

Understanding the life of a caregiver of a child with cerebral palsy: The case for a costing tool for structured settlements for medico-legal claimants

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The authors all have experience with children with disabilities either through actuarial quantum calculations of medico-legal claims (SK), or their clinical background and research (MF and JW).

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Foreword

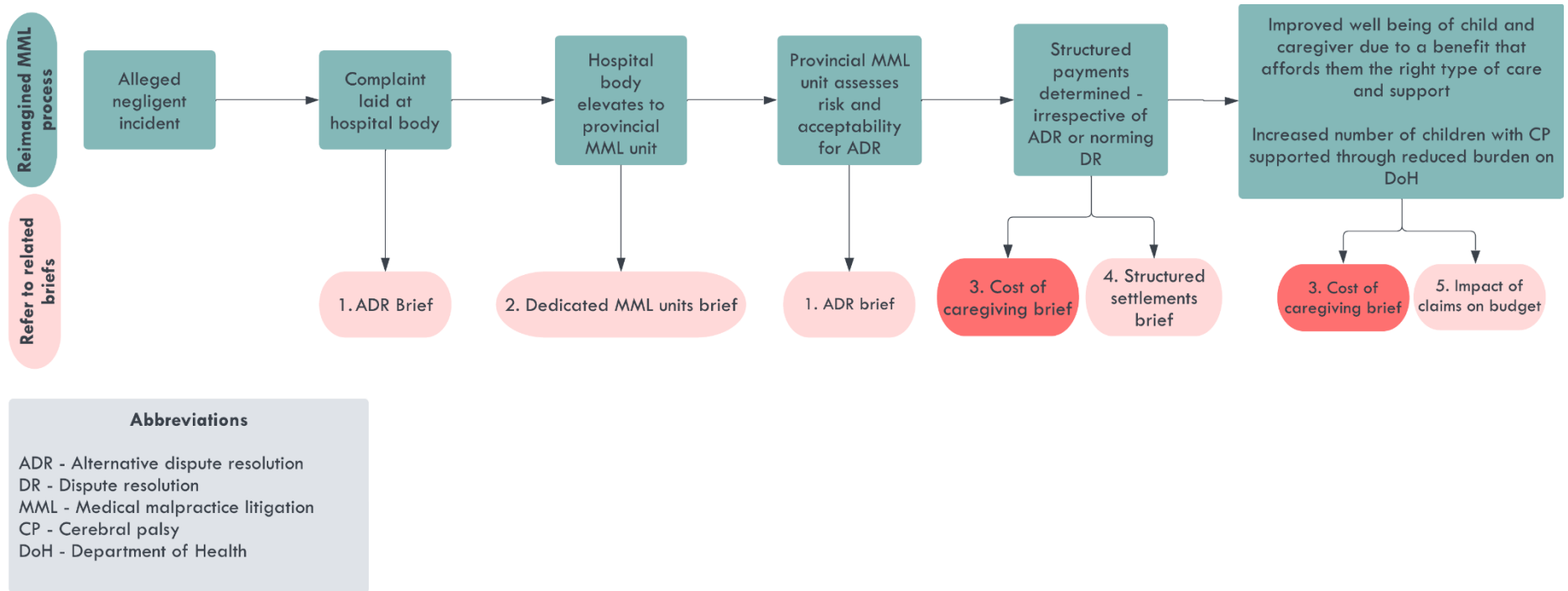
The Public Interest function was created by the Actuarial Society of South Africa (ASSA) to enable the organisation to pro-actively participate in public policy discussions. ASSA seeks to inform debate on matters of public interest in South Africa, especially when it is deemed that actuarial expertise can add value. ASSA can provide facts, figures, comments, and analyses of consequences on a wide range of topics where the actuarial skillset can provide unique insights.

There is no specialised legislation governing the medical malpractice (medico-legal) space in South Africa.^[1,2] Claims are therefore dealt with by way of the common law.^[1,2] This increases the risk of exploitation and abuse. The South African Law Reform Commission (SALRC) seeks to reform the law to address the risks inherent in using common law for medico-legal claims. In collaboration with other experts in this space, such as ASSA, the SALRC aims to draft legislation that will best serve the citizens of South Africa.

ASSA aims to provide feedback, research, and commentary throughout the process to help shape the SA medico-legal legislation space.^[3] A series of work and policy briefs were commissioned to research the recommendations of the SALRC, of which this forms one of the briefs in the series. It is envisaged that the findings from this research would equip the SALRC with the evidence needed to tighten legislation and provide outcomes that are fair to all involved parties. It is our view that by linking these policy briefs together, one can understand the policy levers available to the SALRC to reimagine or shape the future of the medico-legal space. Figure 1 below illustrates our reimaging of this space, based on the research and content of the policy briefs in this series.

Figure 1 below shows the flow of the research briefs Percept was commissioned to write. The briefs follow the same order as a medico-legal claim and thereby paint a story of the necessary reform along the medico-legal journey. The brief herein is the third brief in the series and discusses the cost of caregiving. This is the third brief and sets the background for the development of a benefit schedule for children with cerebral palsy (CP) within a structured settlements system.

Figure 1: Reimagining of the SA medico-legal space



Terminology

- **Caregiver:** this refers to all legal guardians of children with cerebral palsy (CP) and not only to biological parents. In the context of this work, the term 'caregiver' does not refer to professional caregivers.
- **Children with CP:** used throughout the report, as opposed to 'disabled children.' This is in line with the International Classification of Functioning, Disability and Health (ICF) and person-first wording as it acknowledges the child in their own right and not merely a disabled person.

Background

Despite it being well-known that the cost of caring for a child with CP is high, epidemiological data outlining the services required for CP is limited. Much is still to be learned about the variety of needs and care pathways for those affected. To drive quality care and rehabilitation, and justice for families who have suffered due to medical negligence, while also ensuring sound, ethical management of health budgets, we need to better understand the costs of CP care and rehabilitation in South Africa.

This brief:

- Summarises the findings from our primary research with caregivers of children with CP, medico-legal claimants, and CP practitioners in South Africa. Our research showed that caregivers often have needs that are different to what the experts advise in their reports and that their needs are not necessarily more costly than expert recommendations. Understanding what these needs are is crucial to creating a case for structured settlements.
- Proposes a benefit package and costing tool for CP-related medico-legal claims in South Africa. Not only does this assist the Department of Health (DoH) in budgeting and planning, but caregivers would be able to plan and budget in advance – which they deemed to be important.

The International Classification of Functioning, Disability and Health: Conceptualising CP to inform the costing table

To understand CP holistically and how it affects children and their families, it helps to use the International Classification of Functioning, Disability and Health (ICF) for framing. The ICF, developed by the World Health Organization (WHO), moves away from an impairment focussed approach to describing disability (Figure 2).^[4] It recognises the role of the health condition, but also social and structural conditions, and how the interplay between personal and environmental factors affects a person's ability to participate in daily life and community. The ICF shifts health providers to think about disability more broadly. Which illustrates that people with disabilities are a diverse group and that disability can range from short to long term. The WHO encourages use of the ICF as a clinical tool but also to guide policy, research and education. We used the ICF to conceptualise the various components of CP and to inform the table of costs to provide a holistic caregiving plan (Table 1 below).

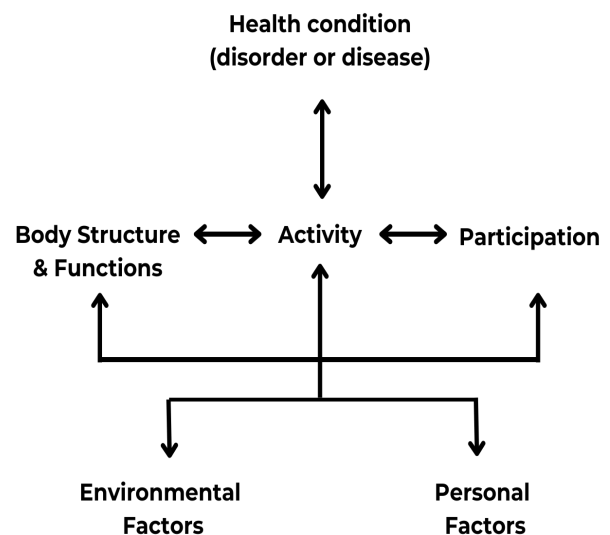


Figure 2: the International Classification of Functioning Disability and Health

Table 1: Considerations for the costing table

ICF Component	Description	Considerations for the costing table
<i>The health condition: CP</i>	<ul style="list-style-type: none"> □ CP is a neurodevelopmental disorder which affects the child's posture and mobility caused by a non-progressive insult to the developing brain.^[2] □ There are different types of CP depending on where the damage to the brain occurred: spastic, dyskinetic and ataxic^[5] 	Although CP is non-progressive, a child's needs can change over time. A standardised costing model must consider these potential changes and make allowances for them at different intervals in the child's life.
<i>Body structure and function</i>	<ul style="list-style-type: none"> □ This describes the parts of the body and how they function together, which is affected by the health condition, the environment, and personal factors of the child. 	We used the 4 classification systems to summarise the severity of CP into three broad categories: mild, moderate, and severe. This helps to determine the amount of the total pay-out. For example, a child with severe CP will need complex

ICF Component	Description	Considerations for the costing table
	<ul style="list-style-type: none"> □ There are 4 main classification systems which health professionals use to describe the severity and functioning in terms of eating and drinking, hand function, gross motor ability and communication.^[6] 	assistive devices, more intensive physiotherapy, and frequent medical appointments. They will therefore need more benefits earlier in life compared to a child with mild CP.
<i>Activities and participation</i>	<ul style="list-style-type: none"> □ Children with severe CP require more assistance with daily activities (dressing, feeding etc) to fully participate in daily life. □ This assistance sometimes requires full time care from a parent or caregiver, which has implications on income generation for the family. 	Using the data gathered from the qualitative phase, we took into consideration the costs involved in caring for a child with CP.
<i>Personal and environmental factors</i>	<ul style="list-style-type: none"> □ Environmental factors make up the physical, social and attitudinal environment in which children with CP live and conduct their lives. □ The child's experience of having CP intersects with demographic characteristics such as their age, gender, urban or rural location and socioeconomic status. 	SA does not have a standard definition of rural area. We used a combination of definitions to determine rural and urban areas. Children living further away from education and health resources, who choose not to relocate, may require more funds for e.g. for travel than those living in urban areas.

A nested understanding of the cost of CP

To build a holistic understanding of the cost of caregiving and the implications on the family and the State, we interviewed five healthcare professionals; a speech therapist, an occupational therapist, a physiotherapist all of whom have extensive experience in working with children with CP in the private, public and NGO sectors, as well as a paediatrician currently working in one of the emerging Centres of Excellence and a rehabilitation Head of Department (HoD) in the Department of Health (DoH). We interviewed six parents of 5 children in total: one interview with a medico-legal claimant and two focus group discussions, one with three parents and the other with two parents of children with CP. These interviews provided us with a nested perspective of life as a caregiver for a child with CP, depicted in Figure 3 below.

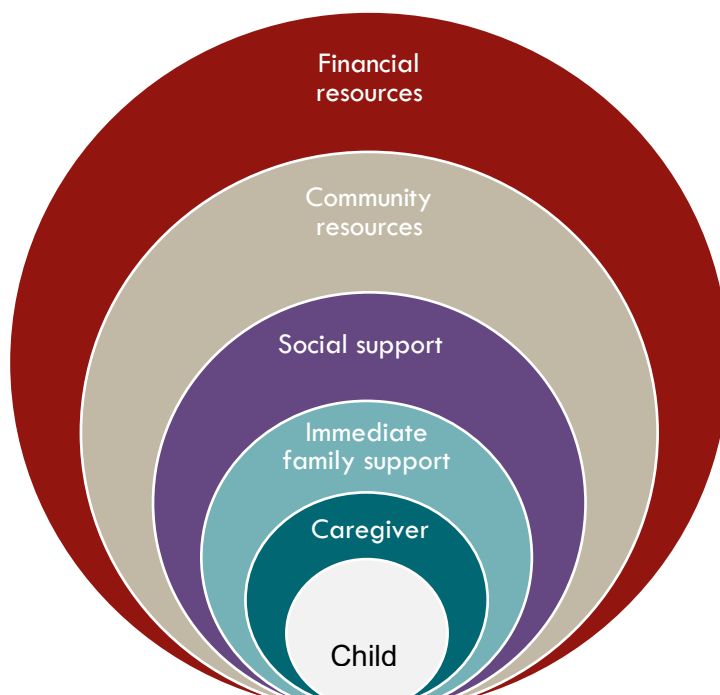


Figure 3: Nested layers of support

The child

CP costing assessments often have a myopic focus on the child, without enough attention to the relationships and contexts in which their wellbeing is nested. The health and wellbeing of children with CP is intimately tied to the health and wellbeing of their caregivers and the extent of support they receive.

The caregivers

Children with severe CP require significant amount of support from their caregivers, who, in turn require support from the family and community.

“With me, nobody’s helping. It’s only God giving me the strength every day. I remember even when I went to give birth to my second child, I spent two days in hospital. [My child with CP] was not sleeping because I was not there.” – caregiver

Immediate family support

Most of the caregivers we spoke to were uniquely supported by their spouses, parents and other children. For example, one caregiver highlights the support that they receive from their partner,

“Even bath time is a struggle with us now, my back is killing me, but, the father is there, and he helps me 100%.” – caregiver

When families lack trustworthy individuals to share the burden of caregiving or when there is a lack of inclusive schooling options, primary caregivers have to sacrifice social and employment opportunities, which leads to a huge amount of social isolation, and deepens poverty in homes that already carry significant health care costs.

Social support

The caregivers we spoke to were identified through an organisation known to the team. This organisation prides itself on enabling peer support – connecting mothers of children with CP to offer practical and emotional support to one another.

“When I came here, I was not working, I didn’t have money. One of the NPO staff, Lerato (pseudonym), would give me food so that I could sleep having eaten some food, and she explained CP to me as a mother of a child with CP and organised for an occupational therapist to explain to me what CP is and what I can do for my child.” – caregiver

Community resources

Many caregivers spoke about how they initially experienced immense discrimination and stigma from the community, further pushing them into isolation and hopelessness.

“We were scared to even go out because of how people in the community treat us.” – caregiver

Some of the caregivers explained how after receiving information about CP, and feeling empowered to care for their child, they were able to explain this to their community who in turn become more supportive.

“Our neighbours involve themselves [in our wellbeing]. It’s what we want and then we don’t feel alone with these children.” – caregiver

Financial resources

Disability and poverty are inextricably linked. When parents must forgo employment to provide fulltime care for their child with CP, there is an economic cost to the parent and the household. Caregivers we spoke to described the cost of fruit and vegetables, as well as the cost of separate meals for children with CP who have specific dietary requirements,

“The food which they eat is not similar to what we eat, which can be expensive because now you have to buy one set of food for your husband and another for your children. You have to buy a blender.” – caregiver

The blender, of course, also has costs attached along with supportive equipment (like feeding benches, diapers, and any specialised toys or communication aids). Many also pay for private transport because it is difficult to travel with a wheelchair (also known as a buggy). Since caregiving is a fulltime obligation, caregivers are unable to secure permanent employment. Although the Care Dependency Grant (CDG) is available for caregivers of children with disabilities, it is often the only source of income for the family and insufficient (R2080 per month^[7]) to meet all the household needs.

Caregivers' perspective on their needs

One cannot begin to build standardised costs without attempting to understand the lived experience of caring for a child with CP. The **role of the caregiver is integral** and is also why the cost of caregiving is usually one of the highest costs in claim awards.

There are trade-offs to whether a parent chooses to be their child's primary caregiver or whether they want to pay someone to fulfil this role. By employing someone, the parent may be able to return to work which may be more economically advantageous or better from a mental health perspective. However, some parents may wish to provide the caregiving role themselves and be paid, through the judgment, to perform this role in lieu of an external caregiver.

Another major cost in CP claims is provision of a **new home versus fully kitting out the current home**. In the past, recommendations have been made to furnish only the living areas of the child with CP. One caregiver explained how the trust managing her medico-legal claim pay-out paid for her house and fully equipped her child with CP's bedroom but left the rest of the house bare. She was not able to furnish the rest of the house with her own funds, making the house uncomfortable for the rest of the family.

One consideration during the costing process would be to fully renovate the family's current house. If the family relocates to another area with more access to services, there is an emotional and financial **impact** on the family. The new community may be unknown, breaking links of social support and the area may be more expensive than the previous area, for example one interviewee spoke about how the cost of fresh vegetables was much higher in her new suburb as compared to the location she lived in previously. The negative impact on the caregiver and the family of being removed from existing social support is an important consideration when costing different housing options.

The voice of the caregiver has been neglected in previous damages reports. What the caregiver truly needs in terms of emotional and financial support may be different to what the award provides for. The true need may not be necessarily more expensive than the recommended budget and it will likely differ from person to person. Caregiver preferences should be included in proposed costs and structure of payments.

Costing tool for structured settlements

From the research conducted, a tool^[8,9] was developed detailing the needs for children with CP. This tool can be used to provide an estimate of the annual amount required to fund the cost of care for a child with CP, for care that cannot be provided by the state. Although these will be unequal from one year to the next, having an estimated budget might assist the Provincial Department of Health, and therefore the caregiver, to understand the requirements of the child and to budget and better plan ahead.

Three benefit tables were constructed with similar high-level benefits, but differed according to the severity of the child's CP diagnosis. The four classification systems which health professionals use to determine the severity and functioning of a child with CP are used in this tool, namely: The Gross Motor Functioning Classification System (GMFCS), the Communication and Functioning Classification System (CFCS), the Manual Ability

Classification System (MACS) and the Eating and Drinking Classification System (EDACS)^[5]. They were combined to classify the child into three broad groups. For each of the four classification systems the child receives points (Table 2).

- 1 point if they fall within level I or level II
- 2 points if they fall within level III and;
- 3 points if they fall within level IV and V.

The points are then tallied up to a score out of 12 and a level of severity category is defined.

Table 2: Points for each classification system

	GMFCS	CFCS	MACS	EDACS
<i>level IV and V</i>	3	3	3	3
<i>level III</i>	2	2	2	2
<i>level I and II</i>	1	1	1	1

These categories are referred to as “Mild”, “Moderate” and “Severe” with mild category having comparatively lower costs due to these children requiring less intensive therapy and less equipment, illustrated in Table 3.

Table 3: Three broad categories of severity of CP

Category	Points	Examples of requirements
<i>Severe</i>	9 - 12	All equipment, therapies and medications
<i>Moderate</i>	5 - 8	Similar equipment as Severe, reduced frequency of therapy and medications
<i>Mild</i>	1 - 4	Reduced equipment compared to Moderate, reduced frequency of therapy and medications

It is recommended that children are recategorised, particularly at certain ages where needs clinically change, to ensure that the correct benefit table is being used as the severity of a child may deteriorate over a lifespan. Although this is atypical of a claim judgment, this recommendation accommodates for changes in the child's functioning over time, which is typical for CP and seems to be the most suitable approach from a clinical standpoint. We envisage the treating facility responsible for the child's therapeutic case management will be responsible for reassessing the child.^[9,10]

Table 4: High level benefit categories

Benefit categories	Examples
Caregiving	Carer and relief salaries
Equipment	Assistive, communication and therapy devices
Medical care	Paediatricians, medication
Support	Education, environmental (housing), nutritional, psychosocial and transport support
Therapy	Regular, block and additional therapy

It is recommended that children with CP are reassessed at various intervals to accommodate for their changing needs. It was found that these chosen age categories allowed for the easy clinical grouping of medical benefits. The benefit tables are also grouped per high-level care category and age band. The age band categories comprise the following ages:

- 0 – 3 years 11 months,
- 4 – 7 years 11 months,
- 8 – 17 years 11 months and
- 18+ years

Children would need to be reassessed and reclassified into severity levels upon reaching a new age band by the treating facility that is responsible for their care.

A schedule of benefits will allow for a more standardised approach towards CP related medico-legal claims thereby reducing the length of time it takes to settle the case as well as the costs for expert opinions and reports. However, the underlying framework of the package should be discussed and signed off by expert health professionals, lawyers, the caregiver and other relevant parties. It also needs to be updated not only for the various age-bands but also for changes in prices such increases if care is sought within the private sector. The user of the tool and/or the case manager should be responsible for ensuring that the child is reassessed at the various age bands, and that the costs are appropriate for that child's specific circumstances e.g. travel from home to place of treatment is accounted for within the travel allowance. We envisage, in the reimagined system that the case management role will be shared by the treating facility (therapeutic case manager) and the provincial dedicated medico-legal teams who will be responsible for the financial case management of a child with CP.

Currently, the tool can also estimate the lifetime cost of a CP claim but this calculation is approximate because it is dependent on the severity of the CP, how the child changes over time, the mortality assumption and cost related factors such as the net discount rate assumption and the cost base used. However, the tool will enable the user to have a more holistic understanding of the child's needs, the frequency in which the benefits are required and the amount required to fund private care over the year ahead. Over time, if the tool is used frequently and the costs are updated to best meet the child at their place of need, then we will collectively have better evidence-based data to understand the true cost for

the state to provide for a child with CP.

Limitations

We believe that the benefit package developed, and the structured settlements tool considers many of the variables that affect a child's ability to participate in their community and activities of daily living. However, there are some limitations to this approach. The full list of advantages and disadvantages of these items and the reimagined system is published in the structured settlements brief.^[9] Below, we outline specific limitations related to the clinical case management of the child:

- The costs will vary based on different aspects. For example, one a child with severe CP may still require very different communication devices to the next child with severe CP. The user of the tool will need to evaluate each case as outlined above (i.e. Determining the severity of CP of the child). This will require a collaborative approach with the health professionals within dedicated medico-legal unit to determine the specific needs at specific times.
- A child's needs may change before the next assessment is due. For example, it was suggested that the child is reassessed at 4 years old and again at 8 years old, but a child might outgrow their wheelchair at 6 years old. Provision has been made for this by giving the onus to the user of the tool.
- There are additional decisions that would need to be made on a case-by-case basis, such as the need for home adaptations or relocations. The medico-legal team will need to decide this in collaboration with the family to determine what is best for each child and their families.

Next steps and Conclusion

Cerebral palsy is a complex and changing diagnosis that has lifetime impacts on the child and their family. To understand the true costs of caring for a child with CP, the child in their entirety and the role of the caregiver needs to be fully understood and each medico-legal case should be evaluated based on its own facts and circumstances. The tool created by the authors will help the user to understand the components of the benefits required and therefore the approximate magnitude of total lifetime cost and the annual period payment costs that will arise, in the hopes of providing a just and comprehensive pay-out. The tool is not to be used to give an exact lifetime cost of caring for a child with CP but rather as a guide. The user of the tool must know and understand the child within their context, the caregiver's needs and must understand that these will change over time.

Our suggested next steps would be as follows:

- For the SALRC and its peers to sign off on the structure of the benefit tables and how it is to be used for a claim
- To recommend annual structured settlements that align with the budgeting processes of the Provincial Department of Health (PDoH) when reimbursing families

for medical negligence. These payments must meet the injured party's needs in terms of cashflow timing and amount.

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