

PWS-Institut-Deutschland gGmbH



Basic philosophy of taking care of people with PWS

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This philosophy is the result of a history of:

- searching**
- learning from mistakes, and**
- finding some solutions/best practices**

Starting point: in the middle of the 90´s

Common understanding (at home or in group homes):

- It is necessary to **structure the environment** for people with PWS – as a must do.
- It is necessary to **handle all things around nutrition** for them - as a must do („food security“)
- We have to **protect them from disappointments**

And at that time we were at a **low level of knowledge** about PWS

Starting point: in the middle of the 90's

As a consequence the central message (philosophy) for staff or parents at the time was:

- **We know what is good for people with PWS.**
- **We make the decisions for people with PWS.**

And that on a very low level of knowledge

What did we learn and see over time by approaching care in this way?

The dogma of: Structured environment

We saw that the very **structured environment** - decided and developed by others - provoked many conflicts:

- A. There were often situations where we could not fully control all elements required to meet the strict structure:
 - car was late for lunch boxes
 - instead of 4 cups of coffee, three cups and a cup of chocolate

- B. With this closed structure we learned them to be inflexible and focused on this structure only.

- C. Often the person with PWS did not create this structure and feels no ownership of it. („is not my way“, „I don't want this in this way“), they do not accept a structure forced on them.

- D. Often they do not understand this structure.

The logical consequence is, they are against 'our' structure, and conflicts and stress arise.

The dogma of: Handling all things around nutrition for the person with PWS

Doing it in this way, we saw:

- A. Forbidden things are interesting things
- B. No chance to learn that food could be a normal part of life
- C. No chance to learn that handling with food can have positive responses
- D. No chance to learn that they can control themselves in contact with food and be proud of themselves when they are able to do this in (small) parts of nutrition

The long term consequence of this way is that they are totally dependant on others for their nutrition over their whole life.

The dogma of: Protect the person with PWS from disappointments

What we saw over time:

- A. We do not go with the person with PWS to the supermarket because we expect a conflict
- B. We decline to go to birthday parties of friends because we expect a conflict
- C. We do not say „no“ to requests to buy yet another toy in a shop
- D. We do not confront them with challenging behavior because we expect a conflict

The long term consequence protecting the person with PWS from disappointments is that we do not give them the chance to develop competences to learn to handle situations in the future by themselves. They are dependant on others over their whole lifetime.

Starting point: Low level of knowledge

We come from a beginning where **trial and error** characterized our work

Today our situation is characterized by differentiated knowledge about

- the genetic causes and physical symptoms
- cognitive, social and emotional characteristics
- developmental phases of PWS
- Training programmes for people with PWS
- Training programmes for staff supporting people with PWS
- a worldwide network of experts

As a result of this, we have the chance to offer people with PWS similar opportunities on the basis of this knowledge in all parts of the world

When we talk today about realizing a philosophy of taking care of people with PWS, we have to accept that we have very different starting points in different parts of the world.

But the point is not if we reach the goal in 1 year or in 15 years.

The main thing is that we follow the same philosophy/principles, whether in families or in group homes or supported living environments.

Fundamental attitudes of a philosophy of taking care of people with PWS

- We have to reach for the highest possible knowledge about PWS by using the PWS worldwide network
- We have to develop training programmes for people with PWS, and
- Training programmes for staff to make them highly competent in supporting people with PWS

Fundamental attitudes of a philosophy of taking care of people with PWS

- We have to accept the individuality of each individual with PWS
- We have to be transparent in communication with them
- We have to give them the chance to have experiences, to be successful and proud of themselves, but also to have experiences with failure to be able to learn from that

Fundamental attitudes of a philosophy of taking care of people with PWS

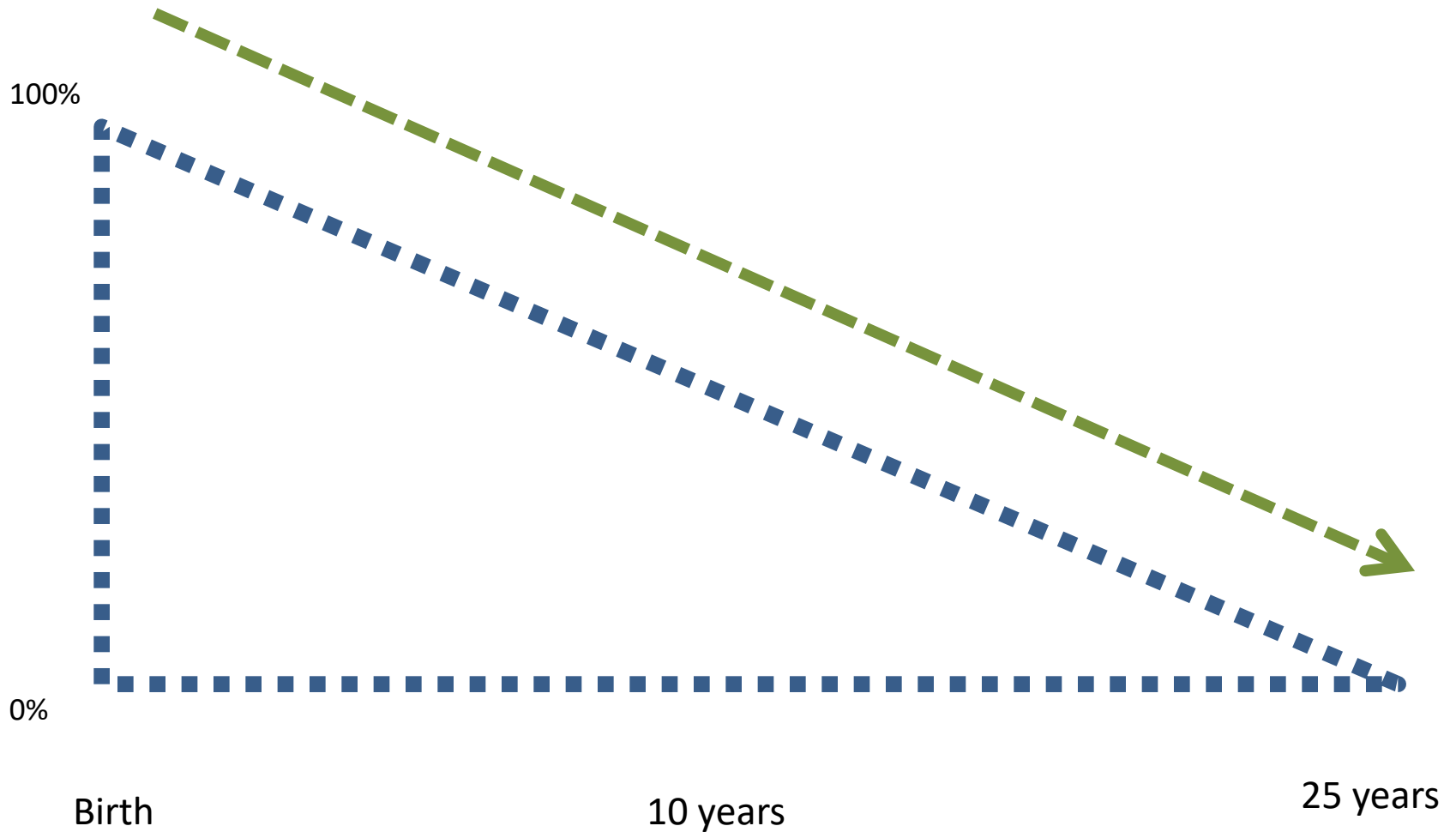
- Include the person with PWS in finding solutions for challenges (for example in challenging behavior) and developing frameworks (not inflexible structures) for their own living-environment

Fundamental attitudes of a philosophy of taking care of people with PWS

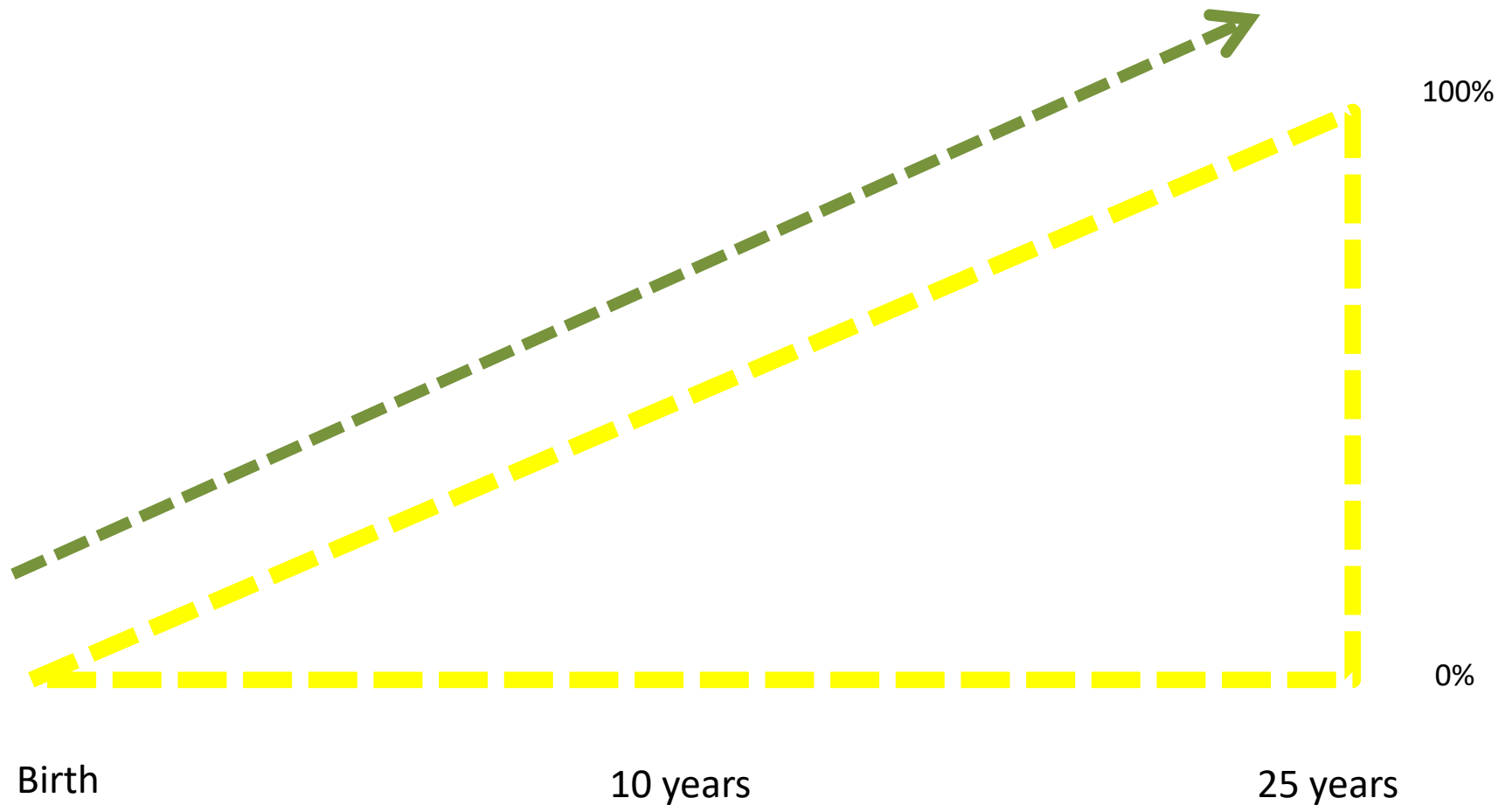
Key takeaway:

- We have to support the person with PWS by moving from:
 - „dependent on others“ (external control)
 - to:
 - „self-determination“ (self-control)

Development of the intensity of the need of external control

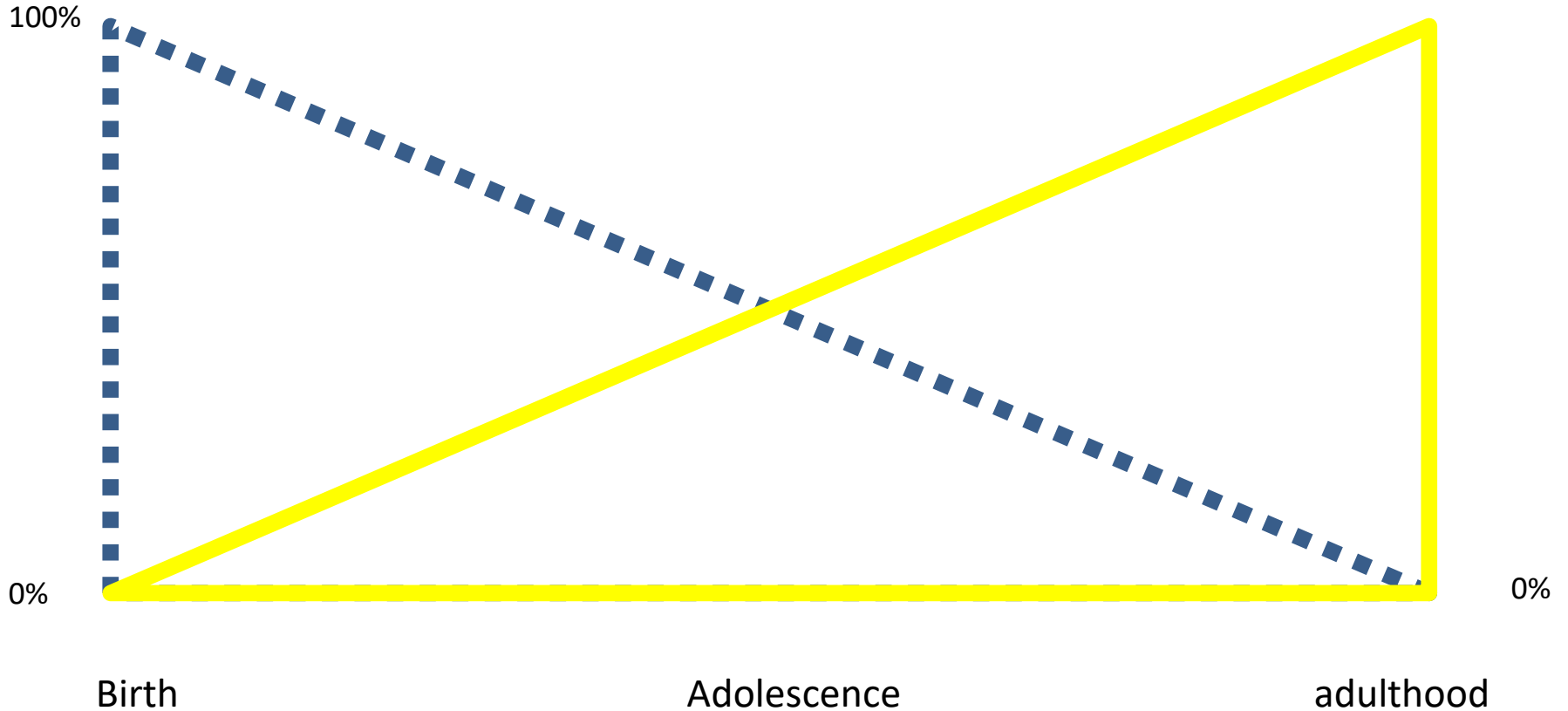


Development of the competence of self-determination



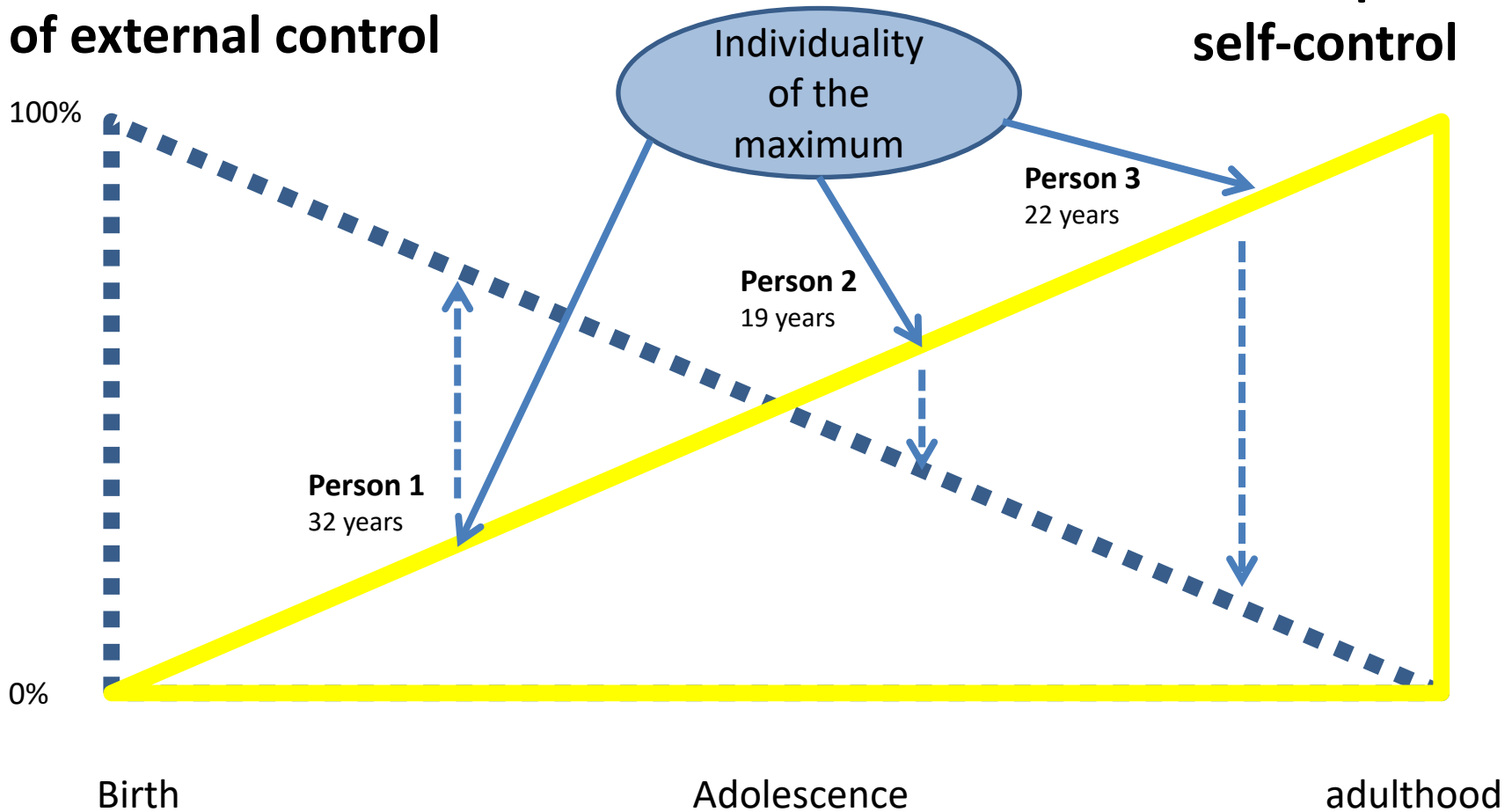
Intensity of the need of external control

Development of self-control

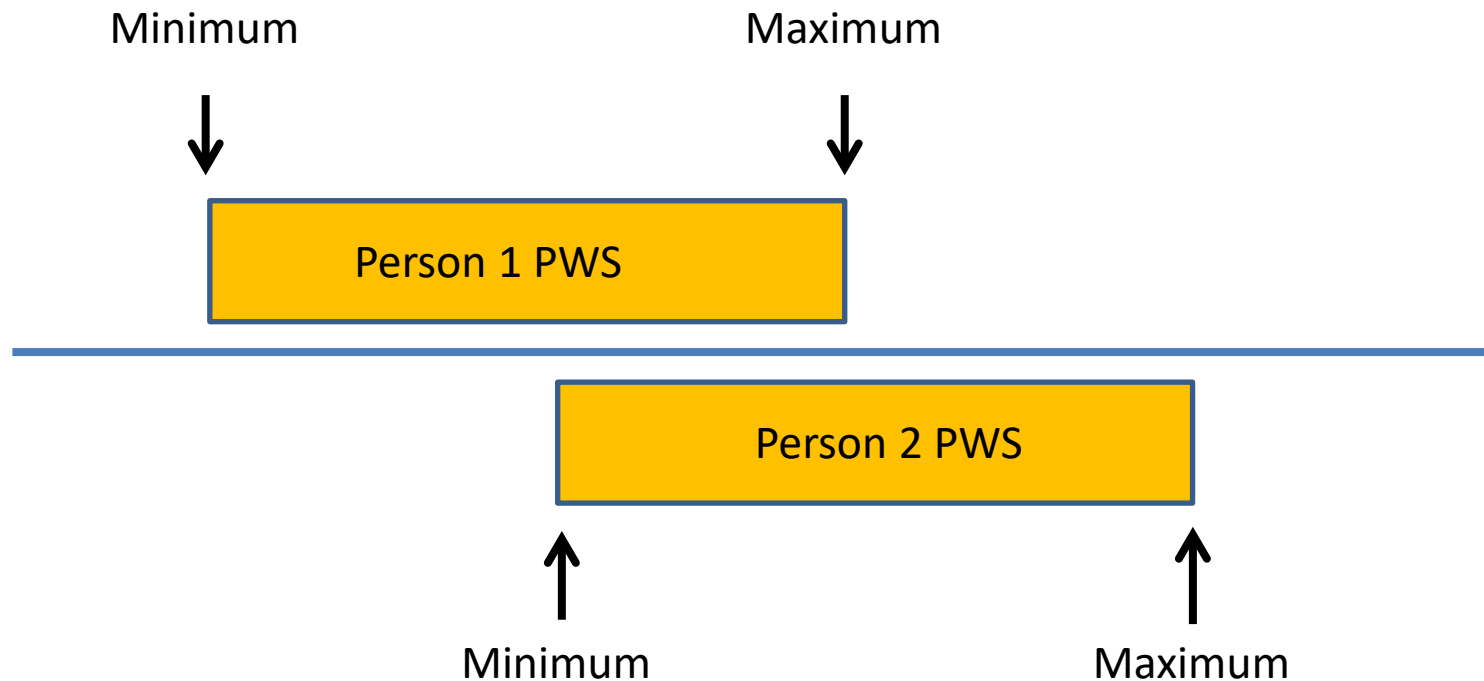


Intensity of the need of external control

Development of self-control



Individuality of the limits of competences



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