

People with PWS

Young and Clever

„Two sides of a medal“

Clever

- Early diagnosed
- Growth hormones → have a positive effect on the development of motoric → positive Effect on cognitive development
- Parents have more and qualified information
- Using of physical therapy – speech therapy - ...
- Information about rights, know more about their rights (school, using social media or internet)

Clever

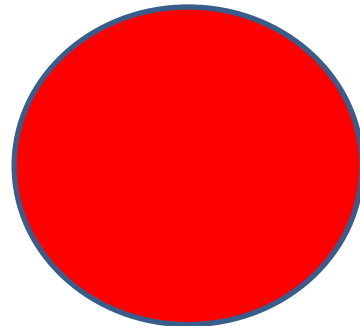
- With 10 or 15 or 20 years they have in the average a higher level of competences than the „first generation“ in all areas.

Situation

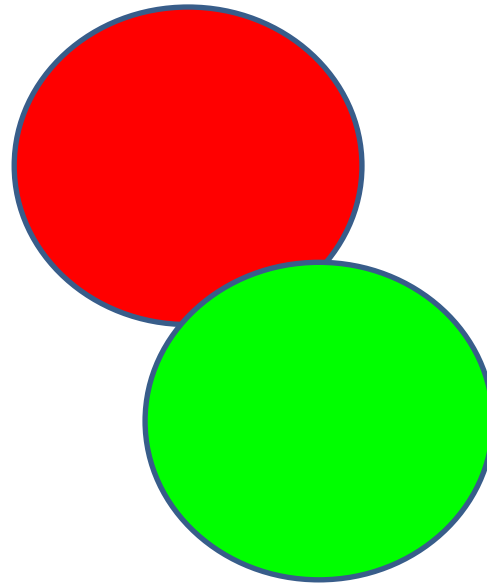
- But they still have:
 - Hyperphagia/ eating addiction

Hyperphagia

Situation der massiven Dominanz der Esssucht
„Vieles/ Alles dreht sich ums Essen“

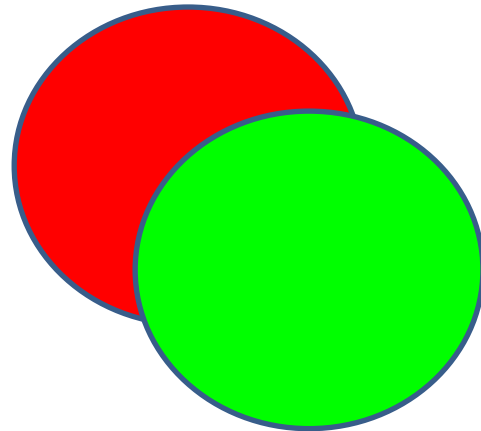


Hyperphagia

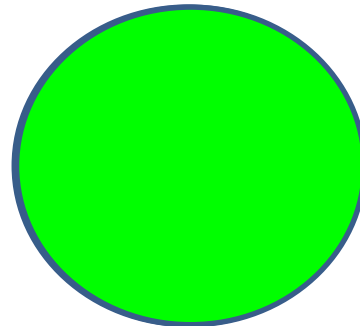


**Positive Aspekte
der Person und/
oder des Umfeldes**

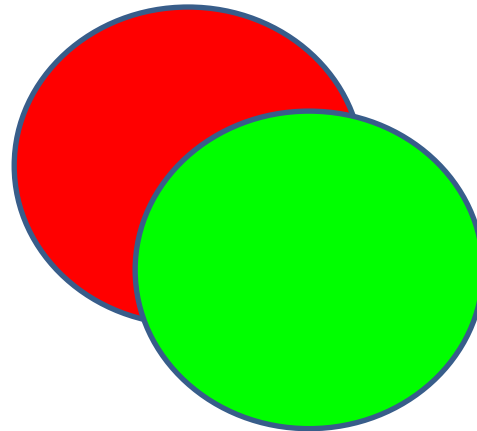
Hyperphagia



Hyperphagia

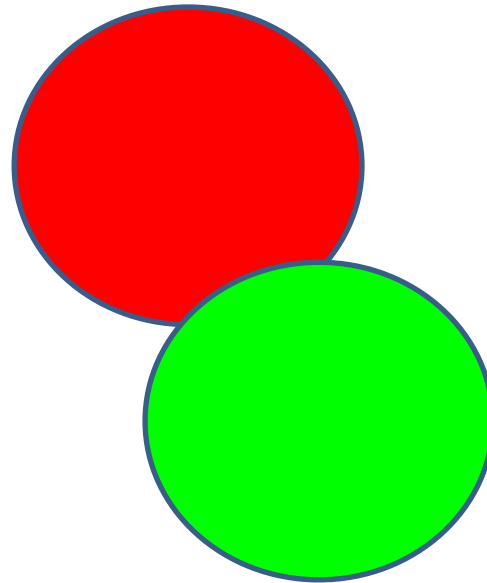


Hyperphagia



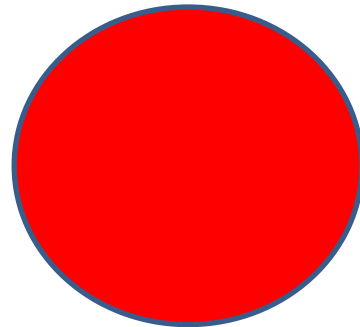
**Negative
Einflüsse**

Hyperphagia



**Negative
Einflüsse**

Hyperphagia

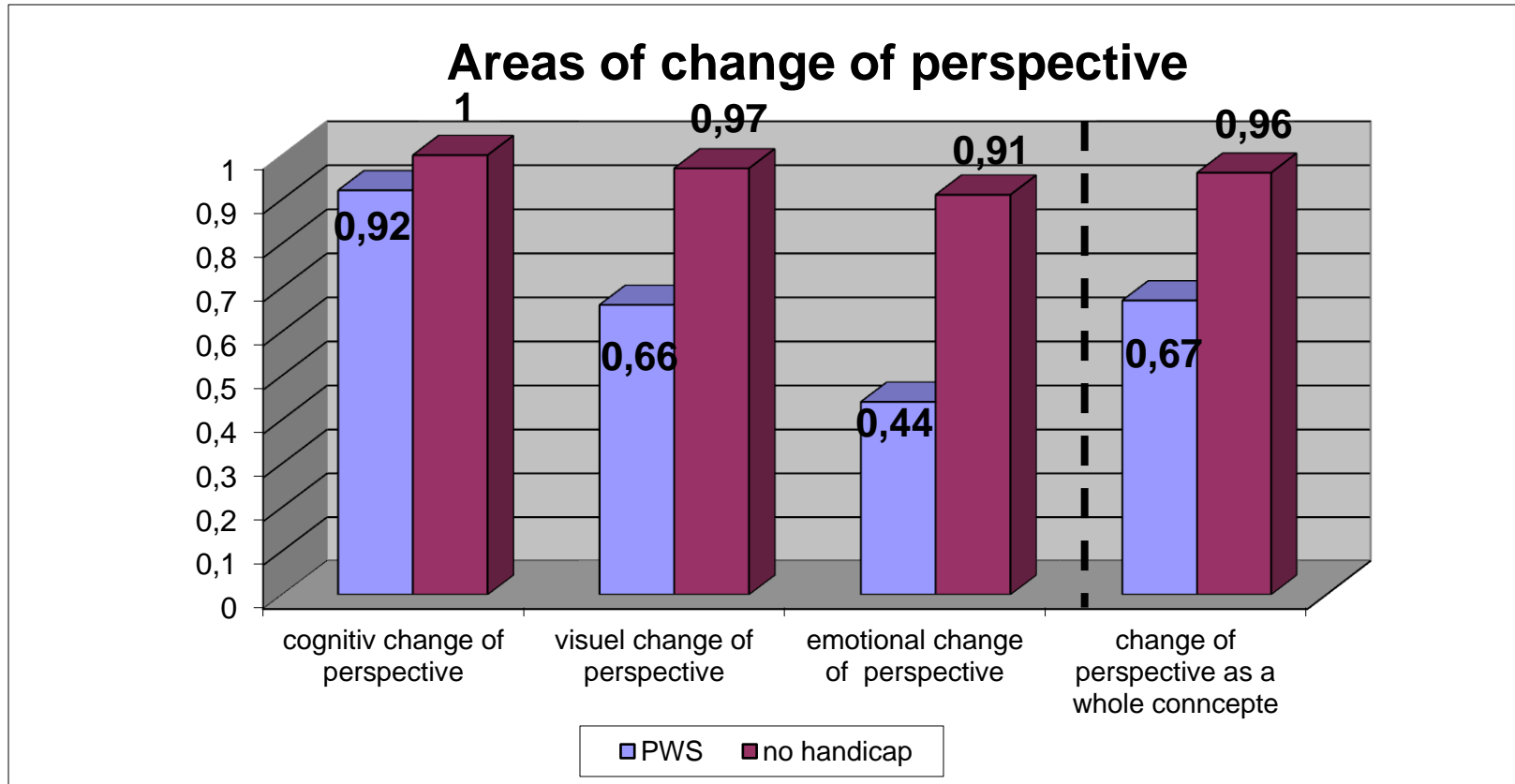


Situation

- But they still have:
 - Hyperphagia/ eating addiction
 - Egocentrism is not completely overcome
 - Normaly it starts around 6 years to 10 years

Situation

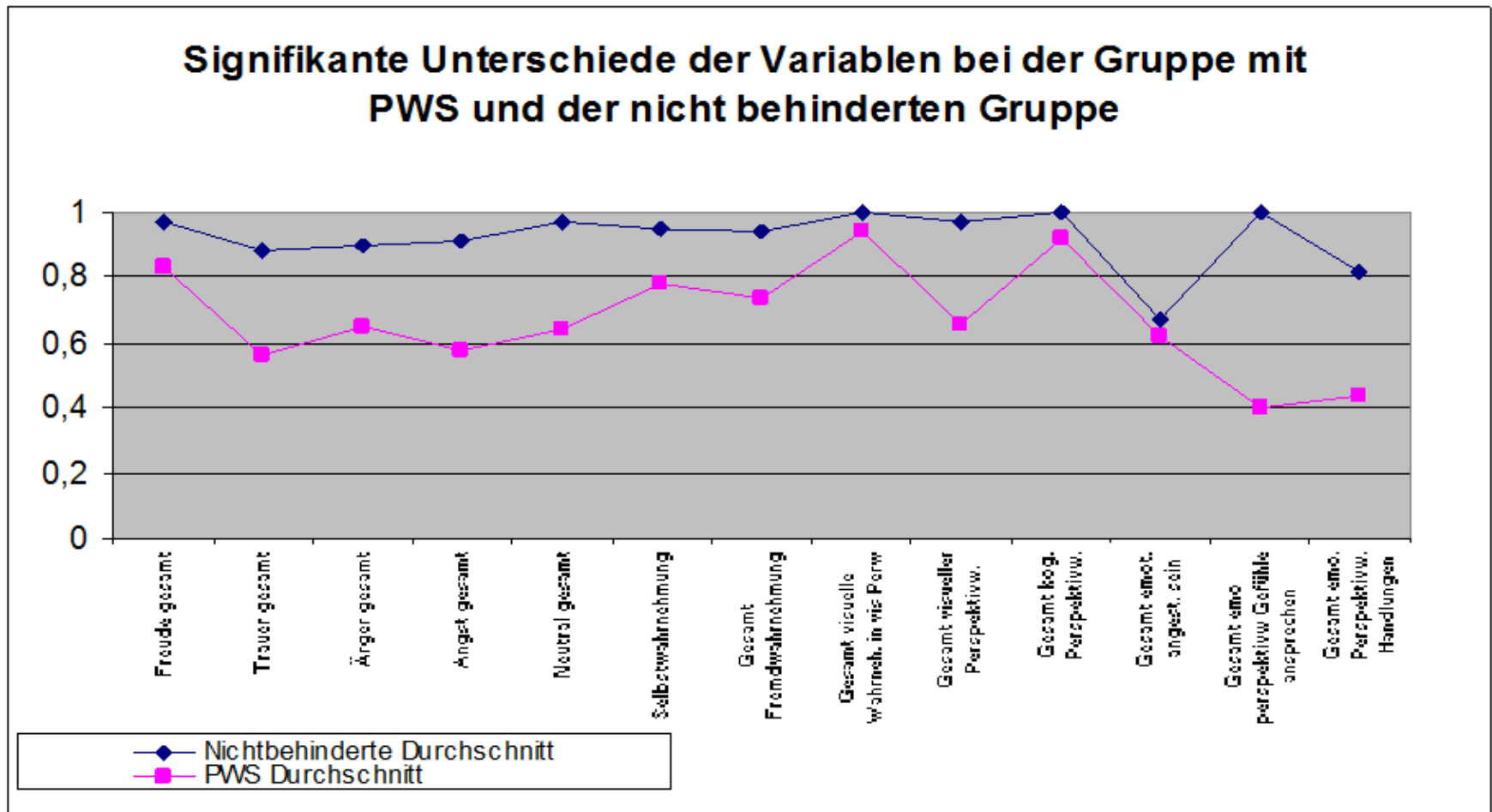
- But they still have:
 - Hyperphagia/ eating addiction
 - Egocentrism is not completely overcome
 - Reduced competence of changing the emotional perspective
 - Reduced competence of recognize feelings by themselves and in the face of others or



Hödebeck-Stuntebeck, 2012

Besonderheiten im kognitiven Bereich

Zusammenfassung der Items zu einem Kompetenzprofil (13 Variablen)



Situation

- But they still have:
 - Hyperphagia/ eating addiction
 - Egocentrism is not completely overcome
 - Reduced competence of changing the emotional perspective
 - Reduced competence of recognize feelings by themselves and in the face of others or
 - Strive for dominance

Situation

Strive for dominance

A necessary behavior to build an own personality in the age of 10 to 16 years (against the parents or other authorities)

Situation

- But they still have:
 - Hyperphagia/ eating addiction
 - Egocentrism is not completely overcome
 - Reduced competence of changing the emotional perspective
 - Reduced competence of recognize feelings by themselves and in the face of others or
 - Strive for dominance
 - Low competence to learn by their own from mistakes (do it again and again with the same negative result)

Situation

With 10 or 15 or 20 years a higher level of competences (cognitive)

and

The social and emotional symptoms of the syndrome

Clever

We see many of this younger generation (second generation)

- being not overweight
- Being in integrated school-classes
- Involved in decisions in the family (in relation to their age)
- Overtaking „tasks and jobs“ in the family and in the community
- Early learned to reflect their (negative) behavior with parents with teachers
- Overcome more and more the egocentrism
- Learn jobs
- Take jobs as adults

Situation

But we also see some of this generation:

- Having a higher level of cognitive competences
- Understand their rights and know about them
- Thinking egocentric
- Being tricky to get what they want
- High competence of changing the cognitive perspective – know what parents (staff, teachers) do in the next minutes
- Refuse reflection about behavior and conflicts
 - Run away
 - „You are not allowed to hold me“ – „I can go where I want“
 - „You are not allowed to be in my room if I do not want it, - go out“
- The chance to support learning from mistakes, from crisis is not given

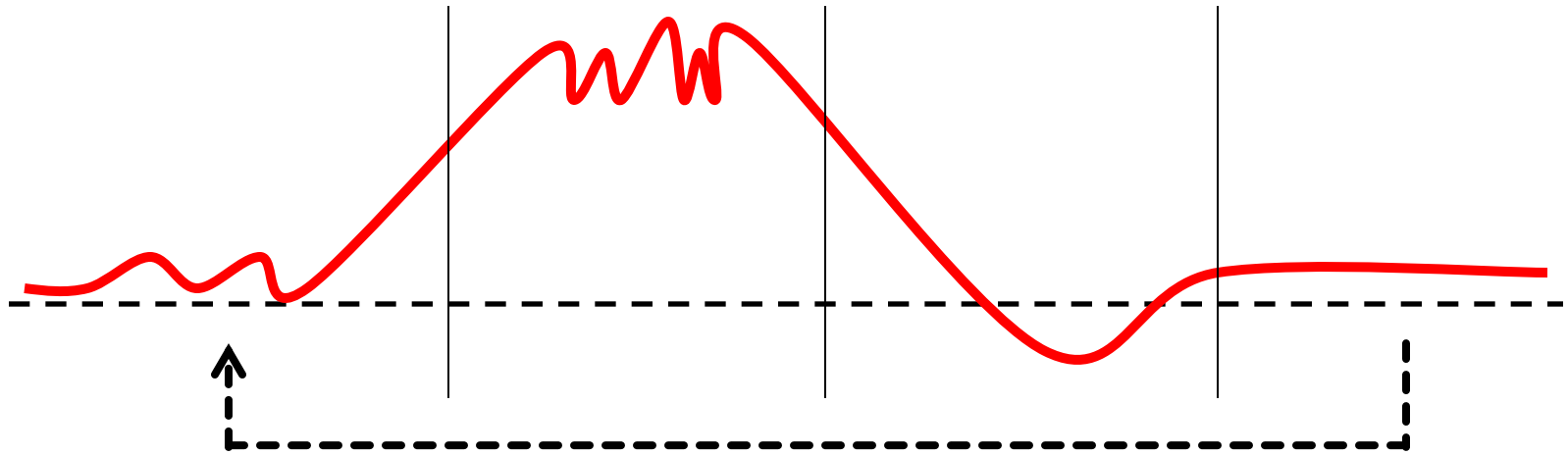
Challenging behavior (Crisis progress)

Prevention

act

After crisis depression

Reflection



Understanding

Caregiver (Parent)

Situation

In our specialised homes with well trained staff (all with three years education and extra 150 hours PWS specialized training) we lost in the last three years:

- two children 12 and 13 years
- And four young adults
- One of them died 6 month later

What to do?