



Disability and Rehabilitation: Assistive Technology

ISSN: (Print) (Online) Journal homepage: informahealthcare.com/journals/iidt20

Understanding the use and benefits of assistive devices among young children with cerebral palsy and their families in Norway: a cross-sectional population-based registry study

Rikke Damkjær Moen & Sigrid Østensjø

To cite this article: Rikke Damkjær Moen & Sigrid Østensjø (2024) Understanding the use and benefits of assistive devices among young children with cerebral palsy and their families in Norway: a cross-sectional population-based registry study, Disability and Rehabilitation: Assistive Technology, 19:4, 1454-1462, DOI: <u>10.1080/17483107.2023.2198563</u>

To link to this article: https://doi.org/10.1080/17483107.2023.2198563

© 2023 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.



6

Published online: 07 Apr 2023.

ſ	
ι	Ø

Submit your article to this journal 🖸

Article views: 3489

\mathbf{O}	

View related articles 🗹



View Crossmark data 🗹



Citing articles: 2 View citing articles

ORIGINAL RESEARCH

OPEN ACCESS Check for updates

Understanding the use and benefits of assistive devices among young children with cerebral palsy and their families in Norway: a cross-sectional populationbased registry study

Rikke Damkjær Moen^{a,b} and Sigrid Østensjø^a (D

^aDepartment of Rehabilitation Science and Health Technology, Faculty of Health Sciences, Oslo Metropolitan University, Oslo, Norway; ^bMedical Manager, Made for Movement, Skien, Norway

ABSTRACT

Purpose: Assistive technology intervention has become an important strategy in enhancing function in young children with cerebral palsy. This study aimed to provide an in-depth knowledge of the use of assistive devices by describing their purposes, the environments in which they are used, frequency of use and perceived benefits from the caregiver's perspective.

Material and methods: This is a cross-sectional population-based study using data from national cerebral palsy registers in Norway. Of a total of 202 children, 130 participated (mean age 49.9 months, SD 14.0 months).

Results: The 130 children and their families used a median of 2.5 assistive devices (range 0–12) to support positioning, mobility, self-care and training, stimulation and play. Devices most commonly had one or two main purposes and were used both at home and in kindergarten/school. The usage rate varied from less than twice a week to several times a day. The majority of parents reported significant benefits for caregiving and/or the child's functioning. Total use increased in accordance with the level of the child's gross motor limitations and was associated with restrictions imposed by housing concerns.

Conclusions: The frequent use of a wide range of devices, and the intended and perceived benefits, demonstrates that early provision of assistive devices can be an effective function-enhancing strategy in young children with cerebral palsy. However, the findings also indicate that factors others than the child's motor abilities must be considered when integrating the use of devices into the child's daily routines and activities.

► IMPLICATIONS FOR REHABILITATION

- Early provision of assistive devices can be a powerful strategy to support everyday functioning and facilitate care in young children with cerebral palsy.
- Assistive devices seems to be most effective when they are well integrated into the child's daily routines and activities across environments.
- The clinical classifications of motor abilities (Gross Motor Function Classification System and Manual Ability Classification System) can be used to estimate the need for assistive devices, however, factors others than the child's motor function seem to be critical for optimum effectiveness, such as type of equipment, its physical and social environment and the intended benefits of use.

Introduction

Environmental modifications such as use of assistive devices (ADs) is instrumental in encouraging the development and participation of children with disabilities, allowing each child to explore and play within their natural environments [1]. Cerebral palsy (CP) is a frequent cause of disabling conditions in childhood with a prevalence rate of around 2.2 per 1000 live births [2]. It has been defined as a group of permanent disorders of movement and posture that limit activity and are attributed to non-progressive disturbances occurring in the developing foetal or infant brain [3]. These motor limitations vary widely when classified with the

Gross Motor Function Classification System (GMFCS) and the Manual Ability Classification System (MACS) [4]. Motor disorders are often accompanied by disturbances in sensation, cognition, communication and/or behaviour [5].

The International Classification of Functioning, Disability and Health (ICF) [6] is a conceptual framework commonly used to describe and understand the various aspects of a health condition such as CP and to ensure that interventions like AT are appropriately targeted to the child and the family. Due to the complexity of the condition, children with CP are commonly provided with a wide range of assistive devices (ADs) to facilitate their functioning

CONTACT Sigrid Østensjø 🖾 sigrid@oslomet.no 🗈 Department of Rehabilitation Science and Health Technology, Faculty of Health Sciences, Oslo Metropolitan University, Oslo, Norway

ARTICLE HISTORY

Received 19 May 2022 Revised 17 February 2023 Accepted 29 March 2023

KEYWORDS

Assistive devices; young children; cerebral palsy; motor limitations; family perspective



 $[\]ensuremath{\mathbb{C}}$ 2023 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group.

This is an Open Access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited. The terms on which this article has been published allow the posting of the Accepted Manuscript in a repository by the author(s) or with their consent.

and care [7,8]. Such devices are considered essential environmental factors from the lens of the ICF [6]. Drawing on the ICF's domains of functioning and disability, AD is defined as "any product, especially produced or generally available, that is used by or for persons with disability: for participation; to protect, support, train, measure or substitute for body functions/structures and activities; or to prevent impairments, activity limitations or participation restrictions" [9]. Aside from an actual device, AT intervention includes the services and strategies associated with the device acquisition and effective use, such as assessment, fitting, training and follow-up [10].

Norway has established a unified national system for AT, giving users the right to necessary and appropriate products, free of charge [11]. Local health professionals are responsible for identifying and assessing user needs, recommending ADs and overseeing their implementation in daily life. Moreover, 12 AT centres at a county level operate as a referral system to ensure that every user has access to the necessary expertise irrespective of where they live [11]. In Norway, approximately 8% of the child population is provided with ADs and it is reported that nine in ten youngsters with CP use one or more types of ADs [7,12]. The overall use of ADs in children with CP is predicted by the child's level of gross motor function [8,13].

The impacts or outcomes of the use of specific ADs among children with CP are synthesised in three review articles. The reviews indicate positive impacts of adapted seating [14–16], standing frames [17], supported walkers [18] and powered mobility [19,20] on the child's functioning and need for caregiver assistance [21].

Although children with CP and their families use a wide range of ADs, no previous study has considered the many aspects of use. Moreover, there is little knowledge about how characteristics other than the child's gross motor abilities relate to the extent of AD usage. To fill some of the gaps in the current literature, the present study aimed to describe the use of ADs in children with CP, in terms of type, purposes, perceived benefits, environments and frequency of use.

The specific research questions were: 1) What types of ADs are used to compensate for motor limitations and what is the extent of their use? 2) For what purposes, in which environments and how frequently are the devices used? 3) What are the perceived benefits of use for caregiving and child functioning? In addition, we explored the associations between child, parent and family characteristics and the overall use of ADs. A greater in-depth knowledge of the use of ADs to promote functioning will further our understanding of which devices is most effective in the everyday life of young children with CP and their families.

Methods

Study design and recruitment

In Norway, all children with CP are offered a systematic follow-up in the Norwegian Quality and Surveillance Registry (NorCP), based in regional paediatric rehabilitation units. This registry is estimated to include 90% of the total CP population [22]. An associated registry, the Habilitation Trajectories, Interventions and Services for Preschool Children with Cerebral Palsy (CPHAB), was established as a project to expand the follow-up of young children. The CPHAB was based on the ICF framework and adopted a family-oriented approach to service provision by including information about the families and the services provided (such as AT). All 21 paediatric units were invited to participate in the CPHAB Child and family functioning were assessed approximately twice each year during the preschool years. Inclusion criteria for participating in the CPHAB, and thus in the current study, were that children were aged four years or younger when registered in the NorCP between January 2012 and December 2014, and that their primary caregivers were able to answer questionnaires in Norwegian or English.

The study was approved by the Regional Committee for Medical and Health Research Ethics South East Norway (Reg.nr 2018/1650). It applied a cross-sectional design using anonymised data from the most recent assessment in the CPHAB and NorCP in 2017. Of the 202 eligible children who fulfilled the inclusion criteria for participation in CPHAB, 11 were excluded due to parental language barriers. Twenty-nine families were not invited mostly due to capacity issues in the units, but also because service provides considered the strain of some families to be too large. In addition, 32 families declined to participate. Thus, 130 children and their families participated in the current study.

Questionnaires and classifications

Information about the use and benefits of ADs were retrieved from the Habserv Questionnaire included in the CPHAB registry. The Habserv consisted four types of services: 1) Training and stimulation of the child, 2) Use of ADs, 3) Parent education and 4) Services and benefits received in the preceding six months. For the current study, only relevant information from the AD section was used, that is, the types of AD in use and their purpose, the environment in which they are used, and the frequency and benefits of use for the child's functioning and care. Thirteen types of ADs that could compensate for motor limitations were included together with four environmental modifications. Orthoses were not included, since they are not provided from the AT system. The purposes of use included reflect the three components of functioning in the ICF (body functions and structures, activity and participation) and were (i) prevention of secondary impairments of body functions, (ii) supporting performance of activities, (iii) enhancing participation in daily activities and (iv) easing daily care. Frequency of use was rated as < once/week, 1-2 times/week, 3-5 times/week, 6-7 times/week, several times daily and do not know. The benefits of use were rated as none/small, some, large, very large benefits and unsure. The face validity of the Habserv was assessed using a multi-professional expert panel. The translation into English followed recommended guidelines [23]. The questionnaire was pilot tested among 19 parents of young children with CP in three rounds [24]. However, its psychometric properties have not been thoroughly examined.

Children's characteristics, obtained from the NorCP, included age, CP subtype and gross motor and manual abilities. Subtypes of CP were classified as spastic (uni- and bilateral), dyskinetic or ataxic [25]. Gross motor abilities were classified according to the five levels of the Gross Motor Function Classification System (GMFCS) [26,27], based on self-initiated movements with an emphasis on sitting, walking and wheeled mobility. Differences between levels are based on functional abilities and the use of ADs. Hand function was classified according to the Manual Ability Classification System (MACS) [28] which describes five levels of ability to handle objects in daily activities, with mini-MACS used for children below four years of age [29]. Both the GMFCS and the MACS/mini-MACS have demonstrated good reliability, predictive validity and stability over time [30–32].

Family characteristics included parents' country of origin, primary caregiver's education \leq 12 years (primary school, secondary school, high school) or >12 years (university, other), employment status (not employed, working part-time <50%, part-time \geq 50% or full time \geq 100%), and financial and housing concerns (yes/no). These characteristics were retrieved from the Norwegian version of the "Parental Account of Children's Symptoms" included in the CPHAB registry [33].

Data analysis

The ADs included were grouped into four categories based on their area of use: positioning, mobility, self-care and training, stimulation and play. Environmental modifications constituted a separate category. The types of devices included in the five categories are presented in Table 3.

Statistical analysis was performed using SPSS software (version 27). Descriptive statistics were computed for participants' characteristics, type of AD in use and purpose, environment, frequency and benefits of use. To compare child characteristics between participants using and those not using ADs, a chi-square test or Fisher's exact test was conducted for categorical data (gender, CP subtypes, GMFCS and MACS levels) and two-sample t-tests conducted for age in months. A Mann-Whitney U test was used to compare the use of ADs between CP subtypes (unilateral and bilateral) and the Kruskal-Wallis test with post hoc comparisons was used for comparisons between GMFCS and MACS levels (I, II/II and IV/V) and age groups (12-35 months, 36-59 months and 60-81 months). A multiple linear regression analysis was performed to explore the association between child characteristics (GMFCS levels, MACS levels and age), parental characteristics (mother's education and employment status), and family situation (financial or housing concerns) and the total number of ADs in use. CP subtypes were not included due to their high correlation with GMFCS levels. All independent variables were entered in a block.

Results

Of the 130 participating children, 78 were reported to use ADs other than orthoses to compensate for motor limitations and enhance functioning. The child, parent (including a few other primary caregivers), and family characteristics are presented in Table 1 and 2, respectively. There was no statistical significant difference between children using ADs and those not using ADs in terms of gender or age, but difference were apparent when looking at CP subtypes and motor abilities. A greater proportion of children using ADs had bilateral (spastic, dyskinetic, ataxic) CP, and severe motor limitations (GMFCS and MACS Levels III – V) compared to non-users. Such differences were to be expected since the majority of children at GMFCS and MACS Levels I and II are not expected to use aids to compensate for motor limitations [26,28], with the exception of orthoses, which were not included in our study [34].

Type and usage of ADs

During the previous six months, the 130 children had used a total of 330 ADs (median 2.5, range 0–12) to enhance functioning. There was no significant difference in the overall use of ADs between the three age groups (p = 0.061), however a significant difference was observed for the use of mobility devices (p = 0.005) and self-care devices (p = 0.001). Children aged 12–

Table 1. Child characteristics, n = 130.

	Using ADs $(n = 78)$	Not using ADs $(n = 52)$	
Characteristics	· · · /	(-)	Sig
	n (%)	n (%)	Sig.
Child gender			0.469 ^a
Female	32 (41.0)	25 (48.1)	
Male	46 (59.0)	26 (50.0)	
Not specified		1 (1.9)	
Age at last assessment (months)			0.827 ^b
Mean (SD)	50.13 (13.8)	49.58 (14.5)	
Age distribution (months)			0.279 ^c
12–23	2 (2.6)	1 (1.9)	
24–35	7 (9.0)	11 (21.2)	
36–47	28 (35.9)	11 (21.2)	
48–59	19 (24.4)	15 (28.8)	
60–81	22 (28.1)	14 (26.9)	
CP subtypes			< 0.001 ^c
Spastic unilateral	26 (33.3)	41 (78.8)	
Spastic bilateral	45 (57.7)	10 (19.3)	
Dyskinetic and ataxic	6 (7.7)	1 (1.9)	
Not classified	1 (1.3)		
GMFCS levels			< 0.001 ^c
I	19 (24.4)	42 (80.8)	
II	16 (20.5)	7 (13.5)	
III	15 (19.2)	2 (3.8)	
IV	18 (23.1)	0 (0)	
V	9 (11.5)	0 (0)	
Not classified	1 (1.3)	1 (1.9)	
MACS levels			< 0.001 ^c
I	14 (17.9)	15 (28.8)	
11	32 (41.0)	34 (65.5)	
III	16 (20.5)	2 (3.8)	
IV	8 (10.3)	0 (0)	
V	8 (10.3)	0 (0)	
Not classified	0 (0)	1 (1.9)	

^aChi-square test, ^bT-test, ^cFisher's Exact test.

Table 2. Parent and family characteristics, n = 130.

	Using ADs	Not using ADs
	(n = 78)	(n = 52)
Characteristics	n (%)	n (%)
Mother's country of origin		
Norway	70 (89.8)	42 (80.8)
Other countries	8 (10.2)	6 (11.5)
Not answered	0 (0)	4 (7.7)
Father's country of origin		
Norway	68 (87.2)	35 (67.3)
Other countries	9 (11.5)	12 (23.1)
Not answered	1 (1.3)	5 (9.6)
Maternal education		
\leq 12 years	18 (23.1)	16 (30.8)
>12 years	58 (74.3)	32 (61.5)
Not answered	2 (2.6)	4 (7.7)
Paternal education		
\leq 12 years	28 (35.9)	21 (40.4)
>12 years	45 (57.7)	24 (46.1)
Not answered	5 (6.4)	7 (13.5)
Maternal employment		
Full time (\geq 100%)	28 (35.9)	28 (53.9)
Part-time (≥50%)	31 (39.6)	9 (17.3)
Part-time (<50%)/not employed	17 (21.9)	6 (11.5)
Not answered	2 (2.6)	9 (17.3)
Paternal employment		
Full time (\geq 100%)	66 (84.6)	40 (77.0)
Part-time (≥50%)	3 (3.8)	2 (3.8)
Part-time (<50%)/not employed	5 (6.4)	2 (3.8)
Not answered	4 (5.2)	8 (15.4)
Financial concerns		
Yes	13 (16.6)	3 (5.8)
No	64 (82.1)	45 (86.5)
Not answered	1 (1.3)	4 (7.7)
Housing concerns		
Yes	29 (37.2)	3 (5.8)
No	48 (61.5)	45 (86.5)
Not answered	1 (1.3)	4 (7.7)

Table 3. Number of children using/not using the different types of ADs, n = 130.

Type and number of ADs in use	Using ADs n (%)	Not using ADs n (%)
,,,	11 (70)	11 (70)
Positioning $(n = 95)$		
Adapted chair/seating system	54 (41.5)	76 (58.5)
Standing frame	41 (31.5)	89 (68.5)
Mobility ($n = 150$)		
Adapted bicycle	44 (33.8)	86 (66.2)
Walking aid	34 (26.2)	96 (73.8)
Special need pushchair	32 (24.6)	98 (75.4)
Manual wheelchair	27 (20.8)	103 (79.2)
Powered mobility device	13 (10.0)	117 (90.0)
Self-care $(n = 48)$		
Bathing aid	19 (14.6)	111 (85.4)
Toileting aid	18 (13.8)	112 (86.2)
Adapted bed	7 (5.4)	123 (94.6)
Eating utensil	4 (3.1)	126 (96.9)
Training, stimulation and play $(n = 16)$		
Training device	10 (7.7)	120 (92.3)
Device for play/stimulation	6 (4.6)	124 (95.4)
Environmental modifications $(n = 21)$		
Ramp	7 (5.4)	123 (94.6)
Automatic door opener	6 (4.6)	124 (95.4)
Lifting aid or hoist	5 (3.8)	125 (96.2)
Threshold eliminator	3 (2.3)	127 (97.7)

35 months used fewer mobility devices compared to the two older age groups (p = 0.017, p = 0.004, respectively), whereas no difference appeared between the two youngest groups in their use of self-care devices (p = 0.335). In contrast, the number used increased with the body parts affected and the severity of the child's motor limitations (p = 0.001). Pairwise comparisons showed a significant difference in the use of ADs between bilateral and unilateral CP and between all GMFCS and MACS levels, both in the total use and the number used within the five areas (p < 0.001).

Most devices provided (74%) were used for mobility and positioning (Table 3). The type of AD in use varied greatly with the most common devices being adapted seating, adapted bicycles and standing frames (42–32%). Fewer parents reported the use of walking aids, special-need pushchairs and manual wheelchairs (26–21%) and even fewer had used bathing and toileting aids or devices to support training, stimulation and play (15–12%). Only 13 children (10%) had used powered mobility. A total of 14 families (11%) had made some modification to their housing environment.

Purposes of AD usage

More than half the ADs could be linked to all the purposes of use included in Table 4. Most commonly, devices had one or two primary reasons for use. Adapted chairs or seating systems were the only devices that often aimed to support various aspects of the child's functioning and care. Increased participation in daily activities was the main reason for the use of mobility devices (except for walking aids and pushchairs), as well as for the use of devices that aim to support play, while standing frames were mainly used to prevent secondary motor impairments and support the performance of activities. The latter was also a principal reason for the use of walking aids and training equipment. Self-care devices and environmental modifications were most often used to facilitate daily care.

Environments in which ADs are used

The devices were typically used both at home and in kindergarten/school (Table 5). Manual wheelchairs and pushchairs were also used during leisure time and in other non-specified environments.

Frequency of use of ADs

Most devices were used at least five times per week, but usage varied from fewer than three times per week to several times daily (Table 6). The greatest variation in frequency was seen for walking aids, wheeled mobility, standing frames and bathing aids. The devices most often incorporated into daily routines were adapted beds, eating utensils, toileting aids and adapted seating. Low-frequency use was most common for adapted bicycles.

Perceived benefits of use of ADs

The majority of parents viewed the devices as beneficial for their child's functioning and/or care (54–100%) (Table 7). Small benefits or unsure responses were most often reported for lifting aids/hoists, powered wheelchairs and training devices (40–60%). Moreover, one in four parents perceived only limited benefits from the use of standing frames, walking aids and pushchairs. When looking at benefits in relation to intended use (as presented in Table 4), mobility, positioning and training devices seemed primarily to support the child's functioning, while selfcare devices and environmental modifications more often facilitated care.

Associations between child, parent and family characteristics and overall use of ADs

The regression model explained 65% of the variation in the total use of ADs. One child characteristics (GMFCS Level) and one family characteristics (reporting housing concerns) were significantly associated with the number of ADs used (Table 8). The number used increased with the severity of the child's gross motor limitations and was associated with concerns around space and the restrictions of the environment.

Discussion

The results confirm that young children with CP use a wide range of devices to compensate for motor limitations in their everyday life, although 40% of the participating children did not use any of the ADs included. Consistent with previous findings, the level of gross motor ability (GMFCS level) seems to be predictive for overall use: the greater the level of physical disability, the more ADs provided [7,8]. Another noteworthy finding was that the use of a high number of devices was associated with housing concerns. As many as 29 families using ADs (37%) reported concerns regarding space and restrictive environments compared to 6% of non-users. This proportion was somewhat higher than in a previous Norwegian study on the same age group [7] in which insufficient space to use the devices and unsuitable toilets and bathrooms were identified as barriers to the incorporation of ADs into daily activities and routines. Overall, these findings suggest a need for greater attention to be paid to families' accommodation to facilitate the everyday use of ADs.

This is the first study to cover multiple aspects of the use of ADs in relation to perceived benefits. The proportion of children using the devices that were covered in the study varied from 42%

Table 4. Purposes of ADs usage, n = 78.

	Prevent secondary impairments	Support performance of activities	Enhance participation in daily activities	Ease daily care	Do not know
Number of children using the ADs	n	n	n	n	n
Positioning					
Adapted chair/seating system ($n = 54$)	33	33	31	22	1
Standing frame $(n = 41)$	31	30	13	3	0
Mobility					
Adapted bicycle ($n = 44$)	4	14	40	6	1
Walking aid $(n = 34)$	10	25	22	6	2
Special need pushchair ($n = 32$)	7	5	21	23	0
Manual wheelchair ($n = 27$)	3	10	20	11	3
Powered mobility device $(n = 13)$	1	2	12	4	0
Self-care					
Bathing aid ($n = 19$)	1	4	6	14	1
Toileting aid $(n = 18)$	0	10	1	13	0
Adapted bed $(n = 7)$	2	3	0	6	0
Eating utensil $(n = 4)$	0	3	1	2	1
Training, stimulation and play					
Training device $(n = 10)$	2	8	3	2	1
Device for play/stimulation $(n = 6)$	0	4	5	0	1
Environmental modifications					
Ramp $(n=7)$	0	2	0	3	2
Automatic door opener ($n = 6$)	0	2	0	4	1
Lifting aid or hoist $(n = 5)$	0	0	1	5	0
Threshold eliminator $(n = 3)$	0	0	1	3	0

Table 5. Environments in which ADs are used.

	Home	Kindergarten/school	Leisure activities	Other arenas
Number of children using the ADs	п	п	п	п
Positioning				
Adapted chair/seating system ($n = 54$)	51	53	1	7
Standing frame $(n = 41)$	34	38	1	6
Mobility				
Adapted bicycle ($n = 44$)	37	33	2	2
Walking aid $(n = 34)$	25	32	7	6
Special need pushchair ($n = 32$)	25	25	3	14
Manual wheelchair ($n = 27$)	18	21	11	13
Powered mobility device $(n = 13)$	6	11	1	5
Self-care				
Bathing aid ($n = 19$)	19	4	1	2
Toileting aid $(n = 18)$	17	15	0	2
Adapted bed $(n = 7)$	7	2	0	2
Eating utensil $(n = 4)$	4	3	0	0
Training, stimulation and play				
Training device $(n = 10)$	7	9	0	0
Device for play/stimulation $(n = 6)$	5	6	0	0
Environmental modifications				
Ramp ($n = 7$)	1	6	0	0
Automatic door opener ($n = 6$)	3	3	0	0
Lifting aid or hoist $(n = 5)$	3	3	0	1
Threshold eliminator $(n = 3)$	3	2	1	0

to 2%. The majority of devices had one or two primary purposes and they were commonly used both at home and in kindergarten/school. Frequency of use varied from less than three times per week to several times daily. For 14 of the 17 types of devices, at least 70% of the parents experienced significant benefits for the child and/or the caregiver.

Devices for positioning

Adapted chairs or seating systems were the most commonly used type of device and the only ones whose purpose was to prevent impairments in body functions and structures as much as to facilitate performance of and participation in daily activities. Frequent daily use indicates that the seating devices were well integrated into the children's everyday life. The intended purposes, and the perceived benefits, seem to reflect the summarised evidence on effects of adaptive seating on postural control outcomes, self-care and play in children with CP (GMFCS Levels IV and V) [16]. A more recent study of the effectiveness of the first adaptive seating received, shows emerging evidence for short-term gains in trunk control and daily activities, as well as overall child and family functioning [35]. Research on the impacts on care is lacking.

Standing frames were another widely provided device for the postural management of the child, used by about one-third of the children. The frames were used both to prevent secondary motor impairments and facilitate the performance of activities. Both the frequency of use, and the perceived benefits were somewhat lower than for adapted seating, but higher than in a previous UK survey [36] in which daily use was considerably lower

	<1-2/week	3-4/week	5-7/week	Several times daily	Do not know
Number of children using the ADs	п	п	п	п	n
Positioning					
Adapted chair/seating system ($n = 54$)	1	1	2	50	0
Standing frame $(n = 41)$	2	10	14	15	0
Mobility					
Adapted bicycle ($n = 44$)	20	7	7	6	4
Walking aid $(n = 34)$	4	6	11	12	1
Special need pushchair ($n = 32$)	7	7	9	8	1
Manual wheelchair ($n = 27$)	6	4	4	11	2
Powered mobility device ($n = 13$)	4	4	1	3	1
Self-care					
Bathing aid $(n = 19)$	6	7	1	5	0
Toileting aid $(n = 18)$	0	1	3	14	0
Adapted bed $(n = 7)$	0	0	0	7	0
Eating utensil $(n = 4)$	0	0	0	4	0
Training, stimulation and play					
Training device $(n = 10)$	1	5	1	3	0
Device for play/stimulation $(n = 6)$	0	0	2	4	0
Environmental modifications					
Ramp ($n = 7$)	0	0	1	4	2
Automatic door opener ($n = 6$)	0	0	0	6	0
Lifting aid or hoist $(n = 5)$	0	1	0	3	1
Threshold eliminator $(n = 3)$	0	0	0	3	0

Table 6. Frequency of use of ADs.

Table 7. Perceived benefits of use of ADs.

	Small/some benefits	Large/very large benefits	Unsure benefits
Number of children using the ADs	п	п	п
Positioning			
Adapted chair/seating system ($n = 54$)	3	50	1
Standing frame $(n = 41)$	7	30	4
Mobility			
Adapted bicycle ($n = 44$)	6	36	2
Walking aid $(n = 34)$	7	24	3
Special need pushchair ($n = 32$)	6	24	2
Manual wheelchair ($n = 27$)	3	21	3
Powered mobility device $(n = 13)$	3	7	3
Self-care			
Bathing aid $(n = 19)$	1	18	0
Toileting aid $(n = 18)$	3	15	0
Adapted bed ($n = 7$)	0	7	0
Eating utensil $(n = 4)$	0	3	1
Training, stimulation and play			
Training device $(n = 10)$	3	6	1
Device for play/stimulation $(n = 6)$	1	5	0
Environmental modifications			
Ramp ($n = 7$)	0	7	0
Automatic door opener ($n = 6$)	0	6	0
Lifting aid or hoist $(n = 5)$	2	2	1
Threshold eliminator $(n = 3)$	0	3	0

Table 8.	Associations	between	child,	parent	and	family	characteristics a	nd the
total use	of ADs, $n = 1$	30.						

Independent variables	В	Beta	p Value	95% CI
Child characteristics				
GMFCS level	2.09	0.53	< 0.001	1.50, 2.69
MACS level	0.66	0.13	0.072	-0.06, 1.38
Age	0.52	0.11	0.065	-0.03, 1.08
Parent characteristics				
Maternal education	0.46	0.07	0.245	-0.32, 1.25
Maternal employment	0.10	0.02	0.696	-0.39, 0.58
Family situation				
Financial concerns	0.56	0.06	0.347	-0.61, 1.73
Housing concerns	1.85	0.25	< 0.001	0.86, 2.83

Adjusted $R^2 = 0.651$, overall model F-test, p = 0.000.

than in our study (18% vs 36%). In a recent cross-over study including children with CP (GMFCS Levels IV and V), the children practised static and dynamic standing from 30 to 60 min daily for a period of four months [37]. After 30 min of dynamic standing,

there was a significant increase in passive range of motion (PROM) in the hip and a decrease in spasticity. After four months, the increase in PROM was still significant in all directions, but no long-term effect was seen for spasticity. Almost no statistically significant differences were observed in PROM or spasticity after static standing. These findings suggest that the type of standing method must be considered when the intention is to prevent secondary impairments.

Mobility devices

When a child cannot independently crawl or walk within the typical range of development, it may be appropriate to look at adaptive aids such as walkers, wheelchairs or powered mobility to support self-directed mobility. Achieving self-directed mobility is found to enhance a child's cognitive and psychosocial development, motor skills, play, exploration and self-efficacy [19,38,39].

A total of 34 children (26%) had used a handheld or support walker in order to improve walking ability and participation in daily activities. The frequent use across environmental settings indicates that parents and professionals put significant effort into enhancing a child's walking abilities, and 71% of the parents experienced great benefit from such use. Outcomes of the use of anterior and posterior handheld walkers have been summarised to determine whether there is sufficient evidence to prescribe one walker type in preference to another for children with CP. All included outcomes referred to body functions. Low quality evidence indicates that posterior walkers may improve velocity, trunk flexion/pelvic tilt and stability [40]. No information about the type of handheld walkers provided was available in our study. The outcomes for support walkers in children with CP have been synthesised in another systematic review [18]. The evidence was scarce and inconsistent, but indicated positive changes in bone mineral density, bowel function, mobility, autonomy, social functioning and participation.

The number of children using powered mobility was relatively low (n = 13) considering that 44 of the participating children had moderate to severe mobility limitations (GMFCS Levels III – V). The main reason for use was to enhance the child's participation in daily activities, but the perceived benefits were small. Early powered mobility is proven to have multiple benefits for young children with gross motor limitations [19,20]. A recent mixed-method evidence synthesis evaluating effectiveness showed strong support for impact on movement and mobility and moderate support for impact on participation, play and social interactions [20].

Our findings that powered mobility devices were perceived as less beneficial than other types of mobility devices, were used less at home than in kindergarten/school, and had less daily use than either manual wheelchairs or walkers indicate that the match between the child, the device and its social and physical environment was not always good. This is consistent with findings from two systematic reviews that concluded that parents experience substantial challenges related to the use of powered mobility, including the device itself (design, weight and technological difficulties), the provision process (training and follow up) and environmental restrictions (lack of space for use and storage and accessible transportation) [19,20]. All of these concerns are likely to be critical for feasibility, acceptability and optimum effectiveness. Chairs that are more child-friendly, lightweight, and easily transportable (e.g., Wizzibug or Permobile Explorer Mini) or adapted ride-on car toys were not available in the Norwegian national AT system when the data for this study were collected. Such devices, as well as parent-friendly information about introducing early powered mobility are now obtainable from the AT system [41]. It is therefore likely that more young children would use powered mobility devices in Norway today. When presented as means of play and moving, both children and parents seem to be more enthusiastic about early powered mobility [20,42]. Several studies have documented that powered mobility intervention is feasible from around 12 months of age when children lack efficient, independent mobility. Regardless of age, children need support and training to develop power mobility skills or to experience self-initiated exploration [20,43].

About one-third of the participating children (34%) had used an adapted bicycle in order to enhance participation and achieve self-directed mobility. However, the bike was used less frequently than other mobility device and, therefore, appears to be an aid for play and movement rather than for transfer in the community. A strong majority of the parents reported significant benefits for the child from its use. The efficacy of adapted cycling on movement-related body functions and motor-skill performance was assessed in a recent systematic review and meta-analysis [44]. The studies included focused predominantly on stationary cycling and ambulant children with CP and the results indicate that stationary cycling can improve muscle strength, balance and gross motor skills. To date, few participation-related outcomes have been reported. There are, thus, considerable gaps in the existing literature on outcomes of adapted dynamic cycling for children with different levels of gross motor function.

Devices to support self-care

The user rate of devices provided to support self-care activities was considerably lower than for positioning and mobility, and use was significantly related to the child's age. The main reason for use was to ease daily care; however, bathing aids also had the intention of enhancing participation in daily activities. Thus, bath time seems to have a dual purpose – getting clean while having fun in the water. Toileting aids and eating utensils had the additional purpose of increasing independence. The perceived benefits of the self-care devices included were in line with findings from the previously referenced Norwegian study [7]. However, research on the use and benefits of ADs to support self-care in children with CP, regardless of age, is scarce.

Devices for training, stimulation and play

A CP diagnosis implies limitations in movement and posture. From previous research, we know that young children with CP and their families invest significant time and effort in practising motor skills [24]. Only ten of the participating children (8%) were provided with training devices through the National Insurance scheme. This includes products to help improve postural control, coordination, balance and gross motor skills (e.g., mats, therapy/training pads and balls) [45]. The limited perceived benefits of using devices as part of home-based training may not relate solely to the device but also to how parents adhere to a training regime in the context of everyday family life [46].

Play is the main priority in early childhood; it has been declared as a basic human right for all children [47] and, thus, every child should be given the same opportunity to enjoy their right to play in their everyday life. For many reasons, children with disabilities experience difficulties in participating in play and often need different forms of support [48]. As discussed earlier, both mobility and positioning devices may enhance play by making it possible for children to move around and interact with objects and people in their environment [16,20]. Moreover, adapted toys and other activity technology have been found to be powerful tools for the development of sensory, motor and perceptual skills [48]. However, only 5% of the participating children had used adapted play devices, despite significant limitations in gross motor function (GMFCS Levels III - V) and/or manual abilities (MACS Levels III - V). The devices provided, most often switch-controlled toys and games and adapted swings [12], was frequently used and perceived to be useful. The low rate of use reflects a decline in the supply of toys as assistive aids from the National Insurance Scheme [12]. This may be due to better access to appropriate play materials and equipment in regular stores. However, it could be questioned whether the equipment general available is tailored to the individual needs of children with the most severe motor limitations. A study of toddlers with severe sensory, motor and cognitive impairments showed that three in

four children learned to use adapted switches to control electric toys and other devices through technology intervention [49].

Strengths and limitations

The strength of this research was its multi-faceted approach in describing the use of ADs in a population-based sample of young children with CP. However, there are some limitations related to the study design, the sample size and the use of registry data. This cross-sectional study used data from the most recent assessment in the CP registers. The number of children reported to use ADs is only indicative as the use may have varied during preschool years. In addition, available ADs today may differ from when the data was collected. Moreover, the registry data contained restricted information about the specific type of device in use, such as static or dynamic standing aid, anterior or posterior walker and powered mobility solutions, and no differentiation was made between child and caregiving benefits. It is also a limitation that the psychometrics of the Habsery Ouestionnaire have not vet been established. Regarding sample size, the number of participants constituted a limitation once the children were grouped into GMFCS and MACS levels. Merging the five levels of the two classifications into three levels may have concealed differences in AD usage between GMFCS/MACS Levels II and III and between Levels IV and V.

Conclusion

The study expands the current knowledge on the use of ADs among young children with CP by reporting on the many aspects of their use as well as the factors related to both child and family that could predict the extent of use. The frequent use of a wide range of devices across environmental settings, and the intended and perceived benefits of these, demonstrates that AT intervention can be an effective strategy in enhancing child and family functioning. However, the findings also indicate that factors other than the child's motor abilities, such as the physical and social environment around the child, must be considered in order to effectively integrate the use of ADs into daily routines and activities.

Acknowledgements

The authors thank the NorCP for access to data from the NorCP and the CPHAB registries to conduct the study.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

ORCID

Sigrid Østensjø (b) http://orcid.org/0000-0002-7418-2973

References

- Kling A, Campbell PH, Wilcox J. Young children with physical disabilities: caregiver perspectives about assistive technology. Infants Young Child. 2010;23(3):169–183.
- [2] Hollung SJ, Vik T, Lydersen S, et al. Decreasing prevalence and severity of cerebral palsy in Norway among children born 1999 to 2010 concomitant with improvements in perinatal health. Eur J Paediatr Neurol. 2018;22(5):814–821.
- [3] Rosenbaum P, Paneth N, Leviton A, et al. A report: the definition and classification of cerebral palsy april 2006. Dev Med Child Neurol. 2007;49:1–14.
- [4] Carnahan KD, Arner M, Hägglund G. Association between gross motor function (GMFCS) and manual ability (MACS) in children with cerebral palsy. A population-based study of 359 children. BMC Musculoskelet Disord. 2007;8:50–50.
- [5] Hollung SJ, Bakken IJ, Vik T, et al. Comorbidities in cerebral palsy: a patient registry study. Dev Med Child Neurol. 2020; 62(1):97–103.
- [6] World Health Organization. International classification of functioning, disability and health (ICF). Geneva (CH): WHO; 2001.
- [7] Østensjø S, Carlberg EB, Vøllestad NK. The use and impact of assistive devices and other environmental modifications on everyday activities and care in young children with cerebral palsy. Disabil Rehabil. 2005;27(14):849–861.
- [8] Novak I, Smithers-Sheedy H, Morgan C. Predicting equipment needs of children with cerebral palsy using the gross motor function classification system: a cross-sectional study. Disabil Rehabil Assist Technol. 2012;7(1):30–36.
- [9] ISO 9999 Assistive products for persons with disability -Classification and terminology. 2016.
- [10] NAV Department of Assistive Technology. Assistive technology in Norway - a part of a larger system. Oslo: NAV; 2017. https://www.nav.no/_/attachment/inline/7b119b1c-fe72-488a-a1ef-be424e72faff:c52b8c6ee759299749538a6fd0554d1efa695abf/assistive-technology-in-norway-170217v2.pdf
- [11] MacLachlan M, Banes D, Bell D, et al. Assistive technology policy: a position paper from the first global research, innovation, and education on assistive technology (GREAT) summit. Disabil Rehabil Assist Technol. 2018;13(5):454–466.
- [12] Solberg A, Sund F, Malasevska I. Kjønnsdelte hjelpemidler [gender-segregated aids]. (Rapport 1). Likestillingssenteret (Norway). 2019.
- [13] Østensjø S, Brogren E, Vøllestad NK. Everyday functioning in young children with cerebral palsy: functional skills, caregiver assistance, and modifications of the environment. Dev Med Child Neurol. 2003;45(9):603–612.
- [14] Chung J, Evans J, Lee C, et al. Effectiveness of adaptive seating on sitting posture and postural control in children with cerebral palsy. Pediatr Phys Ther. 2008;20(4):303–317. Winter
- [15] Ryan SE. An overview of systematic reviews of adaptive seating interventions for children with cerebral palsy: where do we go from here? Disabil Rehabil Assist Technol. 2012;7(2):104–111.
- [16] Angsupaisal M, Maathuis CGB, Hadders-Algra M. Adaptive seating systems in children with severe cerebral palsy across international classification of functioning, disability and health for children and youth version domains: a systematic review. Dev Med Child Neurol. 2015;57(10): 919–930.

- [17] Glickman LB, Geigle PR, Paleg GS. A systematic review of supported standing programs. J Pediatr Rehabil Med. 2010; 3(3):197–213.
- [18] Paleg G, Livingstone R. Outcomes of gait trainer use in home and school settings for children with motor impairments: a systematic review. Clin Rehabil. 2015;29(11): 1077–1091.
- [19] Livingstone R, Field D. Systematic review of power mobility outcomes for infants, children and adolescents with mobility limitations. Clin Rehabil. 2014;28(10):954–964.
- [20] Bray N, Kolehmainen N, McAnuff J, et al. Powered mobility interventions for very young children with mobility limitations to aid participation and positive development: the EMPoWER evidence synthesis. Health Technol Assess. 2020; 24(50):1–194.
- [21] Nicolson A, Moir L, Millsteed J. Impact of assistive technology on family caregivers of children with physical disabilities: a systematic review. Disabil Rehabil Assist Technol. 2012;7(5):345–349.
- [22] Andersen GL, Hollung SJ, Klevberg GL, et al. Norsk kvalitets- og oppfølgingsregister for cerebral parse (NorCP). Årsrapport for 2020 med plan for forbedringstiltak [Norwegian quality and follow-up register for cerebral palsy (NorCP). Annual report for 2020 with a plan for improvement measures]. 2020.
- [23] Cha E-S, Kim KH, Erlen JA. Translation of scales in cross-cultural research: issues and techniques. J Adv Nurs. 2007; 58(4):386–395.
- [24] Myrhaug HT, Østensjø S. Motor training and physical activity among preschoolers with cerebral palsy: a survey of parents' experiences. Phys Occup Ther Pediatr. 2014;34(2): 153–167.
- [25] Cans C. Surveillance of cerebral palsy in Europe: a collaboration of cerebral palsy surveys and registers. Dev Med Child Neurol. 2007;42(12):816–824.
- [26] Palisano R, Rosenbaum P, Walter S, et al. Development and reliability of a system to classify gross motor function in children with cerebral palsy. Dev Med Child Neurol. 1997; 39:214–223.
- [27] Palisano RJ, Rosenbaum P, Bartlett D, et al. Content validity of the expanded and revised gross motor function classification system. Dev Med Child Neurol. 2008;50(10):744–750.
- [28] Eliasson AC, Krumlinde-Sundholm L, Rösblad B, et al. The manual ability classification system (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability. Dev Med Child Neurol. 2006;48(7): 549–554.
- [29] Eliasson A-C, Ullenhag A, Wahlström U, et al. Mini-MACS: development of the manual ability classification system for children younger than 4 years of age with signs of cerebral palsy. Dev Med Child Neurol. 2017;59(1):72–78.
- [30] Alriksson-Schmidt A, Nordmark E, Czuba T, et al. Stability of the gross motor function classification system in children and adolescents with cerebral palsy: a retrospective cohort registry study. Dev Med Child Neurol. 2017;59(6):641–646.
- [31] Palisano RJ, Avery L, Gorter JW, et al. Stability of the gross motor function classification system, manual ability classification system, and communication function classification system. Dev Med Child Neurol. 2018;60(10):1026–1032.
- [32] Wood E, Rosenbaum P. The gross motor function classification system for cerebral palsy: a study of reliability and stability over time. Dev Med Child Neurol. 2000;42(5):292–296.

- [33] Taylor E, Schachar R, Thorley G, et al. Parental account of children's symptoms. Br J Psychiatry. 1986;149:760–767.
- [34] Andersen GL, Hollung SJ, Vik T, et al. Cerebral pareseregsteret i Norge (CPRN), Årsrapport for 2018 med plan for bedringstiltak; Cerebral Parese oppfølgingsprogram (CPOP), Årsrapport for 2018 [Cerebral palsy register in Norway (CPRN), Annual report for 2018 with a plan for improvement measures; Cerebral Palsy follow-up program (CPOP), yearly report 2018] 2019.
- [35] Inthachom R, Prasertsukdee S, Ryan SE, et al. Evaluation of the multidimensional effects of adaptive seating interventions for young children with non-ambulatory cerebral palsy. Disabil Rehabil Assist Technol. 2020;16(7):1–9.
- [36] Goodwin J, Colver A, Basu A, et al. Understanding frames: a UK survey of parents and professionals regarding the use of standing frames for children with cerebral palsy. Child Care Health Dev. 2018;44(2):195–202.
- [37] Tornberg ÅB, Lauruschkus K. Non-ambulatory children with cerebral palsy: effects of four months of static and dynamic standing exercise on passive range of motion and spasticity in the hip. PeerJ. 2020;8:e8561.
- [38] Anderson D, Campos J, Witherington D, et al. The role of locomotion in psychological development [review]. Front Psychol. 2013;4:440.
- [39] Logan SW, Hospodar CM, Feldner HA, et al. Modified Ride-On car use by young children with disabilities. Pediatr Phys Ther. 2018;30(1):50–56.
- [40] Poole M, Simkiss D, Rose A, et al. Anterior or posterior walkers for children with cerebral palsy? A systematic review. Disabil Rehabil Assist Technol. 2018;13(4):422–433.
- [41] NAV Kunnskapsbanken: elektrisk rullestol for barn [Knowledge bank:_powered mobility devices for children] Oslo: NAV. [cited 2023 Feb 12]. Available from: https:// www.kunnskapsbanken.net/bevegelse/elektrisk-rullestol/ elektrisk-rullestol-for-barn/
- [42] James D, Pfaff J, Jeffries LM. Modified ride-on cars as early mobility for children with mobility limitations: a scoping review. Phys Occup Ther Pediatr. 2019;39(5):525–542.
- [43] Huang H-H. Perspectives on early power mobility training, motivation, and social participation in young children with motor disabilities. Front Psychol. 2017;8:2330–2330.
- [44] Armstrong EL, Spencer S, Kentish MJ, et al. Efficacy of cycling interventions to improve function in children and adolescents with cerebral palsy: a systematic review and meta-analysis. Clin Rehabil. 2019; Jul33(7):1113–1129.
- [45] NAV. Hjelpemiddeldatabasen [Assistive technology available in Norway] Oslo: NAV. [cited 2023 Feb 12]. Available from: https://www.hjelpemiddeldatabasen.no/
- [46] Santer M, Ring N, Yardley L, et al. Treatment non-adherence in pediatric long-term medical conditions: systematic review and synthesis of qualitative studies of caregivers' views. BMC Pediatr. 2014;14:63.
- [47] Unicef. Convention on the Rights of the Child: Unicef; 1989. https://www.unicef.org/child-rights-convention
- [48] Baker FS. Engaging in play through assistive technology: closing gaps in research and pratice for infants and toddlers with disabilities. In: da Costa B, Seok S, editors. Assistive technology research, practice, and theory. Vol. 1. Beaverton: Ringgold Inc; 2014. p. 207–222.
- [49] Sullivan M, Lewis M. Assistive technology for the very young: creating responsive environments. Infants Young Child. 2000;12(4):34–52.