



Ontario Prader-Willi Syndrome Association

Activating, Engaging and Leading: A Collaborative Path to Housing for People with PWS

November 30, 2022

Introduction

- OPWSA is actively seeking opportunities to collaborate and partner with families, developers, service providers and funders on proactive, creative housing solutions for adults with PWS
- PWS has historically been a “hard to serve population” in the developmental sector
- The DS sector is undergoing significant transformation from funding group home placements to individual funding
- **Chaos = opportunity! It’s time for our community to activate, engage and lead**



Current Housing Options

Ministry Funded <https://www.dsontario.ca/funded-services>

- Group Living Supports (“group homes”)
- Supported Independent Living (SIL)
- Host Family Home /Associate Living Support (LifeShare)

Supportive / Affordable Housing Programs

- Subsidized housing waitlists (by municipality)
- [Canada-Ontario Housing Benefit](#)

Self-Funded

- Living at Home
- Habitat for Humanity / Options for Homes
- Laneway / Garden Suites
- Secondary Suites

We need housing and related and supports for people with PWS in their communities – status quo is not sufficient or acceptable





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Update

Engaging our Community

- We are actively engaging families, service providers, developers and others on creative housing solutions
- Identified @30 families across Ontario seeking housing for their family member with PWS in the next 5-10 years; there are others in crisis or not known to us
- Spring 2021 workshop for 8 PWS families to develop individual Person Directed Plans for their adult children
- Community and service provider surveys on Adult Planning, Supports and Services
- Connecting with DSO Housing Navigators
- Engagement with Toronto DS Service Provider Committee
- “ThinkTank” co-sponsored by Vita and OPWSA to develop a prototype for creative housing solutions and related supports for people with PWS to be applied to 2-3 Ontario projects: one in the GTA (proposed condominium development at 87 Ethel Avenue, Toronto) and another to be identified



Vita-OPWSA “ThinkTank”

- As the developmental services sector implements *Journey to Belonging* and transforms to more individualized funding and supports, we need to better understand how to address the unique needs of the PWS population and to proactively plan for future success.
- We believe that innovations and learnings from past and current housing initiatives, best practices from PWS residential settings and service providers in Ontario and other jurisdictions, and proactive service provider and community engagement, education and planning can be applied to create positive, successful community-based solutions for our adults with PWS and other Ontarians with complex needs.
- We will develop a prototype for creative housing solutions and related supports for people with PWS to be applied to 1-2 Ontario projects: one in the GTA (proposed condominium development at 87 Ethel Avenue, Toronto) and another to be identified

ThinkTank - Objectives

Looking at how the right build, with the right technology and assisted living supports, might allow people with PWS to live their best life in an inclusive setting within their own community:

- Define potential medical and behavioural issues and associated support requirements (e.g., type of support and qualifications, training, staffing and support styles and models) to inform the support model
- Identify best practices, learnings and examples from housing and related support approaches for people with PWS and other complex conditions
- Explore and incorporate innovations such as technologies, on-demand services (e.g. off-site food preparation and delivery), inclusive communities and building design concepts
- Develop applicable standards and approaches to building and space design
- Identify partnerships to maximize various funding private/public opportunities and sources, including ways to address cross-sector public funding streams and supports (e.g., Ontario MCCSS, Ministry of Health/Home and Community Care, Ministry of Housing; federal and municipal housing initiatives)
- Clarify roles and accountabilities for various parties such as service providers, funders, OPWSA and other associations, families, etc.

ThinkTank – Planning Committee

- Piratheep Santhanarasa, Director of Transitional, Mental Health & Support Services, Vita Community Living Services and Mens Sana Families for Mental Health (co-sponsor)
- Cathy Mallove, Chair, OPWSA Residential Options Committee (co-sponsor)
- Bryan Keshen, CEO, Reena
- Art Mathews, Executive Director, The Salvation Army – London Village and Broadview Village Ministry Units
- Tullio Orlando, CEO, Montage Support Services
- Joe Passaretti, Senior Director, Operations, Community Living Toronto
- Jane Casson, Co-lead, SHEDD Project, University of Toronto
- Kelly Casey, KC Professional Solutions
- Luigi Iacobelli, President, IKORE
- Facilitator: David Carter-Whitney, DCW Consulting

Proposed Framework

- Support, staffing and service models
- Building environment, design, and standards
- Funding
- Partnerships
- Technology and other innovations
- Community integration and inclusion
- Health and safety considerations
- Service provider selection, roles and responsibilities
- Tenant/participant criteria, eligibility, assessment and selection processes
- Human rights considerations – e.g. balancing restrictions / risks

Inputs / Engagement

- People with PWS and families/caregivers
- Agency leadership and supervisors, front-line and clinical staff and related supports
- DSO housing navigators
- People who have experience with designing housing for people with complex needs
- Researchers and subject matter experts on housing for people with complex needs
- Government - MCCSS/Housing/Health
- Technology companies to support innovation
- Developers
- Partners for Planning and Microboards Ontario



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What Can Parents Do? Activate!

**Get Informed, Connect / Network and
Create Your Vision and Plan**

Learn and Stay Informed

- **Developmental Services Ontario**
 - Register for services <https://www.dsontario.ca/>
 - Reach out and introduce your family to your DSO Housing Navigator <https://www.dsontario.ca/find-your-dso>
 - Sign up for DSO updates and webinars <https://bit.ly/2JQjxhg>
 - Follow DSO on Facebook <https://www.facebook.com/dsontario>
 - Check out the DSO Housing Toolkit [DSO Housing Toolkit](#)
- **Steps to Independence Guidebook** <https://connectability.ca/2014/06/24/steps-to-independence-2/>
- **P4P Planning Network** <https://www.planningnetwork.ca/>
- **Plan Institute Safe and Secure Guidebook** <https://planinstitute.ca/learning-centre/publications/safe-and-secure/>



Start to Develop Your Vision and Plan

- Join a DSO or P4P Housing Workshop / Webinar
- Start having the conversation
- Develop your vision and [Person Directed Plan](#)
- Build a support circle (with help from an Independent Facilitator <https://www.planningnetwork.ca/get-connected/facilitators>)

The Support Sequence Creating Your Housing and Support Plan

*Inspired by Helen Sanderson and
Associates Just Enough Supports*



Planning and Preparing

- **Financial Planning and Funding**

- ODSP <https://www.ontario.ca/page/ontario-disability-support-program>
- Passport Funding (through local DSO). Update your priority.
- RDSP <https://www.canada.ca/en/revenue-agency/services/tax/individuals/topics/registered-disability-savings-plan-rdsp.html>
- Disability Tax Credit <https://www.canada.ca/en/revenue-agency/services/tax/individuals/segments/tax-credits-deductions-persons-disabilities/disability-tax-credit.html>
- Home and Community Care Supports <https://www.ontario.ca/page/home-community-care>

- **Estate Planning**

- Inspiring Possibilities Guidebook <https://communitylivingontario.ca/resources/>
- Consult a lawyer familiar with sheltered trusts, capacity for decision making, or other legal items (Pooran Law <https://pooranlaw.com/> , Kenneth Pope Law <https://kpopelaw.com/>, Special Needs Planning Group)



Microboards Ontario <https://www.microboardsontario.com/>

Build Your Network – We are Stronger Together

- **Subscribe to Newsletters – examples:**
 - Community Living Toronto <https://cltoronto.ca/>
 - Lights <https://www.lights.to/>
 - Families for a Secure Future <https://www.familiesforasecurefuture.ca/>
 - Microboards Ontario <https://www.microboardsontario.com/>
- **Connect to PWS families and communities**
 - OPWSA, FPWR, International Prader Willi Syndrome Association (<https://www.fpwr.org/>, <https://www.fpwr.ca/>), [IPWSO](#), [Canadian PWS Families](#)
 - PWSA USA <https://www.pwsausa.org/>
 - Conferences, webinars, families
- **Other Local Networks**
 - Special Olympics
 - School / Programs
 - Local and faith-based communities
 - Local Parent Networks- ask your Housing Navigators



Some interesting resources / studies

- Community Living Ontario [Innovations in Housing for People who have an Intellectual Disability: Spotlighting nine models that support greater independence and choice](#)
- Ontario Developmental Services Housing Task Force: [Report on 18 Innovative Housing Projects](#)
- Individualized Funding Coalition for Ontario: [Now Is The Time: Key Principles and Core Elements to Bring About Effective Individualized Funding Mechanisms](#)
- Ideas and Inspiration for PWS Adult Living: <https://www.sunrisepws.org/>





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What We Can Do Together: Awareness And Advocacy

Change is Underway

- Ontario Government: [Journey to Belonging: Choice and Inclusion](#)
- [Individualized Funding Coalition of Ontario](#) : [Now Is The Time Report](#)
- OPWSA will be actively building a case and advocating for funding for 2-3 pilots across Ontario



Energize and Advocate

- Introduce yourself to your local DSO housing navigators
- Identify agencies/service providers in your area for OPWSA introduction
- Identify potential like-minded families to partner with
- Identify potential housing opportunities – developers, homes, apartments
- Government advocacy – do you have municipal and provincial political connections



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Your Turn

Visioning - Your hopes and dreams

When thinking about a home for your family member with PWS, what matters most to you ?

Visioning – Your hopes and dreams

Where would they live? (City or DSO region)

Visioning – Your hopes and dreams

Who do you see them living with?

1. Family with support
2. Friends and shared support
3. Matched roommates with shared support
4. Alone with supports at designated times
5. Other

Visioning – Your hopes and dreams

What do you see them doing during the day?

1. Work
2. Volunteer
3. Programs
4. Other?

Visioning – Your hopes and dreams

Who would support them ...

... during the Day? Evening? Overnight?

1. Family
2. Designated Support Staff
3. Shared Support Staff
4. Volunteer/Friends
5. Technology
6. Other

Visioning – Your hopes and dreams

What would the staffing/support model look like:

1. Live in
2. Home share
3. Shift work
4. Cluster model
5. Other: Family, technology, other

Where are you in the planning process?

1. Have not started
2. Have a vision
3. Have started taking steps
4. Have a circle and team working with me and my loved one and
5. Have a plan and have moved out but am concerned about sustainability.

Forecasting the challenges

- What are some of the challenges that you foresee that you might need help with?
- What could help you get started, move forward

Moving ahead ... together

Dream big:
How can OPWSA support you?



Keep in Touch – Share and Care

- Cathy Mallove, Chair, OPWSA Residential Committee, cmallove@gmail.com, 416-822-5169
- Jennifer Coens, Executive Director, OPWSA, ontariopws@gmail.com, 416-481-8657

