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

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'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.

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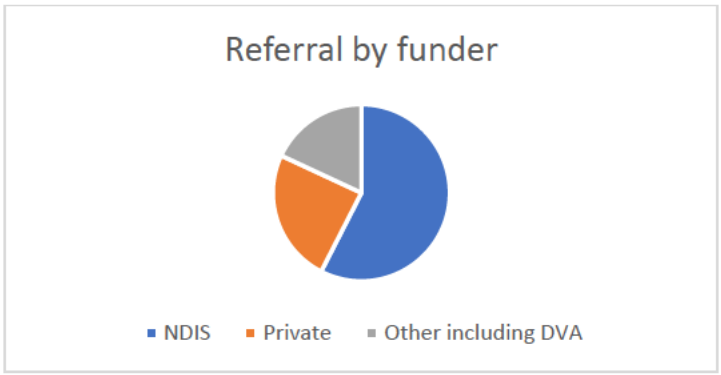
Background

My name is Sandra Ilett. I am a Registered Nurse and Nurse Continence Specialist. I have worked in this field for the past 25 years both in the community and in a hospital setting. In 2018, I started working as an independent Sole Provider. This led to establishment of a company structure in 2019 to enable the employment of other nurses due to an overwhelming workload. Community Nurse Service PTY LTD (CNS) is an independent nurse-led organisation providing Specialist Continence Care in the community. Clients of the service are of any age.

CNS is a Registered NDIS Provider and with Department of Veteran's Affairs. Many brokerage arrangements with other Service Providers are in place. The remainder of clients accessing the service are privately paying clients. Currently there are four nurses working in casual employment in different locations in Queensland which is now up to two full time equivalent positions since July 2021. Current service areas are Bundaberg, Childers and surrounding areas, Hervey, and Maryborough and more recently two suburbs in Brisbane. All work for the nurses is referral-based. The nurses work from their home office and visits are conducted in the client's home or at another location negotiated with the client. No Government funding has been provided for establishing this service or to cover core costs. The nurses can only be employed on a casual basis due to the referral- based arrangement which means if there are no referrals, there is no work.

Since the inception of the service in July 2018, firstly for myself as a Sole Provider and then after transition into a company structure, a total of 1222 referrals have been received for continence assessment and/or catheter care. This has only been in the locations where the nurses work from their home offices. Essentially this means that one full time equivalent nurse received approximately 1000 new referrals in three years. Of these, 25% were unfunded and consequently paid privately for the care provision. Data has not been collected for the enquiries received that do not result in a referral. Many enquiries are taken each week. It is a common comment that the cost of paying privately is unachievable and the enquiry does not convert to a referral.

The following chart further identifies the referrals by funder:



Role of the Clinical Nurses and Nurse Continence Specialists employed by CNS.

The role of the nurses employed by CNS is varied as it includes visiting clients of all ages across the lifespan and includes referrals for bladder and bowel problems. Each nurse must have a very good knowledge of continence management. All nurses work within the scope of practice of a Registered Nurse and operate in a collaborative manner with any other Health Care Professionals involved in the client's care.

The role includes the following tasks:

- Comprehensive nursing assessment of bladder and bowel continence problems
- Development of care plans including conservative management strategies of bladder and bowel problems
- Education of the client & /or carers
- Resources management including effective use of products
- Reports to meet funder and legislative requirements regarding continence care
- Applications to government schemes for access to continence consumable financial assistance with Continence Aids Payments Scheme (CAPS), Medical Aids Subsidy Scheme (MASS), and Rehabilitation Appliances Programs (RAP).
- Clinical Care including catheter changes and trial of voids in the home setting
- Health Professional Education
- Collaboration with other health professionals
- Education of unskilled care workers
- Referral (informal and formal) for other health care
- Community education

Assessment of incontinence includes the following components:

- Identifying contributing factors (Development/Damage/Disease/Decline/Drugs)
- Type of incontinence
- Identification of red flags that require immediate medical review
- Identification of reversible causes of incontinence
- Physical effects of incontinence
- Psychological effects of incontinence
- Effects on activities of daily living
- Financial effects
- Clinical observation &/or examination
- Data collection with bladder and/or bowel diaries
- Verification of health history

Role with NDIS clients

NDIS clients are referred for assessment mostly to establish the cost of Capacity Building activities to improve their access to the community with their continence issues and to establish the cost of continence consumables. NDIS participants are generally funded adequately for a continence assessment.

Incontinence Data

The following excerpt is copied from the Continence Foundation of Australia website (www.continence.org.au) and shows the prevalence of bladder and bowel problems across the lifespan. The summary of the statistics results in a figure of one in five Australians suffering a bladder of bowel problem.

Urinary incontinence

Urinary incontinence affects up to 13% of Australian men and up to 37% of Australian women (Australian Institute of Health and Welfare report, 2006).

65% of women and 30% of men sitting in a GP waiting room report some type of urinary incontinence, yet only 31% of these people report having sought help from a health professional (Byles & Chiarelli, 2003: Help seeking for urinary incontinence: a survey of those attending GP waiting rooms, *Australian and New Zealand Continence Journal*).

The prevalence of urge incontinence, which is strongly associated with prostate disease, is fairly low in younger males and increases to 30% for those aged 70-84 and 50% for those 85 years and over (Australian Institute of Health and Welfare report, 2006).

Faecal incontinence

Faecal incontinence affects up to 20% of Australian men and up to 12.9% of Australian women (Australian Institute of Health and Welfare report, 2006).

Elderly

Faecal incontinence is one of the three major causes (along with decreased mobility and dementia) for admittance to a residential aged care facility (Pearson J. 2003: Incidence of incontinence as a factor in admission to aged care homes, *Australia Government DoHA*).

Bladder and bowel issues can be a large financial burden. According to the Delloite Access Report, The Economic Impact of Incontinence in Australia (2011), the total financial cost of incontinence is estimated at $9,014 per person suffering the problem. This report takes into account health system costs, estimated productivity losses, estimated residential aged care costs, estimated informal carer costs, indirect costs (aids, formal carer expenses) and estimated deadweight losses from transfers and lost taxation. This data is now ten years old.

Bladder and bowel problems affect a wide range of members of our community. The issue crosses all health sectors. Paediatrics, aged care, community health, disabilities, general surgery, obstetrics, gynaecology, colorectal, urology, oncology and palliative care are some examples. This results in funding for continence assistance to clients suffering bladder or bowel issues the responsibility of no specific health funder. Compounding this lack of specific funder is that incontinence is a symptom of an underlying problem. It is not considered as a 'disease' which also affects the provision of funding. The result of this is that many people struggle to find help and assistance by a suitably experienced and trained health professional. It is known that the burden of caring for someone who is incontinent contributes significantly to carer stress and burnout and one of the greatest contributing factors for admission into a Residential Aged Care Facility (RACF). Often that admission is preceded by a stay in hospital before a permanent place is available.

Catheter management and issues

One aspect of the problem in accessing care is with urinary catheter management, either urethral or suprapubic. As I do not have access to data on the number of people discharged from hospital with an indwelling catheter or the numbers of people transferred from a RACF to an emergency department for urinary catheter related issues, then only assumptions can be made with anecdotal knowledge on the situation.

Urinary catheters are known to cause morbidity in persons who are catheterised long term. Rarely is urinary catheterisation trouble free. The health professional changing the catheter must be skilled and competent in the procedure and if they are not, should undergo education and supervision. RACF's are in general known to have a high turnover of registered nursing staff and management. Education and supervision until competent in changing a urinary or suprapubic catheter is a lengthy process and the staff may not stay employed in one location long enough for this to happen. Some RACF's have a policy where they will not allow their employed nurses to change urinary or suprapubic catheters.

General Practitioners (GP) rarely perform a catheterisation as part of a visit to a RACF or at an appointment within their surgery. The procedure is considered to be a nursing responsibility and part of long-term care in a RACF. The procedure is funded through Commonwealth funding to the facility. In the community dwelling population, it is generally accepted that the client will be able to access a Commonwealth Home Support Program (CHSP) funded nursing provider to carry out catheter changes.

I am led to believe that at the present time in Queensland, there are many CHSP funded community nursing providers are unable to take new referrals because they do not have any CHSP nursing funding available. The CHSP funded nursing providers are also known to have a high turnover of Registered Nurses creating the same issues as the RACF's with catheter changes and management.

Therefore, if a client cannot access this care by a Commonwealth funded nursing provider, or at their GP, then the only option is to present to an emergency department for a catheter change. CNS already provides many catheter changes for privately paying clients. If a client cannot afford to pay privately, this option is also unavailable, once again pushing them back to their closest emergency department. The clients that we currently visit on a regular basis to provide catheter changes, support and assistance rarely visit an Emergency Department for catheter related issues.

Long term urinary catheter management can be a troublesome part of nursing care when the Registered Nurses involved have inadequate skills and knowledge or the client who is catheterised has inadequate knowledge on how to care for or troubleshoot issues with the catheter. The back stop for help with catheter management is the local Emergency Department irrespective of if the client is living in a RACF or is community dwelling.

Continence Assessment for access to schemes

Another aspect of continence care is continence assessment and care planning specifically for assistance to access the Government schemes of CAPS and MASS. People who have a permanent and stable continence issue may be eligible for assistance with either or both schemes. A continence assessment can be a lengthy process with inclusions listed on page 2. This process of assessment may take more than one appointment and on average would take four hours of nursing time. Few Registered Nurses have knowledge and skills specific to continence assessment. There is no Medicare item number that covers this assessment by a Practice Nurse in a GP surgery. A GP is excluded from completing an application to MASS. The current deficit in CHSP funding also excludes some people from this avenue of help.

Funding for continence care

There is a sector of the community dwelling aged population that only access services through My Aged Care (MAC) specifically for a continence problem or to have their MASS or CAPS paperwork completed. Accessing MAC includes multiple layers of assessments where at each assessment, they are required to disclose their continence problem. Once they get to the final assessment, the Registered Nurse must have the correct level of skills and knowledge to conduct a thorough continence assessment. It is reported to me that this is not the case in some instances when clients phone with a self-referral to CNS after they have already completed this assessment trail and did not get the help they were trying to access.

Historically, in Queensland, funding was provided for continence services. These services have been closed as the funding was withdrawn. CHSP funding for Specialist Continence Services is difficult to obtain as an organisation with only cyclical funding rounds being offered once every three years. The withdrawal of funded continence services that began more than a decade ago has also meant that the post graduate education for Registered Nurses in this specialty has also disappeared and at present, there is only one course offered by a University in Australia compared to a selection of courses being available ten years ago.

This seems incomprehensible based on knowledge that we have an ageing population with more extensive health co-morbidities and a consequent higher prevalence of bladder and bowel problems than we did a decade ago. Bladder and bowel issues are usually not readily discussed or disclosed by the sufferer due to the emotions elicited by the problem including embarrassment, guilt, and shame. Carers can also feel a multitude of emotions and the constant workload of incontinence is a large burden.

There can be considerable negative effects on self- esteem, social interaction, intimate relationships, and finances. Accessing help for a continence issue necessitates disclosure of the problem and once disclosed, help should be readily accessible, not hidden behind multiple layers of assessments or just totally unavailable. An option for continence assessment and catheter management would be funding of a service to provide this Specialist Nursing Care. Ideally this should be provided within the Primary Health Care principles of equity and access.

My opinion is that funding this type of service would help to reduce the burden on Queensland Health facilities by reducing the presentations at Emergency Departments for catheter care. This type of service would also be able to provide accessible and timely support for sufferers of incontinence and their carers before the burden becomes unbearable resulting in an unplanned admission to a Queensland Health facility. Access to telephone support for troubleshooting in catheter care could also be offered to Registered Nurses in all settings and to clients with an indwelling catheter. This telephone support could also prevent some presentations to an emergency department. My CNS example shows that the service is needed or there would not have been the volume of referrals that have been received in the past 3.5 years.

I understand there are funded services for RACF residents who have acute medical needs and for palliative care. I am aware that this does not necessarily include urinary or supra-pubic catheter changes. I have no desire to de-skill nurses working in RACF's who are confident with catheter changes. This would be a service for clients or facilities who are identified as 'frequent flyers' to emergency departments for catheter changes.

As the Director of an unfunded nurse-led service, I have encountered many barriers to providing this Specialist Nursing Care in the past three years. As nurses, we do not receive any funding through the Medicare Benefits Schedule and are not able to access the support of the Primary Health Networks. There are only three Private Health Funds that I have identified in the past three years that will provide a rebate to a client for a community nursing visit that includes continence assessment or catheter care. This is only with extras cover at the top level. Many people believe that they should not have to pay for services provided by a nurse. This concept is very difficult for some of the older population to comprehend and consequently many pro bono services have been provided by CNS in the past three years because people just cannot pay or simply choose not to pay, even though the care has been provided.

All business expenses for CNS have been met from revenue generated from individual billing. There has been no access to any health care service funding despite the care we provide being so crucial to each sufferer's dignity. As a Registered Nurse and part of the 'caring' profession, it has been enormously difficult to maintain a business model and charge for services at the true cost of the care. I am aware of the funding 'borders' between State and Commonwealth Health funding but at present there are large numbers of clients who cannot access any funding for this type of health care at all, regardless of whether it should be State, or Commonwealth funded.

My drive to continue working in this specialty is the knowledge that the care by a Nurse Continence Specialist does make a significant difference in the lives of the clients that we care for. This drive is fuelled by the constant flow of referrals that come from every sector of healthcare and in the community. My concern has always been the difficulties providing care to clients who have no options for funding as I feel that they are treated unfairly. These clients did not choose to have a bladder or bowel problem and being unable to access help for their issue makes the problems they are suffering significantly worse.

I would be pleased to be involved in further discussions related to my submission.

Please accept my submission to the '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.

Sincerely,

Sandra Ilett

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