

Submission
No 230

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

Name: Mr Gary Dunne
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Partially
Confidential

Submission to Portfolio Committee No.2 – Health and Community Services inquiring into and reporting on the provision of disability services across New South Wales.

Authors:

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Background on Summer Hill:

Originally within the Health Dept, *Grosvenor Hospital* evolved into DOCS/FACS as a nursing model residential service in the 1990s. As less complex clients moved out to non-governmental and other FACS services with a less medical focus, client numbers remained constant through the admission of people who could not be placed elsewhere due to the complexity of their health needs. Palliative Care became an increasing part of the service offered.

In 2008, the twenty long-term residents moved into two 10 bed units purpose built on the site, and the name changed from *Grosvenor Centre* to *Summer Hill Accommodation and Respite*. A separate ten bed unit was also built on site to enable the continuation of Respite Services for children and young adults. The current catchment area for the two permanent-bed units is the whole of NSW. There has always been a waiting list.

Over the past twenty years the residential client profile at Summer Hill has changed from young people with intellectual disabilities to a group of medically frail, complex health adults who need intense specialised support to enable them to maximise their participation in the community. All residents use wheelchairs. All but two receive nutrition via a stomach tube. Almost half are on Palliative Care or have End of life plans of some kind. All have significant communication limitations. And, as they age, due to never having to support their own weight, osteoporosis is increasingly becoming a major issue for all clients. Twenty years ago people with this level of disability generally did not survive to adulthood. Summer Hill now has residents in their thirties, and even their mid forties.

The focus at Summer Hill remains to enable to best quality of life possible for clients within the framework of their current health needs and disability. As the client focus and nature of the service at Summer Hill evolved over the past two decades, nursing staff have upgraded their skills to ensure the best quality care. The authors of this document, for example, have both completed post-grad nursing qualifications in Palliative Care.

Current situation:

At this time the new owners of Summer Hill are being finalised by the department in conjunction with the parents' group. (Front-line staff are not involved in this process.) Client NDIS plans have been underway for over a year. These two complex processes, covered in clause (d) and (e) of the inquiry, are currently happening at the same time.

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

(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,

There are a number of significant areas that remain unresolved when it comes to the ongoing provision of services at Summer Hill. The potential NGO service providers have told the parents that they will provide whatever services the NDIS funds. The NDIS however, by its very nature does not fund health, so planners have the challenge of trying to fit medical needs into what is fundamentally a non-medical model. The easiest way to explain our concerns is by providing case studies that show the current level of service required and our progress in maintaining it through the concurrent processes of NDIS implementation and privatisation .

Case Studies:

Note: Names and identifying details have been changed to protect the privacy of the individuals.

Dan

From southern NSW, Dan was in foster care from the age of 4 months. At 16 (in 2013), following a lengthy stay at the regional hospital, he moved to a local group home. After several months there, with frequent returns to the base hospital, he was transferred to Summer Hill for palliative care as his condition was deteriorating, and the group home was unable to meet his increasing medical needs.

Dan's main conditions are:

Since coming to Summer Hill, Dan has changed from a frail underweight child to a more sturdy young man. Ongoing daily chest physiotherapy and close monitoring by unit RNs, better nutrition and epilepsy management, and better overall nursing care meant that within a year he was able, for the first time, to regularly attend school and, since 2017, an external day program. His overall health has been managed at Summer Hill without the necessity of admissions to a hospital, except for medical procedures related to his tracheostomy.

Attached is the Summer Hill annual budget of Dan's equipment and consumables (\$79,292). Also attached is a snapshot from his NDIS file showing his current annual funding for consumables (\$10,457).

Several points are clear. His "consumables" are medical or in the grey area between medical and disability support. His planners have managed to argue for some, but not all of these, as the disparity between the two figures clearly shows.

Funding for other items on the list remains uncertain at this stage. The cost of his gastrostomy feeds, for example, around \$3,200, is currently all considered part of his board and lodging by FACS at Summer Hill. Other residential services, including now former FACS services, most often charge their clients for all but the actual feed. We do not know what the new service provider will decide. What is clear is that both NGO contenders have told the parents they can only provide what the NDIS funds.

There is a child currently living full-time in Respite at Summer Hill who is fully ventilated. His "consumables" are even great than Dan's. This child was granted accommodation by a previous Minister for Disability as it was felt he did not have a suitable quality of life living full-time in hospital. Again it is currently unclear how his needs into adulthood will be funded after transfer to a non-government service provider.

Liam

Liam is now 34. At the age of 15 he sustained a traumatic brain injury following a farm accident. He moved from Rehab to the first of several nursing homes where he stayed for the next 11 years, over nine of them spent indoors, in bed or a water-chair, without access to a wheelchair.

Liam's main conditions include:

Since coming to Summer Hill, Liam's life has completely changed. As his medical needs continued to be met, he began a journey of discovery, starting with shopping to choose age appropriate clothing, continuing with exploring augmented communication devices with his Occupational Therapist and getting a powered wheelchair, which lead to exploring activities around the inner-city and discovering a world of new interests.

Liam, the young man who languished in a bed or water-chair for almost a decade in the back of a nursing home, is currently excitedly looking forward to attending Pink's concert in Sydney next week.

Clause e of the enquiry says:

(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,

Our concern, based on years of working within the disabilities sector, is that Liam's story is not unique. Rehab services and placement officers find it almost impossible to place young people

such as Liam. There was a specialist team within ADHC/FACS dedicated to finding these young people and facilitating their move to a residential environment more suited to their age, interests and abilities. To the best of our knowledge, this team was disbanded as part of the closure of ADHC services and has not been replaced.

The “temporary placement” of a young person with physical and intellectual disabilities in an aged care facility “until a more appropriate service can be found”, which inevitably leads to nothing happening for years, is still occurring. A number of current clients at Summer Hill have been admitted via a ministerial or departmental directive. (Dan, mentioned above, was one such person.)

With a catchment area covering all of NSW, Summer Hill has become the safety net. Given the complexity of accessing medical goods and services within the NDIS framework, a non-government service provider could, as many have in the past, easily say No to taking on this kind of client. The intensive provision of nursing and allied health services needed to achieve the kind of lifestyle now enjoyed by Liam would simply be beyond the available budget. Neither the minister nor their department can make a non-government service provider take any particular client. There would be no obligation on them.

Our concern is that such young people will end up placed in inappropriate accommodation, such as an aged care facility willing to provide the bare medical necessities within a framework of whatever is available through NDIS funding.

Annie:

Annie is a 44 year old woman who was admitted to Grosvenor at the age of five. Annie’s conditions include:

Annie has been on a Palliative Care Plan for a number of years. Summer Hill nursing staff have extensive experience in this area of practice. This has meant that clients such as Annie can receive quality care, equivalent to or better than what’s available within external palliative care providers, affording them the dignity and comfort of being able to end their days in a familiar environment, cared for by familiar people.

At times Annie’s health, like other Summer Hill clients, can become very unstable, requiring more intensive care. For some clients, this situation may involve a hospital admission, for others, such as Annie, it necessitates extra staff to provide that care at home. For those in hospital, a “special” from Summer Hill is most often required for 8 to 16 hours a day. General hospital staff do not have the familiarity or skills to provide the essential reassurance, support and comfort that our nurses can.

The NDIS, by its very nature, does not cover Palliative Care, nor does the budget allow for the provision of extra staffing at short notice, should that be needed, either at home or in hospital. Our concern for the future is that without the ability to immediately provide the necessary appropriately skilled staffing in these times of particular need, client care will, despite the best intentions, quickly deteriorate.

The willingness of any non-government provider to maintain the skills level and staff mix of nurses at Summer Hill is yet to be demonstrated.

Both these concerns directly relate to a number of areas covered by this enquiry especially:

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

Recommendations:

As RNs currently employed by the NSW government we are acutely aware we are stepping over the line in making a submission to this committee, let alone in making recommendations. The long-term nursing staff at Summer Hill have genuine concerns for the ongoing quality of life of the highly vulnerable people we have cared for much of our working lives. We would rather action was taken before rather than after the negative consequences (despite the best of intentions), of privatising our service and rolling out the NDIS at the same time.

- a) Transfer Summer Hill to Health or keep it within FACS to maintain its role as a safety net for Disability Complex Health. This would continue the multiple advantages the service currently has in many areas from staff training to access to and provision of services regardless of NDIS funding.

Or, should this not be possible, as a stop-gap measure:

- b) When NDIS funding either does not cover, or is insufficient to cover, a client's current needs, an ongoing line of immediate state government credit through either Treasury or FACS should be readily accessible to cover the gap.

Although we have changed names and non-medical details within the case studies above, we would request that specific diagnoses and Dan's full budget be kept confidential and not published. Omitting these details from our submission would have reduced its usefulness in explaining what's happening at Summer Hill, but full publication may be a risk to these people's right to confidentiality.

Mary Sweeten & Gary Dunne

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