



Ontario Prader-Willi Syndrome Association

Exploring Housing Options for Adults with PWS

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What We're Hearing – Community Survey

Stage of Planning

- 35% - would like to start planning but don't know where to start
- 19% - started planning but require more support
- 13% - have started a plan for the distant future
- 11% - are actively planning and have partners
- 7% - have a plan and are in the process of implementing the plan
- 9% - placed in a Group Home or waiting for a system response

Awareness of Resources

- 55% had no knowledge of common planning websites
- 37% knew about Partners for Planning
- 19% were aware of the DSO Housing Tool Kit
- 15% use social media to connect with planning resources
- 2% recommended other websites.

What We're Hearing – Community Survey

Main challenges to implementing a family's plan

- 86% - finding community partners and service providers
- 71% - funding
- 71% - housing
- 71% - trained support staff
- 29% - finding like-minded families

What is needed to help move forward

- 53% - PWS-specific planning workshops
- 48% - more resources/information to support planning
- 46% - local access to supportive housing
- 44% - community partnerships
- 39% - local family groups and networks
- 36% - access to local planner and facilitators







A Changing Landscape

- [Journey to Belonging: Choice and Inclusion](#)
- [Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008 \(SSPSI\)](#)
- [Ontario Autism Program](#)
- Multiple ministries (MCCSS, Housing, Education, Health) and jurisdictions (municipal, provincial, federal)
- [Developmental Services Ontario \(DSO\) “wait list”](#)
- [Developmental Services Housing Task Force](#)
- Evolving role for agencies/service providers
- Shift to individual, person-directed plans and funding

No One “Solution” – Many Models

- Group home: Both Public (through the DSO) and Private providers. Private providers can be expensive.
- Intentional community: On-site resources and supports are managed through a single provider. Buy as much or as little supports.
- Individual supports for independent living: Choice of space and supports. Can be time consuming and difficult to sustain.
- Clusters: One building or neighborhood and shared provider/resources. More sustainable than Individual.
- Aging in place at home
- *PWS-specific environment or not?*

Vision and CORE Goals

PWS considerations? Restricting access to food and money, dealing with challenging behaviours, supporting community participation and integration, and more

My housing vision



What needs to be in the home?

What do I need for a meaningful and productive day?

What does the surrounding community need to have?

What professional services do I need?



- Health/Fitness
- Daily Living
- Housing Living Arrangements
- Finances/Money
- Community Inclusion
- Support Circle

Getting Ready: An imperfect plan is better than no plan, together is better than alone

- Learning and preparing: Practice in Place concept
 - Creating your vision
 - [DSO Housing Toolkit](#)
 - DSO and other workshops
 - [Steps to Independence – Connectivity.ca](#)
 - Practice activities of daily living (dressing, hygiene, budgeting, chores)
 - Financial planning and sources of funding (e.g., ODSP, Passport, RDSP, Home and Community Care Services, housing subsidies ...)
 - Explore technologies
 - Network, network, network – service providers, other families, resources
- Key components to put in place: The 4 pillars of sustainability
 - Support from a planner and/or facilitator
 - Establishing a Microboard
 - Putting together a network of support
 - Working with a transfer agency

Group Dialogue/QA



Some Resources and Links

- [Partners for Planning](#) – programs, facilitators, family networks
- [Connectability](#)
- [DSO Housing Toolkit and Navigators](#)
- [Families for a Secure Future](#)
- [Lights \(Community Living Toronto\)](#)
- PWS social media and websites, e.g. [OPWSA Facebook](#) and [OPWSA Instagram](#), [Canadian PWS Families Facebook](#), [PWS USA](#), Foundation for Prader Willi Research
- [Housing Task Force: Facebook Page](#)
- Join as many mailing lists as you can ...
- Email cmallove@gmail.com or ontariopws@gmail.com to get on our mailing list for sharing ideas, resources, outreach and advocacy – we are stronger together!

