

Wendy Cuneo

Questions from Family, Friends and The Stockton Hospital Welfare Association

Below are a few of the many questions the families, Welfare and friends of Hunter Residences (Stockton, Kanangra and Tomaree) have asked many times and not received adequate answers.

I have attached a copy of the letter I wrote to Minister Ajaka when this first came to our attention-----this letter details a list of the services we have at Stockton and explains the other benefits which the Welfare have provided over many years and why this would be a very retrograde step.

All the government is promising is a house in the suburbs or on some rural area far away from the community they say will welcome our residents into their midst.

1. Will the residents have the choice of which NonGov that controls their house
2. If residents and / or their families do not agree with the selection of a NonGov what process will there be in place to allow them an independent choice.
3. What happen if a NonGov decides after some months that they do not want to support a resident any longer?-----this is already happening in the community, and to move our residents once would be extremely damaging-----to move them more than once would be disastrous.
4. Will the NonGov be able to choose which residents they take or will they have to take all the residents who are going to live in the one area?
5. We are told that our staff will be seconded to NonGov's on a contract of ?3 year.----this is unreasonable, unrealistic and the decrease in salaries will badly impact on their life and the lives of their family.
6. We were told by the NDIA staff who came and addressed the Welfare that those who were already in the disability sector before they turned 65 would be able to remain in the sector and get a NDIA plan, but according

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to what you said yesterday, nobody can get a plan after 65years old----is this correct?

7. If this is correct---what happens to our residents who are over the age of 65---to put them in regular nursing homes would a death sentence.
8. A lot of our residents require a lot of space, and they behave badly if confined or are in close quarters with other people .
9. To restrict residents to the confines of a house and yard is a receipt for disaster, they would require more expensive psychologist's behaviour management plans, expensive training for staff to implement the plan and when these fail they will be heavily medicated. If this appears to be overly dramatic---believe me it's not, some of them have already been in the community and it didn't work.
10. We have two young people in Stockton under Ministerial Order who came in with their own staff and security, they are both more settled now and one can't help wondering what will happen if they have to go back to the same conditions.
11. What guarantee do we have that the NonGov will keep our RN's on after the contract expires?
12. We are told if we are not happy then we can go to the Ombudsman, our Local member we could ask our planner, however that does not seem satisfactory. When ADHC goes there will be no provider of last resort.
13. Our residents have very severe and profound disabilities and would be most unwelcome in most local GP's waiting room and definitely not in a dentist's office where their behaviour would escalate rapidly..
14. The health department is struggling to meet its cost now, so how will it meet the cost's of our residents health needs, these are assuredly not going to improve and the same goes for their dental treatment.

As I said these are only a few of our concerns and they are causing a lot of people many sleepless nights and anguished tears.

**Wendy Cuneo , Retired RN, Parent , Vice president and Publicity Officer
Stockton Hospital Welfare Association**

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Parliamentary Joint Standing Committee
on The National Disability Insurance Scheme

Monday 5th May 2014

Thank you for this opportunity, we all want the NDIS to work and to do this we have to fix the current problems.

I am giving the committee a copy of a plan done by a NDIA Planner in the community and one done by a planner at the Stockton Centre----I have removed their names and numbers , however I think it important that the committee see the difference as the Stockton one is well prepared and easier to understand, although there are still a few anomalies.

The plans done by the community planner is difficult for carers and / family members to understand, a lot of family carers are fairly old and some have disabilities themselves, and if it is incomplete then a reassessment has to be done.

Then whole planning process has to be revisited and updated every year and this is causing great concern and distress.

The one done at Stockton is much more user friendly although even on that one you will see page 7 & 8 it talks about .38 and .08 per hour----what does this mean?

There is also no funding allocated for case management, and while this can be rectified it can be difficult as some planners are not very happy to reassess.

Also in both the plans there is an inadequate allocation for a Psychologist for a consultation around behaviour support and lifestyle management and there is no money allocated to train staff in how to implement the psychologist plan when it is done.

Another one of the problems is that it depends on what planner you have as to what resources you get---

1. Eg: one girl really needs a CPACK machine which helps her sleep properly thereby improving her quality of life but the planner said the NDIS would not cover that.

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However the NDIA allocated an occupational therapist \$1,000 to assess her need for a special purpose phone for people with disabilities, the OT's solution was to laminate a card with large numbers on it and tape it to the back of the existing phone, hardly a professional approach and certainly not worth the allocated amount of \$1,000, if she actually charged the NDIA that amount, and the family have no idea if she did charge the full amount or not.

2. The other example is a man in sheltered employment who has had his own car for a long time and managed it himself, yet they are going to pay for his green slip and give him a gym membership.

I'm sure you can see the inconsistency in these two examples.

The Removal of the mobility allowance means a loss of \$174 per month from their Disability Pension, so they have less for the trains, busses etc. that are a necessary part of their training and community participation.

1. In the Plan for one man, there is an allocation for \$795 per year for a taxi and the other day he spent \$120 in one day on a taxi, he did have a reason that he thought was an emergency, however I see problems with the fact that the person with a disability only has to get in the Taxi, give the driver their NDIS number and the driver charges the NDIA
 - My queries about this is are-----
 - How does the driver know if they have a taxi allocation
 - How does the person know if they are being billed for the correct amount or if the NDIA is being charged that same amount
 - How many intellectually disabled people are capable of keeping track of how much they have spent on taxi's so they don't go over their yearly allocation?
2. Another person has to save any bus and train or taxi vouchers and put in a claim every month to get the return of their mobility allowance--- clearly this is also inconsistent.

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We were assured that no one would be worse off under the NDIS and yet families have increased stress and paperwork.

Planned goals identify need for outings like movies, lunches etc however there is not enough pension left to pay for admission, and the costs to the support person.....eating in front of carer is not community involvement let alone good manners.

The Disability Pension is divided up by

75% -----goes in Accommodation and board

25%-----is expected to cover

- Clothes,
- shoes,
- medications,
- webster packs, This can work out at a considerable sum when you realise that each time a doctor has to alter the medication the chemist has to repackage a webster pack or start a new one.
- bed linen
- hair cuts
- massage
- podiatrist
- continence aids
- Spectacles
- Hearing aids
- dressings for wound care eg; bed sores
- extra costs for day programs, like outings, food for healthy living, etc.

These are only some of the expenses. My husband and I are regularly topping up our children.

In most plans there is no money or time allocated for required documentation to be done by support staff.

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- Eg: if my son has 4 hours allocated for a carer to take him out, the carer first has to
- go to base to collect the non gov. vehicle,
- then go and pick up my son,
- take him out,
- then take him back at the conclusion of the outing,
- return the car back to base
- then do the documentation that is required
- so in actual fact my son gets 2½ to **3 hours out of any allocated 4 hours.**

There are other examples that can be offered however this submission is not a witch hunt but an effort to bring things that need reassessing before the committee, like I said we all want this to work well to improve the lives of our vulnerable people.

Wendy Cuneo - Parent and
Vice President and Publicity Officer
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