

Session 4: IPWSO ECHO Leadership Programme – February 2021

Post Session Report

“This talk has to be presented and discussed with every parent, kindergarten school, and caregiver who has a person with PWS in their care!”

High praise indeed from a participant at Larry Genstil’s presentation on “The child with PWS in the school”

In this session Larry provides a comprehensive overview of how to create a highly structured and consistent school environment to best fit the needs of the child with PWS.

Larry addresses issues such as:

- inclusion and social acceptance
- managing the physical setting
- food security
- preparing the classroom and activities
- visual versus auditory learning
- ongoing training for teachers and all staff within the school setting
- building self-esteem, reinforcing good behaviours and academic activities in which the child with PWS excels
- social skills development and ways to promote empathy
- strategies to manage rigidity, inflexibility, and challenging behaviours.

The importance of creating a positive relationship between the parent and the school is highlighted as key to promoting effective advocacy and inclusion.

The discussions that followed from this session gave us some useful materials and tips.

Tips

- Invite the teachers to PWS family meetings
- Encourage parents to speak out at meetings
- Consider including a psychologist on your PWS Association - they can visit schools and present at teacher meetings
- Explore Montessori education
- Encourage the child with PWS to present to their peers about who they are and how PWS affects them
- Ask to have a session on PWS included in the teacher training curriculum
- Profile PWS on the government websites in your country
- Has your country signed up the UN Convention on the Rights of the Child and on the Rights of People with Disabilities?

<https://www.unicef.org/child-rights-convention/what-is-the-convention>
<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>

- Investigate the rights to education for children in your country. What are their rights to additional support and what provisions are made if the school cannot provide the necessary support?
- Whilst the law might provide some protections, parents and advocates are key. Work with the school and help them stay within the law. The school should demonstrate that they are taking all reasonable steps. Particular attention should be paid around the transition period from post-primary school to ensure that schools continue to invest effort, even though the child will soon be leaving them.
- Check out YouTube for relaxation videos.

Useful Links:

IPWSO Website: <https://ipwso.org/information-for-families/education-and-transition/>

Elisabeth Dykens's Presentation - Food is Poisonousness Drug that Kills Me".

<https://ipwso.org/how-we-can-help/project-echo/about-ipwso-leadership-echo/>

Ontario Teachers' Federation: - teachers gateway to special education.

<http://www.teachspeced.ca/prader-willi-syndrome>

PWSA UK: <https://www.pwsa.co.uk/education-and-skills>

WSEAT - The Wyatt Special Education Advocacy Training - The PWS Community One-Stop Shop for Special Advocacy Information

<https://www.pwsausa.org/resources/wseat/>

Prader-Willi Association Spain:

http://www.aespw.org/export/sites/aespw/.content/Documentos/ENSENANZA-APRENDIZAJE-PW_web-2.pdf

<http://www.aespw.org/export/sites/aespw/.content/Documentos/buenaspracticasaulas.pdf>

Il Puzzle di Matteo: La sindrome di Prader Willi raccontata ai bambini (Uniti per Crescere Vol. 1) (Italian Edition) Kindle Edition

This publication tells the story of Matteo, a child with PWS, and how the children in his class come to understand him, a little at a time, like piecing together a puzzle. The book presents the syndrome in a clear and sensitive way and is a useful resource for teachers and parents.

Thank you to everyone who attended this session, gave advice, and directed us to these valuable resources!

Ends