

Exploring Housing Options for Adults with PWS

Cathy Mallove, Patricia Parker, Kelly Casey
November 10, 2021

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
- <u>Services and Supports to Promote the Social Inclusion</u> 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

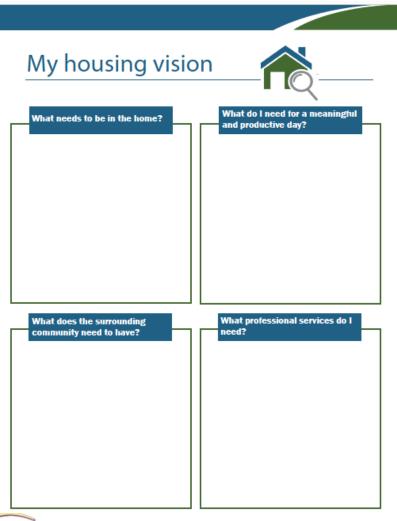


No One "Solution" - Many Models

- 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

- 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 Connectibility.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 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

Ontario Prader-Willi Syndrome Association



Some Resources and Links

- <u>Partners for Planning</u> 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. <u>OPWSA Facebook</u> and <u>OPWSA Instagram</u>, <u>Canadian PWS Families Facebook</u>, <u>PWS USA</u>, 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!

