

## Background

We are the Queensland parents of a 21-year-old female. Our daughter's conditions include cerebral palsy, epilepsy, physical disability with limited mobility (GMFCS Level IV), intellectual impairment with very limited communication, low bone density and other medical issues.

We live in an area that does not commence with NDIS until January 2019.

Since our daughter was quite young, she has required various orthoses and currently wears knee length AFO's. She needs AFO's to enable...

- standing transfers eg. chair to wheelchair, wheelchair to toilet, wheelchair to car etc
- spending time each day in a standing frame to help with bone density and spinal alignment
- walking around our house with a walker and 1-on-1 assistance using a walk belt to prevent falls
- improved access to community and social activities

Her ability to mobilise is paramount to her health in respect of bone density and bowel management.

Her ability to do standing transfers is vital in reducing the physical impacts caused by manual handling on her parents and community support workers.

## Our Recent Experience

Earlier this year, we were advised that she required tendon lengthening surgery to release the contractures in her calves, feet and toes. These had worsened over the years despite a daily physio regime.

Following surgery in May, she had both legs in plaster for six weeks and required vastly different AFO's immediately after the plasters were removed on 19<sup>th</sup> June. If the AFO's had not been immediately available when the plasters were removed, then the benefit of the surgery would have been compromised as her calves and feet would not have been maintained in the newly improved position. This would then have allowed contractures to redevelop as she healed.

Pictures of her old and new AFO's are attached to illustrate the difference made by surgery. There is a considerable difference not only in heel height but also the outwards tilt of her feet.

## Concerns with NDIS processes

The need for this surgery was not expected until after an annual review by her rehabilitation specialist at the local public hospital and it was important that the surgery was done in a timely manner. If we had to delay surgery whilst waiting for the NDIS to approve orthotics, our daughter's mobility would have continued to decline, she would quite likely have gone "off her feet", her muscles would have lost more strength, she would have done more damage to her joints and it would have been more difficult for her to regain her mobility post-surgery -see attached extract of letter from her Orthopaedic Surgeon to MASS QLD (Medical Aids Subsidy Scheme)

Everything we have heard and read about the length of time it takes for AT approvals under NDIS fills us with grave concern about the Agencies ability to respond to emergency or unforeseen change of circumstances in a timely manner.

It also appears that AT requests are considered for approval by NDIS staff who are not trained in relevant Allied Health disciplines such as Physio, OT, Speech etc. This makes it difficult for a lay-person who is making an assessment to understand the technical reports supplied by Allied Health Professionals and Specialist Surgeons.

### Suggestions

1. That NDIS should assess how AT approvals have been handled in each State and adopt a BEST PRACTICE MODEL nationwide.
2. That there needs to be a State or Region based team that is easily contactable for AT applications.
3. That AT assessment teams need to have clear processes for triaging applications as either urgent, priority or routine and the like.
4. That AT assessment teams need the expertise, or ready access to panel of Allied Health Specialists, to quickly identify applications that should be triaged as more urgent.
5. That NDIS should consider streamlined approvals processes that cater for AT...
  - Required as a result of surgery or other medical intervention
  - Where the cost is below certain thresholds
6. That each NDIS State or Regional office should have a greater number of officers that hold a variety of AT delegations based on lower thresholds. Eg...
  - Up to \$2,000
  - Up to \$10,000
  - Over \$10,000

**Our overarching concern is that NDIS is currently ill-equipped to deal with sudden changes in circumstances and respond in a timely manner.**

1. Extract of letter from Orthopaedic Surgeon to MASS QLD &

2. Photo of Orthotics showing the changes after surgery

■■■■■ has recently undergone bilateral lower limb surgery targeting correction of bilateral hallux valgus deformities, and calf contracture in order to improve her foot and ankle alignment and reduce pain when weight bearing. These surgical changes have rendered her current orthotics unusable.

She is requiring to be fitted on **Tuesday 19/6/18** with a new pair of front-back boots with walking sole post removal of bilateral casts, as part of this surgical intervention.

A well-fitting pair of front back boots is an essential support in ■■■■■ efforts to retain her ability to mobilise short distances with assistance at home and in the community, including standing transfers. There is significant risk that ■■■■■ will fail to regain her pre-surgical level of function, and effectively 'go off her feet' if she is not provided with appropriately fitting front-back boots in this early phase of her rehabilitation.

The consequences of losing mobility would have enormous impact on ■■■■■ quality of life, ability to participate in her preferred community activities, and substantially elevate the burden of care on ■■■■■ parents (primary care-givers) at home.



*Post-Surgery heel height on the left is much lower with the foot set at almost 90 degrees, hence why pre-surgery orthotics on the right could no longer be used.*