Aims of research
Determine the real-life expenses of raising a child with cerebral palsy
Determine which services and equipment families are paying for out of their own pocket
Determine the extent to which families forego health and education opportunities for themselves and their children

Cerebral Palsy Education Centre – CPEC www.cpec.org.au
CPEC is a not-for-profit that helps managed by families, allied health and assistants

It is this research that parents wanted CPEC to undertake to:

• highlight the burden of care for families – in particular, the financial costs to families
• ultimately improve the services we provide to the families and reduce the burden of care

The Cerebral Palsy Education Centre is a non-profit organisation dedicated to enhancing self-participation rights for people with cerebral palsy and their families. CPEC has a sound philosophical basis for learning and inclusion.

Incorporate a range of current knowledge and strategies to facilitate participation, learning and development for each individual child and family.

Research methodology
This study was a partnership between CPEC and Monash University Occupational Therapy Department. It is Monash ethics approved.

• Mail survey design (40 families sent survey); 23 responded (58% response rate)
• CPEC managed mailing out potential participants and Monash collected completed forms from families.
• Monash blinded from families identity and CPEC was blinded from who participated.

Who were the families?

• SINGLE PARENTS (n=8); COUPLES (n=21)
• 1 child (n=5); 2 children (n=3); 3 children (n=1)

Work arrangements:
One parent working PT (n=4)
One parent working FT and one working PT (n=2)
Neither parent working (n=5)
Both parents working part time (n=2)
One parent working PT (n=1)

Caretaking role:
Living circumstances:
Families living with living and family with 23 over home

Income
Range: $28,383-$500,000
Median: $65,000

$65,000 not included in slide

Who were the children?

Age range: 2-12 yrs. Mean age: 6.3 years (SD=2.2)

Diagnosis: cerebral palsy (n=23), disability (n=4)

GMFM:
Level 2 – 4 children
Level 1 – 5 children
Level 0 – 20 children

Visual impairment
n=6(23%)

Hearing impairment
n=5(17%)

Epilepsy
n=6(23%)

Uses technology to eat
n=17(70%)
(n for normal food intake)

Use technology to communicate
n=10(43%)

Additional medical needs
n=14(61%)

16 children had disabilities (n=16, not an patient in hospital in previous 12 months

Schooling:
• Need an attending school
11 (46%)
• Local primary/secondary school
16 (65%)
• Private School
2 (7%)

Assistance to Participate Scale
10 able to watch TV independently
12 able to listen to music independently
8 play with toys in home independently
6 able to participate in community activities without parent

After external funding, which families spent out-of-pocket

Item needed by child Cost range Cost median
Indoor housing seats and tables $250-$600 $220
Seating and seating needed outside of home $250-$600
Car travel $180-$500
Mobile phones $420-$100
Communication device $250-$240
Sensory, orthotic and suits $500$500
Technological support and medical health items $140$140
Equipment for eating and dining $200$145
Equipment for toileting, bathing and dressing $90$90
Equipment for driving $150-$700
Modifications to homes $150-$100
Transport to medical appointments $200-$500
Medical, health, alternative, educational services $250-$500

What did families forge in order to provide for their child with a disability?

There were five main areas:
• Basic family items
• Recreation
• Health
• Education
• Financial responsibilities

Basic family items

Basic Food Items
Clothes or items for parents
Clothes or items for children in the family

Essential Bills (gas, electricity, phone etc)

Recreation

Recreation that family forges
Family entertainment outside of home (cin, movies, day trips)
Family entertainment inside the home (movies, paid TV)
Toys for my child with a disability
Toys for the other children in my family

Recreational/holdiay development opportunities for my child with a disability (swimming, music, dance, harnessing other available activities)
Recreational/holdiay development opportunities for my other children (ballet, swim, swimming, music lessons etc)
Recreational/holdiay development opportunities for myself
Recreational/holdiay development opportunities for my partner
Family holidays

Usual gifts that we might give family/ friends
Usual gifts that we might give each other within family
Eating out
Time for my partner and I to spend together (baby sitting/right out)

Health

Health related needs that family forges
Health related activities for my child (dentist, doctors visits)
Health related activities for my other children (dentist, doctors visits)
Health related activities for myself (dentist, doctors visits)
Health related activities for my partner (dentist, doctors visits)

Education

Education related opportunities that family forges
Education related opportunities or needs for my child with a disability (tutoring, school/unschools, camps, books etc)
Education related opportunities or needs for my other children (tutoring, school/unschools, camps, books etc)
Education related opportunities or needs for myself
Education related opportunities or needs for my partner

Financial responsibilities

Financial responsibilities that family forges
Rent or mortgage payments
Credit card payments
Other loan repayments

Other loan repayments

Health related activities for my child (dentist, doctors visits)

Education related opportunities or needs for my child with a disability (tutoring, school/unschools, camps, books etc)

Education related opportunities or needs for my other children (tutoring, school/unschools, camps, books etc)

Education related opportunities or needs for myself

Education related opportunities or needs for my partner

Financial responsibilities

Financial responsibilities that family forges
Rent or mortgage payments
Credit card payments
Other loan repayments

Other loan repayments

Implications

There are excessive expenses incurred by families raising a child with cerebral palsy (CP) and complex disability:
• The financial burden of meeting medical, allied health and education costs in first 6 years is excessive.
• Current funding and reimbursement schemes do not meet the costs of families raising a child with severe CP.
• Some families are spending money on alternative interventions that do not really researched and cost/benefit require future research to understand family motivation and satisfaction.
• Knowledge of disability and service navigation of families may leave some families vulnerable to services that have high cost and low efficacy.
• Better start and the National Disability Insurance Scheme (NDIS) offer opportunities to develop navigation pathways.

References


With sincere thanks to all families, past and present, who attended CPEC for early intervention, and who participated in this study.