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

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Date Received: 7 August 2018

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To The LEGISLATIVE COUNCIL PORTFOLIO COMMITTEE NO. 2 – HEALTH AND COMMUNITY SERVICES

As I am making the submission to the inquiry I thought you might like to know my qualifications and experience.

I became a registered nurse in 1966, my areas of expertise has always been in aged care (I ran a nursing home called Cashell house in Randwick) and disabilities.

I adopted three children with various disabilities, each child had a at least five disabilities, one has seven, the eldest (a boy) had mainly physical disabilities that have being surgically fixed, so he lives at home with asthma and Aspergers Syndrome – he is 44 years old.

My next son has many disabilities including a genetic condition "a double translocation of the chromosomes" epilepsy" although we hasn't had a Major seizure for many years now, however the diagnosis that causes the most trouble is obsessive compulsive disorder with hyperactivity that makes him very hard to handle for many people, he lived at home until the age of 18 ½ years at which time it became impossible to keep him under supervision so he went to live at Stockton Centre where he has been for 20 years.

My daughter also as various disabilities including difficult behaviour and since year 10 at school her mental health has become a serious problem.

She now lives in a group home run by the Samaritans and has done for at least five years previous to that she lived in a Group home run by house with no steps, there have been many complications over these last seven years they have exacerbated her mental health problems.

She is fairly settled at the moment however it has been a very rough ride for their since I serious and then declared in November 2015.

I have to many years being a working member of the Stockton hospital welfare Association and an advocate / person responsible for a gentleman with disabilities living independently within the community.



Parliamentary inquiry into disability services in New South Wales, 21st of July 2018

1. (a) the implementation of the National Disability Insurance Scheme and its success or otherwise in providing choice and control for people with disability,

In my opinion the NDIS was implemented without enough thought, for instance

- According to the NDIS there can only be one NOMINEE for each plan (even though they can have parents, siblings and people responsible on the actual), this means only one person is capable of making decisions, and this causes all sorts of problems if the person responsible is incapacitated for any length of time which may not be permanent so if that person is not capable of making the decisions there is a dreadful process to go through to change the name of the nominees and then if the person responsible gets well again you have to go through the whole process again.
 - I know this and how difficult it is because for some reason my position as nominee disappeared from the two central computer wherever that is (interestingly it only disappeared from my childrens files, not from the person for whom I am responsible within the community which is very strange)
- The other ridiculous position with the nominee is that people who are responsible for people with severe
 profound and complex disabilities I told you get their person to sign a paper stating that they want their
 family member to become their nominee.

In my view it is, or should be a crime to ask anybody to sign a document that they do not understand and Will never understand. The other thing of course that no one in the NDIS appears to be able to understand is that many people with severe profound and complex disabilities cant even move, communicate understanding or agreement, they may be able to not their heads when asked if they would like a drink but this does not constitute understanding of complex documents.

- there is really little choice regarding activities for people with disabilities due to the fact that carers are limited by restrictions on transport kilometres, and whether or not clients can afford to do those activities due to pension restrictions as well as physical and intellectual limitations.
- This whole situation is causing great stress, the NDIS was supposed to make life easier but for families
 and those involved in making decisions for people, ensuring that plans up properly followed and used to
 provide a better quality of life it is a nightmare and we are all drowning under documents, emails and other
 forms of literary persecution.

Example 1 – my son was promised a brand new home of his own, wherever he liked, with the bus stop at the front (this by the minister of the time and John Ryan in front of approximately 40 people at a large meeting of families) and now I have a very dissatisfied son who wants what they promised him without the understanding that he would be unable to have the freedom he now enjoys, he would be frustrated and restricted in such a setup and would be lonely with only one carer for company.

There are a few main reasons why the above promises would be totally impractical, for instance

, my son walks from when he gets up in the morning to when you goes to bed at night, with very small
amounts of resting between (eg:5minutes) he does not watch television for more than a few minutes, he

cannot read and write, although we have tried every possible way to teach him, he is unable to do craft work, also for more than a few men minutes – therefore in the above situation promised by the minister he would try to break out as he did when he was living at home (until 18 ½ years of age) if he is locked in he will try to kick the door down and if he gets out he is so fast he could be in Singapore before you know he is missing.

- Even though my son goes to day programs at Castle personnel Monday to Friday they find that they need
 to change activities frequently and keep him outside the building wherever possible as he hates to be
 confined.
- My son lives in the Stockton Centre where he has the freedom to wander around the complex talking to
 those whose company he enjoys however even allowing for the fact that he is absent from the complex
 six hours a day Monday to Friday, four hours on Saturday and public holidays, and seven hours
 approximately on Sunday the staff at Stockton still find it difficult on occasions to meet his needs.

For instance: on one occasion the facility was in lockdown due to infectious influenza, this meant nobody could go outside the facility, so one of the staff made the mistake of actually locking the Crim safe security screen door during daylight hours so my son who has the freedom within the grounds from 7 AM until dusk calmly removed the screen door, twisting it in the process. The man who came to replace the door made the comment" my God! this door was Crim safe and bullet proof" to which the staff replied "yes but unfortunately it was not David proof"

Example 2, my son genuinely wants to be a pilot and the superhero, we all know that is impossible and yet it is his genuine desire and he keeps telling me" it's my choice mom" which is what the NDIS had been preaching to them which is a lie, none of us have absolute choice and people with disabilities don't understand this.

Example 3 my son wanted to ride a horse so we enrolled him in riding for the disabled however he complained that they wouldn't let him ride a horse, that he had to ride in a cart pulled by a horse, I made inquiries as to the reasons they had for denying him the right to actually ride, however the reasons given were unsatisfactory.

After many inquiries I discovered that he was considered to be too heavy and tall for the horses available, (this being a health and safety problem because if he fell off the horse there was a strong possibility of him hurting himself and the carer - this was considered as too large a risk) when I enquired as to why I had not been informed of these reasons earlier I was told that they didn't want to lose him as they needed to keep his funding. I found this unacceptable and withdrew him from the program.

Due to pension restrictions, the cost of insurance, and carers with the ability to supervise him in such an activity outside this organisation he has unfortunately been unable to ride a horse.

Our people are continually told that it is their choice regarding the activities they wants to do yet it is obvious from the examples listed above that there are many natural and legitimate reasons why their choices cannot be granted.

1. (b) the experience of people with complex care and support needs in developing, enacting and reviewing NDIS plans,

NDIS plans are very difficult to do especially the first few, due to the fact that neither the person and/or planner have the life experience to either understand the wording of the plans or the experience to really understand what options there are to increase the quality of life of the person with a disability.

There are many ways to increase quality-of-life but unless the person has that knowledge they don't know what options there are and therefore can't put into plan those services and possibilities.

For example

There are many technological advancements available on the market to give people the ability to communicate better, to increase mobility, to be able to participate in more areas of community living, however unless you know these things then without a proper assessment by experienced people there is no way for these to be included in a NDIS plan and therefore the person with a disability misses out sometimes for years and sometimes never receives the help that would be available.

When a plan is passed and people realise other services they should have included, or supports that they had not realised would be covered by the NDIS they then had to apply for a review which can take months at least and can be very frustrating.

I personally put in (for the person I support in the community) two change of circumstances review applications, the social worker from the martyr hospital put in two requests for review and the social worker from John Hunter hospital also put in one request, none of these requests were satisfactorily handled until after the crisis was over; this is totally unacceptable a person could be dead before they get what they really need.

Example 2

The way the new NDIS portal is set up really defeats the purpose of helping families and carers to get the best possible results from the plan.

Only the providers have the ability to see what has been charged for i.e. in hours and funding, (unless you are self managing) families and carers can only see what providers are involved in that persons life, not what amount of money is being spent daily on particular activities..

Example three

I cannot see on the portal if a carer who brought my son back early (for whatever reason) has actually charged my son for the full-time he was supposed to be out with that carer.

I cannot see if the carer who did not turn up (and this has happened on numerous occasions) charged my son for that Time.

I cannot see if on the occasions when my daughter is being transported in a vehicle with other people who have disabilities is being charged the full transport cost that she would have to pay in an individual situation or if the cost is being shared between all participants.

These are only a few examples however families and people responsible should be able to view all aspects of the plan and it's instigation, there is a lot of double dipping and mistakes made by providers but without this being

overseen properly by families and people responsible it is not corrected and the person with disabilities is shortchanged.

2. (c) the accessibility of early intervention supports for children,

Not applicable to me

3. (d) the effectiveness and impact of privatising governmentrun disability services,

The decision to privatise all disability services in New South Wales is detrimental to the welfare of people with disabilities.

It is imperative for the government to maintain some control, the main one being a provider of last resort.

This provider of last resort needs to be a service provider who is capable of solving problems quickly when they occur and negotiating for people with disabilities when there is a serious concern between a service provider and the person with a disability/person responsible.

A provider of last resort would need to find appropriate accommodation for people with the disability who for whatever reason, do not cope, and/or are unable to be managed in a regular community setting.

A Person with disability needs to be able to go to a place where he / she can be fully assessed in pleasant surroundings as to what particular disability is interfering with their ability to survive in the general community.

Some disabilities consist of behaviour that causes problems within a group home and the community; sometimes these problems could be solved by doing a compatibility assessment on the people living within the group home. If there is conflict in the house then a person with a disability tends to act out with behaviour that is unacceptable to others, however the person with a disability is unable to explain their unhappiness in any other way.

Many people with disabilities **cannot help their behaviours** as it is part of their disability and this causes offence to others.

For example we have a gentleman who stands in the yard and screams over and over again, he is totally deaf therefore it is useless to try to stop him exercising his vocal chords because he does not know what sound is, in a normal house in a normal Street this would be totally unacceptable to neighbours and the alternative sometimes offered to the family is that maybe he could be put on a rural property, somewhere where he could not interfere with others peace and quiet; this is totally unacceptable, why should he be sent further away from his family and activities to please other people.

Therefore such people should have a place where they can be themselves with the freedom to roam around and be accepted by those they live with and who care for them, in other words they need a sanctuary.

If an assessment showed that the problems faced are caused by medication then a complete medical overhaul would need to be undertaking (also in a safe place) until the medication levels was satisfactory and behaviours have settled down.

If the assessment concluded that the accommodation was the problem then the provider of last resort would need to negotiate with the service provider to either provide satisfactory services and accommodation to help that person Live within the community, or if this could not be accomplished by that provider a new one would need to be sourced.

However with the best will in the world some people just cannot be satisfactorily accommodated in the community and require a sanctuary.

In New South Wales we are blessed by still retaining a large residential that is a sanctuary (however new admissions have been rejected for many years), and this facility could be improved, not only to meet all requirements of "The International Treaty on the Rights of People with Disabilities", but would also be a showcase for the rest of the world on how to help those with profound, severe and complex disabilities and behaviours, who need a more satisfactory solution than group homes, solitary segregation or the other models that are all that is available at the moment.

It is not too late to retain, use and improve this facility to meet the requirements above and to correct the gaps in the current National disability insurance scheme.

Accommodation is very expensive, and therefore the group home model has basically been used for all people with disabilities until, when problems arose that could not be solved within the accommodation provided then the person with difficult behaviours was often moved into a single accommodation with one-on-one carer support, this is often results in a person being isolated from the community (against all the best intentions of the NDIS) with many restricted practices, defeating all ideals of the NDIS. There are many such cases in this state alone.

A person with a disability who was suddenly unable to live at home with ageing or ill parents for example was often put in the only available bed at the time. This is detrimental and damaging to the mental and physical welfare of those forced to live together when they do not suit.

A new person being put into a group home unexpectedly without the compatibility assessment being done can cause untold emotional damage not only to that person themselves but to others within the home, in the past this has often caused people to be moved from one place to another while trying to find a peaceful settlement by which time the psychological damage has been considerable to all those involved.

We at Stockton were promised there would be compatibility assessments for all our people before they were allocated permanent homes, however families and people making those decisions are often unaware that people who have lived together for many years often dislike each other intensely, if the staff who have worked with them had been asked for their opinion there would have been a different outcome.

The Stockton sanctuary could also be used, as it has been for many years, to train carers in understanding many disabilities and giving them information on how best to improve the quality of life of these people.

There is a serious gap within the NDIS in regard to training both carers and healthcare workers in ways to help those with severe profound and complex disabilities and those with severe behaviour problems.

Many health care workers and this includes GPS have a little experience with regular disabilities let alone those more complex and severe and statistics show there is a large amount of mistreatment and unnecessary deaths among people with these complex disabilities. I attach a letter to this submission from the father of a resident from a group home who suffered unnecessarily at the hands of health system, before dying of a different diagnosis altogether.

If recipients request it they can get allowances within their plan for behaviour support from qualified psychologists, however this is often inadequate due to the fact that planners themselves do not have the life experience to understand the number of hours necessary to provide the amount of behaviour support needed.

Non -government Service providers all complain that funding does not cover training for carers to understand how best to improve the quality of life of their clients.

A lot of people with profound, severe and complex disabilities or those with behaviours are not getting a proper service because of these shortcomings, many of those with severe and profound disabilities spend their lives going out for morning tea, lunch etc, without doing any actual activities programmed to their needs which results in clients ending up with weight problems.

I personally have seen carers meet up with a friend, take their clients to housie where the clients were asleep while the carers played housie.

I had also seen carers meet up with others at a club for a meal where they talk among themselves with an occasional remark to their clients or a pat on their hand etc.

These activities are Not providing a better quality-of-life for the clients who need activities suitable for their interests and disabilities.

For example, I have a friend whose son is blind, non vocal in a wheelchair and unable to physically do anything other than move one hand; so one of his carers takes this gentleman to chemist warehouse where he can sample various perfumes, he takes him to fabric shops or carpet shops where he helps him feel the different fabrics, he takes him to the beach where he uses a small bucket to pour sand or seawater over the man's hand. He also takes him to free concerts (provided by some clubs) as well as into music shops where he can play him a variety of different types of music, obviously this carer puts a lot of thought and ingenuity into doing his best to provide a better quality of life for my friend's son.

Not everybody has the ability or ingenuity to think of the type of activities mentioned above, however, training to teach these things would be money well spent as there is so much waste within the NDIS.

At 10 hour disability certificate course Falls way short of achieving this type of dedicated carer.

4. (e) the provision of support services, including accommodation services, for people with disability regardless of whether they are eligible or ineligible to participate in the National Disability Insurance Scheme,

My answer to question 3D also relates to 4E.

As previously mentioned support services and alternative types of accommodation can only be asked for if there is knowledge of what is available so I reiterate strongly that a proper assessment centre be set up staffed by people with the life experience and the knowledge to understand what is available and how best to provide services and technology that will provide a better quality of life for the person involved.

5. (f) the adequacy of current regulations and oversight mechanisms in relation to disability service providers,

5F and 6G really relate to the same issues, as audits done on service providers don't appear to take into account how much actual improvement (to the lives of the people that they serve) is made to the quality-of-life of the participants in their care.

It should not be about ticking the right boxes but rather about each participants satisfaction and pleasure.

6. (g) workforce issues impacting on the delivery of disability services,

Oversight mechanisms in relation to disability services providers are (in my opinion) totally inadequate due to

- There doesn't appear to be any oversight of whether or not service provider has any training and
 qualifications to provide the best possible program for people with severe / profound / complex
 disabilities and those disabilities which contain a large component of difficult behaviours.
- There does not appear to be any oversight of whether or not Service providers are capable of providing
 proper training for carers, and if in fact that training is provided to carers.

Example 1

I have attended some excellent seminars and forums where I have heard service providers state that
they would like to have had some of their carers attend, however because of budget concerns they
cannot afford to pay carers to attend training and seminars when they should be working no matter
how useful it would have been to do so.

I have heard Service providers say that while there are many practitioners across the therapy spectrum who do an excellent job in providing services, however they also complained that often therapists either don't have the ability to properly assist people with complex severe and profound disabilities or they make judgement calls on what is possible for people with these disabilities.

Example 2

This happens particularly when NDIS plans are being written, as many families have remarked "well, the physiotherapist made the remark that my daughter/son has a very severe disability so what do you expect? there is only so much we can do" and these families are well aware that given the right treatment and therapy there is a lot that can be done to improve the quality of life with someone who has a severe profound or complex disability.

Some doctors and other medical practitioners are also guilty of this type of judgement call, there have been occasions when a person has been seriously ill when a doctor will say" well she / he does have a disability what do you want to do?" Families find this very hard to contend with especially when the disability in question is not a profound severe or complex one, are these people less entitled than people in the normal community to the best of care?.

7. (g) workforce issues impacting on the delivery of disability services,

Most professions require regular training sessions and there is no reason why people in trusted to look after our most vulnerable people should be any different, it is imperative that the NDIS ensure that this training is done and unwell..

8. (h) challenges facing disability service providers and their sustainability

I'm not sure how the regular non-government service providers become providers other day programs etc, however I believe that when they tender to take over group homes and other accommodation facilities they tended to put in the lowest Financial budget that they believe can we mean that tender.

My information is that this amount is often way be low what they really require to run that facility to a higher standard which will give residents the best Quality of life.

Example 1

Our people at Stockton Centre and their families were told they would be able to choose the service provider who would run me loved ones accommodation, then we were told that the only suitable non-government provider was a consortium of three non-government service providers under the title of under Valley disability services.

At the time those of us involved made it clear we didn't think of this consortium would work in the Longrun as the attention seem to be that the three organisations would operate under one management and the houses would be allocated to each one, now we are told that the consortium Will be disbanded and the three organisations Will work independently.

The confusion and difficulty for families involved and residents has been considerable and it's my belief this should not happen again.

9. (i) incidents where inadequate disability supports result in greater strain on other community services, such as justice and health services,

A normal medical practice is not equipped to examine properly people with severe and profound physical disabilities, these people often require special examination tables and other equipment due to the fact that their bodies I twisted and misshapen causing incredible pain and discomfort if they are required too late on a normal examination table.

The other point is that many people with the severe and profound disabilities can have their organs in unusual positions within the body, a regular GP might never see more than one person with this sort of disability in a lifetime and is therefore not equipped with the knowledge required to diagnose the condition.

This is the reason why we need a specialist disability care centre that is both equipped with medical staff who have the life experience to diagnose more easily the conditions our people can have as well as being equipped with the necessary aids and equipment.

We also need a specialist disability dental service for this reason outlined above; we already have this at Stockton Centre, yes it is old any need I've renovation however it has been working successfully for many years not only for our own people but for those in the community (particularly children) hey for whatever reason cannot be treated buy regular dentist and or/requires a general anaesthetic.

I reiterate what I wrote above regarding the Stockton Centre to become a showcase for the world I'm just what can be done for people with disabilities who need care that can't be provided as well within the community.

10. (j) policies, regulation or oversight mechanisms that could improve the provision and accessibility of disability services across New South Wales, and any other related matter.

Such a specialist accommodation and care facility as I suggest that Stockton should become should be run by board consisting of people with life experience (not academics who's only knowledge comes out of books) as well as some Family members who had actually and successfully raised a family member with a severe profound complex disability or a person with disabilities including severe behaviour problems.

Such at board could become the provider are the last resort, to do this it would require the members of the board to dedicate three quarters of their working time to running the facilities and the provider properly while spending the other quarter of their working life just spending" hands on experience" with the people who have these complicated disabilities.

Over the years (many years) I have listened to lectures by and interviewed by academics and while they are very good at gathering research this often fails to accomplish much in way of practical solution to the many problems that occur; they must have hands on / Life experience to be any earthly use.