

## Caregiver Delegate Role Description

A Caregiver Delegate Role involves the following responsibilities:

1. The Caregiver Delegate appointed will function as a point person for communication between the Professional Provider Caregiver Board (PPCB) and the professional providers and caregivers in their country;
2. To collaborate with the IPWSO Parent and Professional Delegates in their country around services available for PWS
3. To obtain information (when possible and with appropriate permission) about the demographics of the people with PWS served in their country and send this back to the PPCB, including:
  - ages of people with PWS in the country
  - level of functioning
  - services available for people with PWS in the country for inclusion on the World Map
  - what kind of living situations they have, e.g., living at home, living with a residential provider, or living in some other option like shared living with a family NOT their own?
  - what kind of work they have
  - what kind of medical support they have, i.e., is there a multidisciplinary team for PWS?
  - what kind of education is available for the children and young adults with PWS?
4. To identify concerns about residential living, work or other topics pertinent to PWS in their country, and to bring this information to the PPCB for consideration. (This information may become topics for future Caregiver Conferences, and the Caregiver Delegates will have an opportunity to take an active role in these conferences)
5. To describe successful projects or programs that could become models for other countries to emulate (We want to focus on positive outcomes as well as problems!);
6. To identify parents, professionals or caregivers from their country who have been instrumental in changing the lives of people with PWS (someone who shares values, vision and determination)
7. To attend the IPWSO meetings and Caregivers Conferences so Caregiver Delegates will have the opportunity to meet others and decide for themselves some sense of direction for their group under the leadership of the PPCB. (Ultimately, these caregiver delegates will have the potential to be nominated and elected to become the successors of the current PPCB members)
8. To access resources in IPWSO for translation of information into their country's language and to make this information available and understandable for all who need it.