0	1	12.5
	4-6	9	45	4	57.1	2	20	2	12	60	6	100	4	50
	1-3	3	15	1	14.3	4	40	1	6	30	0	0	3	37.5
	U to C	2	--	--	--	--	--	U to C	--	--	1	--	--	--

i. The ability of AFOs to address family priorities, preferences, and goals	7-9	16	72.7	6	85.7	7	70	3						
	4-6	6	27.3	1	14.3	2	20	2						
	1-3	0	0	0	0	1	10	1						
	U to C	--	--	--	--	--	--	U to C						
j. Clinical goals of AFO use	7-9	18	81.8	7	100	8	80	3						
	4-6	4	18.2	0	0	2	20	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	--	--	U to C						
k. Timing of any other treatments (e.g., botox, serial casting, surgery)	7-9	22	100	5	71.4	8	80	3						
	4-6	0	0	1	14.3	2	20	2						
	1-3	0	0	1	14.3	0	0	1						
	U to C	--	--	--	--	--	--	U to C						
l. Presence of pain that could be relieved by AFOs	7-9	22	100	7	100	9	100	3						
	4-6	0	0	0	0	0	0	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	1	--	U to C						
m. Family readiness for receiving AFOs for their child (e.g., time commitment to adjust to AFO use, emotional readiness, etc.).	New item	--	--	--	--	--	--	3	7	35	3	42.9	3	37.5
		2	10	50	4	57.1	5	62.5						
		1	3	15	0	0	0	0						
		U to C	--	--	--	--	--	--						
n. Presence of foot/ankle deformity	New item	--	--	--	--	--	--	3	14	70	3	50	7	87.5
		2	6	30	3	50	1	12.5						
		1	0	0	0	0	0	0						
		U to C	--	--	1	--	--	--						
o. Accompanying medical conditions that might affect child's tolerance of wearing AFOs (e.g., autism)	New item	--	--	--	--	--	--	3	7	35	2	28.6	7	87.5
		2	13	65	5	71.4	1	12.5						
		1	0	0	0	0	0	0						
		U to C	--	--	--	--	--	--						
<b>Section B.1. Selection of AFO Type</b>	<b>R1 Scoring</b>	<b>R1</b>						<b>R2 Scoring</b>	<b>R2</b>					
		Clinicians		Clinician-researchers		Parents			Clinicians		Clinician-researchers		Parents	
		n	%	n	%	n	%	n	%	n	%	n	%	
a. Visual analysis of gait pattern	7-9	19	86.4	5	71.4			3						
	4-6	3	13.6	1	14.3			2						
	1-3	0	0	1	14.3			1						
	U to C	--	--	--	--			U to C						

b. Gait analysis using video recording (non-instrumented)	7-9	6	28.6	5	71.4			3	4	20	3	42.9		
	4-6	14	66.7	1	14.3			2	8	40	3	42.9		
	1-3	1	4.8	1	14.3			1	8	40	1	14.3		
	U to C	1	--	--	--			U to C	--	--	--	--		
c. Instrumented gait analysis (e.g., gait laboratory)	7-9	1	4.8	2	28.6			3	0	0	0	0		
	4-6	18	85.7	3	42.9			2	4	20	2	28.6		
	1-3	2	9.5	2	28.6			1	16	80	5	71.4		
	U to C	1	--	--	--			U to C	--	--	--	--		
d. Child's daily functional mobility routine (e.g., getting up and down from the floor, moving on the floor, going up the stairs, walking, using mobility aids, etc.)	7-9	20	95.2	6	85.7			3						
	4-6	0	0	1	14.3			2						
	1-3	1	4.8	0	0			1						
	U to C	1	--	0	--			U to C						
e. Gross motor function level (i.e., Gross Motor Function Classification System level)	7-9	12	54.5	1	14.3			3	4	20	1	14.3		
	4-6	5	22.7	4	57.1			2	10	50	2	28.6		
	1-3	5	22.7	2	28.6			1	6	30	4	57.1		
	U to C	--	--	--	--			U to C	--	--	--	--		
f. Child and family priorities, preferences, and goals	7-9	18	81.8	6	85.7			3						
	4-6	4	18.2	1	14.3			2						
	1-3	0	0	0	0			1						
	U to C	--	--	--	--			U to C						
g. Muscle strength	7-9	15	68.2	6	85.7			3	8	40	4	57.1		
	4-6	7	31.8	1	14.3			2	11	55	2	28.6		
	1-3	0	0	0	0			1	1	5	1	14.3		
	U to C	--	--	--	--			U to C	--	--	--	--		
h. Spasticity (e.g., result of Modified Tardieu assessment)	7-9	20	90.9	4	57.1			3	18	90	6	85.7		
	4-6	2	9.1	3	42.9			2	1	5	1	14.3		
	1-3	0	0	0	0			1	1	5	0	0		
	U to C	--	--	--	--			U to C	--	--	--	--		
i. Ankle joint range of motion assessment	7-9	22	100	6	85.7			3						
	4-6	0	0	1	14.3			2						
	1-3	0	0	0	0			1						
	U to C	--	--	--	--			U to C						
j. Presence of foot/ ankle deformity (e.g., midfoot break)	7-9	20	95.2	6	85.7			3						
	4-6	1	4.8	1	14.3			2						
	1-3	0	0	0	0			1						
	U to C	1	--	--	--			U to C						

k. Any other ongoing or recent treatments that could modify the child's muscle tone (e.g., medication for spasticity management, surgery)	7-9	17	77.3	5	71.4			3						
	4-6	4	18.2	2	28.6			2						
	1-3	1	4.5	0	0			1						
	U to C	--	--	--	--			U to C						
l. Shank to vertical angle alignment of tuned AFO-footwear combinations during gait	New item	--	--	--	--		--	3	5	27.8	3	42.9		
		2	8	44.4	3	42.9								
		1	5	27.8	1	14.3								
		U to C	2	--	0	--								
m. Dynamic pedobarography (i.e., pressure measurement)	New item	--	--	--	--		--	3	2	11.1	1	14.3		
		2	4	22.2	3	42.9								
		1	12	66.7	3	42.9								
		U to C	2	--	--	--								
n. Static alignment of joints	New item	--	--	--	--		--	3	7	38.9	3	50		
		2	9	50	1	16.7								
		1	2	11.1	2	33.3								
		U to C	2	--	1	--								
<b>Section B.2. AFO Construction (e.g., materials, aesthetics)</b>														
a. Child preferences for design (e.g., color, pattern)	7-9	12	60	6	85.7	6	60	3	3	15	4	57.1	3	37.5
	4-6	7	35	1	14.3	4	40	2	13	65	3	42.9	3	37.5
	1-3	1	5	0	0	0	0	1	4	20	0	0	2	25
	U to C	2	--	--	--	--	--	U to C	--	--	--	--	--	--
b. Options of alternate materials/construction that are more conducive to hot/cold temperatures.	7-9	10	50	5	83.3	8	80	3	0	0	2	28.6	3	37.5
	4-6	9	45	1	16.7	2	20	2	15	75	5	71.4	5	62.5
	1-3	1	5	0	0	0	0	1	5	15	0	0	0	0
	U to C	2	--	1	--	--	--	U to C	--	--	--	--	--	--
c. Options for thinner materials that allow more flexibility for movement.	7-9	13	65	5	71.4	8	88.9	3	2	10	1	14.3	6	75
	4-6	6	30	2	28.6	1	11.1	2	14	70	5	71.4	2	25
	1-3	1	5	0	0	0	0	1	4	20	1	14.3	0	0
	U to C	2	--	--	--	1	--	U to C	--	--	--	--	--	--
d. Modifications for comfort (e.g., padding over ankles, strap options)	7-9	20	100	7	100	9	100	3						
	4-6	0	0	0	0	0	0	2						
	1-3	0	0	0	0	0	0	1						
	U to C	2	--	--	--	1	--	U to C						
e. Children and families' previous experience with orthoses.	7-9	17	85	5	83.3	4	44.4	3	10	50	3	42.9	2	25
	4-6	3	15	1	16.7	3	33.3	2	9	45	3	42.9	4	50
	1-3	0	0	0	0	2	22.2	1	1	5	1	14.3	2	25
	U to C	2	--	1	--	1	--	U to C	--	--	--	--	--	--



f. Ease of donning and doffing AFOs	New item		--		--		--	3	8	40	5	71.4	4	50
								2	12	60	2	28.6	3	37.5
								1	0	0	0	0	1	12.5
								U to C	--	--	--	--	--	--
g. Use of durable materials so that AFOs can be worn until the child outgrows them.	New item		--		--		--	3	12	60	5	71.4	7	87.5
								2	7	35	1	14.3	1	12.5
								1	1	5	1	14.3	0	0
								U to C	--	--	--	--	--	--
h. Modification of AFO heel height in combination with footwear (i.e., tuning)	New item		--		--		--	3	10	52.6	4	57.1	5	71.4
								2	9	47.4	3	42.9	2	28.6
								1	0	0	0	0	0	0
								U to C	1	--	--	--	1	--
i. Ease of adjustment for growth (e.g., extending the proximal trimline, or footplate)	New item		--		--		--	3	5	26.3	1	14.3	5	62.5
								2	11	57.9	4	71.4	3	37.5
								1	3	15.8	1	14.3	0	0
								U to C	1	--	--	--	--	--
j. Thinner materials (e.g., copolymer plastic) to make AFOs and fit them in shoes more easily.	New item		--		--		--	3	4	20	4	57.1	4	50
								2	14	70	3	42.9	4	50
								1	2	10	0	0	0	0
								U to C	--	--	--	--	--	--
<b>Section C. Communication with families.</b>	<b>R1 Scoring</b>	<b>R1</b>						<b>R2 Scoring</b>	<b>R2</b>					
		Clinicians		Clinician-researchers		Parents			Clinicians		Clinician-researchers		Parents	
		n	%	n	%	n	%		n	%	n	%	n	%
a. Ensure families understand why AFOs have been recommended for their young children.	7-9	22	100	7	100	9	100	3						
	4-6	0	0	0	0	0	0	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	1	--	U to C						
b. Discuss the advantages and disadvantages of different types of AFOs (e.g., hinged, solid) with families	7-9	17	77.3	6	85.7	9	100	3						
	4-6	5	22.7	1	14.3	0	0	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	1	--	U to C						
c. Discuss possible adverse effects of AFOs (e.g., floor mobility restrictions, skin issues) with families.	7-9	20	90.9	7	100	9	100	3						
	4-6	2	9.1	0	0	0	0	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	1	--	U to C						

d. Maximize child involvement in AFO decision-making	7-9	12	54.5	5	71.4	4	44.4	3	2	10	1	14.3	1	12.5
	4-6	10	45.5	2	28.6	5	55.6	2	13	65	6	85.7	5	62.5
	1-3	0	0	0	0	0	0	1	5	25	0	0	2	25
	U to C	--	--	--	--	1	--	U to C	--	--	--	--	--	--
e. Inform families about how to monitor AFOs (e.g., skin integrity and AFO fit).	7-9	22	100	7	100	9	100	3						
	4-6	0	0	0	0	0	0	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	1	--	U to C						
f. Ensure families are aware of safety issues (e.g., risk of falling when AFOs are worn without shoes).	7-9	22	100	7	100	9	100	3						
	4-6	0	0	0	0	0	0	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	1	--	U to C						
g. Ensure families know about AFO size and appearance (e.g., show families AFOs during the first appointment) and the implications for appropriate clothes and footwear (e.g., footwear, pants, and socks to wear with AFOs).	7-9	18	81.8	7	100	8	88.9	3						
	4-6	4	18.2	0	0	1	11.1	2						
	1-3	0	0	0	0	0	0	1						
	U to C	0	--	--	--	1	--	U to C						
h. Advise families where they can purchase specific footwear and clothing brands to fit AFOs within their budget.	7-9	18	81.8	4	57.1	8	88.9	3						
	4-6	3	13.6	3	42.9	1	11.1	2						
	1-3	1	4.5	0	0	0	0	1						
	U to C	--	--	--	--	1	--	U to C						
i. Ensure families are aware of the cost of AFOs and adapted clothes.	7-9	18	85.7	5	71.4	8	88.9	3						
	4-6	3	14.3	2	28.6	1	11.1	2						
	1-3	0	0	0	0	0	0	1						
	U to C	1	--	--	--	1	--	U to C						
j. Schedule regular follow-up sessions with families (e.g., need for adjustments/maintenance and replacement and to address families questions/concerns).	7-9	19	86.4	5	71.4	10	100	3						
	4-6	3	13.6	1	14.3	0	0	2						
	1-3	0	0	1	14.3	0	0	1						
	U to C	--	--	--	--	--	--	U to C						
k. Ensure families are aware of the available support resources for attending appointments to receive AFOs (e.g., financial aid, transportation compensation, etc.).	7-9	17	77.3	5	71.4	9	100	3						
	4-6	5	22.7	2	28.6	0	0	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	1	--	U to C						
l. Ensure families are aware of the time commitment for appointments for AFO construction.	7-9	18	81.8	5	83.3	8	80	3						
	4-6	4	18.2	1	16.7	2	20	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	1	--	--	--	U to C						

m. Inform families about the adjustment period required to increase children's tolerance for AFOs.	7-9	21	95.5	6	100	8	88.9	3						
	4-6	1	4.5	0	0	1	11.1	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	1	--	1	--	U to C						
n. Discuss family concerns related to emotional adjustment to AFOs (e.g., stress associated with child's resistance to wearing AFOs or parent concern about the child looking different because of AFOs).	7-9	17	77.3	6	100	8	88.9	3						
	4-6	5	22.7	0	0	1	11.1	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	1	--	1	0	U to C						
o. Ensure families have information about peer groups in the community (e.g., support groups, children's playgroups), so they can learn from the lived experience of other families.	7-9	8	36.4	3	60	5	55.6	3	0	0	0	0	2	25
	4-6	13	59.1	1	20	4	44.4	2	9	45	6	85.7	4	50
	1-3	1	4.5	1	20	0	0	1	11	55	1	14.3	2	25
	U to C	0	--	2	0	1	--	U to C	--	--	--	--	--	--
p. Ensure ongoing communication with families to obtain information about children's abilities to function in multiple environments such as home, school, child care, and community.	7-9	14	63.6	4	57.1	6	66.7	3	10	50	3	42.9	3	37.5
	4-6	7	31.8	2	28.6	3	33.3	2	9	45	4	57.1	5	62.5
	1-3	1	4.5	1	14.3	0	0	1	1	5	0	0	0	0
	U to C	--	--	--	--	1	--	U to C	--	--	--	--	--	--
q. Ensure ongoing communication with families to obtain information about their goals and the children's needs in multiple environments such as home, school, child care, and community.	7-9	16	72.7	5	71.4	9	90	3						
	4-6	6	27.3	1	14.3	1	10	2						
	1-3	0	0	1	14.3	0	0	1						
	U to C	--	--	--	--	--	--	U to C						
r. Ensure that families are provided with necessary information about AFOs in multiple formats (verbal, written, web-based, video), at different reading levels and languages.	New item	--	--	--	--	--	--	3	8	40	3	42.9	4	50
								2	9	45	3	42.9	3	37.5
								1	3	15	1	14.3	1	12.5
								U to C	--	--	--	--	--	--
<b>Section D.1. Frequency and Duration of AFO Use.</b> Please rate the importance of the following factors for guiding clinical team decision-making with families about the frequency and duration of AFO use in young children.	<b>R1 Scoring</b>	<b>R1</b>						<b>R2 Scoring</b>	<b>R2</b>					
		Clinicians		Clinician-researchers		Parents			Clinicians		Clinician-researchers		Parents	
		n	%	n	%	n	%		n	%	n	%	n	%
a. Family and child preference, priorities, and routines (e.g., fit with family schedule)	7-9	14	63.6	6	85.7	4	40	3	6	30	4	57.1	0	0
	4-6	8	36.4	1	14.3	5	50	2	13	65	3	42.9	5	62.5
	1-3	0	0	0	0	1	10	1	1	5	0	0	3	37.5
	U to C	--	--	--	--	--	--	U to C	--	--	--	--	--	--
b. Goals of AFO use	7-9	22	100	7	100	8	88.9	3						
	4-6	0	0	0	0	1	11.1	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	1	--	U to C						

c. Effects of AFOs on functional mobility (e.g., if AFOs inhibit play time on the floor in daycare, they could be removed)	7-9	19	86.4	7	100	6	66.7	3	17	85	6	85.7	4	50
	4-6	3	13.6	0	0	3	33.3	2	3	15	1	14.3	4	50
	1-3	0	0	0	0	0	0	1	0	0	0	0	0	0
	U to C	--	--	--	--	1	--	U to C	--	--	--	--	--	--
d. Environments that are best suited to AFO use (e.g., AFOs/shoes are not worn at home)	7-9	18	81.8	6	85.7	6	66.7	3	14	70	5	71.4	5	62.5
	4-6	4	18.2	1	14.3	3	33.3	2	6	30	2	28.6	3	37.5
	1-3	0	0	0	0	0	0	1	0	0	0	0	0	0
	U to C	--	--	--	--	1	--	U to C	--	--	--	--	--	--
e. Child's acceptance of AFOs (e.g., child routinely objects to AFO use)	7-9	19	86.4	4	57.1	8	88.9	3	15	75	6	85.7	7	87.5
	4-6	3	13.6	3	42.9	0	0	2	5	25	1	14.3	1	12.5
	1-3	0	0	0	0	1	11.1	1	0	0	0	0	0	0
	U to C	--	--	--	--	1	--	U to C	--	--	--	--	--	--
f. Child's physical tolerance for AFOs	7-9	22	100	7	100	8	88.9	3						
	4-6	0	0	0	0	1	11.1	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	1	--	U to C						
<b>Section D.2. Frequency and Duration of AFO Use</b>	<b>R1 Scoring</b>	<b>R1</b>						<b>R2 Scoring</b>	<b>R2</b>					
		Clinicians		Clinician-researchers		Parents			Clinicians		Clinician-researchers		Parents	
		n	%	n	%	n	%	n	%	n	%	n	%	
a. Provide families with tools to support the adjustment period (e.g., schedule for gradually increasing wear time).	7-9	19	86.4	6	100	9	90	3						
	4-6	3	13.6	0	0	1	10	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	1	--	--	--	U to C						
b. Ensure families have opportunities to share concerns about AFO frequency and duration based on the child's function and daily challenges in different environments (e.g., activity restrictions with AFOs, such as limitations moving around on the floor at daycare).	7-9	17	77.3	6	100	7	70	3						
	4-6	5	22.7	0	0	3	30	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	1	--	--	--	U to C						
c. Plan the frequency and duration of AFO use, including wear-time breaks, collaboratively with families.	7-9	17	77.3	6	85.7	7	77.8	3						
	4-6	5	22.7	1	14.3	2	22.2	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	1	--	U to C						
d. Provide families with guidelines for AFO wear-time and encourage families to decide on the details based on their daily routines.	7-9	18	81.8	5	71.4	10	100	3						
	4-6	4	18.2	1	14.3	0	0	2						
	1-3	0	0	1	14.3	0	0	1						
	U to C	--	--	--	--	--	--	U to C						

Section E. Monitoring AFO use	R1 Scoring	R1						R2 Scoring	R2					
		Clinicians		Clinician-researchers		Parents			Clinicians		Clinician-researchers		Parents	
		n	%	n	%	n	%		n	%	n	%	n	%
a. Monitoring of AFO size as the child grows.	7-9	19	86.4	7	100	9	90	3						
	4-6	3	13.6	0	0	1	10	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	--	--	U to C						
b. Monitoring of pain or discomfort.	7-9	22	100	6	85.7	8	88.9	3						
	4-6	0	0	1	14.3	1	11.1	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	1	--	U to C						
c. Monitoring of the presence of skin redness or pressure points.	7-9	22	100	6	85.7	9	100	3						
	4-6	0	0	1	14.3	0	0	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	1	--	U to C						
d. Monitoring of frequency and duration of AFO use.	7-9	19	86.4	6	85.7	8	80	3						
	4-6	3	13.6	1	14.3	2	20	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	--	--	U to C						
e. Monitoring of child's tolerance and acceptability of AFOs.	7-9	19	86.4	7	100	9	90	3						
	4-6	3	13.6	0	0	1	10	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	--	--	U to C						
f. Monitoring ease of putting on and taking off AFOs.	7-9	16	72.7	5	71.4	8	80	3						
	4-6	5	22.7	2	28.6	1	10	2						
	1-3	1	4.5	0	0	1	10	1						
	U to C	--	--	--	--	--	--	U to C						
g. Obtaining input from the child and family on AFO effectiveness.	7-9	21	95.5	5	71.4	9	90	3						
	4-6	1	4.5	2	28.6	1	10	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	--	--	U to C						
h. Determining if AFOs are contributing to achieving current rehabilitation goals.	7-9	22	100	6	85.7	9	100	3						
	4-6	0	0	1	14.3	0	0	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	1	--	U to C						

i. Monitoring the need for AFO repair (e.g., velcros/straps are worn out)	New item		--		--		--	3	14	70	3	42.9	5	62.5
								2	5	25	3	42.9	3	37.5
								1	1	5	1	14.3	0	0
								U to C	--	--	--	--	--	--
<b>Section F. Outcomes Associated with AFO use</b>	<b>R1 Scoring</b>	<b>R1</b>						<b>R2 Scoring</b>	<b>R2</b>					
		Clinicians		Clinician-researchers		Parents			Clinicians		Clinician-researchers		Parents	
		n	%	n	%	n	%	n	%	n	%	n	%	
a. Joint range of motion (e.g., ankle dorsiflexion)	7-9	18	81.8	5	71.4	8	80	3						
	4-6	4	18.2	2	28.6	2	20	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	--	--	U to C						
b. Prevention of joint/bone deformity	7-9	19	86.4	7	100	8	88.9	3						
	4-6	3	13.6	0	0	1	11.1	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	1	--	U to C						
c. Pain reduction	7-9	18	81.8	6	85.7	9	90	3						
	4-6	3	13.6	1	14.3	1	10	2						
	1-3	1	4.5	0	0	0	0	1						
	U to C	--	--	--	--	--	--	U to C						
d. Gross motor function (e.g., standing, walking, running, kicking, crawling, standing up from the floor)	7-9	18	81.8	6	85.7	9	100	3						
	4-6	4	18.2	1	14.3	0	0	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	1	--	U to C						
e. Movement agility (i.e., moving and changing directions quickly)	7-9	9	40.9	3	42.9	8	88.9	3	2	10	0	0	2	25
	4-6	13	59.1	4	57.1	1	11.1	2	10	50	6	85.7	6	75
	1-3	0	0	0	0	0	0	1	8	40	1	14.3	0	0
	U to C	--	--	--	--	1	--	U to C	--	--	--	--	--	--
f. Gait parameters (e.g., walking speed, gait pattern, trunk control, or posture)	7-9	22	100	6	85.7	7	77.8	3						
	4-6	0	0	1	14.3	2	22.2	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	1	--	U to C						
g. Walking efficiency (energy consumption)	7-9	20	90.9	7	100	9	90	3						
	4-6	2	9.1	0	0	1	10	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	--	--	U to C						

h. Balance	7-9	20	90.9	7	100	8	88.9	3						
	4-6	2	9.1	0	0	1	11.1	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	1	--	U to C						
i. Fatigue	7-9	19	86.4	5	71.4	8	88.9	3						
	4-6	3	13.6	2	28.6	1	11.1	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	1	--	U to C						
j. Safety (e.g., fall frequency)	7-9	22	100	6	85.7	8	88.9	3						
	4-6	0	0	1	14.3	1	11.1	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	1	--	U to C						
k. Psychosocial factors (e.g., child's sense of well-being, body image, confidence, self-esteem, perceived stigma)	7-9	18	81.8	3	50	5	55.6	3	10	50	3	42.9	3	37.5
	4-6	4	18.2	3	50	4	44.4	2	10	50	3	42.9	4	50
	1-3	0	0	0	0	0	0	1	0	0	1	14.3	1	12.5
	U to C	--	--	1	--	1	--	U to C	--	--	--	--	--	--
l. Attainment of goals identified by the child and/or family.	7-9	21	95.5	7	100	9	90	3						
	4-6	1	4.5	0	0	1	10	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	--	--	U to C						
m. Attainment of goals identified by clinical teams.	7-9	20	90.9	7	100	8	80	3						
	4-6	2	9.1	0	0	2	20	2						
	1-3	0	0	0	0	0	0	1						
	U to C	--	--	--	--	--	--	U to C						
n. Participation and inclusion	7-9	20	90.9	6	85.7	9	100	3						
	4-6	2	9.1	0	0	0	0	2						
	1-3	0	0	1	14.3	0	0	1						
	U to C	--	--	--	--	1	--	U to C						
o. Functional independence	7-9	20	90.9	6	85.7	9	100	3						
	4-6	2	9.1	0	0	0	0	2						
	1-3	0	0	1	14.3	0	0	1						
	U to C	--	--	--	--	1	--	U to C						
p. Child satisfaction with AFOs	7-9	19	86.4	4	57.1	7	70	3	10	50	3	42.9	5	62.5
	4-6	3	13.6	2	28.6	3	30	2	10	50	2	28.6	3	37.5
	1-3	0	0	1	14.3	0	0	1	0	0	2	28.6	0	0
	U to C	--	--	--	--	--	--	U to C	--	--	--	--	--	--

q. Parent satisfaction with AFOs	7-9	21	95.5	4	57.1	6	60	3 2 1 U to C	13	65	6	85.7	2	25
	4-6	1	4.5	2	28.6	4	40		7	35	1	14.3	6	75
	1-3	0	0	1	14.3	0	0		0	0	0	0	0	0
	U to C	--	--	--	--	--	--		--	--	--	--	--	--
<b>Section G. Clinical Team Functioning</b>	<b>R1 Scoring</b>	<b>R1</b>						<b>R2 Scoring</b>	<b>R2</b>					
		Clinicians		Clinician-researchers		Parents			Clinicians		Clinician-researchers		Parents	
		n	%	n	%	n	%	n	%	n	%	n	%	
a. Clinical team members communicate regularly with each other to ensure families are provided with consistent information.	7-9	20	90.9	6	85.7	10	100							
	4-6	2	9.1	1	14.3	0	0							
	1-3	0	0	0	0	0	0							
	U to C	--	--	--	--	--	--							
b. Team collaboration is optimized (e.g., multidisciplinary clinics)	7-9	19	86.4	6	85.7	10	100							
	4-6	3	13.6	1	14.3	0	0							
	1-3	0	0	0	0	0	0							
	U to C	--	--	--	--	--	--							
c. Clinical teams ensure collaboration with members of children's communities (e.g., teachers, coaches, school therapists) to obtain information about children's needs and function across environments.	7-9	16	72.7	5	71.4	9	90							
	4-6	6	27.3	2	28.6	1	10							
	1-3	0	0	0	0	0	0							
	U to C	--	--	--	--	--	--							
d. Ensure that clinical team members have the same treatment goals related to AFO use for each child.	7-9	19	86.4	5	71.4	8	88.9							
	4-6	3	13.6	2	28.6	1	11.1							
	1-3	0	0	0	0	0	0							
	U to C	--	--	--	--	1	--							
e. Ensure that there is a main contact person for families	New item		--		--		--		9	45	3	42.9	7	87.5
									11	55	3	42.9	1	12.5
									0	0	1	14.3	0	0
									--	--	--	--	--	--
f. Ensure the systems of care enable the time required for communication with families.	New item		--		--		--		10	52.6	6	85.7	7	87.5
									8	42.1	1	14.3	1	12.5
									1	5.3	0	0	0	0
									1	--	--	--	--	--

a (7-9) & e (3): Critical and should be included in the core considerations; b (4-6) & f (2): Important but not critical and may be included in the core considerations;

c (1-3) & g (1): Not important and should not be included in the core considerations; d (U to C): Unable to comment



## Ratification Meeting

Nine participants from the Delphi survey (two parents, three physical therapists, two orthotists, and two clinician-researchers) participated in the online ratification meeting. Thirty-seven items in total were voted on during the ratification meeting, of which 23 were voted in and added to the core clinical considerations. The results from this meeting are presented in Table 4.5.

*Table 4.5. Ratification Meeting Results*

Items	Participants (n)	Include	Exclude	Final Decision
<b>Section A. Initial Timing of AFO Prescription</b>				
Age	9	5	4	Exclude
Gross motor function level (i.e., GMFCS level)	9	0	9	Exclude
Family ability to travel to and attend appointments (e.g., time off work, costs associated with travel)	9	2	7	Exclude
Family ability to afford AFOs	9	1	8	Exclude
Family readiness for receiving AFOs for their child (e.g., time commitment to adjust to AFO use, emotional readiness, etc.)	9	3	6	Exclude
Presence of foot/ankle deformity	9	8	1	Include
Accompanying medical conditions that might affect child's tolerance of wearing AFOs (e.g., autism)	9	5	4	Exclude
<b>Section B.1. Selection of AFO Type</b>				
Gait analysis using video recording (non-instrumented)	7	4	3	Exclude
Gross motor function level (i.e., Gross Motor Function Classification System level)	7	1	6	Exclude
Muscle strength	7	6	1	Include
Shank to vertical angle alignment of tuned AFO-footwear combinations during gait	7	5	2	Include
Dynamic pedobarography (i.e., foot pressure measurement)	7	0	7	Exclude
Static alignment of joints	7	6	1	Include
<b>Section B.2. AFO Construction</b>				
Child preferences for design (e.g., color, pattern)	9	7	2	Include
Options of alternate materials/construction that are more conducive to hot/cold temperatures	9	4	5	Exclude
Options for thinner materials that allow more flexibility for movement	9	0	9	Exclude
Children and families' previous experience with orthoses	9	7	2	Include
Ease of donning and doffing AFOs with orthoses	9	7	2	Include
Use of durable materials so that AFOs can be worn until the child outgrows them	9	8	1	Include
Modification of AFO heel height in combination with footwear (i.e., tuning)	9	7	2	Include
Ease of adjustment for growth (e.g., extending the proximal trim line, or footplate)	9	4	5	Exclude
Thinner materials (e.g., copolymer plastic) to make AFOs and fit them in shoes more easily	9	4	5	Exclude

<b>Section C. Communication with families</b>				
Maximize child involvement in AFO decision-making	9	8	1	Include
Advise families where they can purchase specific footwear and clothing brands to fit AFOs within their budget	9	8	1	Include
Ensure families have information about peer groups in the community (e.g., support groups, children's playgroups), so they can learn from the lived experience of other families	9	7	2	Include
Ensure ongoing communication with families to obtain information about children's abilities to function in multiple environments such as home, school, child care, and community	9	9	0	Include
Ensure that families are provided with necessary information about AFOs in multiple formats (verbal, written, web-based, video) at different reading levels and languages	9	9	0	Include
<b>Section D.1. Frequency &amp; Duration of AFO use</b>				
Family and child preferences, priorities, and routines (e.g., fit with family schedule)	9	8	1	Include
Effects of AFOs on functional mobility (e.g., if AFOs inhibit play time on the floor in daycare, they could be removed)	9	9	1	Include
Environments that are best suited to AFO use (e.g., AFOs/shoes are not worn at home)	9	8	2	Include
<b>Section E. Monitoring AFO</b>				
monitoring the need for AFO repair (e.g., Velcro/straps are worn out)	9	9	0	Include
<b>Section F. Outcomes associated with AFO use</b>				
movement agility (i.e., moving and changing directions quickly)	9	1	8	Exclude
psychosocial factors (e.g., child's sense of well-being, body image, confidence, self-esteem, perceived stigma)	9	7	2	Include
Child satisfaction with AFOs	9	8	1	Include
Parent satisfaction with AFOs	9	9	0	Include
<b>Section G. Clinical Team Functioning</b>				
Ensure that there is a main contact person for families	9	8	1	Include
Ensure the systems of care enable the time required for communication with families	9	9	0	Include

## Finalization of Core Clinical Considerations

The items in the section “monitoring of AFO use” were merged with the other sections to avoid redundancy and emphasize the importance of constantly monitoring AFOs at different stages of treatment. The final core clinical considerations consisted of six sections and 35 items, presented in Table 4.6.

**Table 4.6. Final Core Clinical Considerations**

<b>SECTION A. TIMING OF INITIAL AFO PRESCRIPTION</b>	
1	<b>Gross motor function</b> (e.g., crawling, sitting, standing, walking, running, climbing up and down the stairs)
2	<b>Gait pattern</b> (e.g., the emergence of equinus gait)
3	<b>Clinical assessment of foot and ankle:</b> 1) The amount of plantar flexor spasticity 2) Dorsiflexion range of motion 3) Presence of foot/ankle deformity
4	<b>Goals of AFO use:</b> 1) Clinical goals 2) Goals identified by families
5	<b>Timing of any other treatments</b> (e.g., botox or serial casting)
6	<b>Presence of pain that could be relieved by AFOs</b>
<b>SECTION B. 1. SELECTION OF AFO TYPE</b>	
7	<b>Visual gait analysis</b>
8	<b>Child's daily functional mobility routine</b>
9	<b>Child and family priorities, preferences, goals and previous experience with AFOs.</b>
10	<b>Clinical assessment:</b> 1) muscle strength 2) spasticity assessment (e.g., modified Tardieu) 3) ankle joint range of motion 4) presence of bone deformity in foot (e.g., midfoot break) 5) Static alignment of joints
11	<b>Ongoing or recent treatments that could modify muscle tone</b> (e.g., medication for spasticity management)
<b>SECTION B.2. AFO CONSTRUCTION</b>	
12	<b>Child preferences for design</b> (e.g., color, pattern)
13	<b>Addressing and monitoring user friendliness:</b> 1) Modifications for comfort (e.g., padding) 2) Ease of donning and doffing AFOs 3) Use of durable materials so that AFOs can be worn until the child outgrows them.
14	Tuning & monitoring the shank to vertical angle alignment of tuned AFO-footwear combinations
<b>SECTION C. COMMUNICATION WITH FAMILIES</b>	
15	<b>Ensure families understand why AFOs have been recommended.</b>
16	<b>Discuss the advantages and disadvantages of different types of AFOs.</b>
17	<b>Maximize child involvement in AFO decision-making.</b>
18	<b>Inform families about the basics of AFO device, use, and monitoring:</b> 1) AFO size and appearance 2) Possible adverse effects of AFOs (e.g., floor mobility restrictions, skin issues) 3) To monitor skin integrity, pain, AFO fit, ease of donning and doffing 4) Safety issues (e.g., risk of falling when AFOs are worn without shoes) 5) Plan the frequency and duration of AFO use, including wear-time breaks, collaboratively with families 6) To monitor frequency and duration and encourage families to decide on the details based on their daily routines if needed. 7) Schedule regular follow-up sessions with families (e.g., need for repair, adjustments/maintenance, and replacement and to address families' questions/concerns).
19	<b>Provide psychosocial support on:</b> 1) The adjustment period required to increase children's tolerance for AFOs 2) Tools to support the adjustment period (e.g., schedule for gradually increasing wear time), 3) Emotional adjustment to AFOs (e.g., stress associated with child's resistance to wearing AFOs or child looking different because of AFOs). 4) Peer groups in the community (e.g., support groups, children's playgroups), so they can learn from the lived experience of other families.
20	<b>Inform families about adapted clothing, cost, and time:</b> 1) Implications for appropriate clothes and footwear (e.g., footwear, pants, and socks to wear with AFOs), 2) Where families can purchase specific footwear and clothing brands to fit AFOs within their budget, 3) The cost of AFOs and adapted clothes, 4) Available support resources for attending appointments to receive AFOs (e.g., financial aid, transportation compensation, etc.) 5) Time commitment for appointments for AFO construction

21	<p><b>Obtaining family input continuously in relation to AFO use:</b></p> <ol style="list-style-type: none"> <li>1) Children's abilities to function in multiple environments such as home, school, child care, and community</li> <li>2) Concerns about AFO frequency and duration based on the child's function and daily challenges in different environments (e.g., activity restrictions with AFOs, such as limitations moving around on the floor at daycare)</li> <li>3) AFO effectiveness</li> <li>4) Family goals and the children's needs in multiple environments such as home, school, child care, and community.</li> </ol>
22	<p><b>Provide the necessary information in multiple formats (verbal, written, web-based, video) at different reading levels and languages.</b></p>
<b>SECTION D. FREQUENCY &amp; DURATION OF AFO USE</b>	
23	<b>Family and child preferences, priorities, and routines</b>
24	<b>Goals of AFO use</b>
25	<p><b>Functional mobility in different environments:</b></p> <ol style="list-style-type: none"> <li>1) Effects of AFOs on functional mobility (e.g., if AFOs inhibit play time on the floor in daycare, they could be removed)</li> <li>2) Environments that are best suited to AFO use (e.g., AFOs/shoes are not worn at home)</li> </ol>
26	<p><b>Child's tolerance for AFOs:</b></p> <ol style="list-style-type: none"> <li>1) Child's physical tolerance</li> <li>2) Child's acceptance of AFOs (e.g., child routinely objects to AFO use)</li> </ol>
<b>SECTION E. OUTCOMES ASSOCIATED WITH AFO USE</b>	
27	<p><b>Foot integrity:</b></p> <ol style="list-style-type: none"> <li>1) Joint range of motion (e.g., ankle dorsiflexion),</li> <li>2) Appearance or progression of joint/bone deformity</li> </ol>
28	<b>Pain</b>
29	<p><b>Motor Function:</b></p> <ol style="list-style-type: none"> <li>1) Gross motor function (e.g., standing, walking, running, kicking, crawling, standing up from the floor)</li> <li>2) Balance related to safety and function: fall frequency</li> <li>3) Functional independence</li> </ol>
30	<b>Gait parameters</b> (e.g., walking speed, gait pattern, trunk control, or posture)
31	<p><b>Walking efficiency:</b></p> <ol style="list-style-type: none"> <li>1) energy consumption</li> <li>2) fatigue</li> </ol>
32	<b>Psychosocial factors</b> (e.g., child's sense of well-being, body image, confidence, self-esteem, perceived stigma)
33	<p><b>Goal attainment:</b></p> <ol style="list-style-type: none"> <li>1) Attainment of goals identified by the child and/or family,</li> <li>2) Attainment of goals identified by clinical teams.</li> </ol>
33	<b>Participation and inclusion</b>
34	<p><b>User satisfaction:</b></p> <ol style="list-style-type: none"> <li>1) Child satisfaction with AFOs</li> <li>2) Parent satisfaction with AFOs</li> </ol>
<b>SECTION F. CLINICAL TEAM FUNCTIONING</b>	
35	<p><b>Optimized Collaboration:</b></p> <ol style="list-style-type: none"> <li>1) Multidisciplinary clinics</li> <li>2) Clinical team members communicate regularly with each other to provide consistent information</li> <li>3) Clinical team members have the same treatment goals related to AFO use for each child,</li> <li>4) There is a main contact person for families.</li> <li>5) Clinical teams collaborate with members of children's communities (e.g., teachers, coaches, school therapists) to obtain information about children's needs and function across environments.</li> <li>6) The systems of care enable the time required for communication with families.</li> </ol>

## **Discussion**

This study provided a comprehensive list of core clinical considerations for AFO prescription and monitoring with young children with cerebral palsy through a systematically developed, consensus-based Delphi. Candidate considerations were rated over two rounds of Delphi survey by pediatric clinicians, researchers, and parents of young children with cerebral palsy. The final product is a set of core clinical considerations categorized into six main sections from clinical and parental perspectives, aimed to help clinicians with decision-making in AFO prescription and monitoring.

AFO prescription is considered a complicated process for clinicians (24), which is supported by the depth and breadth of the items included in this core set of clinical considerations. One of the considerations for prescription of AFOs was the importance of goal-setting with families. While the goals of AFO use has been suggested to be the primary determining factor in deciding when to prescribe the device to children (10), it has not been reported as a widely used factor for AFO provision in clinical practice (8). Most often, assessment of gait pattern, ankle range of motion, and muscle tone (8) are used to determine when AFOs are required. While these factors were also rated critical in this Delphi study, the inclusion of goal setting suggests that clinicians need to also consider the values and goals of families when making decisions about AFOs. By looking at the critical items for the selection of AFO type, it can be concluded that, in addition to clinical assessment of the child, family-related factors such as family input about children's functioning on a daily basis, their preferences, and goals meaningful to them are critical, highlighting the need to involve families at an early stage of decision-making about the AFO type. The inclusion of items based on qualitative research with families and involving parents as expert panelists in the Delphi study highlighted the

importance of ensuring a diverse range of family and child-oriented factors, such as child preferences for design and user-friendliness. Approaching AFO decision-making with a user-oriented lens would likely lead to improved outcomes due to the potential effects of aesthetics on adherence to use plan and child and family satisfaction (25).

The majority of items under “communication with families” were rated critical across all three stakeholder groups, highlighting the need for ensuring effective information-sharing and collaborative decision-making with families and providing adequate background information about AFOs to families. A component of family-centered care includes considering families as experts in decision-making about their children’s care plan (26, 27), which needs to be addressed to a greater extent in pediatric orthotics (11). Families usually tend to identify goals that are meaningful for enhancing functional abilities and participation of children in social activities (28), an aspect that requires more attention when prescribing and monitoring AFOs. Incorporating families’ input in decision-making and communicating effectively with them about their children’s treatment plan will likely make families more confident about the AFO use process (38) and reduce the challenges they experience. Educating and guiding families about the AFO prescription, the benefits and challenges of AFO use, monitoring, adapted clothing, and psychosocial support during the adjustment period could also encourage collaboration with families. This practice may lead to making families as partners (29) and empower their role in their young children’s rehabilitation plan (30).

There is no agreement about the optimal dosage of AFO use in children with cerebral palsy, and consensus is challenging due to a variety of factors, including the lack of human evidence about the optimal dosage to avoid muscle contracture (31), and the lack of longitudinal studies examining effects of AFOs on muscle strength (32). In addition, child and parent

perception of the device (e.g., positive functional effects) (33), aesthetics (33, 34), children's willingness to use the AFOs (25), environmental (e.g., activity setting) (35) and device-related factors (e.g., too stiff and hot) (25), also affect decision-making about optimal wear time, which were identified critical in this Delphi study. Consideration of these factors suggests the importance of individualized use plans according to children's routines and phase of treatment (e.g., the first few months of receiving AFOs likely requires a lower dosage to adjust to the device), child and family goals (11) and clinical objectives of AFO use (10). For example, if the child wears AFOs to maintain balance during walking or running, the dosage could be adjusted for outdoor and floor activities. Reported discrepancies between assumed and actual AFO wear time in children with cerebral palsy have created more uncertainty about the AFO dosage and use adherence recommendations among clinicians (35). The critical items related to involving families in developing meaningful goals and individualized wear-time schedules identified in this study, have the potential to optimize adherence and minimize the discrepancy between recommended hours and actual wear time.

Some of the factors included in the final list of considerations included in the final set are not frequently cited in the literature, such as reduction of pain and prevention is considered one of the goals of the AFO provision (10). Therefore, pain could be included in future research evaluating outcomes associated with AFO use (36). Notably, age was not considered a stand-alone critically important factor for informing the timing of initial AFO prescription. Functional abilities and family routines and activities were considered to be more important than the age of the child. However, age is often reflected in some of the other clinical considerations associated with timing for prescribing initial AFOs such as presence of contracture and gross motor function.

AFOs vary based on their design, stiffness, and materials, which affects the forces they apply to the foot and ankle (4, 37). Due to the lack of rigorous evidence in relation to the indication and effectiveness of each type of AFO, clinical assessment in determining the appropriate AFO type revolves around the level of gait pattern, spasticity, ankle joint range of motion, and presence of deformity in the ankle and foot compartment. All of these factors were identified critical in this study, consistent with the existing literature (6, 8). Visual gait analysis was rated critical in this Delphi survey for the observation of gait patterns. Although the advancement of technology and accessibility of video-recording devices has made instrumented gait analysis and video recording feasible in clinical practice, high-tech options for observation of gait did not reach consensus for inclusion. In fact, instrumented gait analysis was the only item in the survey that was rated less important by the majority of panelists across all three groups. This exclusion may be explained by the lack of availability of advanced motion analysis systems in rehabilitation centers, especially in rural and remote locations across Canada, and the time constraints associated with including it routinely in clinical practice.

Interdisciplinary coordination and teamwork has been introduced as one of the aspects of family-centered care (38), and its success relies on effective collaboration among clinical team, families, and children at all stages of the treatment (39). Effective interdisciplinary clinical team functioning incorporates clear communication, pre-define roles of members, and collaborative discussions with the aim of achieving goals (39) with the child and family, which was identified critical in this study. Kane et al. (6) described AFO provision as an iterative process, requiring the clinical team to feel confident and comfortable about their decisions and dedicate sufficient time for the optimal outcome. Support at the organizational level could help clinicians overcome time constraints accompanied by multiple meetings and discussions around AFO decision-



making (6), leading to better service delivery. It has also been suggested that collaborative team functioning in pediatric orthotics may enhance service delivery by providing families with clear and consistent information (11). It is worth noting that collaborative team functioning requires learning about core principles of inter-professional competency and educating team members about how to work as a team (40). Therefore, educational institutes should consider incorporating inter-professional competency modules in their curriculum to address effective team functioning in a clinical setting.

The majority of the items under the section “outcomes associated with AFO use” were rated critical, highlighting the importance of evaluating the effects of AFO use across all domains of ICF, a consideration that has been suggested previously (7, 8, 10). By identifying outcomes such as functional independence, participation and inclusion, and goal attainment as critical across three stakeholder groups, it is likely to influence a shift in pediatric orthotics toward promoting meaningful activity and participation in desired environments for young children. The goals of using AFOs might evolve due to growth and developmental trajectories over time, and goal attainment should be assessed at different stages of treatment to ensure they still address family and clinical objectives of prescription (10). Some of the outcomes are not commonly measured routinely in clinical practice with families of young children with cerebral palsy, such as fatigue, pain, participation and inclusion, functional independence, and user satisfaction. Clinical assessment tools could be used by multi-disciplinary teams in clinical settings to track changes in meaningful outcomes over time. Identification of specific measurement tools was beyond the scope of this study and could be the focus of future work in this area. Developing a clinical core outcome set that is meaningful to families, which incorporates the definition of each outcome and its associated domain according to the

components of ICF, could be a practical approach to using the introduced outcomes in this study. Validated and reliable assessment tools should be explored and introduced to clinical teams to navigate measuring the core outcomes associated with AFO use for young children. Clinical team members should define their roles in assessing the core outcomes, frequency of assessment, and sharing the results among the team and with families regularly at their institutes.

This study aimed to provide clinical practice considerations for clinicians and families of young children with cerebral palsy to facilitate decision-making processes regarding AFO prescription and monitoring practices. Since AFO receipt and use can be overwhelming for families (11), and there is a significant gap between research and practice in pediatric orthotics (7), this documentation may address and minimize the barriers clinicians face in their decision-making about AFOs with families of young children in need of AFOs.

## **Limitations**

One of the limitations of this Delphi study was the lower proportion of clinician-researcher and parent groups compared to clinicians in the ratification meeting, which likely affected the results (41). Although there is no ideal panel (sample) size for the Delphi studies (14), we attempted to recruit a heterogeneous group of panelists throughout Canada's known pediatric clinician-researchers network and family-focused organizations to overcome the possible attrition between R1 and R2. Some potential panelists declined to participate in the study due to their lack of foundational knowledge about AFOs, regardless of their involvement in prescribing AFOs for young children.

We did not collect socioeconomic information from families who participated in the study, which likely affected the results of the final core considerations addressing family-

oriented items. For example, while the cost of AFOs is mainly covered by insurance in Canada, the socioeconomic status of families probably influenced the importance of the items that addressed affordability, cost, and travel time associated with receiving AFOs. Ensuring a diverse and variable socioeconomic status among participants could provide a more equitable result, clarifying the barriers that may prevent families from receiving services that are available to those with higher socioeconomic status.

Another limitation of this study is lack of assessment of the feasibility of implementing the identified core clinical considerations in practice. Future research studies should focus on rating or ranking the feasibility of the core considerations from both clinical and parental perspectives and evaluate the implementation process.

## **Conclusions**

This study invited different pediatric healthcare professionals, researchers, and parents of young children with cerebral palsy to reach consensus on critical clinical considerations for the prescription and monitoring of AFOs used by young children with cerebral palsy. The core clinical considerations were rated critical by more than 70% of participants across all three stakeholder groups. The final product of this study was documentation to navigate clinicians, researchers, and families in decision-making about AFO prescription and monitoring for young children with cerebral palsy grounded in the ICF and family-centered care models. Although this study targeted young children with cerebral palsy who are likely to receive their first AFOs, most sections, such as AFO construction and selection of the AFO type, communication with families, frequency and duration of use, and clinical team functioning, are applicable for other age groups. Future research also should focus on how to measure the outcomes associated with AFO use and

implementation of the core considerations in clinical practice in collaboration with families to ensure that the document is feasible for families and clinicians. This tool could be used as a stepping stone for developing guidelines for AFO prescription and monitoring for young children with cerebral palsy.

## **Acknowledgments**

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## Appendix A. Search Strategy

Database	Children	Protocols/ Considerations	AFO
Medline (Ovid) 1946- July 21, 2021	exp child/ or exp infant/ or adolescent/ or exp pediatrics/ or pediatric*.mp. or paediatric*.mp. or child*.mp. or newborn*.mp. or congenital*.mp. or infan*.mp. or baby.mp. or babies.mp. or neonat*.mp. or pre-term.mp. or preterm*.mp. or premature birth*.mp. or NICU.mp. or preschool*.mp. or pre- school*.mp. or kindergarten*.mp. or kindergarden*.mp. or elementary school*.mp. or nursery school*.mp. or schoolchild*.mp. or toddler*.mp. or boy.mp. or boys.mp. or girl*.mp. or middle school*.mp. or pubescen*.mp. or juvenile*.mp. or teen*.mp. or youth*.mp. or high school*.mp. or adolesc*.mp. or pre-pubesc*.mp. or prepubesc*.mp.	(experience* or perception* or perceive* or perspective* or opinion* or attitude* or belief* or voice or self report or narrati* or expectation* or impression* or views or values or reaction* or response or responses or stories or reflections or face or facing or Satisfaction or preferences or journey* or facilitat* or challenges or barrier* or difficulties or difficulty or obstacle* or hurdle* or barricade* or hindrance* or obstruct* or disparit* or inequi* or unequal* or impede* or impediment or qualitative or interview* or fieldwork or "field work" or "key informant" or questionnaire* or focus- group* or ethnol* or ethnog* or emic or etic or hermeneutic* or phenomenolog* or grounded-theor* or guideline* or protocol* or consideration* or decision* or consensus*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	Foot Orthoses/ or ((ankle foot or foot) adj8 ortho*).mp. or (Orthotic Devices/ and (ankle/ or foot/)) OR ((ankle/ or foot/) AND (orthos?s OR orthotic*))
CINAHL (1979- July2021)	(MH "Child, Preschool") or (MH "Adolescent") or (MH "Child+") or preschool* or pre-school* or kindergarten* or kindergarden* or elementary school* or nursery school* or schoolchild* or toddler* or boy or boys or girl* or middle	experience* or perception* or perceive* or perspective* or opinion* or attitude* or belief* or voice or self report or narrati* or expectation* or impression* or views or values or reaction* or response or responses or stories or reflections or face or facing or	ankle foot ortho* or ankle foot orthos?s or ankle foot orthotic*

	school* or pubescen* or juvenile* or teen* or youth* or high school* or adolesc* or pre-pubesc* or prepubesc* or child* or adolesc* or pediat* or paediat*)	Satisfaction or preferences or journey* or facilitat* or challenges or barrier* or difficulties or difficulty or obstacle* or hurdle* or barricade* or hindrance* or obstruct* or disparit* or inequi* or unequal* or impede* or impediment or qualitative or interview* or fieldwork or "field work" or "key informant" or questionnaire* or focus-group* or ethno* or ethnog* or emic or etic or hermeneutic* or phenomenolog* or grounded-theor* or guideline* or protocol* or consideration* or decision* or consensus*	
EMBASE (1947-July 21-2021)	exp child/ or exp infant/ or adolescent/ or exp pediatrics/ or pediatric*.mp. or paediatric*.mp. or child*.mp. or newborn*.mp. or congenital*.mp. or infan*.mp. or baby.mp. or babies.mp. or neonat*.mp. or pre-term.mp. or preterm*.mp. or premature birth*.mp. or NICU.mp. or preschool*.mp. or pre-school*.mp. or kindergarten*.mp. or kindergarten*.mp. or elementary school*.mp. or nursery school*.mp. or schoolchild*.mp. or toddler*.mp. or boy.mp. or boys.mp. or girl*.mp. or middle school*.mp. or pubescen*.mp. or juvenile*.mp. or teen*.mp. or youth*.mp. or high school*.mp. or adolesc*.mp. or pre-pubesc*.mp. or prepubesc*.mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]	(experience* or perception* or perceive* or perspective* or opinion* or attitude* or belief* or voice or self report or narrati* or expectation* or impression* or views or values or reaction* or response or responses or stories or reflections or face or facing or Satisfaction or preferences or journey* or facilitat* or challenges or barrier* or difficulties or difficulty or obstacle* or hurdle* or barricade* or hindrance* or obstruct* or disparit* or inequi* or unequal* or impede* or impediment or qualitative or interview* or fieldwork or "field work" or "key informant" or questionnaire* or focus-group* or ethno* or ethnog* or emic or etic or hermeneutic* or phenomenolog* or grounded-theor* or guideline* or protocol* or consideration* or decision* or consensus*).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]	exp ankle foot orthosis/ or ((ankle foot or foot) adj8 (ortho* or orthos?s or orthotic*)).mp. or exp foot orthosis/
Scopus (till July21, 2021)	TITLE-ABS-KEY ( child* OR adolescen* OR preschool OR "pre-school" OR teen* OR youth OR pediat* OR paediat* )	TITLE-ABS-KEY ( experience* OR perception* OR perceive* OR perspective* OR opinion* OR attitude* OR belief* OR voice OR "self report" OR narrati* OR expectation* OR impression* OR views	TITLE-ABS-KEY ((ankle-foot or foot) W/8 (ortho* or orthos?s or orthotic*))

		<p>OR values OR reaction* OR response OR responses OR stories OR reflections OR face OR facing OR satisfaction OR preferences OR journey* OR facilitat* OR challenges OR barrier* OR difficulties OR difficulty OR obstacle* OR hurdle* OR barricade* OR hindrance* OR obstruct* OR disparit* OR inequi* OR unequal* OR impede* OR impediment OR qualitative OR interview* OR fieldwork OR "field work" OR "key informant" OR questionnaire* OR focus-group* OR ethno* OR ethnog* OR emic OR etic OR hermeneutic* OR phenomenolog* OR grounded-theor* OR guideline* OR protocol* OR consideration* OR decision* OR consensus* )</p>	
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## Appendix B. Included Articles in the Literature Review

Author, Year & Country	Study Design	Aim of Study	Population (Diagnosis, Number of Participants & Age)	Outcomes Measured	Results (Direct Quotes from Articles)
Assenza 2020, Italy (42)	Retrospective cohort study	To better identify the correlation among clinical characteristics of the children and the type of assistive device prescribed in order to better predict future equipment needs.	<p><b>Participants:</b> 100 (52.08%) children were affected by CP and 92 (47.91%) by a genetic/ chromosomal/ syndromic condition.</p> <p><b>N:</b> 192 (111 males, 57.81%)</p> <p><b>Age:</b> The average age at the moment of admission: 1.4±1.14 years.</p> <p>The average age at discharge was 6.38 years (SD=2.36) with a mean period of rehabilitation of 5.09±2.34 years.</p>	GMFCS	<p>Strong evidences of a positive correlation with GMFCS has been found relative to AFO (prescription probability increases from 29.38% at GMFCS level I [CI: 16.81-46.12%] to 97.18% at GMFCS level V, dynamic orthoses (prescription probability increases from 7.32% at GMFCS level I [CI: 4.04-12.90%] to 51.19% [ci: 34.12-67.98%]) at GMFCS level V.</p> <p>The data analyzed also demonstrated a very weak negative correlation between communication disorders and the prescription of AFO (with a risk ratio 0.56 times lower [ci: 0.28-0.99]).</p>
Contini 2019, Brazil (43)	Randomized cross-over (the article mentioned observational cross-over)	To develop an instrumented assessment protocol based on wearable gait analysis to support clinicians in ankle-foot orthoses configuration selection.	<p><b>Participants:</b> Children diagnosed with diplegic CP were selected for this instrumented observation from those with a clinical indication of conservative treatment through AFOs.</p> <p><b>N:</b> 10 (3 females and 7 males)</p> <p><b>Age:</b> 4-11 years</p>	<p>Participants were observed walking barefoot and while walking with custom-made sAFO and hAFO.</p> <p>Spatio-temporal parameters were calculated over each 10MWT trial (obtaining four data points/ session/ participant), whereas gait stability and symmetry indices were computed over each step (obtaining a number of data points equal to the number of steps performed by each patient during each session).</p>	<p>All parameters exhibited marked variability (reduced median differences and large IQR values) when comparing each AFO configuration with the barefoot condition.</p> <p>While no common trend appears evident among the resulting differences, few individuals (e.g., subj4, subj5) displayed significant improvements after sAFO prescription, others benefited more from the use of hAFO (e.g., subj1, subj3, subj6), whereas the remaining five patients had similar effects for both orthotic solutions.</p>
Eddison 2020, UK (34)	Pilot study	To investigate perception and adherence to wearing an AFO and FC the participants were	<b>Participants:</b> Children with a diagnosis of spastic CP and a gross motor function	A questionnaire was designed, which consisted of 12 questions. The responses	The results indicate a much higher number of positive responses as opposed to negative responses regarding function when wearing a



		asked to wear as part of their orthotic prescription. In particular, whether the visibly modified footwear affected the users adherence to the orthotic treatment.	classification system level of two, as determined by a pediatric physiotherapist, took part in this study. All participants were long-term AFO users (long-term was defined as having worn an AFO for five years or more).  <b>N:</b> 5  <b>Age:</b> 7-11 years	focused on function, aesthetics, and wear time. These categories were chosen to capture the perceived benefit of the treatment: function; what did the treatment enable the participant to physically accomplish; aesthetics; how did the participant perceive the cosmetic aspect of the treatment; wear time; how often did the participant adhere to using the orthosis	tuned AFO-FC, with all the participants (n = 5) reporting they walked better in their tuned AFO-FC, with fewer falls (n = 3) and improved balance (n = 5).  The participants reported no positive responses regarding the aesthetic element of the AFO-FC but identified a number of negative responses including not liking wearing their splints and their adapted footwear (n = 5) due to the way the splints looked (n = 5) and due to other people noticing them (n = 5).  The results indicate that the children mainly wore their AFO-FC during school time and for approximately 6-8 hours per day 4-7 days per week. With three participants reporting they now wear the AFO prescription more often than they did when it wasn't tuned. None of the participants reported wearing their tuned AFO-FC less often than their previous non-tuned AFO-FC.
Huang 2009, UK (25)	Qualitative	To explore the usability of assistive devices at home by children with cerebral palsy and consider the underlying factors related to the device usage in this setting mainly from the children's perspectives.	<b>Participants:</b> Parents and children with CP who have or had the experience of using assistive devices, now attend primary or junior high school, can communicate either verbally or non-verbally and agree to participate in this study voluntarily. Frequency of device at home: AFOs (n=11), stander (n=7), computer aid (n=2), ambulation aid (n=8), wheelchair (n=7), special tricycle (n=3).	Semi-structured interviews covering topics: feelings about assistive devices, situation of device use at home as well as support and difficulties in relation to device use at home.	Four main factors leading to low device use at home were identified, including children's reluctance, mothers' perspectives, physical environmental barriers, and device-related ones.

			<p><b>N:</b> Total of 30 participants including 15 children with CP (six boys and nine girls) and 15 mothers.</p> <p><b>Age:</b> 8-15 years</p>		
Kane 2019, Canada (8)	Qualitative	To examine how physical therapists (PTs) use evaluation measures to guide prescription and re-assessment of ankle-foot orthoses (42) for children with CP	<p><b>Participants:</b> Licensed PTs in Canada who had been involved in AFO prescription for at least one child with CP in the past two months.</p> <p><b>N:</b> 60 PT</p> <p><b>Age:</b> A median of 15 years of PT experience and a median of 10 years in pediatrics</p>	<p>The survey consisted of 28 questions (six open-ended, 22 closed-ended).</p> <p>Close-ended questions addressed: (1) demographics; (2) evaluation measures used to inform initial prescription and re-assessment; and (3) recommendations for AFO design and adjustments post-fitting. Open-ended questions asked about the clinical indications for different types of AFOs, the most important information examined initially and at re-assessment, opinions about the benefits or harms of a plantarflexed AA-AFO, and the types of adjustments recommended at re-assessment.</p>	Three themes emerged from the open-ended responses, which were supported by closed-ended responses. (1) Focus on impairment-level measures. Although evaluation primarily involved observational, non-standardized measures of impairments and gait patterns, most respondents also considered participation-level constructs. (2) Lack of confidence/knowledge. Respondents reported a moderate level of confidence concerning decision-making about AFO type and characteristics. (3) Inconsistent practices between therapists, possibly reflecting the paucity of available evidence or individualization of the prescription.
Kane 2019, Canada (6)	Qualitative	To identify current AFO prescription and clinical decision-making practices for children with CP in Canada.	<p><b>Participants:</b> Clinicians who were involved in AFO prescription for children with CP.</p> <p><b>N:</b> 4 physiatrists, 17 PTs, 10 orthotists, and 1 kinesiologist</p> <p><b>Age:</b> Clinical experience in pediatrics ranged from 1–39 years</p>	Focus groups were focused on the goals and types of AFOs used, referral and follow-up processes, and clinical evaluation measures.	Categories and themes emerged from the focus groups. Categories included: what is made, how it is used, and factors that either support or challenge outcomes. Strengths and challenges of the current prescription process were discussed, including funding, communication, and technology to enhance clinical evaluation. Throughout the interviews, the theme of prescription as a collaborative, iterative, and individualized process emerged.

Koltsov 2020, Russia (45)	Retrospective cohort study	To assess the type and frequency dynamics of rehabilitation assistive devices in children with spastic forms of cerebral palsy, depending on the level of the gross motor function of the patient	<p><b>Participants:</b> Parents of pediatric patients with infantile cerebral palsy aged 2-17 years.</p> <p><b>N:</b> 214</p> <p><b>Age:</b> n/a</p>	Dynamics and frequency of rehabilitative assistive devices using a questionnaire in two time periods. Period I started from the time of the first orthosis and ended a year before the questionnaire, while period II included the last six months before the survey.	<p>It was revealed that patients used orthopedic shoes and splints for the lower limb of various designs most stably. The frequency of their use in period II was 87% and 75%, respectively, of the same indicator in the period I. In the structure of functional orthoses, the frequency of using devices for hip joints in period II was the highest among all similar orthoses.</p> <p>Based on the analysis of the distribution of functional orthoses on the ankle joints, they were used in complex rehabilitation by patients with all levels of motor activity. The maximum frequency of use was recorded in GMFCS 3–4 groups.</p> <p>over half of the reasons for parents to refuse RADs were subjective and associated with organizational problems when prescribing the products or adapting to them, the negative attitude of the child, and technical errors of the product. In only 17% of cases, the causes of failure were because of an objective change in the patient’s condition.</p>
Lahoud 2020, Australia (46)	Qualitative	To explore, through qualitative content analysis, how children regard the acquisition (i.e. the process of prescription, consultation, and fitting) and use of an from the perspectives of child users, their parents/carers and practitioners	<p><b>Participants:</b> Children using AFOs</p> <p><b>N:</b> n/a</p> <p><b>Age:</b> Children under 18</p>	Data related to user experience with AFO was collected from 15 formal publications and 30 informal online platforms.	<p>Five key themes emerged: materials, structure, aesthetics, service, and impact.</p> <p>Child users had mixed opinions about ankle-foot orthoses, reporting satisfaction with the functional improvements resulting from ankle-foot orthosis wear while noting negative feelings from the experience of acquiring and using the device.</p>
MacFarlane 2020, Australia (47)	Mixed-methods case series	To synthesize and enrich the volume of evidence reported to inform real-world applications of SMotO use in children with CP. This case series also aims to demonstrate the impact of SMotOs and AFOs function, movement, and quality of life in	<p><b>Participants:</b> Children with a diagnosis of CP with any Gross Motor Function classification system level, using SMotOs/AFOs (or have used them) and completed the wearing in</p>	<p>Quantitative (for both AFO and SMO): Timed Up-and-Go, Berg Balance Scale,</p> <p>Qualitative: Three styles of qualitative evidence were included: written feedback from parents compiled from</p>	It appears, through both the qualitative and quantitative results, that children with CP have some preference for using SMotOs. In support of this, when looking at the Q’AIRE qualitative data, parents tended towards more positive comments regarding the use of SMotOs when compared to AFOs for gross motor skills and ease of use. In addition, it was identified that

		the individual, in a way that is clinically relatable.	process, and no surgery in past six weeks.  <b>N:</b> 8 (male=7, female=1)  <b>Age:</b> 3 to 13 years (average age=7 years, SD=3.7 years)	the Q'AIRE, images of pedographs (46), and/or video images of gait.	families do not have follow-up appointments to reassess gait with AFOs and the impact of the AFO on gross motor skills. Clinically, it may also be beneficial to implement a follow-up timeline to reassess the effect of orthoses prescribed.
Morris 2011, UK (32)	Summary of a consensus conference	To present the findings relating specifically to the orthotic management of CP.	<b>Participants:</b> Children with CP  <b>N:</b> n/a  <b>Age:</b> n/a	n/a	Dialogue between the child and family, the orthotist, and other members of the team (therapist, physician, surgeon, bioengineer, etc.) is essential when deciding upon treatment goals and the biomechanical objectives to achieve these goals. The role of the orthotist is to design, fit, align, deliver and review the orthosis which will, in theory, achieve the biomechanical objectives agreed by the team. When an orthosis is prescribed consideration must be given as to when, and for how long in each twenty-four-hour period it should be worn. Adherence to orthotic management regimens is likely to be better when there is a clear agreement between therapists and the orthotist regarding the treatment regimen, and the family fully understands the rationale for the prescription.  There is scant literature reporting on the perceptions of orthosis users and/or their carers regarding the value of AFO use
Naslund 2003, Sweden (49)	Qualitative	To explore how the parents of children with diplegic cerebral palsy experience the use of DAFOs	<b>Participants:</b> Parents of children, aged 4-18 years, with spastic diplegia who were currently using DAFOs. They had been using DAFOs for an average of 18 months and orthoses were prescribed in order to improve sitting,	During the interviews, the researchers used exploratory questions, such as 'How do you think the DAFO affects your child in sitting/in standing/in activities of daily living?' and 'Is there something good/bad about DAFOs?' The use of open-ended interviews meant	Content analysis resulted in the following categories: 'Physical effects'; 'New functions and activities'; 'The orthosis as a part of the treatment'; 'Opportunity for independence and play'; and 'Problems with DAFOs'. According to the parents, DAFOs appeared to contribute to the (mechanical) changes in posture affecting the muscular system. They meant that when wearing DAFOs the foot and ankle are more stable. This in turn enables postural control and

			standing, and walking functions. <b>N:</b> 15 <b>Age:</b> n/a	that parents could raise issues they regarded as important.	alignment, contributing to functional activities under more favorable physiological conditions. The psychosocial effects were regarded by parents as being just as important as the physical effects.
Owen 2019, UK (50)	Commentary	n/a	<b>Participants:</b> n/a <b>N:</b> n/a <b>Age:</b> n/a	n/a	<p>When making decisions about AFO provision the starting place is to determine the goals, short, medium, and long term in all areas of the ICF. It was therefore interesting to see that “Goals” was not ranked higher on the list of “information that physical therapists evaluate at initial and follow-up assessment.” Without a list of goals grounded in the ICF, it is not possible to determine anything about the required AFO design, alignments, and period of use. Determining goals should be a collaborative effort between the team around the child (TAC) and the family, and requires knowledge of prognosis. Most families will require guidance and information in this area if they are to be equal partners in decision-making with the TAC.</p> <p>The findings in Kane and colleague’s paper are unlikely to be unique to Canada. We need to band together at local, national, and international levels to work in teams to find existing clinical algorithms and develop new ones that will facilitate decision-making about which AFO and footwear designs, and what frequency of use, will achieve client goals across all domains of the ICF. To achieve this, the cooperation of professionals and managers is needed to form national and international interest groups. It is time for this work to be given priority as it is long overdue and will result in benefits for children and their families, and also for health economics (Churchill, 2015; Morris &amp; Condie, 2009). This is your call to action—create teams, share knowledge, and write</p>

					clinical algorithms which are based on achieving client-centered goals grounded in the ICF.
Owen 2020, UK	Symposium summary				
Polliack 2001, USA (51)	Cross-sectional	The purpose of this research was to: 1) determine the types of orthoses and materials used for children with myelomeningocele, 2) determine which aspects of current orthotic technology most critically needs improvement, and 3) identify whether some of these needs can be met by advanced composite materials.	<p><b>Participants:</b> Two different surveys were used: 1) for the child with myelomeningocele, or in case of comprehension or language difficulty, via the parent; and 2) for the certified orthotist treating children with myelomeningocele.  <b>N:</b> 26 child survey  32 orthotist  <b>Age:</b> n/a</p>	The surveys investigated issues including prescription criteria, materials and designs used, orthosis comfort, durability, cosmesis, and peer response.	<p>Children:</p> <p>Approximately 80% of those who responded claimed that the primary reason for needing replacement of an existing was due to growth or changes in medical condition. The remaining 20% stated that replacement was required due to AFO fracture or fatigue. Skin irritation tended to be the largest reported problem associated with unsuccessful treatment, with 29% of the respondents rating it as most troubling. Sixty percent of the respondents did not think that wearing AFOs was embarrassing, unattractive, or awkward looking. There was no indication of any specific or significant reasons why the children would be discouraged from wearing the orthoses at all times when needed. Contrary to hearsay, heat, and weight were not identified as an issue for this sample population of AFO users. For example, 64% of respondents gave a rating of "least trouble" when asked if the orthosis ever got too warm, and 75% gave the same rating when asked if the orthosis ever got too heavy after long periods of wear. On the other hand, when asked if the children would wear the orthoses more often if improvements to comfort, weight, profile, and cosmesis were addressed, at least 80% responded positively to all the possible changes, as would be expected. From the various miscellaneous comments indicated, the one suggestion that appeared on various occasions concerned the Velcro strapping used to secure the orthoses to the calf region. The respondents stated that the Velcro damaged household furniture and quickly</p>

					<p>became dirty or “unsightly” due to the lint collection. Other common miscellaneous comments included concern about the limitations of footwear that could be worn comfortably with the AFOs. Eighty-nine percent indicated they wear sneakers; however, 77% would prefer to have more shoe wear options.</p> <p>Orthotist:</p> <p>The most critical steps in the treatment process, as identified by the orthotist responses included, patient evaluation, compliance, casting technique, cast modification, material choice, and physical therapy. There was no statistical significance between these factors. The most prevailing reasons why treatment was found to be unsuccessful were the increased weight of the child and the user’s preference of a wheelchair over the orthosis for mobility. The most common occurrence of material failure was near the medial and lateral malleoli areas of the AFO, as expected. Fifty percent of the orthotists surveyed stated they prefer to use polypropylene material for fabricating AFOs for children with myelomeningocele.</p>
Ribeiro Volpini Lana 2021, Brazil (52)	Qualitative	To understand the perception of mothers of children with CP in relation to their children's ankle-foot orthosis.	<p><b>Participants:</b> Mothers of children with Levels IV and V CP, according to the GMFCS. All the children in this study used a solid AFO placed bilaterally on the lower limbs.</p> <p><b>N:</b> 24 mothers of children with CP. According to the GMFCS classification, 8 children (36.36%) were considered Level IV and 16</p>	Key topics covered in the semi-structured interviews were sociodemographic identification, perception about the orthosis, use of the equipment in the child's daily life, and the mothers' opinions on possible adjustments and/or modifications	<p>The results were grouped into three categories: "Benefits of the orthosis", "The orthosis in the child's daily life", and "what if it were like this?"</p> <p>The first category was subdivided into two subcategories: "Improvement in positioning and mobility" and "Prevention of deformities."</p> <p>In the second category, the subcategories were "The orthosis use in different environments" and "The orthosis usage period."</p>

			<p>children were considered Level V CP</p> <p><b>Age:</b> Mothers aged between 22 and 50 years (38.18 ± 7.73)</p> <p>Children between 5 and 12 years old (8.59 ± 3.17)</p>		<p>Finally, the third category was "Predilections and aesthetic suggestions about the orthosis" and "Usability and practicality of the orthosis."</p>
Roberts 2016, UK (53)	Randomised Controlled Trial	Assessment of the effectiveness and efficiency of using laser scanning to produce ankle-foot orthoses	<p><b>Participants:</b> All patients up to 18 years of age referred for rigid and hinged AFOs at the Trust were candidates for inclusion. Young adults up to the age of 21 years were also included if they were still receiving services for children (e.g. because they were in education).</p> <p><b>N:</b> 134</p> <p><b>Age:</b> 1.5 to 21.3 years with a mean age of 10.7 years (SD=4.9 years) and 9.8 years (SD=4.1 years) for males and females, respectively.</p>	<p>The primary outcome measure was the length of time taken (in minutes) in the molding and rectification process.</p> <p>Secondary outcome measures included the following: (a) length of time (in minutes) spent with subjects to cast and scan limbs; (b) length of time (in minutes) to fit the AFO(s); (c) number of days taken from initial scanning/casting of a subject to the completion of an AFO (or AFOs) that met fitting specifications (any additional time taken for rescanning or remaking was included) and (d) the length of life of the AFO in days.</p> <p>Patient-focused outcome measures included the 'Satisfaction with Device' and 'Satisfaction with Service' questionnaires, which were developed in the United States as part of the Orthotics and Prosthetics Users' Survey (OPUS).</p>	<p>There was no significant difference in the time taken to cast or scan the limbs (p=0.056, paired t-test) with the mean times being 12.5 (SD=4.9)min and 11.1 (SD=9.5)min for cast and scan, respectively, and a mean difference of 1.33 (SD=10.07), 95% CI of paired difference=-0.4 to 3.1. Evaluation of average casting time throughout the study revealed no training effect or trend in casting time. However, a striking difference was seen over time in the time taken to scan as a result of unplanned staff turnover. If we only include scan times for the two orthotists who had received more training and were already familiar with the technique prior to the start of recruitment, a statistically significant difference (p&lt;0.001, two-sample t-test) was then seen with average times 13.1 (SD=4.4) min for casting and 8.9 (SD=2.9) min for scans.</p> <p>There were no significant differences in delays in supply between the two methods (p=0.711, logrank test). A significantly higher proportion of scan-based AFOs failed to meet the specification stipulated by the scanning orthotist.</p> <p>Data were available for 68 of the subjects allocated to the cast group and 62 subjects</p>



				<p>allocated to the scanned group. No significant effects were seen (<math>p=0.12</math>, logrank test) of the allocated group on the time taken from casting/scanning to delivery of a well-fitting AFO/AFOs.</p> <p>No significant difference was seen in the length of life of AFOs manufactured using the casting or scanning method (<math>p=0.57</math>, logrank test).</p> <p>After experiencing both casting and scanning (in random order), 70% of the patients said they preferred being scanned to having the limbs cast in plaster. A Mann–Whitney U test to evaluate differences in responses to 4-point Likert-type scale (Strongly Agree–Strongly Disagree) found no significant differences between the allocated groups when applied individually to the 9 ‘Satisfaction with Device’ questions and the 10 ‘Satisfaction with Service’ questions at each time point (3-, 6- and 12-month follow-up). ‘Agree’ was the pre-dominant category selected by respondents for all questions, thus indicating a reasonable level of satisfaction with the AFOs and services.</p> <p>The economic results for plaster versus scan show no advantage of scan over plaster in terms of cost-effectiveness.</p> <p>The average total societal cost for individuals in the scanning group was £2859, and for those in the casting, group was £2824. The observed incremental cost of scanning for individuals with complete cost and outcome data was £70. For individuals with complete data, the</p>
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					incremental effect of scanning was an increase in the time to delivery of 10days. Traditional casting was found to strongly dominate LSCAD/CAM. The observed ICER is therefore negative, with a 95% bias-corrected and accelerated bootstrapped CI of -£128 to £1.
Wright 2020, USA (4)	Expert's opinion	n/a	<b>Participants:</b> Ambulatory CP <b>N:</b> n/a <b>Age:</b> n/a	n/a	<p>Key points: Challenges exist to the “dosing” of orthoses (duration of wear and design) in ambulatory CP. One concern expressed is that restriction of motion in an orthosis may inhibit the emergence of foot and ankle muscle use, limiting the development of typical movement patterns.</p> <p>Goal setting for an AFO, a critical element in prescribing, can create tensions between allowance of motion for functional goals and movement restriction to preserve musculoskeletal integrity. Some functional activities, such as transitioning to standing and stair climbing, benefit from more ankle ROM than is required for walking. Allowing for ankle dorsiflexion, as with a hinged AFO (HAFO), is based on this premise: that ankle motion is essential for the performance of normal movement patterns and postural responses. However, when there is an ankle ROM limitation imposed by a tight gastrocnemius complex (GSC), the allowance of dorsiflexion creates a circumstance favorable to break-down of the midfoot. Compromise of midfoot integrity impairs postural response by weakening the foot lever, contributing to an unintended decline of posture in gait (crouch). Therefore, goals must be balanced. Consideration of strength, the severity of spasticity, ankle ROM, and anticipation of the potential for worsening crouch must factor into the decision rather than assuming that all children will benefit from 1 style of AFO rather than another. Introduction of an articulation also</p>

					usually compromises intimacy of fit of the brace and control of the hindfoot may be lost. Increased mediolateral motion may increase and skin issues may result.
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### Appendix C. Results of Secondary Analysis of Interviews

Participant ID	Outcomes	AFO prescription & construction considerations	Considerations for communication with families	Considerations for multidisciplinary collaboration	Considerations for ongoing monitoring & support
AFO-01	<p>Lengthening and stretching of calf muscles</p> <p>Avoiding surgery in future</p> <p>Walking better (no toe walking)</p> <p>Foot deformity</p> <p>Balance</p> <p>Safety</p> <p>Foot positioning (flat foot)</p>	<p>Considering skin reaction to AFOs in wearing time recommendation.</p> <p>Considering any accompanying pain or discomfort with AFO use in prescribing recommendation.</p>	<p>Costs of adapted clothing items such as shoes</p>		<p>Strategies for gradually increasing tolerance to adjust with AFOs.</p> <p>Considering child's communication abilities in wearing time recommendation.</p> <p>Considering individualized wear routine specific to the child's mobility and function in relation to AFOs.</p>
AFO-02	<p>Help with toe walking,</p> <p>flat foot</p> <p>balance,</p> <p>in-toeing.</p>	<p>Considering skin reactions.</p> <p>Considering shoe recommendations when prescribing AFOs.</p>			<p>Strategies for adjustment to AFOs</p>
AFO-03	<p>Ankle support,</p> <p>Preventing deformity,</p> <p>Standing,</p> <p>Ankle position.</p> <p>Walking,</p>	<p>Considering skin reactions when recommending wearing AFOs for long hours.</p> <p>Considering recommendations for shoes, boots and pants to wear with AFOs in advance.</p>	<p>Considering parents' emotional and mental status when prescribing AFOs (preparing parents for a new intervention/equipment).</p>	<p>Team work for coming up with wearing recommendations and providing information in advance.</p>	<p>Advice for the event AFOs are causing problems without scaring parents about giving breaks.</p> <p>Considering family's lifestyle and child's individual abilities and routine to recommend wearing hours.</p>

	Ankle development				
AFO-04	Pain Endurance Fatigue Wear pattern	Suggestions about clothing	Regular communication between family and clinical team to reassure families receive ongoing support about establishing routines with AFOs. Also, families inform clinicians about the adverse effects, activity or function restrictions with AFOs	Communication between clinicians should match to avoid confusion for families.	Providing families with wearing-time recommendation schedule, support with adjustment period and how to monitor the AFOs, what to expect from AFO, informing families about the potential adverse effects when AFOs are off.  Considering child's leads on AFO when recommending wear time and breaks preferences
AFO-05	Pain Confidence Independence Balance Stability	Providing info about skin reactions and tightness of AFOs (how tight they should be and what to monitor) when prescribing them.  Suggestions about clothes (shoes, socks, pants)	Communication between families and clinicians to seek information about the AFO routine based on child's function (exp., restrictions in water activity and floor mobility)- two-side communication.		Providing information about transition and adjustment period and possibility of giving breaks in wearing time recommendation.  Considering child's abilities and routine when providing recommendations.
AFO-06	Balance Emotional regulation	Providing basic information such as clothing to families before their appointment and giving information about AFOs to provide families with a better perspective of AFOs so they can prepare children.  Information before giving AFOs: costs, length/ size/ material/ look, frequency of replacing, expected ROM with AFOs, playing sports with them, types of clothes  Child-friendly AFOs (color, pattern, ...)	Collaboration and communication of families with schools to understand the needs of children wearing AFOs.	Communication of multi-disciplinary team to individualize and optimize AFO use for families.	Introducing support groups so families can get answers to their questions.
AFO-07	Standing Walking Independence Confidence	Considering skin irritations and limitations in activities when using AFOs- this affects wearing time schedule and recommendation.	Costs of shoes and other clothing with AFOs		Providing families with the basic information about AFOs (look, material, how often to wear), bigger picture of AFOs and how they affect the child in long term.

					Providing families with a scheduled wearing time, including breaks and considering their lifestyle and resources, child's tolerance- individualized wearing time recommendation.
AFO-08	Endurance  Range of motion (stretch and repositioning of the foot),  Foot clearance,  Emotional regulation		Providing communication opportunities for families to talk about challenges they deal with everyday  Providing families with the long-term benefits of AFOs to help them with the fear/ guilt of giving breaks.  Costs of footwear		Considering child's tolerance and abilities into wearing time recommendation- individualized recommendation.  Recognizing child's cognitive and behavioral characteristics as well as physical abilities when recommending AFO wear-time.  Considering families' access to resources and their lifestyle limitations when recommending AFOs.
AFO-09	Confidence,  Foot clearance,  Safety (balance),  Running	Providing information about AFO-friendly clothing items and shoes to families.	Providing opportunities for parents to ask questions about their concerns.	Team communication to find a wearing time schedule that works for families.	
AFO-10	Positioning of the foot,  Redness or pressure,  Walking,  Standing,  Kicking	Considering providing information (benefits and reason for prescription) about different types of AFOs and why the child is eligible for a certain type in advance.	Communicating with families about follow-up schedules.		Providing individualized documentation to families which includes information about AFO wear-time, maintenance, cleaning and care, tightening, monitoring pressure sores, footwear and socks, and follow-up.  Considering adjustment period for families to add AFOs to routine- providing schedules with gradually increasing hours.

## **Appendix D. Preliminary Delphi Items with Reference Coding**

### **Section A. Timing of Initial AFO Prescription**

Age

Gross motor function (e.g., crawling, sitting, standing, walking, running, and climbing up and down the stairs)

Gross motor function level (i.e., Gross Motor Function Classification System level)

Gait pattern (e.g., the emergence of crouch gait)

The amount of plantar flexor spasticity

Dorsiflexion range of motion

Family ability to travel to and attend appointments (e.g., time off work, costs associated with travel)

Family ability to afford AFOs **(Q; AFO-03, L; 14)**

The ability of AFOs to address family priorities, preferences, and goals

### **Section B. AFO Construction and Selection of AFO Type**

Visual analysis of gait pattern **(L; 7 & 22)**

Gait analysis using video recording (non-instrumented)

Instrumented gait analysis (e.g., gait laboratory) **(L; 9)**

Child's daily functional mobility routine (e.g., getting up and down from the floor, moving on the floor, going up the stairs, walking, using mobility aids, etc.). **(L; 7, 9, Q; AFO-07)**

Gross motor function level (i.e., Gross Motor Function Classification System level)

Child and family priorities, preferences, and goals **(L; 4, 12, 17 & 19)**

Muscle strength assessment **(L; 22)**

Spasticity assessment (e.g., Modified Tardieu) **(L; 22)**

Ankle joint range of motion assessment **(L; 22)**

Bone deformity of the foot (e.g., midfoot break)

Child preferences for design (e.g., color, pattern) **(Q; AFO-06, L; 10, 14, 19)**

Options of alternate materials/construction (e.g., air holes) that are more conducive to excessive temperatures. **(L; 14)**

Modifications for comfort (e.g., padding over ankles, strap options)

### **Section C. Communication with Families**

Ensure families understand why AFOs have been recommended for their young children. (Q; AFO-04 & 07, L; 11)

Discuss the advantages and disadvantages of different types of AFOs (e.g., hinged, solid) with families. (Q; AFO-04, 07, 10, L; 4, 11, 14 & 20)

Discuss possible adverse effects of AFOs (e.g., floor mobility restrictions, skin issues) with families and inform them about monitoring and addressing skin integrity and AFO fit. (L; 11 16, 19 & 22, Q; AFO-05, Q; AFO-04, 06 & 07, L; 11)

Ensure families know about AFO size and appearance and the implications for appropriate clothes and footwear (e.g., footwear, pants, and socks to wear with AFOs) (Q; AFO-06 & 07, 02, 03, 04, 05, 09 & 10, L; 7, 14, 16, 19)

Advise families where they can purchase specific footwear and clothing brands to fit AFOs.

Ensure families are aware of the costs of AFOs and adapted clothes (Q; AFO-01, 07, 08)

Schedule regular follow-up sessions with families and members of the clinical team to check AFO fit, need for adjustments/maintenance and replacement, and to answer family questions/concerns. (Q; AFO-06 & 10, L; 7, 12 & 19)

Inform families about the adjustment period required to increase child's tolerance for AFOs (L; 11, 13, 14 & 16, Q; AFO-01, 02, 04, 05)

Discuss family concerns related to emotional adjustment to AFOs (e.g., stress associated with child's resistance to wearing AFOs or parent concern about the child looking different because of AFOs) (Q; AFO-04, L; 10 & 14)

Ensure families have information about peer support groups (e.g., community and peer support), so they can learn from the lived experience of other families (Q; AFO-06) (L; 12)

### **Section D. Frequency and Duration of AFO Use**

Family and child preference, priorities, and routines (e.g., fit with family schedules) (L; 11, 20, 21, Q; AFO-01, 03, 05, 07 & 08)

Goals of AFO use (e.g., if the goal of AFO use is to prevent falls, then it could be removed for floor mobility) (L; 11, 18, 20, 21, Q; AFO-01, 03, 05, 07 & 08)

Effects of AFOs on functional mobility (e.g., if AFOs inhibit play time on the floor in daycare, they could be removed) (Q; AFO-01, 03, 05, 07 & 08)



Contexts that are best suited to AFO use (e.g., AFOs/shoes are not worn at home) (L; 11, 20, 21, Q; AFO-01, 03, 05, 07 & 08)

Child's acceptance of AFOs (e.g., child routinely objects to AFO use) (Q; AFO-01, 03 & 08)

Child's physical tolerance for AFOs (e.g., general discomfort, temperature regulation) (Q; AFO-01, 04, 07 & 08) (Q; AFO-01, 02, 03, 05, 06, 07)

Provide families with tools to support the adjustment period (e.g., schedule for gradually increasing wearing time). (Q; AFO-10)

Ensure families have opportunities to share concerns about AFO frequency and duration based on the child's function and daily challenges in different environments (e.g., activity restrictions with AFOs such as limitations moving around on the floor at child care). (Q; AFO-04, 05, 06, 08, 09, L; 10)

Plan the frequency and duration of AFO use, including wear-time breaks, collaboratively with families. (L; 11, Q; AFO-03, 04, 05, 06, 07, 09, L; 4, 11)

### **Section E. Monitoring AFOs**

Monitoring of AFO fit (e.g., the child has recently had a growth spurt). (L; 19)

Monitoring of pain or discomfort (Q; AFO-01, L; 7)

Monitoring frequency and duration of AFO use

Assess for the presence of skin redness or pressure points (Q; AFO-10)

Obtain input from the child and family on AFO effectiveness (L; 4, 12 & 16)

Determine if AFOs are contributing to achieving current rehabilitation goals (L; 20)

### **Section F. Outcomes associated with AFO Use**

Joint range of motion (S, L; 2, Q; AFO-01 & 08 (e.g., ankle dorsiflexion))

Prevention of joint/bone deformity (L; 12 & 20)

Pain reduction (Q; AFO-04 & 05, L; 7, 12 & 16)

Gross motor function (e.g., standing, walking, running, kicking, crawling, standing up from the floor) (S, Q; AFO-01, 02, 03, 07, 09, 10, L; 7, 10, 12, 14 & 16)

Movement agility (i.e., moving and changing directions quickly) (L; 16)

Gait parameters (e.g., walking speed, (L; 16) gait pattern, (S, Q; AFO-01, 02, 08 & 09, L; 7 & 12), trunk control or posture)

Walking efficiency (energy consumption)

Balance (S, Q; AFO-01, 02, 05 & 06, L-7, 10 & 16)

Fatigue (Q; AFO-04) (Q; AFO-04 & 08)

Safety (e.g. fall frequency) (Q; AFO-01, 09, L-10 & 16 (security))

Psychosocial factors; (e.g., child's sense of well-being, body image, confidence, self-esteem, perceived stigma) (Q; AFO-05, 07, 09 & L; 11, 14, 16, 20)

Child and/or family goal attainment

Participation and inclusion (S, L; 7, 10, 16)

Functional independence

Child satisfaction with AFOs (L; 7 & 14)

Parent satisfaction with AFOs (L; 7 & 14)

### **Section G. Clinical Team Functioning**

Members of clinical teams communicate regularly with each other to ensure families are provided with consistent information. (Q; AFO-04 & 06, L; 7 & 12)

Clinical teams provide regular opportunities for members to learn about strategies for effective team collaboration. (L; 7)

Clinical teams ensure communication with young children's **families** to obtain information about their goals, the child's needs, and ability to function in multiple environments. (L; 12, 15, 20, 22, Q; AFO-06)

Clinical teams ensure communication and collaboration between the team members and the child's **school** to obtain information about the child's needs and function across environments. (L; 12, Q; AFO-06)

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## CHAPTER FIVE: GENERAL DISCUSSION

This thesis includes three studies that identified gaps in the current state of evidence associated with AFO use with young children (Chapter 2), parent experiences with their young children's AFO use (Chapter 3), and clinical considerations for AFO prescription and monitoring for children with cerebral palsy (Chapter 4). In Chapter 2, a scoping review was used to examine current literature on outcomes, use patterns, and parental and clinical perspectives on AFO use in young children. We reported that the research focuses on the body functions and structures component of the ICF (1), with a lack of literature evaluating activity and participation level outcomes. There was also a significant absence of parent perspectives about AFO use with their children with cerebral palsy and a lack of research evaluating outcomes associated with AFOs with children below six years of age.

Chapter 3 was grounded on the gaps mapped from the findings of the scoping review. I aimed to obtain an in-depth understanding of the experience of parents who had young children with cerebral palsy using AFOs. The findings in Chapter 3 highlighted the need to involve families in research and practice to inform clinical practice about considerations that may hinder the optimal use of AFOs with young children. These considerations included the need to collaborate with families to inform dosage recommendations, ensure families have adequate information about adapted clothing, monitoring AFOs and challenges associated with the adjustment period to AFO use. Parents also reflected on their journey of accepting and adapting to AFOs as part of their daily routines and how they perceived that their children benefited from using them. This qualitative study accentuated the value in family recognition of AFO use and challenges, the gaps in current clinical practices surrounding AFO provision, and clinical implications that could address these gaps.

Chapter 4 aimed to incorporate parental and clinical perspectives into clinical practice considerations for AFO prescription and monitoring through a consensus-based approach. The Delphi study triangulated different sources of data and evidence, including the major findings from the scoping review (Chapter 2), qualitative study (Chapter 3), and current research and practice to provide core clinical considerations for clinical and parental use. The core considerations are intended to support decision-making and practices regarding the timing of initial AFO prescription, AFO type and construction, dosage, communication with families, assessment of outcomes, and team functioning.

Each study in this thesis provides novel and complementary information about the use of AFOs for young children with cerebral palsy and their families, which were not evident in the literature previously (2). The major findings of this thesis highlight the need for adopting an individualized approach when prescribing and monitoring AFOs, ensuring that each child and family is unique in their journey of accepting and using AFOs. The ICF (1) directs us to consider outcomes associated with AFO use beyond their effects on the biomechanical properties of joints and gait. This approach emphasizes the interaction of the device with different components of the framework, such as activity, participation, and environmental factors, from the clinical and family lens. Furthermore, including families of young children with cerebral palsy identified gaps in service delivery that could be addressed by the enhanced implementation of family-centered care in pediatric orthotics.

## **Clinical Implications**

AFO provision is a multifaceted process, and considerations should be taken when prescribing them for young children with cerebral palsy. Some main points related to clinical implications that emerged from this thesis are discussed below.

### **A Holistic Approach; Focusing on Activity and Participation**

This thesis was informed by the definition of functioning described by the ICF and the importance of considering interactions of AFOs with different components of the model (1). The findings in Chapter 2 identified a lack of research addressing the effects of AFOs on activity and participation outcomes for young children with cerebral palsy. A substantial body of evidence in pediatric orthotics focuses on the body functions and structures. Although evaluating impairment level outcomes is essential, a holistic approach that looks at the association of AFO use across all components of the ICF may enhance our understanding of the contributing role of AFOs in functioning in young children in their living environments, such as home, communities, and schools/daycares. This theme emerged in Chapter 3 as families emphasized the need to focus on the whole child, not their ankle or foot, in isolation from their daily routines, values, preferences, and goals.

Activity performance and participation are largely influenced by environmental factors (1). Participation is a multi-dimensional concept and is comprehensible when the context is explained (3) (e.g., participation in play). We recommend conducting research studies focusing on age-appropriate activity and participation outcomes that are meaningful to young children in multiple environments (e.g., home, communities, daycares/schools) and consideration of contextual factors that affect AFO use. Applying this holistic approach in pediatric orthotics may

help clinicians to shift their practice to promote functional abilities rather than fixing impairments, a gap that exists in pediatric orthotics and was emphasized in Chapters 2-4 of this thesis.

### **Individualized AFO Prescription and Monitoring**

Children and families benefit from an individualized and collaborative approach to AFO prescription (4). Different considerations may be applied when deciding about AFOs for children younger than six years of age. Young children with cerebral palsy explore their environments using different movement strategies, such as bottom shuffling and crawling, floor mobility, and transitional movements from the floor. Therefore, when prescribing AFOs, clinicians should be aware of the balance between movement and restriction on the ankle-foot compartment (5) specific to each child. Also, parents and caregivers are the primary support system and advocates for their children at young ages. Service delivery often focuses on the child; however, the goals and treatment plan should be aimed at families, too, since families often make choices to support their young children's development and treatment based on family resources and capabilities (6). The core considerations developed in Chapter 4 have the potential to address this aim by navigating clinicians on what to communicate with families and what families need during the process of adjusting to AFOs. Therefore, incorporating family preferences and values in decision-making about AFO provision may facilitate service delivery according to children's needs and desired treatment outcomes. This theme was highlighted in Chapter 3 of this dissertation.

Goal-setting with families and children would facilitate individualization of AFO prescription and use. Every child and family is unique in their treatment journey; family preferences, biomechanical and musculoskeletal needs of the child, and clinical prognosis drive

the goal-setting process (7). Owen and colleagues (8) have recently developed a pictorial goal-setting tool specific to orthotic devices that could be used in clinical practice to individualize the goal-setting process and AFO prescription. This tool and the core considerations in Chapter 4 could guide clinicians through the steps of AFO provision, such as dosage recommendations, outcome evaluation, and monitoring in collaboration with families of young children.

Extensive research has been conducted on the biomechanical properties of AFOs, and useful factsheets and algorithms have been developed to help clinicians individualize the AFO provision based on children's clinical presentation (9, 10). However, the current AFO prescription is based mainly on the trial-and-error method (5), sometimes resulting in ambiguity and uncertainty in clinical decision-making for children and families. The lack of standardized guidelines, combined with the availability of several AFO designs and construction methods, likely results in clinical decision-making for AFO provision being influenced by the culture of clinical centers and clinicians' comfort with the options known to them (4). Therefore, there is a need to shift the current practice from trial and error to a more standardized, individualized, collaborative decision-making approach with families and children. This theme emerged in Chapters 2-4 repeatedly as a consideration of developing practice guidelines by incorporating family-centered approach in pediatric orthotics.

### **Family-Centered Approach**

Family-centered care is one of the influential models when working with families and children with cerebral palsy, as it focuses on the context of family in designing an intervention and care plan (11). Family affects child's development directly as the main support system and plays an integral part in the progress of child's treatment (11). The main components and principles of the family-centered care model include respect and dignity, information sharing,

collaborative relationship, and partnership (12, 13). By addressing respect and dignity in service delivery, clinicians aim to listen to families and consider their goals, priorities, and values in developing treatment plans (14). The importance of this aspect of family-centered care emerged in Chapter 3 of this thesis. Although families did not specifically state that the orthotic service delivery lacked respect from the clinical team, parents did report that they often felt that their voices were not heard by clinicians. This gap could be diminished by applying family and child-centered care models in pediatric orthotics to focus on family needs and incorporating their values and preferences into the orthotic treatment plans. We embedded family perspectives in the Delphi study (Chapter 4) to address this gap, and the results of the surveys and discussions in the ratification meeting highlighted the need for incorporating family choice and values in decision-making.

Information sharing is beyond providing basic information about treatments to families. It focuses on the necessity of clear communication between clinicians and clients to tailor the information based on family needs (14). Clinicians should ensure that families have enough knowledge about the treatment plan to be able to collaborate on decision-making (14). Lack of information sharing about AFO provision and use emerged in Chapters 3 and 4 of this thesis and described how the paucity of information-sharing affected families negatively and that they had to conduct their own research to be able to find answers to their questions. Dedicating enough time to provide comprehensive background knowledge about AFOs, creating user-friendly documentation about AFOs (e.g., blogs, short videos, pamphlets), and educational tools are some strategies that could mitigate this matter and facilitate the interaction between families and clinical teams. It is worth noting that families of young children receiving AFOs for the first time are likely overwhelmed with the diagnosis and concurrent interventions; hence, they may need

more guidance throughout the process. The perceived stigma of using AFOs in public settings and the accompanying psychosocial factors are important considerations when AFOs are prescribed and introduced to families. Therefore, developing educational tools for families that incorporate sufficient background information about AFOs is recommended, as suggested by other researchers (4, 15). This thesis highlighted the need to empathize with families in the process of receiving and adjusting to AFOs and informing them with enough details about the device so they would be able to make informed choices.

Collaborative relationships and partnerships between families and clinicians should aim at involving families as partners in higher-level decision-making plans and at the organizational level to affect service delivery (14). It has been indicated that family-centered care may enhance successful treatment outcomes, affecting family and child satisfaction with their rehabilitation services and developing parental knowledge about their children's condition and care plan (18); a gap in pediatric orthotics that was highlighted in Chapters 3 and 4 of this thesis. With the emphasis on family-centered care practices in pediatric rehabilitation, it is necessary to reconsider orthotic prescription patterns and amend the current clinical practice to align the service delivery with child and family values and choices.

## **Implementation of Findings**

Rehabilitation practice often occurs in multidisciplinary healthcare organizations, and any changes in practice routine probably involve changes at different levels of the organizations (e.g., policymakers, managers, healthcare professionals, and families and children) (16). Therefore, a systematic approach that matches the culture and context of the healthcare organization is required to apply research findings into practice. Pre-implementation assessment could provide

in-depth information about the readiness for change at the institute and the key barriers or facilitators of applying AFO considerations by an interdisciplinary clinical team in practice.

Implementation is beyond the scope of this dissertation, and applying the proposed AFO considerations in practice is challenging and requires further exploration. However, some general considerations about the implementation of findings are discussed here. Implementation science studies methods or strategies to systematically close the gap between evidence-based research findings and clinical practice. It focuses on adopting new research findings in clinical practice to improve care quality and service delivery and to promote treatment outcomes (17).

Implementation evaluation is crucial to make significant practice changes feasible for the organization, clinical team, and families. Different implementation strategies are available to translate evidence-based research findings into practice, and a multi-faceted approach is usually used to combine different strategies and apply them to a context (18, 19). Powell and colleagues (18) classified implementation strategies into six categories to address implementation processes in health: planning (e.g., assessing readiness, identifying key barriers), educating (e.g., developing educational tools, continuous training), restructuring (e.g., revising professional/clinical roles), financing (e.g., changing patient fees), managing quality (e.g., obtaining family feedback, providing clinical performance feedback), and attending to the policy context (changing credential or professional development standards).

As mentioned earlier in this thesis, each child and family is different in their journey of receiving and accepting AFOs. Furthermore, clinical culture and teamwork vary at different institutes, affecting the scope of practice and interdisciplinary work with families, therefore, the implementation process. For example, a consideration that might be feasible and practical for a family and clinical team in a city may not work for a family or a clinician in a rural town.



Therefore, understanding the context of family, healthcare professionals, their values, and preferences is needed to tailor the considerations and practice routine pragmatically. In addition, the implementation categories could be a starting point for the interdisciplinary clinical team and policymakers in pediatric rehabilitation to plan and apply the implementation process. The considerations proposed in Chapter 4 could be used by the team working with the child (clinicians and families); however, the role of each member should be defined, and regular meetings should be held to discuss the team process. Physical therapists and orthotists often interact more with families during AFO prescription and monitoring and, therefore, are the primary users of the proposed considerations. They could work closely to highlight the gaps in practice at their institute and provide reports to organization-level administrators to tailor their needs according to the proposed considerations. Clinical orthotists could identify evidence-based research and practice to inform educational organizations and assist with changes or revisions of clinical orthotic training. Families could be involved in the implementation process to provide feedback about the services they receive and the changes they may require to enhance their experience. Implementation process requires collaborative and effective teamwork at different levels of organizations. Therefore, healthcare system leaders play a central role in partnering with clinicians and researchers to act on required changes within the culture of organizations to apply new evidence into practice routines. Future research should use implementation frameworks to guide, apply, and evaluate implementation strategies to benefit clinicians and families with evidence-informed practice (20).

## **Strengths & Limitations**

The specific limitations of each study were explained in each chapter. The general strengths and limitations of this thesis are discussed in this section. This thesis included family involvement in different phases of research with the aim of focusing on child and family in relation to AFO use. This approach has enabled us to reflect parents' voice on AFO use with their young children with cerebral palsy to map the gap in service delivery in association with pediatric orthotics and interdisciplinary clinical functioning.

Although goals of AFO use are often set based on the biomechanical needs of children, there are some potential drawbacks to this approach; family and child needs are not incorporated in practice, AFO provision is not tailored to address family preferences, values, and young children's acceptance of the device. This thesis tried to identify and recognize what mattered to families and young children and foreground the absence of family empowerment and autonomy in decision-making about children's AFO receipt and use plan. Including families in Chapters 3 and 4 set the foundation for interpreting results in the context of family and clinical practice. There is a need to include children in the care development plan, and we did not interview children (Chapter 3) or invite them as panelists for the Delphi study (Chapter 4) due to their young age. Children's perspectives of AFO use and what they think of their orthotic device in different environments could bring insight into clinical practice. It has been reported that children identify various aspects of functioning from their caregivers and focus on their strengths and abilities. In contrast, primary caregivers often disclose their concerns about children's functioning and challenges in daily activities (21). Therefore, future research should design studies with appropriate techniques to enable young children to participate in research with their families.

A small sample size recruited throughout Canada was a limitation in this thesis. While we tried to enhance recruitment by expanding the study timeline, the low response rate was a drawback. Also, Chapter 3 was conducted during the Covid-19 pandemic. Although the interviews were conducted online, the shift in service delivery likely affected the recruitment phase, low response rate, and parents' perception of AFO use with their young children. Some parents mentioned that due to restrictions imposed by the Covid-19 pandemic, their children could not participate in group activities in their communities, limiting their functional mobility to indoors and often in isolation. Also, a sample size that includes families of young children with a wider spectrum of socioeconomic and cultural backgrounds could provide a different set of data and shape the results differently.

### **Future Research Directions**

Future directions for research on AFOs for young children with cerebral palsy should include how orthotic devices enhance or restrict activity and participation while considering age-appropriate activities children engage in at home (e.g., play) and in communities (e.g., group play). Studying how AFOs contribute to the participation of young children with cerebral palsy is critical, as meaningful participation is an essential aspect of pediatric rehabilitation (22, 23).

Evaluating the implementation of AFO core considerations presented in Chapter 4 should be the focus of future research to ensure its feasibility in clinical practice and for families. The core consideration is not a standardized clinical guideline for AFO provision and monitoring but rather a checklist that clinical teams could share with families when introducing AFOs. Some items on the list might not be applicable based on the context and scope of practice; however, the items are largely broad, and the sub-items introduced as examples could be selected according to

the needs of families and children. Future standardized practice guidelines that are evidence-based and in line with clinical and family values and considerations are necessary to enhance consistency in service delivery and efficiency in team functioning.

Given the importance of measuring AFO use across all components of the ICF in young children with cerebral palsy, this approach has some limitations. There are not many tools available that are clinically sensitive to measure changes in outcomes across all components of the framework in young children with cerebral palsy who use AFOs. Therefore, future research should focus on developing tools or validating the existing assessment tools for those outcomes that are clinically important and meaningful to young children and families. Some of these outcomes identified in the Delphi study in Chapter 4 are pain reduction, inclusion and participation, goal attainment, functional independence, psychosocial factors, and child and parent satisfaction with AFO use. Future research could consider a consensus-based study to obtain agreement on tools to measure the outcomes identified in Chapter 4 in relation to AFO use.

## **Conclusions**

The findings of this dissertation encourage clinical practice to shift from anecdotal evidence pertaining to AFO prescription and monitoring to applying considerations across all domains of the ICF. This thesis supports the family-centered care model in pediatric orthotics and among the interdisciplinary team to centralize family preferences and values in clinical decision-making about their young children. This approach is also beneficial in mitigating challenges identified in service delivery and shifting the practice from trial and error to a more collaborative, standardized process.

There are some static factors in the documentation provided in Chapter 4 that could be applied across nations for determining AFO type and timing. However, some external factors such as culture, socioeconomic status, family readiness, and the stigma associated with AFO use cannot be ignored when applying the considerations for families. Therefore, it is strongly suggested to involve families and children in decision-making about orthotic devices from an early stage of AFO provision. Families have the capability to inform clinicians about their financial and emotional support and their young children's ability to accept the device. Therefore, developing and adjusting children's treatment plans without the collaboration of families is unlikely to succeed. It is also critical that clinicians are aware of psychosocial adjustment associated with having a child with a disability and the potential implications of AFO use. Psychosocial adjustment to disability should be incorporated into professional training programs. If professionals lack awareness of psychosocial factors related to disability and assistive devices, it is unlikely to shift perspectives in clinical practice about individualizing and tailoring treatment plans according to families' transition time associated with psychosocial adjustment to the device.

Furthermore, families often find it challenging to object to and question the clinical team's decisions. Therefore, creating an effective therapeutic relationship could open up a safe space for families to reflect on their observations and inform clinicians. Adopting individualized prescription and monitoring plan that prioritizes child and family needs and preferences, identifying goals with the help of families for AFO prescription and use, and considering AFO use across all domains of ICF are the main themes developed in this thesis.

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