continence NZ

CONTINENCE NZ
SERVICE USERS

Service Review and Research Project

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2023

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Contents

Glossary

Abbreviation	Stands for
CBA	Cost-benefit analysis
CNS	Continence Nurse Specialist
CRM	Client Relationship Management system
DHB	District Health Board (dis-established in 2022)
DN	District Nurse
GP	General Practitioner
HDEC	Health and Disability Ethics Committee
MOH	Ministry of Health
PHP	Pelvic Health Physiotherapist
RHP	Registered Health Professional
RTA	Reflective Thematic Analysis

Executive Summary

This research was commissioned to deliver a review of the services provided by Continence NZ and make recommendations as to how the organisation can most effectively serve those living with incontinence. To inform these recommendations, the research sought to understand the current situation of continence care in Aotearoa, New Zealand, the experiences of those accessing Continence NZ's services and the experiences of those seeking care for continence concerns.

Continence NZ contracted Sapere to research the current state of continence care, which is documented in the report 'Continence practice in New Zealand' (Dourst et al., 2023). The experiences of those seeking care for continence concerns have been documented in the report 'The lived experience of access to continence care in Aotearoa, New Zealand: A community perspective.' (Williams & Fear, 2023). The results of the feedback on Continence NZ's services are included in Appendices 1 - 4 of this document.

The research observed that:

- The exact prevalence of incontinence is not well understood in Aotearoa, with the last estimate being 25% prevalence in 2017 (Esplin et al., 2017). However, due to the increasing age of New Zealand's population, this is likely to have increased during this time (New Zealand Continence Association & New Zealand Carers Alliance, 2009).
- An investment of $6.4 million per year in Pelvic Health Physiotherapists (PHPs) and Continence Nurse Specialists (CNSs) or District Nurses (DNs), would result in an $8.9 million saving in the cost of products. This does not include any savings in the environmental cost of disposing of products, which is currently estimated at $14.9 million per year (2022).
- Service provision and wait times across the country vary significantly. Literature highlights the importance of health provider education and collaboration to improve patient care, moving away from cleaning and containing incontinence, to place more focus on education and treatment (Ostaszkiewicz et al., 2018; Taylor & Cahill, 2018).
- The significant impact that incontinence has on a person's life was a key theme in the focus groups, including the financial impact, the impact on relationships with whānau, intimate partners and employers, and an association with shame and embarrassment.
- While health professionals noted that attitudes are changing and people are becoming more comfortable asking for treatment, it is still a culturally sensitive subject for Māori and Pasifika and older people.
- People found they had difficulty navigating the system when seeking care for incontinence and often felt they were not heard by those they went to for help. Participants discussed the importance of knowledge, both their own and the clinician's, in their ability to access care.
- Feedback on Continence NZ's services was highly positive. However, it was noted that the services are currently underutilised by Māori and Pasifika. There are opportunities to improve the delivery of Continence NZ's services. In particular, utilising webinars in community education delivery, reshaping the helpline in response to feedback from focus groups around difficulties with navigating the system and health literacy, and increasing the awareness of incontinence and when to seek help.

Executive Summary (cont.)

The report recommends:

- Further investment in nationwide Continence Services to provide an estimated net saving of $2.5m per year through the reduction of product use, as well as a reduction in environmental impact and a significant improvement in the quality of life for those living with incontinence.
- The unification of services across the country would allow for more equitable access to continence care across the country, as well as standardisation of services delivered.
- Increased focus on treatment rather than containment, and collaboration of health professionals across disciplines, as well as further education of health professionals to improve patient outcomes.
- Increased awareness of existing services provided by Continence NZ would address much of the feedback received from focus group participants.
- Further, a review and revitalisation of Continence NZ's helpline, community education delivery, website, resources and membership offering would aid in raising awareness about Continence NZ and incontinence.
- Identified opportunities for Continence NZ to support those experiencing continence concerns to reduce isolation through peer support groups and networks.
- The development of partnerships between Continence NZ and Māori and Pasifika health providers to ensure these communities are well supported.
- Areas for further research were identified, including understanding the prevalence of incontinence and the experiences and needs of Māori, Pasifika and Asian communities.

Background

Continence NZ was established to provide a service to people with continence concerns, caregivers, health professionals and the general public by providing information and continence education. Continence NZ has developed a service in an area that has largely been ignored in the past by health professionals and health providers.

Our organisation has provided information, education and support to thousands of New Zealanders with incontinence. The demand for our services is increasing year on year, and with limited resources and funding, we must ensure we are providing a valuable quality service to this community which meets their needs and delivers better outcomes for them.

An independent and internal valuation of our service will help determine where there may be areas for improvement within our current offerings, and provides us with information on gaps and new opportunities. This will help make a difference and improvements in the lives of people in Aotearoa, New Zealand dealing with continence concerns.

This will be the first independent evaluation our organisation has undertaken since we were established.

Purpose and Process

Research purpose

The purpose of this research is to deliver a review of the services provided by Continence NZ and make recommendations as to how the organisation can most effectively serve those living with incontinence. Priority is given to understanding how Continence NZ can improve the service delivered to Māori, Pasifika and Asian communities.

Stakeholder groups

The research focused on three major stakeholder groups:

- Those working in continence care
- Those already engaged with Continence NZ
- The wider community of people living with continence concerns

Aims and objectives

The aim of this research is to provide a review of the effectiveness and efficiency of services provided by Continence NZ, and make recommendations to inform future strategic and operational planning.

To achieve this the service evaluation will provide us with:

1. Recommendations to improve the efficiency and effectiveness of our existing service delivery.
2. Recommendations to improve the suitability of our service delivery to Māori, Pasifika and Asian communities.
3. Identification of opportunities for Continence NZ to expand our work in education to both health professionals and the public.
4. Identification of opportunities where Continence NZ could work collaboratively with Te Whatu Ora to support high-quality service delivery to those living with incontinence.
5. Effective advocacy approaches and/or policy positions that would improve the lives of those living with incontinence.
6. Identification of opportunities to work collaboratively with health professionals in both public and private sectors in the future.

These recommendations should be based on:

- Increased knowledge and understanding of the resources Te Whatu Ora currently has to support the incontinence community and how these are allocated and reviewed.
- Increased knowledge and understanding of the continence nursing resource and allocations within the private health sector and how these are reviewed.

Aims and objectives (cont.)

- Increased knowledge, information and greater understanding of the changing needs of people experiencing incontinence and those who serve it.
- Identifying gaps in servicing the incontinence community and areas where Continence NZ could provide additional support, focusing on Māori and Pasifika communities.
- An analysis of the existing services provided by Continence NZ, their effectiveness and efficiency, in particular, in reaching Māori, Pasifika and Asian communities.

Ethics

To maintain an ethical approach to this project, as there was the potential for engagement with healthcare consumers (as they may have utilised the services of Continence NZ), the Health and Disability Ethics Committee (HDEC) was consulted. As a result of this consultation, an exemption letter was issued as the research did not meet the threshold for further review by HDEC.

Research approach

Each major stakeholder group that participated in this research was engaged with a different approach. Data was gathered via surveys, focus groups and semi-structured interviews.

1.Those working in continence care

The independent research agency Sapere was engaged to complete a cost-benefit analysis (CBA), literature review and a survey and analysis of services provided by Te Whatu Ora staff.

The literature review focused on best practice in continence care and a CBA. This report, 'Continence practice in New Zealand' (Doust et al., 2023) uses the report, 'Good Practice of Continence Services in New Zealand' (Esplin et al., 2017) as a benchmark and updates key components of this report.

The report looks at the current provision of continence services in Aotearoa, New Zealand through a rapid literature scan and a survey of 20 continence providers and conducts a CBA focusing on investment in community-based management for incontinence.

2.Those already engaged with Continence NZ

Those already engaged with Continence NZ were grouped into three distinct groups:
- Helpline Users
- Continence NZ Members
- Those subscribed to our newsletter or engaged via Facebook

Continence NZ first completed a review of the data that we already hold about our services:
- 12 months of call notes from helpline callers
- Our processes around community education delivery
- 12 months of feedback forms from those who had participated in community education

Surveys were developed for each of these groups, focusing on:
- The demographics of the respondent group
- What services they had accessed
- If those services were useful
- Any suggestions to improve services

3. The wider community of people living with continence concerns

In order to examine the experiences of those in the wider community living with continence concerns, we engaged an independent researcher to facilitate focus groups.

We held a total of five focus groups with 28 participants. Each focus group was held in a different location around Aotearoa and had a different sub-focus. See table 1 over the page:

Some insights shared from the focus groups led to a change in approach for the Māori community, and semi-structured interviews were held rather than a focus group.

Research approach (cont.)

Table 1: Focus group locations and sub-focus

Group location	Sub-focus
Hawke's Bay	Experiences of the disability community
South Auckland	Experiences of the Pasifika community
Christchurch	Experiences of older people
Whanganui	Experiences of families
New Plymouth	Experiences of men

Participant demographics

A total of 28 people participated in focus groups or semi-structured interviews. There were 6 males and 22 females. Half of the participants identified as European, 21% identified as Māori, 7.1% as Pasifika, 3.6% as Samoan/Māori, 3.6% as European/Māori and 14.3% as New Zealanders. The age range of participants was 25 years to 84 years. 82% of participants had tertiary-level education. Two-thirds (68%) of participants cared for a person with a continence concern and 96.4% experienced leakage of urine or faeces themselves.

Focus group facilitation

The focus group discussion focused on the following semi-structured questions:

1. *Tell us about your experiences, both positive and negative, with continence care in New Zealand.*
2. *What support would you or your whānau, client or patient need for continence care? How would that support best be delivered?*
3. *If we could do one thing to make continence care different, how could Continence NZ best meet the needs of the group? What would be your ideal outcome from this discussion today?*

Data analysis

Anonymised transcripts from the focus groups and interviews were analysed using Reflective Thematic Analysis to identify the themes in the data, using both an inductive and deductive approach.

Research Findings

1.Those working in continence care

Sapere's Report on 'Continence Practice in New Zealand' (Doust et al., 2023) offered the following findings:

Prevalence

In 2017 it was estimated that 25% of all New Zealanders experience incontinence (Esplin et al., 2017). It is known that the prevalence of incontinence increases with age, therefore due to New Zealand's ageing population, the overall prevalence of incontinence is likely to have increased in the past six years.
Further research is required to determine the exact prevalence of incontinence in New Zealand.

Service provision around New Zealand

The majority of survey respondents consider their services to provide excellent assessment and management services, as well as great support and education for patients. However, staff acknowledge that patients are at times waiting longer than recommended by the Ministry of Health (MOH) service specification (Ministry of Health, 2012) and called for more dedicated staff and increased education for health professionals and the public.

A significant number of services have wait times longer than recommended in the services specification, and this increases with patient risk:

- 94% of respondents indicated high-risk referrals are seen outside of the recommendation in the service specification (24 hours).
- 53% of respondents indicated medium-risk referrals are seen outside of the recommendations in the service specification (2 weeks).
- 35% of respondents indicated low-risk referrals are seen outside of the recommendations in the service specification (8 weeks).

Research Findings (cont.)

Trends and changing attitudes

Respondents noted an increase in the presentation of specific conditions that align to an ageing population such as dementia-related incontinence. Furthermore, there is an increased presentation of children with developmental delays or additional needs.

Respondents observed changing attitudes as people become more aware and comfortable about talking about their situation with a health provider. This was prevalent in women who are becoming less tolerant of incontinence postnatally. However, respondents noted some limitations regarding cultural considerations which can make this a difficult subject to discuss.

Additionally, attitudes among GPs suggest that incontinence is viewed as an accepted part of ageing. Those seeking support for continence concerns are further limited by the shortage of GPs, meaning people are not able to see the same doctor consistently and making it harder to discuss incontinence when it is not taken seriously.

Literature on best practice

Literature highlights that health provider education and collaboration improve patient care (Ostaszkiewicz et al., 2018; Taylor & Cahill, 2018). It demonstrates the need for patient-centred care, moving away from a focus on cleaning and containing and towards a focus on educating patients and becoming more responsive to individual patient needs (Ostaszkiewicz et al., 2018; Taylor & Cahill, 2018). Literature shows the cost-effectiveness of early non-invasive interventions such as those offered by PHPs, and CNSs for specific high-risk groups such as pregnant women (Woodley et al., 2020, Brennen et al., 2021).

Environmental impact

The total estimated annual cost to the environment of adult nappies is $14.9 million (2022). This comprises just over $12.0 million for the cost of landfill and just over $1.9 million for the cost of CO2 equivalence.

Cost-benefit analysis

An estimated investment of $6.4 million per year for an additional 38 CNSs, DNs and PHPs would result in $8.9 million saved on incontinence products, resulting in cost savings or net benefits of $2.5 million. The CBA relates only to the estimated costs of products, it does not cover other cost reductions:

- The environmental impact of disposing of continence products.
- Quality of life improvements of the extra patients who have reduced or resolved incontinence.
- The savings of costs of care due to falls or other medical issues (e.g. skin infections) due to incontinence.
- The savings from keeping someone in home-based care for longer, as incontinence is a major cause of early rest-home admissions (Schluter et al., 2017).

2.Those already engaged with Continence NZ in some way

Helpline callers

- NZ European callers make up the majority of callers (76%); Māori (11%), Pasifika (4%) and Asian (7) callers are under-represented compared to the New Zealand population.
- Female callers make up the majority (56%) of callers.
- Callers from the Auckland DHB region are significantly overrepresented, as 21% of callers compared to 9% of the population.
- Te Waipounamu is underrepresented with 17% of callers compared to 23% of the population.
- Callers contacted us for a wide variety of reasons. The three main reasons people call the helpline are urinary incontinence (14%), product advice (12%) and constipation (11%).
- Approximately 29% of callers ask for advice for themselves, a further 28% called for advice for a child or grandchild and 15% for a parent or grandparent.

Research Findings (cont.)

- 97% of those who provided feedback said that the support they received made some kind of positive difference.
- 74% said the support they received 'absolutely' made a positive difference.
- Callers appreciated receiving advice but also having someone non-judgemental to talk to, while receiving encouragement and understanding.
- Callers indicated they would appreciate more support and connection with others.

Community education

In 2022, we held 43 community education sessions with a total of 827 participants. The feedback on the sessions was very positive; 81% of those who provided feedback were very satisfied with the session they attended.

In the process of the review, several opportunities were identified to make the delivery process more efficient and improve the quality of the presentation. As a result of the review, revised feedback forms have been implemented and a webinar pilot was conducted through April and May 2023.

We had significantly higher attendance at our webinars than we did overall in our bespoke training sessions, averaging 111 attendees per session compared with an average of 19 attendees in our sessions throughout the year.

92% of participants in the sessions who gave feedback said they were 'very satisfied' with the session.

Continence NZ members

We received only 18 out of a possible 96 responses to our membership survey with a response rate of 19%. A further 13 members responded to the Sapere survey of clinicians conducted at a similar time, meaning that one-third of the members participated in the wider research.

- Members most commonly accessed our conference and education days (87.5%), website (85.71%) and member newsletters (84.62%).
- Almost all members were aware of the helpline (90.91%) however relatively few had actually called us (20%).
- 93.75% of respondents indicated that the support they received made a positive difference.
- Members felt Continence NZ could provide more regional workshops and presentations, more resources and literature in te reo Māori and more government advocacy.

Wider community

We received 190 responses from our wider community, including those who have connected with us on Facebook and those who receive our community newsletter.

- Over two-thirds (69.66%) of respondents have a continence concern themselves, a further 12.63% care for a family member with a continence concern, and 10% are health professionals working with people who have a continence concern.
- The most commonly accessed services are the website (69.66%), the community newsletter (45.58%) and the helpline (38.46%).
- Of those who had accessed our services, over half found the service they accessed 'very useful'.
- Respondents found our online courses (68.75%), helpline (68.42%) and education days (66.79%) most helpful.
- 83.44% of respondents said the support they received made a positive difference.
- Education, awareness, and receiving understanding and support for their concerns was the most helpful thing for respondents.
- Resources, advice and the community newsletter were also themes in the feedback and many respondents reflected on feeling less isolated as a result of the support received.
- When asked what we could improve on, respondents suggested increased awareness and education, and additional support regarding products, including subsidised products, product comparisons and samples.

Research Findings (cont.)

3. The wider community of people living with continence concerns

The full results of the focus groups and semi-structured interviews are documented in 'The lived experience of access to continence care in Aotearoa, New Zealand: A community perspective.' (Williams & Fear, 2023).

The results are grouped by the interview questions:

Experiences of continence care in NZ

Key findings from the experiences of participants highlighted that many people had trouble getting started in the system. Many did not know where to start looking for help, and felt like they were not heard by the people they had turned to for help. Even those educated or trained as caregivers struggled to find support for the people they were caring for who have continence concerns.

Some people found it difficult to ask for help because they were embarrassed, and some had never sought help for that reason. Participants also expressed a belief that incontinence was happening because they hadn't looked after themselves, especially post-partum.

Not being heard by the clinician was a significant theme present throughout all interviews and focus groups, except for men who had experienced prostate cancer. Participants reported their disclosure to a medical professional was often brushed off as normal post-pregnancy or a normal part of ageing. Several women also reported being told their incontinence could not be improved until they lost weight, and this was particularly prominent among Māori participants.

Participants also commented that their GPs didn't know what was 'normal' or 'acceptable' with regard to urinary incontinence.

Some participants were able to share positive experiences when asked for help with the continence concern, whether with a paediatrician, GP, Continence NZ's helpline or a PHP. They felt that barriers began to appear when they were referred to specialists. Participants shared positive experiences where an interdisciplinary team works together for the support of the person needing their service.

The group of male participants who had experienced prostate cancer treatment across both private and public hospitals shared more positive experiences of the care they received. Generally, participants felt more prepared for the journey ahead with continence-related concerns if they received their treatment in the public system. They felt this was because they were supported and well-informed about what to expect as part of their cancer treatment.

What support do people need?

Almost every participant discussed how if they knew how to get started, their journey would have been easier, and this was closely followed by that if they had not been so embarrassed to talk about it, their journey would have been different.

The specific needs of Māori and Pasifika were discussed at length by the Pasifika participants, including the need to gain trust and access into the community through understanding the needs of the people. Once trust can be established, finding out what help is needed is key to being able to deliver effective services. Services that do not focus on trust building, talanoa and breaking down the barriers associated with discussing incontinence are unlikely to be accessed by Māori and Pasifika whānau.

The ability to share stories was identified by participants as an important tool in encouraging Māori and Pasifika to seek help and also to have the confidence to advocate for themselves when someone told them their incontinence was normal. Many participants reflected on being able to share their experiences, noting that the focus groups provided a helpful space to come and share their journeys.

Research Findings (cont.)

Pasifika and Māori participants felt it was important to find an appropriate way to talk about incontinence. A humourous approach was suggested as beneficial for a subject like incontinence that is difficult to discuss. Effectively, Pasifika and Māori need a way to share their experiences of incontinence without losing mana.

It was also clear that many barriers to culturally safe clinical care still exist for Māori and Pasifika. Participants reflected on feeling marginalised by a system that is not responsive to their cultural needs.

Theme 1: The impact of incontinence

Incontinence is described by research participants as embarrassing, isolating and personally costly to them. It comes with an extensive financial burden and can impact relationships with whānau, intimate partners and employers. Many participants did not know they might be eligible for funded products or were told by family members rather than clinicians.

Theme 2: Not being heard

Participants discussed struggling for years to have someone listen and take their continence concerns seriously. Participants expressed the need for a focus on well-being and to be engaged in a holistic and respectful way.

Theme 3: Knowledge is important

People didn't know how to start getting help and how to navigate the system. Many did not know to challenge the information when they were told what they were experiencing was an expected part of life. Even a small amount of knowledge was found to be helpful, and when discussing the barriers to seeking help, the health literacy of both consumers and clinicians made a significant difference to a person's ability to access care.

How can support be delivered?

Participants share a belief that if everyone started talking about continence, whether it was a concern or not, it would improve people's ability to seek help, and allow people to challenge medical professionals who incorrectly informed them incontinence is normal or acceptable. Effectively, communication and education would facilitate better support.

A range of options to achieve this were suggested by participants, from education in schools, to a helpline, to pamphlets in the GP surgery. Education was also a prominent theme when considering what Continence NZ could do to help.

How could Continence NZ best meet the needs of participants?

Participants had a wide range of examples relating to awareness and profile raising, breaking down the stigma associated with incontinence, making services and information more readily available, as well as educating the general public and medical professionals. Many of the suggestions were services that already exist, such as a helpline or an awareness campaign, so working to extend outreach is important to help people to access the support they need.

Recommendations

Recommendations have been grouped into three broad sections:

1. System-wide recommendations to improve continence care in New Zealand.
2. Recommendations related to existing Continence NZ services.
3. Recommendations for new or extended services.
4. Areas for further research or investigation.

1. System-wide recommendations

Investment in nationwide continence services

Our research has found that the investment of an additional 38 CNS, DN or PHPs would result in a net saving of $2.5 million per year, when taking into account the cost of publicly funded continence products only. Additionally, a 25% reduction in product use would result in a $3.7 million saving in costs to the environment.

Recommendations (cont.)

Increased investment would allow for increased focus on treatment over containment, as identified as best practice according to literature (Ostaszkiewicz et al., 2018; Taylor & Cahill, 2018). Furthermore, there are significant quality-of-life benefits and flow on medical costs that are not quantified in the CBA.

The experiences of focus group participants illustrate the impact that lack of continence care has on those experiencing incontinence, as well as the difficulty experienced in receiving care when they sought help.

Providing effective continence care would remove a significant barrier to achieving the goals set out in Te Pae Tata (Te Whatu Ora, 2022), as incontinence significantly affects all individuals in the priority areas listed below:

- Kahu taurima - maternity and early years
- Mate pukupuku - people with cancer
- Māuiuitanga taumaha - people living with chronic conditions
- Oranga hinengaro - people living with mental distress, illness and addictions.

Additionally, incontinence is a leading cause of carer stress, a cause of early rest home admission in the elderly and a cause of preventable hospital admissions for related medical conditions such as falls and skin infections, making it an important component of achieving 'Pae Ora - better health in our communities'.

Unification of services across the country

There is significant variation in operating practice, as well as waiting times across the country. Standardisation and unification of services would create the opportunity to provide more equitable access to those in areas with high waiting times or limited access to services. This may include the provision of some services through telehealth or other arrangements that allow for more flexible distribution of the workload.

Focus on collaboration and education

Articles by Ostaszkiewicz et al. (2018) and Taylor & Cahill (2018) on best practices for continence care highlight the importance of collaboration between health professionals across a wide range of disciplines to obtain the best possible outcome for the individual. Further, the experiences of focus group participants and helpline call data indicate that education of health professionals, especially those working in the community, such as GPs, practice nurses, plunket nurses and midwives is critical in improving the experiencing of those seeking care for continence concerns.

Focus on the delivery of culturally appropriate and responsive care

Māori and Pasifika research participants have shared experiences of feeling like they are being failed by our health system and have given examples of a system that did not accommodate their obligations to whānau, or take into account their cultural needs when seeking to progress treatment. In order to ensure equity and access more focus on the delivery of culturally appropriate care is required.

2. Existing Continence NZ services

Recommendations relate to the following existing services offered by Continence NZ:

- Helpline
- Education
- Website, Community Resources and Awareness Campaigns
- Membership

Helpline

Analysis of the Continence NZ helpline and associated feedback, as well as feedback from focus group participants, illustrates the need for the helpline and also the value delivered via the helpline. Many calls result from a system that is difficult to navigate and with the proper education of health professionals would be avoidable.

Recommendations (cont.)

Continence NZ's remit is education and advocacy. It is a place for reactive support and advice for those who need it, rather than a place to seek treatment and ongoing management of continence needs, as we do not wish to duplicate the services offered by Te Whatu Ora.

A helpline led or supervised by a Registered Health Professional (RHP) is a crucial point of difference for Continence NZ and adds significant value to the service, however, it does not necessarily need to be nurse-led; other RHPs with continence experience would be well equipped to manage calls effectively.

Alternatively, a health improvement practitioner with supervision from a CNS would be able to offer support and navigate common calls effectively and would be able to place a focus on educating health professionals to reduce 'avoidable' calls to the helpline.

Community education

With the success of our pilot webinar success, Continence NZ is in the process of embedding a new strategy for community education with the following components:

- Face-to-face education
- Webinars
- Online learning modules
- Conferences and education days

Face-to-face education

Due to the high cost of face-to-face education because of travel and accommodation requirements, face-to-face education across the regions will be shared across Continence NZ's operational team. It will focus on raising awareness around what is 'normal' or healthy when it comes to bowels and bladder, where to get more information and when to seek help.

Webinars

Webinars will form the basis of the education offered to health professionals and those in professional caring roles, such as teachers and occupational therapists in professional caring roles. Webinars will be hosted permanently on our website or offered as live sessions from time to time. Most webinars are also suitable for family carers, such as parents and are free for anyone to join.

Online modules

Online modules form an important part of the service we provide for members and as ongoing development for professionals. They typically cover more complex or in-depth subjects. These are free if funded by a partner such as IHC, or are free to members if funded by Continence NZ.

Conferences and education days

Conferences and education days provide professional development and networking opportunities for health professionals working in continence care, and in particular Continence NZ Members. Continence NZ is holding a two-day conference in September 2023. Based on the feedback and outcomes from this event, Continence NZ will further review this component of its education offering.

Website, community resources and awareness campaigns

Continence NZ's website contains a significant amount of information, however, Continence NZ is currently looking at re-platforming the website to make the content, tools and resources more user-friendly. We hope to progress this project in the next 12 to 18 months as funding permits.

A review of Continence NZ's brand guidelines and the imagery would be helpful in order to ensure consistency and inclusiveness across resources and campaigns.

While awareness campaigns have been successful in recent years, the size of the issue and the breadth of the population impacted mean that many impacted people have not yet heard about Continence NZ.

Increased media engagement around our awareness campaigns and throughout the year would be helpful to raise our profile.

Recommendations (cont.)

Other awareness activities are also being explored, including the use of a patron or ambassador to increase public visibility and engagement.

Membership

Continence NZ has approximately 90 members, however, as demonstrated by the low participation of members in our research, membership engagement is a challenge. Continence NZ is considering strategies to increase the perceived value for members. This will include a review of the target membership occupations and benefits, and also consider how to increase engagement and perceived value for members.

A broader membership base or different membership types with targeted benefits may help to increase membership and engage members further, and may also help to delivery further education to health professionals.

3. New or extended services for Continence NZ

Several key opportunities exist for Continence NZ to consider new or extended services to the community around the following themes that have been identified in the research:

- Reducing isolation and facilitating peer support for incontinence
- Reaching Māori, Pasifika and Asian communities

Reducing isolation and facilitating peer support

One of the significant pieces of feedback that came out of the focus groups was the value of just being able to share stories with one another, and the reduced feeling of isolation associated with sharing. Several options exist for Continence NZ to be able to offer this type of support, including:

- Online peer support via Facebook or other social media platforms
- Volunteer-led, face-to-face peer support groups

Facebook Peer Support Group
Similar to existing groups such as the Crohn's and Colitis group or the Encopresis group that already exists, the purpose of these groups is to connect people experiencing these conditions with one another, providing moral and social support rather than health advice. The group would need to be moderated by Continence NZ initially, however, this could be developed into a volunteer role so as not to impact the organisation's capacity.

Volunteer-led, face-to-face peer support groups
Similar to the groups run by the Prostate Cancer Foundation, the idea would be that these groups are local support networks that help to reduce isolation, foster connection and provide a platform for education and awareness. Continence NZ would need to develop resources to support the running of these groups, which could be based on the wee chat idea that we already use at Continence Awareness Week. A pilot could be run in one area of the country to work through practical considerations.

Reaching Māori, Pasifika and Asian communities

Effectively reaching Maori, Pasifika and Asian communities is an area that requires further research, however, there are a number of recommendations we are able to make from the current research including:

- Increased participation in leadership and governance to help shape our engagement strategy.
- Developing partnerships with trusted providers.
- Development of guidelines for branding and imagery to ensure our resources are inclusive.

Increased participation in leadership and governance
At the time of writing, Continence NZ is currently interviewing for a Cultural Advisor to join our Executive Committee. This important role will help us to ensure that Māori, Pasifika and Asian communities are prioritised when considering the shape of our organisation and our service delivery going forward.

Recommendations (cont.)

Developing partnerships with trusted providers
Feedback from research participants highlighted the importance of building trust and relationships when discussing such a sensitive topic with Māori and Pasifika. Services that do not focus on trust building and breaking down barriers associated with discussing incontinence are unlikely to be accessed by Māori and Pasifika, - this is evidenced by the low numbers of Māori and Pasifika that call the helpline.

Face-to-face service delivery is more appropriate for this group than a phone-based service. Developing partnerships with Māori and Pasifika health providers is one way for us to ensure we effectively serve these communities without requiring us to fully reshape our services. Some ways we could partner with these providers are to:

- Offer face-to-face drop-in clinics in partnership with providers, with a similar scope to the helpline, in terms of advice, education and advocacy, rather than treatment focused but with the opportunity to develop rapport and trust with those seeking help.
- Support the ongoing capacity development of health professionals within these organisations with education and resources.

Development of guidelines for branding and imagery to ensure our resources are inclusive
Feedback from participants also highlighted that when we translate resources to te reo Māori, we need to pay careful attention to not just the language, but also to the imagery and branding applied to resources to ensure they are culturally appropriate for Māori, Pasifika and Asian communities. Guidelines should be developed in collaboration with a cultural advisor.

4. Areas for further research or investigation

There are a number of areas that warrant further research or investigation:

- Prevalence of incontinence in Aotearoa, NZ
- The experiences of Māori, Pasifika and Asian communities and how to best serve these populations.

Prevalence of incontinence in NZ
Understanding the prevalence of incontinence in Aotearoa is an important part of ensuring that we are able to accurately calculate the impact and cost to our country of leaving this medical condition untreated or managing it only with product distribution.

Experiences of Māori, Pasifika and Asian communities and how to best support these populations
Further research is required into the experiences of Māori, Pasifika and Asian communities, including understanding their experiences of seeking continence care, the barriers that exist for seeking help or receiving treatment and effective strategies to improve continence care for these groups.

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Appendix One: Review of Existing Data

The following data that we already hold about the services we offer was reviewed:
- 12 months of notes from helpline calls
- Existing processes around community education delivery
- 12 months of feedback forms from those participating in community education

Notes from helpline calls

Purpose

To provide a review of the services provided by Continence NZ and make recommendations as to how the organisation can most effectively serve those living with incontinence.

Method

Data relating to helpline calls between 10 February 2022 and 09 February 2023 was extracted from infoodle. Analysis was performed on the data to determine:
- What services were provided to the callers
- How long they stayed engaged and how many times they called
- Demographic data such as age, ethnicity and location
- The main reason they called us

Results

- 620 clients called the helpline 824 times
- On average, clients called the helpline 1.33 times over an average of 12.7 days
- 394 Assessments were completed
- 337 Referrals to Continence Services
- 60 Can't-Wait Cards were issued

Caller demographics

Gender of helpline callers

Client gender	Response percent	Responses
Female	56%	349
Male	32%	196
Organisation	12%	75

Notes from helpline calls (cont.)

Age of helpline callers

Client age	Response percent	Responses
0 - 5 years	15%	94
6 - 15 years	17%	105
16 - 25 years	3%	18
26 - 64 years	14%	85
65 years or older	45%	280
Organisation	2%	11
Unknown	4%	27

Ethnicity

Answer choices	Population percentage	Adjusted percentage of callers*	Percentage of callers	Number of callers
NZ European	70%	76%	65%	406
Māori	17%	11%	10%	60
Asian	16%	7%	6%	36
Pasifika	8%	4%	3%	20
Unknown	-	-	14%	85

*percentage is adjusted to remove callers from an unknown location.

Location by DHB

Answer choices	Population percentage	Adjusted percentage of callers*	Percentage of callers	Number of callers
Auckland	9%	21%	20%	124
Bay of Plenty	5%	7%	7%	41
Canterbury	12%	8%	7%	44
Capital and Coast	6%	8%	8%	47
Counties Manukau	12%	8%	8%	48
Hawke's Bay	4%	8%	8%	47
Hutt	3%	2%	2%	13
Lakes	2%	2%	2%	13
Mid Central	4%	4%	4%	19

Notes from helpline calls (cont.)

Location by DHB (cont.)

Answer choices	Population percentage	Adjusted percentage of callers*	Percentage of callers	Number of callers
Nelson / Marlborough	3%	4%	4%	23
Northland	4%	3%	3%	19
South Canterbury	1%	1%	0%	3
Southern	7%	6%	6%	36
Taranaki	2%	1%	1%	5
Waikato	9%	10%	9%	56
Wairarapa	1%	0%	0%	2
Waitemata	12%	6%	6%	36
West Coast	1%	0%	0%	2
Whanganui	1%	2%	2%	11
Tairawhiti	1%	0%	0%	0
Unknown	-	-	3%	16

*percentage is adjusted to remove callers from an unknown location.

Location by Te Whatu Ora Region

Answer choices	Population percentage	Adjusted percentage of callers*	Percentage of callers	Number of callers
Northern	38%	39%	39%	227
Te Manawa Taki	27%	31%	31%	181
Central	12%	13%	12%	73
Te Waipounamu	23%	17%	15%	96
Unknown	-	-	7%	43

*percentage is adjusted to remove callers from an unknown location.

Notes from helpline calls (cont.)

Reasons for calling

Call reason	Number of clients	Percentage of callers	Average number of calls per client	Time engaged with Continence NZ (days)
Urinary incontinence	86	14%	1.13	5.91
Product advice	76	12%	1.11	7.50
Constipation	52	11%	1.81	24.79
Nocturnal enuresis	48	8%	1.56	24.06
Support with product delivery or supply	49	8%	1.06	2.78
Information request	45	7%	1.14	12.77
B&B advice for a person with chronic health condition	34	6%	1.32	15.79
Faecal incontinence	32	5%	1.53	16.03
Support accessing a Continence Service or PHP	32	5%	1.03	6.28
Toilet training advice	30	5%	1.50	12.27
Faecal and urinary incontinence	27	4%	1.93	18.04
B&B advice for a person with complex needs	22	4%	1.55	20.18
Bowel management advice	17	3%	1.35	9.65
Bladder issues	13	2%	1.15	11.92
B&B advice following an event (e.g. surgery, injury, stroke, prolapse)	15	2%	1.47	29.47
Education opportunity	11	2%	1.09	2.73
Pelvic floor exercise advice	8	1%	1.13	3.38
Stool withholding	8	1%	1.88	26.88
Catheter management advice	7	1%	1.14	8.00
Pelvic floor exercise advice	8	1%	1.13	3.38
Stool withholding	8	1%	1.88	26.88
Catheter management advice	7	1%	1.14	8.00
Toilet card enquiry	6	1%	1.00	1
Unknown	4	1%	1.25	3.25

Notes from helpline calls (cont.)

Who is the caller seeking advice for?

Answer	Number of clients	Percentage of callers
Self	180	29%
A spouse or partner	42	7%
A client	84	14%
A child or grandchild	171	28%
A parent or grandparent	92	15%
Sibling	5	1%
Employee	1	0%
Family member	4	1%
Friend	6	1%
Organisation	35	6%

Top three reason for call split by age

Age group	First	Second	Third
0 - 5 years	Constipation 27%	Toilet training advice 24%	Faecal incontinence 12%
6 - 15 years	Nocturnal enuresis 27%	B&B advice for a person with complex needs 11%	Constipation 8%
16 - 25 years	Nocturnal enuresis 17%	Support with product delivery/supply 17%	Urinary incontinence 11%
26 - 64 years	Urinary incontinence 21%	Information requests 16%	Support with product delivery/supply 12%
65 years and over	Product advice 19%	Urinary incontinence 18%	B&B advice for a person with chronic illness 11%

Data Notes

Population ethnicity stats:
https://www.ehinz.ac.nz/indicators/population-vulnerability
Te Whatu Ora Region stats accessed 11 April 2023:
https://healthshare.health.nz/our-region/te-manawa-taki-midland-region
DHB Population Stats (as at June 30 2022):
https://nzdotstat.stats.govt.nz/wbos/Index.aspx?DataSetCode=TABLECODE7509 and

Notes from helpline calls (cont.)

Insights

Demographics of helpline callers:
- Māori, Pasifika and Asian callers are underrepresented based on the population. This is consistent with the feedback from focus groups discussed in the report 'The lived experience of access to continence care in Aotearoa, New Zealand: A community perspective.' (Williams & Fear, 2023) where a number of respondents shared that because of the sensitivity of the topic, they would be unlikely to speak to someone they didn't already have trust and rapport with. The nature of the helpline service is reactive and it is not within our scope to develop long-term relationships with our clients, making it difficult to reach these groups with this service.
- We don't receive as many calls as we might expect from remote areas of the country, including Southern, Northland, West Coast, Taranaki and Tairawhiti DHBs' areas.
- Parents and whānau of young children are more likely to be 'repeat callers' than any other group.
- Those who have experienced a significant traumatic event like a stroke, surgery or injury tend to stay engaged with us the longest.

Recommendations

Recommendations will be made along with the insights from the helpline survey.

Review of community education

Purpose

To ensure community-based education provided by Continence NZ is effective, efficient and impactful.

Method

- Review of existing approach and processes.
- Review of existing data on community education, including who is participating in it, how much we are delivering, and the feedback received.
- Review of the content and delivery.

Process and approach to community education

We receive approximately $50k per year in funding to provide education to our community. This has been primarily provided by two Continence Nurses with different specialities. The current process is:
- Nurses proactively contact community groups and set up specific sessions to meet the needs of the organisation.
- Many of these sessions are held online. We frequently decline requests for face-to-face education given the cost of travel. There is currently no process in place to evaluate which face-to-face opportunities will be most impactful.
- Feedback should be collected at the end of each session, with all participants having the opportunity to complete a feedback form. This process has not been followed consistently by staff, significantly impacting our ability to measure the impact of our education.
- Feedback forms are short and straightforward, however, there are no questions on the feedback form measuring the impact of the sessions.
- At present, there is no strategy for how we target specific population groups.

Review of community education (cont.)

Data and feedback

In 2022, we held 43 community education sessions with a total of 827 participants. Groups averaged 19 participants, however, several groups were held for as few as 4 participants and in at least one instance, education sessions that were set up specifically or organisations online did not have any attendees.

38% (312 participants) provided written feedback. The feedback showed:

- 80% of respondents strongly agreed that the content was relevant to them.
- 68% of respondents strongly agreed that the information was new to them.
- 62% of respondents strongly agreed that there were ideas that they would implement as a result of the session.
- 80% strongly agreed that the speaker was easy to understand and the terminology appropriate.
- 81% were very satisfied with the session they attended.

Content and delivery

Presentations are often written bespoke and can take a significant amount of time to set up or tweak for each group or organisation.

Overall, the content is of high quality, however:

- There are significant inconsistencies in the branding and readability of the slides (font size, layout, readability).
- Presentations often include typos or spelling mistakes and have not been reliably proofread.
- Presentations are information heavy and not easy to make interactive.
- Language and terminology are not used consistently throughout the presentations.
- Imagery is of varying quality and is not always suitable and it is often not inclusive of high-risk groups (Māori and Pasifika).
- The structure of presentations is inconsistent and there is a lot of duplicated content between presentations.
- Some of the content delivered in community education is also covered in online modules.

Insights

Overall, the feedback received on the community education we have delivered is very positive. The quality of the content is high, however, there is room for us to improve the presentations and delivery.

- There is no logical progression through courses/education sessions or different groups/roles.
- There is duplication of content between online modules and community education, the options for further upskilling and a training pathway.

The delivery process has a number of inefficiencies:

- Rewriting presentations for each individual group is very inefficient, and results in a significant amount of work for only small audiences.
- Combining groups or requesting a minimum number of attendees would mean our education would reach more people with our education with less investment of time.
- Public webinars for popular topics at different times of the day are a good option for delivering education to a larger audience.
- The delivery process could be made more efficient by standardising the presentations and mapping a logical pathway for different groups through education offered by Continence NZ and third-party organisations.
- Imagery and language could be standardised and reviewed to be more inclusive of high-risk groups.

Review of community education (cont.)

Recommendations

- Review and update feedback forms to measure the impact of the training.
- Conduct a 'pilot' webinar series to see if there is greater uptake when webinars on more specific topics are offered to wider groups.
- Develop clear community education 'pathways' for different stakeholder groups to demonstrate a clear progression between webinar sessions and online modules as well as third-party education offerings.
- Share face-to-face education across the wider team for more general awareness raising and promotion of our services to reduce travel costs and ensure our services are promoted more widely across Aotearoa, New Zealand.
- Develop brand guidelines that cover community education presentations, that include:
    - standardised slide layouts that are appropriately readable
    - an image library that is inclusive and culturally appropriate
    - a terminology library that will enable consistent terminology across different education sessions as well as the website

Webinar pilot

The 'Toilet Tactics' webinar pilot, a seven-session webinar series, ran between 13 April and 1 June 2023 hosted by Lisa Smith. The results of the webinar series are below:

Date	Title	Attendees	Feedback recieved
13 April 2023	Healthy bowels and bladder	109	37
20 April 2023	Toilet training	127	32
27 April 2023	Constipation	111	32
4 May 2023	Bedwetting	111	29
11 May 2023	Daytime wetting	92	26
18 May 2023	Stool withholding	113	29
1 June 2023	Toileting children with additional needs	117	11

Consolidated feedback on the sessions is below:

Q1. Overall, how satisfied were you with the support provided today?
Average score: 4.92/5
Percentage of respondents that were 'very satisfied': 92%

Q2. The content was engaging and relevant to me:
Average score: 4.85/5
Percentage of respondents that 'strongly agree': 87%

Q3. The delivery was clear and the language was easy to understand:
Average score: 4.90/5
Percentage of respondents that 'strongly agree': 91%

Review of community education (cont.)

Q4/5. Before the session/After the session, I feel empowered with effective strategies that will benefit me/those I support:
The average score after the session: 4.32/5
Percentage of respondents that responded 'absolutely' after the session: 43%
The average improvement in scores: 1.42

Q6/7. Before the session/After the session, I am confident in achieving my continence goals/the goals of those I support:
The average score after the session: 4.12/5
Percentage of respondents that responded 'absolutely' after the session: 35%
The average improvement in scores: 1.23

Q8. How likely would you be to attend further education sessions offered by Continence NZ?
Average score: 4.68/5
Percentage of respondents who are 'very likely' to attend further education: 84%

Webinar pilot findings

The high levels of attendance at the session and the large amount of positive feedback is an effective way for us to deliver community education on more specialised topics.

Face-to-face education on more generalised topics is useful for awareness raising, as are zoom meetings with partner organisations and groups.

Appendix Two: Survey Findings

Those already engaged with Continence NZ were grouped into three distinct groups:
- Helpline Users
- Continence NZ Members
- Those subscribed to our newsletter or engaged via Facebook

Surveys were developed for each of these groups, focusing on:
- The demographics of the respondent group
- What services they had accessed
- If those services were useful
- Suggestions to improve services

Helpline user survey

Purpose

To provide insight into the impact of the advice received via the helpline.

Method

Data was extracted from Continence NZ's Client Relationship Management system (CRM), Infoodle, for four months (22 November 2022 to 22 March 2023) of helpline callers with valid email addresses. The survey questions in Appendix Three were sent via a Mailchimp invite on 23 March 2023, with a reminder a week prior to the survey closing on 14 April 2023. We received 37 out of a possible 120 responses (31%). The full survey results are in Appendix Four.

Insights

Respondent demographics:
- 86% of respondents identified as NZ European, while Māori, Pasifika and Asian populations were under-represented. This is to be expected in the survey results as these groups are under-represented in the original call data.
- The gender of the respondents was 14% male and 86% female.
- While there is a reasonable geographical spread in the data, there are some areas of the country not represented in the data, including Nelson/Marlborough, West Coast and Taranaki. Canterbury is underrepresented and Southland, Wellington and Bay of Plenty are overrepresented compared to the population.
- Those seeking help for themselves (37%) or a spouse or partner (17%) were over-represented compared with the underlying call data.
- The age demographics of those who responded to the feedback are similar to the underlying demographics of our callers.
- Urinary incontinence (27%), Constipation (17%) and Faecal incontinence (15%) were the top three reasons people contacted us, this is a slight variation from the underlying dataset.

Respondents were asked about the following statements both before and after contacting Continence NZ:

Q1. I feel supported and empowered to manage my continence needs/the continence needs of those I support:
- The average score after contacting Continence NZ: 3.57/5
- This represents an average improvement of 1.00/5
- 43% of respondents said they 'absolutely' agreed with the statement after contacting Continence NZ

Helpline user survey (cont.)

Q2. I am confident in managing my continence needs/supporting others to manage their needs:
- The average score after contacting Continence NZ: 3.60/5
- This represents an average improvement of 0.85/5
- 46% of respondents said they 'absolutely' agreed with the statement after contacting Continence NZ

Q3. I feel hope for the future:
- The average score after contacting Continence NZ: 3.47/5
- This represents an average improvement of 0.85/5
- 33% of respondents said they 'absolutely' agreed with the statement after contacting Continence NZ

74% of respondents said the support they received 'absolutely' made a positive difference.
97% of respondents said the support they receive made some kind of positive difference.

Callers appreciated receiving advice, encouragement and understanding, but also having someone non-judgemental to talk to. Callers also indicated that they would appreciate more support and connection with others.

Recommendations

Due to the pressure on our health system currently and the difficulty in being referred to a CNZ or PHP, the helpline is a valuable tool for education and advocacy. It can also reduce the isolation and shame felt by those living with incontinence. It is not intended to be an alternative pathway for the treatment of incontinence. Staffing the helpline with a health professional allows us to be effective in assisting people to navigate their way through the health system to find the treatment options they are seeking, and allows us to make a referral to services that will only accept referrals from a medical professional. This could be a nurse, health improvement practitioner or other registered health care professional.

A large number of calls to the helpline are 'avoidable' or could be reduced through further education. An example of this is calls requesting changes to products supplied through Te Whatu Ora. These calls could be reduced through appropriate education.

Member survey

Purpose

To provide insight into the impact of Continence NZ services delivered to its members.

Method

All members as of 22 March 2023 were invited to complete the survey. The survey questions in Appendix Three were sent via a Mailchimp invite on 24 March 2023, with a reminder a week prior to the survey closing on 14 April 2023. We received 18 out of a possible 96 responses (19%). Full survey results are in Appendix Four. While this response rate is lower than desired, a further 13 members participated in the Sapere survey of clinicians conducted at a similar time, meaning that 33% of members participated in the wider research.

Member survey (cont.)

Insights

Demographics of respondents:

- There was a reasonable geographical spread of respondents, however, Canterbury and Waikato were over-represented and Auckland and Wellington were significantly under-represented in the feedback.
- A range of occupations were captured in the feedback that is representative of our membership.
- The majority of respondents worked with adults (88.89%), and one-third of respondents worked with children.
- 72.22% of respondents worked in the public health system, one-third worked in private practice and a number were also funded by ACC.

Feedback on Services:

- The Continence NZ website (85.71%), conferences and education days (87.50%), and member newsletters (84.62%) are the most commonly accessed support.
- Almost all members have heard of the helpline (90.91%) but only 20% have actually called.
- Feedback indicates that members highly value our education days and conferences.
- 93.75% of respondents indicated that the support they received from Continence NZ made a positive difference, and 37.75% responded that it 'absolutely' made a difference.
- Members felt Continence NZ could provide more regional workshops and presentations, more resources and literature in te reo Māori, and more advocacy with the government.

Recommendations

Increased engagement and resources for members would enhance the perceived value of our membership. Further promotion of online courses as well as more face-to-face workshops and events throughout the country would help to broaden the appeal of the membership.

Community survey

Purpose

To provide insight into the awareness and impact of Continence NZ services delivered to our wider community.

Method

Those receiving our community newsletter and following us on our Facebook page were surveyed, and the survey was able to be shared on Facebook and forwarded to other stakeholders. The survey questions in Appendix Three were sent via a Mailchimp invite to those receiving our Community Newsletter on 24 March 2023, with a reminder a week prior to the survey closing on 14 April 2023. The survey was also posted on Facebook on 24 March 2023. We received 190 responses, however, it is difficult to determine the population size to determine a response rate. Full survey results are in Appendix Four.

Insights

Demographics of respondents:

- There was a good ethnic and geographical representation of respondents, including areas that were under-represented in other data sets.
- The majority (62.63%) of respondents have a continence concern themselves, 12.63% are caring for a family member with a continence concern and 10% are health professionals working with people who have a continence concern.

Community survey (cont.)

Feedback on Services:

- The Continence NZ website (69.66%), Community Newsletters (45.58%) and the Helpline (38.46%) are the most commonly accessed support.
- Most respondents (63.06%) have heard of the Helpline but many have not actually used it.
- Of those who have accessed our services, over half found the service they accessed 'very useful', participants found our online courses (68.75%), helpline (68.42%) and education days (66.79%) the most helpful.
- 22.29% of respondents said the support they received 'absolutely' made a positive difference, and 83.44% of respondents said the support they received made a positive difference.
- When asked what was most helpful, 76% of feedback was positive, 20% was neutral and 4% was negative. Within the positive feedback, 44% of feedback was around awareness and education: respondents appreciated the education we delivered and the knowledge that there is support available for their issue. Other themes in the positive feedback were the advice received, resources that we offer, our community newsletter and the respondents feeling less isolated.
- When asked what we could most improve on, 34% of feedback was positive, 59% neutral and 7% was negative. The main suggestion for improvement included more awareness and education, and additional support regarding products, including subsidised products, product comparisons and samples.
- We received a number of positive comments about our recent Toilet Tactics webinar series.

Recommendations

Continence NZ services are generally well regarded by the community and increased organisation profile and more community-based education would benefit the community.

Appendix Three: Survey Questions

Helpline user survey

Questions

Q1. What area of New Zealand do you live in?

- Northland
- Waikato
- Gisborne and Hawke's Bay
- Manawatū - Whanganui
- Nelson - Marlborough
- Canterbury
- Auckland
- Bay of Plenty
- Taranaki
- Wellington
- West Coast
- Southland

Q2. What is your gender?

- Female
- Gender Diverse
- Male

Q3. How old are you?

- Under 18
- 25 to 34
- 45 to 54
- 65 to 74
- 18 to 24
- 35 to 44
- 55 to 64
- 75 or older

Q4. What is your ethnicity?

- Māori
- Other European
- Asian
- Latin American
- Other (please specify
- NZ European
- Pasifika
- Middle Eastern
- African

Q5. When you contacted Continence NZ, who were you seeking support for?

- Yourself
- Your spouse or partner
- Another family member
- A client
- Your child or grandchild
- Your parent or grandparent
- A friend
- An organisation

Q6. If you were seeking support for another person, how old is that person?

- 0 - 5 years
- 11 - 15 years
- 26 - 64 years
- n/a
- 6 - 10 years
- 16 - 25 years
- Over 65 years

Helpline user survey (cont.)

Q7. If you were seeking support for another person, what ethnicity is that person?

- Māori
- Other European
- Asian
- Latin American
- I don't know
- Other (please specify)
- NZ European
- Pasifika
- Middle Eastern
- African
- n/a

Q8. How did you hear about Continence NZ?

- A friend or family member
- Facebook
- GP or Nurse
- Another community organisation
- Google search
- Poster or flyer
- Another health professional
- Other (please specify)

Q9. What was the reason for your call?

- Urinary incontinence or bladder leakage
- Advice on choosing the right products
- Support with your regular product deliveries
- Toilet training advice
- Other (please specify)
- Constipation
- Bedwetting (nocturnal enuresis)
- Bowel leakage or faecal incontinence
- Support accessing a Continence Service or Pelvic Health Physio

Q10. What support did you receive from Continence NZ?

- A Continence Assessment
- A Toilet Card
- Bladder management advice
- Information about a Continence Service in your area
- A referral letter
- Information about the disability allowance
- Bowel management advice
- Product samples
- Other (please specify)

Q11. How did you feel about the statements below prior to contacting Continence NZ?

1. *"I feel supported and empowered to manage my continence needs/the continence needs of those I support well."*
2. *"I am confident in managing my continence needs/supporting others to manage their needs."*
3. *"I feel hopeful for the future."*

- Not at all
- Moderately
- Absolutely
- A little
- Very

Helpline user survey (cont.)

Q12. How did you feel about the statements below following your conversation with us?

1. *"I feel supported and empowered to manage my continence needs/the continence needs of those I support well."*
2. *"I am confident in managing my continence needs/supporting others to manage their needs."*
3. *"I feel hopeful for the future."*

- Not at all
- Moderately
- Absolutely
- A little
- Very

Q13. Overall, did the support you received from Continence NZ make a positive difference?

- Not at all
- Moderately
- Absolutely
- A little
- Very

Q14. Thinking about the support you received from Continence NZ, what was most helpful?

Q15. Thinking about the support you received from Continence NZ, what could we improve on?

Q16. Have you accessed any of the following support available from Continence NZ?

- Website
- Online courses
- Brochures
- YouTube channel
- Other (please specify)
- Community newsletter
- Community education
- Facebook page
- World Continence Week campaigns

Q17. Is there any other support you would like Continence NZ to provide, or any other feedback you would like to provide?

Member survey

Questions

Q1. What area of New Zealand do you live in?

- Northland
- Waikato
- Gisborne and Hawke's Bay
- Manawatū - Whanganui
- Nelson - Marlborough
- Canterbury
- Auckland
- Bay of Plenty
- Taranaki
- Wellington
- West Coast
- Southland

Member survey (cont.)

Q2. What is your profession?

- Continence Advisor
- District Nurse
- Fitness Professional
- Occupational Therapist
- Physiotherapist
- Public Health Nurse
- Other (please specify)
- Continence Nurse Specialist
- Doctor
- Midwife
- Pelvic Health Physiotherapist
- Plunket Nurse
- Registered Nurse - Aged Care

Q3. Who do you provide services to? (select all that apply)

- Adults
- Aged Residential Care services
- Community groups
- Children
- Disability services
- Other (please specify)

Q4. Do you work in? (select all that apply)

- Primary care
- Tertiary care
- Secondary care
- Other (please specify)

Q5. Is your service? (select all that apply)

- Publicly funded
- Other (please specify)
- Privately funded

Q6. Have you accessed any of the following support provided by Continence NZ?

a. **Heard of**
b. **Used**

- Continence NZ helpline
- Education days or conferences
- Community education
- Continence NZ website
- Online courses
- Member newsletters

How useful was the resource?

- Very Useful
- Not at all useful
- Somewhat useful
- Not applicable

Q7. Overall, did the support you received from Continence NZ make a positive difference?

- Not at all
- Moderately
- Absolutely
- A little
- Very

Member survey (cont.)

Q8. Thinking about the support you received from Continence NZ, what was most helpful?

Q9. Thinking about the support you received from Continence NZ, what could we improve on?

Q10. Is there any other support you would like Continence NZ to provide?

Community survey

Questions

Q1. What area of New Zealand do you live in?

- Northland
- Waikato
- Gisborne and Hawke's Bay
- Manawatū - Whanganui
- Nelson - Marlborough
- Canterbury
- Auckland
- Bay of Plenty
- Taranaki
- Wellington
- West Coast
- Southland

Q2. What is your gender?

- Female
- Gender diverse
- Male
- Prefer not to disclose

Q3. How old are you?

- Under 18
- 25-34
- 45-54
- 65+
- 18-24
- 35-44
- 55-64

Q4. What is your ethnicity?

- Māori
- Other European
- Asian
- Latin American
- Prefer not to disclose
- NZ European
- Pasifika
- Middle Eastern
- African
- Other (please specify)

Q5. What best describes your interest in Continence NZ?

- I have a continence concern
- I care for a family member with a continence concern
- I am a health professional who works with people with continence concerns
- Other (please specify)
- I am a parent seeking support with toilet training
- I am a teacher or other professional supporting a person with continence concerns
- I represent an organisation that works with people with continence concerns

Community survey (cont.)

Q6. Have you accessed any of the following support provided by Continence NZ?

a. **Heard of**
b. **Used**

- Continence NZ helpline
- Education days or conferences
- Community education
- Continence NZ website
- Online courses
- Community newsletters

How useful was the resource?

- Very Useful
- Not at all useful
- Somewhat useful
- Not applicable

Q7. Overall, did the support you received from Continence NZ make a positive difference?

- Not at all
- Moderately
- Absolutely
- A little
- Very

Q8. Thinking about the support you received from Continence NZ, what was most helpful?

Q9. Thinking about the support you received from Continence NZ, what could we improve on?

Q10. Is there any other support you would like Continence NZ to provide?

Appendix Four: Survey Responses

Helpline user survey

Results

- Total Survey Responses: 37 of 120 possible respondents
- Percentage of Members responding: 31%
- The survey was open from 23 March to 14 April 2023 and included all those with valid email addresses who called the helpline between 22 November 2022 and 22 March 2023

Q1. What area of New Zealand do you live in? n=37

Answer choices	Percentage of population	Response percent	Responses
Northland	3.9%	2.70%	1
Auckland	33.1%	35.14%	13
Waikato	10.0%	13.51%	5
Bay of Plenty	6.8%	13.51%	5
Gisborne and Hawke's Bay	4.6%	0.00%	0
Taranaki	2.5%	0.00%	0
Manawatū - Whanganui	5.0%	5.41%	2
Wellington	10.6%	16.22%	6
Nelson - Marlborough	3.2%	0.0%	0
West Coast	0.6%	0.0%	0
Canterbury	12.8%	2.7%	1
Southland	6.8%	10.81%	4

Q2. What is your gender? n=37

Answer choices	Response percent	Responses
Female	86.49%	32
Male	13.51%	5
Gender diverse	0.0%	0

Helpline user survey (cont.)

Q3. How old are you? n=37

Answer choices	Response percent	Responses
Under 18	0.0%	0
18 - 24 years	2.70%	1
25 - 34 years	0.00%	0
35 - 44 years	27.03%	10
45 - 54 years	16.22%	6
55 - 64 years	24.32%	9
65 - 74 years	8.11%	3

Q4. What is your ethnicity? n=37

Answer choices	Response percent	Responses
Māori	0.0%	0
NZ European	91.89%	34
Other European	0.00%	0
Pasifika	0.00%	0
Asian	0.00%	0
Middle Eastern	0.00%	0
Latin American	0.00%	0
African	0.00%	0
Other (please specify)	8.11%	3

Responses to 'other':

- Australian
- Indian
- South African

Helpline user survey (cont.)

Q5. When you contacted Continence NZ, who were you seeking support for? n=37

Answer choices	Response percent	Responses
Yourself	37.84%	14
Your child or grandchild	24.32%	9
Your spouse or partner	16.22%	6
Your parent or grandparent	2.70%	1
Another family member	2.70%	1
A friend	0.00%	0
A client	8.11%	3
An organisation	8.11%	

Q6. If you were seeking support for another person, how old is that person? n=34

Answer choices	Response percent	Responses
0 - 5 years	17.65%	6
6 - 10 years	11.76%	4
11 - 15 years	2.94%	1
16 - 25 years	2.94%	1
26 - 64 years	2.94%	1
Over 65 years	26.47%	9
N/a	35.29%	12

Q7. If you were seeking support for another person, what ethnicity is that person? n=34

Answer choices	Response percent	Responses
Māori	2.94%	1
NZ European	55.88%	19
Other European	2.94%	1
Pasifika	2.94%	1
Asian	0.00%	0
Middle Eastern	0.00%	0
Latin American	0.00%	0
African	0.00%	0
I don't know	0.00%	0
N/a	35.29%	12
Other (please specify)	0.00%	0

Helpline user survey (cont.)

Q8. How did you hear about Continence NZ? n=37

Answer choices	Response percent	Responses
A friend of family member	10.81%	4
Google search	45.95%	17
Facebook	0.00%	0
Poster or flyer	0.00%	0
GP or nurse	10.81%	4
Another health professional	21.62%	8
Another community organisation	8.11%	3
Other (please specify)	2.70%	1

Responses to other:

- *"A teacher the SENCO for Woodstock school."*

Q9. What was the reason for your call? n=34

Answer choices	Response percent	Responses
Urinary incontinence or bladder leakage	41.18%	14
Constipation	23.53%	8
Advice on choosing the right products	11.76%	4
Bed wetting (nocturnal enuresis)	5.88%	2
Support with your regular product deliveries	8.82%	3
Bowel leakage or faecal incontinence	23.53%	8
Toilet training advice	8.82%	3
Support accessing a Continence Service or Pelvic Health Physio	14.71%	5
Other (please specify)	20.59%	7

Responses to 'other':

- *"Mobility issues."*
- *"School plan and support."*
- *"Skin protection from urine leakage."*
- *"Support for child with complex disability."*
- *"Unusual and complex multiple bowel obstructions (can't evacuate and all has to be done including transit manually)."*
- *"Ways to purchase/seek a subsidy for the products while my Mum is in a Hospital Level care facility under 'ACC Respite' and continence products are not funded."*
- *"Where I could free underlay pads when performing peri care for female client."*

Helpline user survey (cont.)

Q10. What support did you receive from Continence NZ? n=33

Answer choices	Response percent	Responses
A continence assessment	21.21%	7
A referral letter	9.09%	3
A Toilet Card	9.09%	3
Information about the disability allowance	9.09%	3
Bladder management advice	24.24%	8
Bowel management advice	36.36%	12
Information about a Continence Service in your area	27.27%	9
Product samples	12.12%	4
Other (please specify)	33.33%	11

Responses to 'other':

- *"A letter of support and offer of direct contact to my daughter from the nurse."*
- *"A plan for the school."*
- *"Advice on a good cleaning and skin care regimen and products to use."*
- *"Brochures about service and how they can support our organisation."*
- *"Can purchase a bit cheaper through some place (can't remember)."*
- *"Child specific info to show my son in child friendly language and visuals. Follow up phone calls and emails."*
- *"Discussion and advice re whether the nurse had knowledge on my bowel obstructions and kind support and phone numbers I could try."*
- *"Information for my sons school, information for his GP."*
- *"Nappy Pads."*
- *"None."*
- *"Product samples still coming."*

Q11. How did you feel about the statements below prior to contacting Continence NZ? n=31

Statements	Absolutely	Very	Moderately	A little	Not at all	Total
I feel supported and empowered to manage my continence needs/the continence needs of those I support well.	4 13.33%	6 20.00%	5 16.67%	4 13.33%	11 36.67%	30
I am confident in managing my continence needs/supporting others to manage those needs.	4 13.33%	5 16.67%	7 23.33%	9 30.00%	5 16.67%	30
I feel hopeful for the future.	5 16.13%	4 12.90%	6 19.35%	9 29.03%	7 22.58%	31

Helpline user survey (cont.)

Q12. How did you feel about the statements below following contacting Continence NZ? n=32

Statements	Absolutely	Very	Moderately	A little	Not at all	Total
I feel supported and empowered to manage my continence needs/the continence needs of those I support well.	11 34.38%	7 21.88%	7 21.88%	5 15.63%	2 6.25%	32
I am confident in managing my continence needs/supporting others to manage those needs.	9 28.13%	10 31.25%	7 21.88%	4 12.50%	2 6.25%	32
I feel hopeful for the future.	10 31.25%	7 21.88%	7 21.88%	5 15.63%	3 9.38%	32

Q13. Overall, did the support you received from Continence NZ make a positive difference? n=33

Answer	Absolutely	Very	Moderately	A little	Not at all
Number	18	7	4	3	1
Percentage	54.55%	21.21%	12.12%	9.09%	3.03%

Q14. Thinking about the support you received from Continence NZ, what was most helpful? n=32

- *"Absolutely everything - the contact with my son's school, the plan for my son, the information for the GP, the check-in on my son's progress."*
- *"Absolutely helpful."*
- *"Advising me to get referral from doctor to the Continence service at our local hospital."*
- *"Being given ideas to try, and materials to use from someone obviously very knowledgeable on the topic. We had felt completely unsupported by the issue we were facing, but we felt less alone which was amazing. I couldn't recommend this service more."*
- *"Being listened to fully, treated with compassion and aided with individualized practical help. Thank you for all you do."*
- *"Confirming what I needed to know."*
- *"Finding out how the service works."*
- *"Getting advice on different laxatives to those the GP provided and a plan going forward."*
- *"Good."*
- *"Having someone to talk to."*
- *"Just having someone I could talk to about the incontinence and they understood and made suggestions to try and help."*
- *"Just speaking with a nurse was great 👍."*
- *"Knowing where to go for product information."*
- *"Lisa took time to understand and really get to the bottom of what was going on with my daughter and provided us ongoing support."*
- *"Lisa was so well informed and gave very clear and personalised advice."*

Helpline user survey (cont.)

Q14 (cont.) Thinking about the support you received from Continence NZ, what was most helpful? n=32

- *"Louise the English lady is marvelous. I was hoping that she would answer the phone as I had a very lengthy email conversation as well as a couple of phone calls with her in previous years. Whilst nobody in NZ or worldwide can help with my symptoms and conditions. She's been the best in terms of a listening and nonjudgemental ear and in terms of the amout of time and effort she puts into emails and phone calls. Meant so much in my difficult life to know that there is such a kind person who is unshockable when hearing such embarrassing symptoms."*
- *"No help, figuring out myself."*
- *"Okay."*
- *"Problem solving MY student's needs. Thank you."*
- *"Samples and knowing I can get support."*
- *"Suggestions for assistance available."*
- *"Supply of appropriate resources ie pads and pants."*
- *"Talking to the lady from Dundee."*
- *"The face to face support via a zoom call."*
- *"The first time in 27 years of incontinence that I've had advice on how to clean and look after my skin. Step by step instructions I could follow and product recommendations - so very helpful! Also the information that the kind of incontinence I have is not the most common and that it's worth following that up with the doctor."*
- *"The offer of support and provision of training workshop for families we work with."*
- *"The outstanding help given to help me find the number of the contractor I had always used but had unfortunately deleted it on my computer."*
- *"The person were very helpful and I felt I could speak to her honestly and openly about the concerns I had for my client's needs. I appreciated the fact that she called me again to see how I got on."*
- *"The service was efficient and helpful."*
- *"The zoom meetings with Lisa, they were very informative and gave me a better understanding of what we need to do to continue to improve her toileting needs."*
- *"THEY WERE WONDERFUL COULDN'T ASK FOR BETTER RECOMMEND THEM TO ALL MY FRIENDS/ FAMILY."*
- *"To hear that it can be resolved. For the nurse to share her experience as a teenage bedwetter with my daughter. Advice on small things we can work on, not too overwhelming."*

Q15. Thinking about the support you received from Continence NZ, what could we improve on? n=28

- *"-"*
- *"10/10 FOR WHAT WE RECEIVED."*
- *"A superb service. Thank you very much."*
- *"A visit."*
- *"All good."*
- *"Assessments being done sooner I was told 2 months and it has been 3 months and still haven't heard from Tania."*
- *"For me , just having someone ring me now and again to see how I was going. A bit of follow up would be great."*
- *"I felt that Louise (English nurse) although wonderful would benefit from having more knowledge of Auckland district and the hospitals and specialists who work in this region."*
- *"I had excellent support - thank you. I am still struggling to find other health professionals with this understanding and knowledge. I self-referred too. So increasing the level of awareness among GPs, specialists and pelvic physios of incontinence issues and the service you provide would be good."*
- *"Keep up the great work you're doing!!"*

Helpline user survey (cont.)

Q15 (cont.) Thinking about the support you received from Continence NZ, what could we improve on? n=32

- *"Make people more aware of the service. So important for kids. More nurses helping with kids especially with additional needs."*
- *"More examples on your website of mens incontinence issues as most of the subjects were females."*
- *"More follow up."*
- *"Na."*
- *"No, everyone was incredible kind and diligent."*
- *"Not much - in my case you did really well."*
- *"Nothing Fantastic service."*
- *"Nothing she was amazing."*
- *"Nothing."*
- *"Nothing, I felt the service was amazing and empowering."*
- *"Nothing, I have felt so supported & every question I had has been answered."*
- *"Nothing. Prompt service received."*
- *"Nothing. We have not yet made the progress we would have hoped for, but that is on us to contact the support person again."*
- *"Offer Incontinence Samples."*
- *"Possibly a face to face consult initially, especially when children involved so they know that help is coming from a professional not just Mum."*
- *"The response time perhaps could have been faster. Was a phone call and a follow-up email with the information would have helped."*
- *"To have some physical materials posted would be great."*
- *"Unsure."*

Q16. Have you accessed any of the following support available from Continence NZ? n=28

Answer choices	Response percent	Responses
Continence NZ website	50.00%	14
Community newsletter	3.57%	1
Online courses	3.57%	1
Community education	0.00%	0
Brochures	21.43%	6
Facebook page	10.71%	3
YouTube channel	3.57%	1
World Continence Week campaign	3.57%	1
Other (please specify)	32.14%	9

Responses to 'other':

- *"Appointment to have bladder ultrasound."*
- *"I read them, but my symptoms and conditions have never been mentioned."*
- *"No but would like to."*
- *"Referral to hospital continence service."*
- *"Email support."*
- *"Na."*
- *"No."*
- *"None."*
- *"Referral to hospital continence service."*

Helpline user survey (cont.)

Q17. Is there any other support you would like Continence NZ to provide, or any other feedback you would like to provide? n=21

- *"After talking to Continence NZ I was enabled to go about getting referrals from GP, District Nurse, and am now back receiving assistance from local DHB."*
- *"All Good."*
- *"As I have recently been told by my doctor to drink more water, I drench my moly pads and wonder if others with a greater absorption are available."*
- *"Finding regular cheap products for seniors is the aim for our organisation - although Continence NZ could not assist us with that it did point us in a right direction."*
- *"For me , just having someone ring me now and again to see how I was going. It is very hard to keep going and stay positive day after day after day. Some encouragement is great and I would really appreciate that. I guess you are too busy."*
- *"I feel everything my son needed was covered."*
- *"I feel isolated by my symptoms and the fact that nobody else has the same thing. It takes up 14 hours in every 24 hour period to deal with. Plus I have multiple other challenging conditions like M.E. (Myalgic Encephomyeltis) etc and have been almost entirely housebound since my 20s (in my mid-50s now). SO I guess anything that would get me to hear of others would be good. But not well enough for anything like social media or zoom. SO not sure how that would be possible."*
- *"I never knew this service existed but it is such an amazing service. Not knowing if this is happening or not but is it possible to get this service more widely known? None of the GP's I visited or daycares / schools knew about this service yet it is so invaluable for parents in my situation. This service has had such a huge impact (for the better) on my son & my lives; I am so grateful for this service."*
- *"Incredible service! Thank you so much."*
- *"My mother is finding it very expensive to purchase her products at $71 dollars per fortnight. My mother is 89 years old."*
- *"Na."*
- *"No thank you."*
- *"No." (4)*
- *"Samples."*
- *"The client also has to buy additional pads which is already costing them a lot of money. It would be great if she was able to get the medium or large disposable underlay pad /blueish to put under her when doing peri care, opposed to just tusing the washable kind? Hopefully at a very low cost or even free as on google search I found that was quite expensive. I would appreciate it if you are able to assist or support me with the above need for my client."*
- *"They are giving us all support needed at moment."*
- *"Unfortunately, I have not received the Molicare Form premium for this month, April, but did receive the pads. Please investigate. Many thanks."*
- *"Very friendly and supportive service."*

Data Notes

Population data by region was sourced from Stats NZ: https://www.stats.govt.nz/information-releases/subnational-population-estimates-at-30-june-2022-provisional/

Member survey

Results

Total Survey Responses: 18
Total Possible Respondents: 96
Percentage of Members responding: 18.75%
While this is a lower-than-desirable response rate, a further 13 members responded to a Sapere survey of clinicians conducted at a similar time, meaning that 33% of members participated in the wider research.

Q1. What area of New Zealand do you live in? n = 16

Answer choices	Percentage of population	Response percent	Responses
Northland	3.9%	0.0%	0
Auckland	33.1%	18.75%	3
Waikato	10.0%	25.0%	4
Bay of Plenty	6.8%	0.0%	0
Gisborne and Hawke's Bay	4.6%	6.25%	1
Taranaki	2.5%	0.0%	0
Manawatū - Whanganui	5.0%	6.25%	1
Wellington	10.6%	0.0%	0
Nelson - Marlborough	3.2%	6.25%	1
West Coast	0.6%	0.0%	0
Canterbury	12.8%	31.25%	5
Southland	6.8%	6.25%	1

Q2. What is your profession? n=18

Answer choices	Response percent	Responses
Continence Advisor	11.11%	2
Continence Nurse Specialist	22.22%	4
District Nurse	5.56%	1
Doctor	11.11%	2
Fitness Professional	0.0%	0
Midwife	0.0%	0
Occupational Therapist	0.0%	0
Pelvic Health Physiotherapist	11.11%	2
Physiotherapist	16.67%	3
Plunket Nurse	0.00%	0

Member survey (cont.)

Q2. (cont.) What is your profession? n=18

Answer choices	Response percent	Responses
Public Health Nurse	0.0%	0
Registered Nurse - Aged Care	5.56%	1
Other - please specify	16.67%	3

Responses under 'other':

- *"Unemployed RN"*
- *"NGO"*
- *"Community Māori Health 25 years and up"*

Q3. Who do you provide services to (select all that apply)? n=18

Answer choices	Response percent	Responses
Adults	88.89%	16
Children	33.33%	6
Aged Residential Care services	16.67%	3
Disability services	22.22%	4
Community groups	22.22%	4
Other - please specifiy	5.56%	1

Responses to 'other' include:

- *"Not working at present"*

Q4. Do you work in? n=18

Answer choices	Response percent	Responses
Primary care	50.00%	9
Secondary care	27.78%	5
Tertiary care	16.67%	3
Other	16.67%	3

Responses to 'other' include:

- *"Mercy Hospital Outpatient Physiotherapy"*
- *"n/a"*
- *"Community"*

Member survey (cont.)

Q5. Is your service? n=18

Answer choices	Response percent	Responses
Publicly funded	72.22%	13
Privately funded	33.33%	6
Other - please specify	33.33%	6

Responses to 'other':

- ACC and Private (2)
- n/a
- ACC
- Contracted
- Grants and donations

Q6. Have you accessed any of the following support provided by Continence NZ? n=16

Answer choices	Heard of			Used		
	No.	%	Total Responses	No.	%	Total responses
Continence NZ helpline	10	90.91%	11	2	20%	10
Continence NZ website	10	100%	10	14	87.50%	16
Education days or conferences	10	90.91%	11	12	85.71%	14
Online courses	6	66.67%	9	2	22.22%	9
Community education	9	100%	9	4	50%	8
Member newsletter	10	90.91%	11	11	84.62%	13

How useful was the resource? n=16

Answer choices	Very useful		Somewhat useful		Not at all useful		N/A		Total respondents
	no.	**%**	**no.**	**%**	**no.**	**%**	**no.**	**%**	
Continence NZ helpline	3	50%	1	16.7%	0	0%	2	33.3%	6
Continence NZ website	11	84.6%	2	15.4%	0	0%	0	0%	13
Education days or conferences	10	90.9%	1	9.1%	0	0%	0	0%	11
Online courses	2	28.6%	0	0%	1	14.3%	4	57.1%	7
Community education	3	60%	1	20%	0	0%	1	20%	5
Member newsletter	6	60%	4	40%	0	0%	0	0%	10

Member survey (cont.)

Q7. Overall, did the support you received from Continence NZ make a positive difference? n=16

Answer choices	Absolutely	Very	Moderately	A little	Not at all
Number	6	4	5	0	1
Percentage	37.50%	25.00%	31.25%	0%	6.25%

Q8. Thinking about the support you received from Continence NZ, what was most helpful? n = 14

- *"Address for continence advisors."*
- *"Contacts if required, attending study days, sharing resources most helpful."*
- *"I only recently joined so haven't utilised all of the resources and support available yet."*
- *"I was a Continence Nurse at Counties District Nursing for years....over 8 years ago, CNZ keeps me informed, current and resourced, I merely deliver the info using Te Reo, on Marae, to whānau Hapū. Iwi and Tamariki. I have photos of me reading a wee and poo book to a 7 year old male bed wetter, it made him feel better about not being alone, that others shared his experience, his self esteem confidence and group socializing with peers is restored, he has been invited to sleep overs 🤗."*
- *"I'm still waiting to get the information that we were told we could get emailed."*
- *"Info sheets re incontinence and study days."*
- *"Networking."*
- *"Online education opportunities."*
- *"Online resources and info sheets."*
- *"Providing resources for patients and their whānau. Also education for myself on study days."*
- *"Study days Continence website Pamphlets for pts."*
- *"The Courses and the educational material/pamphlets for patients and the packs used for hosting education events in the community."*
- *"The study days, information packs, pamphlets for clients."*
- *"We refer community members who need continence support to Continence NZ. Not enough New Zealanders know about your services, it's good to work together to support the wider community of people who need continence advice and help."*

Q9. Thinking about the support you received from Continence NZ, what could we improve on? n=11

- *"Continence NZ serves a broader community than professionals. It could strengthen its representation and membership and supports to have more consumer input/perspective."*
- *"Keep providing professional education for members both in person and on line."*
- *"More workshops and presentations throughout the country. Especially the South Island."*
- *"n/a."*
- *"None that I can recall."*
- *"Provide advocacy for patients and provider with government, health service etc."*
- *"Resources and literature in Te Reo, not posters with Te Reo and images of non Maori, it does not relate."*
- *"Resources for autistic children. Links to other relevant website and information."*
- *"Send info when told it was coming."*
- *"Unsure."*

Member survey (cont.)

Q10. Is there any other support you would like Continence NZ to provide? n =11

- *"Continence NZ deserves considerably more recognition and government funding. Its helpline and resources are essential in an ageing community, and its professional networks also deserve more recognition, support, and funding."*
- *"I used the resources from the Continence awareness week and delivered the Kaupapa to tamariki but could do with out the coffee and tea sachets, obesity, diabetes are potential contributes to Maori continence so hold off the chocolate as well....thank you."*
- *"If I had the info I would know more about what I'd need or want."*
- *"I'm looking forward to the conference."*
- *"Introducing more online education for health professionals."*
- *"No."*
- *"Quick response to any queries."*
- *"Resources information eg pessary kits, TNS machines, educational resources for pain etc."*
- *"Very good website, cannot think of any."*
- *"Wider inclusion of info for medical people."*

Community survey

Results

Total Survey Responses: 190

Survey respondents volunteered to participate in the research via Facebook, our community newsletter and partner organisations.

Q1. What area of New Zealand do you live in? n=190

Answer choices	Percentage of population	Response percent	Responses
Northland	3.9%	4.32%	8
Auckland	33.1%	21.62%	40
Waikato	10.0%	9.73%	18
Bay of Plenty	6.8%	20.00%	37
Gisborne and Hawke's Bay	4.6%	4.86%	8
Taranaki	2.5%	2.70%	5
Manawatū - Whanganui	5.0%	5.95%	11
Wellington	10.6%	12.43%	23
Nelson - Marlborough	3.2%	3.24%	6
West Coast	0.6%	0.0%	0
Canterbury	12.8%	10.27%	19
Southland and Otago	6.8%	4.86%	9

Community survey (cont.)

Q2. What is your gender? n=190

Answer choices	Response percent	Responses
Female	73.16%	139
Male	26.84%	51
Gender diverse	0.00	0

Q3. How old are you? n=190

Answer choices	Response percent	Responses
Under 18	0.0%	0
18 - 24 years	1.05%	2
25 - 34 years	4.21%	8
35 - 44 years	5.26%	10
45 - 54 years	11.05%	21
55 - 64 years	17.37%	33
65 years and older	61.05%	116

Q4. What is your ethnicity? n=190

Answer choices	Population percentage	Response percent	Responses
NZ European	70%	79.47%	151
Māori	17%	5.79%	11
Asian	16%	4.74%	9
Pasifika	8%	0.53%	1
Prefer not to disclose	-	1.05%	2
Other		4.21%	8

Responses to 'other':

- *"British"*
- *"Canadian"*
- *"Kiwi"*
- *"New Zealander" (3)*
- *"Pakistani"*
- *"South African"*

Community survey (cont.)

Q5. What best describes your interest in Continence NZ? n=190

Answer choices	Response percent	Responses
I have a continence concern	62.63%	119
I am a parent seeking support with toilet training	2.63%	5
I care for a family member with a continence concern	12.63%	24
I am a teacher or other professional supporting a person with continence concerns	2.11%	4
I am a health professional who works with people with continence concerns	10.00%	19
I represent an organisation that works with people with continence concerns	2.63%	5
Other (please specify)	7.37%	14

Responses to 'other':

- *"Have a disability."*
- *"I am incontinent."*
- *"I am retired and in my 70 years I can't afford incontinence product so when home I wear babys nappie liners and keep the pads for going out which is once a week."*
- *"I am retired and want to be ready if I myself face this problem."*
- *"I have continence problems."*
- *"I DO NOT HAVE ANY CONTINENCE CONCERNS."*
- *"Just aware that this may be a problem in the future."*
- *"May have a continence concern one day."*
- *"My problem has resolved itself."*
- *"Night time concern."*
- *"Paraplegic with SPC."*
- *"Preparing for future needs with Parkinsons."*
- *"We are a product supplier."*
- *"Work with Well Health Child (Plunket)."*

Community survey (cont.)

Q6. Have you accessed any of the following support provided by Continence NZ? n=163

Answer choices	Heard of			Used		
	No.	%	Total Responses	No.	%	Total responses
Continence NZ helpline	111	63.06%	111	30	38.46%	78
Continence NZ website	78	69.03%	78	62	69.66%	89
Education days or conferences	28	28.28%	99	17	23.29%	73
Online courses	27	26.47%	102	12	17.65%	68
Community education	36	35.64	101	17	25.37%	67
Community newsletter	53	51.96	102	34	46.58%	73

How useful was the resource? n=163

Answer choices	Very useful		Somewhat useful		Not at all useful		N/A		Total respondents
	no.	**%**	**no.**	**%**	**no.**	**%**	**no.**	**%**	
Continence NZ helpline	26	68.4%*	6	15.8%*	6	15.8*	17	30.9%	55
Continence NZ website	30	55.5%*	25	44.6%*	1	1.8%*	14	20.0%	70
Education days or conferences	14	66.7%*	4	19.1%*	3	14.3%*	24	53.3%	45
Online courses	11	68.8%*	3	17.8%*	2	12.5%*	25	61.0%	41
Community education	16	64.0%*	3	15.8%*	0	0.0%	25	56.8%	44
Community newsletter	17	56.7%*	12	40.0%*	1	3.3%*	18	37.5%	48

*Percentage adjusted to remove those who responded n/a (i.e. had not used the resource)

Q7. Overall, did the support you received from Continence NZ make a positive difference? n=157

Answer choices	Absolutely	Very	Moderately	A little	Not at all
Number	35	33	26	37	26
Percentage	22.29%	21.02%	16.56%	23.57%	16.56%

Community survey (cont.)

Q8. Thinking about the support you received from Continence NZ, what was most helpful? n=148

- *"-" (2)*
- *"A presentation at Katikati PD meeting and newsletters."*
- *"Ability to receive information direct to e-mail."*
- *"Accurate information."*
- *"Advice on products."*
- *"Advice received."*
- *"All."*
- *"Am not alone."*
- *"Amazing resources and videos that are available on website."*
- *"An open question answer/time meant all my queries were answered."*
- *"ATTENDING THE COURSE AND VISUALIZATION OF SCENARIOS."*
- *"Awareness of how big a problem it is and ways of seeking help."*
- *"Being able to attend online sessions when distance to attend face to face can be difficult."*
- *"Being able to talk to someone."*
- *"Being able to talk with someone knowledgeable who understood the problem."*
- *"Being given something practical to try even though it didn't work."*
- *"Being there and answering my questions."*
- *"Can't think of any thing at the moment."*
- *"Clear precise guidance. Able to recognize differences and what they could be a contributing factor."*
- *"Discussion."*
- *"Easy to use information with client's Increased knowledge."*
- *"Education and information."*
- *"Education days."*
- *"Education for paediatric continence nurse that we have been able to share with families we work with."*
- *"Educational talk from your head of Continence to our group at Mt Maunganui a couple of years ago."*
- *"Exercises."*
- *"Explaining the products, filling out charts to find out what type of bowel incontinence it was, and how often to figure out how many products I would need, and how often. The latest developed products were discussed with me so I could choose what to try, see if it fits, and then get repeat orders."*
- *"Factual information about incontinence."*
- *"Financial."*
- *"Finding out about Pelvic Floor exercises."*
- *"Folllow up."*
- *"Gave me clarity of what I am dealing with."*
- *"Gave me incentive to talk to Dr."*
- *"General ideas."*
- *"General information."*
- *"Have only recently found out about them - speaker came to Wellington and presented to our network of elderly people - will probably also get her to present to our staff via web link."*
- *"Haven’t had help.*
- *"Having a visit from the continence nurse from Hospital."*
- *"Havn;t heard or used."*
- *"Help manage and sort my Daughter incontienence issue manageable. I find Paediatrics only offer medication and not much help otherwise."*
- *"Helpful tips."*
- *"I am still waiting for the appointment with the Continence nurse for my 89 year mother. I have had support from Lisa."*

Community survey (cont.)

Q8. (cont.)Thinking about the support you received from Continence NZ, what was most helpful? n=148

- *"I am unsure."*
- *"I have not needed support yet."*
- *"I have not received any support from Continence NZ."*
- *"I have not requested any support."*
- *"I haven't tried it."*
- *"I use the information from the virtual course to help parents understand and ease their children's urine or bowel problems."*
- *"I'm not alone."*
- *"Information and knowing how to receive support."*
- *"Information on the way the body functions. In the past little knowledge was available and we were brought not to discuss any health problem."*
- *"Information re my problem."*
- *"Information." (3)*
- *"It was a while a go. I used the website once. I forgot it was there. I don't watch much TV or listen to the radio so I wouldn't see any ads.... but I am on Facebook more often. How I used the site. I received some pamphlets in the mail with some info. So I got some education about my issues. I also got some cards in the mail I could carry if I needed the toilet in a hurry but I never used it coz it seems a bit embarrassing to use them as I don't think retailers are familiar with it?"*
- *"It was informative and I need more info and support."*
- *"It wasn't."*
- *"It's good to know there is support. I mostly share its resources to others."*
- *"It's most helpful to have plenty of people to host through helpline. But that's not to be as there aren't enough people as I tried ringing them a few times and not been treated as a 24/7."*
- *"It's the norm for our age."*
- *"Just being able to speak with an experienced continence nurse who was able to discuss ways to manage my urinary incontinence. GPs are limited in their knowledge of such matters and their time is limited too, in contrast to the time and knowledge provided by the continence nurse."*
- *"Just getting someone to explain things to make things easier to get help."*
- *"Just knowing that there is support if I need it."*
- *"Just some practical ideas."*
- *"Kegel."*
- *"Knowing I am not alone and getting helpful ideas."*
- *"Knowing I was not alone."*
- *"knowing others in same position."*
- *"Knowing that there are a lot of people out there in the same situation as I am in."*
- *"Knowing that there was support and resources available."*
- *"Knowing there was help when needed."*
- *"Knowing they are available if needed."*
- *"Knowing what I had was not abnormal."*
- *"Knowledge provided."*
- *"Learning about incontinence and resources that are available to someone with this condition."*
- *"Learning that there are solutions to my problems."*
- *"Lined underwater."*
- *"Lisa's 8 online seminars about bowel and bladder continence."*
- *"Mr poo and helping to explain better tips and ideas when dealing with special abilities."*

Community survey (cont.)

Q8. (cont.)Thinking about the support you received from Continence NZ, what was most helpful? n=148

- *"My condition hasn't improved over time, the best thing is hope it might."*
- *"My urologist/gynecologist suggested I subscribe to the newsletter. I find the educational education helpful."*
- *"N/a." (4)*
- *"need to concentrate on questions from audience."*
- *"Never contacted Continence NZ."*
- *"Never heard of them, so no help... Its all word of mouth thru other disabled people!"*
- *"New pessary."*
- *"Newsletters." (2)*
- *"Newsletters and tools."*
- *"Newsletters- we share them amongst our organisations and hope that they share them with their clients"*
- *"No direct communication, just heard about them."*
- *"No idea it existed."*
- *"No."*
- *"None received."*
- *"None to date."*
- *"None yet."*
- *"Not a lot."*
- *"Not applicable as haven't been aware of the service."*
- *"NOT APPLICABLE."*
- *"Not helpful really. I am incontinent of bowel and bladder."*
- *"Not much to date."*
- *"Not relevant." (2)*
- *"Nothing."*
- *"On the spot advice about my husband who suffered a temporary issue."*
- *"Online Education with Lisa was excellent - great explanations to support reasons for actions etc - honest language used - not a big medical intimidating approach."*
- *"online resources."*
- *"Pad use Toilet use Exercise for the bladder."*
- *"Pelvic exercise information and product help."*
- *"Practical information to give genuine support to patients."*
- *"Providing help, support, advice and ongoing supply of the necessary supplies I need to lead a normal life. I appreciate it very much."*
- *"Pubic floor exercise."*
- *"Reading what was available around the country and to different groups."*
- *"Reassurance that we were doing ok."*
- *"Receiving my padded underpants."*
- *"resource content and information on pelvic exercises. wee chat."*
- *"Starting children toilet training as soon as possible after two so that it does not become harder when they are three or four and are not interested."*
- *"Supply of pull ups."*
- *"Supplying pads."*
- *"Talking about it."*
- *"Talking to the men about continance, normalising the condition, highlighting pelvic floor exercise."*
- *"That there is a website available and I am not alone."*
- *"The handouts to give children last yr for continence week."*

Community survey (cont.)

Q8. (cont.)Thinking about the support you received from Continence NZ, what was most helpful? n=148

- *"The Incontinence Training session was excellent for staff so they could have a better knowledge to support their clients."*
- *"The knowledge that practical help would be available at the local hospital (Tauranga) if the suggested measures were inadequate."*
- *"The knowledge that practical help would be available at the local hospital (Tauranga) if the suggested measures were inadequate."*
- *"The latest correct advice - I felt confident sharing the information."*
- *"The newsletter."*
- *"The online webinars by Lisa Smith - fantastic info."*
- *"The pamphlet was interesting and informative. I also listened to a speaker who was very good."*
- *"The supply of Mums continence pads & helpful advice."*
- *"The toileting tactics for tamariki was brilliant."*
- *"They sent me a form to fill for my son."*
- *"this survey is a start."*
- *"Tip and tricks."*
- *"To know what is available to us."*
- *"Toilet training tips."*
- *"Understanding of my problem. Made a huge difference."*
- *"Understanding the problem."*
- *"Useful and relevant info."*
- *"Very little."*
- *"We have only been using the system for a few months but delivery of the product required has thus far been delivered on time and without any problems."*
- *"What other options are available."*
- *"Yes."*
- *"Your newsletter are helpful ."*

Q9. Thinking about the support you received from Continence NZ, what could we improve on? n 134

- *"-" (2)*
- *"?"*
- *"A LONGER CONFERENCE AND INTERACTION. SEEMED TO BE QUICK, UNLESS ITS BECAUSE I FOUND IT RELEVANT AND INTERESTING."*
- *"Accessibility to services that can help you deal with incontinence issues."*
- *"Adolescents and incontinence."*
- *"Advertising & community outreach."*
- *"Advertising. Making continence something that can be helped. That sure there are products available but first and foremost people should see if they can do something to reduce/prevent the continence issues."*
- *"advised already."*
- *"All good."*
- *"All Ok."*
- *"All very good keep up good work."*
- *"As far as I am concerned it is working well for me. No improvement needed."*
- *"As I haven't needed support I can't comment."*
- *"At the moment I cant think of anything."*
- *"At this point I am able to cope alone."*

Community survey (cont.)

Q9. (cont.) Thinking about the support you received from Continence NZ, what could we improve on? n=134

- *"Availability of services and promotion. Not many people know of the service."*
- *"Better marketing."*
- *"Cannot comment as we only use the delivery system."*
- *"Can't think of anything at the moment."*
- *"can't think of anything."*
- *"Communication."*
- *"Continue with support and education for professionals and clients."*
- *"Definitely more people, more volunteers, more resources, and more preferences such as events that focuses all in each kind of people."*
- *"Do you provide incontinence nappies."*
- *"Don't know."*
- *"Easy to navigate website."*
- *"Follow up with an appointment or phone call." (2)*
- *"Following up to see how things are going."*
- *"For health workers working with the older person to have access to education, podcasts, videos, webinars that are free. I can access continence Australia plus subscribe to Bridge magazine for free. Am not going to pay for education from NZ when it costs. It's a shame, because the younger health care workers enjoy and seem to learn more from visual education that having a classroom type education."*
- *"Free samples, there are so many products but it would be nice to try before you spend so much money."*
- *"Getting your name out there so people know you are around."*
- *"Has been good, and thanks for the great service."*
- *"Have not re."*
- *"Have only used Spinal unit urology."*
- *"Having a broader range of classes in other areas."*
- *"Having resources for parents around toilet training."*
- *"I am happy with what you are doing."*
- *"I am in Dunedin Otago not listed at the beginning."*
- *"I am only a new user, I have not established a thought one way or the other."*
- *"I am very happy with the service and see no need to improve on it."*
- *"I can't remember. Maybe a follow up call, some one to guide me through next steps of getting support."*
- *"I dont know yet I have not accessed any services yet."*
- *"I have tried most things over the last 30 years, so can't suggest any."*
- *"I haven’t requested any."*
- *"I haven't tried it."*
- *"I keep hoping there will be some helpful classes in the BOP area - Tauranga."*
- *"i think they do a great job."*
- *"I was very happy with the help."*
- *"I’m not that bad as yet."*
- *"I'd love notes from the lessons if possible."*
- *"It is a great service. I don't feel you need to improve on anythingt is a great service. I don't feel you need to improve on anything."*
- *"I'm happy with support."*
- *"I'm not sure."*
- *"Increased public exposure so that people are more aware of your services."*
- *"Information."*

Community survey (cont.)

Q9. (cont.) Thinking about the support you received from Continence NZ, what could we improve on? n=134

- *"It was fine."*
- *"It would be good if Continence NZ could supply pad & pullup samples from different manufacturers as a "one-stop" source as it can be a problem locating suppliers and knowing what to ask for. A nominal fee could be charged ($10?) to cover postage and packaging."*
- *"It would be good to be forwarded on to the people who could have advised about nappies and size etc. I was a bit lost at sea. The people I was advised about supplied a pretty bad nappy way to big and didn't seem to have anything suitable. Eventually I found Easie Living and Mobility Manawatu. The latter were REALLY helpful and offered samples."*
- *"It's not so much you as the consumables, ACC and DHBs!"*
- *"Keep on doing the great support that you are giving us."*
- *"Let people know what is out there and how to use or access them."*
- *"Making access to supplies easier and cheaper. Pensioners do not have all the resources necessary to simply order online."*
- *"making info easier to find for parent as a lot of them struggle with constipation or getting kids to poo on the toilet."*
- *"more advertising of support on a regular basis."*
- *"More advice on pelvic exercises to strengthen muscles and how to cope when desperate to pee and you are out somewhere and can't find a public toilet!!"*
- *"More awareness."*
- *"More contact I have only had contact in regards to ordering supplies."*
- *"More Education to Paediatricans as even though they have clinical knowledge sometimes they have no idea what their Patients go through. School would also be a good place to have information that Parents can access when they need it. There is so much pressure on kids to be continent Parent's, Teacher's and sometimes Medical Professionals lack practical knowledge to help. Especially around Faecal incontinence."*
- *"More info re the treatment available."*
- *"More online webinars for those in the provinces who cannot attend in person study days."*
- *"More practical tips and tricks - and apps that let you know where the closest toilet is."*
- *"More practice support and ongoing help."*
- *"More workshop."*
- *"My 16 year son dosen't want to talk about his problem, asking him to fill form is out of question. There should be a facility that can try to convince such patients that it is a problem that can be resolved."*
- *"N/a." (6)*
- *"No clear idea."*
- *"No idea at this stage."*
- *"No idea what support you provide."*
- *"No improvement required."*
- *"Not applicable." (4)*
- *"Not aware it existed."*
- *"Not known."*
- *"Not much :)."*
- *"Not really sure."*
- *"Not sure."*
- *"Nothing - more than happy."*
- *"Nothing at this stage." (3)*
- *"Nothing." (6)*

Community survey (cont.)

Q9. (cont.) Thinking about the support you received from Continence NZ, what could we improve on? n=134

- *"Nothing, all good."*
- *"Nothing, everything that this site provides is amazing."*
- *"Nothing, the seminar was very good and covered a lot of practical scenarios, and also addressed misinformation."*
- *"Nothing..they were great."*
- *"Offer continence samples."*
- *"Ok."*
- *"Older ladies I feel is a waste of time doing pelvic floor exercises."*
- *"Our meeting was by zoom, it would be great to have someone available to attend the Prostate Cancer Support Meetings in person."*
- *"Please don't hand out photocopies of pamphlets."*
- *"Probably only the delivery system. Like one time the products didn't turn up. I rung up about it, and they could see they had been sent to me by their records, but they didn't make it to me, they managed to sort it out and there was a form with information on how to track your products. The continence service must have then sorted it at their end, so they turned up. The form tells you when your next products are likely to be delivered next. I'm just wondering if for people who suffer from poor memory, as I do, whether there was a way to streamline it so that products just automatically get to where they are meant to be, as I think it can perhaps be confusing to try to track things. Other than that, a fantastic service."*
- *"Quite happy."*
- *"Range of pants available."*
- *"Reassuring advice."*
- *"Received very little help."*
- *"Reminders."*
- *"Seeing what products are available.To find the least expensive products that are best."*
- *"Self promotion so people are aware of the service."*
- *"Sharing care plans with nurses."*
- *"Some hard copy hand outs to go along with topics - email versions."*
- *"The website is still not easy to navigate. Has a lot of info ...I use the search function."*
- *"Think I am the one that needs to work hard on improving my pelvic floor muscles."*
- *"Think it is more up to me as find it hard to accept."*
- *"This is such an overlooked area for most people, women and men. Simple education, repeated often is key."*
- *"Unsure. Love the presentation and info."*
- *"Very happy but could do with the limit your allowed increased."*
- *"Waste of space."*
- *"Well, hardly anyone in our group has heard about you, so KNOWING it exists is the first step even before improving service delivered."*
- *"Would you provide incontinence panties."*
- *"Your information is good."*

Q10. Is there any other support you would like Continence NZ to provide? n=125

- *"-"*
- *"A comprehensive list of all the services available."*
- *"A local speaker/educator would be helpful."*
- *"A phone call or visit to know what best pads, etc to use , better than I've got. Support in a long term plan."*
- *"Access to products."*

Community survey (cont.)

Q10. Is there any other support you would like Continence NZ to provide? n=125

- *"All good."*
- *"As above."*
- *"As above, so we can do online education from our homes."*
- *"Be in the ear of Te Whatu Ora continence nurses, who provide a fairly lacklustre service down this way!"*
- *"Can't think of any."*
- *"Can't think of anything."*
- *"Children assessment and treatment managent ideas."*
- *"Could there be discounted products for incontinence sufferers?"*
- *"Don't know....What you do not know?"*
- *"Don't know." (4)*
- *"Educate educate educate."*
- *"Education!!"*
- *"F2f sessions in the regions, special interest groups"*
- *"Follow up. Recommend a support group."*
- *"I am a resident at Althorp Retirement Village and greatly appreciated the talk given to us about 5 years ago by one of your team. Since that time we have both lost and gained residents, and I feel there are probably many newcomers who would benefit from a repeat/update of your guidance."*
- *"I am not sure." (2)*
- *"I am unsure."*
- *"I did enjoy the two sessions we attended about incontinence."*
- *"I don't know." (3)*
- *"I have a daughter with intellectual disability and ultra rare genetic mutation who is able to toilet, but uses huge amounts of toilet paper. She is 28 now and I haven't been able to reduce her use without making her hugely upset, and no one has had any advice. So it's not a direct issue with bladder or bowel, but the loo paper. I've never had any advice from anyone other than a shrug. I've thought about the bidet but think she would probably buck against that. My main aim is in thinking about her long term care after I have gone. I wouldn't want her mistreated by people with little patience."*
- *"I wasn't aware it provided any support."*
- *"I'd love to attend more courses on the same topic."*
- *"If Continence NZ could liaise with M.O.H and Work and Income to provide a combined, more personal, turnkey solution to each patient."*
- *"If there is some medical tests required for my son, can be forward to GP so that we start moving towards some solution."*
- *"Incontinence nappies or pads."*
- *"Incontinence products. It is costing my mother 71 dollars a fortnight to purchase."*
- *"Info on different therapies..in particular Ring pessaries..consumer revues etc."*
- *"Information of who to contact if required."*
- *"Keeping up to date with changes that can happen."*
- *"Maybe incontinence mats."*
- *"Monthly update on new products, maybe a case study."*
- *"More detailed easy access to new information that would help me."*
- *"More face to face education."*
- *"More funding and fundraising are important than ever, and that is why we need more continence professionals than today in the wake of an overheated health system in our country."*
- *"More information about services offer by Continence NZ."*
- *"More information re catheters at the meetings."*

Community survey (cont.)

Q10. (cont.)Is there any other support you would like Continence NZ to provide? n=125

- *"More links to products."*
- *"More people for face to face sessions."*
- *"N/A." (2)*
- *"Need to have disposable bins for pads in men's public toilets."*
- *"New pelvic floor muscles!"*
- *"Newsletters for any updates or new available support."*
- *"Nil."*
- *"No not at the moment." (2)*
- *"No not really."*
- *"No thank you." (5)*
- *"No thank you. I am happy with the ongoing support I receive."*
- *"No." (23)*
- *"No. I find information from Continence NZ more helpful than Paediatricans or Public Health Nurse's."*
- *"No. Very satisfied - great place to refer clients to."*
- *"None." (2)*
- *"Nope."*
- *"Not at the moment." (2)*
- *"Not at this stage."*
- *"Not at this stage. Thanks."*
- *"Not really."*
- *"Not sure." (2)*
- *"Not that I have needed yet."*
- *"Not yet."*
- *"Nothing I can think of."*
- *"pleased to see the toileting sessions happening again. I have also suggested to many of the kindys/ECEs to look at accessing these as we are seeing many toileting issues in 4yr olds."*
- *"Practical tops."*
- *"Resources - subsidies for incontinent pants etc."*
- *"See above."*
- *"See previous."*
- *"Seek medication from Dr as urge continence pelvic floor exercises in my 70 plus years did not help."*
- *"Send info would be great."*
- *"Specific targeted advice for 4 year olds pooing in nappy and constipation."*
- *"Still a new user of this website."*
- *"Support for disability kid."*
- *"The only thing from our perspective would be the choice of the incontinence underwear - the product provided is a lot bulkier than the Depend brand that you buy in supermarkets which also fits better."*
- *"Train carers to change spc catheters."*
- *"UNABLE TO SAY AT THIS STAGE. THANK YOU."*
- *"We have 45 Support Groups throughout NZ - it would be helpful for us to know about Continence contacts around NZ."*
- *"What else do they provide."*
- *"What help is available."*
- *"What is the next step if a bowel clear out doesn't work."*
- *"What services do you provide."*
- *"Would like information."*

Community survey (cont.)

Q10. (cont.)Is there any other support you would like Continence NZ to provide? n=125

- *"Would like to work with them to help better support people living in the community with continence issues."*
- *"Yes where can I go to get physio that is fees free. Without having to wait for months for the hospital."*
- *"Yes, the disparity between the type of catheters provided for ministry of health clients versus ACC clients is huge and in many cases has a major impact on health and life."*
- *"You are doing a great service."*

Our sincere thanks to the NZ Lottery Grants Board for funding this research.

Supported by Lotto New Zealand
Funded by NZ Lottery Grants Board

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The lived experience of access to continence care in Aotearoa, New Zealand: A community perspective

Celeita Williams and Laura Fear

Contents

Introduction

The New Zealand Continence Association Incorporated (hereafter referred to as Continence NZ) is a not-for-profit organisation with a mission to "improve the standard of healthcare delivery to those with bladder or bowel incontinence dwelling in the community, in rest homes or hospital settings in New Zealand" (Continence New Zealand, 2022). Continence NZ provides life-changing advice, resources, education and support for the 25 per cent of people living in Aotearoa, New Zealand who are impacted by incontinence or a continence concern, and the one in ten people who are family, whānau and carers of a family member at home with incontinence (Continence New Zealand, 2022).

The purpose of this research project was to provide insights into how Continence NZ can most effectively serve those living with continence concerns in Aotearoa, New Zealand and to ensure the services provided are fit for purpose for the public. The information gathered by this research will be discussed below and will be used to shape and progress the services Continence NZ offers. The aim of this report is to highlight community continence concerns, advocacy, awareness and where Continence NZ can provide support. Ideally, this will help Continence NZ to provide a fit-for-purpose service in conjunction with other continence care providers such as primary health organisations and Te Whatu Ora. The final aim of this research is to provide evidence of the need for support in the community and to assist Continence NZ to secure future funding.

To facilitate community engagement, people were invited to share their thoughts, ideas and experiences using focus groups and semi-structured interviews. The use of these settings enabled people to discuss and share their experience of continence concerns and continence care in Aotearoa, New Zealand and served a further purpose of developing an understanding of the general public's experiences of incontinence, and their knowledge of Continence NZ.

The development of this project involved an independent researcher planning and facilitating each of the focus groups and semi-structured interviews. Where appropriate, a local representative was engaged to help with networking, recruiting, and ensuring cultural safety. To ensure an ethical approach was maintained, the Health and Disability Ethics Committee (HDEC) was consulted.

After ethics was approved and prior to recruitment of each focus group, careful consideration was given to the time of day and venue each focus group was facilitated. In order to remove barriers for participants and allow inclusiveness through ease of access, each venue was fully accessible. Large font and Dyslexie font information sheets were provided, as well as the option of being able to engage and communicate with those who experience mobility, speech and hearing disability. Recruitment was conducted both online and offline through the Continence NZ Facebook page, posters in General

Practice rooms and other community locations. Accessibility information was made available to potential participants prior to engagement in the research project.

A total of 28 people participated in the project: 6 males and 22 females. Data analysis was conducted using reflexive thematic analysis, with key themes identified for further discussion. Once completed, each focus group and interview were transcribed and reflexive thematic analysis was utilised to identify key themes, memorable quotes, and suggestions for transformation in support, access to services, and continence care in New Zealand.

Throughout data familiarisation and analysis there was one message that became clear. Continence care in Aotearoa, New Zealand is a journey of finding solutions and trying to maintain dignity along the way. As such, the report will focus on sharing people's knowledge and experiences of their journey with continence care. It will highlight the support required for each of the participant groups and will conclude with a discussion of the overall project findings.

Ethics, consent and participant confidentiality

Ethics approval was granted through an exemption from the Health and Disability Ethics Committee in Aotearoa, New Zealand. Each participant was provided with an information sheet and given the opportunity to ask any questions prior to the focus group, interview or survey being completed. Signed consent was received from all participants. For those who participated in a semi-structured interview via an online video conferencing software, a consent form was posted in advance with a pre-paid pre-addressed envelope to return the signed consent form to the researcher. Any recordings of the semi-structured interviews were saved to a password-protected file for transcription and removed from online cloud storage. Any identifying information was removed from transcripts and pseudonyms were used.

Methods

A qualitative research approach was selected for this project as it allowed for exploration of opinions and perspectives and for experiences of people to be shared. Focus groups and semi-structured interviews enabled participants to discuss their experiences in a supportive environment, where they were able to speak freely. To ensure that a range of perspectives were considered, recruitment took place both online and offline, through whakawhanaungatanga and snowball recruiting.

Focus groups were the primary source of data collection, with semi-structured interviews introduced towards the end of the project to provide a more culturally responsive approach for Māori participants. Each participant completed a survey prior to participation in the focus group or interview. The survey was available to participants in both hard and soft copy. The purpose of the survey was to collect demographic data and for participants to share their positive and negative experiences with continence care anonymously outside of the group setting. A copy of the survey questions can be found in Appendix A.

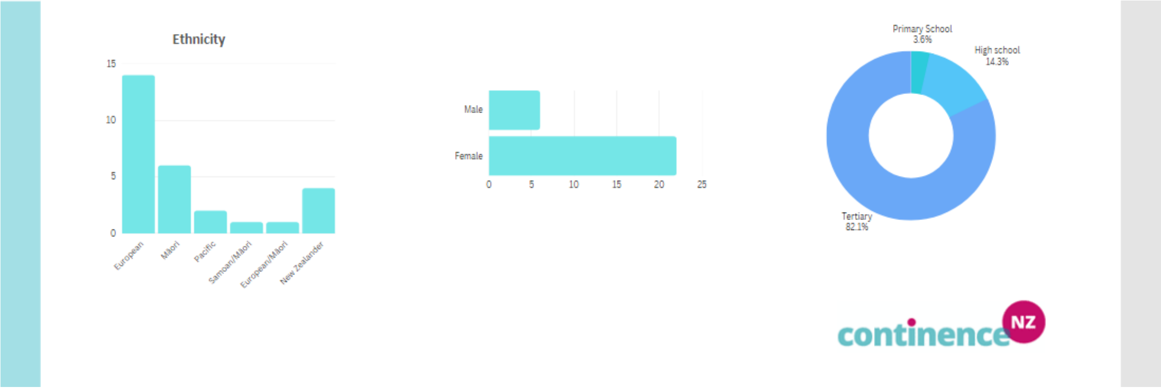
The focus groups were held in five locations throughout New Zealand. Each group had a focus on experiences with incontinence or continence concerns and seeking support, with a sub focus on specific populations. Representation was sought from people with disabilities, the over-65 population, parents of children, people who cared for those who experienced incontinence or a continence concern, men who had experienced prostate cancer, and those from the Pasifika and Māori populations.

A small group of participants in the Pasifika focus group provided feedback that due to the sensitivity of the topic and whakamā, it would have been more appropriate to facilitate their focus group in a different forum. This feedback led to the exploration and introduction of semi-structured interviews for Māori participants. When interviewed, each of the Māori participants agreed that they felt more comfortable participating in this project with a one-on-one conversation. Semi-structured interviews were conducted via an online videoconferencing forum and were one-on-one interviews. Although no time limit was provided for each interview, all interviews were completed within two hours.

Participant demographics

There was a total of 28 participants who participated in focus groups or semi-structured interviews. Participants selected their ethnicity with 14 identifying as European, 6 as Māori, 2 as Pacific, 1 as Samoan/Māori, 1 as European/Māori, and 4 as New Zealanders (self-specified under other ethnicity option). Of the participants, 6 were male and 22 were female. The age range of participants was 25 to 84 years. The highest level of education for the participants was primary school (1), high school (4), or tertiary (23). 19 people also identified they were a caregiver of someone who had a continence concern and 27 experienced leakage of urine or faeces themselves.

Figure one: Participant representation by ethnicity, gender and highest level of education.



Focus group facilitation

Upon arriving at the venue for the focus group, each participant was provided with a participant information sheet and given the opportunity to ask questions about the research project prior to signing a consent form for participation and video recording. After consent was signed, demographic data and an anonymous survey were completed then a whakataukī was shared. After this an introduction of the focus group, setting of ground rules (each group established their own rules for the duration of the focus group), and a general discussion was held.

The discussion led into the three primary questions which were asked with an aim to capture people's lived experience with continence care in Aotearoa, New Zealand. Discussion was allowed to continue if it was respectful of the group's ground rules. At no time did the group facilitator have to intervene or mediate the discussion. Each question was structured in a way that allowed free dialogue and for participants to detail their experiences of continence care. There was no set time limit for each question to be discussed, and the conversation was allowed to continue until it came to a natural end, or the next question was beginning to be discussed. This allowed participants to feel empowered through shared experiences and gave rich data for analysis.

After introductions, the first question was utilised to open dialogue around the room. The group was asked: *Tell us about your experiences, both positive and negative, with continence care in New Zealand?* The second question was around support, and the group was asked: *What support would you or your whānau, client or patient need for continence care?* The third question was: *How would that support best be delivered?* To close the discussion, each of the focus groups was asked the following question: *If we could do one thing to make continence care different, how could Continence NZ best meet the needs of the group? What would be your ideal outcome from this discussion today?*

To close each focus group or interview, people were given the opportunity to discuss any questions or concerns and a karakia was shared.

Data analysis

Reflexive thematic analysis (RTA) was used as the basis of data analysis. RTA was applied as it provided a flexible and reflexive approach to analysis of the data and involved identifying themes in the body of data. Given the nature of the project and the process of data collection in different settings over a six-month period, RTA was completed with both an inductive and deductive approach. Themes identified and considered pertinent to data capture were those recognised as something of importance and those which showed a patterned response or meaning within the dataset. This allowed for conceptual theme development and the researcher to consider questions pertaining to the data (Braun, 2022).

The focus groups and interviews were transcribed verbatim and any potentially identifying information was removed. The anonymised transcripts were imported into a qualitative data analysis software NVivo (Release 1.7.1) to complete the analysis. It should be noted the software only provided a tool to allow organisation of the data during the analysis process and did not offer an objective method of analysis. Using a reflexive process, each transcript was read by the researcher several times and preliminary notes were made of themes and memorable quotes pertaining to the research. Transcripts were reviewed on an ongoing basis to ensure additional codes were applied as they were identified throughout the process of coding all transcripts.

Once initial themes had been identified in the data set, an exploratory coding frame was applied with labels assigned to portions of the transcripts. These were phrases, sentences or paragraphs. The data was then recoded according to the themes as categories became defined throughout the data analysis phase. Initially, the codes were broadly descriptive but in time became more refined and detailed more subtle nuances from the data. The codes were then discussed with the secondary author to ensure validity. Further analysis was completed to ensure RTA was applied.

Results

This section will highlight key findings and themes from initial data analysis of the participants' answers to the questions in the focus groups and semi-structured interviews. It will share the experiences of people who receive continence care for themselves, whānau or those they work alongside in a caregiving role. After initial impressions and experiences are highlighted, there will be a focus on the positive aspects of seeking help and the resilience demonstrated by the people who shared their experiences. It will reflect on the importance of reframing the narrative surrounding continence concerns, as we seek to promote understanding, empathy and support.

To begin we will first reflect on each of the questions asked:

> *"Tell us about your experiences, both positive and negative, with continence care in New Zealand?"*
>
> *"What support would you or your whānau, client or patient need for continence care?"*
>
> *"How would that support best be delivered?"*
>
> *"If we could do one thing to make continence care different, how could Continence NZ best meet the needs of the group? What would be your ideal outcome from this discussion today?"*

When people were asked to share their experiences with continence care, there were remarkably diverse experiences detailed. Factors that contributed to each person's experience included why they needed continence care, how they sought care, who the initial consultation was with, the duration of care they received, and what problem-solving skills they utilised to be their own advocate as they navigated through the system. Many respondents reflected on their experiences being disappointing and that they felt let down by the health system.

The key findings of experiences receiving continence care highlighted that many people had trouble getting started in the system, not knowing where to start looking for help, or feeling like they were not heard by the people they had turned to for help. Frequently there was discussion about there being no real starting point to get help, with people stating comments such as:

> *"Where do we go for help? There's other information that needs to be out there [referring to cervical screening and bowel cancer screening]. But I don't think there is a lot of information about incontinence."*

With another backing this up and stating:

> *"They have everything you know, about sickness, when you're older and all this, but there's nothing about incontinence,"* and another highlighting, *"I think like [sic] as well, for people that I look after, they find it hard to, who do you go to if they're having a problem?"*

These statements imply that even people who are educated or trained as caregivers don't know where to find help for the people they are caring for who have continence concerns. This was reinforced by another participant who provided care for people but was never given any training on how to handle the situation when someone they were caring for experienced incontinence.

Some people had difficulty asking for help because they were embarrassed. Some in fact so embarrassed they never sought help, and their participation in the focus group or interview was the first place they had ever openly discussed their continence concern. Several participants discussed that having to ask for help is an issue, and it was suggested throughout several groups that screening for continence concerns should be as routine as checking blood pressure. There are some good examples of participants' viewpoints when it comes to seeking help because of embarrassment, with participants discussing:

> *"Having to ask is a block, so, like it should be somewhere you can go 'oh, okay it's there somewhere'. You can ask for it from somebody who you know understands what, what I need."* Another expressed, *"I think it is, for me, not talking much about my doctor and, and with my doctor and things about it, I think my mentality has just been I know this is unusual, it's not the, the greater population, but um [sic], we all have our weak genetics or our little quirks, or you know we're all different. From colour blindness to, you know, genetically we've got triggers for*

> *colour blindness right through to cancers and all the rest of it, and mine's bladder weakness, and I've just kind of sucked it up and, because of that I've not been able to ask for help."*

The 'self-weakness' perspective was also expressed several times throughout the interviews, where participants thought they knew their body well, and their incontinence was happening because they hadn't looked after themselves, especially post-partum.

Many of the participants felt that they were going around and around in circles and often felt not listened to. Not being heard by the clinician was a significant theme that was present throughout all focus groups and interviews, except for men who had experienced prostate cancer. Experiences of this were summarised by participants:

> *"It's been a real struggle for years to get anybody to listen or to just not fob off me and my urine incontinence."*
>
> *"Not listening, yeah, and I, I found that a lot. You know I just feel, yeah constantly like not listened to, or they're not listening to the whole story."*

It seems that it is even more challenging for those with children who had a disability or neurodiversity, with many participants discussing the point that they did not feel listened to. One parent expressed:

> *"When your kid is not in the norm, you know there's something different about them, as a parent we should be listened to as well because we're the first ones that know exactly how our kids are, um we just know, probably the only ones that know them best, you know, so when you're putting it on paper, paper is never going to explain how your child is."*

Sometimes when people sought help from a medical professional or other clinician, they felt like they had not been heard. This was a prominent point of discussion for the people who expressed they had been brave enough to disclose to their doctor or nurse they were having trouble with incontinence, most frequently urinary incontinence. Participants reported that often it was brushed off as 'normal because you have had a baby' or 'normal because you are getting old so what do you expect'. Many people had similar experiences and stories to share of feeling like they were not heard, and they also experienced this when they were referred to a specialist. This specialist, whether it was a continence nurse, women's health nurse, gynaecologist, urologist, paediatrician or geriatrician, was noted by participants to do the same thing as the first doctor, and generally didn't get to the cause of the problem.

Not only was not being heard a concern, but several women were also told that their incontinence couldn't be improved or fixed until they lost weight. The dialogue around weight loss continued despite them insisting it wasn't a problem before childbirth, when they were fit, well and the same weight they were before they began experiencing incontinence. This was a theme particularly present among Māori participants who expressed the deep hurt this comment initiated, especially when they later found that their incontinence was not caused by their weight.

The feeling of not being heard was further compounded by having to explain the same situation repeatedly. This experience was not isolated to any population of participants but was most prominent in people with disability or those who have children with neurodiversity. They felt that even though it may have been an expected part of the 'diagnosis', whether that was neurodiversity or disability, they knew something wasn't right, and time and time again they weren't listened to. One participant highlighted the challenges of this situation well and stated:

> *"I suppose the other thing is having to explain yourself over and over again to the different doctors. It is exhausting, especially when we know what is happening day to day, we are living it, why can't they listen."*

Another common comment from participants was that the doctor, referring to the General Practitioner (GP), didn't know what was 'normal' and 'acceptable' when it came to people experiencing urinary incontinence. It was clear that often people were told it was normal to experience incontinence. This theme of incontinence being 'normal' extended through all groups but was especially prominent for women who had birthed a child (whether vaginally or via c-section), women who were ageing, or mothers of children who were wetting themselves during the day or pooing multiple times a day – when in fact there was an undiagnosed underlying condition.

Many women discussed their experiences of giving birth and that they have had urinary leaking post-partum (some for over 30 years). There was a common theme regarding this specific situation, and this was that they had been told it was normal to leak urine because they had had a baby. This normalisation extended through to those of older ages as well, with many women being told that incontinence was just a normal part of ageing. One had been told every time she went to the doctor that everything she was experiencing was because of old age, however when she challenged her gerontologist and used an analogy of her knee (which she also had a problem with), she was yet again told it was because of old age. She promptly replied to this with the following comment:

> *"Well, my other knee's the same age and it doesn't have a problem."*

It was her own comment about her knee being the same age and not having any problems that led her to wonder if she was being told something was a problem because she was old. When she was finally brave enough to talk to her friend about the fact she was leaking urine, and she learnt that her friend of the same age did not, she understood incontinence wasn't an age-associated problem.

What went well – people's positive experiences

Positive experiences of continence care in the 'system' came from sharing stories of each other's journey. For many participants, it was not until they were sitting in the focus group or interview where they were able to reflect on their journey and discuss it with someone else that they realised it had not been quite as bad as they had thought. This was predominantly present in the group of male participants who had experienced prostate cancer treatment in both public and private hospitals. Generally, people felt more prepared for the journey ahead with continence-related concerns if they had experienced care for prostate cancer treatment in the public system. They felt this was because they were supported and provided with information on what to expect as part of their treatment of cancer. This included the signs of continence concerns to look for, who to talk to about it and what could be done to manage it. A participant noted how backward the system felt if you were going privately for treatment of prostate cancer and noted that:

> *"Since I have been with [urologist at public hospital], the care has been, I'd say in, in public's been better and it's put me in contact with a whole lot more people and a whole lot more um [sic], help that's available out there."*

This statement and wider discussion in the focus group show that when there is a plan in place for people to be able to access services and learn what is expected of a condition, it can be a positive process and experience, even for something as difficult to talk about and embarrassing as a continence concern. It is reassuring to know that the whole package of care can be delivered if people know what to expect, where to navigate and how to get the help they need for their condition.

This experience was also discussed by those participants who had sustained an injury, whether it was as a result of an accident or medical misadventure. Usually, continence care went well, because it was expected as part of the nature of the injury – things like spinal cord injury (including cauda equina) or other neurological conditions. However, not everyone's interaction with continence care (in the context of an injury) funded by the Accident Compensation Corporation (ACC) was positive. Several people expressed difficulty in being heard, getting support and receiving the correct allocation of resources to manage their continence concern. Although it is important to acknowledge the challenging experiences participants had with navigating the ACC system, the complexities of individual cases are outside the scope of discussion for this report.

Other positive experiences shared were from those who were brave enough to ask for help with their continence concern and generally had a good experience with their initial consult. This consult may have been provided by a paediatrician, GP, the Continence NZ helpline or a pelvic floor physiotherapist. One participant expressed the importance of support and noted:

> *"When my doctor was committed to me and my care, it helped me to find the right support I needed."*

However, when onward referral was made to other continence services, whether this was through continence nursing, urology, gynaecology or women's health, people started to feel that barriers appeared. This is where it became prominent that if people didn't know how to navigate the system, it became difficult to get the necessary help.

Despite the barriers present with referrals, there were experiences shared where barriers did not appear as frequently. This was the case for some families who had children with high needs because of neurodiversity. These experiences were usually positive when a multi-disciplinary team of professionals became involved and were able to look at the big picture of what was happening for the child experiencing a continence concern. One example was given by the mother of a neurodiverse child who, after an initial consult with a paediatrician, was referred to a continence nurse. The continence nurse then noted the additional needs the child had and made onward referrals to occupational therapy and for further assessment by an organisation called Explore.

What this experience highlights is when the team works together and has good interprofessional communication, there is a clear expectation laid out for the journey ahead. Once a clear pathway of expected situations and to some extent 'milestones' is explained, it takes away the complexity of navigating the system to get answers.

What support do people need?

When participants were asked *"What support would you or your whānau, client or patient need for continence care?"* and *"How would that support best be delivered?"* there was extensive discussion on people's journey to accessing continence care. However, this time the primary focus was different. Nearly every participant involved in this project discussed that if they knew where to get started, it would have been easier. This was closely followed by the fact that if they had not been so embarrassed to talk about something that everybody does (the context of this comment is that everybody wees and poos) and were brave enough to talk to anybody, whether that was a whānau member, friend, or medical professional, they were sure their journey of continence care would have been different.

The importance of sharing experiences with whānau or friends, medical professionals who listened, or support groups and a coordinated approach to care was a positive discussion point for many participants. This was particularly prominent in the focus groups where people had a disability, parents had children with continence concerns, or men who had experience with prostate cancer. Furthermore, participants discussed when they were networked with other parents and offered support to help share experiences, it was reassuring and contributed to positive experiences.

People expressed the need to be empowered to share stories, with support groups a frequent theme discussed. An example of this was shared by men who experienced prostate cancer. They discussed that they were often so preoccupied about the fact they had cancer, that the incontinence 'snuck up on them'. It was not until they were attending support groups that they were fully able to understand the importance of discussing continence concerns with their specialist, and then were able to navigate the system which they had found complex.

Another participant discussed the importance of support groups using a comparison to 'weight watchers' groups:

> *"Like, you know how you have a weight watchers' group and you've got a topic that you can discuss things about weight and things, is there a, a system that has a group like that, that you meet with other people."*

Similarly, parents noted how helpful the focus group was as a space to just come and share their experiences and journey with continence care. One parent highlighted:

> *"The parents' support groups are probably quite a good thing to sort of, you know, talk to and that [sic], because they know, they live it, and they know more than the doctors, the, the everything, you know specialists and so forth,"* with another supporting this and saying *"Also having a support group so you can have someone to talk to, so then when other people have the same issues they can, you can say 'oh there's a support group over here' you know. And then that way you'll guide the message."*

Many parents were so overwhelmed by everything going on, that they really were not sure where to turn to for help. They knew need they needed help and guidance so kept looking until they found it. Support groups were an important topic mentioned by all participants and were discussed as something that helped people to feel heard and learn from each other throughout their journey to continence care.

Support for Pasifika and Māori

Support for Pasifika and Māori needs to be different, and this was discussed at length by the Pasifika participants. The discussion was predominantly around gaining trust and access into the community, through understanding the needs of the people. It was noted that once the trust was established, finding out exactly what was needed to be helpful was the key. Once this information is known the next important step is then being able to deliver care to the community and follow through with delivery of services. This is an important piece of information, because if the service cannot be delivered, then it is likely the service will not be utilised by extended whānau and friends because the trust would be broken and need to be rebuilt again.

Another key point discussed by the Pasifika focus group is the importance of talanoa. At the time it was acknowledged that participants did not feel comfortable with the focus group setting, and when asked for feedback on how we can do better if we were to engage with the Pasifika population again, it was suggested:

> *"It's easy to get your [sic], the result of your research if you, if you just take into account those sort of things, maybe when you go into a home or somewhere where this kōrero can take place, rather than it being here [at the community hall where the focus group was held]."*

It was further discussed that once this had happened, it would be more possible for talanoa and discussion of the topic, which would help to break down the whakamā associated with incontinence and the barriers to seeking care. It was this feedback from the Pasifika focus group that prompted a change to semi-structured interviews for Māori participants.

One important suggestion made about support that was pertinent to Pasifika and Māori participants was that if people who were passionate and had experience with incontinence could share their stories, it might inspire others to seek help for their continence concern. There were several Māori participants who highlighted that if they had the opportunity to talk to someone about their experiences with incontinence, it would have given them more confidence to seek care themselves or challenge the person who told them their incontinence was normal.

Another point that was clearly communicated from our Pasifika and Māori participants was the need for an appropriate way to talk about continence concerns and advisors who can help with appropriate communication. This was particularly relevant for the Pasifika community, who suggested a humorous approach would be beneficial for a subject like incontinence that is difficult to discuss. Further discussion on the point of communication highlighted that Continence NZ had a long way to go to ensure advisors were available to help with appropriate communication. This same point was also noted as a subtheme in the semi-structured interviews with Māori participants. While this comment was made in reflection on what Continence NZ could do to support people with continence concerns, it was also noted to be applicable to other health care professionals, in particular, if a female had a male GP and needed to talk about a problem that was *"below the waist."*

It was also clear that many barriers to culturally safe clinical care still exist for Māori and Pasifika. It was noted by many of the Māori participants that they felt marginalised in a system that is not responsive to their cultural needs. An example of this was when a participant had surgery scheduled at short notice and was told that it was essential to take the opportunity. Yet when they explained they could not have the surgery with such short notice, they were told that they *"should move heaven and earth to attend."* It was suggested by the participant that this felt like the person scheduling the surgery did not seem to understand the additional caring responsibilities of whānau and that sometimes short notice of a procedure and the expectation to attend above anything else was not culturally respectful. This same person went on to have the surgery scheduled a further two times at short notice (despite notifying the hospital they were not available at short notice). When they were unable to make the surgery date for a third time, they were told they would be taken off the surgery list and would need to be re-referred because of too many cancellations.

Perhaps the most powerful statement regarding support needed for Pasifika and Māori participants was summarised by one participant who highlighted the importance of what Continence NZ can do to help make change. It was noted that:

> *"One practical, tangible thing you could do is make sure you have advisors, and Board of Trustees members, like fine [sic], that's, you want keys to the community, you need people who will give you access into the gateways, into those communities."*

Continence NZ acknowledges the need for representation from Māori or Pasifika in the organisation. At the time of writing this report, Continence NZ is actively seeking a cultural advisor to join the Executive Committee.

Discussion

Theme one: The impact of incontinence

Incontinence is already known to have physical, social and emotional impacts (Esplin et al., 2017), with one participant detailing:

> *"It deprives you of a lot, it rips your life apart, destroys it really."*

The impact of incontinence is the first key theme noted in the data. It is described by the research participants as embarrassing, isolating and costly to them personally. Participants shared that the financial burden is extensive and is every day of the week for years and years on end. This cost is not only financial but can impact relationships with whānau, intimate partners and employers.

The financial impact included the cost of medical consultations, prescription part charges, physiotherapy, diagnostic imaging and other medical investigations. It extended to include the expense of paying for additional items of clothing, underwear, nappies and continence products such as pads or nappies. More than one-third of participants did not know they may be eligible for funded pads or continence products. One example of this noted:

> "*My family didn't even know you could go to the public health nurse and get free underpants things [sic], and they were buying them, and they were super expensive and even when they did get funding you only got a certain amount, and then they had to keep buying them and they were spending like hundreds of dollars just to keep her."*

Many other participants validated this and expressed that often it was family members, not clinicians, who told them there were funded continence products available (if the criteria are met for them to be supplied).

Another cost which has not previously been discussed in reports but was shared by the participants, is the expense of extra power and water needed to do the additional laundry created for hygiene purposes. This occurs as people who are experiencing incontinence often need to change their clothing, wash their sheets and bathe more frequently to stay or feel clean – something essential to consider in this current financial climate.

Further to the financial cost comes the worry and impact of embarrassment. Embarrassment was associated with being worried about smelling of urine or faeces, leaking and wetting themselves in a public place or having to buy pads or other continence products in the supermarket. Mothers of children with faecal incontinence highlighted that at school, other children can be cruel and children with continence concerns become at risk of being bullied or excluded from friendships because they soil themselves.

Many people noted they are too embarrassed to seek help for their continence concern, despite knowing that they can do something about it. One participant highlighted that because it is an invisible condition, no one can see it, so they don't know about it. Others stated that when raising a conversation about incontinence they are often met with the reply:

> *"It's not something you talk to anyone about really."*

There was also discussion that incontinence was just part of life, and that they:

> *"Never really thought about discussing that because I just thought it was like a part of, natural part of growing old and I mean, because that's what I've always heard you know."* Another participant was *"Staggered to see that, like is it one in three women, especially after childbirth, have incontinence. And that it's those topics that we should all be talking about, like menopause, we're now starting to talk about."*

There was further discussion wondering if other people were experiencing the same 'thing' as them, and there was often the want to ask someone else about their experience with continence concerns. One participant noted:

> *"Sometimes I've wondered like when I'm standing there, you know, and a lady will come up and she'll buy the same product I'm about to buy, and, you know, and I'm thinking 'I wonder what she's going through' or, you know, 'what they think about it', and then sometimes I wonder 'well do they know I'm doing something right now,' you know. And um [sic], you know, how many other people are going through it."*

Participants expressed that they believe continence concerns are a relatively common problem, with one stating, *"It definitely is a subject that is very, very common yet it's not really known."* For a 'relatively common problem', it was shared that there was difficulty talking about continence concerns and people often feel like they are not heard when seeking help. This is why the second theme 'not being heard' is important to discuss.

Theme two: Not being heard

Examples of not being heard include the fact that some participants have struggled for years to get anybody to listen to their concerns about incontinence as they have been 'fobbed off' and told it was normal. Others had consulted their GP and helplines such as PlunketLine and Healthline and been told things such as, *"Some kids just don't develop."* Others explained that because clinicians have checklists to use, if you don't fit the box, and the point you are trying to make isn't on their threshold for needing intervention or referral, then it's not going to be addressed.

Many participants detailed a solution regarding how they could be heard when asking for help with a continence concern. They suggested that if organisations and clinicians could work together to remove barriers it would enable improved care. This dialogue was predominantly around the importance of taking time to listen to what people were sharing and picking up on the subtle cues disclosed during conversation. It was surmised by the participants that this would be improved through more knowledge and understanding of what incontinence is or continence concerns are, and the impact this has on people's lives.

It is also important to the participants that the information shared when improving people's knowledge and understanding of continence concerns is that management of the condition or situation can be done in a holistic and respectful way. This can be from clinicians and other professionals both medical and non-medical. A good example of this was detailed by Māori participants who incorporated rongoā into management and treatment of their incontinence. This discussion was extended further to highlight the problems associated with a focus on fixing illness, not wellbeing or the whole person. It also included the importance of other 'treatments' as part of a whole-person approach. Examples of this included things such as using specific exercises in Pilates and how important it is to address the impact other body systems can also have on continence concerns.

Theme three: Knowledge is important

The point of discussion regarding holistic knowledge for clinicians leads nicely into the third theme. The theme was identified as 'knowledge is important'. This is because most people didn't know where to start getting help and how to navigate the system. It is also important because many people did not know to challenge the information they were told or the system they were seeking help from. They didn't know that the continence concern they were experiencing was not an expected part of life and was not normal. The same applied to mothers of children who were having problems with soiling at primary school. Many were told it was normal and that some children just take longer to develop, as opposed to knowing where to look for help themselves and get information in order to seek further help and challenge what they had been told.

Accessing continence care can cause concern for people due to barriers as previously mentioned. While these are predominantly self-imposed because of embarrassment and fear that they are the only person with the 'problem', it is up to the clinician to ensure appropriate onward referral is made for management of the condition. The clinician needs to advocate for the person seeking help because many people have the forethought that nothing can be done to help the situation. One participant said they felt like:

> *"I may as well just put up with it and get on with life."*

Fortunately, there were some success stories shared, where those who were brave enough to ask for help generally had a good experience with their initial consult. This led to some positive discussion within the groups about why it is so hard to ask for help. Ultimately these experiences showed that even a small amount of knowledge seems to help when accessing continence care.

One participant raised a very valid point when trying to figure out why the group felt it was difficult to get started and hard to ask for help, and they wondered:

> *"What is it about incontinence that is so ingrained as shameful or embarrassing?"*

This was partly answered by a participant within the same discussion who noted that perhaps it is about the way we see ourselves and the boundaries that are created from our culture and understanding of 'normal' and ageing in society. They said:

> *"We like to see ourselves as closed systems and the boundaries that are imperviable, and somehow incontinence is a, yeah [sic], a violation of that internalised ideal,"* with another adding, *"I imagine like, it's a shame that a child must have and feel because it's so taboo still, if you have an accident at school or whatever, they must just, it must just be absolutely debilitating."*

Ultimately what underpins this situation, the themes, experiences and barriers discussed is health literacy. In this case, it is not only the health literacy of consumers but also clinicians or other providers. This in turn leads to challenges in care, whether this is through access to or delivery of care.

Keeping in mind the challenges experienced by participants when seeking help for continence care, it is imperative that there is discussion regarding what made accessing continence care easy and what people have found helped them along their journey of continence care. While we know there are inconsistencies in care, when people receive the right care, that is the story we need to tell. Positive experiences can help build support systems, develop strategies, integrate change and help overcome the stigma associated with continence concerns.

A good starting point is to share positive experiences and the pathway of expectations. The importance of hearing other people's experiences with continence concerns was discussed by our Māori participants as something that could be helpful for other Māori to understand it is ok to get help. This was followed by the discussion that while it is whakamā to share information about such a personal condition, sharing the experiences of other people will share the load without losing mana. One participant noted:

> *"Sharing experiences doesn't make you less of a person in any way. Reducing stigma, reducing personal embarrassment, doesn't change your mana,"* with another highlighting, *"If we talk about the problem, we will end up finding the solutions."*

A powerful example of this within this project was that many participants drove more than two hours to participate in the focus groups. They felt that strongly about sharing their story. What was even more incredible was that it was the opportunity to participate in the focus group that gave people the first chance to share their continence concern in a safe environment, with some experiencing their condition for more than 30 years. This shows the importance of support and opportunities being available to reach out for that support.

How can support be delivered?

When asked: ‘How would support best be delivered?’ all participants noted that support would be provided through improved communication and education. It was thought that if everyone started talking about continence, whether it was because there was a concern or not, it would improve people’s ability to seek help. This would, in turn, allow people to challenge medical professionals who incorrectly told them incontinence is ‘normal’ or acceptable as part of childbirth, a health condition, or ageing.

How people thought this communication and education should be delivered was different for each participant group. There was a recommendation for the creation of a role called ‘the poo lady’ to educate schools, students and parents to reduce shame and embarrassment and to help educate people while they are young. Another group suggested a wraparound specialist service external to the District Health Boards (now Te Whatu Ora) for specialist continence care, and a helpline so that people can ring when they are not sure who to turn to for help, or that the GPs can give out while people wait for referrals in the system and for next steps in care.

Others suggested pathways for funding for specialised care for those with disability with one person commenting:

> *“It would be nice if they perhaps could think about having a pathway for funding to make that kind of um specialised one-on-one care for that child a thing [sic], because this little boy was um, like pooing all the time basically, and the kids gave him such a hard time and said ‘stinky’ all the time obviously and um but then it’s just come round but if it hadn’t it would have been really nice to say ‘oh WINZ can fund 4 grand’ or someone can, because there must be heaps of kids in the community that haven’t got access to that.”*

Fortunately, there is funding available for people with disability through Whaikaha which helps people to access support, manage their own supports and remove disability-related barriers to achieving goals (Te Kāwanatanga o Aotearoa New Zealand Government, 2023). Continence care could fall into this category, but as the provision of this funding is based on individual needs assessments, commentary regarding this is beyond the scope of this report.

Another suggestion for ways people could receive support was through awareness campaigns and general visibility. This comment is pertaining to the importance of screening for continence concerns and making it as commonplace as cervical, prostate and bowel cancer screening. Participants wanted to make screening for continence concerns part of PlunketLine, before school checks, women's health and maternity care. Suggestions were made about the importance of having pamphlets in the GP surgery, information with continence pad delivery, or information through the newly formed health improvement practitioner position in many primary health organisations.

Education is a prominent theme when considering how Continence NZ can offer and deliver support – this was discussed from multiple perspectives and included education of people who experienced continence concerns right through to whānau, friends, the general public and health professionals alike. This is an important point, as people reported a widely varied experience when people sought help from their GP for continence concerns.

It is the recommendation of the authors that it is time to revisit the education provided for our members of General Practice and establish their current knowledge. This was previously completed in 1996 when a study was conducted to "examine general practitioners' confidence in the diagnosis and management of urinary incontinence, to define their unmet continence training and educational needs, and to evaluate the current provision of continence care in General Practice, including the role of practice nurses" (Dovey et al., 1996, p. 340). As an interim measure, a recommendation for the publication of more comprehensive discussion about continence care and the point that incontinence is not normal could be produced in the New Zealand Doctor magazine, the General Practice research update and continued medical education modules.

How could Continence NZ best meet the needs of the participants?

When participants were asked *'If we could do one thing to make continence care different, how could Continence NZ best meet the needs of the group? What would be your ideal outcome from this discussion today?'* they continued to highlight the supports they had previously discussed but with specific examples. These examples are below and are grouped into themes with further suggestions from participants noted under each theme.

Raising awareness of continence concerns

- Campaign each year.
- Getting high profile people on board.
- Peer support using support groups or people sharing their stories.
- Making a cartoon to break down the barriers and stigma associated with incontinence and to encourage people to get help.
- Using layperson's language like trouble toileting instead of incontinence or continence concerns.

Engaging the community and information sharing

- Providing direction of where to ask for help.
- More easily available information at GP surgeries.
- A helpline to call for general advice on continence concerns.
- Publishing pamphlets of easy-to-read information in layperson's terms and multiple languages.
- Direction on how to access support and what to expect when asking for help with continence concerns.
- Creating a connection with marginalised populations especially our Pasifika and Māori ethnic groups.
- Reaching out into more community organisations including church groups where people already have relationships and trust the people they are sharing with.

Education of the general public

- Changing education about pad use.
- Education sessions and lectures people can attend.
- Incorporating information into schools at puberty and sex education.
- Ensuring people know incontinence isn't a normal part of ageing or childbirth.
- Education for general public through use of case studies to reduce the stigma and embarrassment of incontinence and circulate this on social media platforms.
- Asking providers of continence products to supply information that incontinence isn't normal, and people can get help for it.

Education of medical professionals

- Educating medical professionals that incontinence isn't normal.
- Suggesting screening for incontinence is included in general health checks.
- Including information about continence care at post-partum checks with midwives.
- Making sure there is a clear pathway of what to do when a patient discloses incontinence or a continence concern including providing them with the phone number for Continence NZ.

Continence NZ already offers a number of the suggestions made above through its website and helpline. However, there are some barriers to delivery of the services it has available. The first is the user friendliness and ease of navigation of the website, and the second is the cost to access some of the information, such as pamphlets and courses for health professionals.

For example, Continence NZ does have multilingual pamphlets available for use in General Practice or other facilities, but there is a cost to order and distribute these if there is more than one of each type of pamphlet or booklet required. The cost of each pamphlet is 30 cents, and a booklet is $1.50 (excluding postage costs) (Continence New Zealand, 2023). A logical solution to this problem could be to provide a QR code on medical information boards (where other pamphlets are displayed) at each medical centre or General Practice where people can scan the code and be taken directly to the resource on the Continence NZ website.

There are barriers to accessing the services Continence NZ already offers. This is notable because people are not aware of, or not able to access, the information Continence NZ provides. It also speaks to the point that if people do not know that their experiences with continence concerns are not normal, they do not know to ask for help. And if they do not know to ask for help, they have trouble getting started to get the help they need and then difficulty navigating the system without the supportive information Continence NZ provides. This can have a significant impact on people who live with a continence concern. This research demonstrates that any barrier to accessing continence care makes it hard for people to get the support they need to live their lives without fear, shame or embarrassment.

Recommendations

The global view of continence care is important, and this view should include a culturally appropriate response in order to engage with those who are at risk of marginalisation or harm. Harm could occur through an approach to care that does not respect a person’s culture. It would be ideal if there was a role for Continence NZ to collaborate with existing primary health care providers and perhaps become a ‘hub organisation’ to guide continence care. Working with the Primary Health Organisations (PHOs) could provide relationships with practice nurses and GPs in order to provide continence care in the community. This role would not relieve Te Whatu Ora of its responsibility to provide care to those who live with continence concerns, rather it would complement it and continue the journey of providing support and guidance to help deliver an improved service of continence care for all people in Aotearoa, New Zealand.

If there was the ability to increase engagement of primary care providers, it would also help facilitate care through other means, as more people would have better access to help manage or resolve their continence concern. Being networked with the primary health care providers would offer an opportunity to promote education and a better understanding of how well continence care can be delivered. This would be one step in the right direction towards the increased visibility needed for the services already provided by Continence NZ.

Given the key themes discussed and supports participants highlighted as something they think would be helpful, Continence NZ could best meet the needs of people with continence concerns by increasing its visibility and providing more general advice to navigate the pre-existing services in place. One practical and tangible step Continence NZ could take as a priority to make this happen would be to refresh its website and reframe the existing helpline.

The helpline does not necessarily need to be nurse-led, as other clinicians (for example an occupational therapist who specialises in continence care or a health improvement practitioner) could offer support to navigate the most common calls. Although a separate data analysis of helpline calls has been conducted as part of a service review, there were several participants in this research project who commented that having a tool available to help people navigate the systems that exist would have been helpful to remove barriers to care. Part of the discussion about tools available to navigate the system included the GP being able to provide a phone number to call for support at the time of an initial consultation for a continence concern – this is a good example of where the helpline run by Continence NZ in a new format could be useful.

The discussions from the focus groups and semi-structured interviews further affirm that people need advice on how to navigate the system. The helpline does not necessarily need to deliver health advice for a continence concern. It needs to be a place for people just to be heard and provide education, support and a sense of community without taking responsibility for somebody’s care. This will aid people who need help to navigate their journey through the health care system, and for people to know the person receiving the call is listening, non-judgemental and can give them encouragement and reassurance that they are not alone.

There is no need for Continence NZ to duplicate the system, but Continence NZ can help by getting people to ask for the right things, by providing education and making people feel empowered to seek further support from a place of advocacy. The helpline could be a good place to act as a guide for resources available through not only Continence NZ but other providers such as pelvic floor physiotherapy, the GP, Te Whatu Ora and private providers.

Equity and access for diverse populations

For those who identify as Māori, Pasifika or other diverse populations, it is imperative that continence care can be provided by the health care providers they are already engaged with. This is another reason for Continence NZ to engage with PHOs, as generally the culture of these organisations is one that demonstrates a commitment to accessibility and equity, which translates through into better health outcomes for those who engage in the services available.

Delivery of care in a pre-existing clinic could be completed by clinicians who specialise in continence care and have partnerships with PHOs, because the PHOs already have the trust and cultural understanding required to discuss something that is considered whakamā. This point was clearly made in the Pasifika focus group where there was a key discussion: if we don’t know you, we won’t want to talk about something that is sensitive. This point also resonated in the semi-structured interviews with Māori participants.

Another key concern noted throughout this research project is the seemingly unconscious bias towards Māori, Pasifika, women, people with disability, and other marginalised populations who experience a continence concern. We know the experiences of Pasifika and Māori are not positive and have resulted in the expression that inequity in care is prevalent. This was highlighted by many participants who shared experiences which were hurtful to their hauora wairua and mana. These experiences are unique and identifiable to the people involved and therefore will not be detailed further.

In order to improve equity and access for all people, it is important that the marketing by Continence NZ is more inclusive of all ethnicities. At the time of writing this report, the advertising by Continence NZ for World Continence Week 2023 was noted to include multiple ethnicities and both males and females. This is a change that has already been implemented and a strong step in the right direction towards addressing the concerns raised in the research project.

Conclusion

In a post-COVID-19 climate, the health system seems fractured. It is likely some of the discussions from the focus groups and semi-structured interviews are the results of this, but it is important to acknowledge the work that is going into managing the workforce shortages and improvement of health care service delivery.

Continence NZ provides a range of services which include community and health care professional engagement. These include workshops, webinars, education and other resources including a free phone helpline. If this engagement was extended to include whakawhanaungatanga and talanoa to connect and build relationships to meet the needs of Māori and Pasifika populations, it would allow more inclusion of those impacted by continence concerns. It is important to acknowledge that the facilitation of the Pasifika focus group did not allow talanoa, and it is imperative that this population is further engaged in order to truly develop an understanding of the needs of this community. Further whakawhanaungatanga with a broader age range of Māori will help ensure the continence care of kaumātua, tamariki and other whānau are also included.

By addressing the key themes and recommendations discussed in this report, Continence NZ should be able to improve the experiences of people who live with continence concerns. If Continence NZ can provide advocacy, education and support through navigation, connection and information sharing, it will empower people to maintain dignity, have faith and remove barriers to care as people navigate the convoluted journey of continence care in Aotearoa, New Zealand. However, for this to occur, networking, education and further funding are essential.

Continence NZ is undervalued, underfunded and consequently underpromoted for the services it delivers. This was highlighted by the comments of the research participants, who when asked what Continence NZ could do to better meet their needs, highlighted nearly every service Continence NZ already provides but that they did not know existed.

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Appendix A

Questions used in the participant survey.

Tell us a bit more about yourself

1. **What is your age?**

☐ 18-24
☐ 25-34
☐ 35-44
☐ 45-54
☐ 55-64
☐ 65-74
☐ 75-84
☐ 85-94
☐ 95+

2. **What is your ethnicity?**

☐ European
☐ Pacific
☐ Middle Eastern
☐ African
☐ Māori
☐ Asian
☐ Latin American
☐ Other (please specify)

3. **What is your gender**

☐ Male
☐ Non-Binary
☐ Female
☐ Prefer not to disclose

4. **In which region do you live?**

☐ Northland
☐ Taranaki
☐ Manawatu-Wanganui
☐ Canterbury
☐ Auckland
☐ Hawkes Bay
☐ Wellington

5. **What is the highest education level you have completed**

☐ Primary/intermediate school
☐ High school
☐ Tertiary education

6. **Do you personally have a continence concern such as urine leakage, leakage of faeces (poo), constipation, urinary tract infection, etc.?**

☐ Yes
☐ No

7. **Do you care for or teach someone who has a continence concern such as urine leakage, leakage of faeces (poo), constipation, urinary tract infection, etc.?**

☐ No
☐ Yes (please specify your relationship to them)

Tell us a bit more about your experience with continence services

8. **Before today, did you know about the organisation Continence NZ?**

☐ No
☐ Yes (please specify where you learned of the organisation)

9. **What issues, worries or concerns have you experienced when seeking advice related to continence concerns**

☐ Not applicable
☐ Please provide details

10. **Have you accessed any support for continence concerns?**

☐ No
☐ Yes (please specify what services and by whom they were provided)

11. **What barriers do you think there are to accessing support for continence concerns?**

☐ Not applicable
☐ Please provide details:

12. **Did you find the support you received for continence concerns helpful? Why or why not?**

☐ Not applicable
☐ Please provide details:

Continence practice in New Zealand

Report prepared for Continence NZ

Emma Doust, Kelvin Woock and David Moore
15 May 2023

Contents

Appendices

Tables

Figures

Glossary

Abbreviation	**Stands for**
CBA	Cost-benefit analysis
CPI	Consumer Price Index
DHB	District Health Board (disestablished in 2022)
FTE	Full-time equivalent
LFG	Landfill gas
MECA	Multi-employer collective agreement
NHS	National Health Service
OECD	Organisation for Economic Co-operation and Development
PFMT	Pelvic floor muscle training

Executive summary

This report looks at the current provision of continence services in New Zealand through a rapid literature scan and survey of 20 continence providers, and conducts a cost-benefit analysis focussing on investment in community-based management for incontinence.

The context in which continence services operate in New Zealand

The strategic landscape that underpins continence services is in a state of transition. While the exact prevalence of incontinence within New Zealand is unknown, around a quarter of all New Zealanders are affected by incontinence of any type. As the prevalence of incontinence increases with age, New Zealand's increasingly ageing population means that overall prevalence will also continue to increase.

Best practice articles highlight that health provider education and collaboration improves patient care. The literature shows the need for patient-centred care, moving away from a focus on cleaning and containing, and instead focusing on educating patients and becoming more responsive to individual patient needs.

There is variation in service provision across New Zealand

Survey respondents generally consider their services to provide excellent assessment and management services, with great support and education for patients. However, they stated that patients are sometimes waiting longer than the times suggested by the service specification. Most respondents called for more dedicated staff and more time to spend with patients. They indicate the need for increased education for health professionals and the public.

Cost-benefit analysis show potential savings of $2.5 million per year with investment for an additional 38 continence or district nurses/pelvic health physiotherapists

We estimate that an investment of $6.4 million per year for an additional 38 continence or district nurses/pelvic health physiotherapists would result in $8.9 million saved on incontinence products, i.e. cost savings (or net benefits) to Te Whatu Ora of $2.5 million. In addition, even a modest 25 per cent reduction in adult nappy use could avoid costs of $3.7 million in terms of the environment (landfill costs and the cost of CO_2 emissions).

What next?

Given the current health system reforms, Continence NZ has a unique opportunity to increase advocacy efforts to the government to address continence issues through increased investment and improved models of care.

The case for investment

Due to New Zealand's rapidly ageing population, proactive education and management of continence issues as part of positive ageing becomes increasingly important. There is currently a postcode lottery occurring in the provision of continence services. The CBA suggests that equitable, best practice provision should pay for itself and would have other important benefits in terms of quality of life.

1. Purpose and methodology

This report looks at the state of continence services across New Zealand and was commissioned by Continence NZ as part of a wider stakeholder consultation project aimed at improving services. This report will be part of a suite of reports used to inform future discussions on how to improve continence services in New Zealand.

1.1 This is an update of a previous report

In 2017, Continence NZ contracted Sapere to undertake an independent analysis of the current state of continence services in New Zealand (Esplin et al., 2017). The purpose was to profile the current state against known good practice and to comment on future possibilities.

This current report updates the findings of the 2017 report. While this current report can be read as a standalone report, the two can be read side-by-side to produce a more complete picture of the state of continence services in New Zealand.

1.2 Methodology

This report uses a mixed methods approach, using the following:

- a rapid literature scan
- an e-survey of continence providers across New Zealand
- a cost-benefit analysis.

1.2.1 Rapid literature scan

We performed a rapid literature scan in January 2023, aimed at finding literature on best practice in continence care and any updated data on prevalence of continence issues since 2017. The search strategy is set out in Appendix A.

1.2.2 Survey of continence providers

Continence NZ invited via email approximately 50 people on 20 March 2023 to take part in the survey, with a reminder sent on 29 March 2023. The survey remained open until 6 April 2023. There were 20 responses to the survey, indicating a response rate of around 40 per cent. A list of the questions is set out in Appendix B. Details on the respondents, including location and services provided, are set out in Appendix C.

Limitations

Caution should be applied when interpreting the survey results:

- Due to the number of responses, the results may not be representative of all continence services across New Zealand.

- Most respondents indicated they worked in the Central region, meaning there is an uneven regional distribution and results may not be representative of New Zealand.

1.2.3 Cost-benefit analysis

The cost-benefit analysis (CBA) updated the previous CBA created by Sapere for Continence NZ in 2017 (see section 1.1 for more details). Both the original and the updated CBA focussed on investment in community-based management for incontinence, delivered by nurses and physiotherapists, and includes consideration of environmental costs arising from incontinence product use.

2. The context in which continence services operate in New Zealand

This section sets out the overall context in which continence services are operating and looks at updates in prevalence and best practice evidence since the previous Sapere report was published in 2017.

2.1 The strategic landscape that underpins continence services is in a state of transition

On 1 July 2022, New Zealand moved to a new national health system, aimed at creating a more equitable, accessible, cohesive and people-centred system.[1] At the time of writing, the transition is still underway, and the current state of the health system is in flux as new policies and processes are being designed and implemented to support the transition.

Te Whatu Ora and Te Aka Whai Ora published Te Pae Tata, the Interim New Zealand Health Plan, aimed at supporting the first two years of the health system reform (Te Whatu Ora, 2022). Te Pae Tata has five priority areas for improving health outcomes and equity. Continence issues are relevant to all five of these areas:

- Pae ora - better health in our communities
- Kahu Taurima - maternity and early years
- Mate pukupuku - people with cancer
- Māuiuitanga taumaha - people living with chronic health conditions
- Oranga hinengaro - people living with mental distress, illness, and addictions.

Te Pae Tata aims to build a health system that embeds Te Tiriti as its foundation, recognising the current health inequities that exist in New Zealand (Te Whatu Ora, 2022). The review of the aged care, home and community support services models form part of the overall plan, designed to support the healthy ageing of New Zealand's population (Te Whatu Ora, 2022).As continence management issues become more prevalent with increasing age, government strategies in relation to ageing are key. The interim plan explicitly notes that the Healthy Ageing Strategy, detailed in the 2017 report, remains a part of the government's overall approach to supporting health ageing (Te Whatu Ora, 2022). This strategy sets out a framework that focuses on enhancing participation and social connection and ensuring the dignity of older people, including those with long-term illness or disability (Associate Minister of Health, 2016).

The Ministry of Health service specification, last updated in 2012, currently remains one of the key documents that health providers use in relation to continence management, education and consumables (Ministry of Health, 2012). All District Health Boards (now disestablished as of 1 July

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[1] The future of health (2022), found at https://www.futureofhealth.govt.nz/

2022) were required to follow this service specification. According to the survey responses, services are still following the service specification.

The service specification emphasises prevention and conservative management and sets out the eligibility rules for accessing the service, required referral response times for the service, and guidelines on supply of continence products to those accessing the service.

2.2 The exact prevalence of incontinence in New Zealand is still uncertain

2.2.1 Who it affects

While traditionally, the focus of incontinence issues is on women and the elderly, incontinence can affect anyone – including children, disabled people, and men – with wide-ranging impacts such as humiliation and loss of self-esteem (New Zealand Continence Association & New Zealand Carers Alliance, 2009).

Continence issues are more prevalent in certain ethnicities. For example, previous New Zealand studies have found that Māori women were significantly more likely to have urinary continence (46.8%), compared with European women (31.2%) or Pacific women (29.2%) (Lara & Nacey, 1994).

2.2.2 What the literature says

The 2017 report noted that around a quarter of all New Zealanders are affected by incontinence of any type, but stated that it was difficult to estimate the prevalence of incontinence due to high rates of under-reporting (Esplin et al., 2017). The literature scan found no updated data on the prevalence of incontinence in New Zealand but did find studies in other countries, the majority relating to urinary incontinence:

- An estimated 22.1 per cent of adult US women had moderate or severe urinary incontinence, based on a population-based survey held between 2015-2018 (Patel et al., 2022). When looking at all urinary incontinence, this increased to 61.8 per cent, with 32.4 per cent reporting symptoms at least monthly.
- A cross-sectional study held in 2017-2018 in nursing homes found varying urinary incontinence rates across Austria (35.1%, median age 86), Netherlands (27.9%, median age 85), Turkey (13.8%, median age 74) and the UK (18.4%, median age 85) (Hoedl et al., 2022).
- An estimated 53 per cent of US adult women had urinary incontinence, based on a population-based survey between 2005 and 2016. Twenty-four per cent reported that the condition affected their daily activities (Lee et al., 2021).
- A systematic review and meta-analysis of prevalence of urinary incontinence in pregnancy found a mean weighted prevalence of 41 per cent based on 44 included studies (Moossdorff-Steinhauser et al., 2021).
- A systematic review and meta-analysis of women aged 55 years or older found a prevalence of urinary incontinence of 37.1 per cent based on 29 included studies (Batmani et al., 2021).

- A nationally representative sample of Canadian adults, surveyed in 2017, found a prevalence of urinary incontinence of 23.7 per cent (Shaw et al., 2020).
- A narrative review of 14 studies estimated that the prevalence of faecal incontinence in adults aged 65 years and over was 12-13 per cent. This rose to 50 per cent of those living in residential aged care (Guinane & Crone, 2017).
- The Continence Foundation of Australia estimates that 5 million Australians aged 15 years or over, or one in four, suffer from any type of incontinence. They predict this will rise to 6.5 million by 2030 (Continence Foundation of Australia, 2023).

As the prevalence of incontinence increases with age, New Zealand's increasingly ageing population means that overall prevalence will also continue to increase. It is estimated that approximately 34 per cent of women and 22 per cent of men aged 55 years and over residing in the community have issues with urinary incontinence, rising to 50 per cent of older people aged 55 years and over in residential care (New Zealand Continence Association & New Zealand Carers Alliance, 2009). This is compared to the estimated 25 per cent of all New Zealanders noted above (Esplin et al., 2017). In 2022, one in every six people were aged 65 years and over. This will increase to one in every five people in 2028, and one in every four people by the 2050s (Stats NZ Tatauranga Aotearoa, 2022).

Survey respondents suggested that there has been an increase in certain types of issues, for example, dementia-related incontinence and other age-related issues, more children with developmental delays or special needs, multiple comorbidities, and sexual dysfunction.

> Patients with multiple co-morbidities. Older people with declining health. A lot more dementia patients. – survey respondent

2.3 Best practice articles highlight that health provider education and collaboration helps with patient care

The 2017 report noted that literature showed there is good evidence about what works but appropriate assessment and treatment can be neglected due to a lack of nurse and therapist continence specialists, and inadequate time or resources (Esplin et al., 2017). Since the 2017 report, there have been further articles published regarding best practice for incontinence issues that mirror the earlier findings:

- A cost-effectiveness analysis of pelvic floor muscle training (PFMT) models of care for pregnant women found that providing group-based training for all women during pregnancy is likely more efficient than individual training for urinary incontinent post-natal women (Brennen et al., 2021).
- The above study was based on a systematic review undertaken in 2020 that analysed 46 trials and found that early, structured PFMT in early pregnancy for continent women may prevent the onset of urinary incontinence in late pregnancy and postpartum (Woodley et al., 2020).
- A best practice implementation project showed that nursing education and formalised assessment pathways in acute settings can improve nursing compliance with the assessment and management of surgical adult patients with urinary or faecal incontinence (Trad et al., 2019). The design and implementation of the project happened collaboratively

across the entire healthcare team (e.g. continence nurses, physiotherapists, medical staff specialists, stomal therapy nurses, community participation coordinator) (Trad et al., 2019).

- Similarly, another best practice implementation project on managing urinary incontinence in older people (in medium to long-term Spanish hospital care) used seven audit criteria based on best available evidence (Martín-Losada et al., 2020). The project team included nurses, a physiotherapist and a rehabilitation doctor – some of which were chosen for their previous collaboration in other projects, recognising that this is a key part of a successful project (Martín-Losada et al., 2020):
  - Clients are assessed for incontinence.
  - The assessment includes an indication of the type of urinary incontinence.
  - There is a documented management plan for older people with diagnosed incontinence.
  - Relevant methods of management are documented as being used.
  - Continence products are changed as required and documented.
  - Staff have received training on continence management.
  - Clients are assessed for incontinence at discharge.

The National Health Service (NHS) guidance for excellence in continence care highlights that developing the workforce (including doctors, nurses, physiotherapists and care assistants) is one of the principles of 'what good looks like' for commissioning a continence service (NHS England, 2018). All NHS Trusts were required to have a strategy to reduce incidence of UTIs by 50% in 2020, and stated that this would require a collaborative approach across the whole health and social care system to achieve (NHS England, 2018). Other principles include:

- needs-based analysis undertaken and improvement plan developed
- co-production with public, service users and carers and acting on their feedback
- integration across health, care and education
- inclusion of the voluntary sector
- prevention methodologies
- specialist diagnostics and evidence-based treatments including technology solutions
- public education and awareness strategy
- evidence of people's involvement in decision making and care to improve their experience
- every patient being offered baseline assessment and timely treatment interventions.

2.4 A focus on patient-centred care is important

The literature scan identified several studies highlighting the need for patient-centred incontinence care – moving away from a focus on cleaning and containing, and instead focusing on educating patients and becoming more responsive to individual patient needs (Ostaszkiewicz et al., 2018; Taylor & Cahill, 2018).

- Taylor & Cahill (2018) suggest that in order to shift to a patient-centred care model, education at both the clinical level and the lay-person level is the most important to help remove stigma and focus on proactive methods designed to promote continence.

- With a focus on nursing homes, Ostaszkiewicz et al (2018) similarly suggests a focus on education that challenges beliefs that limit continence care practice to cleaning, containing and concealing.
- An evidential review of what works to improve and manage faecal incontinence in dementia patients in care homes argued that interventions are more likely to achieve good outcomes when continence care is reframed as integral to intimate and personal care work for older people with dementia. The authors note that intimate and personal care requires a set of skills that can ensure care is responsive to the individual resident's preferences and needs (Buswell et al., 2017).
- The NHS England guidance document detailed above specifically includes patient and family involvement in decision making as one of the principles of 'what good looks like', to allow people to feel they are an active partner in their care (NHS England, 2018).

This finding on the importance of education and responsive care is echoed by survey respondents, who noted that people's attitudes to continence are changing, and people are becoming more aware and comfortable with talking about their issues with a health provider.

> Women are much less tolerant of continence issues especially post-natally. – survey respondent

While most survey respondents considered that awareness of continence issues is improving, there are still some limitations, with one respondent noting cultural differences in the ease of talking about issues, some doctors' attitudes that incontinence is a normal part of ageing, and the lack of a consistent GP meaning some people are not comfortable with talking about their issues. One respondent suggested it was not well addressed at the primary care level. Another respondent noted that while awareness of urinary incontinence is increasing, faecal incontinence awareness is not.

> This is an issue that culturally is not talked about. Some doctors still have the attitude that it is part of ageing and don't refer. Inability to see just one doctor consistently means people don't feel comfortable talking about this issue. We have a huge doctor shortage here. – survey respondent

3. There is variation in service provision across New Zealand

This section sets out the findings of the survey in relation to service provision of incontinence services across New Zealand. The 2017 report highlighted that a key issue was the significant variation seen in access to services across New Zealand (Esplin et al., 2017). As detailed below, variation in service provision remains.

Survey respondents indicated a range of settings where they provide to clients, including:

- provision of continence education and support within Community Services/District Nursing Services
- working across community and hospital as a Clinical Nurse Specialist
- working within a hospital service
- working as part of a urology clinic, both inpatient and outpatient clinics
- contracting to ACC to provide continence assessments and education
- Helpline nurse.

Survey respondents generally consider their services to provide excellent assessment and management services, with great support and education for patients. However, some respondents highlight the increasing demand for their services means that they cannot spend as much time as they would like with patients and on wider education. As one respondent noted, their workload is massive, and is only increasing with the ageing population. They warn that their service is getting too big, they are behind on reviews, and struggling to get ongoing finance.

3.1 Patients are sometimes waiting longer than the times suggested by the service specification

Respondents were asked how long their patients waited for an initial appointment, according to urgency. Table 1 sets out the results. Not all services are meeting the current service specification guidelines, and this worsens with increasing risk.

Table 1: How long, on average, do your patients wait for an initial appointment?

Type of referral	Service specification guideline[2]	Survey results (bold text indicates a result within the service specification)*	
Low-risk (n=20)	Within 8 weeks of receipt of referral according to assessed need	Over 8 weeks	35%
		Over 4 weeks to 8 weeks	**30%**
		1 to 4 weeks	**35%**

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[2] Ministry of Health, Community Health, Transitional and Support Services - Continence Services Tier Three service specification, November 2012, p.5.

Medium-risk (n=19)	Within 2 weeks of receipt of referral	- Over 2 weeks - **1 to 2 weeks** - **Less than a week**	53% **37%** **11%**
High-risk (n=19)	Within 24 hours of receipt of referral	- Over a week - Over 2 days to 1 week - 1 to 2 days - **Within 24 hours**	33% 28% 33% **6%**

* where a range was given as an answer to the survey, the upper estimate was used for the purposes of this table.

3.2 The majority of respondents called for more dedicated staff and more time to spend with patients

Respondents were asked how they think their services could be improved. Results are set out below in Table 2.

Table 2: What else do you think could be improved with your services (select all that apply)

	Number	**%**
Dedicated staff for Continence Services	12	63%
We need more time to spend with patients on education and/or options	10	53%
Waiting times are too long	8	42%
The services provided are too limited, we would like to offer a wider range	4	21%
We need more resources for patients (e.g. bladder diaries)	2	11%
Other (please specify)	10	53%

There were 10 'other' responses, where a common theme was an increase in continence hours or staff.

Respondents often highlighted education as an opportunity for improvement:

- improved education to other health professionals
- more community-based education e.g. support groups or at a gym
- more time for educating carers in Disability Services
- educating management and government about the service.

> Our service being understood by management and government, it's not just about handing out pads! – survey respondent

Other additional suggestions were:

- more qualified staff
- improved facilities
- creating a separate service for children

- access to working with a multi-disciplinary team
- shifting the enuresis service from an adult community service to a paediatric service
- catheter consumables to be managed by District Nurses
- increased incentives to become a nurse specialist e.g. financial.

3.3 The majority of respondents consider that the service specification allows for the right amount of consumables

Fourteen respondents (74%) thought that the service specification provided the right amount of consumables. One survey respondent stated they thought that clients should be expected to subsidise.

Five respondents (26%) thought that the service specification allowed for an insufficient amount. No respondents thought that the service specification over-catered to need.

> Need more allocation for patients - I give according to clinical need. – survey respondent

When asked whether they would like to see changes to the amount of consumables available, eight answered in the affirmative, either suggesting an increase or more flexibility, at the discretion of the nurse prescribing. One respondent specifically stated that children need a higher allocation.

When asked whether they would like to see changes to the consumables list, six respondents wanted to see more choice in the brands, suppliers or types of products available (e.g. washable underwear). Another respondent noted that they would like more allocation ability as patients are individuals, while another noted that it appears as though patients need to jump through hoops to access the products needed.

It is important to note that this report does not capture the views of patients. With the current concerns regarding the increasing costs of living, coupled with the fact that many people with incontinence will be on a fixed income (e.g. pension), consideration of patient views on the amount of consumables available should also be taken into account.

4. Awareness of the support that Continence NZ provides is high

Continence NZ was established to provide information and educational services to people with continence problems, caregivers, health professionals and the public. This section sets out the findings of the survey in relation to views on the support that Continence NZ provides.

4.1 The vast majority of survey respondents have heard of the services Continence NZ provides, but fewer have actually used them

The survey asked respondents whether they had heard of and used the services that Continence NZ provides. Results, as set out in Table 3, show very high awareness of the services, but a lower utilisation rate.

Table 3: Have you heard of and/or used or attended the following?

	Awareness	**Used**
Continence NZ Helpline	100%	50%
Continence NZ website	100%	100%
Education days/conferences held by Continence NZ	100%	88%
Continence NZ e-newsletter	100%	79%
Continence NZ online courses	94%	29%

4.2 Over two thirds (68%) of respondents indicated that that they were already a member of Continence NZ

Respondents often noted the great support and education that Continence NZ provides.

> Thank you, Continence NZ, for all of the support and education you offer to all of the nurses and patients – survey respondent

Some respondents indicated that increased support of linking continence nurses around the country is needed, and cited the conferences as a great opportunity where this already happens. However, they noted there could be other ways to support enhanced linkages to help relieve the isolation that some workers feel.

Regarding attendance at education days and conferences, one respondent suggested improved virtual attendance options. One respondent requested more continence workshops, while another noted that the recent education days had been mainly for physiotherapists.

5. Cost-benefit analysis shows potential savings of $2.5 million per year with investment for an additional 38 continence or district nurses/pelvic health physiotherapists

As part of the reform of the health system, the New Zealand Government has set out its priorities for the publicly funded health sector for 2022-2024. Priority five is aimed at ensuring a financially sustainable health sector to ensure resources are managed and allocated in a way that achieves the best possible levels of population health and equity (Ministry of Health, 2022). As part of this priority, one objective is to reduce the health system's environmental impact.

With these priorities in mind, Sapere has updated the cost-benefit analysis (CBA) undertaken in 2017 for Continence NZ. The focus of the CBA remains on investment in community-based management for incontinence, delivered by continence nurses and pelvic health physiotherapists. The update of the CBA is primarily focused on inputting more recent figures and values (e.g. population, cost estimates, etc.) and the consideration of environmental costs arising from incontinence product use.

We estimate that an investment of $6.4 million per year for an additional 38 continence or district nurses/pelvic health physiotherapists would result in $8.9 million saved on incontinence products, i.e. cost savings (or net benefits) to districts of $2.5 million. There may also be wider benefits such as improved productivity and environmental cost savings because of reduced product use. There will also be other benefits we have not quantified such as:

- the quality-of-life improvements of the extra patients who have their incontinence reversed
- the savings of costs of care due to falls or other medical issues (such as skin infections) due to incontinence
- the savings from keeping someone in home-based care for longer, as incontinence is a major contributor to the decision to move someone from home-based care to rest-home care.

The total estimated annual cost to the environment of adult nappies is $14,878,157 (in $2022). This comprises of a cost of $12,950,630 for the cost of landfill and $1,927,527 for the cost of CO_2 equivalence (CO_2e). **With a 25 per cent reduction in adult nappy use and therefore disposal, we estimate an annual cost saving of $3.7 million. This rises to $11.2 million for a 75 per cent reduction in adult nappy use.**

5.1 Key assumptions

The following assumptions underpin the base case analysis:

- Total nationwide current expenditure on incontinence products is estimated to be $9.8 million.
- Three quarters of districts are currently staffed at rates below best practice. An additional 38 continence or district nurses or pelvic health physiotherapists (FTEs) would be required to take them up to best practice rates of staffing per head of population.
- Thirty-eight extra FTEs were calculated by taking the difference between current state staffing and a scenario where all DHBs in New Zealand offer best practice staffing rates. These staffing rates were informed in the initial report by looking at two DHBs – one that had a low staffing rate, and one that had a relatively high staffing rate. The current state assumes 25 per cent of DHBs nationally are offering a "best practice" staffing rate of 1.25 nurses/physiotherapists per 100,000 population, and the remaining 75 per cent of DHBs are offering a "partial service" of 0.25 nurses/physiotherapists per 100,000 population. The latter scenario assumes 100 per cent of DHBs have staffing rates of 1.25 nurses or physiotherapists per 100,000 population.
- Product spend per head of population for the "best practice" DHB was $0.18, spend for the "partial service" DHB was $2.49 (using 2023 population figures).
- Therefore, Te Whatu Ora districts with increased staffing will have a 93 per cent reduction in incontinence product expenditure in the base case. This is because with increased staffing (toward "best practice" staffing rates) it is expected there will be decreased product spend because of better incontinence management. The 93 per cent reduction is calculated by taking 1 minus the ratio of product spend per head of population in the "partial service" and "best practice" scenarios.[3]
- The total financial cost of incontinence in New Zealand is estimated to be $8 billion per year. Between 2 and 20 per cent of this cost may be avoided with the extra provision of nurses/physiotherapists.

5.2 Costs of providing the service

We estimate the total cost of providing an extra 38 specialist nurses/physiotherapists is $6.4 million annually, with half the cost coming from salaries and the other half from overheads. These costs are summarised in the table below.

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[3] $1 - \frac{Best\ practice\ product\ spend\ per\ head}{Partial\ service\ product\ spend\ per\ head} = 0.93.$

Table 4: Cost of extra resourcing to deliver best practice across New Zealand each year

Cost type	Annual amount
Total salary	$3.2m
Overheads	$3.2m
Total cost	**$6.4m**

The salary costs are based on a weighted average salary of $84,000. The average salary assumes that two thirds of staff will be nurses (either continence specialists or district nurses) and the other third will be physiotherapists. Each FTE may be made up of nurses/physiotherapists working part-time in the incontinence space. A summary of these costs is shown in the table below, including the source of information.

Table 5: Average salary based on teams with a mix of nurses and physiotherapists

Staff	Salary	Weight	Source
Nurse specialist (continence or district)	$80,932	66%	Step 6 of the nurse MECA (New Zealand Nurses Organisation, 2020)
Physiotherapist (specialist)	$88,500	34%	Midpoint of low physiotherapist salary and high senior physiotherapist salary on (Careers New Zealand, 2023)
Average	**$84,000**		

We have assumed the average annual salary for nurse specialists is $80,932, based on the multi-employer collective agreement (MECA) between the New Zealand Nurses Organisation and the DHBs (New Zealand Nurses Organisation, 2020), with salaries from 6 September 2021 and the step 6 pay scale. The pay scale for district nurses ranges from step 1 to step 8, with step 8 being the highest salary. We expect continence nurse specialists will be more senior and experienced and therefore closer to the top of the pay scale.

We have estimated the average annual salary for continence physiotherapist specialists to be $88,500. This estimate is a midpoint of the lower bound salary for physiotherapists and the higher bound salary for senior physiotherapists on the Careers New Zealand website (Careers New Zealand, 2023).

We have included overheads to cover costs such as:

- Management
- Office space and equipment
- Support staff, administration, accounts, and human resources
- Transport.

We have estimated that the overheads are equal to the salaries of the nurses and physiotherapists. The ratio of overheads to salary is uncertain, and we have included a range of 50 to 125 per cent of salary (i.e. $1.7 million to $4.1 million annually) in our sensitivity analysis.

5.3 Benefits from providing the service

The economic impact of incontinence in New Zealand is uncertain and the benefits of better treatment are difficult to quantify. However, we have provided a broad range of possible benefits based on the information available.

Our estimation of the benefits from providing the service relies upon the method used in the 2017 analysis and is informed by the experience of two DHBs in New Zealand and estimates from Australia. The benefits are split and reported as:

- direct benefits to districts (the former DHBs) through reduced product use
- indirect benefits that include productivity improvements for those with incontinence and environmental costs avoided from reduced product use
- unquantified benefits such as improved quality of life from more patients whose incontinence is reversed or prevented.

5.3.1 Direct benefits remain from expected reduced product use

The 2017 analysis found that an understaffed large DHB (“partial service”) was unable to offer best practice in terms of incontinence services and therefore there was poor management of products resulting in high product spend. Contrarily, an average sized but better-staffed DHB (“best practice”) had a significantly lower level of continence product spend. In the 2017 analysis, the staffing rate from the average sized DHB was used as “best practice” for the purpose of the base case.

The updated analysis uses this same staffing rate as best practice for the purpose of the base case. Our sensitivity analysis uses the same rate recommended by the NHS (1 FTE per 100,000 population).

Table 6: Average district spending on incontinence products per head of population, comparing low service provision with best practice

Nurse/physiotherapist staffing	Product spend	Spend per head of population
1 nurse per 500,000 total population	$1,200,000	$2.49
3 nurses plus support for 200,000 (best practice)	$50,000	$0.18

If extra resourcing was provided for half of New Zealand to have access to best practice continence community care, our best estimate is that $8.9 million in district incontinence product spend could be saved. However, given the uncertainty in the benefits, we estimate the plausible range to be $4.8 million to $9.1 million. The lower end of the range is based on the assumption of a 50 per cent reduction in expenditure on continence products where there is an increase in nurse/physiotherapist staffing; the upper end of the range is based on the assumption of a 95 per cent reduction. These estimates are based our best estimates given the information available to us for this review.

When limiting benefits to direct benefits from reduced product spend only, our best estimate is that districts save 1.4 times the amount invested (i.e. the benefit-cost ratio is 1.4). We estimate the plausible range to be savings of 1 to 2 times the amount of investment.

5.3.2 The introduction of environmental costs for consideration

The use of continence products which are typically disposable has a considerable impact on the environment. For this analysis we have estimated the total cost to the environment, consisting of landfill costs and the cost of CO_2 emissions, based on the tonnage of adult nappies going to landfill in New Zealand. Investment in more nurses/physiotherapists is not only expected to reduce product spend, but also the amount of product being given to incontinence patients and therefore the amount of incontinence products going to landfill and the cost to the environment of their disposal.

Our assumptions

There is a lot of uncertainty to deal with when estimating environmental costs and therefore a range of assumptions we have made to simplify this analysis.

- We are looking at annual costs to the environment in 2022 terms (i.e. a static picture), and therefore do not account for temporal changes in populations and behaviours. It is possible that with an ageing population in New Zealand, the number of incontinence products given to and used by patients would increase in the future and therefore the benefit (i.e. avoided costs to the environment) of investment in more nurses/physiotherapists would become greater.
- Our estimation of environmental costs has focused on adult nappies only. This is because, given project constraints, the only data we were able to source was for adult nappies. We recognise that adult nappies are not the only form of incontinence product delivered in New Zealand (as per Ministry of Health guidance for community continence management) and therefore the estimates of the costs to the environment of incontinence products (and the benefits of avoided costs) are most likely understated. We also assumed that most infant nappies going to landfill are not necessarily able to be reduced through community incontinence services and are instead a normal part of being an infant. We have therefore not included infant nappies' contribution to environmental costs.
- We have assumed that all adult nappies going to landfill are because of adult incontinence and are therefore considered in our analysis.
- Where appropriate, costs have been inflated to $2022 using the CPI.

Sources of information

Our analysis makes use of multiple sources of information:

- Data from the OECD on the waste impact of absorbent hygiene products (Velasco Perez et al., 2021) in OECD countries. This shows the proportion of municipal landfill waste in New Zealand attributable to adult nappies in 2017. We have assumed this proportion has remained constant over time.
- Variables from a study estimating the environmental and waste impact of adult incontinence products in Australia (Thompson Brewster et al., 2022). This study has estimates of average mass of adult absorbent hygiene products that we have used to sense check our findings.

- Ministry of Health guidance on community incontinence services and product provision (Ministry of Health, 2012). We have assumed the number of nappies provided to patients is four per day (the maximum specified in guidance).
- Ministry for the Environment data on waste generated at a national level going to Class 1 landfills (those taking municipal household waste) (Ministry for the Environment, 2022a). We were then able to work out the proportion of annual waste attributable to adult nappies by multiplying the proportion attributable to adult nappies by the tonnage of waste.
- Emissions factors for nappies from the Ministry for the Environment (Ministry for the Environment, 2022b). We assume that there is landfill gas (LFG) recovery used in most landfills in New Zealand and therefore have taken the lower reported emissions factors. Emissions factors may be higher for nappies with faecal matter and the factors also include all nappies (not just adult), but given the difference in average mass of each used infant and adult nappy reported in (Thompson Brewster et al., 2022), this may all cancel out.
- The New Zealand Treasury CBAx tool guidance on the cost of waste per tonne going to Class 1 landfills in New Zealand to monetise the cost of nappy waste (New Zealand Treasury, 2021a). This cost has been inflated using the CPI from 2021Q4 to 2022Q4.
- The shadow price of carbon from the New Zealand Treasury to monetise the CO_2 impacts of adult nappy waste (New Zealand Treasury, 2021b). We have used the central estimate of the shadow price for 2022.

Total cost estimates of adult nappies on the environment

Our choice to estimate the environmental costs in this way rather than follow the method described by Thompson Brewster et al., (2022) was largely informed by data availability and project constraints. Future studies may benefit from repeating the exercise using a bottom-up approach.

The table below shows the key inputs used in estimation of the environmental costs.

Table 7: Key inputs for estimating the environmental costs of incontinence products annually

Key input	Value
Adult nappies as proportion of total municipal waste in New Zealand in 2017	2.6%
Waste to Class 1 landfills in New Zealand in 2022	3,601,265 tonnes
Contribution of adult nappies to annual waste to landfill in 2022	93,933 tonnes
Cost of waste to Class 1 landfill in $2022	$138
Shadow price of carbon per CO2e tonne $2022 (central estimate)	$94
Ministry of Health guidance on nappy provision for incontinence	Up to 4 per day

The total estimated annual cost to the environment of adult nappies is $14.9 million (in $2022). This comprises of a cost of just over $12.9 million for the cost of landfill and just over $1.9 million for the cost of CO_2 equivalence (CO_2e).

The benefit of avoided costs to the environment from decreased product use

We have assumed the decrease in product spend will result in a decrease in product delivery also, but not necessarily proportionately. Our choices of sensitivities for this estimate are not scientific but illustrate that even with a 25 per cent reduction in product use, there is the potential for considerable cost avoidance. The table below illustrates this estimate.

Table 8: Estimated cost savings given the reduction in product spend

If a 93% reduction in product spend results in…	Cost savings annually
25% reduction in adult nappy use and therefore disposal	$3.7 million
50% reduction in adult nappy use and therefore disposal	$7.4 million
75% reduction in adult nappy use and therefore disposal	$11.2 million

5.3.3 Possible wider benefits are the same as in the 2017 report

Our consideration of possible wider benefits remains the same as in the 2017 analysis, based on the 2011 report assessing the financial impacts of incontinence in New Zealand (New Zealand Continence Association, 2011). The listed costs of incontinence are:

- health costs excluding continence products
- productivity costs due to lower-than-average employment
- productivity costs due to friends and family opportunity costs (such as whānau and informal carers)
- cost of formal care and aids
- aged care
- other indirect costs.

The possible wider benefits of investment in the incontinence service arise from reduced costs in each of the above areas (e.g. people can be more productive, require less care and aids, etc.). In the 2011 report, the estimated total of the above costs was $8.05 billion annually. While these costs are in 2010 dollars, the 2017 analysis did not inflate them. For the updated analysis we have not inflated the costs either.[4]

Table 9 below shows how these costs are translated into estimated benefits, through potential avoidance because of investment in more nurses/physiotherapists to deliver incontinence services. The current annual amount column reports the costs from the 2011 report (New Zealand Continence Association, 2011).

It is difficult to know how much of the adverse impacts from incontinence may be avoided by the investments in more nurses/physiotherapists, therefore the estimated benefit column reports a

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[4] A more comprehensive study to update estimates of the costs of incontinence and therefore the benefits of avoided costs could be done in the future.

reduction of 10 per cent in the costs per year, with a range of 2 to 20 per cent reported in the brackets that follow.

Table 9: Estimated possible wider benefits of an investment in more nurses/physiotherapists

Area	Current annual amount	Estimated benefit
Health costs excluding continence products	$53m	$5m ($1m - $11m)
Productivity costs due to lower-than-average employment	$6.7b	$670m ($134m - $1,340m)
Productivity costs due to friends and family opportunity costs (such as whānau and informal carers)	$530m	$53m ($11m - $106m)
Cost of formal care and aids	$385m	$39m ($8m - $77m)
Aged care	$314m	$31m ($6m - $63m)
Other indirect costs	$63m	$6m ($1m - $13m)
Total costs (estimated)	**$8.05b**	**$805m ($161m - $1,609m)**

5.4 Benefit-cost ratios

Here we consider the findings of the analysis when considering all costs and benefits gradually. The table below shows the benefit-cost ratios when we take the narrowest focus (product savings only), widen our scope to include environmental costs avoided, and then also consider wider benefits.

Table 10: Benefit-cost ratios when considering different scope of benefits

Scope of benefits	Benefit-cost ratio
Direct benefits	1.4
Direct benefits + environmental benefits	2.6
Direct benefits + environmental benefits + wider benefits	129

When considering direct benefits only (i.e. of product spend reduction) the benefit-cost ratio is 1.5. This implies for every dollar spent, $1.50 of benefits will accrue from product spend savings.

The inclusion of environmental benefits increases the benefit-cost ratio to 2.6. This implies for every dollar spent, $2.60 of benefits will accrue from environmental cost savings (lower landfill costs and CO_2 emissions) compared to the base case with lower investment in nurses/physiotherapists.

The inclusion of wider benefits and environmental benefits increases the benefit-cost ratio substantially. The benefit-cost ratio of 129 implies every dollar of investment will return $129 dollars in benefit.

5.5 Sensitivity analysis

The sensitivity analysis conducted for this update remains the same as the previous analysis and is set out in Appendix D.

6. What next for continence services in New Zealand?

As New Zealand's population continues to rapidly age, there is a pressing need for a greater focus on preventative and early treatment measures within the continence service to effectively manage the future increase in service demand. Urinary and faecal incontinence are two of the top condition-related risk factors that influence admission to residential care, and the prevalence of incontinence increases with the length of time in care (Cockerell, 2022). A focus on early intervention and effective community care can save on product costs, keep people well for longer and improve quality of life (NHS England, 2018).

Awareness raising is important to shift peoples' belief that the focus of continence care is mainly on management (i.e. provision of pads). Incontinence is a treatable medical condition and the focus of care provided by continence services is on treatment, in other words, resolving the issue.

The survey findings show that there is service variation across New Zealand, with respondents highlighting the need for more staff and/or more time to spend with their patients. Respondents indicate the desire and need for increased education for health professionals and the general public. This suggests that there are still improvements to be made in the provision of continence services across New Zealand.

> This is an ambulance at the bottom of the cliff service...unfortunately. The referrals reflect this requesting "free pads" rather than conservative measures to improve continence. Patients' expectations are for free products and want a magic fix without the effort. A lot of education to other health professionals is needed but there is no time. – survey respondent

The updated CBA shows that an investment of $6.4 million per year for an additional 38 continence or district nurses/pelvic health physiotherapists would result in $8.9 million saved on incontinence products i.e. cost savings (or net benefits) to districts of $2.5 million. In addition, even a modest 25 per cent reduction in adult nappy use could avoid costs of $3.7 million in terms of the environment (landfill costs and the cost of CO_2 emissions).

There are benefits that were not quantified in financial terms as part of this CBA. Such benefits are no less important. Urinary incontinence is significantly associated with poor quality of life (Pizzol et al., 2021) and preventing or reversing incontinence will enable participation in social life and employment, family life, community and intimate relationships.

Given the current health system reforms, Continence NZ has a unique opportunity to increase advocacy efforts to the government to address continence issues through increased investment and improved models of care. By taking proactive steps to address these issues, we can avoid a large increase in future costs associated with New Zealand's rapidly ageing population, while also improving the quality of life for those affected by incontinence.

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Appendix A Literature scan search strategy

We undertook a non-systematic review of published academic and grey literature published from January 2017 onwards. This scan is intended to update the scan performed in 2017.

Search terms included, but were not limited to:

Main keywords and phrases:

1). Continence OR Incontinence AND (“best practice” OR “good practice” OR “models of care”)

- United Kingdom
- Canada
- Australia

2). Continence OR Incontinence AND (prevalence OR increase OR decrease)

- New Zealand
- United Kingdom
- Canada
- Australia

If the outcome of this search strategy results in too many or too few items, the search may be narrowed/broadened to include the following keywords:

Broader:

- Urinary incontinence OR fecal incontinence
- Cost benefit analysis OR costs OR burden of costs OR expenditure
- Effectiveness

Narrower:

- Data & statistics
- Continence aids/pads/products
- Treatment outcome
- Commissioning of services

Sources

For peer reviewed literature, sources included:

- PubMed
  - MESH: Urinary Incontinence / Fecal incontinence
- ABI Inform
- Gale
  - OneFile – Health and medicine
  - Academic OneFile

    - General OneFile
    - Health and Wellness
- Proquest Research Library
- Business Source Premier
- MasterFILE Complete
- Google Scholar
- Specific journals may be targeted. Eg. *JBI Database of Systematic Reviews and Implementation Reports*

Grey literature sources included government and non-governmental sources, and comparable international organisations.

Exclusions

Literature were limited to a publication date of 2017 or later.

Appendix B Survey questions

1. Which area do you work in? (select all that apply)
    - Northern
    - Te Manawa Taki
    - Central
    - Te Waipounamu
    - Other (please specify)
2. Do you provide services to (select all that apply)
    - Adults
    - Children
    - Aged Residential Care services
    - Disability Services
    - Community Groups
    - Other (please specify)
3. Do you work in (select all that apply)
    - Primary care
    - Secondary care
    - Tertiary care
4. Is your service (select all that apply)
    - Publicly funded
    - Privately funded
5. What is your profession (e.g. Specialist Continence Nurse, District Nurse, Physiotherapist, General Practitioner)?
6. Can you please describe your service briefly, including your position and department/ward (if relevant)
7. What kind of support does your service provide (select all that apply)?
    - Assessments
    - Bladder retraining
    - Pelvic floor exercises
    - Medications
    - Surgical interventions
    - Urological investigations/interventions
    - Education to patients
    - Education to other health professionals
    - Bowel Management Liaison

- Patient advocacy
- Products
- Other (please specify)

8. What do you think your service does well?

9. How long, on average, do your patients wait for an appointment?

- Initial appointment - low-risk
- Initial appointment - medium-risk
- Initial appointment - high-risk

10. When thinking about the product needs of your patients, does the service specification allow for

- insufficient consumables for most patients
- about the right amount of consumables for most patients
- more consumables than most patients need

11. What changes would you like to see to:

- the consumables list
- the amounts of consumables available

12. What else do you think could be improved with your services (select all that apply)?

- Waiting times are too long
- Dedicated staff for Continence Services
- The services provided are too limited, we would like to offer a wider range
- We need more resources for patients (e.g. bladder diaries)
- We need more time to spend with patients on education and/or options
- Other (please specify)

13. Any further comments on your suggested improvements e.g. what other types of services would you like to provide?

14. Do you visit patients in (select all that apply)

- Hospital
- Outpatient clinics
- Community clinics (e.g. GP, physiotherapy)
- Aged Care Facilities
- The patient's home
- Other (please specify)

15. Do you accept referrals from (select all that apply)

- Primary care
- Secondary care

- Self-referral
- Social Worker
- Other (please specify)

16. In your opinion, are people’s attitudes to continence issues changing (e.g. are people becoming more comfortable about talking about continence, are people more aware)?

17. Are there any trends in the types of issues you are seeing (e.g. seeing more patients with continence from prolapse)?

18. Have you heard of and/or used or attended the following in provision of your services?

    - Continence NZ Helpline
    - Continence NZ website
    - Education days/conferences held by Continence NZ
    - Continence NZ online courses
    - Continence NZ enewsletter

19. Are you a member of Continence NZ?

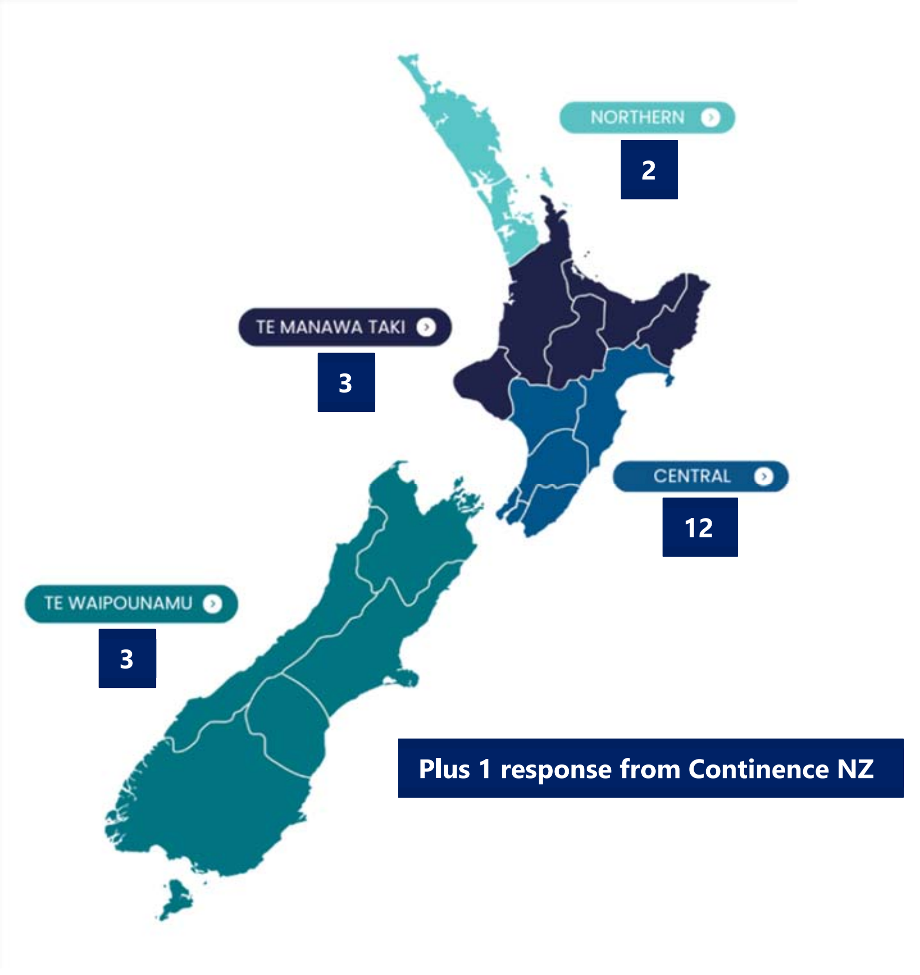
20. What support do you need from Continence NZ, that you are not already receiving, to help you deliver your services?

21. Is there anything else you'd like to add on Continence NZ support, or in general?

Appendix C Survey respondents and service profiles

Majority of respondents from the Central region (n=20*)

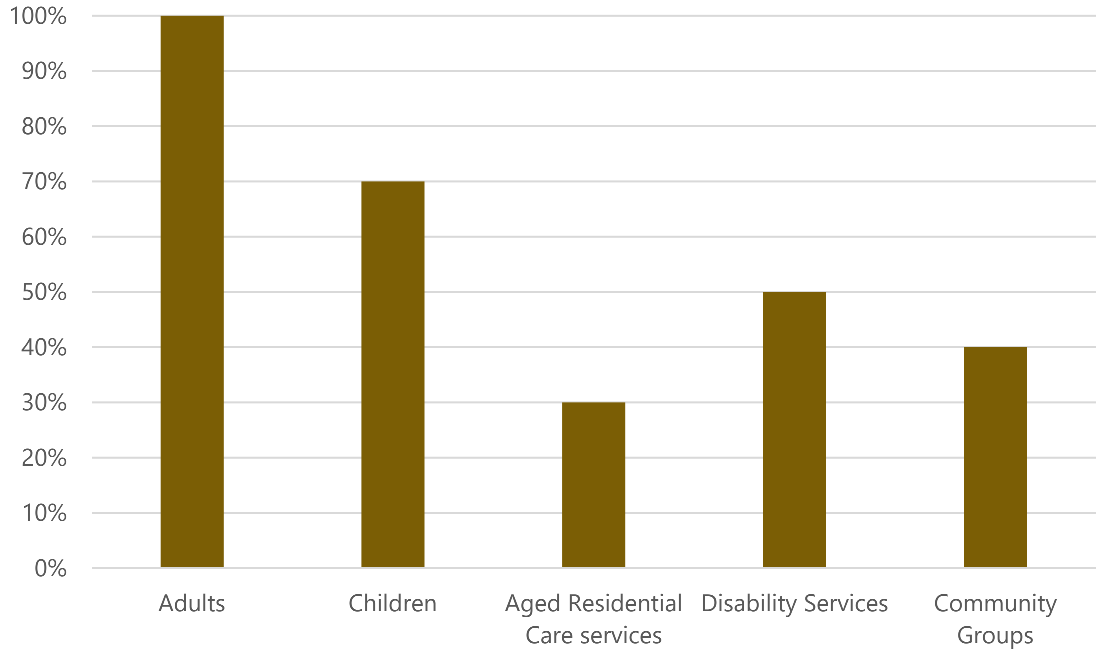
Figure 1: Location of respondents



* One respondent indicated they worked across two regions (Central and Northern)

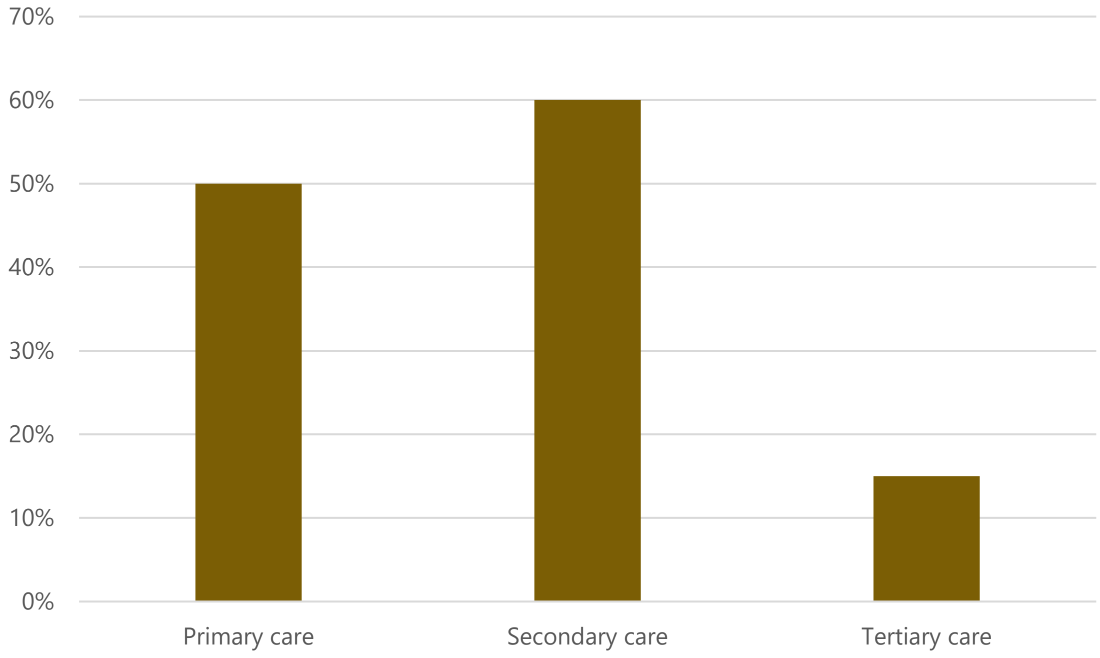
Respondents mostly provide services to adults and children (n=20)

Figure 2: Do you provide services to (select all that apply)



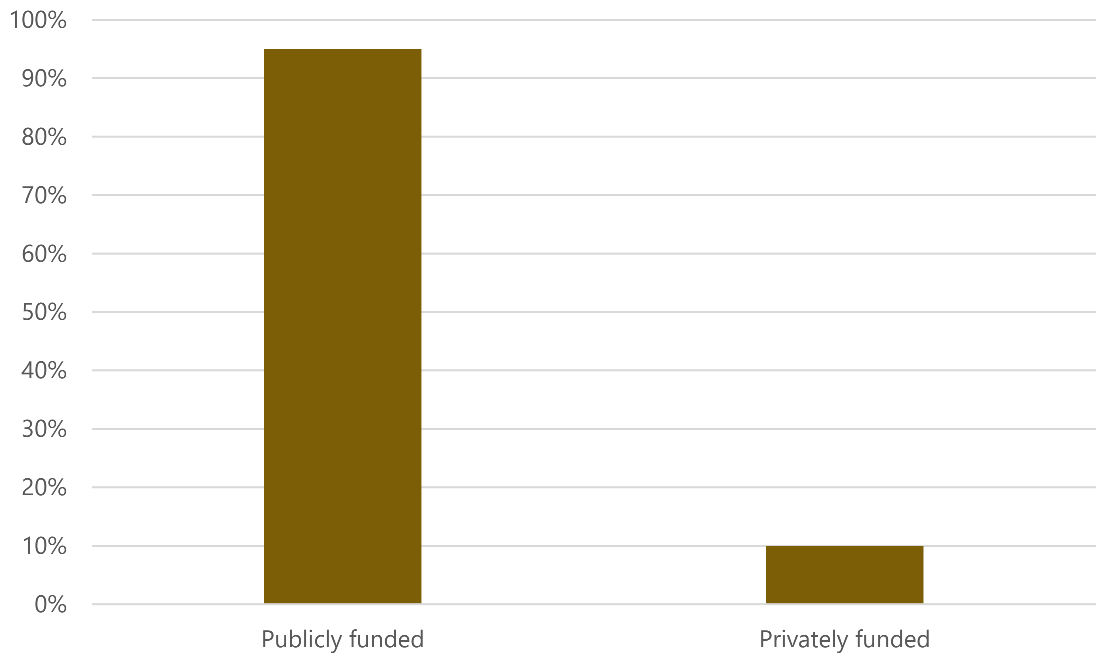
Majority of respondents work in secondary care (n=20)

Figure 3: Do you work in (select all that apply)



Almost all respondents worked in publicly-funded care, with one working in both, and one working solely in private (n=20)

Figure 4: Is your service (select all that apply)



The majority of respondents were Continence Clinical Nurse Specialists (n=20)

Table 11: What is your profession?

Profession	Number
Continence Clinical Nurse Specialist	14
Physiotherapist	3
Nurse Practitioner	1
Continence Nurse Helpline Education	1
Continence Advisor	1

All services provided assessments, bladder retraining, and pelvic floor exercises (n=20)

Table 12: What kind of support does your service provide (select all that apply)?

Profession	Number
Assessments	20
Bladder retraining	20
Pelvic floor exercises	20
Education to patients	19
Education to other health professionals	18
Bowel Management Liaison	17
Products	17
Patient advocacy	15
Medications	9
Urological investigations/interventions	7
Surgical interventions	1
Other (please specify)*	6

*'Other' services included intermittent catheter teaching and support, referrals to other health care providers, and intradetrusor botox.

The most common locations for patient visits were outpatient clinics and home visits (n=19)

Table 13: Do you visit patients in (select all that apply)

Profession	**Number**
Outpatient clinics	15
The patient's home	14
Aged Care Facilities	10
Hospital	9
Community clinics (e.g. GP, physiotherapy)	7
Other (please specify)*	5

*'Other' visits included schools, telehealth, and marae visits.

All respondents accepted referrals from primary and secondary care (n=19)

Table 14: Do you accept referrals from (select all that apply)

Profession	**Number**
Primary care	18
Secondary care	19
Social worker	12
Self-referral	7
Other (Please specify)*	8

*'Other' referrals included schools (e.g. special education needs co-ordinators) and ACC.

Appendix D Sensitivity analysis conducted in 2017

We undertook one-way sensitivity analysis to gain an understanding of which variables and assumptions have the largest impact on the result, and to gain a better understanding of the possible range of results given the uncertainty regarding each of the key assumptions.

Decreasing the benefit from reduced product use

When the benefits are limited to the direct benefits of reduced expenditure on products, the analysis is most sensitive to the assumptions regarding the reduction in product use and the amount of nurses/physiotherapists required to achieve the reduction in product use and improvement in quality of life and health outcomes. As mentioned in the cost-benefit section, assuming a reduction of continence product expenditure between 50 and 95 per cent results in a net benefit of -$1.6 – $2.7 million. We tested the impact of assuming 50 per cent decrease or increase in the number of nurses/physiotherapists required to achieve the reduction in continence product expenditure; assuming a range of between 19 and 57 nurses/physiotherapists needed results in a net benefit of $-0.7 – $5.7 million (holding the proportion of DHBs requiring extra staff constant).

Including wider benefits

When we include the possible wider benefits, the analysis is most sensitive in the reduction in the wider impacts of incontinence and the proportion of DHBs requiring extra specialist nurse/ physiotherapist resources. Assuming that the additional nurse/physiotherapist resource results in between 2 – 20 per cent reduction translates to an estimated net benefit of $163 million to $1.6 billion. Assuming that between 50 and 85 per cent of DHBs require additional resources to meet best practice translates to an estimated net benefit of $538 million – $915 million. If more DHBs require more additional resources the cost will also increase, although the additional benefits are expected to outweigh the additional costs.

Applying NHS best practice staffing rates

In our base case we assumed that best practice is to employ 1.25 nurses/staff per 100,000 population. In this section we estimate the costs and benefits if we assume a rate of 1 per 100,000 i.e., the same rate as recommended by the NHS. The cost is relatively easy to estimate, as we scale our estimate of the number of additional staff. Using a rate of 1 nurse/staff per 100,000, we estimate 29 extra nurses/physiotherapists are needed. This investment is estimated to cost $4.9 million per year (i.e., using this lower rate results in 9 fewer nurses/physiotherapists which will require $1.5 million less in investment).

It is relatively difficult to estimate the benefits of investing at a nursing/staff rate of 1 per 100,000. We have estimated that the ratio of benefit to cost will be the same as in our base case. Given we are assuming a 20 per cent reduction in the investment needed, we assume a 20 percent reduction in benefit. Therefore, under this scenario we assume a 74 per cent reduction in product use, resulting in an estimated direct benefit of $7.1 million. The return on investment (1.4) is the same as our base case, if limiting the benefits to reduced spending on incontinence products.

Applying a 20 per cent reduction in our estimate in avoided wider costs of incontinence results in an 8 per cent reduction in possible wider community benefits. Therefore, our estimate of the possible wider benefits under this scenario is $640 million per year.

Table 15: Sensitivity analysis

Variable	**Base case**	**Changed to**	**Net benefit – limited to direct benefits**	**Net benefit – including possible wider benefits**
Base case			$2.5m	$807m
Reduction in continence produce expenditure	90%	50%	-$1.6m	$803m
		95%	$2.7m	$807m
Reduction in wider impacts of incontinence	10%	2%	$2.5m	$163m
		20%	$2.5m	$1.6b
Increase in Nurse/Physio	38	19	$5.7m	$810m
		57	$-0.7m	$804m
Proportion of regions requiring extra nurses	75%	50%	$1.6m	$538m
		85%	$2.m	$915m

Unquantified benefits are significant too

As already mentioned, there are benefits that can’t be quantified in financial terms but are no less important. These include improved quality of life of patients, particularly those extra patients whose incontinence is reversed or prevented. This includes enabling participation in social life and employment, family life, community and intimate relationships.

Comparison with published estimates

It is difficult to draw comparisons of other cost-benefits analyses with our analysis. Our analysis is based on a specific investment in nurses/physiotherapists and assumes that many DHBs are currently under-resourced to deliver good practice, whereas existing cost benefit analyses we identified are based in other countries, comparing different interventions and based on the provision of a different set of existing treatment and services. Nevertheless, other studies have found that nurse specialists result in improved health outcomes and savings on incontinence products.

For example, one analysis from the Netherlands found that adding a nurse specialist to an existing primary care team would generate cost-savings (Holtzer-Goor et al., 2015). The savings arose from increased percentage of successfully treated and improved patients, leading to reduced costs for formal home care, informal care and incontinence products. The analysis reported that there would be a small additional cost if the perspective is limited to the health care payer perspective; however, we consider the cost-effectives ratio under this scenario of €19,400 to be reasonably cost-effective.

Another study compared advice and training provided Nurse Continence Advisors with urogynaecologists in Australia (Foote & Moore, 2007). This study found that both options led to significant improvements in patient outcomes and reduced expenditure on incontinence pads. After three months, patients trained by the Nurse Continence Advisors had a 66 per cent reduction in expenditure on incontinence pads.[5]

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[5] Reported as an initial expenditure of $4.4 per week with a reduction of $2.9; values in 1995 AUS.

About Sapere

Sapere is one of the largest expert consulting firms in Australasia, and a leader in the provision of independent economic, forensic accounting and public policy services. We provide independent expert testimony, strategic advisory services, data analytics and other advice to Australasia's private sector corporate clients, major law firms, government agencies, and regulatory bodies.

'Sapere' comes from Latin (to be wise) and the phrase 'sapere aude' (dare to be wise). The phrase is associated with German philosopher Immanuel Kant, who promoted the use of reason as a tool of thought; an approach that underpins all Sapere's practice groups.

We build and maintain effective relationships as demonstrated by the volume of repeat work. Many of our experts have held leadership and senior management positions and are experienced in navigating complex relationships in government, industry, and academic settings.

We adopt a collaborative approach to our work and routinely partner with specialist firms in other fields, such as social research, IT design and architecture, and survey design. This enables us to deliver a comprehensive product and to ensure value for money.

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