IaNQ Independent Advocacy NQ

" To assist people with disability through independent advocacy."

4th February 2022

Qld Parliamentary Service
Parliament House
Cnr George and Alice Streets
Brisbane. Qld 4000

ATTENTION: Melissa Salisbury
Acting committee Secretary
Health and Environment committee
Melissa.salisbury@parliament.qld.gov.au

Dear Sir/Madam,

RE: Inquiry into the provision of primary, allied, and private health care, aged care and NDIS care services and its impact on the Queensland public health system.

Independent Advocacy in the Tropics Inc. ("IATI") including all registered Business Names, is a community organisation formed in 1989 then incorporated in 1991, to provide advocacy support for people with disability of all ages, genders, and cultural identities. *We provide a quality service accredited under the National Disability Advocacy Standards for both Individual and Systemic Advocacy.*

The Need for Advocacy

People with a disability are in particular need of advocacy because they often experience or are vulnerable to discrimination, neglect, exploitation and/or abuse. This is particularly so for the people with a disability who are confined to hospital as social patients due to not having sufficient NDIS funds to support them to live independently in the community and to live in appropriate accommodation. These issues are problematic to a discharge from hospital.

People with disability are just as valuable as any other human being regardless of what they do or don't do. They need the same things that all people need to live well in this world, their own place, sense of belonging, love and affection, safety. We are all connected within a community and in our world and people with disability must be fully included in this. People with disability should not be separated, segregated, or isolated. They should be able to make their own decisions, make mistakes, have courage, be fearful, be likeable, be unpleasant just as any other person. This is everyone's basic human right.

Please see below examples of issues experience in my role as an Advocate.

Issues Experienced:

People with a Disability, who enter our public hospitals are generally admitted as a result of falls, neglect from family/carers/support staff, and poor health which often is determined they can no longer live independently in their homes and need increased care to live in the community. Discharge is not free flowing as it would be for a person without a disability to leave the hospital and return to their home with informal supports, and a discharge plan. A person with a disability needs to ensure the following:

CARE:

- are there care providers, either informal or formal in the home?
- who is funding this care?
- is the funding sufficient to meet the needs of the person?
- is the funding specific to the disability or is there some health-related matters to be considered?
- Is there a decision maker for the person with a disability who will not agree to a discharge unless these criteria are met? This could be informal (family/friend) or formal (EPOA / Public guardian).

ACCOMMODATION:

- Will the person with a disability be able to return back to their home?
- Are there home modifications required?
- Is the home owned, rented or public housing?
- If the home is rented, will the owner agree to any modifications and fund these modifications

SERVICES:

- Does the person with a disability have services to care for them?
- Will these services/ supports need to be increased?
- Who will pay for these services?
- Are there allied health professionals needing to provide additional therapies?

Past experiences:

Client 1

Mr TB, a 55-year-old Indigenous man from a remote community was injured and suffered a traumatic ABI. TB was transferred to Regional Hospital for treatment where he stayed for over two years, firstly as an acute patient and then as a social patient. TB was stabilised and ready for discharge for over 12 months, but it was the constant delays finding suitable accommodation, having sufficient NDIS funding and suitable service providers to care for TB on discharge. The greatest blockage to discharge for TB was accessing adequate funds from the National Disability Insurance Agency. TB needed high level of care and required 24/7 care with added care of 2 persons for times of personal care, transfers, and community access. Finding the appropriate accommodation was also a blockage for discharge. TB required SDA accommodation and the application processes were long and difficult. TB could not be discharged to a residential aged care centre due to his young age, nor was this appropriate. Stakeholders were committed to ensuring this vulnerable, nonverbal, non-mobile man would have a quality of life with the appropriate supports with care and affection provided by a nursing agency funded by the NDIS. TB was now isolated from his community and family who live in a remote Indigenous community. TB's discharge should have been a faster transition, but delays between the NDIA and their requests for more reports and assessments saw extended delays unnecessarily.

Client 2

Mr EW is a 69-year-old man with mental health and intellectual impairments. Mr EW lived in social housing independently with NDIS funded supports. Mr EW had a fall and was admitted to hospital in April 2021. Mr EW was not able to be discharged from hospital as it was reported he was no longer safe in his Dept of Housing home. A larger man, Mr EW was not able to access his bathroom safely and if there were repeated falls, Qld Ambulance could not safely transport him out of the house. Mr EW could not return to his home. It was also identified that he now needed 24/7 supports with an additional support person for personal care and transfers. Mr EW needed disability accessible housing. The National Disability Insurance Agency were delaying in funding appropriate supports to have him return to community living and making claims his blockage to discharge were health issues not disability issues. EW had many assessments by public and private allied health professionals, but these reports were scrutinised and advised by the NDIA delegate, there was insufficient evidence for NDIA funding. NDIA were trying to offload EW to the health sector, but stakeholders fought for EW's rights to have his disability recognised as the primary reason he was a social patient in hospital.

When Mr EW was living in his Dept of Housing home, he was mobile and continent. He lost that ability to be independent with his mobility and continence during his long hospital admission. His physical and mental health also deteriorated. Nursing staff do not have the time to support people with a disability with high needs, this is a speciality area of training in the disability sector. In the hospital setting, it was easier to put a continence aid and allow him to soil himself, and to sit in a wheelchair without trying to keep him mobile. His overall health deteriorated. The discharge only occurred with intervention between a high delegate from the NDIA and the Advocate who was supporting EW at the time. NDIS funding was short term only, and now we are going through the process of trying to keep EW living in the community, as NDIA now state, EW is best placed in a Residential Aged Care Facility. As EW's Advocate I will be fighting to have him remain in the community, as he is happy, healthy, and building his capacity which is a NDIS catchphrase. NDIA do not want to fund a 69-year-old man with high needs disability, and again are tying to make this a health-related matter to have him live in a facility where there are insufficient staff to care for him and his high needs. We know through media reports the aged care facilities are currently not coping through this COVID pandemic, with staff shortages, but the NDIA are advising they are ceasing EW's funding at the end of February, so this is his next option. Stakeholders again are trying to advocate for him to remain in his current home where he is well and happy.

Client 3

Mr AB is a man diagnosed with cerebral palsy with intellectual impairment. He has poor mobility due to his left sided spastic hemiparesis. He has been a social patient for 2 years in a rural hospital. Mr AB was admitted to hospital after a fall in the home in November 2019 and remains there today, with no discharge date. This delayed discharge has had an effect on his mental health, and he now suffers depression and a reduced wellbeing. AB has had his family home modified by the National Disability Scheme ready for his discharge mid-2021, but currently we are no closer to a discharge as National Disability Insurance Scheme have challenged medical reports and functional assessment reports stating they do not believe he is requiring the level of care a medical professional has assessed him as needing.

So like many before him and many who will appear after AB, long term patients linger in a hospital bed, waiting for a discharge, whilst the NDIA continue to ignore recommendations from health professionals and dictate to the disability support services on how services are to be delivered, without ever meeting the person behind the NDIS participant number. The NDIA do not take into account the daily challenges the support staff face with behaviours, body weights and risks, but they deem a high needs disability person to require only one to one staffing when a lot of the times two to one staffing is required. Anything less is a risk to the person with a disability and to the support person trying to transfer, bath or mobilise.

People with Disability enter hospital when unwell but getting discharged on recovery is challenging. Getting a discharge generally requires a NDIA Change of circumstances, where more supports may be needed, or new equipment or a review of the current accommodation. This is where the issue starts and the delays for a discharge.

Having people with disability in a hospital for longer than required has a huge impact on them, their families, their support networks. Some of these impacts are:

- Staff in a hospital do not have the experience or time to care for a person with a disability generally, especially if this disability is a mental or intellectual impairment.

- Some people with an intellectual impairment are on behaviour support plans where specific strategies are required to deescalate, redirect, or use other strategies when their behaviours are heightened.

- The person with a disability become institutionalised in a hospital setting, where they are so dependent on the routines, staff, and ward cultures, they struggle to transition to a life living in the community.

- The person with a disability may lose some of their daily functions – continence, mobility, communication skills, regressing them several years, and possibly never regaining those daily functions/skills.

- The person with a disability often does not leave the inside of the hospital if no informal supports are in their life. Some people with a disability have supports which can take them onto the grounds of the hospital and some may be fortunate to have leave for a few hours to attend workshops in the community or return to their home if it is safe to do so.

- When a person with a disability is a long-term inpatient, their support staff lose their rostered hours, which results in lost income for the support staff.

Discharges could and should be an easier transition with a faster turn around if the National Disability Insurance Agency have a refocus on long stay hospital patients and have a team, not a Health Liaison Officer (HLO) as they have currently, but a team to make decisions. Currently the current processes of seeking new reports and assessments, more reports, and assessments and then escalations to a higher delegate within NDIA are frustrating and time delaying. Often the NDIA are trying to avoid responsibility in funding by saying the patient has health issues, and it is not disability. So often the health issues are disability related.

Often when the NDIA do not accept responsibility for funding these very vulnerable people, the option is to take the matter to the Administrative Appeals Tribunal to appeal the decision where funding is reduced or not provided. The NDIA have Lawyers and Barristers to defend their decisions, where the person with the disability relies on informal supports or Advocates, who are not legally trained. Rarely does a person with a Disability have access to a Lawyer to fight for their rights to have the funding assessed by a medical professional as reasonable and necessary. This legal expense paid by the NDIA, could have funded some additional supports or some equipment, or allowed an early discharge from hospital for a person with a disability.

Information released under FOI by The Guardian December 2021 reported-

“The NDIA paid about $17.3m in the last financial year to law firms to fight challenges from NDIS participants at the Administrative Appeals Tribunal. This spending rose 30% last financial year.”

The report also states, “community legal services are at capacity and are struggling to take on new clients”.

The report also states “The new figures come a day after the Morrison government pointed to a $26b increase in costs for the NDIS over the next four years”

The Guardian also reports “the increased controversy over the scheme amid growing reports of deep cuts to individual packages, while The Guardian Australia revealed that NDIS appeals to the AAT (Administrative Appeals Tribunal) have tripled since July”.

Information by the World health Organisation, November 2021 reports-

- Over 1 billion people live with some form of disability.
- The number of people with disability are dramatically increasing. This is due to demographic trends and increases in chronic health conditions, among other causes.
- Almost everyone is likely to experience some form of disability – temporary or permanent – at some point in life.
- People with disability are disproportionately affected during the COVID-19 pandemic.
- **When people with disability access health care, they often experience stigma and discrimination, and receive poor quality services.**
- **There is an urgent need to scale up disability inclusion in all levels of the health system, particularly primary health care**.

Disability inclusion is critical to achieving universal health coverage without financial hardship, because persons with disabilities are:

- three times more likely to be denied health care
- four times more likely to be treated badly in the health care system
- 50% more likely to suffer catastrophic health expenditure.

Barriers to healthcare

People with disability encounter a range of barriers when they attempt to access health care including:

Attitudinal barriers

- People with disability commonly report experiences of prejudice, stigma and discrimination by health service providers and other staff at health facilities.
- Many service providers have limited knowledge and understanding of the rights of people with disability and their health needs and have inadequate training and professional development about disability.
- Many health services do not have policies in place to accommodate the needs of people with disability. Such policies could include allowing longer and flexible appointment times, providing outreach services and reducing costs for people with disability.

- Women with disability face particular barriers to sexual and reproductive health services and information. Health workers often make the inaccurate assumption that women with disability are asexual or are unfit to be mothers.
- **People with disability are rarely asked for their opinion or involved in decision-making about the provision of health services to people with disability.**

Physical barriers

- Health services and activities are often located far away from where most people live or in an area not serviced by accessible transport options.
- Stairs at the entrance to buildings or services and activities located on floors which do not elevator access are inaccessible.
- Inaccessible toilets, passages, doorways, and rooms that do not accommodate wheelchair users, or are difficult to navigate for people with mobility impairments, are common.
- Fixed-height furniture, including examination beds and chairs, can be difficult for people with disability to use.
- Health facilities and other venues for activities are often poorly lit, do not have clear signage, or are laid out in a confusing way that makes it hard for people to find their way around.

Communication barriers

- A key barrier to health services for people who have a hearing impairment is the limited availability of written material or sign language interpreters at health services.
- Health information or prescriptions may not be provided in accessible formats, including Braille or large print, which presents a barrier for people with vision impairment.
- Health information may be presented in complicated ways or use a lot of jargon. Making health information available in easy-to-follow formats – including plain language and pictures or other visual cues – can make it easier for people with cognitive impairments to follow.

Financial barriers

- Over half of all people with disability in low-income countries cannot afford proper health care.
- Many people with disability also report being unable to afford the costs associated with travelling to a health service and paying for medicine, let alone the cost of paying to see a health service provider.

My submission was written after receiving notification from Aaron Harper MP Thuringowa where he wrote_ *As Chair of the Queensland Parliament Health and Environment Committee, I would like to advise you of the current Inquiry into the provision of primary, allied, and private health care, aged care and NDIS care services and its impact on the Queensland public health system.*

This submission is focused on the Public Health System and the National Disability Insurance Scheme issues. As primary providers of health and disability, the two need to have a working group focused on 'the person' and their rights - their basic human right to be treated as a human being, and not a commodity with a financial burden attached to them.

There are 3 basic rights of all humans?

Everyone has **the right to life, liberty and security of person**. Examples which need to be heeded

- The right to life.
- The right to liberty and freedom.
- The right to the pursuit of happiness.
- The right to live your life free of discrimination.
- The right to control what happens to your own body and to make medical decisions for yourself.

I am seeking change in this particular area where a vulnerable person in a hospital setting is denied a timely discharge back to the community and to their families, friends, and networks. I trust this submission is referred to, with other submissions from this hearing as we progress forward to effect change in the Queensland Public Hospital system.

Warmest Regards

A. Hansen

Anne Hansen
Advocate
Independent Advocacy NQ