

**Central East Region Service Providers  
Prader Willi Syndrome Survey  
May – November 2007  
Final Report** (January 2008)



**Background:**

In the spring of 2007, the Toronto Network for Specialized Care supported a research project about the needs and available supports for individuals with Prader Willi Syndrome. This was an expansion of research conducted by the PWS Network in 2006 in Central West Region of the Ontario Ministry of Children and Youth Services/Ministry of Community and Social Services.

As a first step, a link to a web-based survey was e-mailed to 47 developmental services in Central East Region. Other service providers, such as service resolution facilitators and SSAH were contacted in a second round of outreach. The purpose of the survey was to assess service providers' 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:**

The research project encompassed information from 23 agencies, plus the Ontario Prader Willi Syndrome Association and the Special Services at Home program of the Ministry of Community and Social Services.

These 23 agencies were from the following communities in Central East Region:

- Durham 8
- Northumberland 1
- Peterborough 1
- Simcoe 6
- York 2
- Serving multiple communities 5  
(including Haliburton and Kawartha)

Services provided by these agencies cross the wide spectrum of developmental and children's services. Staff qualifications and training also represent the broad spectrum.

In response to a question about whether the agency provides support to individuals with PWS, 19 respondents answered, as follows:

- 8 Yes
- 6 Not currently
- 5 Never, and do not expect to

Of the 19 agencies which completed the web-based survey, four provide or access some specialized training resources for staff who work with individuals with PWS.

## Prader Willi Network:

Respondents were asked about what benefits would motivate them to participate in the Prader Willi Syndrome Network. Respondents could check as many answers as wanted.

The responses in order of frequency were:

- 1 Training and staff development resources, events
- 2 Information about best practices
- 3 Nutritional management
- 3 Medical aspects
- 4 Access to basic information about PWS
- 4 Access to in-depth information about aspects of PWS
- 4 Behaviour management
- 5 Access to new research about PWS

All respondents to this question had an interest in participating in the PWS Network (five respondents skipped this question). If resources can be found to compile a directory of agencies supporting individuals with PWS, eight agencies are interested in being included.

## Clients with PWS

The results of the client survey are incomplete, often due to agency constraints regarding confidentiality and consent. As a result, client profiles were provided by 9 organizations, while 5 other organizations did not provide profiles for the individuals they serve. This prevented the researcher from ensuring those clients were not already in the database. However, sufficient information was obtained to confirm 43 individuals with PWS residing in Central East Region.

Analysis of the 43 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 Behavioural supports required	Place of residence
21 males	4 under 5 yrs	1 Minimal	
22 females	19 age 5 – 19	3 Moderate	11 Group Home
	14 age 20 – 44	5 Considerable	1 SIL
	6 age 45, older	3 Extensive	

Respondents reported that two of the clients have received growth hormone treatment or but none have received treatment at the PWS Clinic at the Pittsburgh Rehabilitation Institute.

## Distribution of individuals with PWS across Central East Region

The incidence of PWS is believed to be between 1:12,000 and 1:15,000 births. When the higher ratio is applied to the total population in Central East Region (2,180,900 in 2006), this would indicate the probable number of individuals with PWS as being

between 145 and 181. But when the ratio is applied only to the age ranges of the identified individuals, the proportionate number of individuals with PWS is 127 (using the more conservative incidence of 1:15,000). This research project identified 43 individuals in Central East Region, or about 34% of the lower incidence.

However, the identification rates were not evenly spread across age ranges. The table below 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 2006 census numbers.

Ages	Total ID's	Proportionate rep across CER
0 - 4	4	8
5 to 14	11	20
15 to 19	8	11
20 to 24	2	9
25 to 44	12	40
45 to 54	4	23
55 - 64	2	16
<b>Totals</b>	43	127

**Ages of individuals with PWS identified in CER Survey**

**Observations:**

The Survey was effective in identifying which agencies are supporting individuals with PWS and what kinds of services they provide. Almost all the key agencies involved in developmental services in Central East Region responded.

The Survey identified what benefits should be addressed by the Prader Willi Network. There is interest in Central East Region in having a Resource Directory of PWS service providers.

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 a child is born. 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:

- What can we do to improve the rates of identification and early intervention?
- How can the specific needs of individuals with PWS be effectively communicated to the ministry and service providers?
- How can these findings be used to plan more effectively for future needs?
- How can the system ensure that service providers have the resources they require to deliver good services to individuals with PWS?

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

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