

Young children with cerebral palsy: families self-reported equipment needs and out-of-pocket expenditure

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Abstract

Background Costs to families raising a child with cerebral palsy and complex needs are direct and indirect. This study investigated the self-reported real-life costs, equipment needs, and associated characteristics of children who had the highest equipment and care needs.

Method The purposive sample ($n = 29$) were families with a child with cerebral palsy: gross motor function levels 5 ($n = 20$), level 4 ($n = 5$), level 3 ($n = 4$); complex communication needs ($n = 21$); medical needs ($n = 14$); hearing impairment ($n = 5$) and visual impairment ($n = 9$). Participants completed a specifically designed survey that included the Assistance to Participate Scale. Equipment and technology purchases were recorded in the areas of positioning, mobility, transport, home modifications, communication, splinting and orthoses, self-care, technology, communication devices, medical, adapted toys/leisure items and privately hired babysitters/carers. Descriptive and inferential statistics were used to analyse the data.

Results Families had purchased up to 25 items within the areas described. The highest median number of items were recorded for positioning (15 items), mobility devices (9 items) and adapted toys/leisure items (9 items). Median costs were highest for home modifications (AUD\$23 000), transport (AUD\$15 000), splints and orthoses (AUD\$3145), paid carers (AUD\$3080), equipment for toileting/dressing/bathing (AUD\$2900) and technical/medical items (\$2380). Children who needed more parental assistance to participate in play and recreation also required significantly more equipment overall for positioning, communication, self-care and toys/leisure.

Conclusions The equipment needs of young children with complex disability are extensive and out-of-pocket expenses and parental time to support participation in play/recreation excessive. Substantial financial support to offset costs are crucial to better support families in this life situation.

Keywords

cerebral palsy, complex needs, family support, parents, physical disabilities, socio-economic status

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Introduction

Cerebral palsy (CP) is characterized by permanence, disorders of movement and posture, and possible co-existing distur-

ances of sensation, perception, cognition, communication, behaviour and secondary musculoskeletal issues (Baxter 2007; Rosenbaum *et al.* 2007). Related to the complexity of CP and similar disabilities, children with the condition can be highly

dependent on caregivers (Davis *et al.* 2010), dependant on equipment and technologies for many aspects of their daily care, participation in play, recreation and educational activities (Bourke-Taylor *et al.* 2009; Chantry & Dunford 2010) and dependant on physical and attitudinal environments that are enabling (Dickinson & Colver 2011).

Cerebral palsy occurs in about 1 in 400 children (Reddihough & Collins 2003). A literature review of published research into the incidence and co-existing conditions experienced by people with CP (from 1965 through 2004) revealed many complex co-existing conditions. Conditions include 75% have visual disturbances (~75%); hearing impairment (up to ~25%); speech impairment (~80%); epilepsy (20–40%) and feeding/gastrointestinal problems (~50%) (Odding *et al.* 2006).

Implicit in the complexity of CP and associated conditions, is the specialized support that may consequently be required by children and their families. The extent of care needs have been described as 'daunting challenges' encountered by 'care providers, educational institutions, advocacy groups, policy makers and others' (Montovani, in Baxter 2007, p. 42). Although many countries provide some access to services and funding via social or health services, medical insurance, government schemes or philanthropic support, research about the efficacy of such services is minimal.

In Australia, where the current study occurred, there is some government funding that contributes towards some equipment and technology during the first 6 years. However it remains as to the extent that available schemes cover the entire cost of assistive devices, or if families are left to cover significant out-of-pocket portions. Gaining access to such funding frequently requires allied health practitioners to justify the need for the device to payers and administer applications for funding; prescribe the appropriate device that will meet the child's needs immediately and in the future; and provide direct services to the child and family to assist mastery, and safe or competent use of the device (Chantry & Dunford 2010). Professional expertise and assistance is an additional though crucial expense, so that appropriate advice, opportunity to trial, and timely prescription of appropriate aids, technology and devices can occur.

The impact of caring such as parental health and well-being has been studied (Raina *et al.* 2004, 2005; Bourke-Taylor 2010; Bourke-Taylor *et al.* 2010; Davis *et al.* 2010), although the associated issues with the financial impact has not been thoroughly researched. The financial impact on families is double barreled. First, described by Lukemeyer and colleagues (2000), families shoulder 'the private costs of disability' (p. 399). Children needs impose direct costs on families in the form of extra medical attention, equipment, technology, devices, medications and

specialized therapy services. The family home and car may require modification to accommodate the child's needs at different ages and stages of development.

Second, families incur indirect costs in the form of loss of productive output because of required specialized care that cannot easily be provided by someone else. Mothers are typically the primary carer (Brehaut *et al.* 2004; Crowe & Florez 2006). Whether the family includes one or two parents, the primary carer often foregoes paid work to provide the care that the child needs, organize the multiplicity of medical and therapeutic services needed by the child and meet the child's daily needs (Porterfield 2002; Powers 2003; McGuire *et al.* 2004; Bourke-Taylor *et al.* 2011). Although costs are higher, it is not surprising that family income is lower when there is a child with a disability in the family (Lukemeyer *et al.* 2000; Park *et al.* 2002; Parish & Cloud 2006).

In Australia, the community economic impact resulting from supporting the needs of people with CP has been measured. The burden of cost related to health services utilized by people with CP and their families was conservatively estimated at AUD\$40.5 million in 2007 annually. Individuals with CP bear the cost of 5.2 million and families bear the cost of 1.8 million. These costs do not include equipment and technology costs for devices that provide the person with CP with the capacity to participate in home, educational and community life.

There is no research that has investigated self-reported real-life family cost estimations, or lost opportunity related to costs, during the early preschool years. The aim of this study was to gain estimations of out-of-pocket expenses and equipment needs of families raising a child with CP and complex needs during the early years. Specific research questions were:

- 1 What are the equipment needs of children with CP during the first 6 years?
- 2 What are the out-of-pocket expenses shouldered by families during the first 6 years?
- 3 What is the relationship between the extent of care needed and required equipment for play and recreation?

Method

This anonymous mailed questionnaire was specifically designed for the families attending a single early intervention centre for children with CP in Melbourne, Australia. The study was approved by the Monash University Human Ethics Research Committee. This research was a collaboration between a community early intervention centre and a local university. The community early intervention centre [Cerebral Palsy Education

Centre (CPEC)] specializes in service provision for children with complex and multiple needs.

Participants and recruitment

Inclusion criteria required that the person was a Victorian parent and primary carer of the child with a CP; that their child had attended at least 1 year of early intervention through the Cerebral Palsy Education Centre (CPEC); and were able to complete the survey in English. All participants self-selected in response to the letters inviting participation and returned the mail out survey within the required timeline. CPEC sent the letter describing the study and the explanatory statement to 48 families who were or had attended early intervention at the centre. Forty-eight families represented all local families who continued services with the centre: currently receiving early intervention, or receiving school support services after early intervention. Interested families completed the survey and sent it to the researcher anonymously. This method of recruitment and data collection aimed to optimize family confidence in disclosing financial information, while protecting the anonymity of families from both the community agency and researcher. CPEC remained unaware of which families participated in the study throughout the recruitment and data recruitment process, and questionnaires were not viewed or stored at CPEC.

The specifically designed mail out survey

The survey was designed and piloted with three different families and eight experienced therapists at the centre (occupational therapists, speech language pathologists and physiotherapists). The questionnaire consisted of demographic questions, work status; accommodation situation; income; questions about the child with CP; and questions regarding equipment use, and out-of-pocket expenses related to equipment. Families were asked to only record and cost *'equipment that your child has needed during their early years . . . We would like to know about additional costs to families, above standard child-related equipment. Therefore, we do not require your inclusion of standard child equipment . . . (only equipment) that your child has needed specifically due to their disability. If off-the-shelf products were suitable . . . do not include these . . . (unless) adaptations or other equipment (were) added to these items . . .'*

Thirteen categories of equipment or services were included (see Table 3, column 1). A list of common items was constructed through family and therapist collaboration (see Table 3, column 3). Families were instructed to *'provide the best estimation of costs possible'*.

To determine the extent of assistance that a child needed to participate in enjoyable play and recreation within and outside of the home, the Assistance to Participate Scale (APS) was used (Bourke-Taylor *et al.* 2009; Bourke-Taylor & Pallant 2013). The APS is a short, psychometrically sound scale that measures parental report of the level of assistance required to participate in play and recreation. The APS has strong construct validity and differentiates between children with disabilities who require more lifting, equipment, and who also require assistance in other daily tasks such as dressing and toileting (Bourke-Taylor *et al.* 2009).

Statistical analysis

The SPSS Version 20 statistical package was used for all data entry and management. The data were analysed using descriptive statistics (median, range, mean, range and frequencies) as well as Spearman rho correlation to determine significance within the sample. The items within categories were tallied and presented as total number of pieces of equipment purchased and total calculated cost.

Results

Details about the families are presented in Table 1. Twenty-nine families responded to the call to participate out of the 48 families offered the opportunity (60% response rate). Approximately half of families ($n = 14$, 48%) reporting gross family income between \$50 000 and \$125 000. Four families reported family income below \$50 000. The children, as described by their parents, had multiple developmental, self-care, medical needs and more severe physical disability (see Tables 1 & 2). There was a moderate correlation between the age of the child and the number of years that the child participated in early intervention ($\rho = 0.51$, $P = 0.005$). The average number of years spent in early intervention was 4.1 years (SD = 1.5 years). A set of questions about the child's ability to move and perform regular daily tasks revealed information about the children from their parent's perspective (see Table 2, part A). Parental estimation of the amount of assistance provided to their child during play and leisure activities is presented in Table 2, part B.

Six families reported costs and service use for the full 6 years of early intervention. Parents with children aged over 7 years were included in the study and completed the questionnaire retrospectively. When the characteristics of this sample are considered, the majority of children were 6 years of age or younger ($n = 17$, 59%). Therefore, in this sample, the costs were still

Table 1. Basic demographic information: family characteristics, child characteristics ($n = 29$)

Characteristics	Participant status ($n = 29$)
<i>Person completing questionnaire</i>	
Child's mother	26
Child's father	3
Family	
Coupled	21
Single parent	8
Number of children	
1	5
2	16
More than 3	8
Income (range: AUD\$28 853–AUD\$600 000)	Median 88 121*
Work arrangements of families	
One parent working full-time	14
One parent working full-time, one working part-time	9
Both parents working part-time	2
One parent working part-time	1
Neither parent working	3
One parent receiving 'carer payment'†	9
Accommodation	
Renting	4
Own home	23
Living with relatives‡	2
Children	
Age range (2–12 years)	
	Mean = 6.2 (SD = 2.6)
2 years	3
3 years	2
4 years	2
5 years	5
6 years	5
7 years	3
8 years and over	9
Time spent in early intervention services	
1 year	2
2 years	3
3 years	1
4 years	12
5 years	5
6 years	6
Reported conditions	
Cerebral palsy	23
Like disability§	6
Epilepsy	8 (28%)
Additional medical needs	14 (48%)
Sensory processing differences	21 (72%)
Complex communication needs	21 (72%)
Visual impairments	9 (31%)
Hearing impairment	5 (17%)
Gross Motor Function Classification system	
Level 1	0
Level 2	0
Level 3	4 (13.8%)
Level 4	5 (17.2%)
Level 5	20 (69%)
Had been an inpatient in hospital in previous year	11 (37.9%)
My child rejects carers outside of known family members	6 (20.7%)
Schooling	
Not yet attending school	11 (38%)
Local primary school	16 (55%)
Special school	2 (7%)

*\$600 000 income removed from computation because of extreme outlier.

†Australian Government payment to parents who have a child whose needs are demonstrated to prevent participation in paid work.

‡Two families lived with in-laws and rented out their family homes for financial reasons.

§Includes diagnoses such as lissencephaly, microcephaly.

accumulating for the first 6 years of the child's life. Eleven (38%) children were still receiving early intervention.

Details about the equipment or service out-of-pocket expenses are described in Table 3. All categories of equipment are reported, along with the number of items available for parents to select from within each category; examples of some items for the readers information; and the range and median of total costs within each category. These results indicate that there were moderate correlations (Spearman rho) between the amount of assistance to participate in at home activities and the number of pieces of equipment (items) required for seating/standing; mobility; communication/technology; toileting, bathing and dressing; and specialized adapted toys/recreational items (see Table 4). There was also moderate correlation between the amount of assistance that the child needed to participate in community activities and the items required for sitting/standing and toys/recreational items.

Overall, the extent of assistance required to participate in play and leisure (total APS) was correlated moderately with equipment needed for sitting/standing, communicating and the number of specialized adapted toys/recreational items (see Table 4). These results indicate that children who require the highest levels of parental assistance to participate in play and recreation also require the greatest number of pieces of equipment and technology for sitting, standing and communicating, as well as specially adapted toys/recreational equipment.

Discussion

The majority of families who responded to this study were coupled, two income families, with a median income of around \$88 000. Other Australian two income families have a median income of \$120 120 (Australian Bureau of Statistics 2013), 26% higher than the families in the current study. The equipment usage, out-of-pocket expenses, and care, support and device needs among the children with CP in this sample, were excessive.

The families who responded to the study were raising a child with significant and complex disability, including gross motor, sensory, complex communication and medical issues. Compared with other children with CP within the state, this group of children represented a higher proportion of children with Gross Motor Function Classification (GMFC) levels 4 and 5. In Victoria, about 28% of children with CP are classified level 4 or 5 (Australian Cerebral Palsy Register Group 2013). In the current relatively small sample, 83% of children were classified level 4 or 5. Further, when compared with other children with CP, vision, hearing and communication needs were similar. Within the

Table 2. Estimation of ability (parent report), and Assistance to Participate frequency response to items (N = 29)

A. Motor and self-care skills (parent selects 'yes' characteristics describes their child)		Number of parents indicating 'yes' (N = 29)	Number of parents indicating 'yes' (N = 29)
Statement			
My child behaves like other children their age	8 (27.6%)	My child stands using a standing frame/equipment.	24 (82.8%)
My child enjoys other children	24 (82.8%)	My child sits on a regular chair unaided	5 (17.2%)
My child uses equipment to eat	11 (37.9%)	My child sits in a specialized chair	22 (75.9%)
My child uses a toilet independently	2 (6.9%)	My child gets on and off a chair independently	6 (20.7%)
My child gets in and out of bed independently	6 (20.7%)	My child sits on the floor unaided	12 (41.5%)
My child uses their hands to play independently	12 (41.4%)	My child sits on the floor with the help of equipment	15 (51.7%)
My child gets up and down from floor independently	6 (20.7%)		
My child stands unaided	5 (17.2%)	My child walks with assistance*	16 (55.2%)

B. Frequency of responses to each Assistance to Participate Scale (APS) item (N = 29)					
Scale item	Unable to participate	Participates with my assistance at all stages of activity	Participates after I have set him/her up and help at times during activity	Participates with my supervision only	Participates independently
1. Watching television (n = 27)	2 (7.4%)	1 (3.7%)	12 (44.4%)	2 (7.4%)	10 (37%)
2. Listening to music (n = 28)	1 (3.6%)	2 (7.1%)	12 (42.9%)	1 (3.6%)	12 (42.9%)
3. Playing inside the house (n = 29)	3 (10.3%)	8 (27.6%)	7 (24.1%)	3 (10.3%)	8 (27.6%)
4. Playing outside the house (n = 28)	15 (53.4%)	6 (21.4%)	2 (7.1%)	2 (7.1%)	3 (10.7%)
5. Playing with a friend at our home (n = 28)	3 (10.7%)	10 (35.7%)	11 (39.3%)	1 (3.6%)	3 (10.7%)
6. Playing at a friend's house (n = 28)	4 (14.3%)	13 (46.4%)	8 (28.6%)	1 (3.6%)	2 (7.1%)
7. Playing at a playground/outdoors (n = 29)	1 (3.4%)	21 (72.4%)	2 (6.8%)	4 (13.8%)	1 (3.4%)
8. Participating in an organized club (n = 27)	9 (33.3%)	14 (51.9%)	0 (0%)	4 (14.8%)	0 (0%)

*Child may need adult assistance to mobilize using equipment.

Table 3. Sample items within categories of equipment for participant selection

Categories of equipment or service	Number of items within category	Examples of items within each category	Range and median number of items selected in each category (N = 29)	Number of families recording costs; range of total costs	Total median cost, for all items combined within category of equipment or service for families recording a cost
Indoor home seating, standing and specialized tables	26	<ul style="list-style-type: none"> • Commercially available high-low chair • Slant boards for table top • Customized wooden chair • Standing frame • Table/tray for standing frame • Pressure cushion 	Range: 6–21 items; median = 15 items	(n = 25) \$20–\$37 700	\$1 501
Out of home seating, standing and specialized tables	28	<ul style="list-style-type: none"> • Shoulder supports for chair • Slanted clipboard • Shoulder supports • Ankle weights • Sit to stand chair • Sticky matting 	Range: none–21 items; median = 15 items	(n = 16) \$90–\$10 580	\$897
Car travel, car seating specialized and suitable car, or modifications to your car	14	<ul style="list-style-type: none"> • Modified vehicle • Door widening modification • First aide or specialized equipment for the car • Purchased modified vehicle • Extra strapping • Portable ramps for car 	Range: none–9 items; median = 1 item	(n = 11) \$250–\$107 136	\$22 300
Mobility devices	37	<ul style="list-style-type: none"> • Junior manual wheelchair • Specialized bike • Pusher/stroller with modified supports • Crutches • Walker • Basket for walker • Communication software 	Range: 1–25 items; median = 9 items	(n = 25) \$80–\$24 100	\$2 200
Communication devices, equipment, technology	22	<ul style="list-style-type: none"> • Switch • Mounting for switch • Dynavox • Dynavox battery • Pragmatic Organization Dynamic Display communication book 	Range: 1–16 items; median = 8 items	(n = 23) \$40–\$22 240	\$1 378
Splints and orthoses	13	<ul style="list-style-type: none"> • Ankle foot orthoses • AFO socks • Hand splints • Helmet/head orthoses • Thumb splints • Hip brace 	Range: 1–8 items; median = 5 items	(n = 24) \$50–\$16 210	\$3 145
Technological support and medical/health items	28	<ul style="list-style-type: none"> • Hearing aide • Eye glasses • Medication • Sterilization equipment • Monitoring device (blood/sugar) • Suction machine 	Range: 0–15 items; median = 8 items	(n = 25) \$131–\$9 413	\$2 380
Equipment for eating and drinking	22	<ul style="list-style-type: none"> • Adapted cup • Adapted spoons • Large Bib/clothing item • Stand to hang non-oral food source • Adapted lunch box containers • Food technology (tubes, bottles, pegs) 	Range: 0–19 items; median = 6 items	(n = 21) \$80–\$55 155	\$442
Equipment for toileting, bathing and dressing	34	<ul style="list-style-type: none"> • Commode chair • Shower chair • High/low or customized change table • Large nappies • Wet bed alarm • 'Jocks'/underwear with velcro 	Range: 0–20 items; median = 5 items	(n = 19) \$20–\$91 663	\$2 900
Equipment for sleeping	19	<ul style="list-style-type: none"> • Height adjusted bed • Body position supports • Pressure relieving mattress • Mattress protector • Night c-pap mask • Bed pole, stick, grasp bar 	Range: 0–7 items; median = 2 items	(n = 15) \$90–\$7 700	\$630
Modifications to your home	20	<ul style="list-style-type: none"> • Ramp at front access • Change floor space (move walls etc.) • Hoist tracking • Change door width • Elevator • Landscaping for outdoor access 	Range: 0–9 items; median = 1 item	(n = 11) \$300–\$100 000	\$15 000
Toys/recreational opportunities specifically related to your child's disability	31	<ul style="list-style-type: none"> • Adapted swing • Adapted crayons/texta/paint brushes • Angled clip boards • IPad • Adapted scissors • Water play tank and stand 	Range: 1–24 items; median = 9 items	(n = 24) \$140–\$8 848	\$1 438
Specifically trained or capable paid carers, kinder or school aides	4	<ul style="list-style-type: none"> • Paid babysitter/carer • Paid assistant for kinder • Paid aide for school 	Range: 0–4 items; median = 1 item	(n = 16) \$300–\$50 290	\$3 080

Table 4. Correlations between total items of equipment needed by child in specific areas and Assistance to Participate Scale (APS) subscale and total scores

Total items needed by child	correlation with APS – Home	Correlation with APS – Community	Correlation with total APS score
No. items for home sitting/standing	–0.45	–0.31	–0.43
No. items for out of home sitting/standing	–0.40	–0.32	–0.37
No. mobility items	–0.30	–0.15	–0.27
No. communication/technology devices	–0.40	–0.23	–0.38
No. items for eating and drinking	–0.05	–0.07	–0.06
No. items for toileting, bathing, dressing	–0.36	–0.11	–0.28
No. items, toys and recreational items	–0.33	–0.36	–0.34

state, visual impairment is around 31%; hearing impairment is around 17%; and some communication need around 80% of all children with CP ($n = 1589$) currently residing in the state (Australian Cerebral Palsy Register Group 2013).

Most families in this study required multiple items for their child to sit, stand, mobilize, communicate, for self-care and medical needs. Associated with the number of items required, is a variation in expenditure. Out-of-pocket expenditure for items required for child's basic daily care and participation at home and elsewhere, ranged from a median cost of AUD\$442 for eating and drinking items to a median cost of AUD\$3045 for splints and devices. Median costs depict the midpoint, indicating that 50% of families have paid more. Other research has investigated the financial well-being of families during the early years (Parish & Cloud 2006), although no other studies have occurred specifically related to children with CP with complex needs.

The two highest costs outlaid by families were home modifications and travel/vehicle expenses. In this study, 11 families spent between AUD\$250 and \$107 136 on transport. More than half spent AUD\$22 300 on vehicle modification or purpose to accommodate the safe transport of their child with CP. Home modifications were similarly expensive. Eleven families spent a median range of AUD\$300–\$100 000 on home modifications to accommodate their child's needs. More than half of families had already spent \$15 000 out of pocket. Given the age of this cohort of children, it is reasonable to expect that families will face more expenses in relation to all equipment and service item categories, most particularly home and vehicle modifications, as their child grows.

Technology and equipment are environmental and activity adjustments and modifications that are intended to facilitate and enable a child's participation in home, educational and community activities, as well as ease of care by family members. The SPARKLE group of studies have been innovative in demonstrating the role of the environment as a crucial enabler for children with CP (Colver 2006). The European Child Environment Questionnaire (ECEQ) developed during the research,

surveyed 818 parents across seven European countries (Dickinson & Colver 2011). The questionnaire identified unmet needs within the physical environment in the home and transport as detrimental to participation. The ECEQ measured parent's perceptions of the unmet home and transport needs for their child with CP, aged 7 through 13 years. Percentages represented parents' judgement that their child needed but did not have the adjustment as follows: 21% did not have enlarged rooms at home; 16% did not have an adapted toilet; 23% did not have a modified kitchen; 16% did not have hoists at home; 9% did not have communication aids at home; and 15% did not have an adequate vehicle.

Past research has shown that people with CP participate in life opportunities less frequently than other people (McGuire *et al.* 2004; Imms *et al.* 2008). Children with CP participate less in the school environment (Schenker *et al.* 2005, 2006a) in play, their own self-care, social interactions and healthy leisure pursuits (Varni *et al.* 2005). Past research has identified technology, equipment and a helpful caregiver as are crucial to the child's ability to participate at home, school and the community (Ostensjo *et al.* 2004; Morris *et al.* 2006; Schenker *et al.* 2006b). In the current study, children who needed the most equipment and technology also had the highest need for assistance to participate in play and leisure demonstrating the high load born by families. More recent direct service models have been family centred (Palisano *et al.* 2004) and emphasized adjustments and changes to the contextual, or environmental aspects, of the child's daily life. Support for families of children with disabilities is currently under the spotlight because the long-term care frequently falls on the families involved. The health of caregivers (Brehaut *et al.* 2004; Bourke-Taylor *et al.* 2012a) and support available to them (Stok *et al.* 2006; Bourke-Taylor *et al.* 2012b) is crucial to provide a stable and resourced backdrop to assist the child to thrive and experience a quality of life on par with other children.

Limitations to this study include the relatively small sample size and challenges of verification for financial report. Future

research should include a larger randomized or stratified sample size; possible mixed methodology design to provide interviews with participants about the use, suitability, value for money, amount of support received to retain the devices/services, and more pertinent situational information that is lost in anonymous survey design methodology. Future research might also measure the extent that the child with a disability actually participates in various tasks, supported by the equipment/technology; and the impact of excessive family resources being directed towards disability need, and diverted from the family unit.

The implications for service providers includes attention to thoroughly evaluating a young child's need for equipment and technology; administrative support for funding applications for financial aid; and advocacy for children and families to receive whatever financial support is available. Service providers and policy makers can assist by supporting equipment libraries, buy back schemes and interest free loans.

In closing, the situation of children with less well resourced families cannot be forgotten, as required equipment and technology that enables an enjoyable and interesting life are unlikely to be available. This paper adds to the much needed family perspective about the equipment needs and costs of raising a young child with CP. Families appear to be making up the shortfall to retain the technology, equipment and resources necessary for their child to participate in the opportunities available in daily life. Out-of-pocket expenses appear to be considerable and urgent action is warranted to reduce the financial burden faced by families who are dedicated to the long-term care of their family member.

Key messages

- Many children with complex disability require extensive equipment and technology to participate in daily life.
- Equipment needs are excessive and out-of-pocket expenditure for families is significant.
- Children who require the most assistance in play and recreation, also have the highest equipment needs for sitting, standing, communication and adapted toys and leisure items.

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