

6th International Prader-Willi Syndrome Caregivers' Conference

21-23 May 2024, Berlin, Germany

„People with PWS give themselves a voice“

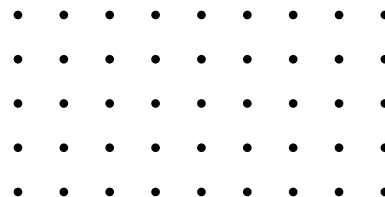
- Requirements and Solutions -

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(Metalworker)



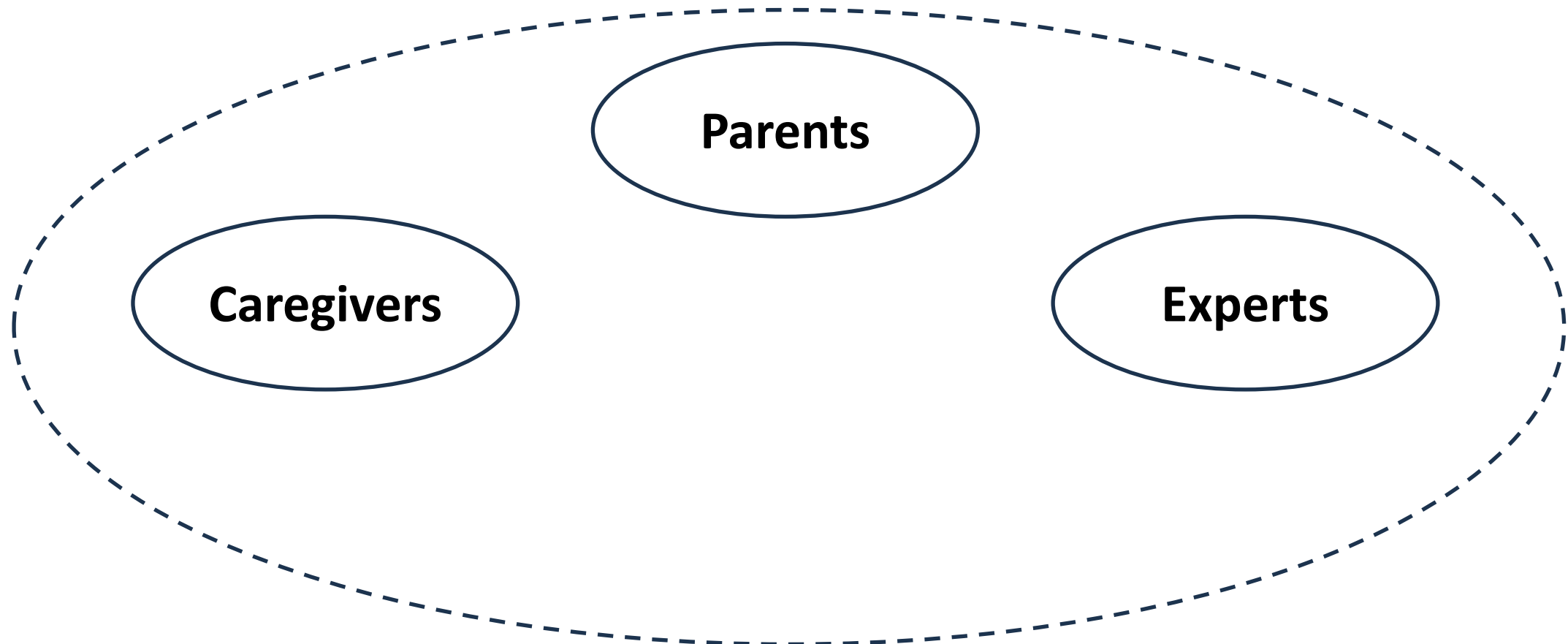
#PWSCARE24



The aim of our group is:

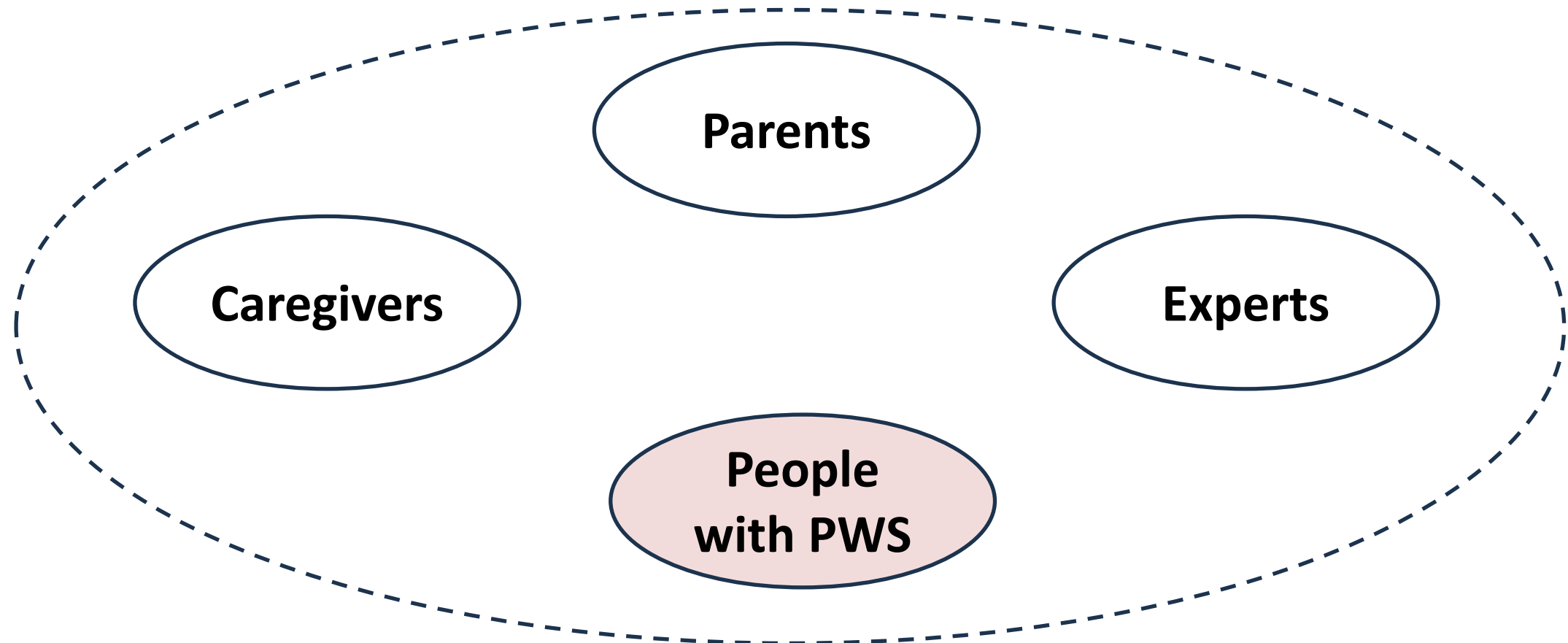
- To represent ourselves
- To represent ourselves in the International Prader-Willi-Syndrome Organisation

International Prader-Willi-Syndrome Organisation (IPWSO) Today



International Prader-Willi-Syndrome Organisation (IPWSO)

Future



„ People with PWS give themselves a voice“ – Group Löhne, Germany

We started in September 2023

Four meetings

Three more meetings planned for 2024

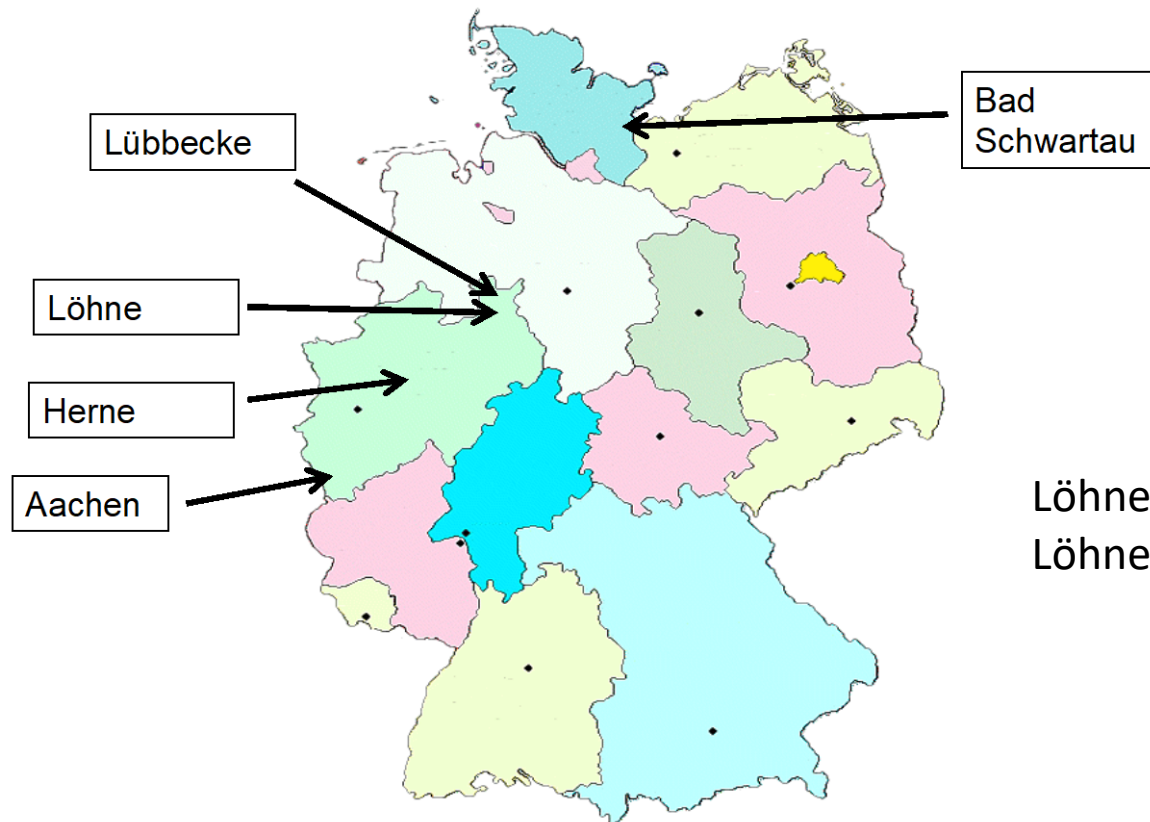
**„ People with PWS give themselves a voice“ –
Group Löhne, Germany**

We are 13 to 14 people in the meetings

Young Adults (20 – 45 years old)

We come from different regions in Germany

3. Treffen
„Menschen mit Prader-Willi-Syndrom eine Stimme geben“



Löhne – Bad Schwartau = 300km
Löhne – Aachen = 300km

How do we work in the group?

- As a whole group together
- In small groups (break-out-groups)
- We make minutes from each meeting
- We currently use an assistant in the meetings (Norbert). In the future we will do more and more alone

What are our topics?

1. Leisure time,
2. Work,
3. Living
4. Partnerships and relationships,
5. Equal rights

How do we work at each topic?

- We collect requirements
- We collect proposals for solutions

Example from our first topic: „Leisure time“

Requirement:

“It must be ensured that the employees who are necessary to support vacations - are paid”

Solutions:

- The clients pay themselves if they have enough money.
- Parents or relatives pay if they have enough money and have been included in the planning
- The state or the government pays
- The national PWS association can and should be co-funders
- The International PWS Organisation can and should co-funders

The people or institutions listed can pay it alone or together. “Everyone can give something.”

Requirement:

“There should be more leisure activities for people with PWS.

Solutions:

- Holidays in your own country or abroad with the support of parents or carers
- Sports activities: horse riding, swimming,...
- Have the opportunity to keep animals in the living area.
- Hiking, choosing paths that are possible for everyone to walk. Fast or slow walking must be possible.
- Holiday offers for couples

Requirement:

“When it comes to holiday offers, providers must be informed about people with PWS.

Solutions: what they must know

- People with PWS can be unsteady because they have a poor sense of balance. Therefore, accessibility is important.
- People with PWS have less muscle. That's why it's helpful if the area is at ground level. An elevator is helpful. People with PWS get tired more quickly.
- Some people with PWS cannot handle freely available foods. In such cases, no food should be left lying around.
- Staff trained in PWS can support people with PWS. Untrained people don't know what to do or how to help.

Requirement:

“When it comes to holiday offers, providers must be informed about people with PWS.

Solutions: what must they know

- Some people with PWS have difficulty concentrating, which is why they are more easily distracted. For example, when they want to go shopping, they may get distracted by other things and forget to shop.

It was clearly emphasized by all participants that people with PWS are very different.

Requirement:

“People with PWS also have to learn to make changes to their own food-management - even in their leisure time or on vacation.”

Solutions

„What can we do by ourselves?“:

- Use calorie tables to calculate calories, alone or with the help of employees
- Use the food pyramid
- Create your own meal plan and then have it checked by employees
- Have self-discipline. Whatever you can do yourself, you should do it yourself.
- Include handling of food as a goal in the support plan, with the specific aim of: greater self-control in food preparation and eating; E.g.: Prepare food yourself before trips and then take it with you on the trip.
- Attend training courses on nutrition. Goal: get to know food; understand what effect each food has on the body; How does the body process different foods?
- Attend the training courses together with other people with PWS.
- Use employees or parents for support: ask if you are unsure
- Check, discuss and, if necessary, change the nutritional concept in the living group or at work.

Solutions

“What additional support do we need?”

- Nutritionist advice, if necessary, specifically for people with PWS
- Plan holiday destinations with the help of brochures and preliminary information about the hotel with regard to the food and drinks on offer. Speak to the accommodation in advance to see whether changes are possible.
- After your holiday, evaluate whether you would use this accommodation again or are looking for a new holiday destination, also with regard to the food and drink offerings in the hotel.
- Exchange with other people with PWS, for example: in the residential group, online, calling, self-help group

Solutions

„Who can support us?“

- Employees in housing and at work
- Parents and family members
- Experts, medical doctors, nutritionists
- People with PWS help themselves

Next steps in our group

Work on requirements and solutions for the other topics:

- Partnership and relationship,
- Work,
- Living
- Equal rights

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- Partnership and relationship,
- Work,
- Living
- Equal rights

Next steps in our group

- Sending recommendations and solutions to IPWSO
- Online meeting with IPWSO in November 2024
- Writing an article about the group in the newsletter of the German PWS association

And remember, our big goal is:

International Prader-Willi-Syndrome Organisation (IPWSO)

Future

