

**Submission
No 256**

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL
DISABILITY INSURANCE SCHEME AND THE PROVISION
OF DISABILITY SERVICES IN NEW SOUTH WALES**

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My daughter's first plan had three elements that have made the last 9 months very difficult. She is aged 11 and lives with cerebral palsy and requires help with almost all aspects of her life including mobility, communication, fine motor operations, self care, learning and safety. She also lives with uncontrolled epilepsy and this means she requires constant supervision.

Firstly she received a very low funding amount for core supports (around \$3600 including a number of equipment needs so the actual support hours amounted to around 1 hour per week for staff. This was significantly lower than her pre-NDIS plans (around \$9500). I clearly outlined during the planning process that she had been using around 4 hours of support a week but that owing to our changed life circumstances she needed around 8 hours a week - she got 1 hour in response. When this was questioned the planner replied that parenting my daughter was the same as parenting any child of her age and support workers were therefore unnecessary. I have heard this is a common belief from planners and highlights the importance of training and lived experience of disability in staff. I cannot begin to adequately describe how parenting my daughter is nothing like parenting my other child or the parenting I witness of her peers in our community.

What follows is but some of what her support looks like.

M requires constant supervision, either through being in earshot or visible at all times, preferably both.

One parent always sleeps less than a metre from M in case of a seizure, which includes going to bed when she does and staying nearby until she wakes. She typically sleeps for 12 hours or more so I am in a supervisory role with limited options for getting other tasks completed for a large part of the night. This supervision is not just about the possibility of SUDEP (Sudden Unexplained Death in Epilepsy) but also because of a history of vomiting with seizures and an inability to change positions independently. It is also because she cannot get up and get a parent or call out easily either and so is assisted with water, blankets and with repositioning throughout the night as needed. This is the primary reason we have bought and partially trained a service dog for M, as the dog will hopefully be able to take over some of this role.

SUDEP is also obviously a risk in the daytime so again her supervision needs remain high. She also experiences a high risk of getting stuck in furniture, falling, pulling something heavy down on herself, choking and other dangers not present for more mobile and verbal children.

M requires help to do most ordinary things like moving around, self care and communication

From the moment M wakes up, her every day tasks need planning, equipment and support so she can live an ordinary life with dignity and safety. She gets help out of bed, into clothes, shoes and ankle splints, with the toilet, with washing, teeth, and hair. She then needs help with taking medicines, eating (every spoonful of anything sloppy or crumbly is supported). M's mobility is also highly assisted. She requires help in and out of the car, chairs, wheelchairs, walking frames and on and off the toilet, and in and out of the bath or shower. She needs help with communicating her needs and interests throughout the day - every day offers up some challenging puzzles as we all strive to understand M's unclear speech. She needs a great deal of help in her learning, including modifications, accommodations and physical intervention, such as hand-over-hand support on physical tasks. She also needs help with things like keeping her nose clean and her chin free from dribble and food.

M requires help to do all the other things that make for a real life like community participation and learning

To participate in ordinary community things M needs support. She is a very sociable and outgoing girl and loves going to markets, music, dance, plays, festivals, to friends houses, and doing activities with her peers, like yoga. She also loves the outdoors, like the beach and forests. All of this requires close supervision, complex management of her stamina and mobility, motor skill, self

care and communication support. Some of the activities she has previously enjoyed and benefited from have stopped without support hours, such as drama, parkour and martial arts.

There is a whole lot that goes on behind the scenes to keep M's ordinary life happening

Supporting M occupies at least 12 hours over the evening and night, as outlined above, and days are largely made up of constant supervision and support with self care, communication, social support and participation, and learning. As her primary carer I am left with very little time (and almost no interrupted time) to keep on top of the paperwork required to support her, the planning, the phone calls, the appointments, etc, not to mention my other child and meeting his needs, cleaning, shopping, etc. Both children are homeschooled also so this support is reasonably constant. I also work and volunteer part time. Somewhere in there I look after myself! It is not unusual for days to go by without getting to have a shower and I frequently eat standing up in between other tasks.

Most people with M's level of disability experience difficulty around eating, chewing, swallowing, choking, digestion, constipation and continence. That M has had few of these problems is not as a result of luck but persistent and daily hard work and planning over the last 10 years. I plan her meals carefully to keep her fibre and nutrients high, her chewing exercise at point that is neither too exhausting or too easy such that her ability to chew a range of textures isn't lost. It's a careful balancing act and requires thought and a lot of time in food planning, shopping, preparation and support in the eating.

While things like cleaning, washing and managing appointments impact all families, the degree that these impact our lives is significant. Cleaning for example is a constant since M when at home (which is too small to accommodate her mobility equipment) moves around on the floor and does lots of activities (including some eating) on the floor. This means the floors need to be cleaned constantly. The introduction of the service has only magnified this need.

Clothes and bedding washing is also a constant with frequent soiling from eating, drinking, dribbling, crawling on the floor and in the backyard, as well as frequent urine accidents and less frequent faecal accidents. It is not unusual to have changes of clothes 3 times a day and changes of bedding a few times a week. Again the introduction of the dog as a nighttime supervisor (on M's bed) has dramatically increased the need for bedding washing.

Managing appointments is always bigger than it sounds but M sees a huge range of specialists and is a frequent visitor to the GP. Every appointment involves preparation, confirmation, follow ups, and a lot of rescheduling. Trips to Sydney to see specialists involve travel by car to accommodate all her equipment (and now also the service dog), breaking the journey each way for an overnight stay and a day or 2 around each appointment before returning. These appointments are therefore time-consuming, expensive and exhausting.

Another big part of managing M's health is her medications. This includes including monitoring and recording side effects, mapping seizing activity, keeping meds at the appropriate temperatures (especially when not at home) and keeping in stock 4 different meds

Her health management also includes a lot of little but important things that are side effects of either epilepsy or cerebral palsy, such as minor injuries, skin infections from dribble, etc. These is usually something going on at any one time requiring treatment.

The management of M's essential and other equipment is also a major task. This includes maintenance, repairs, planning for the next size or need. The dog has been a major addition to this workload and includes all the things that dogs need plus her unique needs as M's constant companion.

Managing support staff is also a big job, particularly as staff turn over from time to time as their lives change. This includes timetabling, timesheet, induction at the beginning of each session and initial induction, as well as ensuring those skills and understandings about M's needs stay current.

Aside from paid supports, our support network is reasonably small as a result of the kind of supervision and support M needs. Most family cannot care for her unassisted, friends who have their own children struggle to meet her needs in addition to those demands and most friends we wouldn't even ask to care for M unassisted. Our paid supports are therefore a very important part of her care.

Secondly, she also received a very low funding amount for improved daily living, only enough for therapists to assess, trial and script new equipment for her. In previous years support from a physiotherapist, and occupational therapist and a speech therapist have been vital to her development, safety and health. The result of less input from these specialists (coupled with less input from support workers to help facilitate community connection and participation has been a physical deterioration. She has experienced reduced capacity to do tasks and reduced independence. She has also experienced pain as her body tightens and her functions reduce. There have also been impacts on me as her primary carer, including experiencing increasing pain and injury around this lack of support, particularly as her weight has increased to over 20kg and her capabilities have decreased. There are very real and very long-term impacts of inadequate support.

Finally her plan failed to provide for existing equipment maintenance and repair. This should be standard. No funding for such a range of expensive repairs have been stressful and time-consuming to address. These pieces of equipment are vital parts of daily living and being without them means an increase in stress, injury and risk for both the person and the carers.