



Ontario Prader-Willi Syndrome Association

***Supportive Housing for People with
PWS: Residential Options Working
Group Report***

**Ottawa Fall Mini Conference,
Family Gathering and AGM 2018
October 20, 2018**

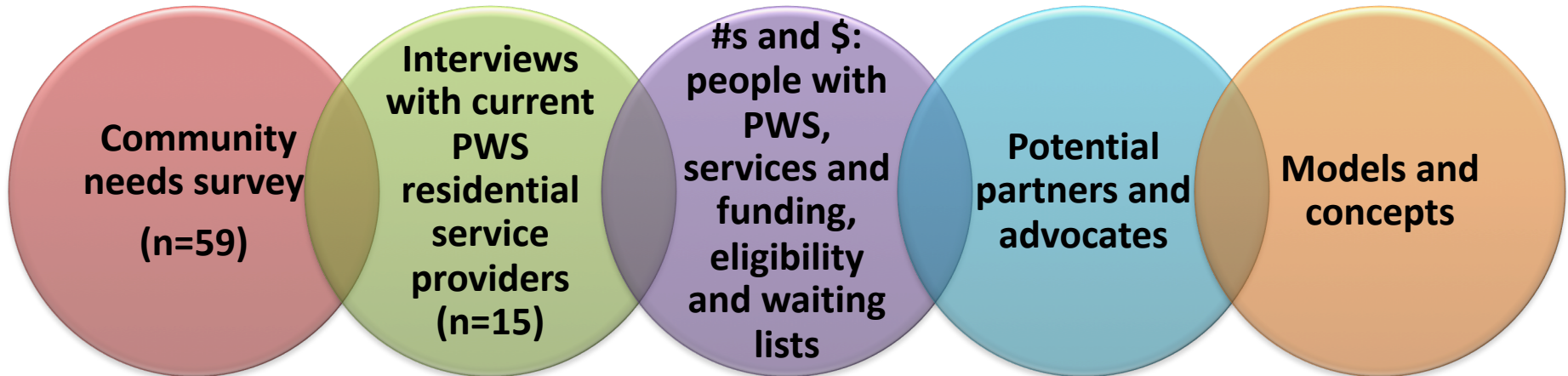
Our Mandate

Established 2016 to work with families, the provincial government, municipalities, service providers, funders, developers, advocates and others to address a critical need: **supportive housing for adults with PWS**

Working Group Participants

- Cathy Mallove (Chair)
- Jennifer Coens
- Zoe Silverberg
- Michelle Anderson
- Kathy Costa
- Carole Barron
- Marina and Geoff Clayton
- Stefania DeMaria
- Carole Elkhall
- Iris Gershon
- Deborah Haralovich
- Susan Johnson
- Tanya and Keegan Johnson
- Heather Ann Lowry
- Sue McMahan
- Anne Merklinger
- Erin Mlotek
- Gina Parigoris
- Patricia Parker
- John and Karen Pingree
- Rob Pividor
- Bonnie Porter
- Melonie Sampson
- Lisa Saul
- Holly Sine
- Ana Snjaric
- Joanne Stefanini
- Maha Surani
- Joanne Taylor
- Tessa Watson
- Dan Yashinsky

Our Approach



Institutionalization



Community Living



Individual, Self-Directed



What We Heard From Families

- Range of understanding of programs, options, and access to services
- Challenges in accessing PWS-appropriate adult services
- Limited resources – waitlists, crisis mentality
- Lack of awareness and understanding of unique PWS needs
- Geographic differences – urban/rural, different DSO offices, local programs/services
- Open to creative and innovative models
- @25 families identified as seeking housing within the next 10 years
- *Ready to work together!*

PWS Service Provider Interviews ...

- Success and challenges, in both PWS-only and non-PWS specific environments
- Food and behaviour management is essential
- Isolation and boredom can be an issue - lack of appropriate day programming, and some challenges to community integration (often related to food access)
- Need more training and resources for staff
- Open to creative and innovative models, and ...
- *Ready to work together!*

Conclusions

- Ontario's PWS community is highly engaged, organized and ready to work together
- Immediate opportunity to work with @25 families seeking housing within the next 10 years
- PWS is a complex condition often requiring multiple supports. Some issues are PWS-specific, but many are common in the developmental sector
- There is no one simple solution or housing model for people with PWS. Many opportunities for innovation
- Effective, collaborative solutions today will prevent/reduce significant issues and challenges in the future

What's Next

- 1) Engage target group of families and potential partners (service providers, developers, government) to
 - Understand individual and overall needs and opportunities
 - Educate families on available programs and services
 - Apply principles and learnings from other innovative projects
 - Identify and assess potential housing models, options and providers
 - Develop housing solutions to address needs
- 2) More data on current and potential funding and supports for PWS population
- 3) Develop longer-term roadmap and planning model for PWS families to support transition to adult services and housing

What Can You Do?

- Seek to understand and access programs, services, funding
- Apply early, make your voice heard
- Link with other families to share information and ideas
- Let us know what you're up to – ontariopws@gmail.com