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Original article

Medical service use in children with cerebral palsy: the role of child and family characteristics

Short title: Cerebral palsy and medical service use

Elaine Meehan [1,2], Susan M. Reid [1,2], Katrina Williams [1,2,3,4], Gary Lee Freed [5], Jillian R. Sewell [1,6,7], Dinah S. Reddihough [1,2,3]

[1] Department of Paediatrics, University of Melbourne, Australia, [2] Developmental Disability and Rehabilitation Research, Clinical Sciences, Murdoch Childrens Research Institute, Melbourne, Australia, [3] Developmental Medicine, Royal Children's Hospital, Melbourne, Australia, [4] Deakin Child Study Centre, School of Psychology, Deakin University, Melbourne, Australia, [5] Health Systems and Workforce Unit, Centre for Health Policy, School of Population and Global Health, University of Melbourne, Australia, [6] Centre for Community Child Health, Royal Children's Hospital, Melbourne, Australia, [7] Community Health Services Research, Population Health, Murdoch Childrens Research Institute, Melbourne, Australia

Corresponding author: Ms Elaine Meehan, Developmental Disability and Rehabilitation Research, Murdoch Childrens Research Institute, Royal Children's Hospital, 50 Flemington Road, Parkville, Victoria 3052, Australia

Email: elaine.meehan@mcri.edu.au

Telephone: +61 (03) 9345 4808

Word count

Abstract: 249

Main body: 2500

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/jpc.13163

Medical service use in children with cerebral palsy: the role of child and family factors

Abstract

Aim To investigate the patterns of medical service use in children with cerebral palsy (CP), taking into account child and family characteristics.

Methods: 901 parents and carers of children registered with the Victorian CP Register were invited to complete a survey. Participants were asked about their child's appointments with general practitioners (GPs) and public and private paediatric medical specialists over the preceding twelve months. Information on family characteristics and finances was also collected. Data on CP severity and complexity was extracted from the CP Register.

Results: 350 parents and carers (39%) participated. Of these, 83% reported that their child had ≥1 appointment with a GP over the preceding twelve months, while 84% had ≥1 appointment with a public or private paediatric medical specialist. Overall, 58% of children saw 2-5 different paediatric medical specialists, while 9% had appointments with ≥6 clinicians. Children with severe and complex CP were more likely to have had ≥1 appointment with a publically-funded paediatric medical specialist, and had seen a greater number of different clinicians over the study period. Family characteristics were not associated with service use.

Conclusions: Children with CP are managed by a number of paediatric medical specialists, and they continue to see a range of specialists throughout adolescence. In Victoria, differences in service use are not based on family characteristics; instead the highest service users are those with severe and complex CP. For this group, care-coordination and information sharing between treating clinicians is important, if gaps in care are to be avoided.

Key words

cerebral palsy, service use, health expenditure, health services

What is already known on this topic

- Compared to their typically-developing peers, children and young people with cerebral palsy have additional medical care needs, and require input from a range of medical disciplines

What this study adds

- Most children with CP receive medical services from a number of different providers, and this continues into adolescence and early adulthood. Among this patient group, care-coordination and adequate information sharing between treating clinicians is important, to prevent gaps in care arising.
- Service use is influenced by CP severity and complexity, but not by family characteristics, and in general, highest service use is among children with a more severe gross motor impairment and/or epilepsy.
- Many families of children with CP experience financial difficulties that they perceive to be attributable to the costs of providing medical care for their child.

Introduction

Cerebral palsy (CP) is the most common cause of childhood physical disability in developed countries worldwide, affecting approximately two in every 1,000 children. [1] It is an umbrella term for a group of permanent, but non-progressive, disorders of movement or posture, caused by an injury or insult to, or maldevelopment of, the developing brain. [2] Compared to their typically-developing peers, children with CP are at an increased risk of epilepsy, as well as impairments of intellect, vision, speech and hearing, and progressive musculoskeletal pathologies, all of which influence the severity and complexity of their condition. [3] Approximately 29% of individuals with CP have a severe gross motor impairment, [4] and 30-40% have epilepsy. [5, 6]

Children and young people with CP have medical care needs beyond those of typically-developing children, and their healthcare requirements change over time. [7] Early in life, they are likely to see a number of medical specialists in various settings as their diagnosis is confirmed. [8] Medical and surgical management throughout childhood and adolescence is focussed on improving or maintaining functional abilities, reducing the impact of co-impairments, preventing pain, and promoting independence, participation and quality of life. [9] Depending on the severity of the motor impairment, and the number of co-impairments present, ongoing medical management can involve specialists from a range of disciplines.

While a number of groups have investigated how factors such as CP severity and family characteristics affect the patterns of use of therapy services in children and young people with CP, [10-12] there has been little research to date investigating how such factors affect medical service use in this population. The primary aim of this study was to investigate the patterns of use of various medical services in a representative sample of children and young people with CP, taking into account child and family characteristics. A secondary aim was to assess the financial burden, if any, experienced by families, attributable to their child's additional medical care needs. A better understanding of how children and young people with CP are using medical services, and the factors that influence this, will assist tailoring service delivery for this group.

Materials and methods

This was a retrospective cross-sectional survey of parents and carers of children and young people with CP. The study population comprised individuals registered with the CP register for the Australian state of Victoria who were born between 1995 and 2008. Those who were alive and able to be contacted for research purposes in April 2014 were eligible. The study was carried out at the Melbourne Children's campus, and was approved by the Human Research Ethics Committee of the Royal Children's Hospital, Melbourne.

Data sources

Eligible parents or carers received a letter of invitation from the manager of the CP register, followed by up to two phone calls from another staff member. Participants could complete the purposefully designed survey online, over the phone, or via mail. Verbal consent was obtained from those who completed the survey over the phone, and written consent from those who completed it online or via mail. The survey contained questions about the child's use of general practitioner (GP) and publicly- and privately-funded paediatric medical specialist services during the twelve months prior to survey completion. Participants were also asked about their family and household (parent education, family composition, main income source, and private health insurance status). Finally, they were asked if their child's CP had caused financial problems for the family over the previous twelve months, and to describe the overall financial impact that the cost of providing medical care for their child with CP had on their family over that period. Data on each individual's age, severity of gross motor impairment according to the Gross Motor Function Classification System (GMFCS), [13] epilepsy status, and area of residence were obtained from the CP register. Data on whether or not they had a gastrostomy tube inserted were also obtained from the CP register.

Statistical analysis

To gauge generalisability of the sample to the wider CP population, descriptive analysis and comparisons between responders and non-responders were conducted using chi-squared tests. GMFCS levels were dichotomised (levels I-II as mild motor impairment, and levels III-V as moderate to severe motor impairment). Among participants, household characteristics and use of various services were tabulated, and chi-squared analysis was used to test for equality of percentages between various sub-groups. P-values were defined as the probability that differences between sub-groups as large as, or larger than, that observed in this cohort could have arisen due to random chance alone; a value of less than 0.05 was considered to provide strong evidence of difference. Statistical analysis was carried out using Stata 13.1. [14]

Results

Overview of participants

In total, 901 parents and carers were invited to participate, of which 350 (39%) completed the survey. Responders and non-responders did not differ across the categories of sex (40% vs 43% male; p=0.401), GMFCS (p=0.100) or epilepsy (29% vs 30% with epilepsy; p=0.772); however, children of responders were more likely to have a gastrostomy tube in place (18% vs 13%; p=0.033) and to reside in metropolitan Melbourne (76% vs 70%; p=0.043). (Table 1)

Of the 350 responders, 39% (n=135) had a secondary school education or lower, 22% (n=79) had an apprenticeship, diploma or other type of qualification, and 39% (n=136) had an undergraduate or postgraduate degree. Most were from two-parent households (n=264; 76%), with at least one parent in full-time employment (n=213; 67%). (Table 2) The majority of responders (n=289; 85%) identified as being the biological mother of the child with CP, and 9% (n=33) as being the child's biological father. The remainder (n=18; 6%) comprised adoptive and foster parents, or grandparents who were the child's full-time carer.

Use of medical services

During the twelve months prior to survey completion, 83% (n=289) of children had at least one appointment with a GP, 71% with a public paediatric medical specialist and 38% with a private paediatric medical specialist. Combined, 84% (n=293) had at least one appointment with a paediatric medical specialist in either the public or private healthcare system over the previous year. (Table 3)

The proportions of children that had seen GPs and private paediatric medical specialists did not vary according to age, GMFCS level, epilepsy status, or between those who did and did not have a gastrostomy tube in place, or according to the education level of the survey responder, household type or income source (p>0.05). However, those residing in regional Victoria (p=0.039) and those with private health insurance (p=<0.001) were more likely than others to have seen a private paediatric medical specialist over the preceding 12 months.

The proportions of children that had seen public paediatric medical specialists did vary according to age as well as CP severity and complexity. Specifically, children who were aged 5-9 years, were classified as GMFCS III-V, had a co-diagnosis of epilepsy, or had a gastrostomy tube in place were more likely to have seen at least one public paediatric medical specialist during the previous twelve months compared to those with who did not fulfil any of these criteria (p<0.001). (Table 3)

Number of services used

During the twelve months prior to survey completion, 58% of children (n=202) had appointments with between two and five different paediatric medical specialists, and 9% (n=32) had appointments with six or more. When appointments with GPs were included, 65% (n=229) of children had appointments with between two and five different medical professionals, and 17% (n=59) had appointments with six or more. Children classified as GMFCS III-V and younger children were more likely than those classified as GMFCS I/II and older children to have seen a greater number of different paediatric medical specialists over the study period. However, older children and adolescents continued to use a

number of different paediatric medical services, with almost one-half of those aged 15-19 years seeing between two and five paediatric specialists over the previous 12 months. (Table 4)

The types of publically-funded medical specialists most commonly seen across all GMFCS levels were general/developmental paediatricians (n=194) paediatric orthopaedic surgeons (n=149), paediatric rehabilitation specialists (n=73) and paediatric neurologists (n=66). Of the 133 parents/carers to report that their child had at least one appointment with a paediatric medical specialist in the private healthcare system, the majority reported seeing a general/developmental paediatrician (n=74) or orthopaedic surgeon (n=53). With the exception of ophthalmologists, relatively few other paediatric medical specialists were consulted privately.

Financial impact

As outlined in Table 2, 34% of responders (n=115) reported that their families had experienced financial problems attributable to their child's medical issues over the previous 12 months, and 16% (n=55) described the financial impact of providing medical care for their child with CP to be "large" or "huge". Although the families of children classified as GMFCS III-V were similar to those of children classified as GMFCS I/II in terms of family composition and main source of income (p>0.05), the parents and carers of children and young people classified as GMFCS III-V were more likely to report having experienced financial problems attributable to their child's medical issues during the 12 months prior to survey completion (42% vs 27%, p=0.003). They were also more likely to describe the financial impact of providing medical care for their child with CP to be "large" or "huge" (19% vs 13%, p=0.016). When those who had at least one appointment with a private paediatrician were compared to those who had not, there were no differences in the proportions reporting having experienced financial problems due to their child's medical issues (38% vs 32%; p=0.292) or in the proportions reporting the financial impact of providing medical care for their child to be "large" or "huge" (16% vs 16%; p=0.704).

Discussion

Using a representative sample of children and young people with CP, this study investigated how child and family characteristics influence how this group uses various medical services. The key findings were: (1) differences in medical service use were largely associated with CP severity and complexity, and not by family characteristics; (2) most children received medical services from many different types of medical professionals; (3) the number of different services used remained high among older children and adolescents; and (4) many families experienced financial problems attributable to their child's medical issues.

Differences in patterns of service use

Among this group, CP severity and complexity influenced the use of public paediatric medical specialist services, but not GP or private paediatric specialist services. Specifically, during the twelve months prior to survey completion, children with more severe and complex CP were most likely to have had at least one appointment with a paediatric medical specialist in the public healthcare system, but there were no differences across categories of GMFCS and epilepsy in the proportions that had seen a GP or privately-funded paediatric medical specialist. This suggests that children with milder forms of CP are more likely to use services in the community e.g. GPs and community-based paediatricians, whereas children with more severe and complex CP are more likely to be managed by hospital-based paediatricians. Differences in service use were not found to be associated with parent education, family composition, income source or private health insurance status. Instead, the highest service use was found consistently in those with severe and complex CP, who would be expected to have the greatest medical care needs. As such, it seems that the delivery of publically funded medical services are equitable, if equity is defined by service delivery according to need. However our data do not tell us if service delivery is *adequate* in terms of healthcare needs.

Information sharing and care co-ordination

For children who have multiple people involved in their medical care, the potential to experience gaps in care is high. [15] In this study, we found that many children with CP had appointments with a combination of different medical specialists over a twelve month period. This information provides further evidence for the need for adequate systems of information sharing between service providers involved in the care of children with CP, and for formal systems of care coordination to be in place. Of note, a high proportion of 15-19 year olds had seen a range of different paediatric medical specialists. confirming that in this population, the need for multi-disciplinary medical care does not end in childhood, but continues into adolescence and early adulthood. This reinforces the need for adult medical care providers that are familiar with childhood-onset disabilities.

Financial burden

Despite being entitled to publically-funded medical care, many parents and carers, particularly those of children with more severe CP, reported that their family had experienced financial problems attributable to their child's medical issues during the twelve months prior to survey completion. It is well known that the parents of children with disabilities experience additional direct and indirect costs related to their child's disability. [16] Given that there were no differences between those who did and did not utilise private paediatric services in the proportions that reported experiencing financial difficulties, it is likely that the financial problems experienced are not due to paying for medical care directly, but due to indirect costs. These could include costs associated with medications, equipment and travel, or loss of income due to being unable to work or having repeated absences from work due to appointments and caring for an acutely ill child.

Strengths and limitations

There may be differences between participants and non-participants on characteristics that we were unable to measure. The collection of data on service use from parents retrospectively introduces the potential for recall error. In addition, the survey design did not allow information to be gathered on the specific contributors to the financial burden experienced by families. The strengths of this study lie in the recruitment of participants from a population-based CP register; this allowed for the use of clinical data on CP severity and complexity in the analysis, and enabled some comparisons to be made between responders and non-responders.

Conclusions and implications

In recent years, there has been growing interesting in the patterns of service use in children with complex medical conditions. [17-20] They are known to be high utilisers of medical services, and it is thought that by understanding how they use various services, aspects of care delivery such as care co-ordination can be improved, leading to an improvement in healthcare outcomes and a reduction in unnecessary service use. [21] This study adds to the existing literature by providing an Australian perspective for children and young people with CP, uncovering how factors such as severity and complexity, and family characteristics influence medical service use in this complex patient group.

This information has implications for families, medical professionals, and planners. For parents and carers, the finding that the need for medical care from a range of disciplines remains throughout childhood and adolescence may prompt them to think about their child's needs going forward and the importance of appropriate transition to adult care. Those involved in the care of children with CP should appreciate the importance of adequate information sharing within and across organisations, and begin planning for transition to adult services during the early adolescent years.

For policy makers and decision makers, information about the nature of children receiving services and knowledge about the types of services being used may be useful in addressing gaps in care, while supporting initiatives to improve inter-organisation coordination of service delivery. Such initiatives may include additional funding for care coordinators for children and young people with complex medical conditions, to assist parents in navigating the healthcare system, co-ordinating multiple appointments, and assisting with transition to adult care.

Acknowledgements

The authors gratefully acknowledge individuals on the Victorian Cerebral Palsy Register and their families for completing the surveys, and for their ongoing support and willingness to participate in research projects. We also thank Ms Christine Westbury for assisting with telephone surveys. Funding for the Victorian Cerebral Palsy Register was provided by the Victorian Department of Health, and infrastructure support was provided by the Victorian Government's Operational Infrastructure Support Program.

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Tables

Table 1: Differences between responders and non-responders

	Invited		Responders		Non-responders		*p*-value [#]
	n	(%)	n	(%)	n	(%)	
Total	**901**	**(100.0)**	**350**	**(39.0)**	**551**	**(61.0)**	
Sex							0.401
Female	376	(41.7)	140	(40.0)	236	(42.8)	
Male	525	(58.3)	210	(60.0)	315	(57.2)	
GMFCS level							0.100
I	245	(27.1)	95	(27.4)	150	(27.4)	
II	254	(28.1)	83	(23.9)	171	(31.3)	
III	122	(13.5)	56	(16.1)	66	(12.1)	
IV	157	(17.4)	63	(18.2)	94	(17.2)	
V	115	(12.8)	50	(14.4)	65	(11.9)	
Unknown	8	(1.0)	3		5		
Epilepsy							0.772
No	627	(69.6)	246	(70.7)	381	(69.8)	
Yes	267	(29.6)	102	(29.3)	165	(30.2)	
Unknown	7	(0.8)	2		5		
Gastrostomy inserted							0.033
No	765	(84.9)	286	(81.7)	479	(86.9)	
Yes	136	(15.1)	64	(18.3)	72	(13.1)	
Area of residence							0.043
Metropolitan Melbourne	648	(71.9)	265	(75.7)	383	(69.5)	
Regional Victoria	253	(28.1)	85	(24.3)	168	(30.5)	

[#] χ^2 test for equality of percentages in the two groups

Missing values for GMFCS level and epilepsy were excluded from χ^2 analysis.

GMFCS: Gross Motor Function Classification System

Table 2: Family characteristics

	All (n=350)		GMFCS level I/II (n=178)		III-V (n=169)		p #
	n	(%)	n	(%)	n	(%)	
Level of education (survey responder)							0.987
Secondary school incomplete	71	(20.4)	34	(19.3)	36	(21.4)	
Secondary school complete	64	(18.6)	34	(19.3)	30	(17.9)	
Undergraduate degree	85	(24.4)	44	(25.0)	40	(23.8)	
Postgraduate degree	51	(14.7)	26	(14.8)	25	(14.9)	
Diploma/Certificate/Apprenticeship/Other	76	(21.9)	38	(21.6)	37	(22.0)	
Unknown	3		2		1		
Household type							0.378
Two-parent household	264	(76.1)	134	(76.1)	127	(75.6)	
One-parent household	73	(21.0)	39	(22.2)	34	(20.2)	
Other	10	(2.9)	3	(1.7)	7	(4.2)	
Unknown	3		2		1		
Main source of income							0.063
≥1 parent in full-time employment	231	(66.6)	120	(68.2)	108	(64.3)	
≥1 parent in part-time employment	54	(15.6)	33	(18.8)	21	(12.5)	
Pension	56	(16.1)	21	(11.9)	35	(20.8)	
Other	6	(1.7)	2	(1.1)	4	(2.4)	
Unknown	3		2		1		
Private health insurance							0.721
Yes	187	(53.9)	93	(52.8)	92	(54.8)	
No	160	(46.1)	83	(47.2)	76	(45.2)	
Unknown	3		2		1		
Financial problems caused by the child's medical issues							0.003
Yes	115	(34.0)	46	(26.9)	69	(42.1)	
No	223	(66.0)	125	(73.1)	95	(57.9)	
Unknown	12		7		5		
Overall financial impact of providing medical care for the child with CP							0.016
None/very little impact	133	(38.6)	80	(45.5)	51	(30.7)	
Some/moderate impact	157	(45.5)	73	(41.5)	83	(50.0)	
Large/huge impact	55	(15.9)	23	(13.1)	32	(19.3)	
Unknown	5		2		3		

χ^2 test for equality of percentages in the two GMFCS subgroups
Missing values were excluded from χ^2 analysis.
GMFCS: Gross Motor Function Classification System; CP: cerebral palsy

Table 3: Proportion of children who had at least one appointment with a general practitioner and various paediatric medical specialists during the 12 months prior to survey completion

		≥1 appointment with a general practitioner			≥1 appointment with public paediatric medical specialist [a]			≥1 appointment with private paediatric medical specialist [b]		
	(n)	n	(%)	*p* *	n	(%)	*p* *	n	(%)	*p* *
All participants	(350)	**289**	**(82.6)**		**249**	**(71.4)**		**133**	**(38.1)**	
Child factors										
Age				0.968			0.001			0.857
5-9 years	(106)	87	(82.1)		87	(82.1)		41	(38.7)	
10-14 years	(132)	110	(83.3)		97	(73.5)		52	(39.4)	
15-19 years	(112)	92	(82.9)		65	(58.6)		40	(36.0)	
GMFCS level				0.501			<0.001			0.493
I-II	(178)	150	(84.3)		112	(62.9)		71	(39.9)	
III-V	(169)	137	(81.6)		135	(80.4)		61	(36.3)	
Unknown	(3)									
Epilepsy				0.269			<0.001			0.677
No	(246)	207	(84.2)		163	(66.3)		96	(39.0)	
Yes	(102)	80	(79.2)		86	(85.2)		37	(36.6)	
Unknown	(2)									
Gastrostomy tube inserted				0.242			<0.001			0.389
No	(286)	240	(83.9)		192	(67.1)		112	(39.2)	
Yes	(64)	49	(77.8)		57	(90.5)		21	(33.3)	
Parent report of child's health				0.008			0.002			0.197
Excellent/Very Good	(214)	167	(78.0)		139	(65.0)		74	(34.6)	
Good	(95)	84	(88.4)		75	(79.0)		43	(45.3)	
Fair/Poor	(40)	38	(95.0)		35	(87.5)		16	(40.0)	
Unknown	(1)									
Household and family factors										
Level of education (survey responder)				0.760			0.946			0.740
Secondary school incomplete	(71)	58	(81.7)		48	(67.6)		27	(38.0)	
Secondary school complete	(64)	55	(85.9)		46	(71.9)		21	(32.8)	
Undergraduate degree	(85)	67	(78.8)		61	(71.8)		31	(36.5)	
Postgraduate degree	(51)	44	(86.3)		37	(72.6)		23	(45.1)	
Diploma/Certificate/Apprenticeship/Oth	(76)	63	(82.9)		56	(73.7)		30	(39.5)	
Unknown	(3)									
Household type				0.955			0.796			0.351
Two-parent household	(264)	218	(82.6)		187	(70.8)		106	(40.2)	
One-parent household	(73)	61	(83.6)		53	(72.6)		23	(31.5)	
Other	(10)	8	(80.0)		8	(80.0)		3	(30.0)	
Unknown	(3)									
Main source of income				0.449			0.280			0.061
≥1 parent in full-time employment	(231)	190	(82.3)		158	(68.4)		99	(42.9)	
≥1 parent in part-time employment	(54)	42	(77.8)		41	(75.9)		17	(31.5)	
Pension	(56)	50	(89.3)		45	(80.4)		14	(25.0)	
Other	(6)	5	(83.3)		4	(66.7)		2	(33.3)	
Unknown	(3)									
Private health insurance				0.342			0.384			<0.001
Yes	(187)	158	(84.5)		130	(69.5)		93	(49.7)	
No	(160)	129	(80.6)		118	(73.8)		39	(24.4)	
Unknown	(3)									
Area of residence				0.396			0.417			0.039
Metropolitan Melbourne	(265)	222	(83.8)		192	(72.5)		93	(35.1)	
Regional Victoria	(85)	67	(79.8)		57	(67.9)		40	(47.6)	

* χ^2 test for equality of percentages in the various subgroups

Missing values were excluded from χ^2 analysis.

GMFCS: Gross Motor Function Classification System

[a] Publically-funded general/developmental paediatrician, paediatric neurologist, paediatric neurosurgeon, paediatric gastroenterologist, paediatric cardiologist, paediatric respiratory physician, paediatric orthopaedic surgeon, paediatric ENT surgeon, paediatric rehabilitation specialist, paediatric ophthalmologist

[b] Privately-funded general/developmental paediatrician, paediatric neurologist, paediatric neurosurgeon, paediatric gastroenterologist, paediatric cardiologist, paediatric respiratory physician, paediatric orthopaedic surgeon, paediatric ENT surgeon, paediatric rehabilitation specialist, paediatric ophthalmologist

Table 4: Total number of different medical services used

			Number of different services received										
			None		1 only		2-3		4-5		6 or more		*p* *
	All	**(n)**											
Public/Private Paed [a]		(350)	57	(16.3)	59	(16.9)	129	(36.9)	73	(20.9)	32	(9.1)	
Any [b]		(350)	15	(4.3)	49	(14.0)	120	(34.3)	107	(30.6)	59	(16.9)	
	GMFCS	**(n)**											<0.001
Public/Private Paed [a]													
	I/II	(178)	36	(20.2)	43	(24.2)	59	(33.2)	28	(15.7)	12	(6.8)	
	III-V	(169)	21	(12.4)	15	(8.9)	69	(40.8)	44	(26.0)	20	(11.8)	
Any [b]													0.001
	I/II	(178)	9	(5.1)	32	(18.0)	72	(40.5)	40	(22.5)	25	(14.0)	
	III-V	(169)	6	(3.6)	17	(10.1)	46	(27.2)	66	(39.1)	34	(20.1)	
	Age	**(n)**											
Public/Private Paed [a]													0.029
	5-9 years	(106)	10	(9.4)	15	(14.2)	43	(40.6)	25	(23.6)	13	(12.3)	
	10-14 years	(132)	18	(13.6)	22	(16.7)	50	(37.9)	32	(24.2)	10	(7.6)	
	15-19 years	(112)	29	(25.9)	22	(19.6)	36	(32.2)	16	(14.3)	9	(8.0)	
Any [b]													0.061
	5-9 years	(106)	3	(2.8)	9	(8.5)	35	(33.0)	36	(34.0)	23	(21.7)	
	10-14 years	(132)	4	(3.0)	16	(12.1)	47	(35.6)	42	(31.8)	23	(17.4)	
	15-19 years	(112)	8	(7.1)	24	(21.4)	38	(33.9)	29	(25.9)	13	(11.6)	

* χ^2 test for equality of percentages in the subgroups of age and GMFCS.
Missing values were excluded from χ^2 analysis.
GMFCS: Gross Motor Function Classification System
[a] Publically- or privately-funded general/developmental paediatrician, paediatric neurologist, paediatric neurosurgeon, paediatric gastroenterologist, paediatric cardiologist, paediatric respiratory physician, paediatric orthopaedic surgeon, paediatric ENT surgeon, paediatric rehabilitation specialist, paediatric ophthalmologist
[b] General practitioner, or publically- or privately-funded paediatric medical specialist (as listed above)