

Parliamentary Inquiry NDIS Assistive Technology

Shirley Humphris 25/8/18

I would like to thank the Inquiry team for looking at this issue.

I am a grandmother of a 6-year-old child affected by many equipment delays. My granddaughter has been a participant since 2013. She is a six-year-old girl with intense complex needs, intractable epilepsy, cortical vision impaired, hearing loss, non verbal, unable to self support, very limited controlled mobility, hypotonia and pe/j/g tube fed.

Recommendations

1. RETROSPECTIVE FUNDING

Because hold ups seem inevitable RETROSPECTIVE FUNDING (whether agency managed or other) for items subsequently approved. Indications of likely hold up time from NDIA.

2. STAFFING

Minister to lift STAFF CAPs for extra additional team immediately to address serious backlog. NB real staff cap lift as a proportion of roll out numbers. Also Note staffing needs an additional boost over and above a “settled” numbers in future years because of the mess they are in. Likened to needing unscrambling an egg. Eg extra, extra staffs on say a one-year contract to specifically clear equipment and put some better strategy in place. Attrition will enable retention of good staff for the future.

3. SIGN OFF PROCESS

Look at redundant processes and why unqualified planners have the final rejection to override experts. Concern with NDIA employed OT being impartial however.

4. OUTGROWN OR WORN OUT AT

Approval for replacement items for growth etc. flagged and fast tracked as less scrutiny is necessary.

5. EARLY “APPROVAL”

Call the initial “approval” on the plan preliminary approval not approval, as approval is misleading.

6. INTERNAL REVIEW ON AT

Difficulties of not being able to take an “approved” item to Internal Review and then AAT if later refused or delayed often months or years. This lack of control for participants needs to be addressed

Summary of the most recent complaint from this family:

EQUIPMENT DELAY AND HARM TO CHILD

- **Hold up of first standing frame so long that it was nearly outgrown when it arrived.**
- **Second standing frame delivered.**
- **Standing frame is needed, amongst other things, to aid bone density for non-weight bearing.**

- **The opportunity to build bone was significantly reduced by delay.**
- **Ankle foot orthotics to stabilise foot in the standing frame are supposed to be used.**
- **Outgrown AFOs were approved to be replaced in the November 2016 plan.**
- **Held up despite Internal Reviewer telling planner AT was business as usual to process because not part of Internal Review.**
- **Planner did nothing for 8 months of Internal Review or months after.**
- **AFOs (and other equipment) delayed and not processed.**
- **Family forced to use standing frame in shoes only to get the benefit of the standing frame.**
- **Child now has foot fracture and severe low bone density on radiology reports.**
- **Delayed diagnosis due to non-verbal requiring nuclear medicine scan of whole body to discover source of pain.**
- **Ironically AFOs were picked up on the way home from hospital after nuclear medicine scan and x-ray confirming fracture.**

Other past hold ups:

- **Outgrown wheelchair - orthopaedic Dr stated existing wheelchair was not helping developing scoliosis. Note once ordered supply was only a few weeks. NDIA –hold up many months.**
- **Bath seat took so long coming one carer used a novel approach of dipping child in the bath for a splash while in the hoist. Not sure how safe this was especially for many seizures a day, and floppy child, but desperate for water experience.**
- **Bed with rails delay of many many months child at risk of rolling out**
- **Outgrown sling causing pressure marks and lack of support**
- **Therapy bench delay restricted OTs range of therapy.**
- **Leg wraps, orthotic shoes and walking sling still waiting but now ordered.**

Copy of complaint to NDIA 16/7/18 – no reply yet as of 25/8/18

Escalation emails and medical reports sent to complaints are not attached for the inquiry but can be sent if required.

This is an email complaint to feedback@ndis.gov.au regarding equipment delay; particularly AFOs that were not a new request just a larger size for growth. The AFOs were noted in the OT report for the Nov 2016 plan. This plan was under internal and external review until June 2018 (but not for AT and was determined not to be held up for review). Planner [REDACTED] was told by the Internal Reviewer [REDACTED] not to hold up equipment but she did. We now finally have the AFOs as of Wednesday last week.

There is now a possible consequence of AFO delay.

[REDACTED] had severe pain on moving her right leg Sat 7/7/18, a week ago. ED X-ray of hip and pelvis and ultrasound showed nothing. Examination by all docs flagged hip as likely source of pain.

She has been needing endone for breakthrough pain after regular panadol and nurofen (over a week) and docs are waiting to see if anti inflammatory meds would settle but we have been unable to move her much out of bed for crying. She cries with her myoclonic jolts and crying at night.

On Friday she had nuclear medicine bone scan. This showed a hotspot on ankle meaning either stress fracture or viral or traumatic arthritis. Foot and ankle X-ray showed possible but equivocal fracture as a cortical irregularity of the talus (the articulate bone of the ankle).

Waiting again to give another few days to see if inflammatory arthritis would settle, then possible MRI to confirm if another injury, but this needs a general anaesthetic so Drs holding off. They think the viral arthritis is less likely as no prior temp, no prior illness and no significant markers. There was no prior injury we know of she has 24/7 care with active care nights. Her epilepsy is not tonic clonic. No bruise

or anything. She is, however, severely osteopaenic (low bone density) on radiology report as are wheelchair kids and susceptible fracture with minimal trauma and desperately needing weight bearing AT for bones. Her first standing frame was nearly outgrown when it arrived after delay and lost opportunity to build bone.

Now the question for NDIA?

Is it more than coincidence that her AFOs were delayed by over 6 months and now she has a possible injury from this? The grown out of ones were abandoned 3 months ago when her foot was hanging over the edge. We later began using the standing frame with only shoes as the standing frame is vital for her bones and compromised lung function and seemingly a necessary choice. We do not feel “ guilty “ at using the frame without correct protocol only angry at this forced choice in order to build her bone density and protect her compromised lung function.

Today [REDACTED] is still in severe pain needing endone. Unable to attend school for likely some time with consequent care hours impact. [REDACTED] is also ill, needing [REDACTED] care. No school for sister [REDACTED] until Tuesday.

23/7/18 Just a follow up to confirm that a report from Radiology have confirmed [REDACTED] has an undisplaced ankle fracture. It has taken 3 weeks to be able to stop endone heavy duty pain relief with side effects. Her severe pain is likely due to neurological movement disorder (muscle twitching within the immobilisation) and myoclonic jolts of her epilepsy.

As mention earlier this injury is more than coincidence that her 6 month wait for AFOs led to using the standing frame with only shoes and consequent lack of ankle foot support.

Attached:

The escalation emails

Internal Review and earlier emails re equipment

2016 OT report

Summary timeline:

OT report 2016 for November 2016 Review

Escalation emails show requests for equipment to be actioned including from internal reviewer

@SA quality to planner and repeated requests:

3/5/18

28/5/18

30/4/18

20/11/17

17/10/17

Oct 2017 OT Summary table

With Regards
Shirley Humphris

Note attachments not included in this submission happy to supply if needed with privacy.