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Complementary, Alternative, and Mainstream Service use Among Families with Young Children with Multiple Disabilities: Family Costs to Access Choices

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ABSTRACT. Families raising a young child with multiple disabilities are charged with significant responsibilities such as learning about their child's condition and navigating mainstream and alternative services. *Aim:* Describe service choices, costs, out of pocket expenses, and the impact on families. *Methods:* Survey design using a custom questionnaire was used to collect extensive retrospective and current data. Purposive sampling ($N = 29$) occurred from one early intervention facility specialized in servicing children with cerebral palsy (CP) and, or multiple disabilities in Australia. Descriptive statistics were used for analysis of data. *Results:* Twenty-three (79%) families reported caring for a child with CP. Twenty-three families reported using at least one complementary/alternative intervention. Out-of-pocket amounts were reported including: chiropractic services (10 families); naturopathy (9 families); point percussion therapy (7 families), and Chinese medicine (6 families). Expenses resulted in families reporting forgoing clothing items, family entertainment, recreation/hobbies for parents (55%); family holidays (59%); time for parents alone (66%); and health services for parents (38%). *Conclusions:* Families of young children with multiple disabilities select a wide range of services for their child, with consequential out of pocket expenses. Early intervention professionals can be an important resource for families as they evaluate their choices and select interventions for their child.

KEYWORDS. Cerebral palsy, complex needs, complimentary medicine, family costs, family support, parents, physical disabilities, service use, socio-economic status, therapy

Cerebral palsy is a complex condition that may occur with other diagnoses, including epilepsy, sleep disorders, sensory impairments, feeding issues, respiratory

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problems, musculoskeletal dysfunction, and chronic pain (Odding et al., 2006; Reddihough and Collins, 2003; Rosenbaum et al., 2007). A family of an infant diagnosed with cerebral palsy and other conditions will likely interact with personnel from multiple medical and allied health services before the child enters school (Cooley, 2004). Local early intervention services should target the child's education, health, and development as well as family concerns and needs within a family centered paradigm (Dunst et al., 2007; Palisano et al., 2004; Rosenbaum et al., 1998).

Family centered practice necessitates recognizing the family as central to decision making about their child's needs and service access (Dunst et al., 2007). Family satisfaction with services received for their child is influenced by the extent to which the agency provides information, collaborates, provides centrally received comprehensive care, and by the health and developmental progress or problems experienced by their child (Law et al., 2003). Pediatric services aim to support the family of a child with a disability to enable that family to become capable of managing the child's needs and able to provide an environment within which the child may thrive (Rosenbaum et al., 1998).

Meeting the day-to-day needs and long-term requirements of a child with cerebral palsy and complex needs can be difficult (Davis et al., 2010). Previous research has identified some of the issues that families may face including parental mental and other health issues (Bourke-Taylor et al., 2012; Raina et al., 2005), financial strain related to costs (Bourke-Taylor et al., 2014; Parish and Cloud, 2006), inability or considerably reduced ability, to participate in the paid workforce (Bourke-Taylor et al., 2011; Powers, 2003), and lack of time for other responsibilities or activities that are unrelated to caring (Bourke-Taylor et al., 2010; Butcher et al., 2008; Davis et al., 2010). Understanding the perspective of families allows professionals to be more responsive to family's needs.

Mainstream services that are commonly available during early intervention include various specialized medical services depending on the child's needs, physiotherapy, occupational therapy, speech pathology, early childhood special education services (Cooley, 2004; Liptak et al., 2006; Palisano et al., 2004). Families may engage with publicly funded service organizations that provide access to services through outpatient or specialized centers or clinics, or at home; or may seek out private practitioners. Professionals are charged with the responsibilities of fulfilling the families need for education, service navigation, service access, and any other important area of family life affected by disability (Cooley, 2004; Liptak et al., 2006). However, few studies have taken a wider angled lens to investigate the types of interventions and services that families are seeking, retaining, and utilizing outside of early intervention services.

Families of children with disabilities have access to as many sources of information about nontraditional health services as families of children without disability. A decade ago, medical experts documented the increasing use of nontraditional approaches within pediatrics (Kemper et al., 2008). Both complementary (used in conjunction or additional to traditional medicine) and alternative (used instead of mainstream medicine) treatments are increasingly used by families of children with chronic medical conditions including asthma, attention-deficit/hyperactivity disorder, autism, inflammatory bowel disease, and cerebral palsy (Kemper et al., 2008). A report by the American Academy of Pediatrics stated that families who do

use complementary or alternative treatments frequently do so in addition to mainstream care, and that the majority of families do not inform their medical practitioners (Kemper et al., 2008). The report also estimated that 30–70% of families with a child with a disability used complementary and alternative treatments, and that many nontraditional options were covered by insurance (Kemper et al., 2008).

Many families do have access to reliable sources of information about interventions that have been shown to benefit children with disabilities. Such sources may be medical practitioners and allied health practitioners who share information with families (Novak et al., 2013; Rosenbaum, 2003), or organizations set up to support families raising a child with a disability. However, beyond medical and allied health practitioners who are working with families, families are also exposed to unreliable information, personal opinion and testimonials from the internet, through social connections, and information from the local community. Families seek information to make decisions that will benefit their child with a disability, improve their health, capabilities and provide hope for development alongside other children in the community (Majnemer et al., 2013; Matson et al., 2012).

Families raising a child with an Autism Spectrum Disorder (ASD) have been reported to use alternative and complementary interventions more frequently than families of children with typical development (Wong and Smith, 2006). In a review, Matson et al. (2012) highlighted the large number of interventions available for ASD, some effective and evidence based and others empirically unsound, even harmful. Families of children with ASD often sought out different types of interventions that may be pharmacological, dietary, behavioral, restrictive, developmental, educational, and alternative in nature (Matson et al., 2012). Families who were *less* likely to follow up with intervention seeking and trialing were identified as: minority groups, families with lower parental education, financially stressed families, culturally and linguistically diverse families to the mainstream culture, and geographically disadvantaged families (Matson et al., 2012).

Adolescents and adults with cerebral palsy have been reported to pursue alternative and complementary interventions (Carlson and Krahn, 2006; Hurvitz et al., 2003; Majnemer et al., 2013), however, little is known about the extent to which families of young children with cerebral palsy utilize mainstream, complementary or alternative services. Research suggests that massage is a common add-on service to improve sleep, comfort and wellbeing among children with cerebral palsy (Glew et al., 2010), and that families commonly use nontraditional interventions to address hypertonicity (Rosenbaum, 2003). Further, families report being dissatisfied with physician knowledge about such alternative and complementary interventions for their children (Liptak et al., 2006). Hurvitz et al. (2003) investigated use among a sample of families with children with cerebral palsy under 18 years and identified significantly higher use of alternative and complementary interventions among families of younger children.

The aim of this research was to gain estimations of families' out of pocket expenses, service choices and costs; and the impact of meeting the care, health, and development needs of their child with multiple disabilities in the first 6 years. A local non for profit center, Cerebral Palsy Education Centre (CPEC), specializes in providing early intervention services for children with physical disabilities (mainly cerebral palsy) and complex needs. Children tend to have physical disability with

high need for mobility aides or assistive devices and complex communication needs. CPEC collaborated with researchers from Monash University to investigate the situation among families. In Australia, families raising a child with cerebral palsy or multiple disabilities receive services through numerous sources—state run early intervention; federally funded package support for therapy and equipment; as well as individually funded health insurance.

Specific research questions were:

1. What are the out of pocket mainstream, alternative and complementary service expenses shouldered by families during the first 6 years?
2. What is the impact of meeting financial obligations related to a child's care in terms of foregoing health, recreation and education needs within the family unit?

METHODS

This research project was a collaboration between Monash University and CPEC in Melbourne, Australia. The anonymous survey design was specifically configured in conjunction with advice and feedback from parents of children with cerebral palsy and allied health professionals. The questionnaire was piloted several times with all groups. The content included questions to identify costs, describe equipment, technology, and required environmental supports (see Bourke-Taylor et al., 2014 for more detail), as well as to determine service use and directly related family cost, to meet the needs of their child with cerebral palsy. The study was approved by the Monash University Human Ethics Research Committee.

Participants and Recruitment

Letters of invitation were sent to 48 families who had attended CPEC for early intervention at some time during the previous 5 years. Twenty-nine families responded to the call to participate (60.4% response rate). Inclusion criteria required that the person completing the mail out questionnaire was a parent and primary carer of a child who had attended at least 1 year of early intervention (for children 0–6 years) through CPEC; that the family resided in the state of Victoria, Australia; and were able to complete the questionnaire in English. Interested families contacted the researcher directly, or completed the questionnaire and sent it to the researcher anonymously. This method of recruitment and data collection aimed to optimize family confidence in disclosing financial information, whilst 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 process, and questionnaires were not viewed or stored at CPEC. Monash University researchers were unaware of the names of the respondents.

Questionnaire

The questionnaire was designed according to the specific life situation of young children with cerebral palsy and complex medical or communication need, such as a likelihood that the child has had contact with many medical and allied health therapists, early intervention, various equipment and technology options, as well as different play, self-care, and mobility status compared to typically developing

children. As this research was novel and individualized to the families at the center involved, no frameworks underpinned the selection of questions other than to fully explore the family, finances, capabilities and disability of the children involved and factual information about services and equipment. The content and rating scales were piloted with three different families of young children with cerebral palsy for feedback, as well as eight experienced therapists at CPEC (3 occupational therapists, 2 speech pathologists, and 3 physiotherapists). Revisions were made based on feedback and pilot questionnaire varied from 40 minutes to 3 hours to complete, depending on the families situation and the child's needs.

The questionnaire was 40 pages, spiral bound and required extensive time to complete (Table 1). Although Table 1 describes the content of the questionnaire, only data relevant to the research questions are described in the results section of this paper. Further details about the questionnaire and data collected about equipment and technology costs have been published elsewhere (see Bourke-Taylor et al., 2014).

Families were asked to select from a list of services that had been identified through the piloting process. For each service the child received, families were asked to report their out of pocket expense, after rebate from health insurance or any funding subsidy. Families were asked to refer to financial records, and where families did not have a record, they were instructed: "*Please provide the best estimation of costs that you can*". With regard to what families forgo in order to meet financial obligations related to their child's disability, families were asked "In the past year, has your family forgone any obligations, events, needs or opportunities due to financial restraints or obligations related to your child's disability?" Following this question, families were asked "What obligations, events, needs or opportunities have you been unable to meet?"

Data Analysis

The SPSS Version 20 statistical package was used for all data entry and management. Descriptive statistics (mean, standard deviations medians and frequencies) were used to analyze the data. Due to the relatively small sample, costs and service use were calculated for the group of children as a single sample.

RESULTS

Twenty-nine families completed the survey (Table 2). Most respondents were two parent families ($n = 21$, 72%) with two children ($n = 16$, 55%). About half of families had one parent working full time ($n = 14$, 48%) and nearly one-third of families had one parent working full time, while the other worked part time ($n = 9$, 31%). There was a wide range for family income with approximately half of families ($n = 14$, 48%) reporting gross family income between AUS\$50,000 and \$125,000.

The children's age range at the time that the parents recorded costs was 2 years through 12 years of age. The average number of years spent in early intervention was 4.1 years ($SD = 1.5$ years). Six families reported costs and service use for the full 6 years of early intervention, and the remaining 23 (79%) families recorded costs and service use for 1 ($n = 2$), 2 ($n = 3$), 3 ($n = 1$), 4 ($n = 12$), or 5 ($n = 5$) years. Eleven children (38%) were still receiving early intervention and nearly 50 percent

TABLE 1. Description of Questionnaire Contents

Type of questions	Number of questions	Sample question/s	Sample response items
Demographic questions	7	Where do you live?	Options: In rental accommodation In your own home Other (please specify) Yes/no
Questions about the family's service use	2	Do you or any family member receive medical or health care service related to raising your child with a disability?	If yes: Describe the service, the number of visits and the cost to your family (open ended table provided) Yes/no
Questions about the child and skills	45	My child has a visual impairment. My child is able to speak so that others (nonfamily) can understand him/her.	Yes/no
Questions about equipment, technology	12	"The following questions are all about equipment that your child has been prescribed and used during the first six years (before age seven). Each section is about different equipment for different aspects of your child's day and experience. You are asked to complete the tables to demonstrate the additional costs of equipment that your child has needed during their early years." Sections include seating, standing, toys, bathing etc. (see Bourke-Taylor, Cotter, Stephan, 2014). Example Car travel, car seating, specialized and suitable car.	Examples (please tick): Door widening modifications, specialized strapping, modified vehicle, wheelchair life, portable ramps, etc. Table provided "Please list item; was the item loaned; was this item purchased?; total cost to your family; what of any funding support did you receive?"
Questions about services for the child's health and development	41	Service options presented in table, i.e. Private physiotherapy; surgeons; dietician; chiropractor, etc.	Yes/no If yes: Table provided "List services; how many visits or how much did you use the service; did you receive a rebate, if so how much? Total cost to your family)"
Questions about "obligations, events, needs or opportunities" that families were unable to meet.	29	"What obligations, events, needs or opportunities have you been unable to meet?". Options presented, i.e. Basic food items; toys for my child with a disability; family holidays; credit card payments, etc.	Yes/no
Open ended:	1	"Please add comments or notes here"	Space provided

were not yet 7 years of age. These results indicate that the majority of families were still accumulating the costs of supporting their child for the first 6 years.

In line with the specialized services offered by CPEC for children with GMFCS levels III, IV, and V (Russell et al., 2013), complex communication needs and multiple disabilities, the motor abilities of the majority of children were described by their parents as gross motor function level V ($n = 20$, 69%). Most children used alternative and augmentative communication systems to communicate ($n = 21$, 72%). Eleven children (38%) required technology to eat, including five children who required a non-oral food source. Nine children (31%) had a visual impairment, five (17%) had a hearing impairment and eight (28%) children had epilepsy.

TABLE 2. Demographic Characteristics of Participating Families and Children (N = 29)

Characteristics	Participant Status (N = 29)
Person completing survey	
Child's mother	26
Child's father	3
Family	
Coupled	21
Single parent	8
Number of children in the family	
1	5
2	16
More than 3	8
Income (range: AUD\$28,853-AUD\$600,000)	Mean \$88,121* (SD = \$48,971)
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
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
Reported conditions	
Cerebral palsy	23
Like disability***	6
Epilepsy	8 (28%)
Additional medical needs	14 (48%)
Complex communication needs	21 (72%)
Visual impairments	9 (31%)
Hearing impairment	5 (17%)
Gross Motor Function Classification System	
Level I	0
Level II	0
Level III	4 (13.8%)
Level IV	5 (17.2%)
Level V	20 (69%)
Had been an inpatient in hospital in previous year	11 (37.9%)
Schooling	
Not yet attending school	11 (38%)
Local primary school	16 (55%)
Specialized school	2 (7%)

*\$600,000 income removed from computation due to extreme outlier.

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

***Families reported exact diagnosis without using term cerebral palsy in six cases (brain malformation, primary cause of brain insult, or were awaiting diagnosis in younger children).

Most children who were school aged attended their local primary (elementary) school. The capabilities of the children in this sample included independence to watch television ($n = 10$); listen to music ($n = 12$); play inside the house ($n = 8$); or play around outside of their house ($n = 3$). As described by parents, five children were able to sit on a regular chair without assistance; 12 children were able to sit on the floor independently; 6 children could get in and out of a chair independently, 6 children could get up and down from the floor independently, and 6 children who could get in and out of bed independently; 12 children used their hands independently to play; and 2 children used the toilet independently. Further details about the functional capabilities of children are described elsewhere (see Bourke-Taylor et al., 2014).

Families selected a range of services in addition to available state funded early intervention services. CPEC early intervention services included substantial service between 4 and 9 hours/week of allied health services), including access to speech pathology, occupational therapy, and physiotherapy services on site as well as mobile services to support participation at home, early education or child minding services. Out of pocket expenses for child related expenses for medical, allied health, complementary and alternative services are described in Table 3.

All families had utilized medical and allied services for their child and 23 (79%) of families had utilized alternative or complementary interventions for their child. Families self-reported examples of items/events/obligations that they were unable to meet due to their financial responsibilities related to their child's needs and disability is described in Table 4. The authors remind the reader that "costs" were related to equipment expenses (see Bourke-Taylor and Pallant, 2013), as well as the service expenses described in this paper.

Of note, over one-third of participants who completed the survey said that their family went without clothing items for parents; family entertainment outside of the home (i.e. zoo, day trip); recreation or hobbies for themselves; family holidays; gifts for each other, family and friends; eating out; time with partner; and on health services for themselves. Further, the highest frequency item that participants went without was time out with their partner (66%); family holidays (59%); and Recreational activities or hobbies for themselves (55%).

DISCUSSION

This research describes the parent reported service use and consequential family estimations to forgo other family needs among 29 families raising a child with multiple disabilities (including cerebral palsy) in Victoria, Australia. In line with the specialization of CPEC to address the participation and communication needs of young children with multiple disabilities who would experience severe activity limitation without extensive interventions, technologies and equipment, the children described in this sample of families are not representative of all children with cerebral palsy.

The results indicate that the children of the families surveyed received alternative and complementary interventions in addition to mainstream services. Median costs were reported, suggesting that 50% of families spent more than the reported cost of services. Some findings were surprising, including that 15 families

TABLE 3. Out of Pocket Expenses for Child Related Expenses for Medical, Allied Health, Complimentary and Alternative Services (N = 29).

Item or service used by child	Number of families selecting service for child	Recorded cost range for service	Median cost for service
Allied health and developmental services for child			
Private physiotherapy	15	\$300–\$18,000	\$1,965
Private speech pathology	10	\$1000–\$15,210	\$600
Private occupational therapy	5	\$200–\$400	\$200
Psychologist	6	\$60–\$1080	\$300
Optometrist	11	\$20–\$500	\$280
Audiologist	12	No cost–\$60	\$60
Early intervention program (provided occupational therapy, physiotherapy and speech pathology)	29	\$120–\$10,000	\$3,000
Dietitian	5	No cost–\$80	\$80
Hydrotherapy*	10	\$150–\$2010	\$140
Medical services used by child			
Pediatrician	18	\$60–\$1080	\$300
Neurologist	11	\$150–\$1800	\$250
General practitioners	19	\$65–\$3,480	\$400
Dentist	9	\$125–\$800	\$462
Inpatient hospital stay	12	\$500–\$8000	\$4,250
Surgeons	9	\$1070–\$4330	\$4,000
Anesthetist	8	No cost–\$315	\$300
Orthopedic surgeon	7	\$500–\$4330	\$2,900
Gastroenterologist	4	\$300–\$2000	\$1,700
Ophthalmologist	7	\$120–\$1800	\$500
Complementary and Alternative services for child			
Naturopathy	9	\$100–\$5760	1250
Kinesiologist	4	One cost recorded	\$150
Chiropractic service	10	\$500–\$2212	\$1,800
Chinese medicine	6	One cost recorded	\$360
Bowen therapy	3	One cost recorded	\$4,500
Laser Acupuncture	3	One cost recorded	\$2,365
Point percussion therapy	7	\$100–\$6000	\$1,000
Osteopathy	5	\$100–\$4320	\$2,350
Feldenkrais	1	One cost recorded	\$20,000
Doman Delacato	2	\$1000–\$6000	\$3,500
Stem cell implants	1	One cost recorded	\$35,000
Hyperbaric oxygen	3	\$10,000–\$20,000	\$15,000

*Hydrotherapy provided by a physiotherapist.

purchased additional physiotherapy to their state provided service, and the median expense was nearly \$2000. Families also paid more than \$4000 out of pocket for surgeons and hospital inpatient stays, and nearly \$3000 for orthopedic surgeons. Excessive out of pocket amounts were spent on nontraditional, or unproven interventions such as hyperbaric oxygen (\$15,000), Bowen therapy (\$4,500), Feldenkrais (\$20,000), and \$35,000 for Stem Cell Implants, which are not available in Australia. The most common interventions sought in the nontraditional sector were chiropractic services (10 families); naturopathy (9 families); point percussion therapy (7 families) and Chinese medicine (6 families).

Examination of the services used demonstrates that while more families utilized mainstream medical and allied health services, costs were mainly in the hundreds

TABLE 4. Families Self Report of Items that all Family Members Forgo (go without) to Provide for needs of Child with Cerebral Palsy

Family life area	Items within the area of family life	Number of participants selecting (N = 29)
Basic family items	Basic food items	1 (3%)
	Clothes or items for parents	11 (38%)
Recreation	Clothes or items for other children in the family	4 (14%)
	Family entertainment outside of home (zoo, movies, day trips)	12 (41%)
	Family entertainment inside the home (movies, paid TV etc.)	7 (24%)
	Toys for my child with a disability	7 (24%)
	Toys for the other children in our family	4 (14%)
	Recreational/hobby/development opportunities for my child with a disability (swimming, music, dance, horseriding other available activities)	7 (24%)
	Recreational/hobby/development opportunities for my other child/ren (ballet, scouts, swimming, music lessons etc.)	4 (14%)
	Recreational/hobby/development opportunities for myself	16 (55%)
	Recreational/hobby/development opportunities for my partner	12 (41%)
	Family holidays	17 (59%)
	Usual gifts that we might give family/friends	13(45%)
	Usual gifts that we might give each other (within family)	10 (35%)
	Eating out	13 (45%)
Time for my partner and I to spend together (babysitting/night out)	19 (66%)	
Health	Health related activities for my child (dentist, doctors' visits)	1 (3%)
	Health related activities for my other children (dentist, doctors' visits)	2 (7%)
	Health related activities for myself (dentist, doctors' visits)	11 (38%)
	Health related activities for my partner (dentist, doctors' visits)	9 (31%)
	Education	Education related opportunities or needs for my child with a disability (tutoring, school excursions, camps, books etc.)
	Education related opportunities or needs for my other children (tutoring, school excursions, camps, books etc.)	2 (7%)
	Education related opportunities or needs for myself.	9 (31%)
	Education related opportunities or needs for my partner	3 (10%)
Financial responsibilities	Rent or mortgage payments	4 (14%)
	Essential bills (gas, electricity, phone etc.)	1 (3%)
	Credit card payments	7 (24%)
	Other loan repayments	1 (3%)

compared to the less used, but more costly complementary and alternative options. All families were utilizing traditional medical, surgical, and allied health services, although 23 (79%) of families had used at least one complementary or alternative intervention for their child. Our findings suggest that the early years of their child's life may involve trialing non-traditional interventions. It seems reasonable to suggest that parents are making decisions about available interventions and treatment in the hope of bettering their child's health and future, during a period when the child's future is largely unknown.

Previous research has described that families of adolescents and children with fewer motor skills and higher care needs tend to utilize complementary and alternative options with higher frequency than families of children with higher functional capabilities (Glew et al., 2010; Majnemer et al., 2013). In a North American study about the use of massage, 80% of families ($N = 106$) with a child/youth with cerebral palsy under 21 years had tried massage with use being associated with severity (higher GMFCS level) although not the child's age (Glew et al., 2010). Massage was the most frequently used complementary intervention among adolescents with cerebral palsy in another North American study, and use was associated with extent of need for support in daily living (daily activities, communication, mobility, intellectual capacity) (Majnemer et al., 2013). Hurvitz et al. (2003) studied 213 North American families and found that children with cerebral palsy were more likely to be exposed to complementary and alternative interventions when they had greater extent of disability, although the study also identified the child's age (younger) as one of the strongest predictors of exposure. In the same study, 56% of families had tried at least one complementary or alternative intervention with their child (age range of children in the study 0–18 years, and mean age 8 years).

Our study may be the first to use de-identified data to describe family self-report about use of interventions—traditional and nontraditional. Previous research that has examined the issue of service choice among families have occurred using identified survey design (Liptak et al., 2006; Majnemer et al., 2013). If families are identified in research, the likelihood that they will disclose may be reduced, given research findings that suggests that families may not share their use of nontraditional interventions with their child's service provider. (Kemper et al., 2008), and that families do not believe that physicians are well informed about such interventions (Liptak et al., 2006). Therefore, family report might be interpreted with caution in these studies.

The findings in this current study might be interpreted in relation to current understanding about the challenges faced by families in the early years. Parents have consistently reported emotional upheaval and commencement of seeking behaviors that are about knowledge and skill acquisition to meet their child's needs and locate skills/skilled people to assist their child in the early years (Bourke-Taylor et al., 2010; Green, 2007). Some parents describe their new parenting experience as life changing and a period of "lost dreams" (King et al., 2012, p. 358), characterized by sadness and grief (Green, 2007; Reid et al., 2011), though followed by reconstruction of a life built on hope and new life values (King et al., 2012; Reid et al., 2011). Parents describe being focused on the disability "In the early days it was about never doing enough for Andrew. That was... before I knew where he'd end up on the scale of disability. When I was really putting in the hard

yards and trying to make that first milestone with the movement or whatever and I chased around all the different therapies, gave everything a go” (Bourke-Taylor, 2010, p. 35). Parents reflect prioritizing decisions and actions aimed at “fixing” their child’s challenges experienced as a result of cerebral palsy (King et al., 2012).

During the early years, parents are likely to be engaging in both seeking and disability focused behaviors that have the function of linking families with the services and professionals that their child needs (Bourke-Taylor, 2010). In the current study, families reported that the impact of meeting financial obligations (equipment, technology, medical services) and services choices for their child (additional private mainstream allied health services, as well as nontraditional options) resulted in decisions not to use other services for parental health, recreation, and education needs within the family unit.

There are several salient messages for practitioners working in early intervention who adopt a family centered paradigm and apply evidence informed practice. The need for such professionals to be open, informed and able to provide measured and evidence informed advice to families is paramount (Kemper et al., 2008; Liptak et al., 2006; Rosenbaum, 2003). Families raising a child with multiple disabilities shoulder excessive responsibility and harm that may result from unhelpful service use might be viewed in terms of lost family resources, time, and hopes. However, in the case of useful and helpful complementary and alternative interventions, benefits must be recognized, measured, and described for other families.

Our findings cannot be generalized and may not be representative of all families of young children with multiple disabilities. The convenience sample provided opportunity to commence research in this area, although findings may be limited geographically to the small community from which it was gathered. Findings cannot be generalized to other children with cerebral palsy with a higher level of mobility, or to other children with multiple disabilities. Larger, multi-center studies might determine a broader and representational sample that would provide more reliable estimates of usage of complementary and alternative interventions among young children with cerebral palsy. Costs and usage could not be verified or confirmed due to the nature of data collection. Future research might use a larger sample and use mixed methodology to investigate reasons for pursuing complementary and alternative interventions, and perceived benefit from the child and families perspectives. Research is also recommended to investigate the ways in which the experiences of children/families not receiving early intervention services, or children at other functional skill levels might be the same or different from the children in the present report. Future research might also determine the effectiveness of nontraditional interventions, such as those described in this paper.

This research describes the service choices, costs, out of pocket expenses and impact on families caring for a young child with multiple disabilities. Although the sample size was small, some salient messages were evident and suggest that further research is necessary to identify reasons, satisfaction and any benefits of the nontraditional interventions that families spent time and money accessing for their child. The findings highlight some unexpected choices regarding service use and costs, particularly with regard to complementary and alternative medicine. Further, families reported that service costs and other expenses related to raising their young child with a disability did impact on family resources and opportunities Medical

and allied health practitioners who work with families raising a child with cerebral palsy are charged with the responsibility to ask themselves “Am I doing the right thing, in the right way, with the right person, at the right time, in the right place, for the right result and am I the right person to be doing this. . .and is it at the right cost?” (Cusick, 2001, pp 103). Professionals are also in a prime position to encourage parents as consumers to also reflect: *Am I choosing the right professional, with the right attitude, knowledge and skills, to assist my family and our child in the right way, at this time, and will I get the right result at the right cost?* Responsible family centered service providers might encourage families to do so in an endeavor to support and protect the family unit as a whole.

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