

# Reaching Across Australia

Bringing State Associations together  
with a united vision

James O'Brien, Chair

Prader-Willi Syndrome Australia Ltd



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# Today's Presentation

- **Government assistance for people with a disability**
- **History of State/National PWS Associations**
- **Building organisational and individual capacity**
- **Current and future plans for PWSA**



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# Disclaimer

The person delivering this presentation is not a physician. Any opinions expressed are those of the presenters alone unless otherwise specified, and may not represent the opinions of Prader-Willi Syndrome Australia. This presentation is intended to provide information only, not to impose particular treatment options. Any decision about treatment options should be made in consultation with your own medical team.



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# Government assistance for people with a disability



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# Healthcare / Treatment

- Medicare
  - Gives Australian residents access to healthcare
  - No cost or low cost
- Pharmaceutical Benefits Scheme
  - Medicines are Government subsidised
- Private Health Insurance for a doctor of your choice or private hospitals



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# Social support (social care)

- Disability Support Pension (means tested)
  - Permanent medical condition that stops you from working
  - Funds for daily living
- National Disability Insurance Scheme (NDIS)
  - Funding to purchase **'reasonable and necessary'** supports to live an **'ordinary life'**



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# Supports that can be funded by NDIS

- Assistive technology
- Early childhood intervention
- Household tasks
- Supports to get and keep a job (training and higher education)
- Personal Care
- Supported Independent Living (SIL)
- Specialist Disability Accommodation (SDA)
- Medical aids



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# History of State/National Associations



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# State and National Associations

- 1970's – 3 States formed local Associations
- 1980's – 2 further States formed Associations
- 2006 – PWSA Association was formed
- 2016 – Representatives from all States and Territories met to investigate amalgamation



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# Unmet Need for Consistency

- Ongoing challenges in equity and consistency
- Decision to strive for 'postcode free' service delivery
  - Consistency of message
  - Delivered into local community
- Sharing of scarce resources
- Led to relaunched PWSA Ltd in 2018 (ACN 625 483 909)
- Commenced trading in July 2019



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# Vision

An Australia where every person living with PWS has equal access to high quality supports to enable them to be included in community, achieve their goals, and live happy, healthy, fulfilling lives.



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# Mission

We exist to empower those impacted by PWS and to improve their quality of life.

We aim to simplify pathways by connecting, educating, advocating, and transforming lives together.



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# Values

## OUR VALUES

Empathy  
Leadership  
Collaboration  
Integrity  
Diversity



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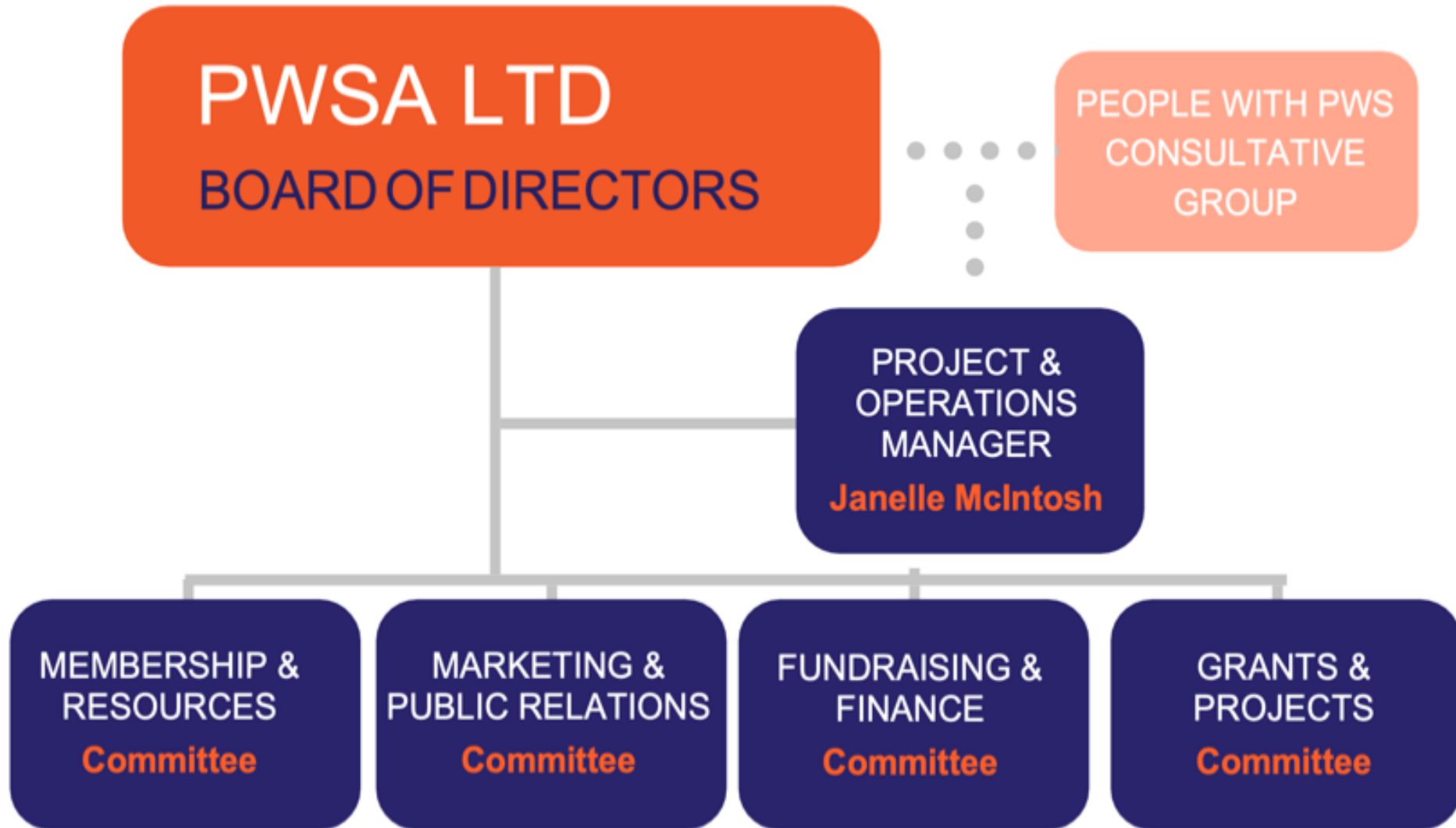
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# Structure



# Building organisational and individual capacity



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# NDIS funding for organisational capacity building

- Strategic and Business Plans
- Form Board, Committees and Sub-committees
- Establish policies and procedures
- Secure fundraising licenses and funding
- Employ Projects and Operations Manager
- Renew website, Facebook, Twitter, YouTube
- Undertake education and support activities



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# NDIS funding for individual capacity building

- Variation in average life expectancy by country
  - Knowledge, healthcare, support
- Fireside chat – regular Zoom meetings and/or Webinars
  - International speakers delivered into family homes
- Establish ‘Our Way of Life Australia’



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# UN Convention of the Rights of People with Disabilities

OWLA will be *their* group

- Their ideas
- Their opinions
- Their feedback
- Their chance to speak out and be heard
- Build their confidence

OWLA might

- Make some short films
- Set up chat groups
- Make new friends
- Build new skills
- Run their own conferences



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# Current and future plans



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# Education and Information

- **Diagnosis;** Improve the experience of Initial Diagnosis for people with PWS and their families
- **Clinical Management;** Support the development of high quality clinical and therapy services
- **Support for daily living;** Develop NDIS individual, family and organisation knowledge resource. Work closely with participants, families and stakeholders to educate and guide them with NDIS funding applications
- **Life-stage Transitions;** Develop a full set of 9 life-stage brochures and videos that educate and guide people living with PWS to transform lives



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# Resource Library

Convert PWSA UK brochures to short film

- Training videos made by people with PWS
- Training received alongside people with PWS
  - QR code, Google Docs, YouTube channel

Project ECHO (Extension of Community Healthcare Outcomes) [Project ECHO](#)



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# Advocacy and support for research

- **Mentoring;** Monitor and disseminate information on national and international research findings and progress towards outcomes
- **Fundraising;** Promote public awareness campaigns and exploring high impact fundraising opportunities
- **Teamwork and Promotion;** Promote and facilitate involvement in national and international PWS clinical trials
- **Advocacy;** Advocating for the PWS community at a national, state and local level to improve integration and supports in society



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# Connections and community

- **Linkages;** connecting the Australian PWS community with international and national support groups; encouraging international, national and local dialogue with individuals and groups via face-to-face and technology
- **Community;** Developing PWS community across Australia; Fostering a supportive, energetic and compassionate environment for people with PWS, families, carers and providers on an individual and system basis
- **Our Way of Life Australia;** Enabling a voice for people living with PWS by developing and fostering a Persons with PWS Advisory Group



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# Collaborations

- IPWSO and other National PWS Associations
- Other Australian Support Groups, with a particular focus on 15<sup>th</sup> chromosome
- Prader-Willi Research Foundation Australia
  - Develop a PWS clinic and Centre of Excellence at a major medical centre/university



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# Further Information

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