Submission
No 162

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

Organisation: Voices for Central Coast Disability

Date Received: 7 August 2018

VOICCD
VOICES FOR
CENTRAL
COAST
DISABILITY

Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales

Terms of Reference

Portfolio Committee No.2

Submission by Voices for Central Coast Disability members:
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Voices for Central Coast Disability is a newly formed user-led peer to peer group on the Central Coast. We are not yet a legal entity and are run entirely by volunteers and in receipt of no government grants. We have participated in community consultation through surveys and community meet and greets. Our named working party members have provided their own individual stories and opinions on policy. Some of the stories were also presented at the NDIS Roundtable with Emma McBride our federal member for the electorate of Dobell. The views presented here form our own opinions on the current state of the NDIS and are not representative of every single person in VOICCD.

Health and Community Services inquire into and report on the provision of disability services across New South Wales, and in particular:

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

- Our members feel that Choice and control seems to be in name only. As we are located on the central coast the number of our services are limited to meet our specific needs. It seems that many companies in our region are merging into larger entities because they could not sustain under the new disability services model. The client is now becoming an asset instead of an individual.

- The new scheme has removed Case Management from disability services. Our service provider network has mentioned to us that instead of being able to spend quality time with the client one-on-one in a case management model, the burden has now shifted to co-ordination of supports. In support co-ordination pricing is done in 15 minute increments similar to a lawyer or accountant and all elements of time with the client must be related to their goals or co-ordinating services. It is noted that providers have less time or flexibility to spend with the client on an individual supportive basis. Case Management needs to be reinstated into the NDIS.

- Choice and control is often being taken away from clients, for example, private providers vehicles are heavily monitored because they need to keep track of where the participant is and account for every kilometre and every second of time. There is a group consensus that there is a limit of choice, spontaneity and ultimately an impact on choice and control in an environment where this kind of monitoring or business practice takes place. In general, there is a lack of spontaneity as clients have to book transport days and weeks in advance. General social and community participation is therefore quite limited under these conditions.

- Private providers have limited some risk averse activities. Saying the individual has choice and control in theory and a provider actually allowing them to have this is two different things. For example, our providers on the central coast rarely allow an individual to choose to go swimming at the beach as it is viewed as a risk. How can an individual have choice and control if private companies are disallowing basic activities? How does that business classify risk considering every person with a disability has a broad range of ability and impairment? What may be a physical risk to one client, is not to another. For a provider to have blanket rules for all clients means choice and control about activities is technically being limited.

- Again we believe that choice and control as buzz words being used in name and theory only. The majority of plan managers only allow activities or services claimable against line items. As individuals we were meant to have the flexibility to use this funding innovatively. We find that the approach to services is still based in the old model of thinking with very little innovative flexibility allowed. While self-managed participants have more flexibility, we found the NDIA is hesitant to allow participants to self-manage even if they are more than capable of doing so.

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

- It seems to be a common theme among our members that the Local Area Co-ordinators contracted by the NDIA lack experience, education, training and knowledge around disability and disability services. These LACs don’t wish to take responsibility when something goes wrong during the planning phase of the participant’s plan. Many members and other people in our networks have made official complaints against their Local Area Co-ordinators for lack of understanding, threatening and rude behaviour towards family members, carers and participants.

- Planners taking advice from contracted LAC’s make plans for the participant without any direct contact with the participant. The NDIS plan is approved without the participant seeing any draft plan or being able to review the draft and notify the LAC if is wrong, missing or has been misconstrued during the LAC interview. Participants should be able to see a draft plan, request minor changes and sign off on that plan.

- If a person wishes to make a change to their plan, the person must make request for a full internal review. This has added time, strain and stress to the process and also an unnecessary step to receive the services a person could have been entitled in the first instance. Internal reviews are taking months to process due to the overwhelming number of them, the AAT has also been inundated with similar requests. This adds costs to the NDIA, stress and un-needed burden on a person with disability and their family and carer network. Should the person be able to review a draft plan in this process, many of these reviews could be avoided.

- Our group suggests having pre plan meetings, especially for those who haven't been in disability support services before. Some participants have no prior knowledge or experience in expressing their daily needs to a stranger to be allocated funding. Another issue on this point is no knowledge of the terminology. If participants lack the knowledge or ability to express their needs in NDIA terminology, they often miss out on having their needs met.

- Plans should be open to change at any time, especially if the client or major informal supports experiences emergency. There should be an internal trigger mechanism to have the plan reviewed and changed urgently within 14 days. A 6 to 8 month waiting period is too long if a clients' circumstances drastically change

- On the other note, those with a sustained, permanent, established disability whose needs are stable should not have to undergo the process of review every year. Each year people with a disability are being told to provide reports and evidence on why they still have a disability. If the benchmark has been met in the first instance and a person's plan is adequate and they do not seek review, there plan should rollover automatically with the same amounts annually. A participant can request review at any time, trigger an emergency mechanism as suggested above but otherwise plans should last for 3 to 5 years depending on a person's preference. To make a person go through the arduous process of having to prove year after year they are still disabled seems counter productive and a misuse of time and resources.

(c) the accessibility of early intervention supports for children

- Capacity building supports for children including speech and physical therapies are not are once off cost. We have found that members have often been given Capacity Building monies in the first plan, only for them to be removed or reduced in the second plan. The NDIA views that being given CB Supports once only means the participant has therefore gained that capacity. This is not the case. Some disabilities will require lifelong therapies under this scheme to maintain function and gains and these participants' needs must be funded accordingly.

(d) the effectiveness and impact of privatising government-run disability services

- An impact of concern about privatisation of services has meant that participants are now viewed as assets and a providers priority is now making profit or the meeting KPIs (even in terms of the NDIA the participant is viewed as a commodity and market lever). There needs to be true reflection and awareness about the impact of this mindset shift. For example, instead of agency collaboration, providers are now merging as we stated above or competing against one another. In the previous model of funding, collaboration and resource sharing was commonplace. This fostered a vibrant sector that intersected at various service areas. The increased competition is meant to allow more choice and a wider variety services for an individual however it has the possibility of having the opposite effect as the focus shifts to competitive business sustainability.

- As participants are now the consumers funding these providers they should be able to have more of a say about how they run and operate. For example, business mergers, the clients should be notified early, updated on the business rationale behind the decision, assurity of staff continuity for those who can't adapt quickly, continuity of programs during a merge. Failure to notify a participant about issues that affect their day to day life adversely impacts on the person and their family. Some participants may require respite or further support during a process such as this.

(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

- In Australia there are 760,000 people on DSP. On full roll-out only 440,000 people will be on NDIS at full roll out. Some of these are children. There is no back up state Disability Services system for the more than 50 per cent of those with a disability who do not qualify for the NDIS

- The majority of these people seem to be those where the NDIS views the disability as related to health, or those suffering from Mental Health Disorders and Mental Illness

- Our members have noted that previous mental health group programmes or services they participated in and most notably PHaMS have been reduced or ceased operating. The support for Mental Health clients who are ineligible for NDIS seems to be reduced at a drastic rate and many are disillusioned with a system that keeps rejecting them. Either Mental Health needs to be FULLY included in this scheme, or not at all, and that funding put back into the state services if the latter is decided.

- While the DSP system is a function-based assessment, the NDIS seems to still be relying not on functional impact but on diagnosis alone. This is confusing and contradictory to have two government institutions making people with a disability undergo two completely different tests of impairment

- The provision of services to those who do not qualify for NDIS seems up in the air. Some not for profit programs still exist or programs that exist under Family and Community Services and NSW Health. What is worrying is no commitment to continue services, the duration of continuation of those services or what will exactly remain for those who do not qualify for NDIS. These people deserve the same level of access and care as those who are on the NDIS.

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

- Our members agree that the disability sector should make qualification standards for carers and operators before they can care for clients. We find it worrying that in disability services as in aged care there is no legislative minimum qualification standard to currently work with this vulnerable population. We believe it not even compulsory to have a first-aid certificate. While some providers make their own rules around this issue, it is not legislated or consistent across providers. This is an accident waiting to happen.

- For those people who don’t have qualifications and are given on the job training, it is one individuals experience from our group that sometimes new support workers are given only 4 to 8 hours of on the job training for high level complex 1 on 1 Supported Accommodation Work. This is very concerning. This client had severe ASD, partial blindness and was part deaf and we have been told it is common practice for these staff to leave the girl to self-harm with repetitive distressing behaviours as staff aren’t trained to deal with her violent outbursts or deem her too dangerous. Carers in this instance really should be trained mental health professionals, registered nurses or those with psychiatric care qualifications, not untrained support workers with the minimum level of skills.

- Clients should be able to review the skill-set and qualifications of the carer being provided for them

- Transport providers should be regulated. As some of these people are transporting children and those with intellectual disability, providers should be ensuring that anyone driving or transporting should have a working with children’s check, national police check and first aid qualification. While this person’s role may only be driving participants, the person is till responsible for those in their care. Were to an emergency to occur they need to have the skills to respond and also ensure they do not pose a risk to the clients.

- It is concerning that anyone with an ABN can start a disability service or become a carer for someone who has an NDIS package. It just seems too easy. Policy and regulation really just needs to look at the risks of inexperienced pop-up carer services.

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

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(h) challenges facing disability service providers and their sustainability

- In this new business model it seems to be unsustainable because the individual participants absorb the administration costs in the hourly fee. The only time a provider can do their administration work is during the individually billed hours to the client. Therefore, the client is paying not for individual attention but for administration. Many service providers have found it unsustainable to continue previous group programs due to the impact of the administration work as well as the cuts to previous collaborations through the grant scheme

- Because of the yearly review of plans, consistency of services is not guaranteed. A participant who may be using 10 hours a week in this plan may be reduced to only 5 hours a week in the next plan depending on the lottery of who they get as LAC and planner. For this reason, a business cannot rely that its client numbers and hours will remain consistent for any period longer than a year. Were plans to be 2 or 3 years in duration both the client and the providers could plan for long term sustainability and person-centred approach to care.

- We fail to understand why penalty rates have been cut for retail workers and workers in other sectors however NDIS participants still have to pay increased rates on Saturdays, Sundays, Public Holidays and even evenings. NDIS participants pay the maximum rate of penalties. There is a lack of consistency in government policy around penalty rates. Also, in a flexible workforce or shift-based environment we find that evening rates being higher than the standard rate is without reason. We are not against penalty rates but the time of day and the rate of pay when a person needs that stated support needs to be taken into account when planning for the person and worked into their NDIS funding so the person does not run out of funds. This again comes back to LACs and reviewing a draft plan stated above.

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

- One of our members stated that because the regular mental health services were unavailable for him in the community, he was forced into an involuntary mental health hospitalisation for 7 weeks. Had the community care been present for him to participate in a program or for an outpatient service to monitor his condition, there is a likelihood a long-term admission could be avoided.

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(j) policies, regulation or oversight mechanisms that could improve the provision and accessibility of disability services across New South Wales, and

- NDIA Policy and policy changes should be readily available and in plain English for participants their family and carers. In addition to the NDIA Newsletter, any major policy changes should be emailed and mailed to participants. This enables participants to understand the ins and out of the scheme that is in place to provide and care for them. Any major changes should be accessible and understandable.

- Transport is a major area of concern. There is no legislative cap on transport charges. While the default rate is 0.78c per kilometre, many providers are charging upwards of a dollar and more. For those who live in rural or regional areas, simple trips to recreation events or hospital appointments result in sky high transport costs. The default transport allowance is $1606. This amounts to $30 a week. This barely covers the cost of half a trip to a recreation activity or event.

- Similarly, in relation to transport costs, individual outings around the Central Coast average around 60km per round trip (Gosford to Wyong return for example). If a provider is charging $1 per kilometre, that is $60 per client per day for transport. Let's say an average provider takes out 6 clients per day using 2 fleet vehicles (we assume it is much more than this given some providers have a large support worker workforce and upwards of 80 clients on the books). That cost is equal to $93,600 per year. That is enough to fully replace the cost of the 2 fleet vehicles. Kilometre charges should not be covering the cost of vehicles, only reasonable petrol costs, depreciation and maintenance.
  The amount being claimed in transport costs is staggering and the majority of these costs are passed onto participants who no doubt go well over $30 a week being transported to and from their engagements and appointments. The amount is just simply not enough and the per kilometre charges not regulated.

- On that note, the transport costs need to be regulated and capped and only increased at the rate of CPI. The default rate should be standard for all providers. The increase in transport per km rate seems to be another way for providers to take advantage of participants to cover the increasing costs of administration. It is not up to participants to cover the cost of administration and maintenance of fleet vehicles.

(k) any other related matter.

- Advocacy funding and grants to peer-based networks such as ours are vital to the success of the scheme. In a confusing bureaucratic process, it is imperative that participants have access to an advocate, knowledge of their rights, education, representation and information. Specified advocacy funding needs to continue state to state in perpetuity.

- Our group proposes the creation of a new role called a disability liaison officer at all not for profits providing LAC services. This person would sit in with the individual going through a planning process or review, support them through the process, explain any misunderstood impact of the disability to the LAC doing the plan
  This person would be a person with a disability or with lived experience of disability, have knowledge or the NDIS, have understanding of the background and understanding of the client's needs and be employed by NDIA not the NFP company to oversee all planning meetings. The person would then help the person review the draft plan and sign off on the plan for the year.

- Under NDIS, equipment requests seem to be complicated and time consuming. Participants are expected to get whole new reports therefore wasting their Capacity Building Funding. Participants should be allowed to use existing reports for equipment and not have to undertake the process of proving their disability on each and every piece of equipment requested or modification. There should be one form for the whole person. The waiting time for application approvals is too long currently sitting at nearly 12 months. For a participant to go without a hoist, commode or piece of vital equipment for their day to day living for a period of 12 months is ridiculous.

- As stated above, Capacity Building Funding should be allocated for more than one year. It is our belief that once NDIS believes a person has received CB funding for one year, they are have improved functionally and no longer need it again. This is not the case and applied to both children and adults. Some conditions need lifelong therapies, continued intervention and continued instruction.

- Technological assistive devices such as Ipads and laptops seem to be impossible to get approved. These devices should not be viewed as everyday expenses, many people with a disability only need these technologies because they need them to assist in communicating and writing. While yes, it is an expense for the everyday Australian, it is a necessity for these people with a disability. NDIA should not be averse to allowing participants who have genuine need for technological devices to use their plan for these items. This is the definition of true choice and control to allow them to choose to use their funding for items such as this.

- Social and Community Support funding should be able to be used to help pay for entry for support worker to access activities with a person. Currently a person can either use their companion card if they qualify which allows free entry for the carer (to some events however not all) however those that do not qualify are forced to pay out of pocket out of their own money or pension for the support worker to gain entry or to participate in the activity with them. This has resulted in many people being out of pocket to access community activities. Costs of activities should be fully absorbed into agreed funding amount for the daily activity and NDIS should cover the full amount including worker entry.

- Social and Community funding should be able to be used to help pay for membership to a peer to peer network. These networks provide invaluable community network, education opportunities, increased self esteem and sense of community. If the government allows funding to be used for membership of sporting associations for example to create this sense of community, there is no reason why peer to peer networks cannot be afforded the same privilege.

- Social and Community funding should also be allowed to be used for peak body membership to allow a person to have representation, education and have systemic support should they have complaints, issues or concerns.