

**Submission
No 40**

EMBEDDED NETWORKS IN NEW SOUTH WALES

Name: Penny Graham

Date Received: 10 October 2022

Dear Chairman,

Re: Al Graham

My name is Penny Graham and I wish this to be a written submission to the Parliamentary Enquiry on behalf of my son Al Graham, a 21 year old young man with severe physical disabilities. Al moved into a newly constructed building [REDACTED] on 28.06.22 . Al resides in a small 2 bedroom rented unit owned by a Special Disability Accommodation (SDA) provider who have purchased 10 units in [REDACTED], on the ground floor.

The SDA provider has six modified units for people with high physical needs and 4 units for people with accessible needs. I wish to make clear that the SDA provider has listened to our concerns at all times and Al Graham is very happy living at [REDACTED]

After a 4 year search for accommodation within the Hornsby community where Al has lived his whole life, we were extremely pleased to receive Supported Disability Accommodation (SDA) funding through NDIA for accommodation in a regular block of units. (This is not a disability specific group home or complex)

Al Graham has led an inclusive life despite his disabilities. A documentary about his life called Al's Story

<https://www.youtube.com/watch?v=lkbsmv22wCg> was shown in Parliament house in September 2018. Although unable to attend on the day, Matt Kean Al's local member was invited to the screening and has met Al on several occasions. Al is a registered constituent in his Electorate and has exercised his right to vote!

Al Graham has severe disabilities including:

- He has a deep brain stimulator to control a movement disorder and requires charging every few days
- Requires 24 hour personal care including swabbing of his mouth, turning, hoisting to his powerchair, dressing and toileting
- Dual gastric and duodenum peg liquid feeds via a pump
- Receives Life support Rebate, palliative rare genetic condition GNAO1
- Receives Medical rebate
- Is in top 6% severity of physical disabilities
- Non verbal but with normal intelligence
- Al needs access to a back up generator, (in case of a black out) due to needs for his pump feeds, charging his power chair, charging his deep brain stimulator, and power for pressure bed and ceiling hoist.
- Al requires on going significant crushed medications via his tube/ and regular flushes
- 3 monthly Botox injections into his limbs to control his dystonia (muscle contractions)

The Facts and Background.

- Al's unit electricity is part of an Embedded Network
- There appears no breakdown of electricity charges to heat the water in Al's uni on his bill to date.
- Al Graham's bill remains proportionally higher than his support worker [REDACTED] whose electricity bill with Origin (no gas) covers 3 adults in a three bedroom suburban Sydney

house, 3 TV's, 2 refrigerators and a ducted air conditioning. This is even after Al Graham's rebates. We have compared these very closely.

- His bills are charged at continuous 'Peak Rate' and showing to be at the usage level expected of a 4 person household.
- The meter has been checked.
- I have queried the billing and lack of variable rates with Origin, spending over 1.5 hours on the phone with Origin.
- I wrote to Origin CEO Mr Frank Calabria to raise this issue including the bills on 2.9.22 His office is clearly aware of the issue as I have been in touch on several occasions.
- Origin offered a reduction in kilowatt rate just for Al Graham and asked me to sign a document which I refused as it is about all the tenants in the building.
- Al Graham is a disability pensioner (as are others in the 10 units) on a fixed income. We need to be the voice for the most vulnerable in society.
- Al is being charged at a higher rate than the general community.
- I have discussed the issue with [REDACTED], Commercial Operations Manager, specialising in Embedded Networks.(arranged by Matt Kean)
- Origin have not been in contact since I spoke with [REDACTED], nothing further was offered.
- His advice was they could lower Al's charges, or Al could change providers, at the risk of not having power for a period of time with no guarantees another provider would put in the infrastructure . He mentioned there were rebates available through Service NSW which we already receive. He did feel Al was not being charged more than others in the local community. Again I asked [REDACTED] to consider the impact his embedded network is having on the disability pensioners in the building. He did not feel it was significant.
- Al was also required to chose internet providers from a list (more expensive than many) and renters could not select their choice

The following has been done by myself and on Al's behalf.

- I have made phone and written contact with the Hon Matt Kean, Al's local State member for Hornsby, who knows Al Graham well and myself. I have raised my serious concerns on behalf of all people in the building [REDACTED] and particularly the renters in the 10 units owned by the SDA provider. I believe some people are already requiring charitable assistance to pay their electricity bills.
- I have spoken with the General Manager of the SDA provider and alerted them to the serious concerns for their disabled tenants.
- I have also made contact with the Office of the Hon Ray Williams and alerted staff to the serious concerns regarding the high electricity charges and the embedded Network.
- I have made contact with the Disability Royal Commission [REDACTED] with respect to exploitation of people like Al.

I wish to have this submission considered and am available on [REDACTED] if you require any further details.

Kind regards,

Penny Graham on behalf of Al Graham.