

Training PWS 26-27.02.2018 – Timisoara

Behavior and psychiatry in PWS Typical problems and how to manage

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Definition

„Challenging behavior“

The term was introduced by the US Association for People with Severe Handicaps in the 1990s.

More terms:

- problematic behavior
- abnormal behavior
- disturbed behavior
- maladjustment
- behavioral problems
- striking behavior
- limitations in behavior

Definition Challenging behavior

Deadlocked Behaviors

"The word "deadlocked" expresses the totality of the difficulties that not only the person concerned, but also the people in their environment have come to Even people with normal development can get deadlocked, can end up in a dead end and have the feeling that they can not find their way out People with deadlocked behavior ... It's about people with intellectual disabilities with very complex problems "(Heijkoop, 2014, p. 16).

Definition Challenging behavior

"Challenging behavior is a behavior that causes problems for people around the person" (Hejlskov Elvén, 2017, p.17)

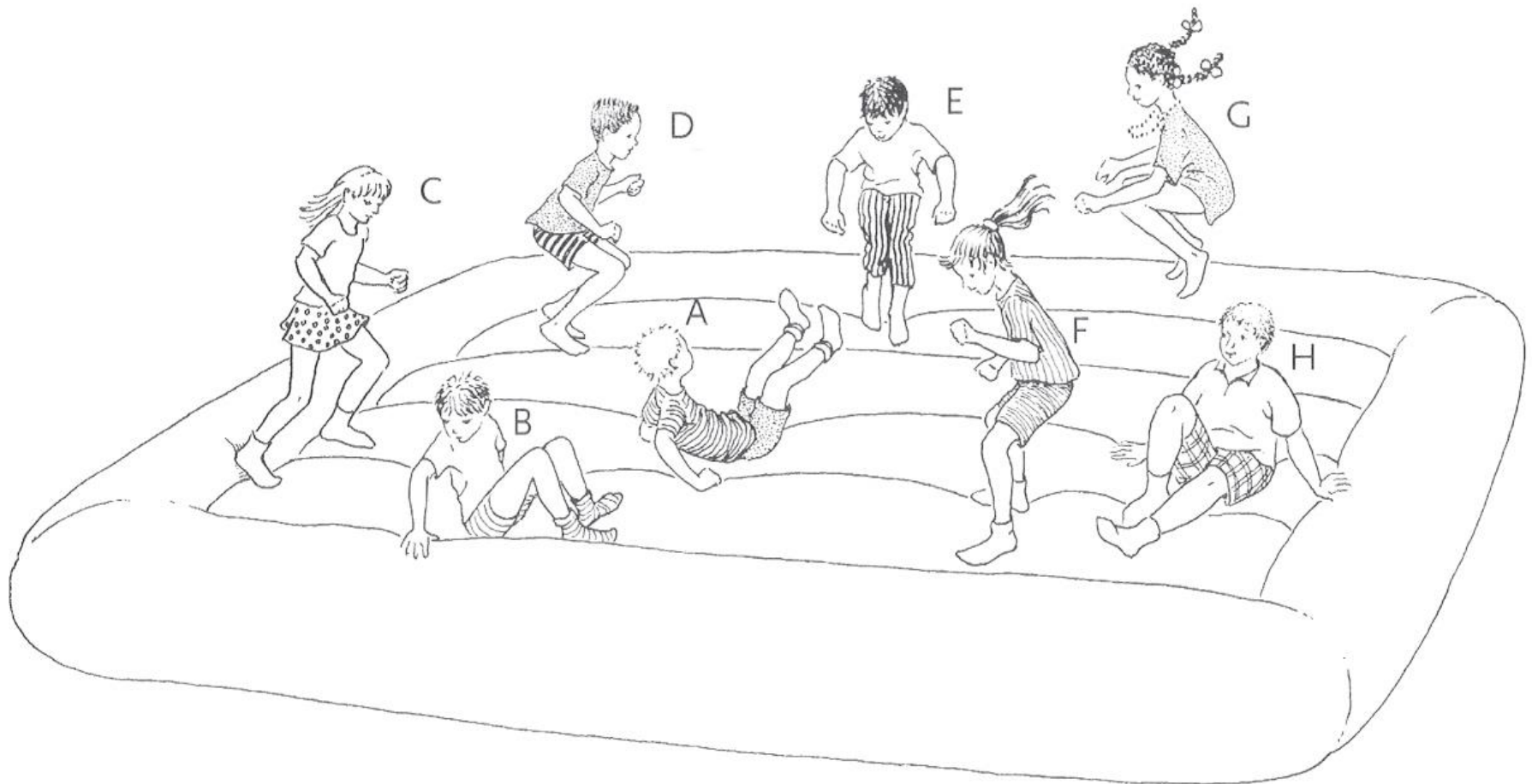
"Challenging behaviors are social phenomena that can not be understood independently of the interaction processes. They are, as Theunissen (1996) put it, an expression of a disturbance of the relationship between the individual and his ecological context "(Dieckmann, Haas, Bruck, 2007, p. 17).

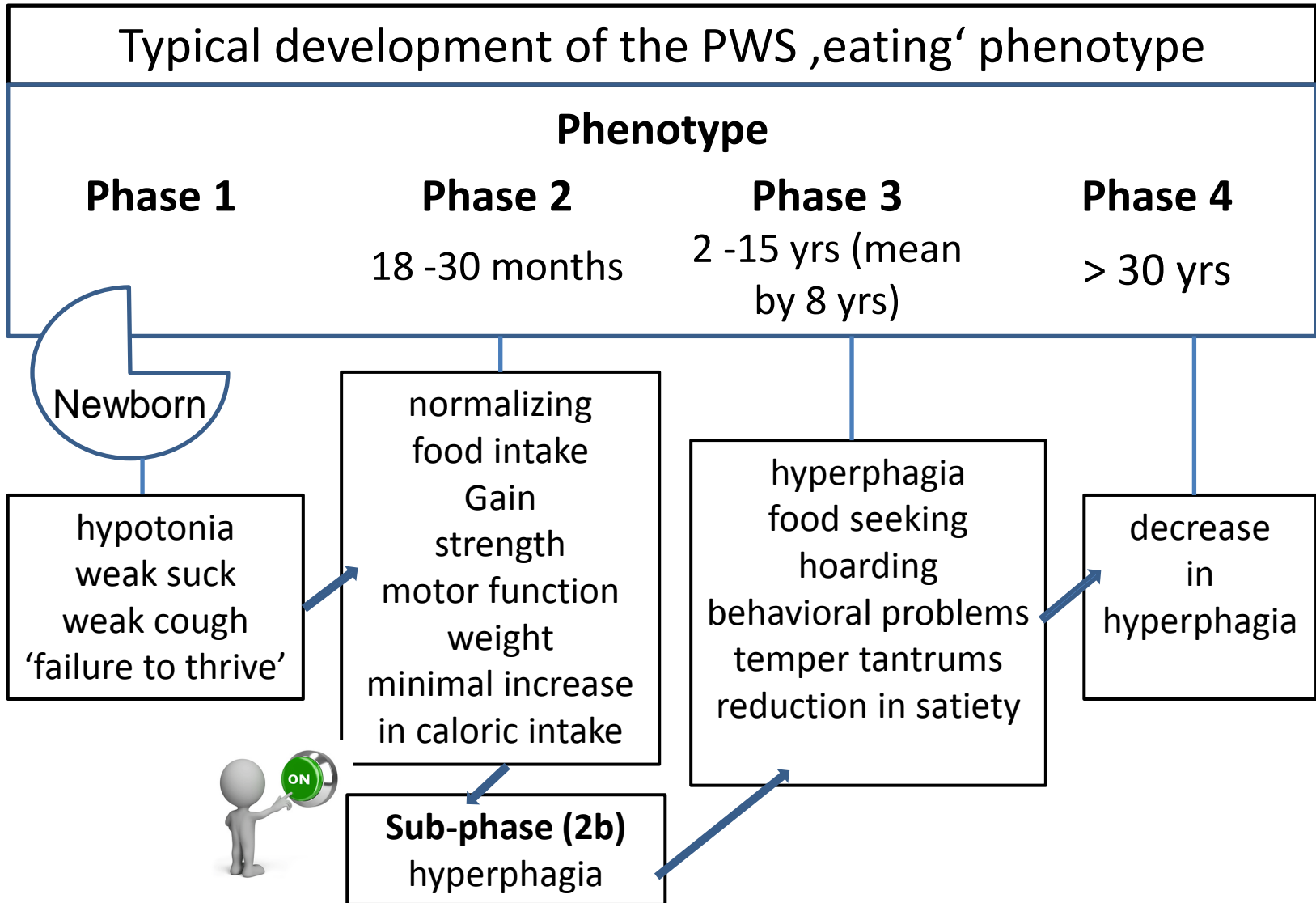
Challenging behavior

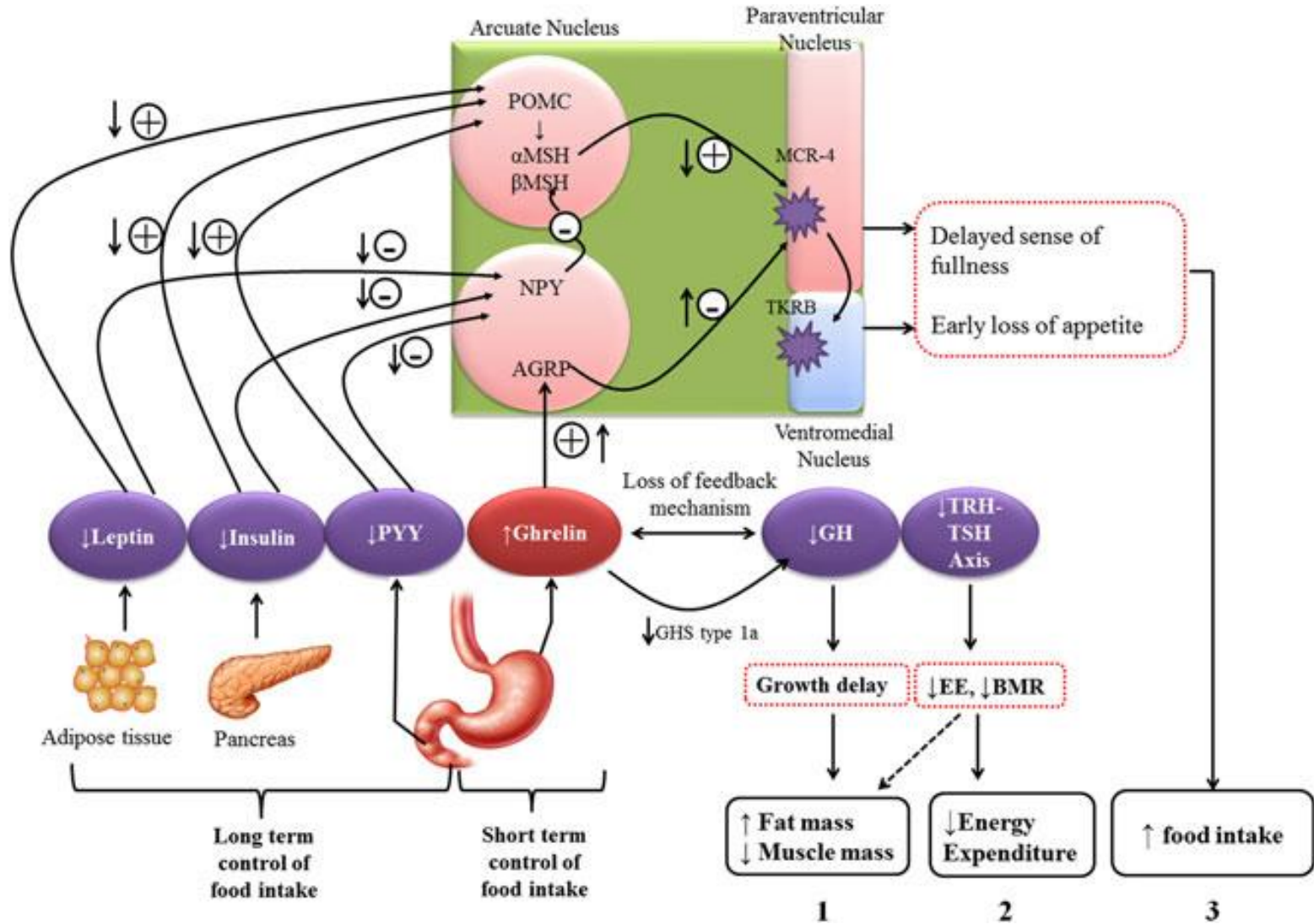
Kicking, beating, scratching, biting, spitting, self-injury, destroying objects, throwing, scratching, beating the head (often stereotyped), pulling the hair, continuing to scream, yelling, constant shouting, insulting, threatening, ridiculing, devaluing, denying, blocking, running away, arson, compulsive sexual acts, clawing, refusing food, dealing with an action almost uninterruptedly (a word, a thought), stealing, hoarding, irritability, apathy, depression, anxiety, delusions and hallucinations, disinhibition, euphoria

Systemic basics

Interaction between person and environment







AGRP = agouti-related protein;

BMR = basal metabolic rate;

EE = energy expenditure;

GH = growth hormone;

MCR4 = melanocortin receptor 4;

NPY = neuropeptide Y;

POMC = proopiomelanocortin;

PYY = peptide YY;

TRH = thyroid hormone-releasing hormone;

TRKB = tyrosine kinase receptor B;

TSH = thyroid-stimulating hormone;

α -MSH = alpha-melanocyte stimulating hormone receptor;

β -MSH = beta-melanocyte stimulating hormone receptor

Mechanism of obesity in Prader–Willi syndrome

(Adapted from Mutch and Karine (2006) (59)

Decreased plasma insulin and PYY result in loss of stimulatory signals to the POMC neurons and loss of inhibitory signals to NPY neurons in the arcuate nucleus that fails to stimulate α -MSH and β -MSH to control satiety via activation of MCR4 in the paraventricular nucleus.

The role of leptin is still under investigation (marked with ‘?’ in the figure) as overall evidence suggests no difference in leptin concentration in PWS obese vs. non-PWS obese. On the other hand, **persistent increase in plasma ghrelin** results in stimulation of neurons expressing NPY and AGRP that inhibit MCR4 signaling and hence increase drive towards food intake (3).

Mechanism of obesity in Prader–Willi syndrome

(Adapted from Mutch and Karine (2006) (59)

Alteration in TRH–TSH axis results in reduced energy expenditure (2).

Deficiency of GH due to loss of feedback mechanism despite persistent increase in plasma ghrelin results in growth delay, increasing weight for height ratio, reduced muscle mass and increased body fat (1).

Appetite and Hyperphagia

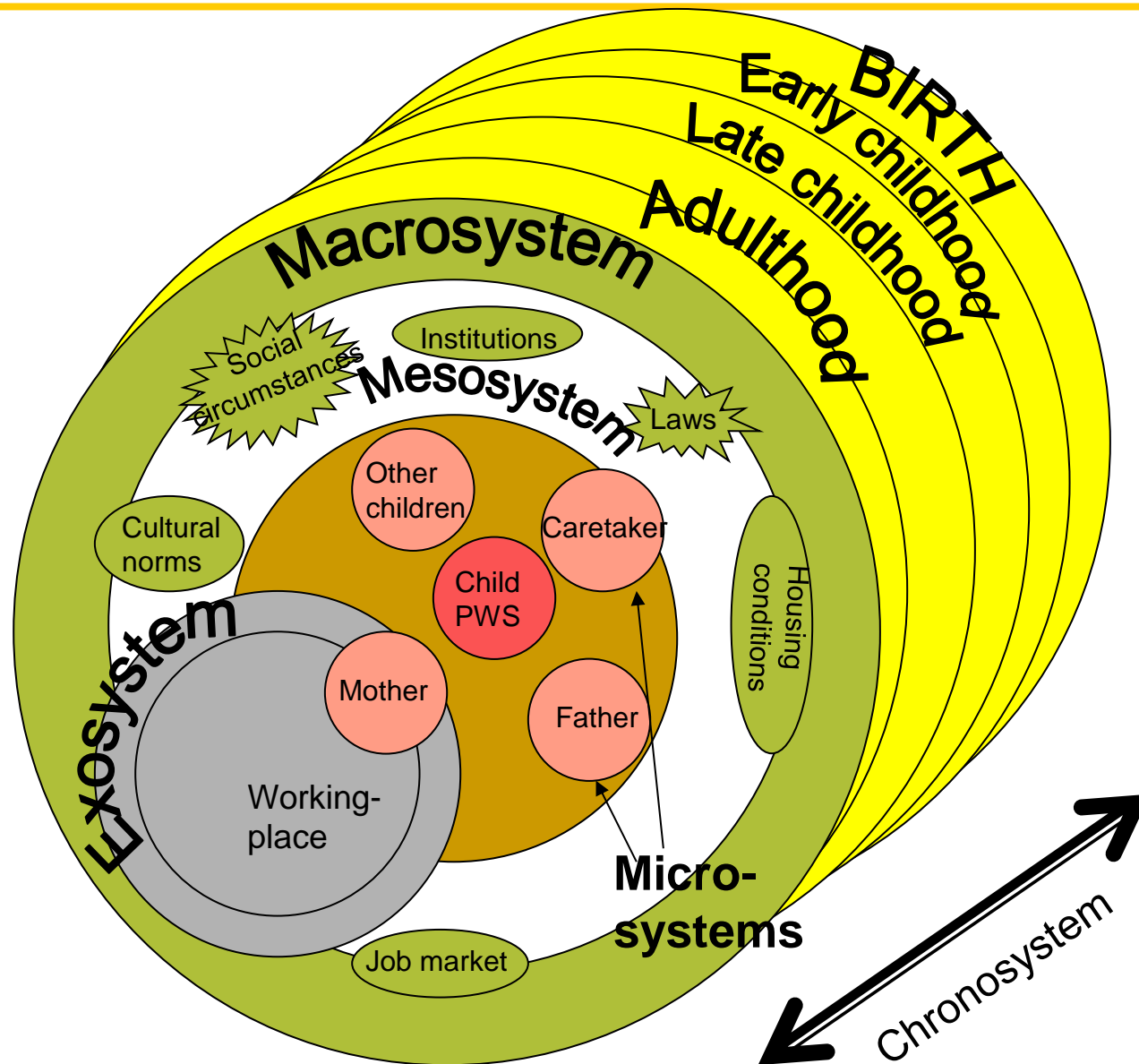
- Appetite is regulated by a couple sets of neurons in the hypothalamus
- One set of neurons, NPY/AgRP, acts as the accelerator of appetite
- The second set, the POMC neurons, act as the brakes
- Neurons are regulated by leptin and insulin, hormones produced elsewhere in the body
- Insulin regulates so that after a meal, your hunger level drops
- Leptin relates to the longer term: If you've eaten well for a long period of time, your appetite is suppressed
- In PWS, because of the loss of at least one gene, the appetite accelerator is active, but the brakes aren't working

What we know

Social layer and social milieu influence self-development, education, ethical values, financial scope, eating habit, health care ...

What we should know

Does social layer and social milieu have a special influence on persons with PWS



What we know

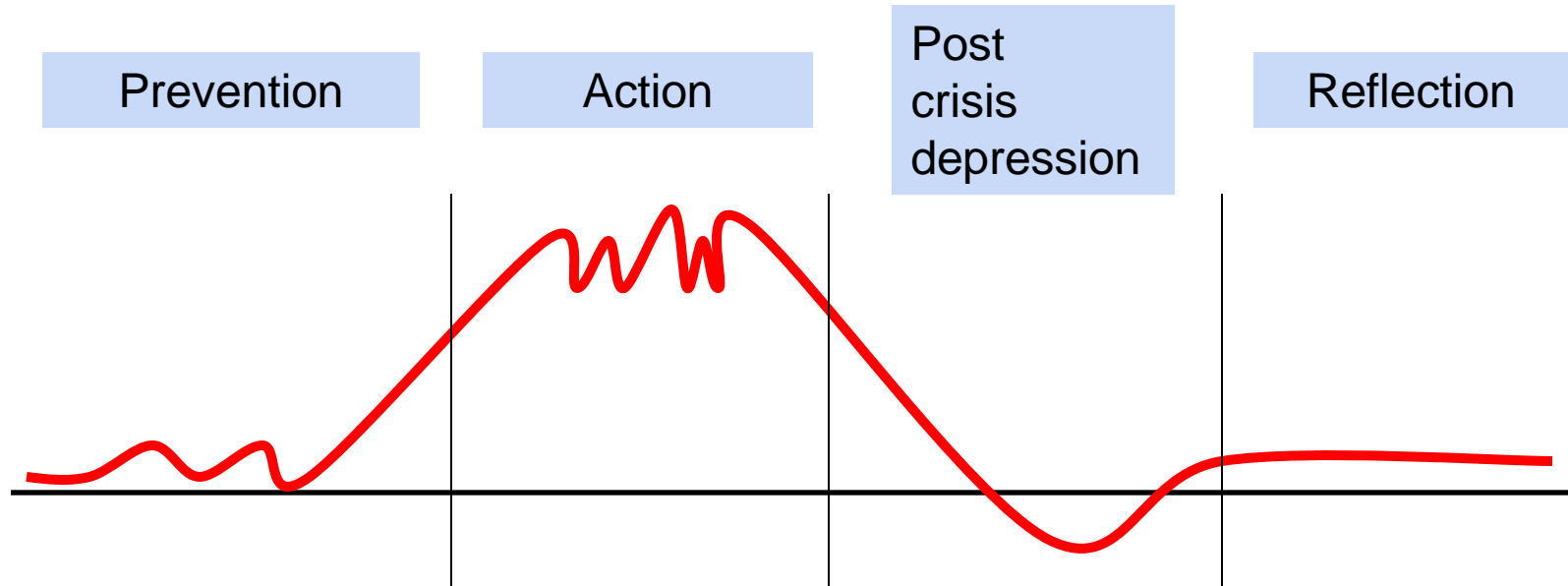
Environmental influence is most efficient in the microsystem

The influence in the meso- and macrosystem becomes more important in the course of growing-up

What we should know

Are there special conditions for persons with PWS in the micro-, meso- and macrosystem?

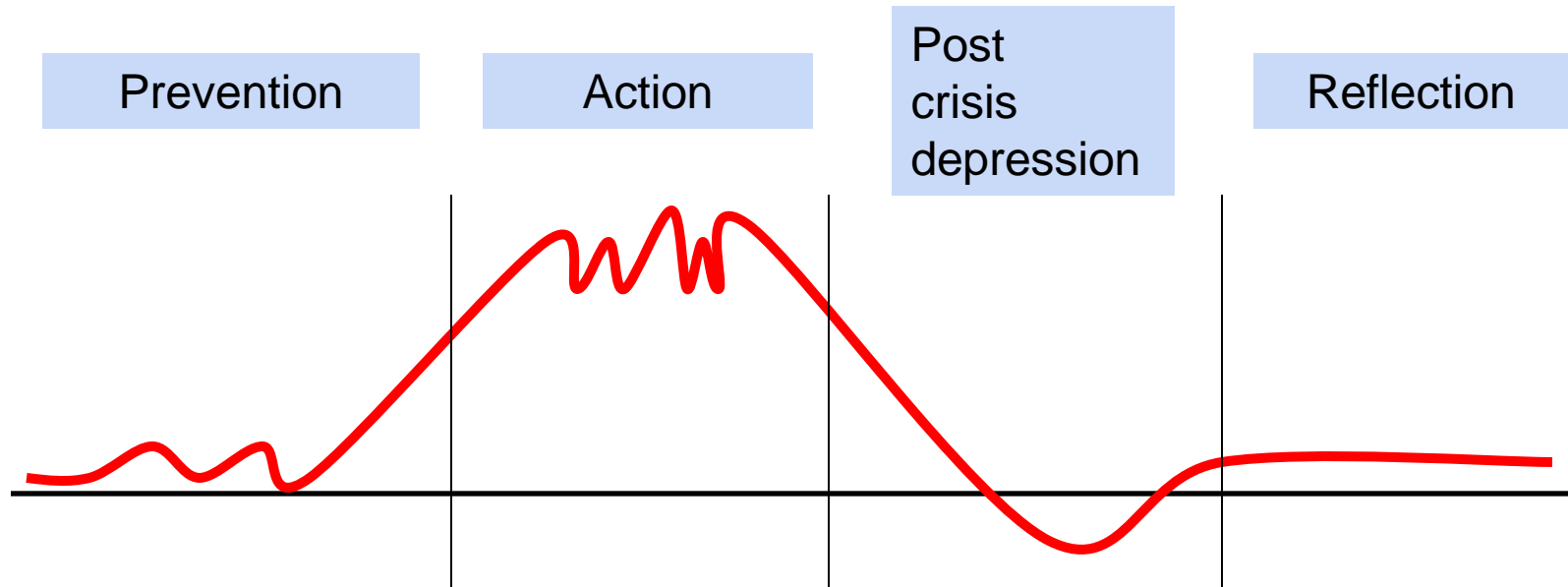
Course of a crisis or „What are we talking about?“



Understanding

Caregiver

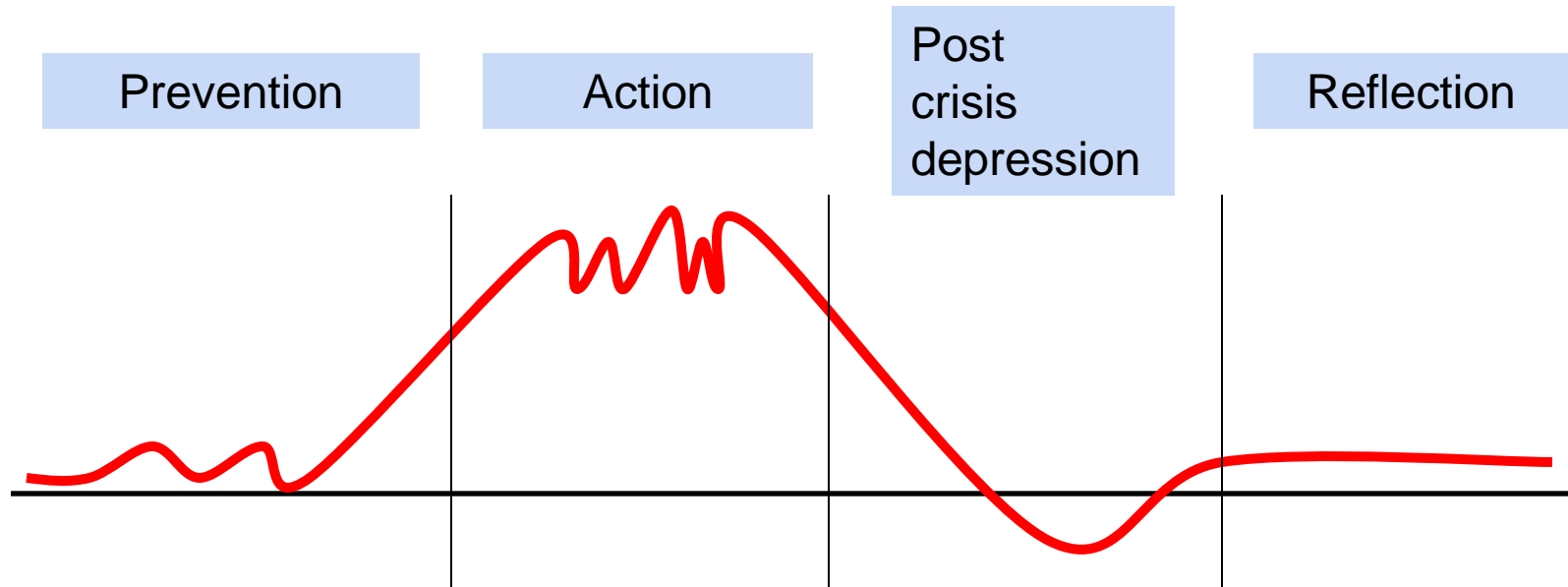
Course of a crisis



Understanding

Parents, Caregivers

Course of a crisis



Understanding

Parents, Caregivers

Behavior analysis

- Understanding the behavior -

1. “Behavior in a given situation“/ “Investigative questions“

1.1 Physical signals: what is visible, what exactly is he/she doing,

- What does he/she say; verbal statement
- Eye contact
- Facial expression
- Gestures
- Posture
- Movements

1.2 Perception: what part of the whole situation is someone aware of?

1.3 Cognition: what is he/she thinking during that process?

1.4 Cognition: are there any thought patterns in comparable situations?

Behavior analysis

- Understanding the behavior -

- 1.5 **Emotions/ Feeling:** Which feeling (non-visible) is there? What kind of emotions (physical) are visible?
- 1.6 Are there **physical characteristics** (e.g.: pain, drugs, genetic disposition PWS, ...)?
- 1.7 What is his/her **underlying goal/** the intention behind this behavior (which role does it play)

Behavior analysis

- Understanding the behavior -

2. Social conditions (during the behavior)

- who was present (persons)?
- what was happening around him/her (processes)?
- is anything about the environment unusual?

3. Preceding conditions

- what happened before the behavior?

temporally:

- immediately
- five minutes ago
- hours ago
- yesterday

concerning people

concerning processes

Behavior analysis

- Understanding the behavior -

4. Consequences

- which positive consequences arise after a behavior?
- which negative consequences arise after a behavior?
- which impact do these consequences have (in the current situation)?
- which impact did these consequences have in the past (experiences)?

5. Biography

- Characteristics of a development process
- Family
- School – Profession (Work)
- Traumatisation

Behavior analysis

- Understanding the behavior -

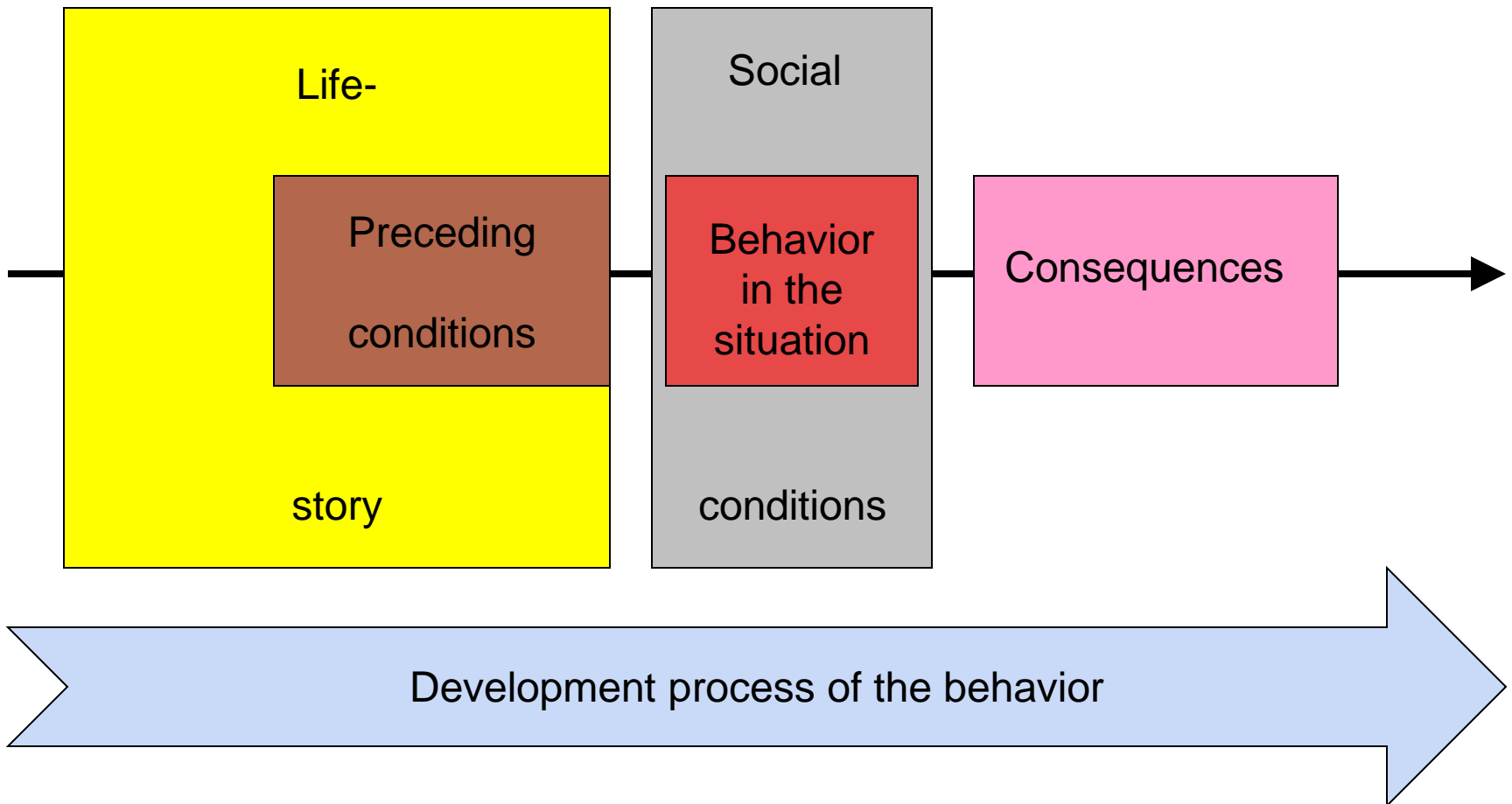
6. Development process of behavioral disorder

- when did the behavior occur (for the first time)?
- how did the behavior develop over time (continuously increasing or suddenly escalating)?

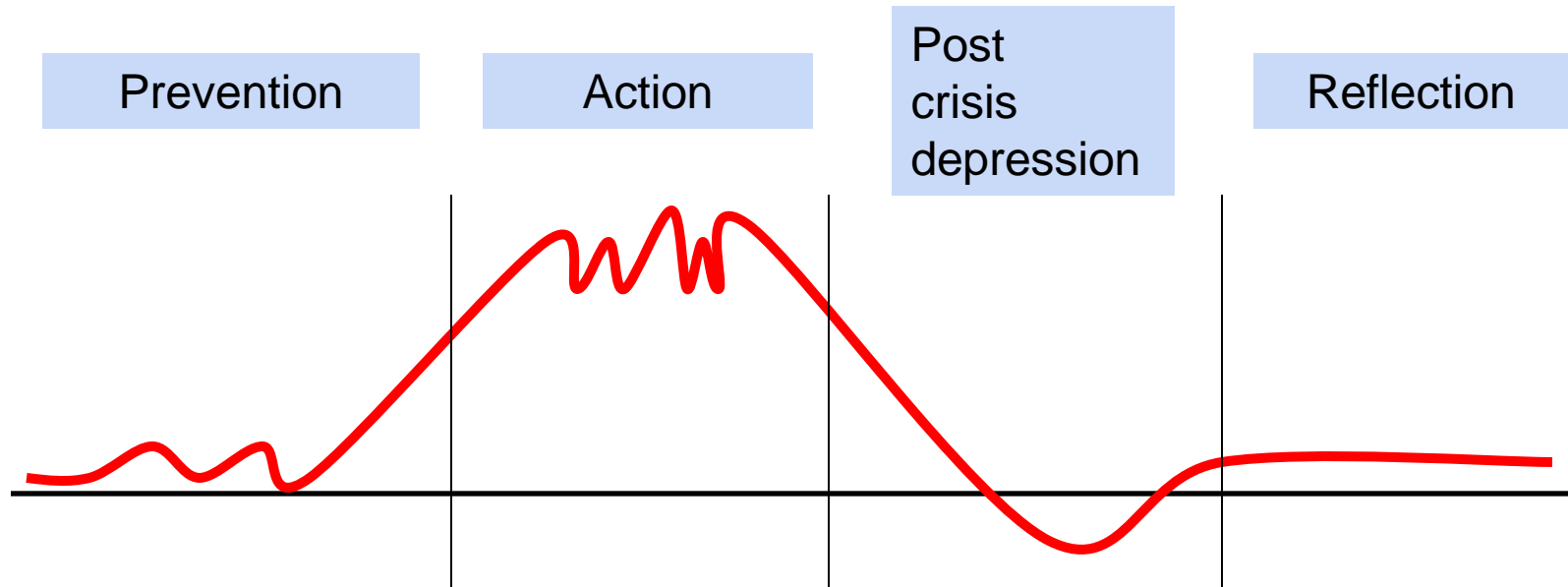
Final question:

What is his/her **underlying goal**/ the intention behind this behavior (which role does it play)

Parts of the behavior analysis



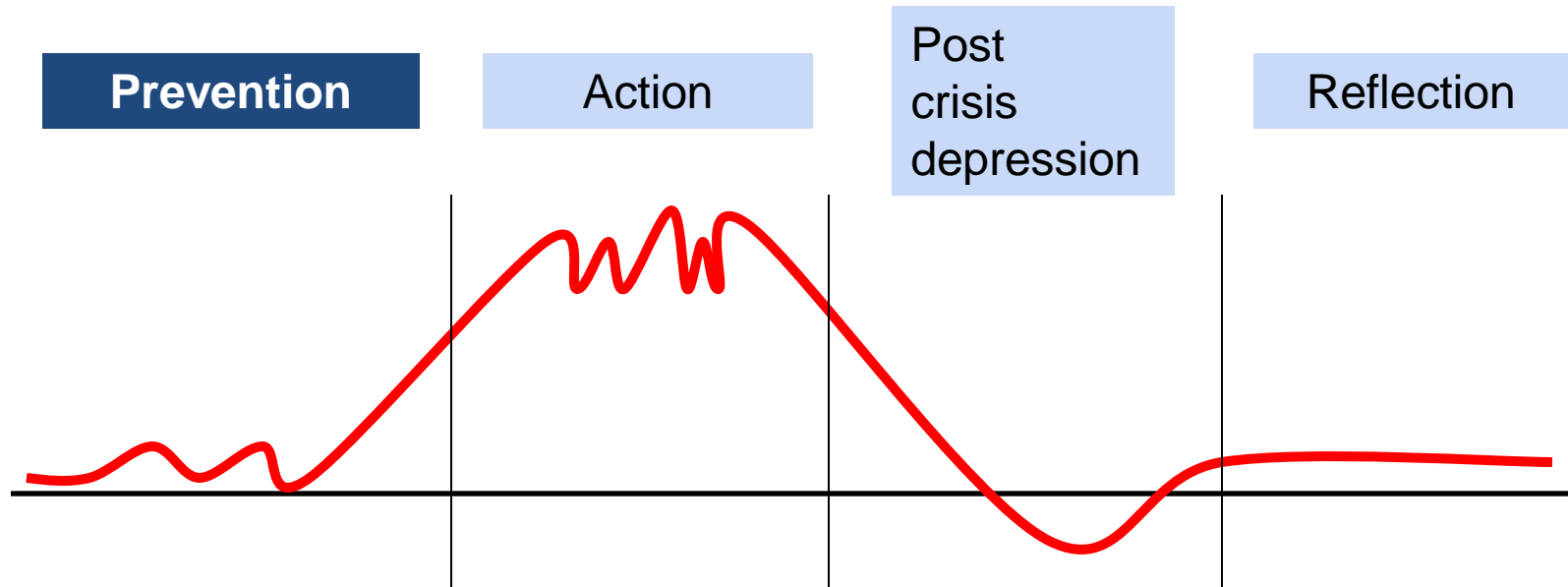
Course of a crisis



Understanding

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Understanding

Parents, Caregivers

Prevention

„After the crisis is before the crisis“ (based on Sepp Herberger)

Prevention

refers to situations in which a person's perception is still sufficiently open to consider other people, cue stimuli, incentives or requests.

Prevention

„After the crisis is before the crisis“ (based on Sepp Herberger)

- **Daily and weekly process**

Structuring the daily routine:

- is it reasonable,
- is it too difficult/hard/stressful?,
- is it mentally challenging enough?,
- is it too mentally challenging?

Does he/she have rights, does he/she realize them

Does he/she have duties, does he/she realize them

Does he/she have space to realize his “great passions”

Prevention

- **Daily and weekly process**
 - Changes of the process should be announced and explained properly
 - Use communicative tools to convey the plan, visualize it
 - Finally test his/her understanding by asking for an explanation of the plan

Prevention

„After the crisis is before the crisis“

- **Energy reduction**

- where can he/she blow off steam which he/she is currently turning into aggression?
- are there standard programs (activities) where he/she reduces excess energy (duties/chores)? – Reconsider the daily and weekly process plan accordingly.
- are there opportunities for reducing energy voluntarily, e.g. additional movement = bonus points? (voluntariness)
- Reducing excess energy through (exercising and) applying relaxation methods.

Prevention

„After the crisis is before the crisis“

- **Sufficient number of employees present (Staff)**

If conflicts are foreseeable there should be at least two people
(at least two employees in service)

Prevention

„After the crisis is before the crisis“

- **Knowledge** (Qualification of the team)
 - Use sources of information
 - Exchange knowledge
 - Seminars/ advanced education programs
- **Well trained staff**
 - Specific advanced education and staff training

Prevention

„After the crisis is before the crisis“

- **Ensure external support**
 - Therapists - psychologists - doctors
 - Advice center
 - Family, friends, acquaintances
 - Integrate attendant services
- **Ensure internal reflection**
 - Team meetings
 - Exchange among colleagues

Prevention

„After the crisis is before the crisis“

- **Flow of information between social environments**
 - School, home, group home, work area, leisure time
 - Ensure the exchange of necessary information

Prevention

„After the crisis is before the crisis“

- **Having a backup room available**
 - Be informed about rooms
 - Prepare rooms
 - Prepare a way there
 - If necessary, time out room
 - If necessary, Snoezelen or relaxation room
- **Secure environment, rooms and items**
 - Preventively clear dangerous or fragile objects
 - If necessary, move persons at risk out of the danger area (protective role)

Prevention

„After the crisis is before the crisis“

- **Reduce trigger stimuli**
 - Separate conflict parties spatially
 - Take them away from audience
 - Change the number of involved employees
- **Switch rooms**
 - Client leaves room (or place)
 - Employees (and other persons) leave room (or place)
- **Give support for structuring information**
 - Help “order” content of a question (concerning a topic), (“Do you mean ...?”)

Prevention

„After the crisis is before the crisis“

- **End a situation by**
 - Changing the room
 - Changing the topic, switch to (known) positive topics, talk about hobbies
 - Changing the topic by starting a new topic
 - Changing the topic by humor
 - Returning questions, mirroring (if necessary refer to already given answers)
 - Ignoring/not reacting on particular questions, but providing reliability for later discussion

Prevention

„After the crisis is before the crisis“

- **Use surprise effect**
 - Paradox intervention (symptom prescription)
 - Mirroring the behavior, including non-verbal behavior
 - Unexpected action (words, noise,...)
- **Metacommunication**
 - Verbalize the current situation (“Let’s think about what is just happening... What are we just doing to each other?”)

Prevention

„After the crisis is before the crisis“

- **Allow behavior**
 - Do not prohibit every challenging behavior
 - Assess danger
 - Gives a chance for independent coping (progress)
- **Consequences**
 - Refer to previously discussed consequences
 - If possible make him/her name consequences himself/herself

Prevention

„After the crisis is before the crisis“

- **Motivate to contribute to finding solutions**
 - Ask for ways to help (“What would help you?”)
 - Signalize “naivety” and “alleged ignorance” (“I really don’t know what to do now. Do you have an idea?”)
 - Circular and miracle questions - “What would your friend say about what you need?”
 - Role reversal “What would you do in my position?”
 - (Ask for) application of learned methods in social competence trainings

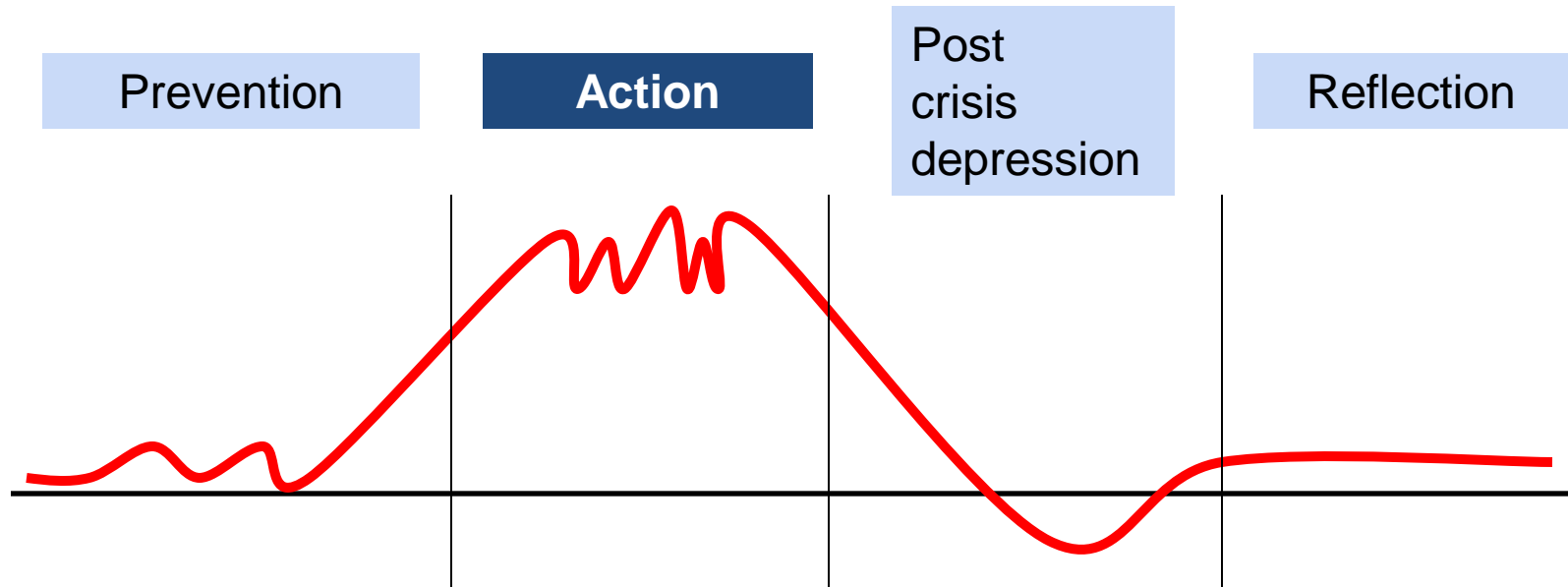
Prevention

„After the crisis is before the crisis“

- **My first reaction in crisis situations**
 - How do I now react in such situations?
 - How do I want to react in the future?
 - Can I learn to react (standard strategy)?

- 1. take time (catch a breath)
- 2. get an overview
 - watch your back (physically)
 - assess danger
- 1. action / behavior

Course of a crisis



Understanding

Parents, Caregivers

Handling behavioral disorder

„What can I do in a certain situation?“

I. Key statements

1. Be aware of **goals**,

„I have to know my goal in a situation“

2. **Take the lead** in a situation

define own rules before

if possible discuss with the affected person before

- „I (don't) want ... to happen!“
- „You are now going to do ...!“
- „You will now go ...“

Handling behavioral disorder

„What can I do in a certain situation?“

II. Realization “or what actions are possible”

- **Give space**
 - Give the affected person space, so he/she is able to control himself/herself (chance for self-control)
 - Only act if limits are violated
- **Keep distance**
 - To give/have sufficient space and to feel secure

Handling behavioral disorder

„What can I do in a certain situation?“

- **Language**

- loud
- clear
- direct
- determined
- slow and with emphasis (modulation)
- simple (rule of five)
- use his/her words
- use language in conjunction with the respective action
- give instructions, this helps the person to re-introduce order into the situation
- give space
- breaks

Handling behavioral disorder

„What can I do in a certain situation?“

- Do **not mention consequences during** a discussion (most of them can not be immediately implemented which undermines your credibility)
- **Don't try to win at any price during** a situation, it will be much easier to reach the goal later on
- Consider **own reduced cognitive capabilities**

Handling behavioral disorder

„What can I do in a certain situation?“

- **Interrupt the line of thinking** by
 - changing the topic
 - using surprise effect
 - introducing a second (additional) person
- **Divert thoughts by**
 - reinterpreting and
 - attributing a new meaning to the behavior (designate)
- **Ignore** (Behavior, words and content, persons)

Handling behavioral disorder

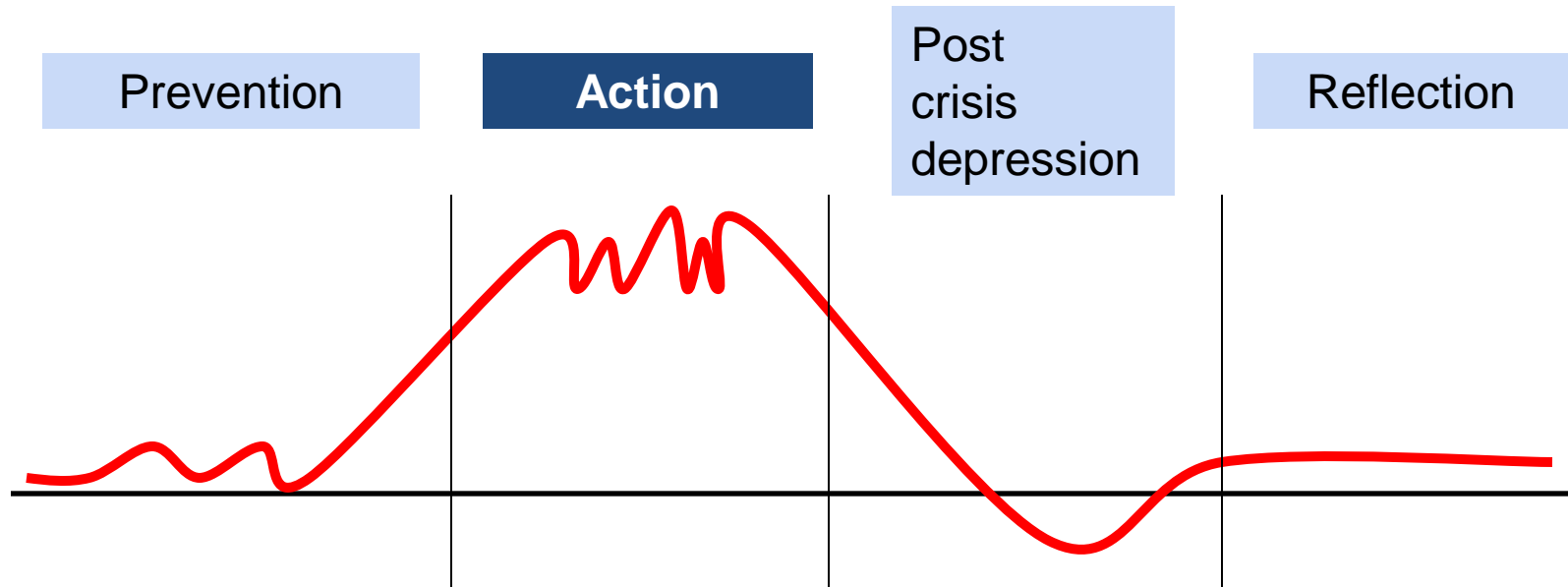
„What can I do in a certain situation?“

- **Keep calm**
- **Know your own limits** and name them if necessary before crossing your limits (and having regrets afterwards, “bad conscience”)
 - psychological
 - physical
- **Take out of the situation**
 - time out (reduction of stimuli)
 - make him/her leave the room (reduction of stimuli)
 - leave the room
 - avoid building up an “audience”
- **Secure the environment**

“Action”-Toolbox

- Ignore
- Body contact
- Visual stimulus
- Fixing - body fixation
- Mirroring
- Call by name
- Surprise
- Give space
- Provide security - make other people leave the room
- Call co-workers for support
- Interrupt eye contact among two counterparties
- No discussion

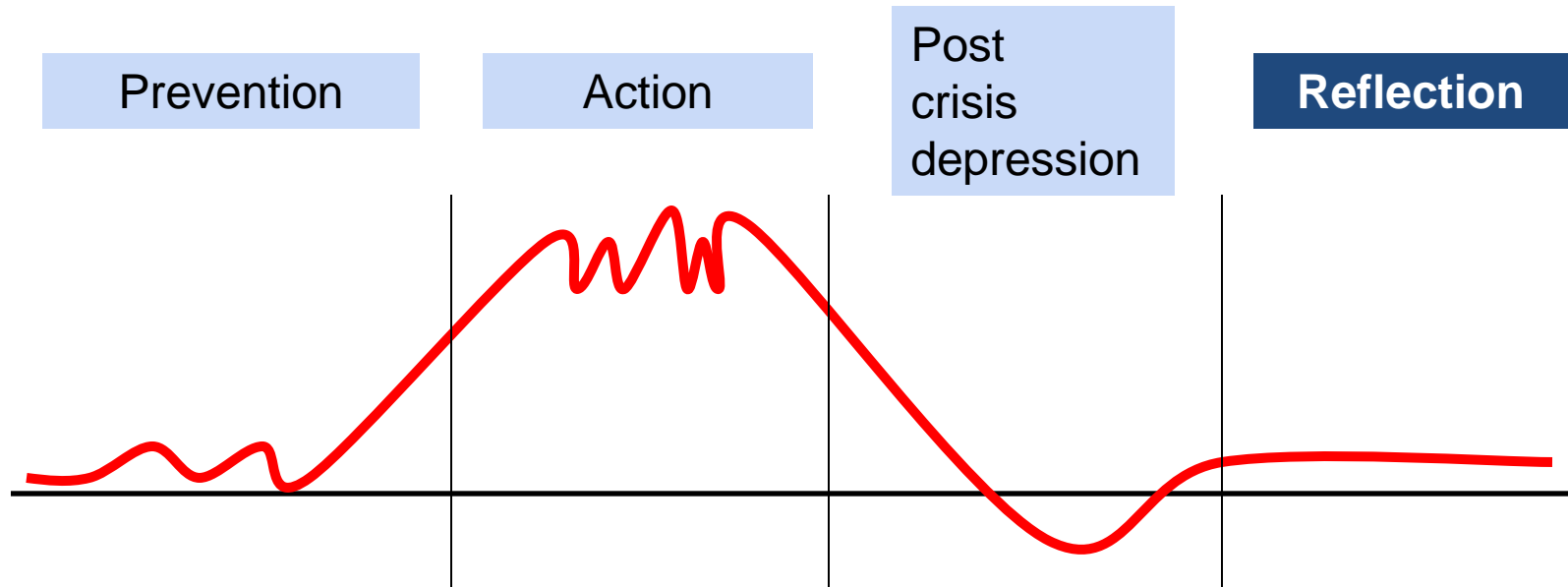
Course of a crisis



Understanding

Parents, Caregivers

Course of a crisis



Understanding

Parents, Caregivers

(Post) Processing after crisis

„What can I do afterwards?“

I. Key statement

‘Every’ behavioral disorder will be treated at a suitable time.

This has to be executed in a reliable and predictable way (but not at any price).

(Post) Processing after crisis

„What can I do afterwards?“

II. Realization

- Processing the crises must always include a change in perspective.

The ability to change one's perspective is a condition for changing aggressive behavior.

- „How was he/she doing, what did he/she feel?“
- „How would you feel in such a situation?“
- „What would you do in my place as an employee?“
- Role play
- Change of position
- Employee change his workplace/position
- Mirror

(Post) Processing after crisis

„What can I do afterwards?“

- Show or develop suitable behavioral alternatives for the shown behavior. Build (new) positive behavior patterns, that are incompatible with old patterns. They ...:
 - must be simple and clear
 - can contain if ... then ... statements
 - can contain fixed sequences of actions (1. ... , 2., 3., ...)
 - can have jointly developed reward systems: Token-Programs, self-enhancements
- You should ...:
- find long-term targets and wishes, for which achieving is highly motivating
 - derive subgoals (from “unrealistic goals”)

(Post) Processing after crisis

„What can I do afterwards?“

- **„Building bridges“ (Exercise)**
 - strengthening ego functions
 - caregivers in the auxiliary ego function
- **Use meta level**
- **Place/Time:**
 - preferably neutral place/room
 - arrange enough time
 - announce time of conversation to clients
 - sufficient number of persons present (relatives, employees)
 - allow for additional time

(Post) Processing after crisis

„What can I do afterwards?“

- **Conversation techniques and structuring**
 - Announce conversation
 - At the beginning, get a description of the critical situation by the client to hear his/her perception (what did he/she focus on)
 - What was the employee's perception
 - Clarify the goal
 - ‘I - messages’, ‘You - statements’
 - Get suggestions and reasons for consequences by the affected person
 - Get suggestions for required support by the client, or provide alternatives he/she can choose from
 - At the end let the client explain the result with his/her own words

(Post) Processing after crisis

„What can I do afterwards?“

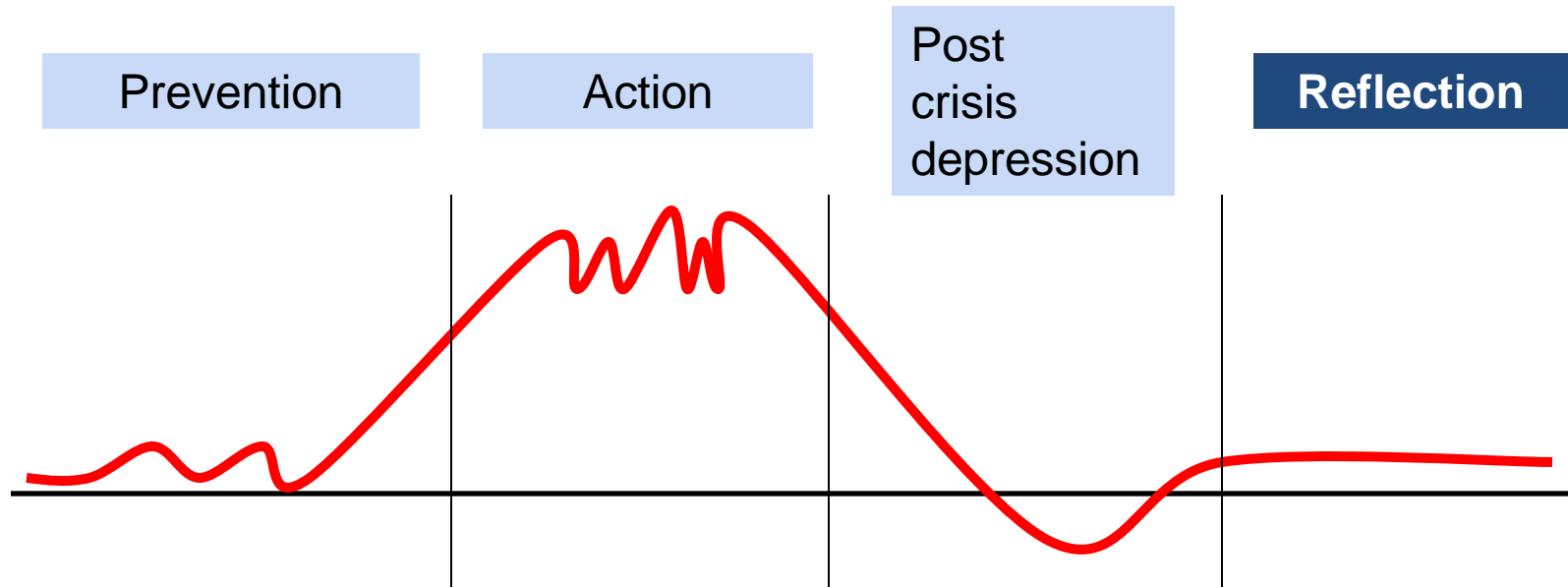
- **Demand eye contact:**

- increases the statement's intimacy and commitment

- **Affected people**

- Affected employee (or specific other person)
 - Second person
 - Psychological service
 - Parents
 - Superiors

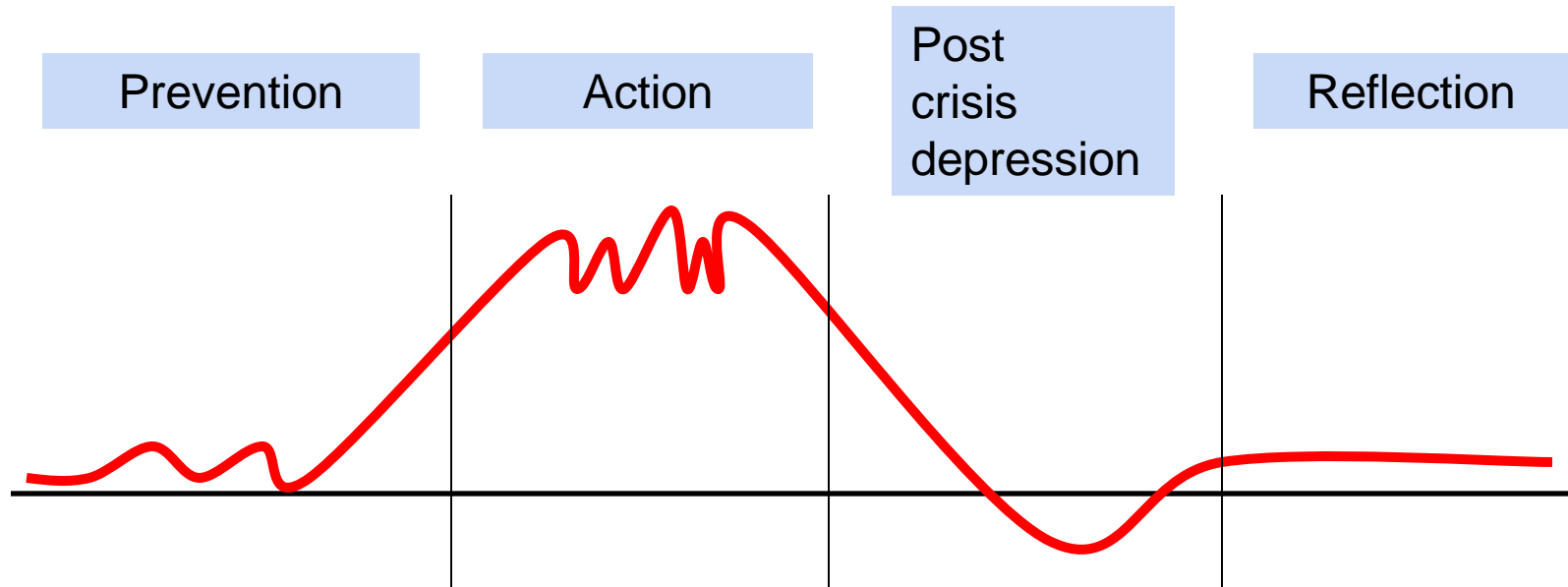
Course of a crisis



Understanding

Parents, Caregivers

Course of a crisis



Understanding

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