Submission No 241

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

Organisation: Prospect Farm Accommodation

Date Received: 9 August 2018

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Submission by Prospect Farm Accommodation Pty Ltd to:

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

About Prospect Farm:
Prospect Farm Accommodation is a small business engaged in NDIS – funded support of people with disability. Established in 2010 by Dr Richard Brown and Dr Erin O'Neill as Prospect Farm Respite, Prospect Farm employs 30 staff throughout the Hunter region and offers Supported Independent Living and Access to the Community services.

The people we support variously live with intellectual disability, autism, acquired brain injury, cognitive impairment due to disease, and require support ranging from "Standard" level to "Complex" level as defined by the NDIS.

Our homes are based in the Hunter region and we support a hinterland model where most of our homes are on small, semi - rural acreages in quiet surroundings but less than 20 minutes from all facilities.

We provide the following submission to the inquiry. Our submission is based on our experience as a small provider.

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

Choice is an essential and legislated right of a person with disability. The NDIS at times limits the extent of and opportunity to make choices. Our experience has shown that the choice of where and how a participant chooses to live can at times be very restricted by NDIS processes as follows:

Turn around time for approval of Supported Independent Living Quotes:

When a participant moves homes it is sometimes due to issues at the current home such as incompatibility with housemates or staff, or a deep dissatisfaction with the current services provided. On the other hand participants who can no longer be supported by family members are also in sometimes urgent need of a new, safe and supported home. In our experience, and from their own stories, participants must have evidence of hardship, abuse, impending homelessness or other severe conditions before they are considered eligible for a fast transfer of their funding from one provider to another. This implies that in some instances a person's disability alone is not a sufficient prerequisite for SIL funding but both disability AND hardship, are required to activate the SIL process.

In my personal experience, I have dealt with NDIS call centre staff who have stated that a person cannot move homes "unless they have a really good reason." This is of course a misinformed response and denies participants true, unconditional choice; rather, as in the cases mentioned above, only when there is a "really good reason."

Increased Choice of Services:

The NDIS has provided opportunities for a dramatic increase in the number of providers for various services available for participants. This increase leads to increased choices for participants and, it is hoped, higher quality of service due to increased competition among providers. To date this does not appear to have occurred to any large extent but as the market is young, with time it is hoped that increased choices will stimulate increased quality of service.

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

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

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

As a private, for – profit company we have the opportunity to work in a large, vibrant sector doing meaningful work. From our point of view we see the introduction of private providers as an opportunity for diversity and choice of service for participants. Small, private organisations can react to needs far quicker than larger, board - driven not - for - profit or government agencies. This is the strength of the privatisation of the NDIS sector, namely that more choice is available, more rapidly in a wider range of settings.

There are some negative impacts on the privatisation move however. The first is the "many are called but few are chosen" phenomenon where there is a surge in provider numbers only to be followed by a drop in provider numbers due to multiple issues ranging from:

1. Prohibitive entry costs – verification, insurances, establishment of business costs.
2. Profiteering resulting in short lived organisations that offer poor or low standard support and fail due to financial or enforced closure.
3. Lack of managerial expertise. For example, support workers who open a day placement service only to find they are ill-equipped to run a small business and provide first rate care.
4. So-called "stillborn" businesses who are registered with the NDIS but never trade.
5. Poor staff quality due to increasing demand as well as training not keeping up with the standards required by the NDIA and the community in general.

(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,

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

Providers in New South Wales are subject to various controls and regulations. Among these are the offices of the New South Wales Ombudsman and the Office of the Community Visitor. Both these agencies provide essential and critical oversight, mediation and advice to all stakeholders.

The necessary and important responsibility of providers to answer queries is nonetheless a financial, personnel, and time cost. Our own experience and those of our other small provider colleagues suggests that some issues raised by these offices could be dealt with in an informal manner rather than in the more formal written response.

For instance we have over the past 12 months been asked to provide detailed information to the NSW Ombudsman's Office on the following issues:

1. An extensive explanation as to why a participant cooked cakes from fresh ingredients rather than from a packet. The investigating officer put to us that our reason for cooking from fresh products was because it was cheaper. Our explanation included the description of the multiple benefits to the participant such as improved eye - hand coordination, sense of achievement, practice in organisational skills, social interaction, and contribution to his own self - worth. We also pointed out that the cost for fresh ingredients was 500% higher than a packet cake bought from the supermarket, as well as being superior in nutrient value and variety. We further pointed out that the cost of labour due to the close supervision required was significantly higher due to the longer time needed.

2. An officer required us to provide extensive measurements and descriptions of a newly installed, fully - equipped kitchen because the officer believed that the kitchen was inadequate.

3. In a follow – up request from the Ombudsman's Office we had to contact the builder who installed the kitchen to find out the ***actual date*** the kitchen was installed and relate it back to the officer.

4. An officer required us to provide her with copies of current qualifications for each and every staff member because a complainant had stated that no employees were qualified. A list of all qualifications was produced for the investigator showing a very high rate of training and experience for staff. The time taken to assemble and verify this list – with copies of qualifications – was extensive and, in our view, meaningless.

Most small service providers are time - poor with regard to administrative duties and responsibilities. Many owners including us work as carers, shift stand - ins, financial managers, HR managers, trainers, compliance managers, and so on.

Each of the above issues could have been rapidly dealt with over the phone rather than requesting in writing the details required. Furthermore, such an informal discussion on smaller matters would also save the Ombudsman valuable time and resources.

We submit that regulatory bodies take a less formal approach at least in the first instance to any enquiries and establish whether or not further information should be produced on any issue. While we understand that this is a discretionary function of the Ombudsman's office we further submit that most enquiries should be in an interview or phone format in the first instance. This has not been our experience in the past but we are hopeful that at least more use of telephone interviews will reduce the need for hours of resources wasted on responses such as those illustrated above.

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

Recently we have had the opportunity to prepare and plan services to several high support participants. We have the support and encouragement of the NDIS as well as financial backing. We have land available for development of specific and innovative housing designs.

The project will be a significant boost to our services and will employ an additional 30 staff. The level of expertise of the required staff is at the high end.

Staffing, however, is a major and potentially fatal obstacle to the development and growth of this project. Currently we cannot source enough suitably able workers who have the appropriate understanding and skills to support people at the very high end of behavioural needs. We believe that a major factor in this shortage is the training programs currently available to potential carers.

Training Shortcomings:

Many people supported by the NDIS live with complex, chronic and interacting consequences of their disability. For instance a participant whom we support has autism, depression, diabetes and high cholesterol. The management and

understanding of the interaction of the multifaceted symptoms, medication regimes and treatment regimes is onerous even for the medical specialists who support him.

Yet, after he leaves the specialist's rooms, gets his prescriptions and heads home, it is support staff who have to make critical decisions about the participant's well being during day – to - day, even moment - to - moment support against the background of complex medical, cognitive and psychiatric factors.

The most commonly studied qualifications in disability support in Australia are the Certificate three (Cert 3) and Certificate four (Cert 4) in Disability. Currently there is little or no entry requirement for these courses beyond basic year 10 literacy and numeracy (See Attachment 1). It is our experience that many potential employees who arrive for interviews in possession of Cert 3 or 4 are deficient in these basic skills.

Therefore it comes as little surprise that even a basic understanding of the complex care needs of, for instance, the man cited above are beyond the kin of most carers.

A comparison of the study material offered for these qualifications by various training providers shows large discrepancies in:

Quantity & Quality:

For example, Attachment 3 shows a 23 word description of Down Syndrome. No more details can be located in the course describing Down Syndrome, its phenotypy, health effects, cognitive impact and psychological support needs.

On the other hand, Attachment 4 spends paragraphs on bone structure with descriptions such as, "The thin plates of periosteum - covered compact bone are on the outside with endostenum [sic] – covered spongy bone (dipoles) on the inside."

The relevance of detailed bone cytology to support work escapes us, as does the necessity of including 29 pages of medical terminology in the course (See Attachment 5).

Factual Accuracy:

Attachment 2 shows a page from a presentation for Cert 4 module, HLTAAP001 Recognise Healthy Body Systems. It contains two fundamental errors of basic immunology, namely that T Cells are produced in the Thymus - they are not, and that B Cells produce antigen - they do not. When facts are mixed, and at times wrong, a student with little or no knowledge beyond Year 10 literacy will be lost in the confusion.

Relevance:

Some aspects of the Cert 4 in Disability course are, for reasons beyond us, directed at Assistants in Nursing. The course provider has not altered the course material for carers who are typically working in group homes or day placement settings. Hence we have direct reference to nursing practice (See Attachment 6), and assumptions that the students will be working in Aged Care facilities (See Attachments 7, 8). While ageing may be seen as a time of life when people acquire disabilities, it is by no means the only focus that a course on disability care should have. Such a lack of attention to the needs of the student is disappointing at best and careless at worst and helps explain the unreadiness and inadequacy many students feel and demonstrate when they first enter the disability care sector.

Perhaps one of the most surprising aspects of the Cert 4 in Disability is the course's ***almost complete silence on descriptions of any kind of disability***.

Nowhere in any of the core modules can be found any module explaining in any detail the many types of disability. There are simply no detailed descriptions of, for instance, paraplegia, Down syndrome (a few lines only - see Attachment 3), Fragile X syndrome, traumatic brain injury; these are all disabilities that are among the most commonly supported disabilities in the care sector.

Lack of Training in Medications and their Actions:

Medications are a pervasive aspect of the lives of many people with disability. There is little or no information on the supervision of medication administration or about the actions of common drugs such as antiepileptics, antidepressants, and other commonly prescribed medications to people with disability. Any understanding of the relevant basic biology of medications and how they work will result in an improvement in carers' understanding and allow them at least to have a basic understanding of the conditions they are supporting.

This has to be better than "I dunno, I just give it to her at six o'clock."

A student can graduate with a Certificate 4 in Disability and know very little, if anything, about any of the common causes of physical disability, intellectual disability or mental illness (up to 60% of people with intellectual disability experience mental health conditions).

When training of workers misses the mark in a sector where some of the most complex care requirements are encountered by support staff, then it is little wonder that the quality of support in the sector is variable.

There is a pervasive and dismissive notion that support work is the "last resort" of a person looking for work. Indeed, we have heard our own employees say from time to time that they are working in the sector "until something better comes along". The introduction of the NDIS has created for the first time a career pathway for all workers in the sector. The certainty of funding and the diversity of service providers have the potential to make the sector a hub for both learning and career advancement. Currently the courses offered in the sector do not meet the increasingly sophisticated criteria and knowledge - base required for modern day support of people with disability. It is therefore incumbent upon the government to provide training that is both relevant and up to the minute, reflecting the latest advances in all aspects of support.

Suggestions for a new disability course for carers and support workers.

The 21st century is a time when we are witnessing dramatic advances in the treatment, diagnosis and understanding of many conditions that cause disability. These advances are research – driven and are seen in the biomedical and psychological fields. Consequently any course offering a qualification in disability support should emphasise relevant, basic biological and behavioural principles. These principles include:

1. A thorough understanding of the more common causes, presentations and life effects of disability.

2. A good understanding of medications and how they work.

3. Thorough understanding of the principles of learning, motivation and mental health.

4. Promotion of and training in critical thinking and problem – solving.

Point 4 above is, we believe, essential in the disability support sector. Faced with a person who has complex, sometimes multiple disabilities and inter – related support needs, problem – solving at a practical care level is an essential tool in the repertoire of the contemporary support worker.

Disability vs Medical Condition:

There is also a division between what the NDIS considers "disability" and what it considers "medical" conditions. For instance, the NDIS will fund supports for a person with severe intellectual disability but not his diabetes. This is of little help to the support worker who must supply the day – to day care of the person, settle their behaviour, read their blood glucose levels, prepare their diet and get them to their day support on time. Such a division is in reality a falsity, as the support worker must attend to ALL the needs of the individual, funded or not. To do otherwise would be unthinkable.

Therefore the necessity of a strong biological basis to training of support workers addresses what is a reality to many workers, namely that they attend to the care of the whole person and not just their "disability". This reality should be considered when designing the future support worker courses.

(h) challenges facing disability service providers and their sustainability,

Small size:

As a small provider we are mindful of our size and lack of access to resources that larger organisations possess. This places us at a disadvantage when competing with larger organisations for work. We cannot afford to have specialist staff on tap to write submissions, prepare meetings with agencies nor respond to enquiries, suggestions or complaints from families or agencies of government. Thus the owners typically wear many hats as is common in all small business sectors.

In this respect, small businesses in the disability sector have no incentives or encouragement. There is no disability – specific incentive such as the $20,000 instant tax write - off for a "tradie truck".

Mega Businesses:

One recent and worrying development is the appearance of "aggregator" companies on the disability horizon. These companies, like the ones that have subsumed small private dental and medical practices, are offering to buy out or buy into small disability providers and place their business under one banner. The result is a mega company producing franchise – like services with little variation and no local innovation or incentives.

We have been approached by one such company, based in China, to sell our business. This is a chilling development for the sector, especially in the small provider end of the market.

Time Lags for Approvals:

Approvals of plans and SIL quotes are wildly variable in time from submission to outcome. This is a very stressful situation for any organisation especially a small business such as ours. For instance, we have been waiting for approval for a participant to move into one of our houses since May. We have had to keep a room vacant as we committed to support him in accommodation provision. The empty room has not generated income during this time yet we still have to pay staff to support the other participants. At times we have also been waiting for months for plan renewals – in essence a simple roll over process. To carry costs in a small business is sometimes the difference between fluidity and insolvency.

The NDIS needs to focus on the rapid turn around of approvals and renewals as lengthy delays and interruptions to cash flow can mean the end of a small business.

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

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

(k) any other related matter.

Richard Brown PhD
Director
PROSPECT FARM ACCOMMODATION PTY LTD

Attachments

Attachment 1:

Course Outline

CHC43115 Certificate IV in Disability

Inspire Education (RTO #32067) will provide you first-class training and student support while you undertake your studies in the Nationally Recognised CHC43115 Certificate IV in Disability.

Training Delivery

The most effective and popular delivery method is via Self-Paced Online Learning. This Certificate IV in Disability online course is ideal if you want to study according to your own schedule and gain your qualification as fast as you can.

You will complete a Personal Learning Plan Evaluation as part of your enrolment. You will then be provided with a training plan that identifies your Cohort, taking into account your existing level of relevant knowledge and skills. The amount of training and support required for each learner will vary on these 4 Cohorts:

Beginner (Full Study Model) – Limited relevant knowledge or skill in the competence contained in this qualification. No recent related industry experience. Study hours is up to 1440 hours.

Intermediate (Partial Study Model) – Moderate relevant knowledge and skill in with limited recent related industry experience. Study hours is up to 1296 hours.

Advanced (Partial Recognition Pathway) – Extensive relevant knowledge and skill with recent related industry work experience of 1 year or more. Study hours is up to 1112 hours.

Expert (Assessment only) - Current industry experience of 2 or more years and extensive relevant knowledge and skill in. These candidates are recommended to undertake a full recognition pathway. Study hours is up to 718 hours.

Course Code:
CHC43115

Delivery Method:
Self-Paced Online Learning

Course Duration:
Up to 12 months

Expected Study Hours:
Up to 1440 hours depending on industry experience. (includes Vocational Placement)

Entry Requirements:
There are no prerequisites, however it is preferred that students:

- Are 18 years or older
- Have sound language and literacy skills (at least Year 10 English, or equivalent)
- Have basic computer skills
- Provide a valid ID with his/her picture and signature
- Undertake a Language, Literacy and Numeracy Evaluation
- Undertake a Personal Learning Plan Evaluation before accessing the course materials and commencing studies

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Attachment 2:

Lymphocytes:

T cells, B cells.

- T cells are produced in the thymus. T cells account for 70% - 80% of all lymphocytes.
- T cells attack antigens which are substances the body recognises as foreign.
- B cells are produced in the bone marrow . B cells account for 20% - 30%. B cells secrete antigens.

Attachment 3:

Some genetic disorders are caused by mistakes occurring during meiosis, where too much or too little DNA information is contributed to the cell. Down syndrome, for example, is a genetic disorder where individuals have an extra chromosome in each cell. This chromosome is called number 21.

Klinefelter Syndrome is another disease which is caused this way. Individuals with Klinefelter syndrome have a total of 47 chromosomes instead of the normal 46. In this syndrome, the individual is always male, and the extra chromosome results in sterility and slightly enlarged breasts. Inherited diseases (those passed from generation to generation) are caused by single genes. Huntington's disease, colour blindness and cystic fibrosis are all examples of inherited diseases.

Attachment 4:

Structure of long bone

Long bones consist of a diaphysis and an epiphysis.

Diaphysis: This is the tubular shaft that forms the axis of long bones. It is composed of compact bone that surrounds the medullary cavity. Yellow bone marrow is contained in the medullary cavity.

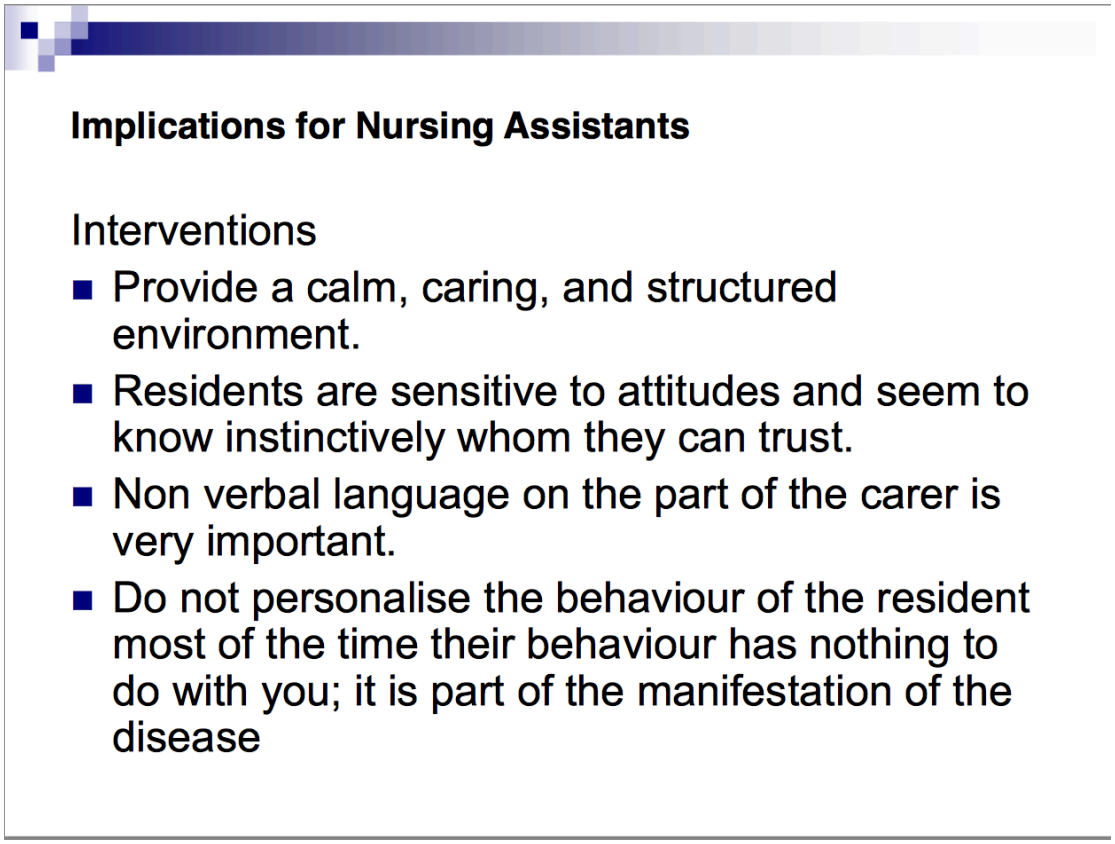
Epiphysis: This is the expanded end of a long bone. The exterior is compact bone and the interior is spongy bone. The joint surface is covered with hyaline (articular) bone. The epiphyseal line separates the diaphysis from the epiphysis in adults. It is a remnant of the epiphyseal plate (disc of hyaline cartilage) which grows during childhood to lengthen the bone.

Structure of short, irregular and flat bones: The thin plates of periosteum-covered compact bone are on the outside with endostenum-covered spongy bone (diploes) on the inside. They have no diaphysis or epiphysis and contain bone marrow between the trabeulae.

Attachment 5:

Course Contents

Attachment 6:



Attachment 7:

Outcomes: By the end of this session the student will be able to:

- Discuss the cardiovascular system
- Identify the normal changes that occur with ageing
- Explain the nurses role in the care of residents with cardiovascular disease

Attachment 8

Dementia

Dementia is an irreversible mental state characterised by decreased intellectual function personality change and impairment of judgement

- Dementia manifests in the following conditions:
- Alzheimer's Disease.
- Vascular problems.
- Parkinson's disease.
- Chronic alcoholism.
- Pick's disease.
- Huntington's Disease