

United in HOPE

2025 PWS CONFERENCE



Promoting and fostering self advocacy

Workshop 26 June, 2025

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Advocacy Workshop – 4.30pm to 6.30pm

4.30pm to 4.45pm - Introduction

4.45pm to 5.00pm - Self Advocacy

5.00pm to 5.15pm - Brooke Fuller

5.15pm to 5.30pm - James Towle

5.30pm to 6.00pm - Group Advocacy

6.00pm to 6.30 pm - Case Study and Questions



Empowering People with PWS

The IPWSO People with PWS Committee

Who We Are

- International group supporting people with PWS to advocate for themselves
- Work with individuals to identify the best platforms for expression
- Promote meaningful participation in local communities, National Associations, and IPWSO

Why It Matters

- All people share fundamental needs:
 - **Belonging** – feeling safe and included
 - **Autonomy** – having control over one's life
 - **Purpose** – being respected and heard
- Disabilities like PWS can create barriers to fulfilling these needs



Digital booklet



www.ipwso.org/get-involved/guidance-on-pws-inclusive-meetings/



"WITH US"
NOT
"ABOUT US"

INCLUSIVE MEETINGS FOR PEOPLE
WITH PRADER-WILLI SYNDROME

When & Where?



Online

- Easier to access
- Shorter meetings work best (60 mins)
- Harder to focus for long periods



In-Person

- Easier to engage and focus
- Can run longer (2–6 hrs with breaks)



Timing & Routine

- Choose a time that suits most members
- Weekends may work, but check for conflicts
- Announce meeting times early
- Send reminders before each session
- Stick to a regular schedule for consistency



Creating Inclusive Spaces for People with PWS

Inclusive Engagement

- People with PWS need opportunities to:
 - Share ideas and feelings
 - Build confidence and advocacy skills
- Differences in social and cognitive abilities must be considered to ensure full participation

Community & Support

- Peer-to-peer connections improve mental health and well-being
- Safe, inclusive forums empower individuals

Our Goal

- Help improve or launch new PWS groups around the world with effective, inclusive approaches



Different types of advocacy

- 1. Self-Advocacy** This is when **you speak up for yourself**. You explain what you want, need, or how you feel, and make decisions about your own life.
- 2. Group Advocacy** This happens when **a group of people** come together to speak up about something that affects them all. Working as a team makes your voice stronger.



What is Self – Advocacy?

Self-advocacy means:

- speaking up for yourself,
- making your own decisions,
- taking control of your life.

It's about knowing your rights, expressing your needs and preferences, and standing up for what's important to you.

For people with disabilities, self-advocacy empowers you to have a say in decisions that affect your life—whether it's about the services you receive, your personal goals, or your community



Self Advocacy

COMMUNICATING YOUR

FEELINGS
AND
THOUGHTS

NEEDS

VIEWS
AND
INTERESTS

EXPRESSING YOUR

REPRESENTING

Using your voice

Ken



Self – Advocacy and Decision-Making Legislation

The UN Convention on the Rights of Persons with Disabilities (2005)

Ireland signed this UN Convention in 2007 and ratified it in 2018. The purpose of the Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Assisted Decision Making (Capacity) Act (2015)

The Act supports decision-making and maximises a person's capacity to make decisions. It applies to everyone and is relevant to all health and social care services. This Act will assist in complying with human-rights obligations contained in the Constitution of Ireland, the European Convention on Human Rights, and the United Nations Convention on the Rights of Persons with Disabilities.





PWSA | USA Speakers

Brooke Fuller and James Towle















<https://support4pws.com/jims-adult-journey-with-prader-willi-syndrome/>



How? Steps to setting up a group

Phase 1 - Planning

Phase 2 - Research and Recruitment

Phase 3 - Group Development

Phase 4 - Review and Measure Impact



Phase I - Planning

- Research and consult with existing advocacy groups
- Engage with key actors to build support
- Pre-empt potential negative reaction to the plan
 - Driving Forces vs Restraining Forces (Challenges)
- Consider risk and risk management
 - Lack of Funding – Loss of Key Staff – Lack of Access to Tech
- Present a developed business plan and agree a budget.



What are the potential challenges?

- PWS Personality
 - Theory of Mind – Executive Functioning – Rigid Thinking
- Interactional Issues
 - Mixed Levels of Comprehension
 - Risk of only choosing members based on ability to speak up
- Managing 'Supporters'
 - Parents / Board Members / Facilitator
 - Potential to act in their own interests



Phase 2 – Research and Recruitment

- Engage with the membership to establish a need for the group
 - Based on communication needs
- Develop a plan to meet that need.
 - Quantitative research
 - Focus groups
- Interviewing shortlisted candidates, the purpose of an interview is described as threefold:
 - 1.To collect information in order to predict how well an individual may perform in a role
 - 2.To provide candidates with full details of the role requirements
 - 3.To give each candidate a fair hearing



Phase 3 – Group Development

1. Education

- Individualised Learning
- Make it effective for each individual
- Provide opportunities to learn with a more skilled adult

2. Group Logistics

- Roles
 - Each has a role in group effectiveness
- Group Identity
 - Togetherness / Strong Bond
- Regular Interaction
- Facilitation
 - Skilled



Phase 4 – Review and Measure

Collect data over three stages, these are:

1. Before members join the group
2. Shortly after joining the group
3. Approximately three months after joining and ongoing.

Benefits from undertaking an evaluation :

- Provides a catalyst for change and improvement of services.
- Confirm that advocacy accomplishes positive outcomes and is an efficient use of resources.
- Attracts new members and volunteers



Why? The objectives of your group

- 🤝 Support a network of people with PWS
- 🌐 Reduce isolation and build connection
- 🗣️ Empower public and social speaking skills
- 👥 Create peer-to-peer support and community
- 💬 Offer a space where voices are heard
- 💡 Share ideas to raise awareness of PWS
- 🎓 Provide training in life and job skills
- 🌍 Explore roles in global PWS advocacy
- 🏛️ Involve people with PWS in your organisation's work
- 🎤 Learn firsthand what it's like to live with PWS
- 🌐 Collaborate with IPWSO's initiatives



Who? Support and inclusivity

Moderators

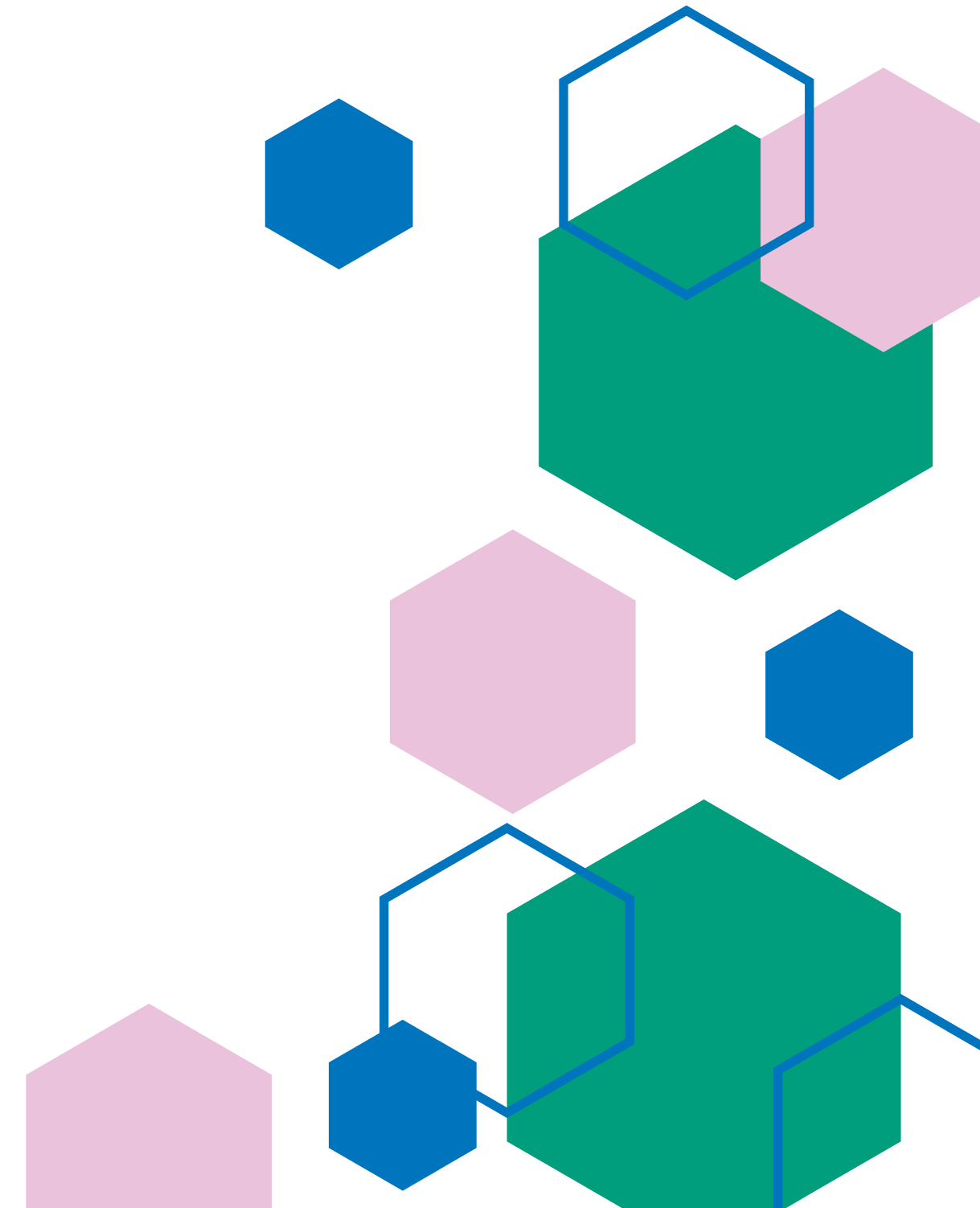
- Trained person should host meetings
- A co-host can help
- Less support needed as group grows

Communication

- Use simple, slow speech
- Allow time to respond

Inclusion Tips

- No eating/drinking
- Respect different abilities and comfort levels
- First names only for privacy
- Caregivers may attend
- Follow local safeguarding rules



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What? Meeting topics

Let the Group Decide

- Topics should come from participants
- Create a safe space for all views
- Respect different opinions — consensus isn't always possible

Popular Topics

- Mental health & wellbeing
- Friendships, relationships, sexuality
- Food security
- Education & employment
- Starting a business
- Exercise & fitness
- Mentoring & peer support
- Bullying prevention
- Independent travel
- Raising awareness about PWS

How? Tips for supporting participation

Start Simple

- Focus on topics that matter to people with PWS
- Let understanding of your organisation grow over time

Use Visual Aids

- PowerPoint boosts focus
- Support individuals to lead with their own ideas

Creative Sharing

- Record presentations (with permission)
- Use personal stories, projects, or pets to spark discussion

Make It Accessible

- Share agenda early
- Allow written input
- Caregivers can support communication



Restrictive Practices

David

PWS AND RESTRICTIVE PRACTICES

BY DAVID WEST - AUGUST 2024



Breakout groups - Case Study

Improving Educational Inclusion

Background:

Students with PWS typically experience challenges in college settings due to a lack of understanding and support for their needs.

This can affect their ability to participate fully in activities and social interactions.

Question:

As the facilitator of a national PWS advocacy group, what actions might you take to support the group to improve outcomes in educational settings for adults with PWS.





Thank you!

