

**Prader Willi Syndrome
Survey of Central West Region Service Providers
March 20, 2006 (update Oct. 2006)**

Background:

In 2005/06 Central West Region of the Ontario Ministry of Children and Youth Services funded an Innovation Project proposed by Community Living Dufferin to develop a Network for service providers supporting individuals with Prader Willi Syndrome. The purpose of the Network is to promote collaboration among agencies in the exchange of information concerning resources, best practices, research opportunities, and educational needs.

As a first step, a link to a web-based survey was E-mailed to 76 children's services and developmental services in Central West Region, plus three service resolution facilitators. The purpose of the survey was to assess needs and conduct an inventory of services. The survey also requested information about individuals with PWS currently being supported by these agencies.

Profile of responding agencies:

Responses were received from 39 agencies, as follows:

- 26 out of 40 developmental services responded, plus five additional organizations
- 8 out of 33 children's services responded, plus one by Email and one declined

These 39 agencies were from the following communities in Central West Region:

- Dufferin 3
- Halton 8
- Peel 5
- Waterloo 9
- Wellington 7
- Serving multiple communities 7

Services provided by these agencies cross the wide spectrum of developmental and children's services.

Staff qualifications and training also represent the broad spectrum. Twelve agencies provide or access some training resources for staff who work with individuals with PWS.

In response to a question about whether the agency provides support to individuals with PWS, 47 respondents answered, as follows*:

- Yes 19
- Not currently 16
- Never, and do not expect to 13

*Note: this includes duplicate answers from some agencies

Prader Willi Network:

Respondents were asked about what benefits would motivate them to participate in a Prader Willi Network. Respondents could check as many answers as wanted. The responses in order of frequency were:

- Access to in-depth information about aspects of PWS 27
- Resources for program planning 26
- Information about best practices 25
- Behaviour management 24
- Training and staff development resources, events 24
- Access to basic information about PWS 23
- Access to new research about PWS 22
- Nutritional management 21
- Resource directory of PWS service providers in S. Ont 21
- Medical aspects 19
- Physical fitness 16
- Resources for residential facilities 15
- Peer support for front line workers 13

Eight respondents had no interest in participating in a PW Network (and a further nine skipped this question).

Nineteen agencies are interested in being listed in a PWS directory for Central West Region.

Clients with PWS

Twenty agencies reported supporting individuals with PWS. Client identification codes and profiles were requested, in order to determine how many separate individuals are being supported. Due to confidentiality concerns of some agencies, profiles were available for only 47 of the 52 individuals.

Analysis of the 47 client profiles is as follows (Note: answers were not provided in every category for every client, particularly for clients under the age of 4):

Gender	Age	Level of disability due to PWS	Level of Behavioural supports required	Place of residence
18 males	12 under 5 yrs	7 Mild	4 Minimal	19 Family
24 females	12 age 5 – 19	12 Moderate	5-7 Moderate	11 Group Home
	21 age 20 – 44	9 Complex	4 Considerable	1 SIL
	2 age 45, older		4 Extensive	1 Other

Eight of the 47 clients are Dually Diagnosed, with four others noted as being too young for a diagnosis.

Two of the clients have received hormone treatment, with a third to start soon. Two (and possibly a third) clients have been treated at the PW Clinic at the Pittsburgh Rehabilitation Institute.

Distribution of individuals with PWS across Central West Region

The incidence of PWS is believed to be between 1:12,000 and 1:15,000 births. When applied to the total population in Central West Region (2,041,000 in 2001), this would indicate the probable number of individuals with PWS as being between 135 to 170. There were no individuals over age 46 identified in the survey. So, focusing only on the age ranges of the identified individuals, the proportionate number of individuals with PWS would be 111 (using the more conservative incidence of 1:15,000). This survey identified 52 individuals in Central West Region, or about 47% of the lower incidence.

However, the identification rates were not evenly spread across age ranges. Table 1 illustrates the number of identified individuals in each age range, compared to the predicted number, based on the incidence of 1:15,000 applied to 2001 census numbers.

Ages	Total ID's	Proportionate rep across CWR
0 - 4	12	9
5 to 14	8	20
15 to 19	4	10
20 to 24	7	9
25 to 44	14	44
45 to 54	2	19
ID no age	5	
Totals	52	111

Table 1: Ages of individuals with PWS identified in CWR Survey

Similarly, the identification rates varied across the five communities which comprise Central West Region.

	Duf ID	Halton ID	Peel ID	Erino ID	Wat ID	Wel ID
0 - 4			8	3	1	
5 to 14	1		6		1	
15 to 19		1	2	1		
20 to 24	2		1		3	1
25 to 44	1	6	4		3	
45 to 54		1				1
ID with age	4	8	21	4	8	2
ID no age			2		1	2
total IDs	4	8	23	4	9	4
Predicted incidence	4	20	55		23	10
1:15,000						

Table 2: Individuals identified with PWS in CWR communities

Note: "Erino" is Erinoak, the children's treatment centre which serves Dufferin, Peel, Halton. Community of residence was not provided for 4 clients, who may live in any of the three communities.

Table 2 displays the age breakdown of individuals in each of the five communities. The numbers of adults in Halton and Dufferin include individuals with PWS who may have moved to one of the two PWS residential programs in those communities.

Based on Table 1, it appears providers in CWR are doing an exemplary job of early identification. But Table 2 shows that all but one of the identified children, age 0 to 4, reside in Peel (including the clients of Erinoak).

Observations:

The Survey was effective in identifying which agencies are supporting individuals with PWS and what kinds of services they provide. While the overall response rate was 50%, all the key agencies involved in developmental services in all five communities responded. With only a couple of exceptions, it does not appear that respondents shared the Survey with other, non-funded service providers. A future task could involve widening the “net” to include a broader range of services in the PW Network.

The Survey identified what benefits should be addressed in the creation of a Prader Willi Network. There is strong interest in having a Resource Directory of PWS service providers in Southern Ontario.

The client profiles present a description, though incomplete, of the scope of the present and future need for supports for individuals with PWS. As research into PWS demonstrates the positive impact of early interventions, it becomes more urgent to identify the presence of PWS soon after birth. As children make the transition into school, and later, into adulthood, other services will be needed.

Consideration of the results raises questions for further investigation:

- Why are there such disparities in the patterns of identification? Are there similar disparities found in other Regions?
- What can we do to improve the rates of identification and early intervention?
- How can we learn more about the profiles of those who are not currently receiving any supports and are not members of OPWSA?
- How can we use our findings to plan more effectively for future needs?

Additional effort can be invested in compiling more complete data, in order to become useful for planning purposes by both providers and the ministry.

Author: Barbara Horvath, PWS Network Project Manager, for
PWS Network Steering Committee