



# Epilepsy New Zealand Wellbeing Opportunity Assessment Report

Working Towards a Seizure  
Smart Aotearoa New Zealand

January 2024

Prepared by:





**Mā te whakarongo, ka mōhio, mā te  
mōhio, ka mārama, mā te mārama, ka  
matau, mā te matau, ka ora.**

Through listening, comes knowledge, through knowledge, comes  
understanding, through understanding, comes wisdom, through wisdom,  
comes wellbeing.







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# Executive Summary

## Context

People living with epilepsy or unexplained seizures (PLWS) can have very different lived experiences. Epilepsy New Zealand (ENZ) is a leading advocacy, support, and training association in Aotearoa New Zealand for PLWS. Describing themselves as “the voice for people living with epilepsy”<sup>1</sup>, ENZ partnered with Melde and Huber Social to undertake an opportunity assessment to better understand the self-reported holistic needs most predictive of increased wellbeing in the lives of people affected by epilepsy. ENZ had particular interest in better understanding the experiences of Māori to support planning for and delivery of more equitable services.

Over six and a half weeks, 430 people contributed to this study including 307 PLWS and 123 caregivers. Within this total, there was a contribution from 76 Māori respondents (18% of total cohort). Participants included people both engaged and not yet engaged with ENZ.

## Report Overview

This report presents results from this wellbeing opportunity assessment undertaken. It presents findings through three wellbeing snapshots including the overall cohort of people living with seizures, overall carer cohort and an individual snapshot of Māori respondents. This report additionally details insights to maximise wellbeing for those affected by epilepsy. Findings show shared themes across both PLWS and caregiver groups, including many parallels between areas of strength, challenge, and need.

## Key Findings

**Overall wellbeing of both PLWS and caregivers is below the national average.** Less than half of respondents reported feeling at least a little satisfied with their current life conditions indicating that there are underserved wellbeing needs among both communities and

that organisations like ENZ have a role to play in supporting them.

**Drivers of wellbeing vary for PLWS and caregivers.** For PLWS, empowerment and self-belief were found to be most important to their overall wellbeing; for caregivers, this was enjoyment and community connection.

**Strong communities and access to suitable work options are shared opportunities to maximise wellbeing.** For both Māori and non-Māori PLWS and caregivers, having a strong sense of belonging to community and access to suitable work options were found to be drivers of wellbeing. However, both cohorts report low scores in these factors indicating challenge and need for prioritised support in these areas.

**Māori PLWS and caregivers have unique strengths and drivers of wellbeing.** Results demonstrate the difference in wellbeing drivers among Māori, and the need for tailored approaches to best address their holistic needs.

## Applying the Findings

Report findings illustrate a series of wellbeing needs thereby guiding ENZ with opportunities for where they can have the greatest impact. Such opportunities include strengthening community connectedness amongst both PLWS and caregiver groups; supporting empowerment and sense of self amongst PLWS; and continuing to build public awareness around epilepsy.

For Māori respondents particularly, findings show opportunities for ENZ to support employment processes for Māori PLWS; build coping skills and self-acceptance amongst Māori PLWS, and strengthen community connectedness for Māori caregivers.

Recommendations in respondents' own words can be also found within the report.

<sup>1</sup>Epilepsy New Zealand, 2023.





## Living with Epilepsy: Not a One-Size-Fits- All Experience

Epilepsy is one of the world's oldest and most common neurological conditions, affecting 50 million people globally and roughly 50 thousand in New Zealand.<sup>2, 3</sup> Epilepsy affects a wide spectrum of people, and often involves recurring seizures which can significantly impact a person's ability to live the life they want.

While for some living with epilepsy may be easy, for approximately 30% of people for whom medication does not effectively control the condition day-to-day life is incredibly challenging. For these individuals, living with unexplained seizures can be especially uncertain and difficult, particularly after a prior to diagnosis and after a new diagnosis.

Symptoms can affect routine and necessary tasks such as driving a car, and attending school or work can be difficult or dangerous. Many may worry about what a diagnosis might mean for their daily life, relationships, goals, and aspirations. Families caring for a person living with epilepsy or seizures (PLWS) may face challenges as well when navigating back-to-school and work transitions while ensuring there is sufficient support and care available in their absence. Both PLWS and caregivers may struggle with feelings of shame, being able to talk about their experiences, and finding the information and support they need.

Epilepsy New Zealand is a leading advocacy, support, and training association working towards their vision of a 'seizure smart' Aotearoa New Zealand that is free of discrimination and stigma, where the negative impacts of seizures and epilepsy on a person's life, and that of their whānau and community, are minimised. With roughly 2,000 newly diagnosed individuals in New Zealand every year<sup>3</sup>, the need for appropriate health services and support for PLWS continues to grow, and Epilepsy New Zealand aims to meet that need.



“Supporting people, and those who care for them, so that no one goes it alone.”

- Epilepsy New Zealand

<sup>2</sup>New Zealand Ministry of Health, 2019.

<sup>3</sup>World Health Organization (WHO), 2023.

<sup>4</sup>Centers for Disease Control and Prevention (CDC), 2020.

<sup>5</sup>International League Against Epilepsy (ILAE), 2017.



I'm a Purple Hero



KNOW ME, SUPPORT ME

EDUCATE ME, INCLUDE ME

UNDERSTAND ME, SUPPORT ME





# Epilepsy New Zealand Service Summary

Epilepsy New Zealand's (ENZ) mission is to improve the quality of lives of people living with epilepsy or unexplained seizures (PLWS) in Aotearoa New Zealand.

They are working towards their vision of a 'seizure smart' New Zealand that is free of discrimination and stigma, where the negative impacts of seizures and epilepsy on a person's life, and that of their whānau and community, are minimised.

ENZ's Educators offer nationwide support that is current and grounded in evidence pre-diagnosis and far beyond. This support includes tailored services, building more supportive and informed community networks (i.e., school and workplace visits), growing public awareness, and representation or advocacy services. ENZ's resource-rich website also provides evidence-based and current information and strategies for living with epilepsy. The three main areas of ENZ's service offerings include:

## Understanding Epilepsy

ENZ Educators provide in person and online resources to support better understanding of epilepsy, including about their diagnosis, treatments, seizure management and support available.

ENZ's website includes resources for seizure First Aid, developing Seizure Management Plans (SMPs), strategies for recording seizures, and current recommendations for seizure alarms/devices.

## Managing Epilepsy

ENZ Educators provide information and online resources to better manage some of the common issues associated with living with epilepsy across different life stages and situations.

This includes information about managing health and wellbeing, lifestyle, relationships, as well as navigating education, employment, funding and transport needs.

## Education and Training

ENZ Educators offer evidence-based, person-centred education and training programs to increase awareness and understanding of epilepsy in the community. ENZ provides online and in-person training sessions for

- whānau
- education settings
- disability sector
- health sector

## Seizure Smart

Through their Seizure Smart evidence-based online training programmes, ENZ seek to upskill schools, workplaces, aged care and disability support services to become supportive and inclusive environments for PLWS.



## How We Measure Social Impact

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# Why Measure Social Impact?

Melde, together with Huber Social, were engaged to conduct an opportunity assessment to better understand the holistic needs and wellbeing priorities of both people living with epilepsy or unexplained seizures (PLWS) as well as caregivers of those living with epilepsy. This is with the goal for Epilepsy New Zealand to better understand the needs of the people they seek to support and identify opportunities to better direct its resources so that their services can maximise its wellbeing impact.

## 1. Measure

To measure the needs of the general population of both PLWS and caregivers of PLWS, Huber Social's Wellbeing Approach and Wellbeing Framework were utilised to measure holistic factors in the lives of these communities, as well as measuring the correlated strength to overall wellbeing.

Measurement provides a data-driven approach for ENZ to capture the priority needs and predictors of wellbeing for these groups thereby empowering ENZ to contribute data about the needs of PLWS in disability and healthcare sectors.

## Why Wellbeing?

*Measures overall progress and supports the systematic solving of social issues*

Ultimately, the goal of all social impact is to put people in the best position to fulfil their potential and achieve wellbeing. It is therefore important to measure wellbeing to ensure that overall, programmes are having a positive impact.

Taking a wellbeing approach also provides a whole-of-life understanding of a person's needs. Instead of starting with the issue at hand, which tends to focus on the crisis end of a problem and place artificial limitations on the needs of people, strengthening wellbeing supports building a person's capability and opportunity to fulfil their potential, thus working to systematically address social issues.

In case of additional future measurement to measure the social impact of programmes and interventions, Huber Social measures overall wellbeing and specific programme outcomes that contribute to it.

## 2. Maximise

Beyond a focus on outcomes the approach considers the holistic needs of a person to be in the best position to fulfil their potential.

This approach identifies opportunities for improved resource allocation to maximise the potential impact that ENZ can have on the overall wellbeing of both PLWS and their caregivers, and particularly Māori members of these communities.





# Epilepsy New Zealand Social Impact Thesis

Epilepsy New Zealand's Impact Thesis outlines the impact it has on the wellbeing of people it supports. Through measuring each level of impact, ENZ can use a data-driven approach to demonstrate what works and what is needed to maximise impact and outcomes.

## 1. Impact

People living with epilepsy or unexplained seizures (PLWS) in Aotearoa New Zealand are supported to fulfil their potential and live a life of value to them.

## 2. Outcomes

ENZ achieve this impact by building capabilities and providing access to opportunities across the following areas:

- *Supported*: feeling supported in relationships of genuine personal connection and tailored care
- *Safe*: increased public awareness as well as opportunities for personal communities to support the emotional and physical safety of PLWS
- *Empowered*: informed and empowered to manage their health and successfully advocate for themselves and others

## 3. Outputs

ENZ delivers the following outputs both short and long-term:

- # Clients delivered tailored services (all attendees).
- # Attendees at support group sessions (physical and virtual)
- # Attendees at community network capability building sessions, i.e., teachers at school visits, extended family at education sessions (physical and virtual)
- # Attendance at presentations / seminars
- # Individuals reached through media and other public awareness activities
- # Clients represented
- # Organisations co-ordinated with

## 4. Activities

The above outputs are achieved through:

### *Tailored Services*

- # New client personal visits
- # Existing client personal visits

### *Community Building*

- # Support group sessions facilitated - physical and virtual
- # Support network capability building - physical and virtual

### *Public Awareness*

- # Presentations given / # Seminars held
- # Public information requests responded to
- # Media and public advocacy and awareness activities, including social media.

### *Representation*

- # Representation requests received
- # Client representations attended
- # Organisations met with – by sector





## Measurement Approach

Melde, an accredited Social Impact Consultancy, and Epilepsy New Zealand (ENZ) have worked together to conduct an opportunity assessment to better understand the holistic needs and priorities of those affected by epilepsy or unexplained seizures in Aotearoa New Zealand. This holistic approach included outcomes within the scope of ENZ services, as well as broader whole-of-life outcomes beyond their remit. ENZ had particular interest in understanding the experiences of Māori to support planning and delivery of services to achieve more equitable outcomes..

### Participants

This study sought to capture the experiences of those affected by epilepsy or unexplained seizures, including those living with the conditions and those who care for them. Participants included people living with epilepsy or unexplained seizures (PLWS) aged 16+, and parents and caregivers of those aged 0 – 16. Research groups expanded to include caregivers of PLWS aged 16+. This included those both engaged and not yet engaged with ENZ services. Analysis focused on individual wellbeing needs for both groups, as well as a standalone snapshot to specifically understand the experiences of Māori respondents.

### Survey Tool and Distribution

A survey tool was co-developed with ENZ and volunteers from each measurement group as based upon Huber Social's Wellbeing Framework<sup>6</sup> (see page 10 for Social Impact Thesis and Appendix 3 for the question set). Survey questions were based on existing validated survey scales specific to each metric; including, for example, the Fear/Seizure Worry and Energy/Fatigue subscales from the Quality of Life in Epilepsy Inventory.<sup>7</sup> Where no evidence-based tools existed or practicality prevented the use of a full scale, Huber Social, in collaboration with relevant stakeholders, developed questions based on research in the particular area.

<sup>6</sup>Huber Social, 2018.

<sup>7</sup>Mollaoğlu, Durna, & Bolayir., 2015.

<sup>^</sup>As of released estimates in December 2022, there is a national population of 5,151,600 and a Māori population of 891,600. Source: Stats NZ, 2023.

This study aligned to the principles and requirements of both the New Zealand National Ethical Standards and Te Ara Tika Guidelines for Māori Research Ethics. To ensure the survey questions were culturally, linguistically and ethically appropriate, PLWS and carer representatives in partnership with ENZ were given access to the surveys in advance of roll out for feedback. The pilot study was submitted to the Huber Social Ethical Review Board for ethical assessment (Committee No. EC0047773). It was granted approval on 31 May 2023.

### Data Collection and Response Rates

Surveys were distributed and made publicly available via various means, as well as utilising the reach and direct contact from ENZ's partnering organisations. The survey was live for six weeks between 15 June to 31 July, capturing responses from 430 people. Responses include 123 caregivers, 307 PLWS and of these, a combined total of 76 Māori respondents. While the survey was open to all PLWS, 93% of all respondents reported having a confirmed diagnosis of epilepsy. Almost one quarter of people surveyed (23%) were not engaged with ENZ.

### Limitations

The study aimed for a high target sample size of Māori respondents in order to have a strong representation of this group. While this target was not reached, 18% of overall responses are from Māori respondents making up 15% of the total PLWS respondents and 25% of the total carer respondents. Māori representation in this study is proportionate with national population figures of 17% across New Zealand.<sup>^</sup>

### Ongoing Measurement

This study was developed for ongoing measurement should ENZ decide to conduct further measurement and analysis to understand the impact engaging with ENZ services has on meeting the holistic needs of the communities they aim to support.



# Participant Demographics: Overview of Respondents

There were a total of 430 survey responses. Of these responses, 71% were from people living with seizures (PLWS) (n=307) and 29% from carers of people living with seizures (n=123). 18% of all responses came from persons identifying as Māori (n=76), and within this group 59% identified as PLWS (n=45) and 41% identified as carers (n=31).

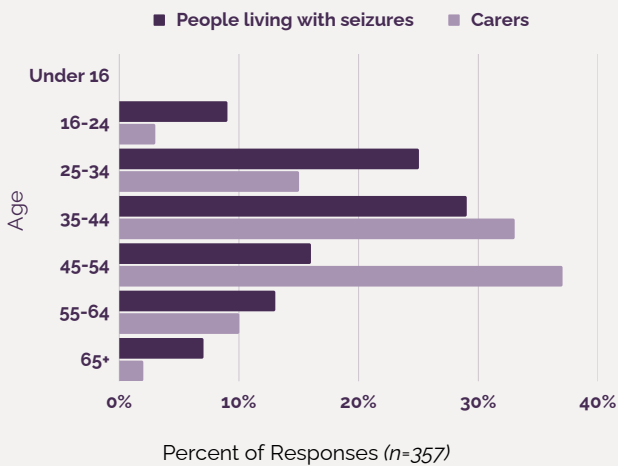
## Age

The majority of PLWS were between the ages of 25-44 (54%). The majority of carers were between the ages of 35-54 (70%).

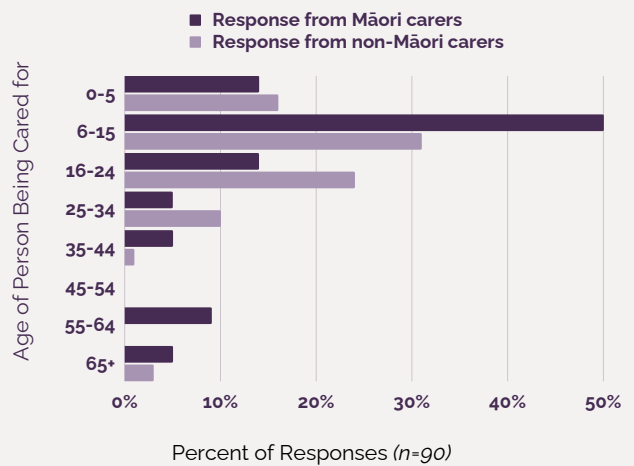
## Age of Person Being Cared For

The majority of persons being cared for were under the age of 15 for both Māori and non-Māori carers.

All responses, by age



Responses from carers, by cultural heritage



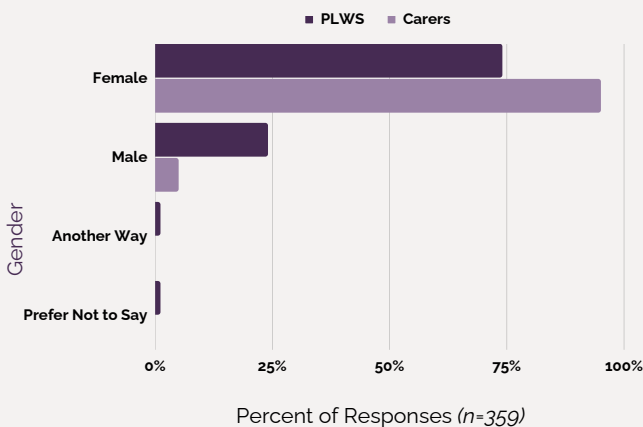
## Gender

The majority of respondents identified as female (79%), with 19% identifying as male.

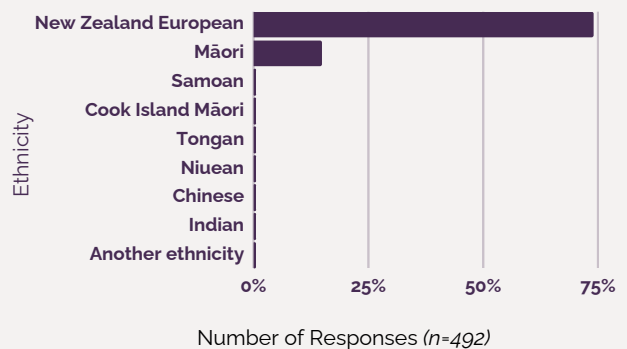
## Ethnicity

Respondents could select up to two ethnic groups, with New Zealand European being the most common response (74%).

All responses, by gender



All responses, by ethnicity





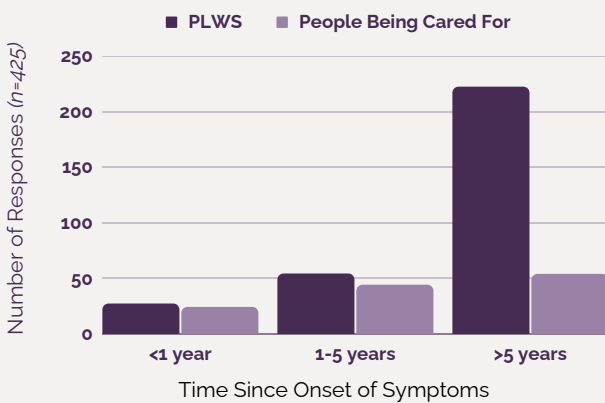
# Participant Demographics cont.

Following on from the previous page, this page details diagnosis information and how long people have been living with seizures.

## Time Since Onset of Symptoms

For PLWS the majority of respondents have experienced epilepsy symptoms for at least five years (78%).

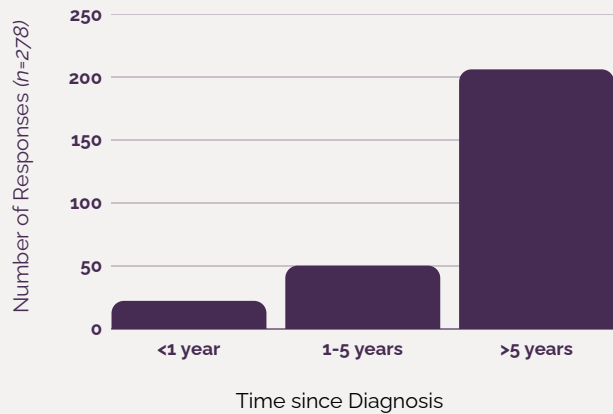
All responses, by time since onset of symptoms



## Time Since Diagnosis

For those with a formal diagnosis of epilepsy, the majority of respondents received their diagnosis over five years ago (78%).

All PLWS responses, by time since diagnosis



## Diagnosis

While the majority of respondents had an active diagnosis, not all diagnosed had a Seizure Management Plan in place.

- 93%
**PLWS respondents had active diagnosis**  
*n=299*
- 53%
**PLWS respondents had Seizure Management Plans**  
*n=278*
- 67%
**Carer respondents reported the person they care for had a Seizure Management Plan**  
*n=120*



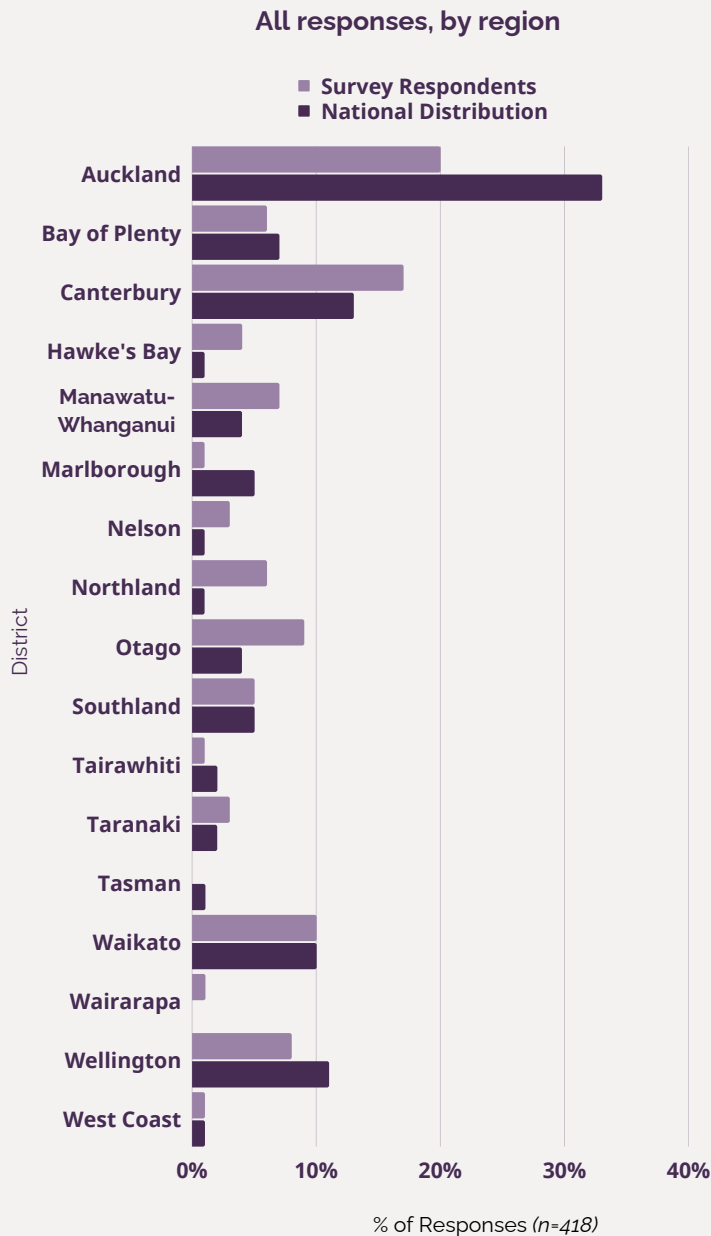




## Participant Demographics cont.

This page details spread of respondents as based on residential region. To compare representativeness, these proportions have been compared alongside national populations distribution figures, by region.<sup>8</sup>

The majority of respondents lived in Auckland. Further, 74% of respondents self identified as living in urban areas, compared to 26% for regional/rural.



<sup>8</sup>Stats NZ, 2023.



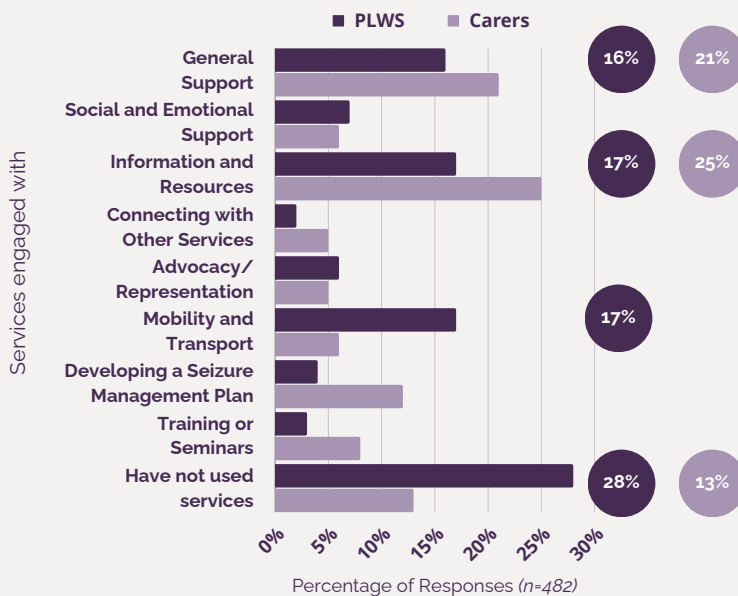


# Participant Demographics: Engagement with ENZ

This page outlines which services and information sources were most used by people living with seizures (PLWS) and their carers. Of 430 responses total, 71% were from PLWS (n=307) and 29% from carers of PLWS (n=123).

## ENZ Services Respondents Engage With

All responses, by services engaged with



Respondents engaged most with these ENZ resources and services

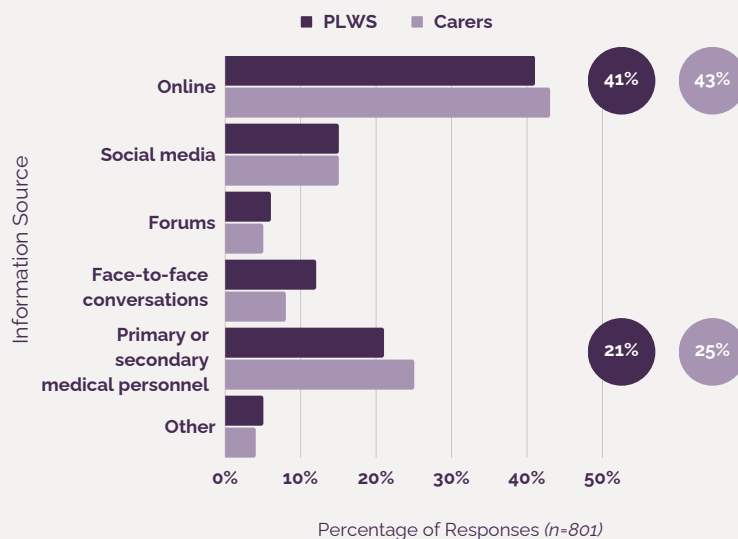
PLWS engaged most with ENZ's *Information and Resources, Mobility and Transport and General Support* services. Carers most engaged with *Information and Resources and General Support*.

A large subset of PLWS had not used ENZ resources or services. Combined, 60% of all respondents reported engaging with ENZ in some way.

Respondents could select multiple options. 244 PLWS and 88 carers engaged with this question.

## Respondents' Main Sources of Information

All responses, by information source



Respondents could most easily find information about living with epilepsy via these channels

PLWS and carers most easily found information *Online* and through *Primary or secondary medical personnel*.

Write-in options under *Other* included peers and support groups, being a medical professional or having one in the family, neurologists and educators.

Respondents could select multiple options.



# Participant Demographics: Engagement with ENZ Services cont.

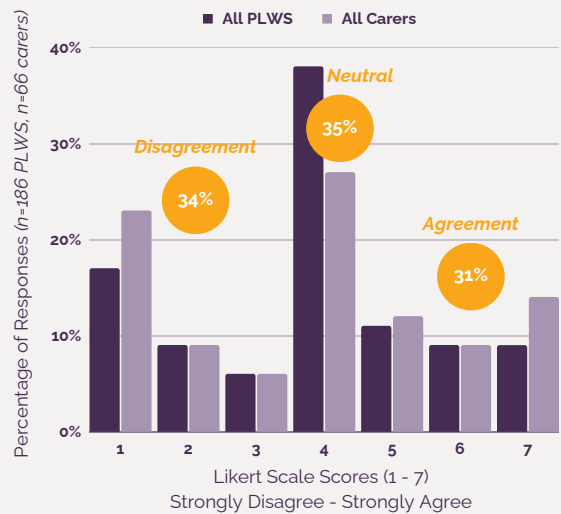
## Respondents' Engagement with ENZ as their Main Support Service/Resource

Overall, all people living with seizures (PLWS) and carer respondents reported a fairly even distribution of agreement with roughly one third of both cohorts in either disagreement, agreement, or neutral standing about engaging with ENZ as their main support service/resource.

Of the spread of scores, both PLWS and carer respondents both have the highest cluster of scores at 'strongly disagree' and 'neither agree nor disagree'.

**An Opportunity:** With only 31% in agreement that ENZ are their main support resource when needed, this is an opportunity for ENZ to consider how to optimise their reach and relevance for the remaining two-thirds of the population measured.

Q: *Epilepsy NZ is my main support service/resource when required, by spread of scores*



## Overall Support Resources and Services Most Used by Respondents

Respondents listed their main services they engage with in relation to living with or caring for someone living with epilepsy or unexplained seizures. Based on the data provided, the lists below represent the three most commonly mentioned resources. It is worth noting that while one third of respondents report not using ENZ as their main support service, it is still one of the most frequently cited, suggesting that most people rely on medical professionals and online resources for support.

### People Living with Seizures

#### Medical Professionals

*Including: General Practitioners, neurologists.*

#### Online Resources and Social Media

*Including: Online forums and social media platforms, such as Facebook groups; internet searches; YouTube.*

**Epilepsy Support Organisations**, inclusive of ENZ.

### Carers

#### Medical Professionals

*Including: GPs, neurologists, pediatricians, hospital specialists, nurses, pharamists.*

#### Online Resources and Social Media

*Including: Online forums and social media platforms e.g., Facebook groups; internet searches.*

**Epilepsy Support Organisations**, inclusive of ENZ.



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## Key Findings

### 1. Overall wellbeing of both people living with seizures and caregivers is below the national average

Of both Māori and non-Māori survey respondents, less than half (44%) of people living with seizures (PLWS) and their caregivers reported feeling at least a little satisfied with their current life conditions. This is well below the national average<sup>9</sup> for both the general population (81%) and those living with a disability (67.5%), indicating that there are underserved wellbeing needs among both communities and that organisations like ENZ have a role to play in supporting them.

### 2. Drivers of wellbeing vary for PLWS and caregivers

For PLWS, empowerment and self-belief were found to be most important to their overall wellbeing; for caregivers, this was enjoyment and community connection. While there are many similarities between the two groups' wellbeing needs, their relative importance differs. ENZ will want to prioritise different resources and initiatives for PLWS and caregivers so as to best address each cohort's wellbeing needs.

### 3. Māori PLWS are hopeful and their caregivers enjoy life

The wellbeing of Māori PLWS is driven by their strong sense of hope and purpose; however, they were found to have slightly lower wellbeing than non-Māori PLWS, due in part to low confidence in their coping skills and self-acceptance. However, overall Māori caregivers had slightly higher wellbeing than non-Māori caregivers. These results demonstrate the difference in wellbeing drivers among Māori communities with epilepsy, and the need for tailored approaches to best address their holistic needs.

### 4. Strong communities and access to suitable work options are shared opportunities to maximise wellbeing for all

For both Māori and non-Māori PLWS and caregivers, having a strong sense of belonging to community and access to suitable work options were found to be drivers of wellbeing. However, both cohorts report low scores with respect to each factor, indicating that they feel disconnected from a community with shared experiences and unable to find the right work for them. Qualitative data echoes these findings. These are two opportunities for ENZ and others supporting this community to maximise their positive social impact, as improvements across either factor are likely to result in stronger wellbeing for PLWS and caregivers.

<sup>9</sup>New Zealand Treasury, n.d.



# Snapshot 1: People Living with Epilepsy or Seizures

*The following represents responses from participants living with epilepsy or unexplained seizures. This report acknowledges that not all people living with seizures have a confirmed diagnosis of epilepsy. Results show 93% of PLWS respondents do have a confirmed diagnosis.*

- Wellbeing Overview 20
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- Predictors of Wellbeing 22
  - Empowerment and sense of self

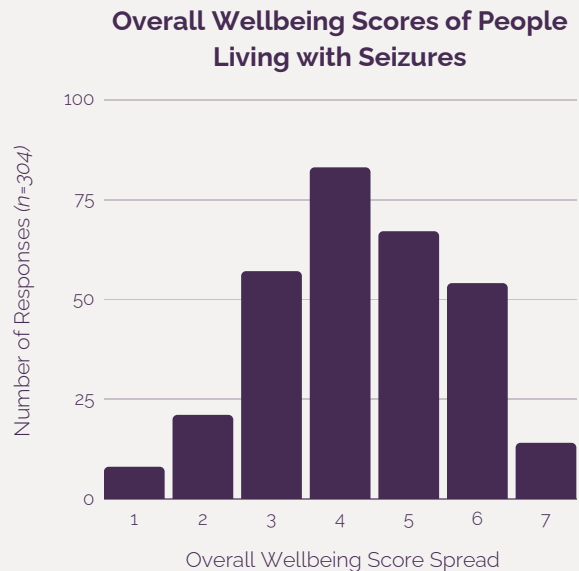




# Wellbeing Overview: People Living with Epilepsy or Seizures

## Overall Wellbeing Summary

- People living with seizures (PLWS) have an average overall wellbeing score of 4.29 out of 7, with less than half (44%) stating that they are at least slightly satisfied with their life.
- This is significantly lower than the national proportion of people who are satisfied with life, both among the general population and persons living with a disability.\*
- These findings suggest that there is a need for organisations like ENZ, dedicated to supporting the wellbeing of PLWS.
- There was no significant difference in average overall wellbeing between PLWS and carers, nor with respect to factors such as gender, location, or length of diagnosis.

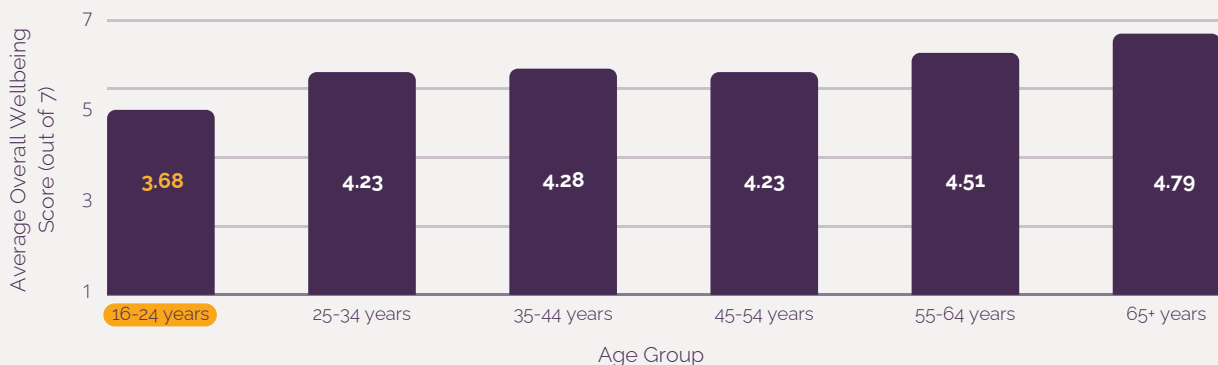


## Young Adults More Likely to Have Lower Wellbeing

At 3.68 out of 7, young people ages 16-24 years old were found to have significantly lower wellbeing than any other age group measured. This may speak to the unique challenges faced at this life stage, where transitions to a more independent lifestyle may be met with resistance due to continuing support needs, a lack of knowledge or confidence in managing their epilepsy, or lack of certainty for what the future holds.

ENZ may wish to explore the wellbeing needs of this age group in future research, so that the organisation can best direct its resources to have the greatest impact on young people living with seizures.

## Average Overall Wellbeing of People Living With Seizures, by age



\*The Living Standards Dashboard uses the Cantril Ladder scale to measure subjective wellbeing; scores range from 0 to 10. According to the Living Standards Dashboard<sup>10</sup>, 81% of the general population and 65.2% of disabled persons indicate that they are at least somewhat satisfied with their lives (score 7 or higher). Huber Social uses the Satisfaction with Life Scale; people are at least somewhat satisfied with their lives if they score a 5 or higher (out of 7). <sup>10</sup>Source: New Zealand Treasury, n.d.



## Wellbeing Overview: Management Plans and Advocacy Services Benefit Wellbeing of PLWS

The work of ENZ has a very clear, positive impact on the lives of people living with seizures (PLWS) in the form of two particular areas: advocacy services and seizure management plans.

Research has found that if a PLWS has a seizure management plan in place, or has used ENZ's advocacy services, they are significantly more likely to have higher wellbeing as compared to individuals who have utilised neither support service.\* Among study respondents, just over half of PLWS report having a seizure management plan (54%) but only 6% have used advocacy services.

Seizure management plans offer PLWS the security of knowing that their needs will be met in the event of an episode, particularly when a person-centred approach is taken and the plan is developed collaboratively with persons and carers. Similarly, having the knowledge and skills to advocate for oneself and one's needs empowers individuals living with epilepsy to have a central, deciding voice in the care and management of their condition. Both services support greater sense of agency and self-determination, factors which play a critical role in being in a position to live a life of value on their terms, rather than what their carers or society deem possible.

As ENZ provides tools to develop seizure management plans and resources for enabling informed self-advocacy, the organisation is positively contributing to the overall wellbeing of people it serves. These are two areas which the organisation should continue to resource and grow, particularly with services directed at those persons more likely to have lower wellbeing such as young adults living with epilepsy.

*\*People who have a seizure management plan in place had 7% higher wellbeing on average than those who did not have a plan. People who had used advocacy/representation support services had 15.5% higher wellbeing on average than those who have not engaged with the service.*



# Predictors of Wellbeing: Empowerment and Sense of Self Drives Wellbeing for People Living with Seizures

Understanding what matters most to the wellbeing of people living with seizures (PLWS) is critical to improving it. Huber Social uses correlation analysis to identify which of all factors measured have a significant, positive relationship with overall wellbeing - these are called 'predictors of wellbeing'.\* A positive change in these factors is statistically more likely to lead to an increase in overall wellbeing as compared to factors which do not have a strong association with wellbeing.

**The following eight factors were identified as having the strongest relationship with wellbeing for all PLWS:**



Predictors of wellbeing largely cluster around two outcomes: self-empowerment and sense of self. This indicates that these two areas are of significant importance to the wellbeing of PLWS. These findings are also generally supported by the qualitative data collected in the study.

**An Opportunity:** While ENZ strives to develop the knowledge and skills necessary for self-empowerment among its persons served, there is an opportunity for ENZ and other support organisations to direct further resources towards supporting PLWS to work on self-acceptance and identifying purpose and direction in their lives, beyond their identity as someone living with a health condition.

\*See Appendix 5: Significance Tables for a complete list of Predictors of Wellbeing.





## Snapshot 2: Carer Wellbeing

*The following represents responses from caregivers of those living with epilepsy or unexplained seizures. This group has been included in the study to represent the needs of children and adolescents under 16 years of age not included in this measurement. Additionally, this measurement is led with the hypothesis that both the holistic wellbeing of caregivers and the individual needs for this group will have a flow on effect to the wellbeing of PLWS and their broader whānau. Understanding the wellbeing needs of PLWS's carers is therefore important to better support seizure communities.*

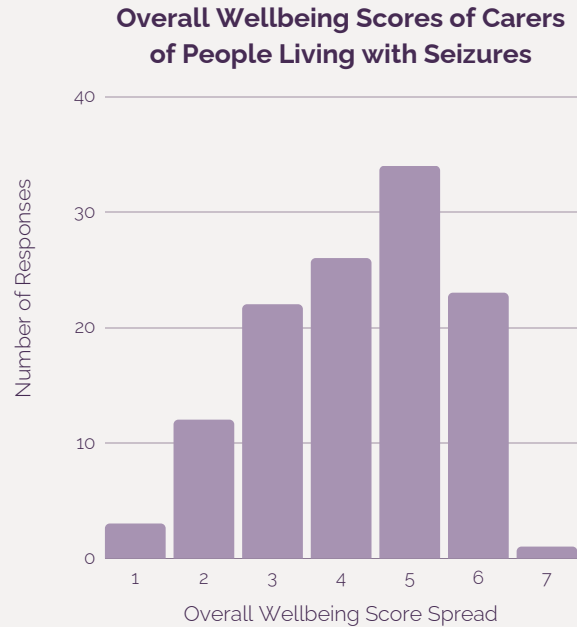
- Wellbeing Overview 24
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  - Employment and financial security



# Wellbeing Overview: Caregivers of PLWS

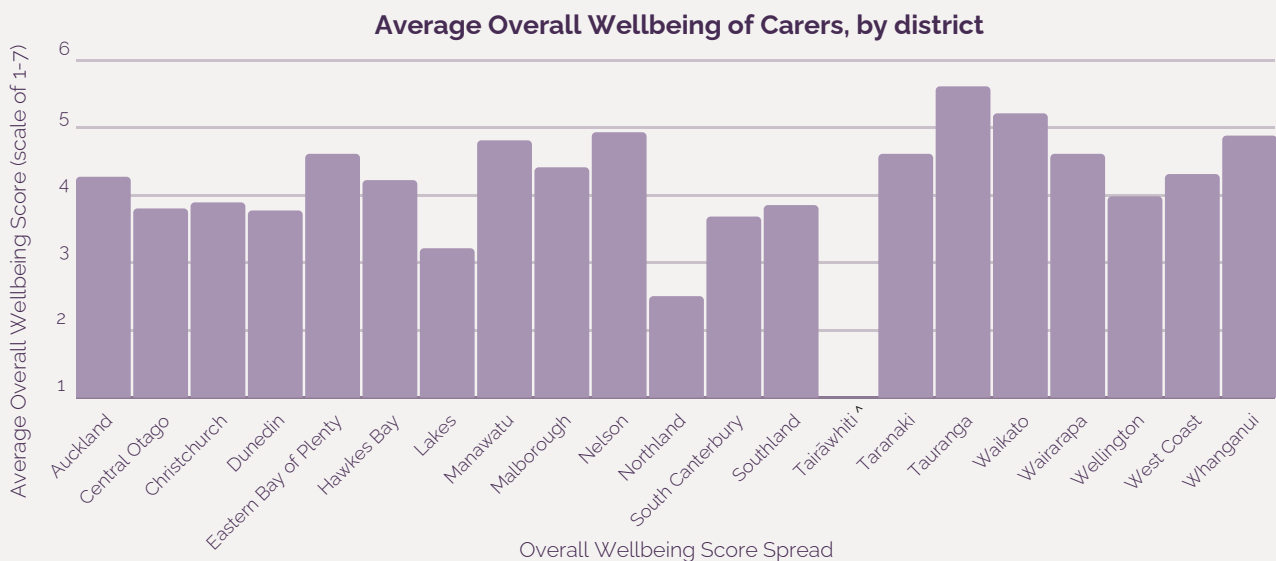
## Overall Wellbeing Summary

- Carers of people living with seizures (PLWS) have an average overall wellbeing score of 4.21 out of 7, with slightly less than half (48%) stating that they are at least slightly satisfied with their life.\*
- While there are fewer carers at the far ends of the spectrum, there is a higher concentration of carers feeling slightly satisfied with life compared to the people they care for.
- As with PLWS, carers average wellbeing is found to be lower than the national average.
- There was no significant difference in average overall wellbeing between carers and PLWS, nor with respect to most demographic factors measured such as gender, age, or cultural background.



## Carer Wellbeing Varies by Location

Results show that overall wellbeing among carers tends to vary by location. As the graph below shows, carers living in Tauranga and Waikato have higher wellbeing scores on average as compared to carers from all other districts, while Northland and Lakes districts were found to have significantly lower wellbeing. This can inform ENZ and other organisations in their allocation of support provision and resources nation-wide.



\*People are at least somewhat satisfied with their lives if they score a 5 or higher on the Satisfaction with Life Scale (scale of 1-7).  
<sup>^</sup>There were no carer responses from Tairāwhiti district.



# Wellbeing Overview: Use of Advocacy and Mobility Services Associated with Lower Wellbeing for Carers

While self-empowerment resources like seizure management plans and use of advocacy services were found to have a positive influence on the overall wellbeing of people living with seizures (PLWS), the same trend was not observed among carers. In fact, use of advocacy services as well as mobility and transport services was found to be associated with lower wellbeing among carers.<sup>^</sup>

However, this is not to say that use of these services has a negative impact on carers' wellbeing. Carers who used advocacy and/or mobility services also reported feeling more anxious, worried and overwhelmed as compared to carers who did not use either of these

services. They also reported feeling significantly less connected to a community, a driver of wellbeing for both carers and PLWS.

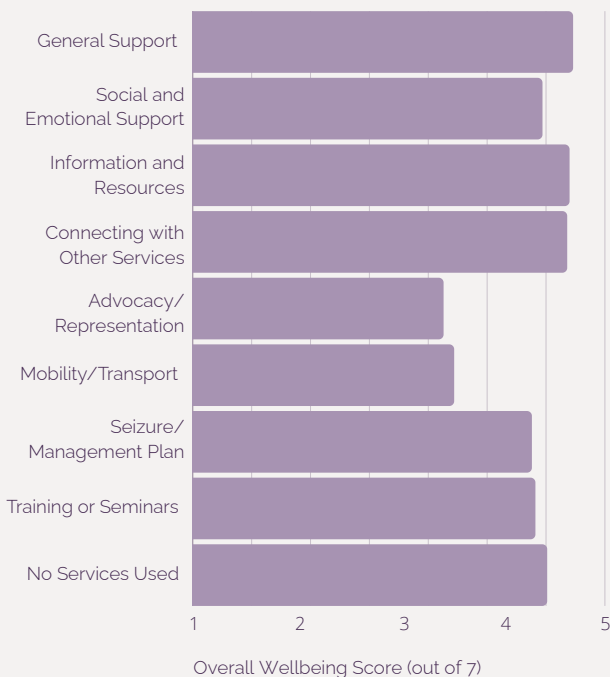
Therefore, **it is more likely that use of these services by carers may be an indication of underlying emotional distress or lack of community support.**

**An Opportunity:** ENZ may wish to further investigate these findings to better understand how to address the specific needs of carers using these services.

## Carers who use advocacy and mobility services:

Average Overall Wellbeing Scores  
of Carers, by services used

n=64



### Community Connection

**-30%**

Feel less connected to a community than other carers



### Feelings of Fear

**+24%**

Feel afraid more often than other carers



### Feelings of Overwhelm

**+23%**

Feel overwhelmed more often than other carers



### Feelings of Anxiety

**+20%**

Feel anxious or worried more often than other carers

<sup>^</sup>Of the 88 carer respondents for the question "select which ENZ services you engage with", 10 reported using Mobility/Transport Services and 7 reported using Advocacy Services. Statistical testing showed people who engaged with these services have lower wellbeing in comparison to those not engaged ( $p < 0.05$ ). It is important to note that these remain small sample sizes and should therefore only be taken as indicative findings at this stage.



## Predictors of Wellbeing: Employment and Financial Security are Important for Caregivers' Wellbeing

Among carers of people living with seizures, four factors emerged as having a significant, positive relationship with their wellbeing.

**The strongest predictors of wellbeing\* for carers of people living with seizures are:**

*Within the ENZ Impact Thesis:*

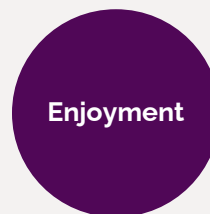


**Feeling connected to a community**



**Access to suitable employment options**

*Beyond the ENZ Impact Thesis:*



**Being able to enjoy life and have fun**



**Having enough income to cover daily costs**

These findings indicate that for carers of people living with seizures, having a steady source of sufficient income that is compatible with their knowledge, skills, and carer responsibilities is critical to their overall wellbeing. For some, finding a job that satisfies both financial and logistical requirements may be difficult; less than half of carers feel that they have both access to suitable employment options and enough income to cover daily costs.<sup>^</sup>

Furthermore, only two out of five carers feel that they are connected to a community,<sup>^</sup> indicating that it is an underserved wellbeing need among this population. This presents an opportunity for ENZ to maximise its impact on the wellbeing of carers, as an improvement in carers' sense of belonging to a larger community is statistically more likely to accompany an increase in overall wellbeing as compared to improvements across any other factors measured.

When asked for suggestions for how life could be improved for people living with epilepsy, there was repeated commentary around support in securing work and increased understanding from employers:

**"[There needs to be] easier access with benefit payments... We will need to take time off work. With everything already so costly we can't really afford my husband to take time off work. It's affecting our own wellbeing at the same time."**

**"[We need] some type of benefit for parents who can't work due to their child having epilepsy."**

*\*See Appendix 5: Significance Tables for a complete list of Predictors of Wellbeing.*

*<sup>^</sup>49% of carers indicated that they felt at least a little bit satisfied with both their access to employment and access to income (scored a 5 out of 7 or higher across both factors. 41% of carers indicated that they felt at least a little bit connected to a community (scored a 5 out of 7 or higher).*





## Snapshot 3: Māori Respondents

- Demographics
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- Priority Needs
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# Participant Demographics: Overview of Māori Respondents

There were 76 Māori survey respondents out of 430 responses total (18%). Of these responses, 59% were people living with seizures (PLWS) (n=45), making up 15% of total responses from the total PLWS cohort measured. 41% identified as carers (n=31), comprising a quarter of total carers (25%).

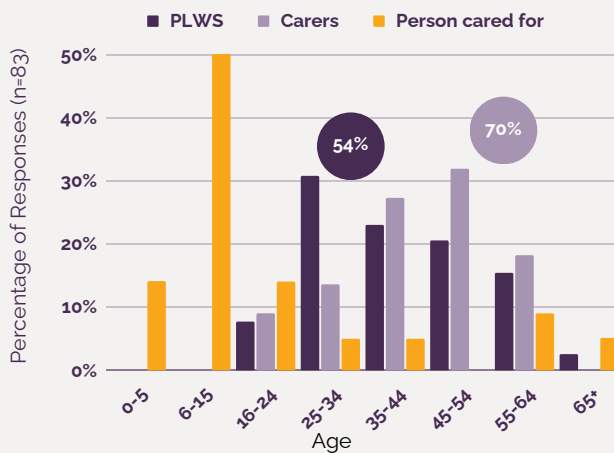
## Age and Age of Person Cared For

The majority of PLWS respondents were between the ages of 25-44 (54%). The majority of carers were between the ages of 35-54 (70%). Carer responses indicated half of PLWS who are being cared for are between ages 6 - 15 years.

## Gender

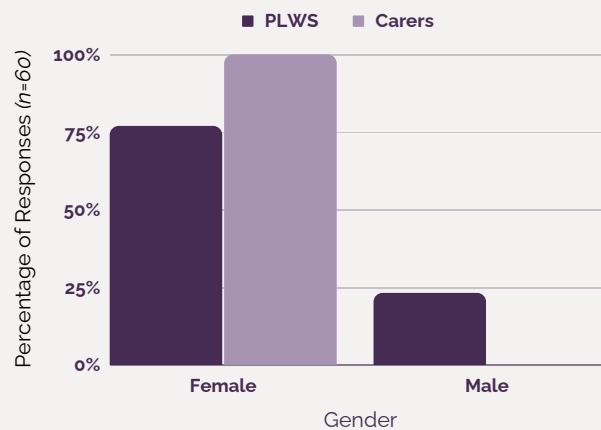
77% of Māori respondents living with seizures identified as female (n=30), while all 21 Māori carers identified as female (100%).

Māori responses, by age + age of person cared for



Note: The person cared for cohort were not respondents but their carers responded on their behalf.

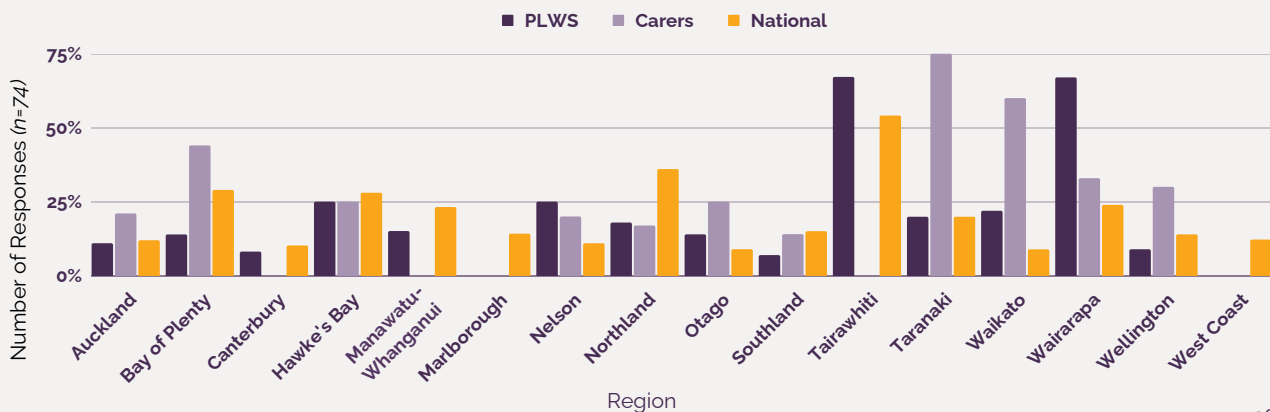
Māori responses, by gender



## Region

The largest variation of Māori representation in the survey sample compared to the average regional population occurred in Tairāwhiti and Wairarapa for PLWS and Taranaki and Waikato for carers.

Proportion of Māori responses out of total sample, by region







# Participant Demographics: Overview cont.

Continuing on from the previous page, this page details the percentages of Māori respondents with an active diagnosis, time since onset of symptoms and diagnosis, and the Epilepsy New Zealand services and resources with which they engage.

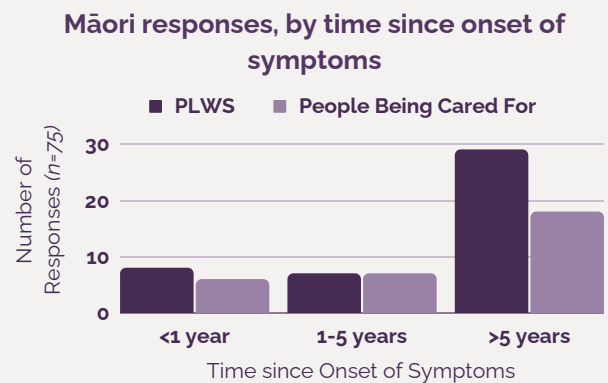
## Diagnosis

A higher proportion of Māori carers report having a Seizure Management Plan, compared to non-Māori carer respondents.

- 93%** Māori PLWS respondents have an active diagnosis  
*n=43*
- 53%** Māori PLWS respondents have Seizure Management Plans  
*n=43*
- 77%** Māori carer respondents report that the person they care for has a Seizure Management Plan  
*n=30*

## Time Since Onset of Symptoms

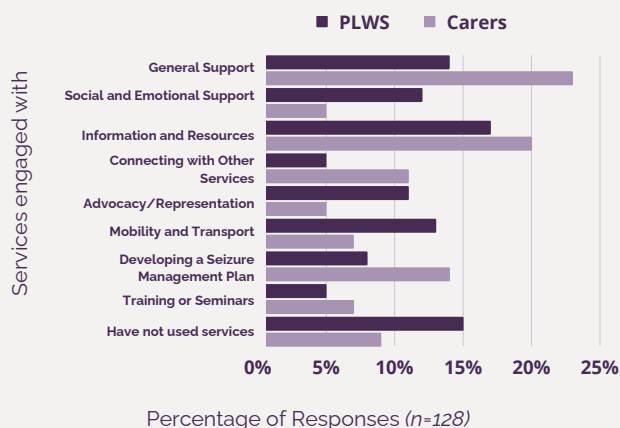
The majority of Māori respondents had symptoms of epilepsy for at least five years (66%), in line with total survey respondents (78%). 18% of Māori respondents first had symptoms less than a year ago, which was higher than the overall respondent population (12%).



## ENZ Services Engaged with

Māori people living with seizures engaged most with *Information and Resources* (17%), and Māori carers with *General Support*. Respondents could select multiple options.

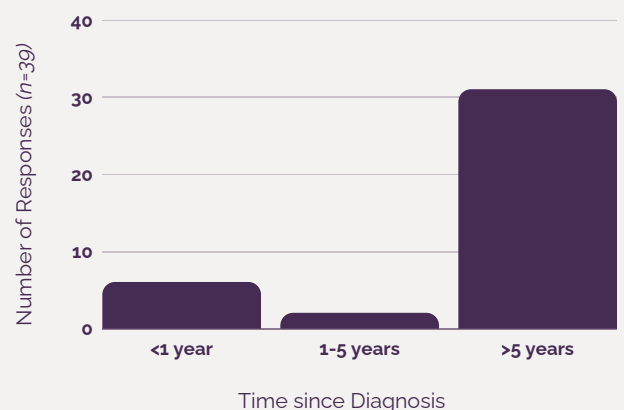
### Māori responses, by services engaged with



## Time Since Diagnosis

79% of Māori respondents received their diagnosis over 5 years ago. As above, a larger proportion of diagnoses for Māori respondents were less than a year ago (15%) compared to total survey respondents (8%).

### Māori PLWS responses, by time since diagnosis





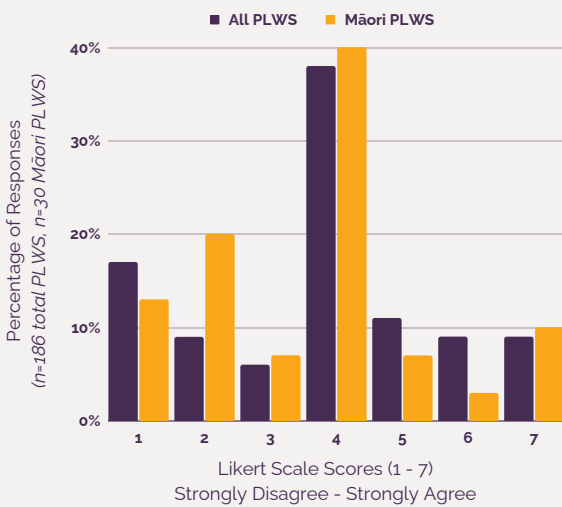
# Participant Demographics: Engagement with ENZ Services

## Māori Engagement Levels with ENZ as *Main Resource/Support*

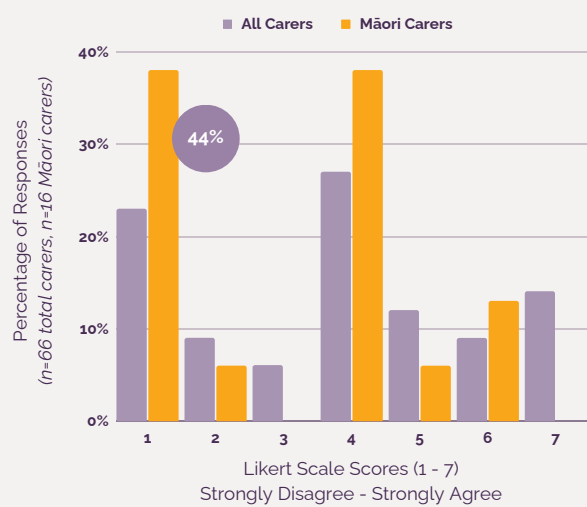
When combined overall, all PLWS and carer respondents reported a fairly even distribution with regard to use of ENZ as their main support resource. On average, Māori respondents report relying on ENZ less than non-Māori respondents, and of all groups, Māori carers report engaging with ENZ the least.<sup>^</sup> Given these lower levels of engagement, it is impressive that ENZ was able to reach beyond their networks and hear from many voices.

**An Opportunity:** This suggests a difference in how Māori communities are engaging with ENZ in comparison to other cultural groups and presents an opportunity for ENZ to consider how they make themselves visible and accessible across different communities.

**Agreement Scale of ENZ as Main Support for PLWS, by spread of scores**



**Agreement Scale of ENZ as Main Support for Carers, by spread of scores**

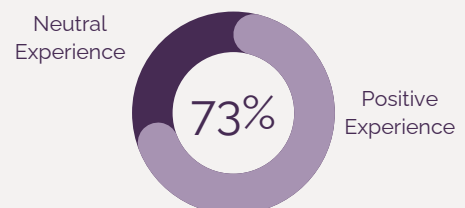


## ENZ's Demonstration of Respect for Culture and Identity

While only a small sample\* of feedback, almost three-quarters of Māori respondents report positive experiences when asked if ENZ demonstrated an understanding and respect for their culture and identity in their dealings with ENZ. In comparison to non-Māori respondents, Māori respondents did not report any negative dealings with ENZ.

**"ENZ ran a learning class in our whare with whānau. We appreciated it being in our own space and being able to learn and ask questions as a whānau."**

- Māori respondent



<sup>^</sup>On average, only 20% of Maori respondents report using ENZ as their main support services (compared to 33% for non-Maori respondents), and 44% of Maori caregivers stated they do not use ENZ as their main support service.

\*11 responses (14% of total Māori sample) were collected for this question. Similarly, only 9% of the overall non-Māori sample also responded to this question. Of these 32 non-Māori responses, 59% report positive dealings in relation to culture, as well as 13% report negative dealings and 28% neutral experiences.



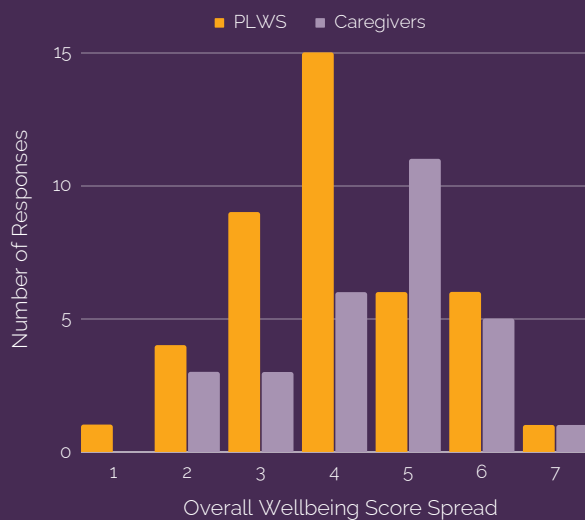
# Wellbeing Overview: Māori PLWS and Caregivers

## Overall Wellbeing Summary

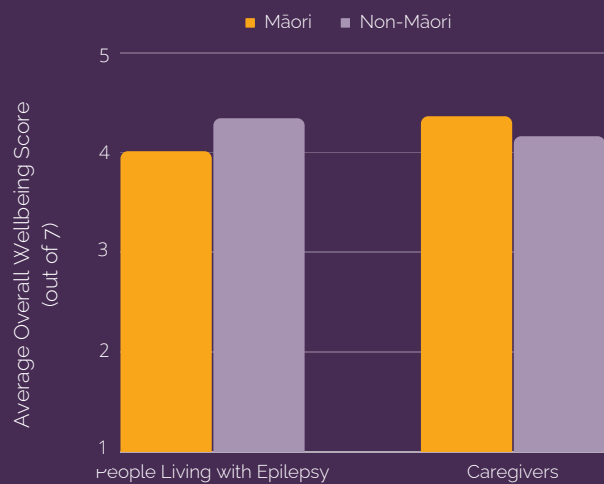
- The average overall wellbeing of people living with seizures (PLWS) who identify as Māori is 4.01 out of 7; among Māori caregivers, it is 4.36.\*
- The wellbeing relationship between Māori PLWS and caregivers appears to be opposite of that between non-Māori cohorts (i.e., non-Māori PLWS have slightly higher wellbeing than their caregivers).
- While over half (59%) of Māori caregivers report being at least a little bit satisfied with their current life conditions, less than one-third (31%) of Māori PLWS report the same.
- With over two-thirds of Māori PLWS feeling unsatisfied with life, and both groups falling below the national average of life satisfaction<sup>^</sup>, these results indicate that there are a number of underserved wellbeing needs among these populations.



Overall Wellbeing Scores of Māori PLWS and Caregivers



Average Overall Wellbeing Scores, by group and ethnicity



\*Note that there was no statistical difference between average wellbeing of Māori PLWS and caregivers, nor between Māori and non-Māori cohorts.

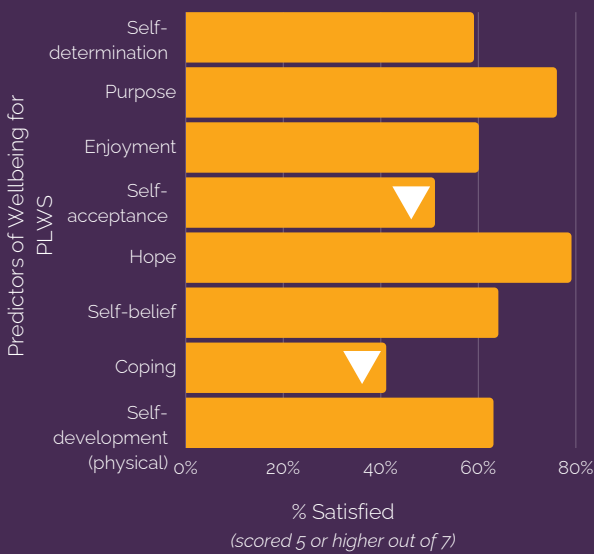
<sup>^</sup>As of 2021, 73.2% of the national Māori population report feeling satisfied with their current life conditions (score 7 or above out of a possible 10). Source: Living Standards Framework, NZ Treasury.



# Predictors of Wellbeing: What is Driving Wellbeing for Māori PLWS

How Māori people living with epilepsy (PLWS) are tracking against their respective predictors of wellbeing.

**Top Predictors of Wellbeing Performance  
for People Living with Seizures**



## Māori PLWS Wellbeing Benefits from Strong Sense of Hope and Purpose but Struggle with Coping Skills

- Among the predictors of wellbeing for people living with seizures (PLWS), Māori PLWS wellbeing is being buoyed by their strong sense of hope and purpose.
- However, only 2 out of 5 Māori PLWS feel they are able to handle many things at a time, and just half are happy with who they are.
- If ENZ is able to support Māori PLWS to strengthen their coping skills and have greater self-acceptance, they will be more likely to have a positive impact on this cohort's overall wellbeing.







# Predictors of Wellbeing: What is Driving Wellbeing for Māori Caregivers

How Māori caregivers are tracking against their respective predictors of wellbeing.

**Top Predictors of Wellbeing  
Performance for Caregivers**



▼ *Low triangle indicates a priority need*

## Māori Caregivers' Wellbeing is Supported by their Ability to Enjoy Life but Feel Disconnected from Community

- 9 out of 10 Māori caregivers say they are able to enjoy life and have fun. As this is one of the strongest drivers of wellbeing for caregivers, scoring high in this factor may explain in part why Māori caregivers have the highest wellbeing score of all four cohorts.
- More Māori caregivers also feel that they have access to enough income to cover their daily costs as compared to non-Māori caregivers.
- Like other caregivers, most Māori caregivers do not feel well connected to a community; strengthening this sense of belonging is an opportunity for ENZ to increase its positive impact on caregivers' wellbeing.







## Priority Need: Finding the Right Employment is a Challenge for Māori Respondents

Access to employment opportunities that provide financial stability, personal safety and flexibility is both a driver of wellbeing and an underserved need for all people living with seizures (PLWS) and their caregivers.

Māori PLWS feel particularly challenged by the lack of employment opportunities, with less than half reporting that they can find work that's right for them, and only two in five stating that they have enough income to cover their daily costs.\*

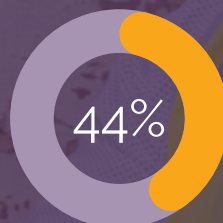
Qualitative feedback has similarly identified these barriers to wellbeing, as improved access to employment support services, increased financial support when unable to work, and broader transport services were all named by PLWS as means to improving their overall wellbeing.

This presents an opportunity for ENZ to concentrate its support and advocacy for greater employment opportunities for Māori PLWS. Beyond greater financial security, this may also improve their sense of purpose and self-determination, thereby improving the wellbeing of Māori PLWS through multiple mechanisms to have an even greater impact.

**"Epilepsy needs to be more accepted by people in NZ. It is difficult to get employment when there may be a risk of having a seizure. No matter how often?! You don't even get a chance at all? Why?"**

*- Māori respondent, living with epilepsy (not pictured)*

*\*Encouragingly, Māori caregivers report feeling more satisfied in terms of employment access (63%) and financial security (78%).*



The minority of Māori PLWS are able to find suitable work



Only 41% of Māori PLWS are able to cover their daily living costs







**"I would like to see services that help [people with epilepsy] get into the workforce and courses/university.**

Only because I don't have the confidence to do so alone... I don't seek pity or special treatment when it comes to studying or working because I know academically I can keep up with everyone around me, it's just mentally and emotionally I struggle with feeling displaced, useless, and not worth it. Thus feeling singled out, intimidated by everyone else's self confidence, mental and physical health control. I feel alone having no one to talk to cause nobody here [has epilepsy] and they won't understand me so as always I run away and never go back. But **I believe being with people who understand what I go through will definitely encourage me to continue working and studying.**"

*- Māori respondent, living with epilepsy (not pictured)*





## Priority Need: Strengthening Communities Will Benefit Both Māori PLWS and Caregivers

Feeling a sense of connection to community is important to both Māori and non-Māori people living with seizures (PLWS) and caregivers. However, community connection was one of the lowest-scoring factors on average across the board, with the majority of people across all cohorts feeling disconnected from community.

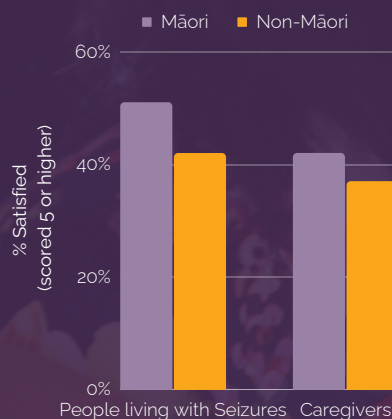
However, it is worth noting that slightly more Māori PLWS and caregivers appear to feel connected to a community, suggesting that connection to cultural community may offer protective benefits to wellbeing.

As community connection is a priority need for all, this is an opportunity for ENZ to maximise its potential impact with the most efficient use of its resources. It is also something that has been specifically identified as a need by PLWS and caregivers themselves. Strengthening connections within communities of people living with epilepsy and seizures benefits all constituents, thus improving the wellbeing of many with a single strategic intervention.

**"[We need] a support group for the kids and parents/caregivers where you can go and be with people who are going through or have gone through what you have. This is also good for the kids/adolescents to talk to each other."**

*- Māori respondent, carer*

**Sense of Belonging,  
by group and ethnicity**







## Unique Differences in Māori Responses, Compared to Overall Totals

In order to understand the specific needs of Māori PLWS and carers, comparisons were made between responses from Māori respondents as compared to the overall response sample in this study. PLWS and carer responses were compared as separate groups.

**Māori carers report *higher* confidence with access to income to cover everyday needs, enjoyment, resilience and mental wellness than overall carer respondents.**



Access to Income

+13%

Having enough income to cover everyday needs



Enjoyment

+10%

Enjoying life and having fun



Coping

+9%

Ability to handle many things at one time



Self-Belief

+7%

Belief in themselves gets them through hard times



Purpose

+5%

Feeling their life has purpose

**Māori people living with seizures report *less* confidence in employment opportunities, health and safe homes than overall PLWS respondents.**



Employment

-16%

Finding work options suitable for them



Physical Health

-10%

In general, their physical health is good



Safe Home

-6%

Access to a safe and stable home

All shifts are significant to  $p < 0.1$

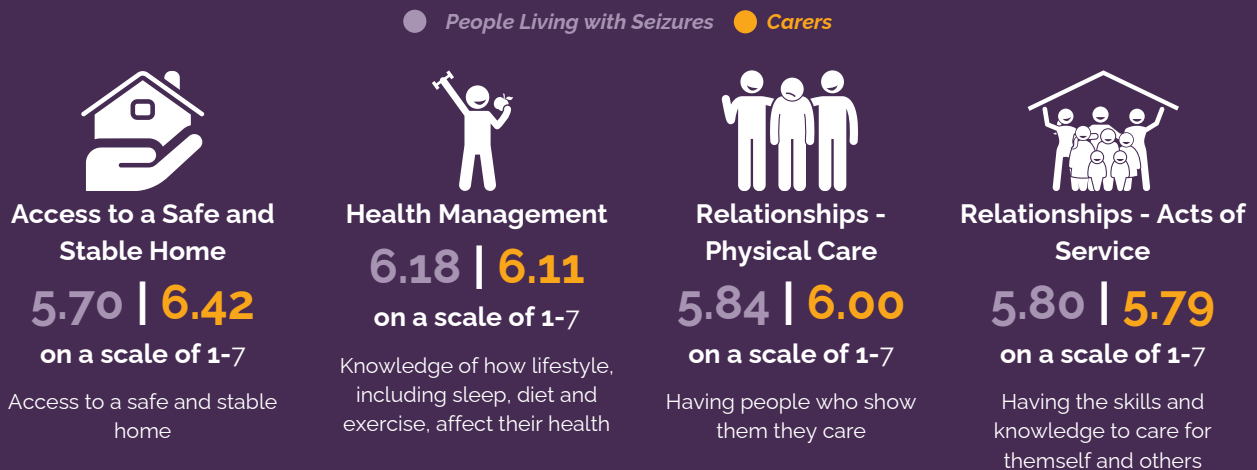




# Respondent Shared Strengths: Māori Respondents Share Strengths around Relationships and Care

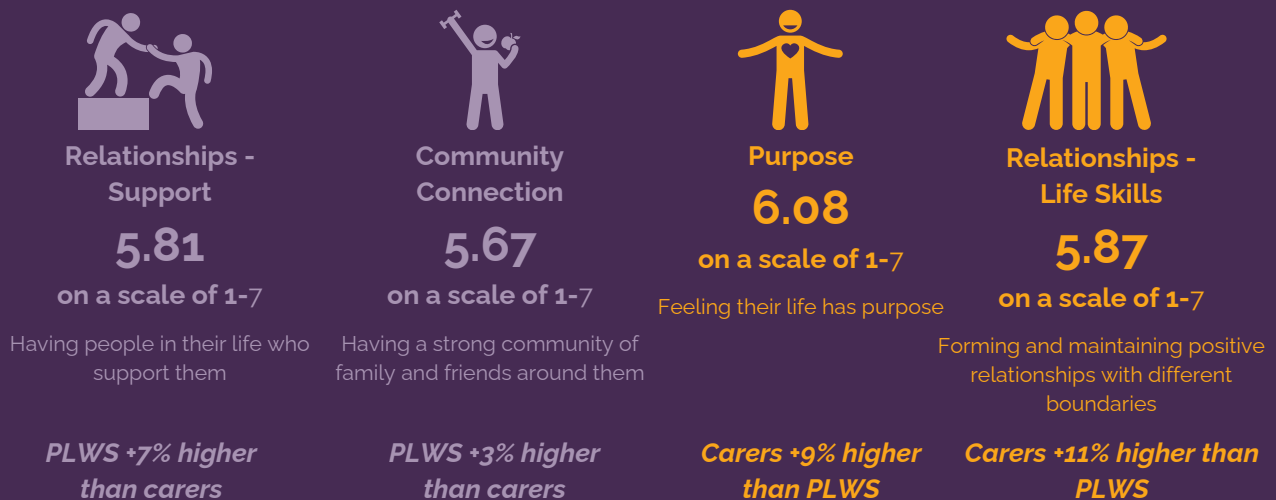
## Shared strengths between people living with seizures and carers

The following highest factor scores shed light on areas where Māori respondents feel the most confident. The majority of these strengths centre around types of relationships, indicating that people living with seizures and carers both feel they have caring and supportive relationships. Analysis showed that the two respondent groups shared a number of strengths such as:



## Distinct strengths

Beyond the shared strengths above, there were several high-scoring factors that were unique to each respondent group:



Comparing high scores from each group, people living with seizures feel more strongly that they have a strong community of friends and family in their life who support them compared to carers, while carers feel more strongly that their life has purpose.

# Maximising Wellbeing for the Epilepsy New Zealand Community

- Priority Needs: Maximising wellbeing for both PLWS and carers.
  - *Employment opportunities* 40
  - *Strengthening seizure communities* 41
- Shared Challenges 43
- In Their Own Words: Respondents' Recommendations for Improvements 45
  - *In PLWS' own words* 46
  - *In caregivers' own words* 48
- Shared Strengths







## Priority Need: Supporting Employment Opportunities Benefits PLWS and Caregivers

For both people living with seizures (PLWS) and carers, employment was found to be a driver of wellbeing. PLWS and carers need jobs that are compatible with their knowledge, skills, and interests, while also being safe and flexible to their health needs and, for caregivers, compatible with their other responsibilities.

However, both PLWS and carers indicated that they have poor access to suitable employment options, with less than half of carers and PLWS (49%) agreeing they have access to suitable employment.\*

Commentary in open feedback expands upon this need further; employers' lack of seizure awareness and education was a repeatedly mentioned barrier to successfully finding work, whether that be for PLWS seeking employment or the need for flexibility for caregivers' responsibilities.

**An Opportunity:** These findings encourage ENZ and other organisations to consider pathways for supporting PLWS and caregivers into suitable employment for them, as well as continue education and advocacy for employers and workplaces to drive inclusive employment.

**"I have been self taught and lived in the shadows my working life praying I wouldn't have a seizure. I lied on job application forms as I knew I wouldn't get jobs if they knew I had epilepsy."**

*- Respondent, living with epilepsy (not pictured)*

*\*49% of each group scored a 5 or higher when asked if they have access to suitable work options (scores out of 7). See Appendix 5: Significance Tables for a complete list of Predictors of Wellbeing.*



**Employment Opportunities**

**49%**

of PWLS and carer groups feel they have access to work options suitable for them







## Priority Need: Strengthening Community Benefits PLWS and Caregivers

For both people living with seizures (PLWS) and carers, feeling connected to a community was found to be a driver of wellbeing. However, both groups scored relatively low in this factor, indicating that neither group feels a strong sense of community belonging, with **only two out of five reporting that they feel connected to a community.**\*



### Community Connection

**4.24 | 4.04**

out of 7

Feeling connected to a  
community

● **People Living with Seizures** ● **Carers**

There may be different motivations for PLWS and carers which explain their lack of community connection. For PLWS, it may be perceived limitations or barriers to their full participation in certain aspects of their broader social community. For carers, the unique challenges they face and concerns for the person they're caring for that prohibit full engagement with a community beyond the family unit.

**An Opportunity:** This presents a clear opportunity for ENZ to maximise its social impact. **If ENZ is able to encourage greater community connection among these two cohorts, then both will more likely see improvements in their overall wellbeing.** The organisation may wish to explore how it can boost use of support groups, encourage engagement in external communities, or even promote the benefits of community connection for both PLWS and caregivers.

\*42% of PLWS and 41% of caregivers scored a 5 or higher when asked if they feel connected to a community (scores out of 7). See Appendix 5: Significance Tables for a complete list of Predictors of Wellbeing.



## Both PLWS and Carers Repeatedly Request Strengthened Community

Strengthening connection to community was found to be statistically correlated to increased overall wellbeing amongst PLWS and caregivers. Interestingly, when both groups of respondents were asked what PLWS most needed for improved quality of life, qualitative responses mirrored this statistical finding with a resounding commentary around the importance and need for more points of connection with others in similar circumstances.

The following captures example commentary from respondents. To improve the quality of lives for PLWS, respondents recommend:

“ **Have more support groups for the both parents and person with epilepsy.**

*Organised support groups where s can help each other and know they're in a safe place physically and mentally because we're all living with the same issue.*

**It would be nice to have a database of people who suffer from epilepsy so I could meet people who are at my age and stage with a similar condition.**

**Community support to meet other people with seizure disorders.**

*A way for people with epilepsy in NZ to communicate with each other like an app? Possibly meet ups but most of us can't drive so an online option is better.*

**Targeted support groups. Not just one size fits all type of support groups.** Perhaps support groups for different ages/stages of life. As well as support groups for families, friends, carers, etc.

**Having a local meet up where people with epilepsy can connect or just chat with each other about anything and feel safe and not judged.**

*A support group of people with epilepsy specific to my particular needs/ demographic ie, people under 60, mothers of children and teenagers.*

**FAR MORE social media help in NZ is needed.**

**Social events/coffee groups for people/carers** with epilepsy, wider community fun events, e.g. walk/fun run family events, purple day events, network meetings e.g. zoom which educates and supports others, sharing of stories.

**[We need] support groups locally and re[garding] children.**

**Support groups including meet ups with other groups.**

”



# Shared Challenges: Safety is a Shared Challenge Among PLWS and Carers

Huber Social looks at lowest overall factor scores to understand where respondents are reporting the least confident, in terms of their capabilities and access to opportunities. Findings show that both people living with seizures and carers have a cluster of shared challenges\*, including:



### Embarrassment and Social Problems

**2.74 | 2.02**

out of 7

Worry of themselves or the person they care for being embarrassed or having social problems resulting from having a seizure



### Worry of Being Hurt

**2.86 | 2.00**

out of 7

Worry of being hurt or the person they care for being hurt during a seizure



### Anxiousness and Worry

**3.06 | 2.85**

out of 7

Frequent feelings of anxiousness and worry



### Fatigue

**3.05 | 3.02**

out of 7

Feeling worn out



### Sense of Safety - Wider Community

**3.41 | 3.45**

out of 7

Trusting people in the wider community to keep themselves or the person they care for safe



### Trust in Community Awareness

**3.51 | 3.35**

out of 7

Believing the wider community have enough information to know what to do to keep themselves or the person they care for safe

- People Living with Seizures
- Carers

Each of these low-scoring factors cluster under the overarching outcome of 'Safe' where worry and difficulty trusting in the wider community are two key threads throughout the findings. Similarly, additional low-scoring areas include frequent feelings of fear and overwhelm.^

**An Opportunity:** Respondents are reporting challenge in wellness factors and managing frequency of emotions of worry. This therefore presents ENZ an opportunity to review how their services seek to target this need within the epilepsy community.

*\*It should be noted that these are challenges relative to all factors measured respective to both cohorts; while a score may appear lower for carers than people living with seizures, the score is still high relative to all other scores for factors measured among carers.*

*^See page 48 for a discussion on strengths experienced by PLWS and carers.*





## The Need for Community Knowledge

Both PLWS and caregivers report low confidence in trusting the community and believing the wider community have enough information to keep themselves or the person they care for safe. Quantitative findings reinforce this where respondents strongly recommended for increased public knowledge and awareness, particularly in relation to safety and supporting peace of mind for PLWS.

**An Opportunity:** ENZ carried out this measurement to better understand the experiences of PLWS to support planning for and delivery of more equitable services. Therefore, while the reported challenges of PLWS reinforce ENZ's aligned mission for a seizure smart New Zealand, it presents an opportunity to consider the best delivery and accessibility of this knowledge-building considering the sustained challenges experienced by respondents despite interventions in place.

The following captures feedback from respondents when asked what PLWS to improve the quality of their lives for PLWS:



**More education for the community about how to support someone having a medical event so I feel safer when out and about.**

*The general public having understanding of our triggers. E.g. cyclists don't have to use strobe lights on their bike.*

Education for people that don't know anything about what to do with a person having a seizure.

**Educate public on different types of seizures and remove the stereotypes of seizures.**

Way more public education is needed on the types of seizures that exist. I am working in a hospital as a health care assistant and even the knowledge there is extremely lacking!

A specially trained dog would be hugely beneficial for me in terms of some independence and **feeling safe to leave the house on my own not to mention my mental health.**

**More people to understand about seizures and to understand how to deal with them in public.**

The wider community needs to be better educated. After my husband had a tonic clonic in Pak n Save. The first thing I was asked was what drugs was he on.

More information on what seizures can look like, not all are tonic clonics but that doesn't mean that they aren't dangerous and don't seriously affect someone.

**Make the public more aware of what to do.**

*Get more info out to the general public! I tried to find a pamphlet about epilepsy in the hospital and couldn't find one, not good enough. We don't have a specialist here and it's hard to find info. I truly worry for the others in this area with epilepsy.*

**Educating society on how living with epilepsy looks for different people.**

*For the wider community to have knowledge and understanding of how to manage and keep someone safe during a seizure. Maybe people learn this as part of life saving and health education and training. Especially taught in school health classes.*





# In PLWS's Own Words: Feedback for Improved Lives for those Living with Seizures

The following four themes emerged in feedback from people living with seizures on what they need to fulfil their potential:



## Increase education and community awareness around epilepsy

- More resources, **information** and help readily available for those diagnosed.
- Increased **community education** around supporting someone having a seizure.
- Increased **community understanding** around triggers for people living with seizures.
- **Reduced stigma**, increased empathy, increased patience.



## Strengthen seizure support community

- Supporting channels for people living with seizures to **communicate and connect** with each other e.g. having a local meetup or an app for communication.
- Local meetups, more social media help, and connections within the epilepsy community.
- Increased support services, **support groups**, and epilepsy groups.



## Improve quality of medical practices and support

- **Better access** to information and support in the health system.
- Increased **quality of treatment** and therapeutic relationships with healthcare staff.
- Increase **education of medical practitioners** on epilepsy and different types of seizures.
- Increased **support for mental health** due to epilepsy-related anxiety and depression.



## Enable greater financial security for people living with seizures

- Increased support for **finding appropriate work/employment**.
- Financial help towards people who have seizures including **compensation** for time off work or disability allowance not income-tested on spouse.
- Increased **logistical and financial support** for people losing their license, particularly in rural areas.



# In Carers' Own Words: Feedback for Improved Lives for those Living with Seizures

The following five themes emerged in feedback from caregivers when asked how life could be improved for people living with seizures. Notably, there are many parallels between the suggestions from PLWS respondents (see page 45). Within these similar themes, only suggestions which differ or expand upon previously mentioned recommendations by PLWS are included below. The need for support groups and mental health support were most frequently mentioned by carers.



## Increase support groups and seizure communities

- Increase **support groups** for children/adolescents living with epilepsy and carers.
- Access to **peer support groups** for families and caregivers.
- Improve **support for families**, including caregivers and siblings.
- Building community amongst children/ adolescents living with epilepsy and their siblings e.g. **shared camps/activities**.



## Increase education and community awareness

- Increase **public knowledge** e.g. awareness campaigns.
- Increase education about epilepsy in schools, workplaces, with employers and medical professionals, including **training for handling seizures**.
- Better **access to information** packs including tools, information about epilepsy, and resources.
- Advocacy for **disability recognition** for epilepsy.



## Improve medical care, services and support

- **Better access** to neurologists, specialists, alternative medications, seizure alarms and ambulances.
- **Shorter wait times** for medical tests and appointments.
- Need for **accurate diagnosis** and management plans.
- Improving medical professionals' **communication and sensitivity**.
- Need for **consistent medical care** throughout individuals' lives.



## Strengthen mental health support


- Increase **support for mental health** due to epilepsy-related anxiety, especially amongst adolescents.
- **Supporting exhaustion** and burnout of caregivers/parents.
- Normalising epilepsy and **reducing stigma**.



## Increased financial and social support

- Assistance with **independent living**.
- Support and information for **transitioning from school** to adulthood.
- Support for **learning difficulties** and education.
- Financial support (including **micro support** for devices and alarms).
- Accessible **benefits for caregivers** and parents.





**"There needs to be more help with the way people with epilepsy are treated ... people with epilepsy are all under the same umbrella and are often stifled by their lack of independence and [lack of] help to try and become independent adults."**

*- Respondent, carer (not pictured)*

## Shared Strengths: Strong Personal Relationships Are a Shared Strength Among PLWS and Carers

Huber Social looked at the highest overall factor scores to understand and celebrate where respondents are feeling the most confident in themselves, in terms of their capabilities and access to opportunities.\* Among people living with seizures and their carers, there were a number of shared strengths identified:



Relationships - Support

6.14 | 5.57

out of 7

Having people who support them



Relationships - Physical Care

6.08 | 5.69

out of 7

Having people in who show them they care



Relationships - Acts of Service

6.01 | 5.86

out of 7

Having the skills and knowledge to care for themselves and others



Health Management

6.28 | 6.12

out of 7

Knowledge of how lifestyle, including sleep, diet and exercise, affect one's health



Access to a Safe Home

6.06 | 6.32

out of 7

Access to a safe and stable home



Passions

5.75 | 5.61

out of 7

Having passions and interests

● People Living with Seizures ● Carers

The majority of these strengths centre around types of relationships, indicating that both people living with seizures and carers feel they have many different types of relationships in their lives that satisfy various functions and needs.

**An Opportunity:** Despite this, both cohorts have also indicated that they do not feel connected to a community.<sup>^</sup> While they feel satisfied with their personal relationships, there is still a need for greater community development amongst people living with seizures and carers.

*\*It should be noted that these are strengths relative to all factors measured respective to both cohorts; while a score may appear lower for carers than people living with seizures, the score is still high relative to all other scores for factors measured among carers.*

<sup>^</sup>See page 43 for a discussion on challenges experienced by PLWS and carers.





## What's Next

- Applying the Findings 50
- Recommendation for ongoing measurement 52
- Get in Touch 53
- Report Appendices 54





## Applying the Findings

This opportunity assessment represents the holistic needs to help support PLWS and their carers to be in the best position to live a life of value. Understanding the next steps forward from these findings is key for ENZ and other organisations to drive change for the people they support.

The way in which wellbeing scores of both PLWS and caregivers are well below the national average for both the general population and those living with a disability indicates that there are underserved wellbeing needs among both communities. This highlights the importance of organisations like ENZ and the role they have in creating targeted supports and interventions to best support these groups of people. From this study's results, key themes for further focus and action are listed below. Opportunities for consideration have also been interwoven throughout the report.

### Applying the Overall Findings

#### **Strengthen Opportunities for Community Connection**

Feeling connected to a community was found to be a driver of wellbeing yet only two out of five respondents reporting that they feel connected to a community. Therefore, if ENZ is able to encourage greater community connection among these two cohorts, then both will more likely see improvements in their overall wellbeing. See page 42 for respondents' own recommendations in their open feedback.

#### **Direct Resources towards building PLWS's Sense of Empowerment and Self**

Self-empowerment and sense of self were two areas found to be of significant importance to the wellbeing of PLWS, therefore, for ENZ to direct further resources towards supporting PLWS to work on self-acceptance and identify purpose in their lives could be highly impactful for increasing their overall wellbeing.

#### **Support Those Seeking Employment**

Finding a job that satisfies both financial and logistical requirements was found to be a challenge for carers and repeated through open feedback as an additional challenge for PLWS. This is a key area for ENZ to strengthen support and intervention.

#### **ENZ to Continue to Accelerate Community Education and Awareness**

Strong qualitative commentary as well as low scores around respondents' trust and belief in the public's knowledge to keep PLWS safe thereby indicate ENZ's well-aligned mission in promoting and driving epilepsy education in Aotearoa New Zealand. These findings both encourage ENZ to keep pressing forward on this mission yet presents an opportunity to consider how to optimise their knowledge-building processes and systems considering the sustained challenges experienced by respondents despite interventions in place.

### Applying Specific Findings for Māori People

Report results demonstrate certain differences in wellbeing drivers among Māori surveyed, and the need for tailored approaches to best address their holistic needs. The following details next steps from the findings from the Māori respondents.

#### **Support Opportunities for Suitable Employment for Māori PLWS and Carers**

With less than half of Māori PLWS respondents reporting that they can find work that's right for them and with this repeatedly echoed in open feedback, this presents an opportunity for ENZ to concentrate its support and advocacy for greater employment opportunities suitable for Māori PLWS. Beyond greater financial security, this may also improve their sense of purpose and self-determination, thereby also supporting other key wellbeing needs to have an even greater impact.



## Applying the Findings cont.

### **Support Māori PLWS's Skills in Coping and Self-Acceptance**

With only 2 out of 5 Māori PLWS feeling they are able to handle many things at a time, and with only 50% reporting they are happy with who they are, this presents an opportunity for ENZ to have a positive impact of the wellbeing of Māori PLWS by creating supports which strengthen their coping skills and build greater self-acceptance. There is the potential for ENZ and other epilepsy support organisations to partner with Māori health providers to optimise this.

### **Build Community Connectedness and Sense of Community Belonging for Māori, Particularly Caregivers**

Considering the ways ENZ promotes community connectedness not just amongst PLWS communities but also caregiver communities is an opportunity for ENZ to increase its positive impact on both Māori and non-Māori caregivers' wellbeing.

*Recommendations from respondents themselves for improving the lives of PLWS can be found on pages 45-46. Suggestions for improvements specifically around community-building and increasing public awareness can be found on pages 43 and 44..*





## Recommendation for Ongoing Measurement

Equipped with an impact thesis, measurement tool and baseline dataset of their target audience, ENZ are positioned to continue longitudinal impact measurement and data insights according to people's engagement with ENZ services and/or interventions. This will build ENZ's understanding of not just what the people they support need but additionally how their services are meeting these needs.

Continued measurement further allows ENZ to keep their finger on the pulse of the changing needs of PLWS and carers over time and can equip ENZ with further deep-dives into particular groups of needs e.g. age-based needs for adolescents and adults.

**"Every case of epilepsy is unique and everyone with epilepsy will need some form of support in their life."**

*- Epilepsy New Zealand*





## Get in Touch



### Epilepsy New Zealand

Free phone: 0800 611 116  
[www.epilepsy.org.nz](http://www.epilepsy.org.nz)



### Melde

Melde offers, in partnership, tools and frameworks to support the effective, and safe, elevation of people's voice and measurement of their lived experience. Melde believes that the further inclusion, and weight given to, lived experience in strategic decision making will benefit us all.  
[www.melde.co.nz](http://www.melde.co.nz)



### Huber Social

Huber Social is an independent third party and expert in social impact measurement. Recognising the goal of all social impact is the wellbeing of people, Huber Social has developed a universally applicable framework that measures not only overall wellbeing but also the driving factors to maximise it.  
[www.hubersocial.com.au](http://www.hubersocial.com.au)

*This report was prepared and written with Huber Social on the lands of the Dharawal people and Cammeraygal people of the Eora Nation. Huber Social acknowledges the traditional owners and custodians of country throughout Australia and acknowledges their continuing connection to land, waters and community. They pay their respects to the people, the cultures and the elders past, present and future.*





## Report Appendices

1. Huber Social Wellbeing Measurement Framework
2. Data Transparency Page
3. Papātai Oranga Wellbeing Survey Question Set
4. Predictors of Wellbeing
5. Significance Tables
6. Reference List

# 1. Huber Social Wellbeing Measurement Framework

To be able to fulfil their potential and achieve wellbeing, each individual needs to have the capability and the opportunity to do so. Everyone has different needs within these categories depending on their context.

When it comes to measuring the social impact of a service, Huber Social measures the 'shift' the service creates in terms of wellbeing and the specific program outcomes achieved to create this. Results are then consolidated at a sector, community and global level.

Longitudinal measurement monitors effectiveness of programs to meet these needs; ensuring resources are directed to have the greatest impact. The vision is a wellbeing measurement system that delivers us the whole picture, to put each of us in the best position to achieve wellbeing and leave no one behind.

**The goal for each of us is the same; wellbeing. The part that differs are our individual needs.**

## The Huber Social Wellbeing Measurement Framework

---

### IMPACT

---

## Wellbeing

To be in the best position to fulfil your potential and live a life of value. The overall goal for all services working with people.

---

### OUTCOMES

---

Through building

## Capability

Resilience  
Life skills  
Wellness - mental,  
physical and spiritual

---



---

### OUTCOMES

---

and providing

## Opportunity

Resources  
Self development  
Societal structures  
Relationships

---





## 2. Data Transparency Page

To ensure the integrity of findings always, Huber Social includes a Transparency Page for every project. This ensures both the rigour of evidence and rigour of analysis is clear for each project, across every stage of the data lifecycle.



Phase	Questions on the Treatment of the Data		Points allocated	Yes or No
<b>Design</b>	SAMPLE	Everyone in the program included in the measurement	2	Y
		OR Survey sample population designed to be representative of group	1	N
		Sample description : <i>People living with epilepsy Carers of people living with epilepsy Both PLWE and carers could be engaged or not yet engaged with ENZ.</i>	N/A	N/A
	EXCLUSIONS	Details of people specifically excluded from the measurement: <i>Survey only open to residents of New Zealand 18 years or older.</i>	N/A	N/A
<b>Data Collection</b>	DISTRIBUTION	Online surveys		Y
		OR hardcopy surveys		N
		Data collection supervised by Huber Social consultant	1	Y
		Translation or guidance provided	N/A	N/A
		Response rate description: <i>430 responses were collected from the ENZ community including 307 PLWE and 123 caregivers. Within this total, there was a contribution from 76 Māori respondents.</i>	N/A	N/A
	DATA SOURCES	Data mining of other sources	1	Y
		Data included from previous years/measurements	1	N
	Details of other data sources used: <i>National Life Satisfaction Data referenced from Living Standards Framework.</i>	N/A	N/A	
<b>Cleaning</b>	CLEANING	Partial responses removed or no partial responses	1	Y
		Details of any responses removed: <i>Responses removed if surveys incomplete. Responses missing 50% or more of outcomes data were excluded.</i>	N/A	N/A
<b>Analysis</b>	TEST APPLIED	Basic analysis	1	Y
		Statistical Correlation Test	2	Y
		Details of statistical tests used: <i>Pearson's and Spearman correlation tests run in addition to independent t-tests and ANOVA.</i>		
<b>Reporting</b>	REPORTING	Client published Outcomes Report (prove)	1	N
		OR Client received Social Performance Report (improve)	2	N
		OR Client published full Social Impact Report	3	Y
<b>RIGOUR SCORE</b> LOW: 1-6; MED 7-9; HIGH 10-12			<b>HIGH</b>	<b>11</b>



## 3. Papātai Oranga Wellbeing Survey Question Set

Do you consent to participating in this survey?	Yes / Āe No / Kāo, I do not wish to continue.
Right now I am feeling...	(Select the image you feel closest to)
Are you:	Living with epilepsy / living with unexplained seizures A parent/caregiver to someone living with epilepsy / living with unexplained seizures
Which ethnic group do you identify with?	Please select up to two ethnic groups. New Zealand European Māori Samoan Cook Island Māori Tongan Niuean Chinese Indian Another ethnic group, e.g., Dutch, Japanese, Tokelauan, (please write in)
What district do you live in?	Auckland Central Otago Christchurch Dunedin Eastern Bay of Plenty Hawkes Bay Lakes Manawatu Marlborough Nelson Northland South Canterbury Southland Tairāwhiti Taranaki Tauranga Waikato Wairarapa Wellington West Coast Whanganui
Is the place you live in:	Urban Regional/Rural
Do you have a formal diagnosis of epilepsy?	Yes
	No
If yes, what is the approximate length of time since receiving the formal diagnosis?	<1 year 1-5 years >5 years
How long has it been since the onset of symptoms / first seizures?	<1 year 1-5 years >5 years
Do you have a Seizure Management Plan?	Yes No Currently being made
Does the person you care for have a Seizure Management Plan?	Yes No Currently being made



In most ways my life is close to my ideal	7-point Likert Scale, Strongly Disagree to Strongly Agree
The conditions of my life are excellent	"
I am satisfied with my life.	"
So far, I have gotten the important things I want in life.	"
If I could live my life over, I would change almost nothing.	"
I have people in my life who support me.	"
I have a strong community of family and friends around me.	"
I have the opportunity to meet people who have similar experiences to me.	"
I feel connected to a community (a community is a group who you share interests or attitudes with).	"
I feel that I can handle many things at a time.	"
In the past month, how often have you felt anxious or worried?	7-point Likert Scale, Never to Always
In the past month, how often have you felt emotions of fear?	7-point Likert Scale, Never to Always
How often during the past month have you felt overwhelmed?	7-point Likert Scale, Never to Always
I have people in my life who do things for me.	7-point Likert Scale, Strongly Disagree to Strongly Agree
I have people in my life who show me they care.	"
I have the skills and knowledge to care for myself and others	"
I understand how my lifestyle, including sleep, hygiene, medication, diet and exercise, affects my health	"
I can easily find the answers I need about living with epilepsy/unexplained seizures.	"
When I need information about living with epilepsy/unexplained seizures, I can most easily find it via:	Online Social media Forums Face to face conversations Primary or secondary medical personnel Other – please write in
In general, my physical health is good.	7-point Likert Scale, Strongly Disagree to Strongly Agree
I feel worn out.	"
I have access to the healthcare resources and support I need	"
My friends, family and whānau know how to keep me safe / My friends, family and whānau know how to keep the person I care for safe	"
I think the wider community has enough information to know what to do to keep me safe / I think the wider community has enough information to know what to do to keep the person I care for safe	"
I trust people in the wider community to keep me safe / I trust people in the wider community to keep the person I care for safe.	"
I am worried about being hurt during a seizure / I am worried about the person I care for being hurt during a seizure.	"
I fear feeling embarrassed or having social problems resulting from having a seizure / I am worried about the person I care for being hurt during a seizure.	"
I have things to hope for	"
I believe I can live a life of my choosing / I believe the person I care for can live a life of their choosing.	"
My belief in myself gets me through hard times.	"
I am able to communicate my needs to others in my life.	"
I can adapt when unexpected events happen	"
When I am confronted with a problem, I can usually find a good solution.	"
I can find work options that are suitable for me.	7-point Likert Scale, Strongly Disagree to Strongly Agree, plus Not Applicable
I can find education options that are suitable for me / I can find education options that are suitable for the person I care for.	7-point Likert Scale, Strongly Disagree to Strongly Agree, plus Not Applicable

I know what services I am entitled to.	7-point Likert Scale, Strongly Disagree to Strongly Agree
I know how to access the support services I need.	*
I like who I am.	*
My life has purpose.	*
I have things that I am passionate about	*
When I interact with others, my culture and identity are respected.	*
I feel comfortable asking for help when I need it.	*
I enjoy life and have fun.	*
I am able to form and maintain positive relationships that have different boundaries (e.g. family, friends, partners, people you're living with, professional).	*
I am able to share my thoughts and feelings with others	*
I have enough income to cover my everyday needs.	*
I have access to safe and stable home	*
I have the time and energy to take care of myself.	*
Please list the top three resources/services you use in relation to living with epilepsy/unexplained seizures / Please list the top three resources/services you use in relation to caring for someone living with epilepsy/unexplained seizures	Open text
Do you have any suggestions on how life could be improved for people living with, or people caring for others living with, epilepsy or unexplained seizures in Aotearoa New Zealand?	Open text
Select the following Epilepsy NZ services you engage with (if any):	General support. Social and emotional support. Information and resources. Connecting with other services. Advocacy/ Representation. Mobility and Transport. Developing Seizure Management Plan. Training or seminars for people you interact with. Not applicable, I have not used Epilepsy NZ resources/services before
When dealing with Epilepsy NZ, how have they demonstrated an understanding and respect for your culture and identity?	Open text
Epilepsy NZ is my main support service/resource when required	7-point Likert Scale, Strongly Disagree to Strongly Agree
Unique ID# (Optional)	
How old are you?	0-5 6-15 16-24 25-34 35-44 45-54 55-64 65+
How old is the person you care for?	0-5 6-15 16-24 25-34 35-44 45-54 55-64 65+
How do you describe your gender? Please select all that apply:	Male Female Transgender Gender non-binary I identify another way (please describe): I would prefer not to say



## 4. Predictors of Wellbeing

To inform the education sector in how best to support the wellbeing of students, correlation analysis is used to identify which factors measured have a significant relationship with students' overall wellbeing; these are known as predictors of wellbeing.

The predictors of wellbeing can be found listed in the following table in order of statistical strength. The stronger the relationship between an outcome and overall wellbeing, the more confidence there is that a change in the outcome will correspond with a change in wellbeing.

Relationship strength is based on both the statistical significance (p-value) and beta coefficient value (r). All predictors listed are statistically significant to  $p < 0.001$  (unless otherwise noted), meaning there is 99% confidence that the relationship identified between the predictive outcome and wellbeing is true, rather than produced due to sampling error or chance. The beta coefficient (r) describes how closely each outcome and wellbeing are likely to move together in relation to each other.

For the purposes of this study, a strong relationship between an outcome and overall wellbeing is defined as any outcome with a beta coefficient value greater than 0.7; a moderate relationship is between 0.699 and 0.4; a weak relationship less than 0.4. Even though a relationship may be weak, there is still a significant association between the outcome and overall wellbeing.

The following page presents all predictors of wellbeing that have a significant relationship with overall wellbeing for both student cohorts used in this pilot measurement.







## 5. Significance Tables

**Table 1. All Strong to Moderate Predictors of Wellbeing for People Living with Epilepsy**

Indicator	R-value	P-value	Strength
I believe I can live a life of my choosing	0.635	0.000	Strong, Positive
My life has purpose	0.616	0.000	Strong, Positive
I enjoy life and have fun	0.581	0.000	Moderate, Positive
I like who I am	0.546	0.000	Moderate, Positive
I have things to hope for	0.499	0.000	Moderate, Positive
My belief in myself gets me through the hard times.	0.492	0.000	Moderate, Positive
I feel that I can handle many things at a time	0.455	0.000	Moderate, Positive
I have the time and energy to take care of myself	0.44	0.000	Moderate, Positive
I can find work options that are suitable for me	0.432	0.000	Moderate, Positive
I am able to form and maintain positive relationships that have different boundaries	0.424	0.000	Moderate, Positive
I have enough income to cover my everyday needs	0.419	0.000	Moderate, Positive
I feel connected to a community	0.418	0.000	Moderate, Positive
In general, my physical health is good	0.410	0.000	Moderate, Positive
I have the skills and knowledge to care for myself and others	0.403	0.000	Moderate, Positive

**Table 2. All Strong to Moderate Predictors of Wellbeing for Caregivers**

Indicator	R-value	P-value	Strength
I enjoy life and have fun	0.504	0.000	Moderate, Positive
I feel connected to a community	0.487	0.000	Moderate, Positive
I have enough income to cover my everyday needs	0.477	0.000	Moderate, Positive
I can find work options that are suitable for me	0.472	0.000	Moderate, Positive



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**EPILEPSY**  
NEW ZEALAND

*Kia titiro ki te tangata | See the person*



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