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DAACCS LATEST NEWS

February 2024

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International Angelman Day - 15th February 2024

Angelman syndrome (AS) is a rare neuro-genetic disorder that occurs in one in 15,000 live births or 500,000 people worldwide. It is caused by a loss of function of the UBE3A gene in the 15th chromosome derived from the mother. Angelman syndrome shares symptoms and characteristics with other disorders including autism, cerebral palsy and Prader-Willi syndrome.

Due to the common characteristics, misdiagnosis occurs often. People with Angelman syndrome have developmental problems that become noticeable by the age of 6 – 12 months. Other common signs and symptoms usually appear in early childhood like walking and balance disorders, gastrointestinal issues, seizures and little to no speech. Despite these symptoms, people with Angelman syndrome have an overall happy and excitable demeanor. An individual with AS will light up a room with their smile and laughter.

[Angelman Syndrome Association Australia Home - Angelman Syndrome Association Australia](#)

The 2024 National Multicultural Festival is back, 16-18 February 2024, with a packed program of song, dance and cooking demonstrations. While you eat your way around the globe you will be entertained by performances, cultural workshops, and cooking demonstrations on 8 stages located throughout the city centre and Glebe Park.

With more than 170 multicultural communities sharing their culture and heritage over the weekend there is something for everyone. Please let us know if you would like support to attend one or all the events.



Fun Fact: Did you know that "February" is one of the most misspelled words in the English language?



LATEST NDIS NEWS

Independent Advisory Council's Annual Report 2022-23

The Independent Advisory Council (IAC) has published their [Annual Report 2022-23 on the IAC website](#) .

The Annual Report tells you about the advice and work the IAC did during 2022-2023. It highlights the IAC's achievements for the year, and its work to bring the views of people with disability, their families, carers and sector experts to the heart of the NDIS.

- IAC's advice to the NDIA Board
- IAC's input and expertise on the NDIA's co-design work
- Principal Member and Members' views about the IAC's work
- Milestones and achievements for the year
- Current IAC members and their experience. These are the members who helped develop IAC's advice and are the voice of participants at the highest level.
- Ways the IAC has worked according to its Operating Model and Work Plan.
- Ways the IAC has worked to provide transparent and accessible communications.

IAC's Annual Report helps to maintain the accountability and performance of the IAC's work.

About the IAC

The IAC's role, outlined in the NDIS Act 2013, is to give independent advice to the NDIA Board. IAC advice aims to improve the NDIS, participant experience and outcomes.

The IAC comprises of a [Principal Member and no more than 12 other members](#) , who represent a wide range of disability and advocacy sectors, bringing their own lived experience or expertise of disability.

They are the voice of the participants at the highest level, bringing skills, expertise and knowledge that will help the IAC perform its function.

For more information about the role of the IAC visit the [Independent Advisory Council website](#)

NDIS Participant Statistics September 2022 to September 2023

The National Disability Insurance Agency (NDIA) regularly shares reports and data aimed at improving knowledge and understanding of how people with disabilities are experiencing the Scheme.

The dashboard series includes summary reports and data for 15 primary disability types, I have reviewed the data and compiled a table for easy reference. As of 30 September 2023, there are 631,529 active NDIS participants nationally. In the ACT we have 10,595 participants.

Autism appears to represent the greatest number of participants. Intellectual Disability represents the largest portion of funding.

Quick snapshot - ACT v's National data

| Primary Disability | #of participants nationally, out of a total of 631,529 | #of participants in the ACT, out of a total 10,595 | National total amount spent for the reporting year (million) |
|----------------------------|---|---|--|
| Acquired Brain Injury | 18,335 | 234 | \$2,542.4 |
| Autism | 223,650 | 3,761 | \$7,155.1 |
| Cerebral Palsy | 17,762 | 305 | \$2,556.4 |
| Developmental Delay | 74,364 | 1,150 | \$773.4 |
| Down Syndrome | 11,633 | 228 | \$1,344.9 |
| Global Developmental Delay | 15,956 | 202 | \$241.7 |
| Hearing Impairment | 26,951 | 454 | \$240.7 |
| Intellectual Disability | 90,014 | 1,301 | \$8,872.9 |
| Multiple Sclerosis | 10,603 | 231 | \$965.9 |
| Other Neurological | 22,903 | 416 | \$2,872.8 |
| Other Physical | 20,103 | 524 | \$1,282.6 |
| Psychosocial | 63,010 | 1,178 | \$4,546.7 |
| Spinal Cord Injury | 5,955 | 81 | \$899.7 |
| Stroke | 9,198 | 146 | \$1,147.4 |
| Visual Impairment | 10,288 | 183 | \$400.9 |

To access the full data please visit: [Participant dashboards | NDIS](#)



Sunday 4th February - World Cancer Day

[World Cancer Day](#) is an initiative of the Union for International Cancer Control (UICC), the largest and oldest international cancer organisation dedicated to taking the lead in convening, capacity building and advocacy initiatives that unite the cancer community to reduce the global cancer burden, promote greater equity, and integrate cancer control into the world health and development agenda.

The theme of World Cancer Day 2022-2024 is Close the Care Gap. While we live in a time of awe-inspiring advancements in cancer prevention, diagnosis and treatment, many of us who seek cancer care hit barriers at every turn. Income, education, geographical location and discrimination based on ethnicity, gender, sexual orientation, age, disability and lifestyle are just a few of the factors that can negatively affect care.

Canberra Cancer support groups

Cancer support groups can offer you support and information. They usually bring together people, families or carers affected by cancer to offer mutual support and a safe place to discuss and manage challenges. Some groups are for specific cancer types, while others are more general.

You may find one of the following groups or resources useful:

- [Canteen](#): for 12-25 year olds whose world who have been affected by cancer
- [Bosom Buddies](#): for people affected by breast cancer
- [Brain Tumour Alliance](#)
- [Rise Above](#): Rise Above - Capital Region Cancer Relief, provides financial assistance and support to cancer patients and family residing with them within the ACT, Queanbeyan and surrounds
- [Heads Up](#): supporting women with hair loss
- [Leukemia Foundation](#)
- [OvCan](#): Ovarian cancer awareness and support for the ACT region
- [Palliative Care ACT](#): for those with a life limiting illness, their carers and families
- [Myeloma support group](#)
- [Prostate Cancer Support Group](#)
- [Cancer Council ACT](#)
- [Pink Sisters](#): headwear for people experiencing hair loss
- [Carers Australia](#)
- [McGrath Foundation](#): support and care for people experiencing breast cancer
- [Melanoma Patients Australia](#)
- [Mensline](#): telephone and online counselling service offering support for Australian men
- [My Parents Cancer](#)
- [Palliative Care Australia](#)
- [Redkite 15-24 years](#): for families facing childhood cancer
- [Australian Centre for Loss](#)
- [Caring Bridge](#): free online tool for sharing health updates
- [Good Grief](#)



Reach out to meet new people - Canberra

The best way to make new friends in any new city is to get involved in organised activities. Find like-minded people by:

- taking up a hobby
- enrolling in a class
- volunteering
- joining an interest group or social group

Canberra has many [meetup groups](#), which are open to everyone. You'll find groups of people who are interested in the same things as you. There are meetups for everything from adventure sports to book clubs, truffle hunting, drama, zentangling and more. [Meetup | Find Local Groups, Events, and Activities Near You](#)

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