

## Eating disorder service development and lived experience organisations in Australia

Eating disorder organisations (excluding those with a predominantly clinical focus) can broadly be grouped into two categories, defined below:

**Lived experience organisations –** organisations that advocate for, educate, support, and provide evidence-based information about eating disorders to people with lived experience and their families/supports, as well as to the broader community. Some lived experience organisations also provide clinical services and/or conduct service development activities.

**Service development organisations –** organisations that focus on upskilling health professionals and services, and/or developing policy to guide health services and policymakers to plan for and effectively respond to eating disorders. Some service development organisations also provide clinical services and/or conduct lived experience activities.

National and state/territory-based eating disorder organisations across these two categories are shown on the map of Australia below.



Figure 1: Map of national and state/territory-based eating disorder service development and lived experience organisations in Australia, current as of August 2023.

As shown in Figure 1, there are three lived experience and three service development eating disorder organisations nationally. At a state/territory level, there are two lived experience and five service development eating disorder organisations. The InsideOut Institute is included in both the national and state categories, as it has a national and a state-based remit.

A number of the lived experience and service development organisations have joined together to form the Eating Disorders Alliance of Australia (EDAA), to represent the voice of consumers, carers and health professionals. Members of the EDAA are marked with an asterisk in the tables below.

The broad core functions carried out by each lived experience and service development organisation are shown in the tables below. While the lived experience organisations and service development organisations generally have distinct functions, there is some overlap. As such, some functions appear across both the lived experience and service development tables. In recognition of the fact that some lived experience organisations also provide clinical services and/or conduct service development activities (and vice versa), the final column of each table captures these additional functions that the organisations may provide.

The tables below are not intended to provide a comprehensive description of all activities conducted by each organisation, nor should they be viewed or interpreted as a quantification of the amount of work conducted by each organisation. For more detailed information about each organisation, refer to the website links in the tables below.

## **Lived experience organisations**

		Functions provided by lived experience organisations								
Organisation	Description	Helpline	Navigation/referral assistance	Support groups and/or individual peer support	Training/education (including resource development)	Advocacy (individual and/or systems level)	Activation of lived experience workforce	Policy/guideline development	Research and evaluation	Additional functions
National										
Butterfly Foundation* https://butterfly.org. au	The national charity for all Australians impacted by eating disorders and body image issues, and for the families, friends and communities who support them.	(phone, email, online chat, Chatbot)	✓	✓	(includes a dedicated prevention work stream)	✓	✓	<b>√</b>	✓	Clinical services (group-based); Service improvement and integration
EDFA* https://edfa.org.au	A national not-for- profit run by carers with lived experience, connecting, supporting and educating families and carers of people with eating disorders.		<b>√</b>	(includes a daily online support forum)	✓	<b>√</b>	✓	<b>√</b>	<b>√</b>	

EDNA https://www.edneuro aus.com/	A not-for-profit organisation whose board members are all neurodivergent folk with lived experience of an eating disorder. EDNA advocates for better prevention efforts and systemic changes in clinical care for members of the neurodivergent community.			•	✓	<b>✓</b>		<b>√</b>	<b>✓</b>	
EDQ* https://eatingdisorde rsqueensland.org.au	A not-for-profit organisation providing integrated eating disorder support services to Queensland individuals and families living with and recovering from an eating disorder, their carers and loved ones.		<b>✓</b>	Clinical services (individual and group-based); NDIS psychosocial support/ therapeutic interventions; Service improvement and integration						
EDV* https://www.eatingd isorders.org.au	A not-for-profit organisation providing support services, information and guidance to	√ (phone, email,	<b>√</b>	<b>√</b>	<b>✓</b>	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	Clinical services (individual); Service improvement and integration

people impacted by	online				
eating disorders in	chat)				
Victoria.					

<sup>\*</sup>Member of the Eating Disorders Alliance of Australia (EDAA)

## Service development organisations

		Function	nisations				
Organisation	Description	Professional/workforce development (including supervision, training, education, resource development)	Clinical consultation/ outreach	Service improvement and integration	Policy/guideline development	Research/evaluation	Additional functions
National							
ANZAED*  https://www.anzaed.org  .au	The peak body for eating disorder professionals involved in research, prevention, treatment and advocacy in Australia, New Zealand and beyond.	<b>✓</b>		<b>✓</b>	<b>√</b>	<b>✓</b>	
InsideOut Institute https://insideoutinstitut e.org.au	Australia's national institute for research and clinical excellence in eating disorders, and lead of the national eating disorder research centre.  InsideOut also has a statewide function (see next section of table).	✓	✓	✓	✓	<b>√</b>	
NEDC https://nedc.com.au	An initiative of the Australian Government dedicated to developing and implementing a nationally consistent, evidence-based system of care for the prevention and treatment of eating disorders. NEDC has a key role in fostering national collaboration and national coordination, and reducing duplication across the sector.	<b>√</b>		<b>√</b>	<b>√</b>	<b>√</b>	

State							
CEED https://ceed.org.au	A state-wide program of Victoria's specialist public mental health services managed by North Western Mental Health, committed to the provision of quality services to those with eating disorders and their families.	<b>✓</b>	<b>√</b>	<b>✓</b>	<b>✓</b>	<b>√</b>	Clinical services (group- based)
EDP Child and Youth Mental Health Service https://www.childrens. health.qld.gov.au/servic e-eating-disorders- program	The EDP provides assessment and treatment services for families living in the Greater Brisbane area, as well as assessment, treatment, supervision, training and consultation-liaison services statewide.	<b>✓</b>	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	Clinical services (individual and group- based)
InsideOut Institute https://insideoutinstitut e.org.au	In addition to its national functions (see first section of this table), InsideOut Institute undertakes NSW-specific policy development and implementation, and service and workforce development.	✓	✓	✓	✓	<b>✓</b>	
QuEDS https://metronorth.heal th.qld.gov.au/rbwh/hea lthcare-services/eating- disorder	A state-wide service dedicated to developing and improving the quality of eating disorders services in Queensland and enabling better access to a range of services for people affected by eating disorders.	<b>√</b>	✓	✓	✓	<b>✓</b>	Clinical services (individual and group- based)
WAEDOCS https://www.nmhs.healt h.wa.gov.au/Hospitals- and-Services/Mental- Health/Specialties/Eating	A state-wide service that aims to ensure youth and adults in WA with an eating disorder can access optimal best practice care.	<b>√</b>	<b>√</b>	<b>√</b>	<b>✓</b>	<b>√</b>	

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