

The role of national PWS Associations in improving the lives of people with PWS and their families

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Setting the scene

- PWS associations operate as part of “Civil Society”
- PWS associations can be considered Patient Advocacy Groups, Rare Disease Support Groups or various other forms of non-profit associations
- 41 national PWS associations form IPWSO’s current membership



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Why do we form PWS associations?

“Together we can do the world for our PWS kids and adult people much better”

Marina Verbiskaya,

Prader-Willi Charitable Foundation Russia

“[Prader-Willi France is] a second family, we are connected “genetically” too, but otherwise, and we feel understood and supported”

Dagmar Kiderlen, Prader-Willi France



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Finding our tribe

- A Special Needs Parent Fell in a Hole
- Family member: What hole?
- Boss: Oh that's a shame. You can take the day off.
- Doctor: Can you keep a diary of your experiences in the hole?
- DBHDD: We will assess the size of the hole. However, it may take up to 18 months.
- Local authority: Sorry we don't have enough money for a ladder.
- Charity: Here's a form. Fill it in to apply to get on the waiting list for a ladder.
- Another special needs parent: I'm here! I'm coming down there with you. I've been here before. I know how to get out and I won't let you do it alone.



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Originally shared as "An autism parent fell in a hole" on the Special Parents' Handbook Facebook page.

Roles of civil society organisations*

- Service role
- Innovation role
- Advocacy role
- Expressive and leadership development role
- Community-building and democratization role



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* Salamon, Lester M., Leslie C. Hems, and Kathryn Chinnock. "The Nonprofit Sector: For What and for Whom?" Working Papers of the Johns Hopkins Comparative Nonprofit Sector Project, no. 37. Baltimore: The Johns Hopkins Center for Civil Society Studies, 2000.

Combining and changing roles

“...we can provide training that helps parents ...”

“Our hopes are... to be able to count on the support of government to access free treatment for patients with PWS...”

... to be able to help more families in the country by creating a feeling of unity and support.”

Gabriela Erazo,

Prader-Willi Ecuador Foundation



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Key concepts

Legitimacy

“the right to be and do something in society – a sense that an organisation is lawful, admissible and justified in its chosen course of action”*

Accountability

“the process by which an NGO holds itself openly responsible for what it believes, what it does and what it does not do in a way that shows it involving all concerned parties and actively responding to what it learns”**

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* Edwards, M. 2000. NGO rights and responsibilities: a new deal for global governance. London: The Foreign Policy Centre in Association with NCVO

**Slim, H. 2002. By what authority? The legitimacy and accountability of non-governmental organizations. Geneva: International Council on Human Rights Policy..



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Some challenges

- Planning
- Defining needs
- Prioritising work
- Developing a shared understanding of PWS
- Resources
- Sustainability and keeping the community together
- Measuring impact
- Inequality - "...the children we have lost over the years have been [ones whose] parents have not kept in touch with us" Shikha Metharamani, Indian PWSA



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Thank you.

