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Submission to the Senate Community Affairs References Committee

Inquiry into Epilepsy in Australia

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Executive Summary

The Neurological Alliance of Queensland (NAQ) welcomes the opportunity to contribute to the Senate Community Affairs References Committee Inquiry into Epilepsy in Australia.

NAQ is a Queensland alliance of community neurological organisations advocating for improved neurological care, system coordination, research and community support for people living with neurological conditions and their families.

NAQ's experience across neurological conditions demonstrates that outcomes for people with epilepsy improve when systems are designed around coordinated, whole-of-life care rather than fragmented episodic treatment. Current systems remain organised around siloed funding structures and acute episodes of care, resulting in delayed diagnosis, avoidable emergency presentations, workforce disengagement, carer burnout and widening inequity for regional and remote communities.

These challenges are particularly pronounced in Queensland, where geography, workforce shortages and service concentration create significant barriers to specialist neurological care. Queensland requires deliberate networked models of care, including specialist hubs, shared-care arrangements, telehealth-enabled pathways and multidisciplinary workforce development.

Epilepsy also highlights broader neurological system challenges. Many people live with multiple neurological, developmental and psychosocial conditions requiring coordinated responses across health, disability, education, mental health and community systems. However, care pathways and funding arrangements are not consistently designed around complexity, fluctuating capacity or lifelong support needs.

NAQ believes the Inquiry should prioritise:

- nationally consistent diagnosis-to-support pathways;
- coordinated neurological workforce planning;
- integrated neurological care across health, disability and community systems;
- improved support for carers and families;
- sustained public awareness and seizure capability initiatives;
- and investment in research, implementation and translation.

NAQ also supports development of a funded National Action Plan(s) aligned to the World Health Organization's Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP).

Epilepsy is not solely a clinical issue. Outcomes are profoundly shaped by system design, coordination and access to support. Nationally coordinated reform is required to improve safety, participation, equity and long-term system sustainability.

Neurological System Issues Exposed by Epilepsy

Coordinated care and diagnosis-to-support pathways

Epilepsy demonstrates the consequences of fragmented neurological care systems. Across Queensland, people frequently move between emergency departments, general practice, specialist services, disability systems and community organisations without coordinated pathways or consistent follow-up.

A diagnosis often marks the start of medication management, but not the beginning of coordinated support. Many people and families are left to independently navigate education systems, disability supports, transport barriers, psychosocial impacts and seizure safety without structured guidance.

NAQ supports nationally consistent diagnosis-to-support pathways that embed:

- epilepsy education;
- seizure safety planning;
- navigation support;
- psychosocial support; and
- warm referral to community epilepsy organisations

as routine components of clinical care at diagnosis and following emergency presentations.

Community epilepsy and neurological organisations provide essential infrastructure through education, self-management support, stigma reduction, workforce training and navigation services that reduce avoidable crisis presentations and improve participation outcomes.

Workforce constraints and regional inequity

Queensland's geography and specialist workforce shortages create substantial inequities in access to neurological care.

Limited access to neurologists, epilepsy specialists and multidisciplinary neurological services contributes to delayed diagnosis, fragmented follow-up and avoidable reliance on emergency care. These pressures are amplified in regional, rural and remote communities where travel burden, workforce shortages and service concentration reduce continuity of care.

NAQ supports development of a national neurological workforce and capability strategy addressing:

- neurology and epilepsy specialist shortages;
- epilepsy nurse specialist roles;
- neuropsychology and allied health capability;
- neurodiagnostic workforce development;
- regional workforce sustainability; and
- telehealth-enabled and shared-care models.

Without coordinated workforce planning, inequities in neurological outcomes will continue to widen.

Disability systems, multimorbidity and functional impact

Epilepsy highlights broader limitations in disability and support systems that do not consistently recognise fluctuating neurological conditions, episodic risk or multimorbidity.

Many people living with epilepsy also experience additional neurological, developmental, cognitive or mental health conditions requiring coordinated responses across multiple systems. Functional impact may vary significantly over time and cannot be understood solely through diagnosis labels or fixed impairment models.

NAQ supports disability frameworks that better recognise:

- fluctuating capacity;
- recovery burden;
- supervision and safety requirements;
- psychosocial impacts;
- and cumulative functional limitations across the life course.

Disability systems should also strengthen epilepsy capability through improved planner guidance, seizure-response protocols and workforce training.

Carer, mental health and psychosocial impacts

The psychosocial impacts of epilepsy are substantial and often persistent. Anxiety, social isolation, loss of independence, workforce disruption and stigma affect not only the individual but also carers, siblings and families.

Carers provide essential coordination, supervision, transport and advocacy support, often at significant personal and financial cost. Many experience reduced workforce participation, chronic stress and mental health impacts without adequate recognition or support.

NAQ supports:

- routine identification of carers within health systems;
- integrated respite and practical support pathways;
- timely access to affordable psychological support;
- trauma-informed and culturally safe care models; and
- recognition of the needs of young carers, siblings and ageing carers.

Mental health and psychosocial care should be embedded within neurological pathways rather than relying on crisis-driven referral.

Public awareness and community capability

Low epilepsy and neurological literacy contributes directly to stigma, exclusion and unsafe responses across schools, workplaces, disability services and public settings.

NAQ supports sustained public awareness initiatives alongside practical seizure capability and neurological training across:

- schools and early learning;
- workplaces;
- disability and aged care services;

- emergency and frontline health services; and
- other public-facing environments.

Reducing stigma is both a participation and safety issue.

Research, implementation and translation

NAQ supports increased Commonwealth investment in epilepsy and neurological research, including:

- drug-resistant epilepsy;
- SUDEP prevention;
- integrated neurological care models;
- workforce and service planning;
- implementation research; and
- translation of evidence-based non-medical interventions into routine practice.

Australia must strengthen its capacity to retain neurological research and clinical expertise through sustained and coordinated national investment.

Commonwealth Reform Priorities

NAQ considers the following Commonwealth levers critical to improving epilepsy and neurological outcomes nationally.

National coordination and accountability

The Commonwealth should use national mechanisms, including the National Health Reform Agreement and national safety and quality frameworks, to drive greater consistency in:

- first seizure pathways;
- diagnostic access and turnaround expectations;
- escalation pathways for ongoing seizures;
- transition between paediatric and adult care;
- and discharge and referral practices.

People should not experience fundamentally different neurological pathways based on geography or service availability.

National Epilepsy Action Plan
NAQ supports development and funding of a National Epilepsy Action Plan aligned to the WHO IGAP framework, with measurable implementation targets across:

- diagnosis and specialist access;
- workforce capability;
- disability interfaces;
- education and community capability;
- stigma reduction;
- research and translation; and
- data collection and reporting.

Investment in community neurological infrastructure

Community neurological and epilepsy organisations should be recognised and funded as core system infrastructure.

These organisations deliver essential services that improve safety, navigation, education and participation while reducing avoidable pressure on acute health systems.

Economic sustainability and prevention

Epilepsy and neurological conditions generate substantial avoidable costs through delayed diagnosis, fragmented care, preventable hospitalisation, workforce disengagement and unpaid caring burden.

Investment in coordinated neurological care, workforce capability, community navigation and earlier intervention represents value-for-money reform that can improve participation while reducing downstream acute care demand.

NAQ notes Deloitte Access Economics estimated the annual economic cost of epilepsy in Australia at $12.3 billion in 2019-20.

Recommendations

1. Develop and fund National Action Plan(s) aligned to the WHO Intersectoral Global Action Plan on Epilepsy and Other Neurological Disorders (IGAP).
2. Implement nationally consistent diagnosis-to-support pathways embedding epilepsy education, seizure safety planning, navigation and warm referral to community epilepsy organisations.
3. Embed coordinated epilepsy care models across emergency care, primary care, specialist neurology, mental health, disability and community services.
4. Develop a national neurological workforce and capability strategy addressing specialist shortages, multidisciplinary workforce development and regional workforce sustainability.
5. Expand networked and telehealth-enabled neurological care models to reduce inequity for regional, rural and remote communities.
6. Ensure disability systems recognise fluctuating neurological conditions, episodic risk and multimorbidity, including appropriate seizure-response capability and planner guidance.
7. Fund community neurological and epilepsy organisations as core system infrastructure delivering education, navigation, workforce capability and prevention functions.
8. Embed mental health and psychosocial support within neurological pathways, including timely access to affordable, culturally safe and trauma-informed care.
9. Strengthen recognition and support for carers, siblings and families through integrated respite, navigation and practical support pathways.
10. Invest in sustained public awareness and seizure capability initiatives across schools, workplaces and frontline services.
11. Increase investment in epilepsy and neurological research, implementation and translation, including drug-resistant epilepsy, SUDEP prevention and integrated care models.
12. Reduce avoidable economic burden through coordinated neurological reform that improves early intervention, workforce participation and prevention of avoidable acute care demand.

Conclusion

Epilepsy exposes critical gaps in how Australia designs and delivers neurological care.

Without coordinated reform, people and families will continue to experience avoidable harm, fragmented support and widening inequity, particularly in regional and remote communities.

NAQ urges the Committee to prioritise nationally coordinated reforms that strengthen neurological care pathways, improve specialist access, embed diagnosis-to-support responses, recognise the role of carers and community organisations, and build consistent capability across health, disability, education and community systems.

This Inquiry presents an important opportunity to improve safety, participation, equity and long-term system sustainability for Australians living with epilepsy and other neurological conditions.