NATIONAL ADVOCACY TRUST
EMPOWERMENT THROUGH ADVOCACY

Annual Report
2019 - 2020

Chair's Foreword

Tēnā tātou katoa,

The National Advocacy Trust has again demonstrated an ability to deliver an agile, consumer centric service over the past year. As was the case for everyone in Aotearoa, Covid-19 demanded a rapid response by our service delivery team in how we supported consumers, to ensure continuity of services. While complaints understandably dropped over the period of the Level 4 lockdown, the Trust was able to take on the management of the Health and Disability 0800 phone number during this time and our systems enabled our advocates to work from home with no interruption to consumers. The Trust introduced a new rapid response, specifically to enable consumer concerns to be quickly escalated and resolved directly with the provider. The success of this approach, which was initially specifically designed for the Covid-19 Level 4 isolation period, is now informing how we can incorporate this into our everyday practice.

In October 2019 we introduced live chat on our website, which was integral in supporting the Board strategy, affordably extending our reach to all Health and Disability consumers. Since its introduction there have been over 1000 conversations with consumers, who have reported 86% satisfaction. Similarly, our advocates are involved earlier on in supporting consumers and providers achieving earlier resolution of complaints and supporting lasting changes in provider's behaviour. Additionally, our website now supports multiple translation options, accessibility for consumers with visual impairments, and a growing range of resources for consumers and providers.

For almost two decades the Trust has delivered a free and independent service for all consumers of health and disability services in Aotearoa. Over this time, we have seen consumer complaints increasing in complexity, we have invested in building the competence of our advocates, with more of our team having tertiary qualifications, in addition to advanced training in models of advocacy. We have also seen that where our advocates are involved earlier in consumer complaints, this provides greater opportunity for earlier resolution, enabling the Health & Disability Commissioner to focus on serious systemic complaints. From a consumers' perspective, the service embodies empowerment enabling consumers to be supported in achieving resolution of complaints. The Trust continues to extend its reach into Māori, Pacifica and Asian communities and consumers of Mental Health and Disability services, enabling greater confidence that complaints are truly representative of all consumers.

Funding is always a constraint for the Trust, managing the balance between service development and service delivery, while living within our means is constantly complex and increasingly more demanding. The Trust is reliant on our single contract with the Health & Disability Commissioner, through the Director of Advocacy, this is to maintain the independence of the National Advocacy Trust and we are appreciative of the strategic relationship that we have with the Commissioner. Over the next year the Trust will be continuing to extend our use of technology and our strategic partnerships, developing and enhancing how consumer's voice and complaints can be heard, as ultimately, this improves the health experience and outcomes for all people living in Aotearoa.

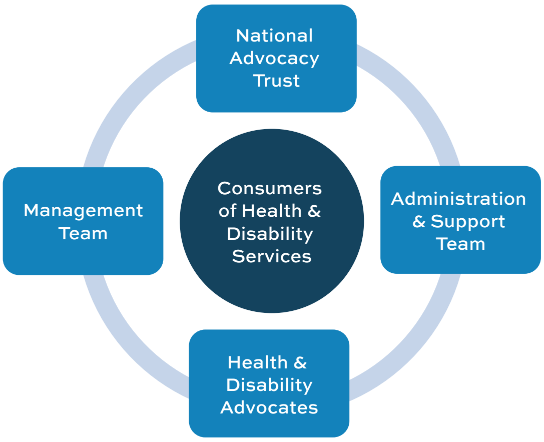
Finally, it is only with the tremendous mahi and passion of our advocates, call centre and support team, that the Trust can again deliver outstanding achievements.

Nāu te rourou, nāku te rourou, ka ora ai te iwi.
With your basket and my basket, the people will flourish.

Nāku noa nā
Randal Southee -Chair
National Advocacy Trust

Introduction

National Advocacy Trust Organisation Chart



As the provider of the Nationwide Health and Disability Advocacy Service the Trust's core focus continues to be on the provision of highly skilled, professional advocates who effectively manage and resolve complaints. The Trust supports the activities of the service by adhering to the six pillars of good governance i.e. obeying the rules of law, having moral integrity, operating transparently, encouraging participation, being responsible and accountable, and providing direction that promotes effectiveness and efficiencies.

The success of the service is in having advocates based in their local communities, allowing them to develop close relationships with community groups and constructive relationships with providers of health and disability services through networking and education.

In the last year we have redesigned the advocacy pamphlet, produced advocacy posters which are downloadable from the website, added a translation feature to the website, and had advocacy information translated into the six most common languages of those using the service.

> We have advocates in 22 offices located between Kaitaia and Invercargill and operate our free phone, enquiries email, Facebook, and Live Chat on the website.

In December 2019, an Omnibus Survey by Research NZ helped us determine the level of knowledge the public have about the Nationwide Health and Disability Advocacy Service. When prompted, one-third (35%).of about 1000 respondents said they had heard of the Health and Disability Advocacy Service.

The Trust would like to take this opportunity to acknowledge Anne Carnie who after 24 years of being the Health and Disability Advocate based in Timaru has retired from the service. Anne joined the service on its very first day, having previously worked in patient advocacy. During her years as an advocate, Anne demonstrated her commitment to the work of the service, her colleagues, managers, and employers. We wish her all the best for retirement.

As it did for everyone in New Zealand, the COVID-19 lockdown impacted on our service delivery. We wish to thank our team for the professional manner in which they adapted to an ever-changing environment while keeping the support needs of consumers at the forefront of their minds and actions.

Highlights for 2019-20

LiveChat

In October 2019 the Trust, which manages the advocacy website, introduced LiveChat. LiveChat enables people to type their questions and have them answered in real time. In nine months there have been 1000 conversations. It suits complainants who aren’t able to, or prefer not to, speak on the phone. A post-chat survey of users shows around 86% satisfaction.

Many of the LiveChat queries can be answered by the Call Centre staff, and others are sent to the advocates in the complainants’ local area – allocated as they come in. Access has also been increased by offering options including Facebook, email and a website contact form.

> Over the past twelve months the advocacy website received 34,614 visits – 83% of those being people who had not previously visited. The top three regions visitors came from were Auckland 8,598, Wellington 3,151 and Christchurch 3018. 31% of people had been to the HDC website before visiting the advocacy website.

Website administrator James Price says,

> "Our team is a unique bunch of people who take a range of enquiries – on the phone, email and LiveChat. It can be a busy place, multi-tasking in real time. Of course, we get a number of queries for services we don't provide, so we have to triage the questions. Our advocates are amazing, you know you're transferring the consumer to someone who can help and know the person will be supported."

Health & Disability Commissioner 0800 number

A planned approach for the Trust to answer the Health & Disability Commissioner's 0800 phone number occurred mid-March. Trust National Manager Oliver Halford says a positive outcome of this was that people who contact the Commissioner's office via that telephone number have the option to choose advocacy, which can be a quicker resolution of their complaint (than an investigation by the Commissioner). For example, in a day's tally of 33 calls, 23 were answered immediately or referred to an advocate and ten were directed to the Commissioner's office.

We've also been collaborating with the Commissioner on resolving complaints sent to his office. Where the Commissioner considers it appropriate, following receipt of a provider response, he refers the matter to the advocacy service for an advocate to make contact with the complainant to discuss the response, in particular whether it addresses the complainants concerns, if not, what needs to be done. It's a better outcome for the complainant, a more personal approach.

> In a day's tally of **33** calls,
>
> **23** were answered immediately or referred to an advocate,
>
> and **ten** were directed to the Commissioner's office.

Rapid response

The COVID-19 lockdown caused huge disruption to health and disability service providers and complainants, however, the Trust was able to adapt its processes to allow advocates to offer a 'rapid response'. For those consumers highly reliant on providers it could be very stressful if they didn't receive their expected service.

Oliver says,

"Advocates would ring providers on consumers' behalf and facilitate the process to resolve the issue quickly. We don't usually talk on behalf of consumers but where it was needed it worked really well. Advocates have been asked for feedback on what worked and what didn't and factors to be considered if the Trust were to adapt processes to include the option of continuing, where appropriate, to use phone calls as a resolution tool. We've seen there's a place for the reintroduction in our process."

When we listen, you'll hear about it.

We are here to help.

The Nationwide Health and Disability Advocacy Service is a free service that operates independently from all health and disability service providers and agencies. If you want to know more about your rights when using health or disability services, get questions answered, or talk through your options for making a complaint, we can help.

For the period 01 July 2018 - 30 June 2019, the service closed 2644 complaints – 83% of those were closed within 3 months and almost 100% in 6 months. 88% of the complaints closed during the year were resolved or

ntact an Advocate now

Website

The website continues to be a well-used tool. It's accessible – with translation options of English, French, Chinese (simplified and traditional), Somali, Arabic, Maori, Samoan, and for those with visual impairments text can be enlarged, contrast altered, or the page read. There are also options for keyboard navigation, highlight link, altering text spacing and enlarging the cursor. The website also contains the resources produced by the Trust for promotion of the advocacy service. Some resources may be downloaded, for example posters and the health passports, others may be purchased by providers, consumers have the option of making a request for a free copy.

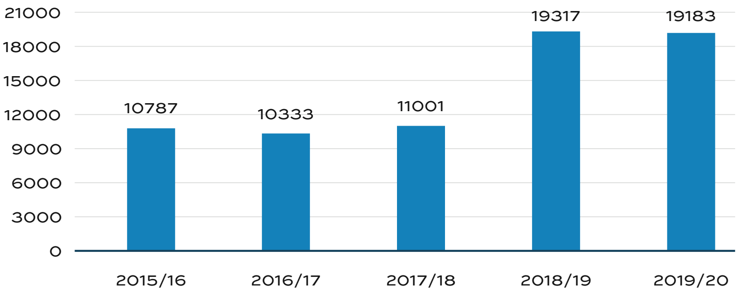
Enquiries

The total number of enquiries received this year is not dissimilar to the total received for the previous year (19,317). There were no significant changes in the subject, referral method or outcome of enquiries.

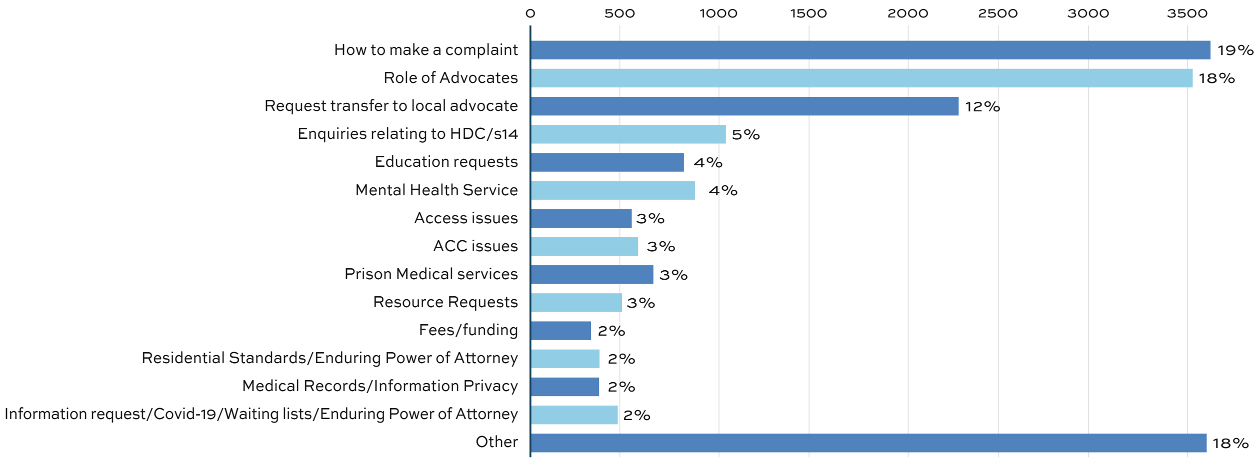
We had begun discussions with the Health and Disability Commissioner (HDC) about the Trust managing calls to the Commissioner's free phone number. The Trustees believed that presenting the advocacy process as the first option would provide greater opportunity for resolution for consumers than having their complaints referred to providers or being closed based on papers provided to the Commissioner.

The transition to providing this service happened more quickly than anticipated, due to the COVID-19 lockdown, with the Trust managing calls from the end of March 2020. Between 31 March and 30 June 2020, the advocacy team managed 1115 enquiries that came through on the HDC free phone number. Of those, 70% of callers chose to work with an advocate or were provided with information that enabled them to manage the situation themselves. The successful management of the HDC 0800 calls by the advocacy team has resulted in the Trust being requested to take this on as part of its contract from 1 July 2020.

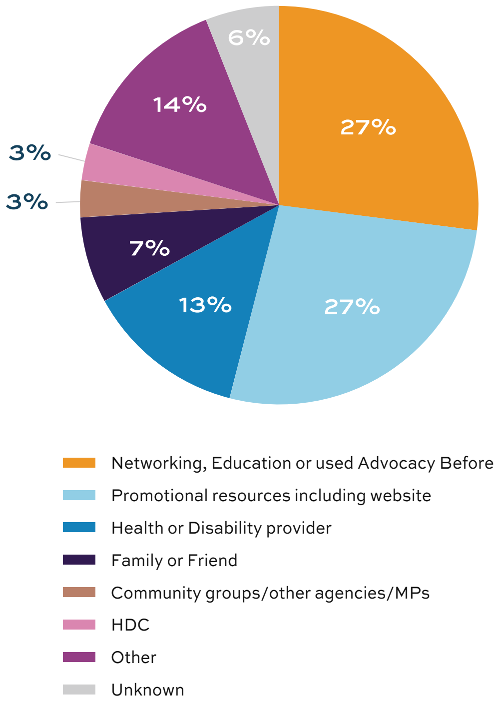
Enquiries closed by year



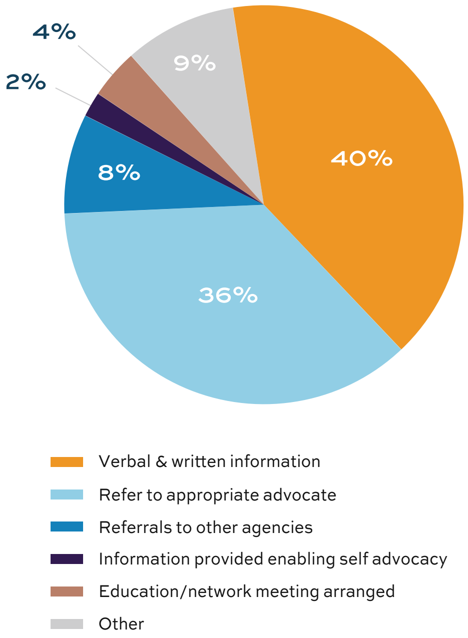
Subject of enquiries 2019/20



Enquiries - Referral method 2019-20



Enquiries outcome 2019-20



Gillian Adams

The advocacy service has become more focused on its core business over the years, but the skills of advocates are more relevant than ever, says long-term advocate Gillian Adams, Dunedin.

> “You have to balance the concerns of the complainant with the reality-check of the situation. I enjoy helping people see things from other perspectives. It’s never linear, you have to clarify the complainant’s concern and do some straight-talking, and it can be difficult to assign the impact of a situation. It’s endlessly fascinating.”

Gillian has been an advocate for 19 years and says, compared to when she began, there is now a clearer understanding of the function of the Trust and the role of advocates. She’s noticed some of the benefits of the COVID-19 lockdown in some parts of the community. Corrections facilities reported a feeling of security and safety, and there were no complaints about restricted access for visiting family.

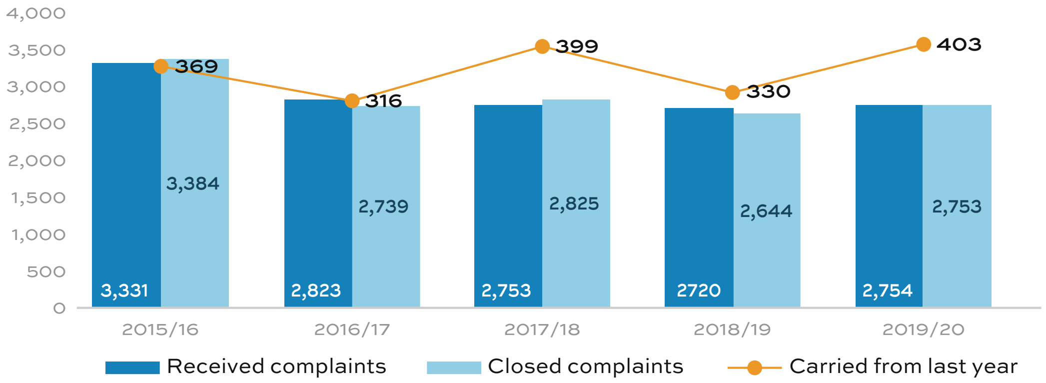
In her own education outreach, an unexpected outcome was the benefit of using video conferences, particularly among medical students.

> “The students were far more engaged, participating more and the usual group dynamic changed. I noticed a huge difference, there was so much more participation. They were more confident calling in from their own homes and able to text in questions. I’ll be suggesting we use video conferencing more in the future.”

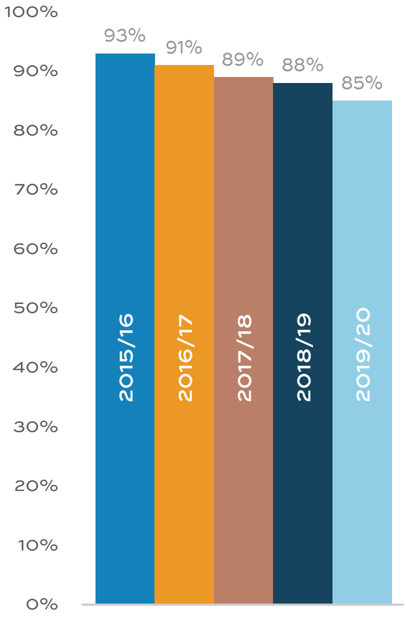
Complaints

We continue to receive and manage a steady volume of complaints, and 85% are resolved within the year. 93% of consumers and providers who responded to complaint resolution surveys indicated they were satisfied or very satisfied with the service.

Complaints by year



Resolution by year

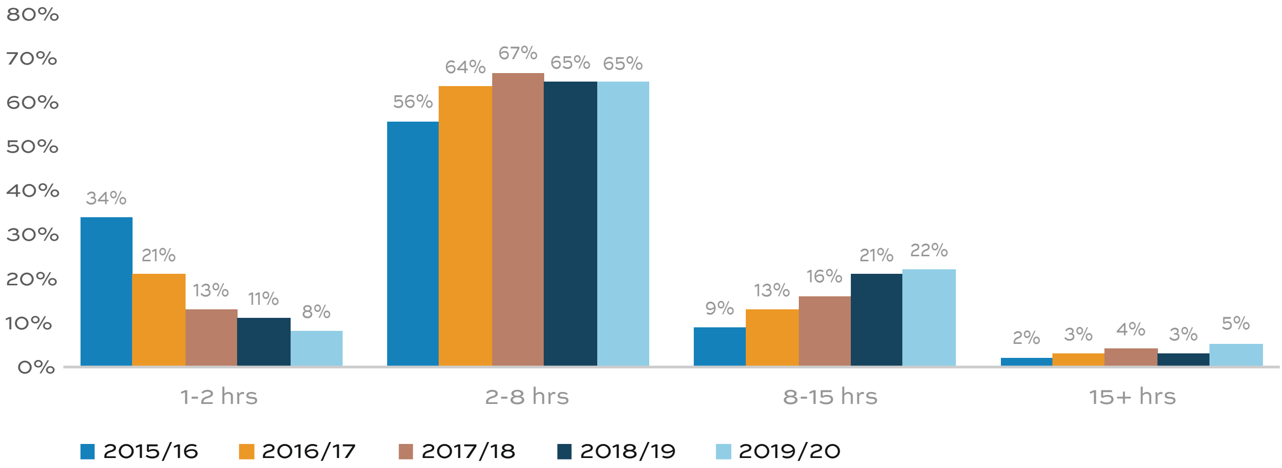


We believe the decline in resolution rates has a correlation to the increasing complexity of the complaints being managed by the advocacy service (see graph on following page).

Complaint complexity

Since 30 June 2018, complaints classified as simple, i.e. those that take one to two hours, decreased in volume by 3%. Standard complaints which take between 2-8 hours have remained at the level of the 2018/19 year i.e. 65 %. Those taking between 8-15 hours from opening to closing have again increased this year by 1%, and those that take over 15 hours have increased to 5%, the highest they have been over the past five years. The average time spent from receipt to closure of complaints has also increased by 30 minutes, from six hours in the 2018/19 year to six and half hours in the 2019/20 year.

Complaint complexity by year



Louise Grant

The advocacy service provided by the Trust changes to suit the times, but the consumer remains at its heart, says Napier-based advocate and learning coach Louise Grant.

"As long as I keep the consumer at the centre of my practice I'm doing well," she says.

Louise divides her time between advocacy/education and as a learning coach to new advocates. New hires are put through three months of orientation and induction, with support from peers and more experienced advocates. Extended modules and further training are also possible.

"It's a tailored programme for our needs and practice. We're there for every health and disability service consumer in the country and our service is ever-evolving."

Health and disability service providers are now reflecting on their experience during the COVID-19 response, and what the 'new-normal' will look like. Some, such as disability vocational services, may not be offered in the same way. Louise says she's having conversations with providers about what they have learnt, what changes they may make, and considering how this will affect consumers.

During the COVID-19 lockdown, advocates also had to adjust to a new way of working.

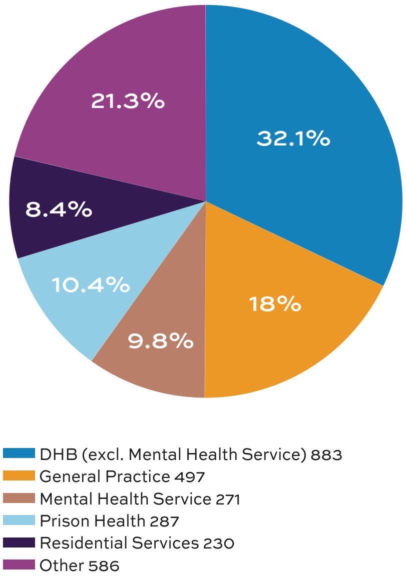
"We used rapid response to address the immediate needs of those who were vulnerable or at risk, while managing expectations for other, less urgent enquiries," she says.

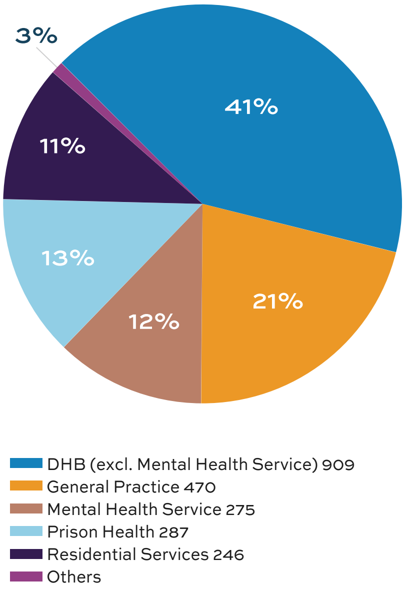
Phone calls with providers are now being considered for some situations where it would help achieve an effective and efficient resolution of complaints.

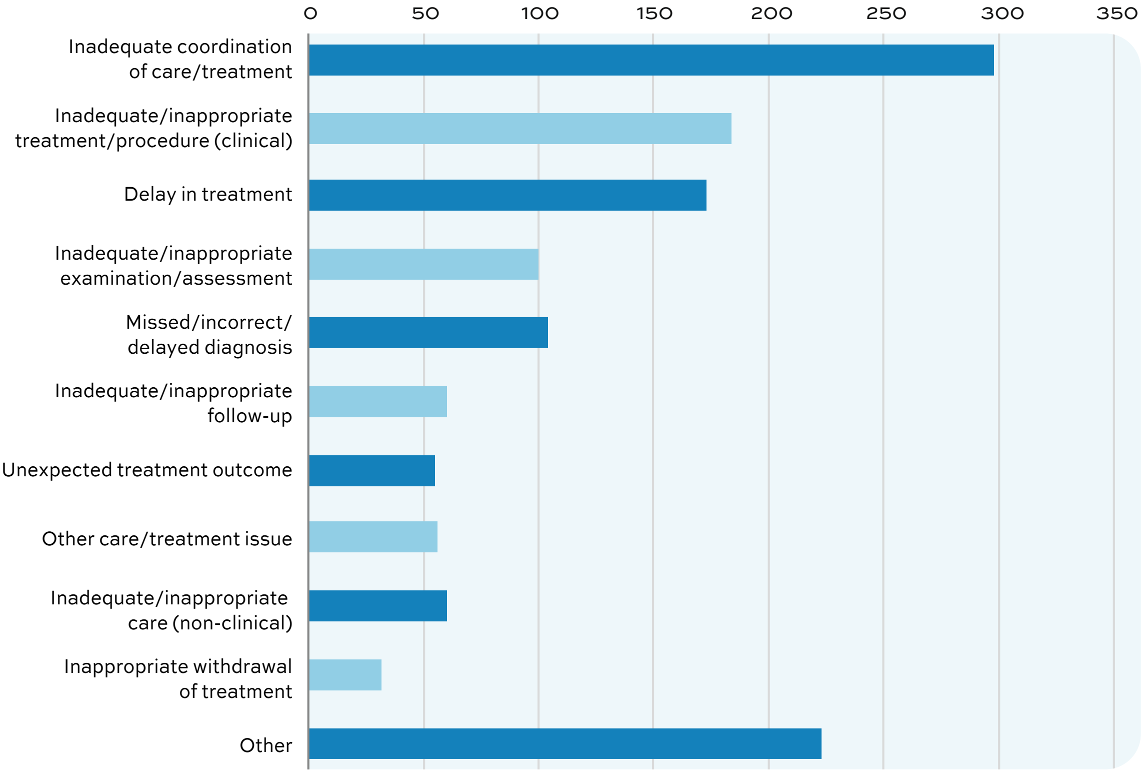
CASE STUDY

During the Level 4 COVID-19 lockdown, an elderly man visiting from another region became unwell with a suspected brain tumour and was admitted to the local hospital. His daughter contacted the advocacy service as she was concerned her dad would become extremely anxious at the prospect of an MRI scan, and she felt her voice wasn't heard by the clinicians. Louise phoned the oncologist facilitator at the hospital and asked her to intervene. The hospital subsequently arranged alternative treatment (a CT scan) for the man, and also facilitated a video call between the daughter and her dad. The issue was resolved with good communication and a holistic response for the family.

Complaints received


Complaints received by service type 2019/20


Complaints closed by service type


Complaints received - Issues - Care/treatment breakdown 2019/20

As in previous years the most common issues raised by consumers/complainants relate to care and treatment and communication. As may be expected 58% of DHB complaints (excluding Mental Health Services) relate to care and treatment issues, and 27% relate to communication. Across all mental health services communication issues make up 42% of complaints, followed by 39% of complaints being about care and treatment issues. 42% of complaints about GPs relate to care and treatment issues and 40% relate to communication issues.

Examples of changes by providers after our intervention:

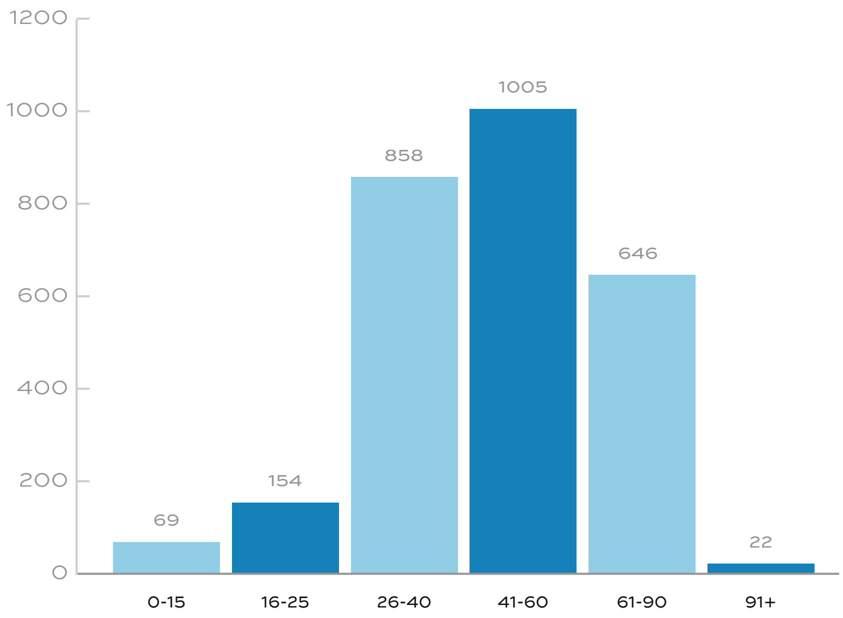
One provider identified they could improve one of their processes to prevent a similar occurrence for other consumers. They advised the complainant that they had consulted with staff on how the process could be improved and had been actively and consciously assessing the workflow, and as a result had rewritten their Standard Operating Procedure.

In response to a complaint about how respite care can be used, the provider advised they are developing a new leaflet. They have sought input from the complainant to ensure the language and phrasing of the information is easy to read and provides clarity about when and how respite care can be used.

Complaints by age and gender

Complaints received by age and gender have not significantly changed from previous years i.e. those aged between 41 to 60 years (36%), followed by those aged between 26 to 40 years (31%) bring most complaints, and people identifying as female account for 59% of all complaints received.

Complaints received by age group



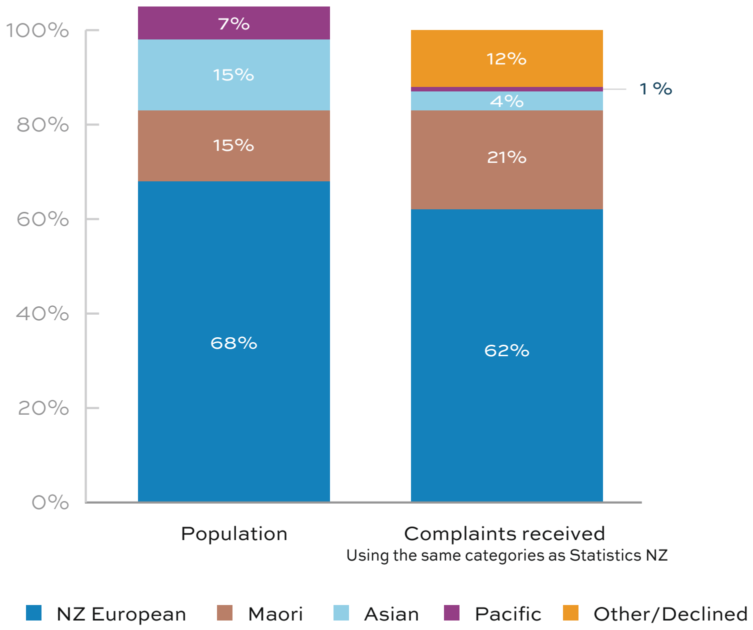
83% (2286) of the complainants were people identifying as NZ European or Maori and as above, the majority of people were in the 41 to 60 age group. Further analysis shows that Maori aged between 26 to 60 years account for 74% of the total complaints from Maori, while 65% of all complaints from NZ European fall within that age group. The significant difference occurs in the age group between 61 to 90 years where NZ European are twice as likely to complain as their Maori counterparts.

Complaints by ethnicity

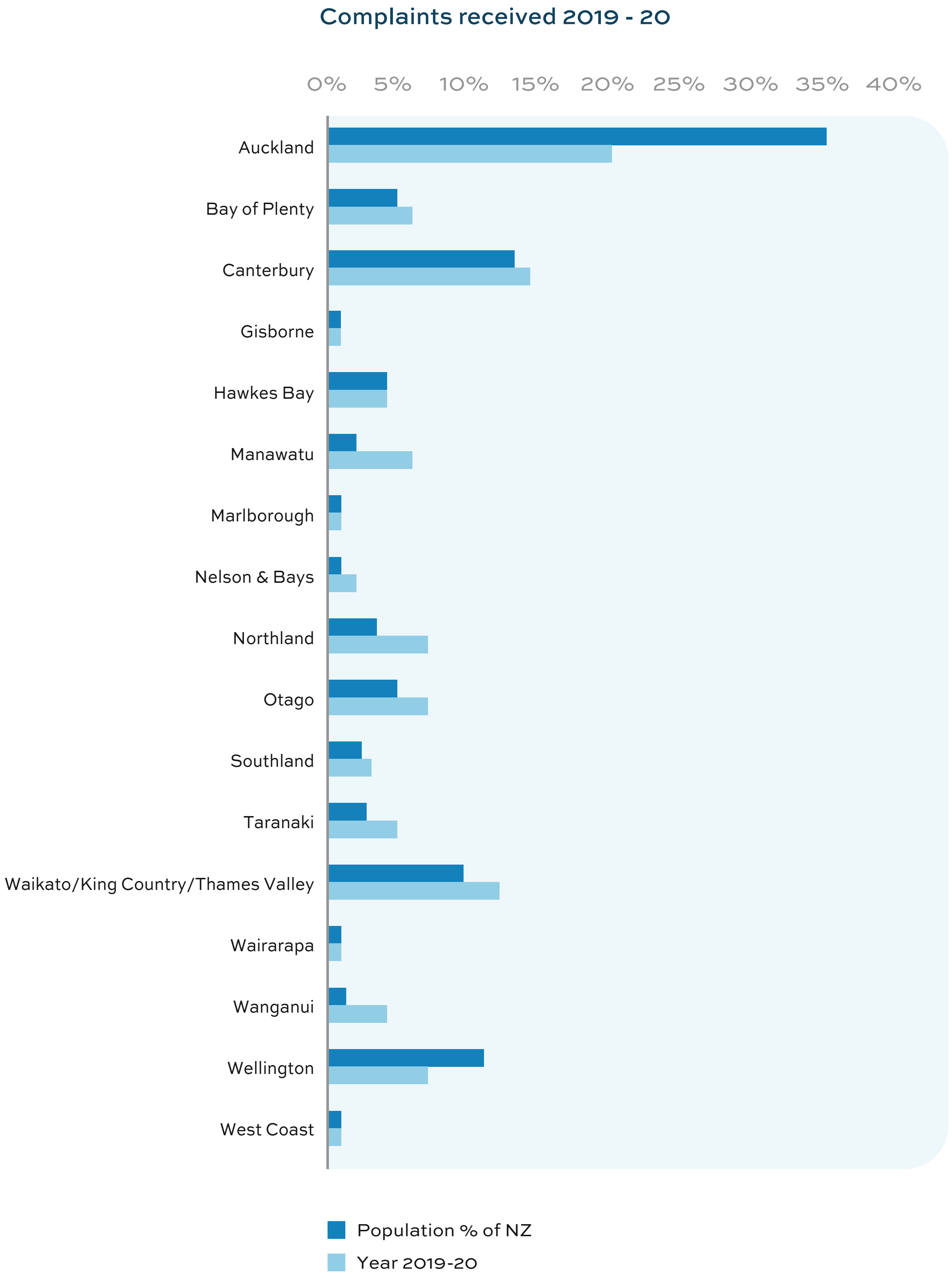
For ease of comparison to national data, ethnicity has been grouped in the same four categories used by Statistics NZ. As can be seen in the graph, three of the four defined ethnic groups are under-represented when compared to the national data. The Trust is pleased however, to see that the gains made last year in respect of NZ Maori bringing complaints has not diminished.

The top six ethnic groups who made complaints are:
NZ European 62%, Maori 21%, Indian and Pacific Peoples 2%, English and Chinese each 1%.

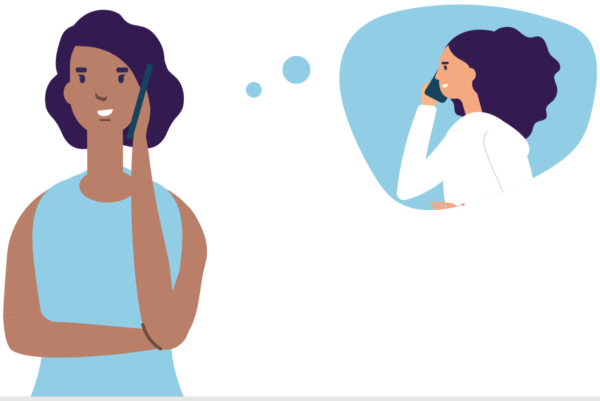
Statistics NZ ethnicity data vs Complaints received



Complaints by region



The above graph of complaints by region compared to population shows no significant changes when compared to historical data. From comparative information previously shared with us by the Health and Disability Commissioner we know that people in both Auckland and Wellington are more inclined to take their complaints directly to the Commissioner.



We received this unsolicited email: “I had attempted a variety of ways of communication, over some months to no avail. I finally sought your advocacy support through [advocate]. He was so wise, totally professional, and very supportive. His skilled gentle approach demonstrated this so well at all times...I very much doubt I would have reached this place without the support and expertise given to me by [the advocate] from Health and Disability. I can now leave this behind me”.

Another consumer emailed: “Your assistance with the many issues that have occurred lately has been undeniably helpful. You made direct contact with me on many occasions, explained the process in detail, reassured me that the changes I had asked for from various providers was and is helpful. You have also helped me to make changes on how [the provider] interacts with [town’s] citizens and most especially the 60% Maori population....Words cannot express my gratitude. Your professionalism is second to none.”

Comment from a consumer:
“I think [advocate] understands that sometimes people just need to get things “out there”, very tolerant listener. Certainly, supportive as can be when clients face difficult circumstances. Simple and no fuss. Explained and reiterated when necessary so I understood...”

Comment from a provider:
“Excellent service from the advocates. I refer consumers to them as they are very good at helping clarify what their issues are and how they would like them resolved.”

Education & Training

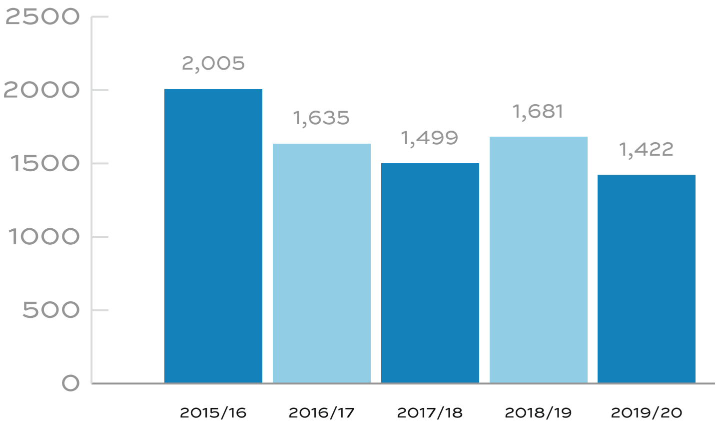
Educating the public on their rights and providers on their duties is an important part of the advocacy services' role. Education for consumers includes the Code of Health and Disability Services Consumers' Rights (the Code), how to speak up when things go wrong, and the tools needed for self-advocacy. Provider education includes the Code, open disclosure, and complaint management. Of the 1422 sessions provided by advocates, 50% were for consumer or consumer focussed groups, provider groups were 48% and the remainder were mixed consumer and provider groups.

We were able to hold fewer education sessions this year due to the Covid-19 lockdown. From early March residential facilities and community groups began cancelling education sessions as the country prepared for Covid-19 reaching New Zealand. While the service continued to offer education through electronic channels, such as Skype and Zoom, many organisations had other priorities around maintaining good health, or were not set up for electronic education.

Education sessions provided by advocates are generally well attended. Overall, 78% of education provided by advocates was to groups of five or more. Those participating in education sessions are asked to give feedback via paper surveys. Last year 4,190 surveys were returned by both consumers and providers, with 89% of attendees indicating they were either satisfied or very satisfied with the session.

Last year 47% (663) of all education sessions were to consumers and providers who have contact with older people, Pacific people, Deaf people, those with a disabling condition, Maori, refugees/migrants, mental health consumers and their family/whanau. Other important audiences for education sessions were consumers and staff of aged care and residential disability services (41% of sessions).

Education visits by year



Advocate Profile

Kristie-Anne Scott

Learning and finding new ways to challenge herself are important for Kristie-Anne Scott, Invercargill.

Kris is the sole-charge advocate for the Southland area, yet she feels supported through peer support and networking with other advocates.

"There's regular contact up and down the country, I liaise with different teams and enjoy the connectedness between the advocates."

With a smaller population to service – though a large geographic area – she has peaks and troughs through the year. After a brief stint with another organisation, she returned to the Trust, appreciating the clear boundaries of the role and how advocates work to the goal of resolving people's concerns.

"When I came back to this role, I was keen to look at ways to increase my learning and challenge myself. We're in the business of helping people find other perspectives, so I thought I should do this too."

Kris has undertaken Health & Safety training and tapped into education offered by the DHB. Another area is learning how to engage with people from different cultures, for example, the Pasifika community. Kris says she also has a good relationship with the local runanga.

Networking

The Advocacy Service prioritises developing positive and productive relationships with consumer and provider organisations to ensure awareness of consumer rights and build confidence in the advocacy process and service, which in turn assists with the resolution of complaints.

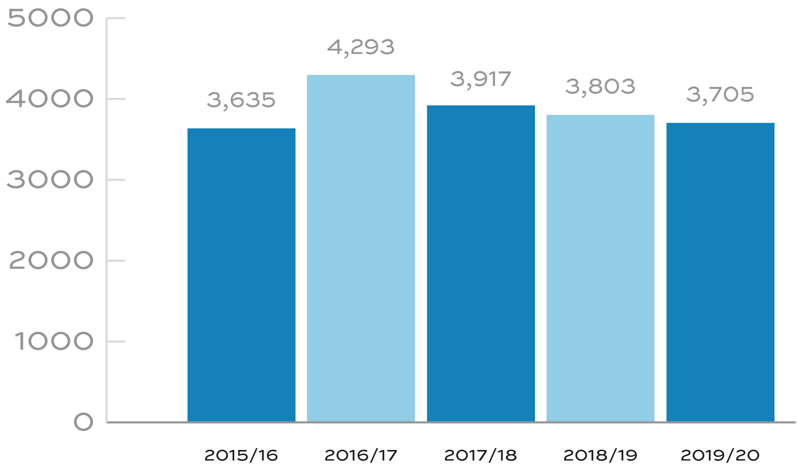
Despite losing two months' networking to the Covid-19 lockdown, advocates visited or met with 3,705 people/groups during the past year.

Advocates visited aged care, residential disability services and day-based facilities throughout the country (1134 visits). Fifty percent of the visits were to meet consumers to make them aware of the advocacy service and its work, and to provide access to an advocate for consumers who may have no other way of speaking to an independent person about any concerns.

Forty-four percent of the remaining 2571 visits by advocates were to consumer or consumer focussed groups, provider groups 50% and mixed consumer and provider groups six percent of visits. Other priority audiences for networking sessions were older people, Pacific people, Deaf people, those with a disabling condition, Maori, refugees/migrants, mental health consumers and family/whanau and their carers (31% of visits).

The Trust contracts an independent service to spot-check some of the organisations visited each month to ensure the visits add value for consumers and providers. In the past year the feedback has been overwhelmingly positive. Those spoken to commented on the professionalism, approachability, helpfulness, and knowledge of advocates, and many commented that they had booked future education sessions as a result of the advocate's visit.

Network visits and meetings by year



Lillian Hague

Lillian Hague, Christchurch, is one of the Trust's newest advocates – she's been in the job since February 2020 – yet she's positive and confident.

"What I find good about advocacy is it's so focused on finding a resolution. It can be challenging as you're hearing about people's negative experiences but if I can help them get some answers it helps me stay optimistic."

A new graduate, with a degree in Psychology and Human Services, Lillian says she loves her work and the collegial environment where other advocates are only a phone call away and willing to advise. She had barely started the role when staff had to work from home for the COVID-19 lockdown. During this time, she provided information and support to complainants about how to meet their immediate needs.

"I talked with people about how they could advocate for themselves or suggested another service to help them such as Age Concern. For example, some people struggled with the rules around visiting family in hospital during the lockdown, so I helped them see how they could put their case [for visiting] to the Charge Nurse."

Typically, the advocacy process takes two to three months, from receiving an initial query, to resolution from the provider. It can include mentoring the client to advocate for themselves or writing a letter to the provider on their behalf.

"The service works on a strengths-based model, people do what they're able to. We work with some vulnerable people who aren't able to speak up for themselves or they see their issue as big, scary and hard to untangle. The main thing is I'm not emotionally involved – although I care about the outcomes – so I have a clear head to look objectively at the concern."

Lillian says it's very important for complainants to be clear about what outcome they want from the process, and to be happy with the resolution offered by the provider.

"I like helping people, no matter how tangled and sticky the situation, I know I can help them get some answers and that gives me confidence going forward."

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www.advocacy.org.nz
Freephone: 0800 555 050
Email: advocacy@advocacy.org.nz