Submission
No 269

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

Name: Mr Peter Fletcher

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Partially
Confidential

9th August 2018

Peter & Victoria Fletcher

Dear people of the Enquiry,

Thank you for taking the time to supervise the implementation of the NDIS and for taking this and the other submissions into account. We'd like to state up front that we are very grateful for all of the help our son receives, without which he would be far worse off. We would also like to state that the self-managing option has allowed us to obtain good value for the services and treatments he requires, which saves taxpayer dollars and stretches our NDIS package.

Our issue with the NDIS relates to in-home-care. Our son requires constant supervision and so, before the implementation of the NDIS, received 100 hours per week of in-home-care. The care was fully funded by the Special Childcare Benefit. Knowing that this system would be replaced by the NDIS, we requested same as part of our NDIS package but only received enough funding for about 22 hours per week. A subsidised partly user paid alternative, the NSW family day-care association has come into existence, for which we will have to pay $3 to $8 per hour. While the subsidy is generous, we cannot afford $300, let alone $800 per week of extra costs. We find ourselves, therefore, in a far worse situation after implementation of the NDIS than we were in before it.

We do not have the option of leaving unattended, even for a moment, so are not entirely sure how to proceed. If one of us is to work, we need in-home-care so that the other has a free hand to take care of our other child (soon to be children) as well as . It is also not possible to stay awake all of the time. We have of course requested a review of our package and contacted our local MP. It is a work in progress.

Overpage we have included some notes on why requires 24 hour monitoring, and why the best option for this is in-home-care.

Regards,

Peter and Victoria Fletcher

Notes on

is a happy little fellow, 3½ years old, with a good sense of humour and room brightening smile. He does, however, have very severe disabilities including grade five cerebral palsy. This is due to oxygen deprivation during his difficult birth. His symptoms include:

- Quadriplegia;
- Poor eye sight (cortical vision impairment);
- Daily seizures;
- Frequent choking and vomiting episodes;
- He is non-verbal;
- Cannot swallow and is therefore tube fed; and
- Poor sleep cycle, i.e. he is awake much of the night.

He has been hospitalised five times since May, once via ambulance and with the most recent visit having occurred last week (on Thursday 2nd August). We write all this so that you understand his needs are very high and that he cannot be left alone, even for a minute. Despite his many difficulties he is a courageous boy with a shining spirit and delightful nature and we love him dearly.

Constant Monitoring

has many choking episodes each day, any of which could end his life. The episodes occur at random, any time of the day or night. The main cause of these episodes is vomiting which, combined with his inability to swallow or turn his head, leads to an obstruction of his airways. For a variety of reasons, tends to vomit quite a lot. Depending on the severity of the episode, clearing his airway can be achieved by rolling him over and patting his back or by using a specially designed suction device. His parents and carers are accustomed to performing these procedures and, so long as someone is with him, he is usually able to recover from these episodes quite well. In addition to the immediate threat of asphyxiation, inhalation of vomit can lead to aspiration pneumonia. This is another reason for us to respond as quickly as possible to any sign of vomiting. His most recent hospitalisation (2nd August) occurred after a particularly alarming choking episode during which he had completely stopped breathing and gone blue. The event occurred at 12:15 AM and was observed by his night carer. If she had not been there, or if she had been asleep, he would have died. He requires constant monitoring by an alert adult.

also has seizures nearly every day. These must be treated with the appropriate medicines or they can also lead to a cessation of breathing. Sometimes the seizures are ‘absent seizures’ where he just quietly stops breathing. This occurred a little over a month ago and resulted in a hospitalisation. On that particular occasion we were walking in the park with in a stroller and it was his carer who noticed and alerted us to the situation. If she had not been there, probably would have passed.

The need for in-home-care

needs are such that mainstream day-care is not appropriate or available. Even if it were available, he is too medically frail to cope with the illnesses that he would be exposed to in such an environment. He therefore has to stay at home with us most of the time.

mother Victoria (Vita) is 7½ months pregnant and finding it very difficult to lift and carry She is also occupied with looking after his energetic two year old sister, Vita cannot, therefore, be expected to manage all of this on her own. The current arrangement is for a carer to work from 9:30AM to 7:30PM, allowing Peter to leave for work at 9:30, work from 10AM to 6PM and return home before the carer leaves. We also have care on Sundays to allow us to have a bit of family time and to get housework done. This is a satisfactory arrangement and one we would like to have continue. The day shift comprises 60 hours of in-home-care per week.

We also have 40 hours of night care, which was added to our care plan when was 2 years old. Night care was added because, once was born, the night shifts fell to Peter and he became very tired working all day then staying up all night. The night shifts comprise 40 hours of in-home-care per week