

Prader-Willi-Syndrom InterNational



Qualität ist die Basis

The role of Diagnostic in supporting people with Prader-Willi-Syndrom

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Thesis:

„Diagnostic must be one of the standard components in taking care of people with PWS“

„Using the results of the ‘appropriate’ Diagnostic is the guarantee for a higher quality of taking care of people with PWS and by this way for a higher quality of life for people with PWS“

Why Diagnostic:

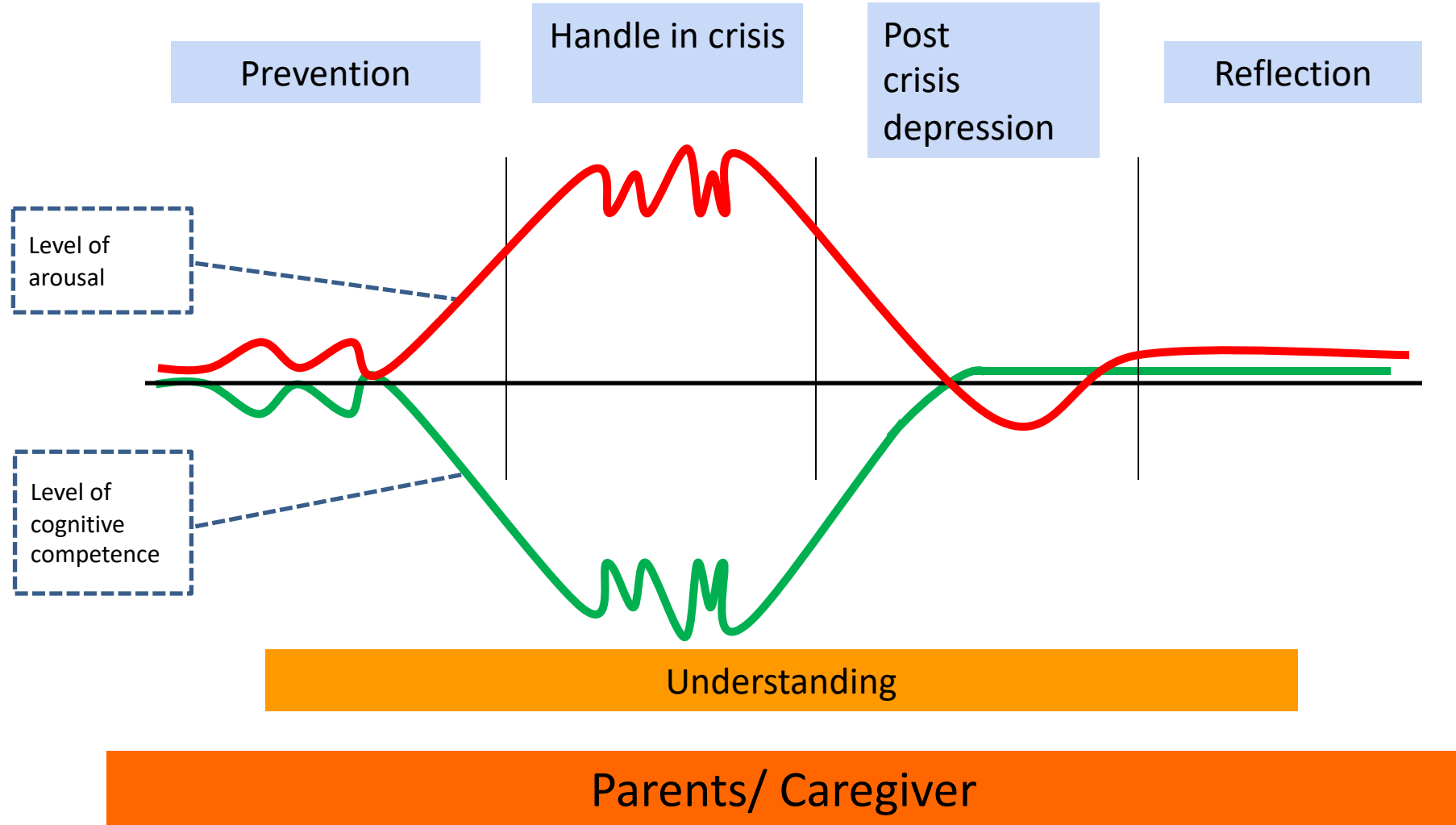
Challenging behavior is today the most important thing/theme, when you live together with one with PWS (family, group home).

Diagnostic helps us to understand the challenging behavior of people with PWS in a more appropriate way.

And a better understanding of it is the basic (guarantee) for a better support of this challenging behavior.

Course of a crisis

or „What are we talking about?“



Understanding:

1. To know so much as possible about the symptoms of the syndrom (physical-, cognitive-, social- and emotinal characteristics)
2. To make a Bio-Psycho-Social Analysis of the background of the behavior
3. Diagnostic of the (competences of the) person with PWS

3. Diagnostic

My **goal**/ the target is:

To have a „paper“ of international agreement where is described

- in which area (physical, cognitive, emotional, social, ...)
- which diagnostic methods are accepted to use

Today we can start with examples and a first draft And we should finish it latest at the next IPWSO conference in 2025 in ...?

(Draft) Diagnostic - System in PWS

Developmental Diagnostic		Competence Diagnostic		Physiological Diagnostic	
Motoric		Concentration		Blood presure	
	Test 1		Test 1		Methode
	Test 2		Test 2		
	Test 3		Test 3	Heartrate	
		Methode
Cognition		Speech		Insulin	
	Test 1		Test 1		Methode
	Test 2		Test 2		
	Test 3		Test 3	...	
		Methode
Egocentrism		Perceiving emotions by others			
	Test 1		Test 1		
	Test 2		Test 2		
	Test 3		Test 3		
		
...		...			
	Test 1		Test 1		
	Test 2		Test 2		
	Test 3		Test 3		
		

Examples where diagnostic was helpful:

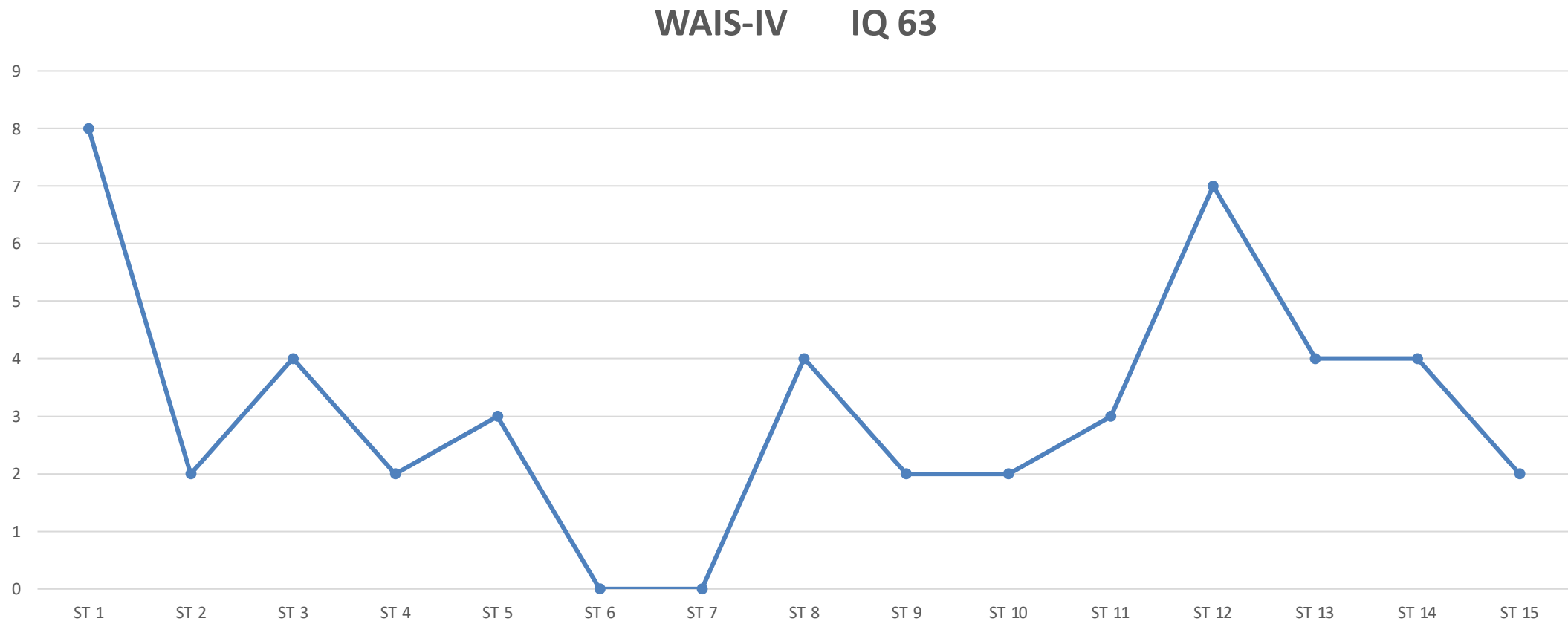
- to understand the behavior
- to understand the reasons for the behavior
- to develop treatment or an appropriate care in critical situations

Example for using IQ Test-Results

„Always when Bastian try to manage a conflict between other people with PWS in the group home it ends in the way, that he was the one who gets stress with all other“

Example for using IQ Test-Results

WAIS (Wechsler Adult Intelligence Scale)



Example for using IQ Test-Results

Result: ST 6 and ST 7 - perception and understanding of complex situations

Intervention/ Prevention / Treatment on the basis of the result of the test

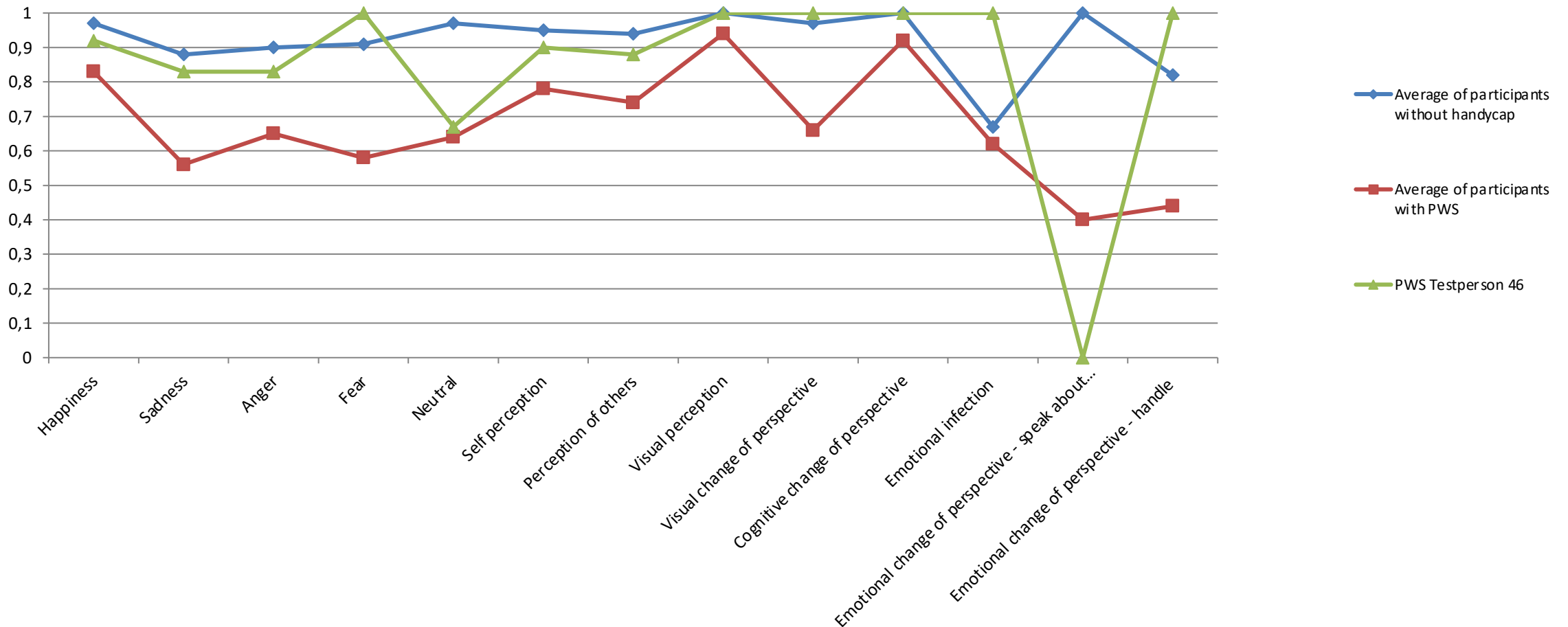
Example for „Test to change perspective by people with PWS (TPPWS)“

„John saw, that someone is falling down on the street. He went to the person, take his arm and helped him to stay up.

The person is looking angry to him and said: „Do you think I am a child, and I am not able to help my self?“ and pushed John away. John was angry and showed a challenging behavior later in the group home about it.

Example for „Test to change perpective by people with PWS (TPPWS)“

Profil test-person 46 PWS



Example for „Test to change perspective by people with PWS (TPPWS)“

Result: Item „Emotional change of perspective – speak about it“

Intervention/ Prevention / Treatment on the basis of the result of the test

Example for Social-emotional development (SEO)

Maria – 21 years old, is in her new group home since 5 days.

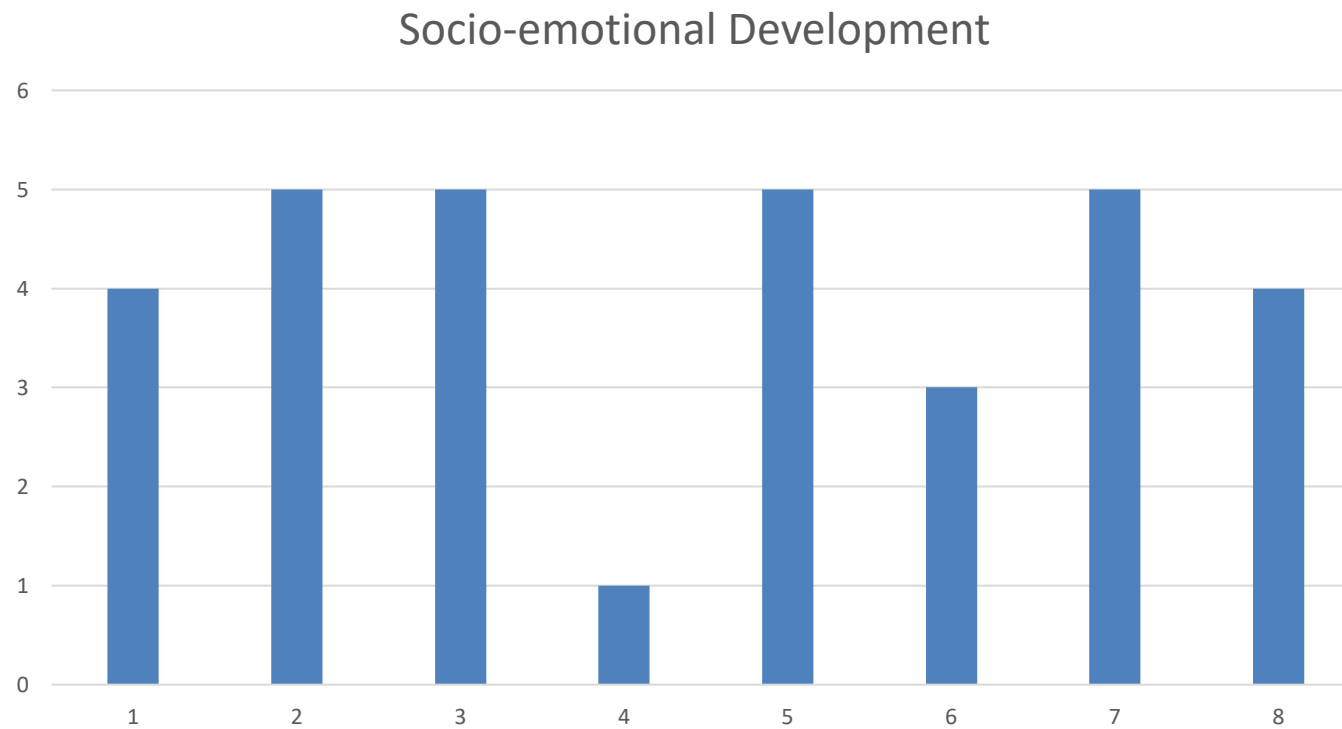
More times a day she take things from others, play with them in her room and looks very happy, when she is playing with it.

The others in the group home are angry or sad, that her favorite things are away.

One member of the staff said in the team-meeting: „we should take also things from her away, than she will see how the others feel when things are away. Than she learn to do it no longer“.

When the team handle it in this way, Maria gets a big crisis with crying, shouting, throwing things. And the steeling of things of the others is in the same frequenz in the next days.

Example for Social-emotional development (SEO)



Example for Social-emotional development (SEO)

Result: Item 4, Emotional Differentiation

Intervention/ Prevention / Treatment on the basis of the result of the test

Example Concentration and attention: d2 - Test

Harry 35 years, is working in the sheltered workshop, he said he like it and also the money he earns there.

Harry showed often negative behavior/ challenging behavior in the sheltered workshop, but only in the afternoon.

One option which was discussed is, that he could no longer work in the sheltered workshop.

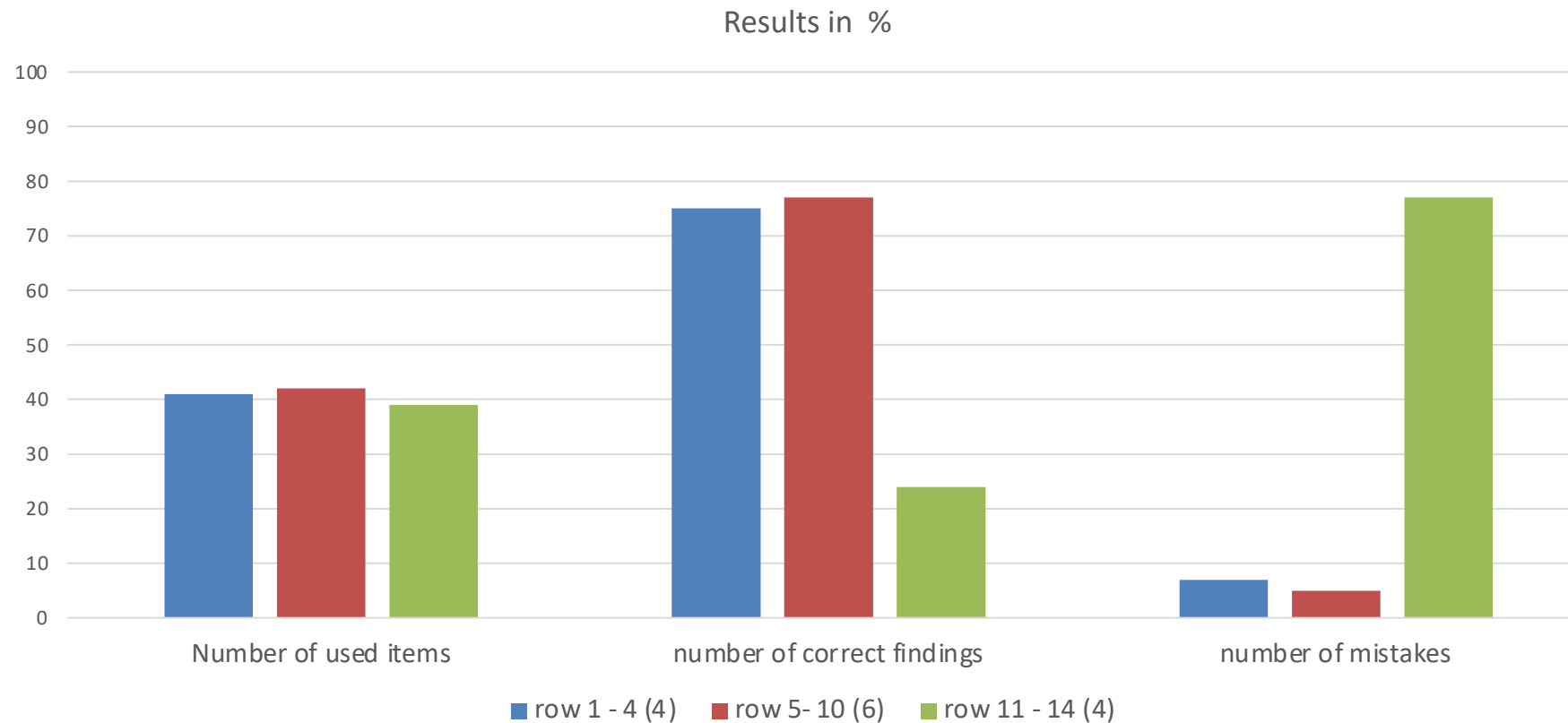
Example Concentration and attention: d2 - Test

1. dppppqqqppddbbbbdddddppbbbqqqpqbddqqdpppbpbbb
2. bddppbddqdqppppdbqbqbbdppbqdbppdbqbqbdpppqbdbq
3. bbbdqppdpqdpdpdbbqdpdbqqbdpdbqqqdpddbqbqbdpdp
- ...
14. bddppbddqdqppppdbqbqbbdppbqdbppdbqbqbdpppqbdbq

Results of d2-Test

	Number of used Items	Number of correct finding	Number of mistakes
row 1	11	8	1
row 2	9	7	1
row 3	10	9	0
row 4	11	8	1
total 1 - 4	41	32	3
row 5	11	9	2
row 6	10	8	1
row 7	12	8	1
row 8	9	7	0
row 9	11	9	1
row 10	10	8	1
total 5 - 10	63	49	6
row 11	9	4	4
row 12	11	3	5
row 13	11	2	5
row 14	10	2	6
total 11 - 1	41	11	20

Example Concentration and attention: d2 - Test



Example Concentration and attention: d2 - Test

Result: Last part of the test show a low concentration and attention

Intervention/ Prevention / Treatment on the basis of the result of the test

Example Behavior-Observation-Instrument

In a group home is a team of 8 staff members (one of them is coming in 3 weeks ago) and 6 people with PWS.

In the last team-meeting the hypothesis was coming up:

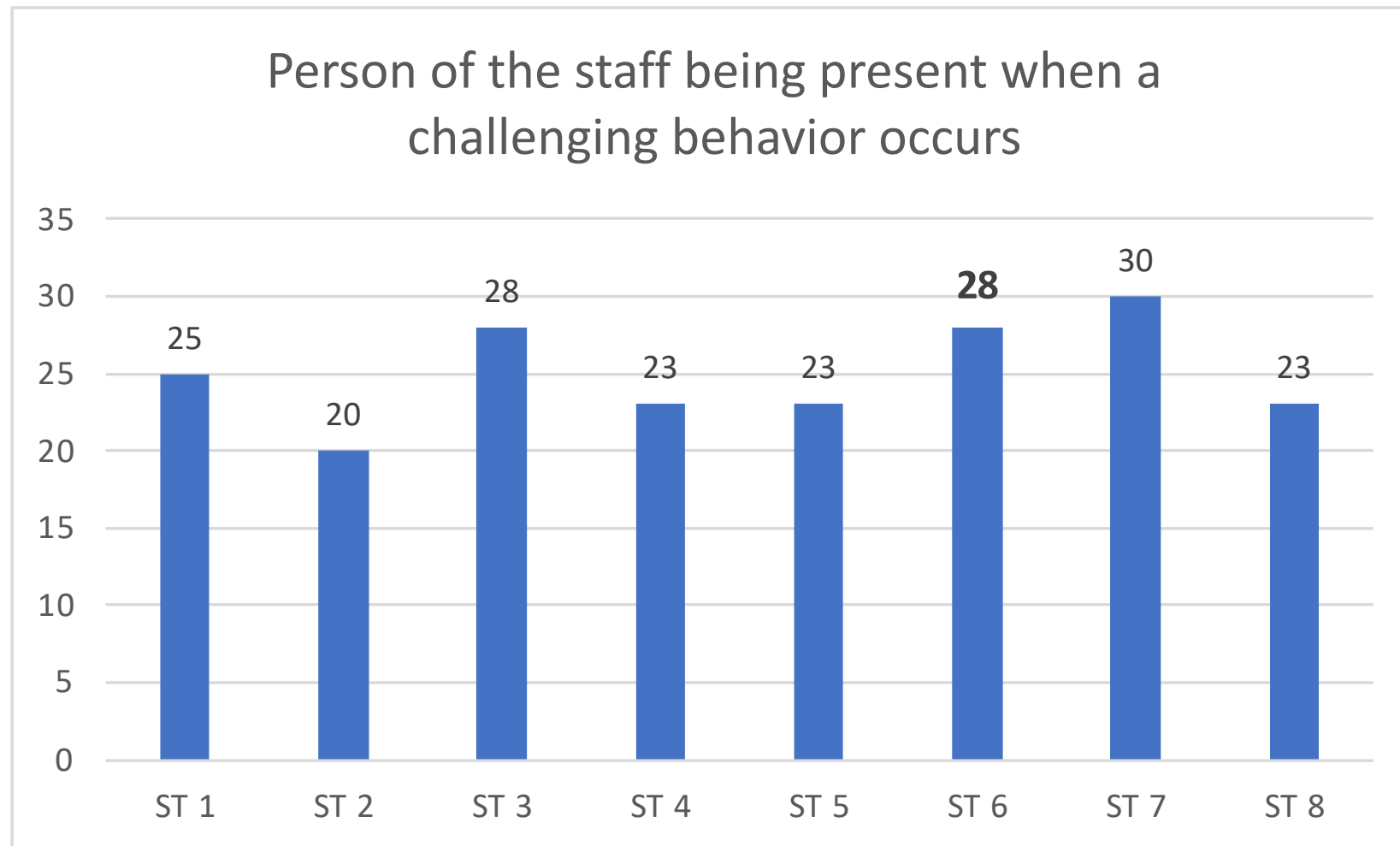
„Since the new member of the staff is there, the number of challenging behavior is increasing in the group home.“

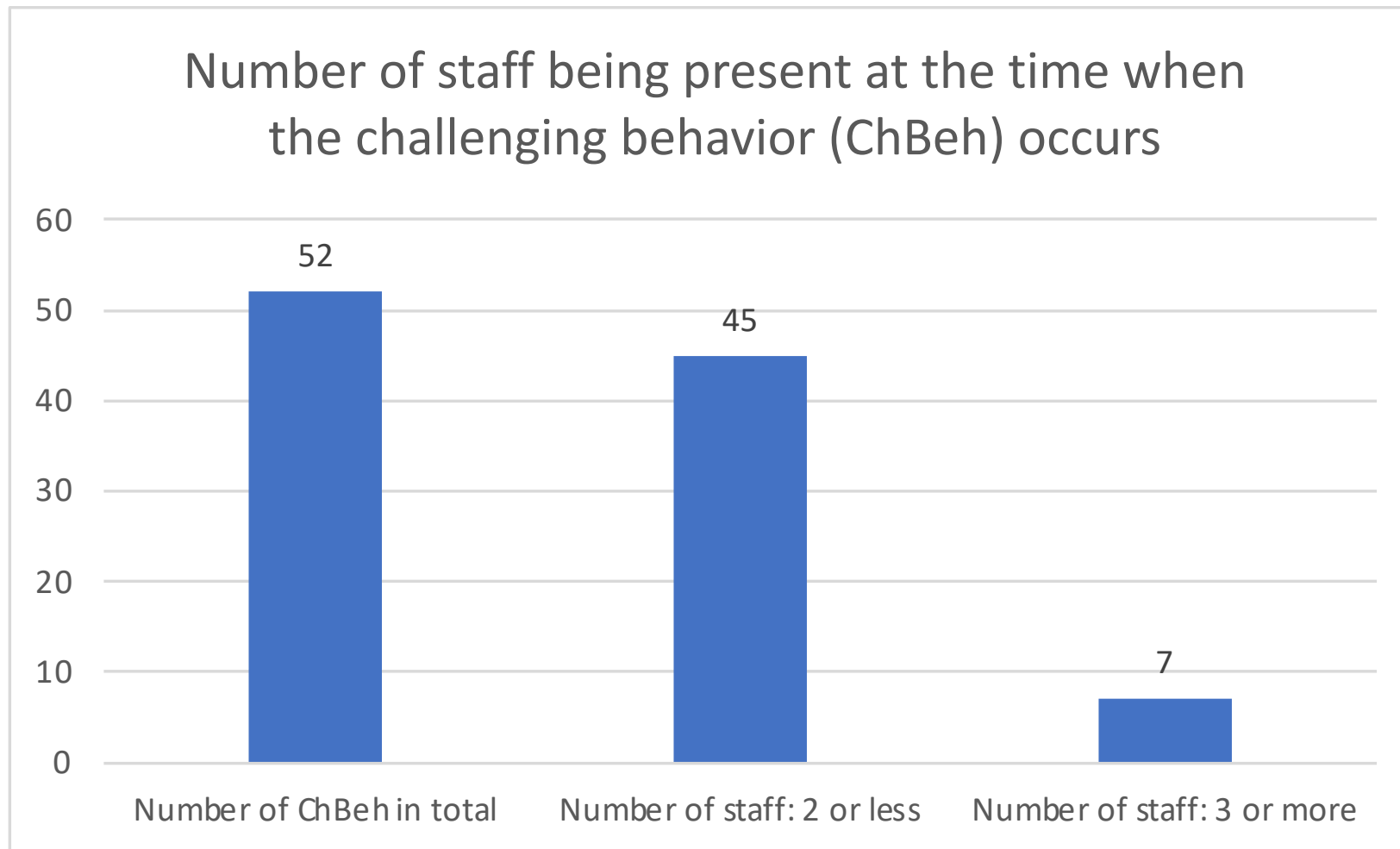
„Can he still working in the group home or should we „fire“ the new member of the staff?“

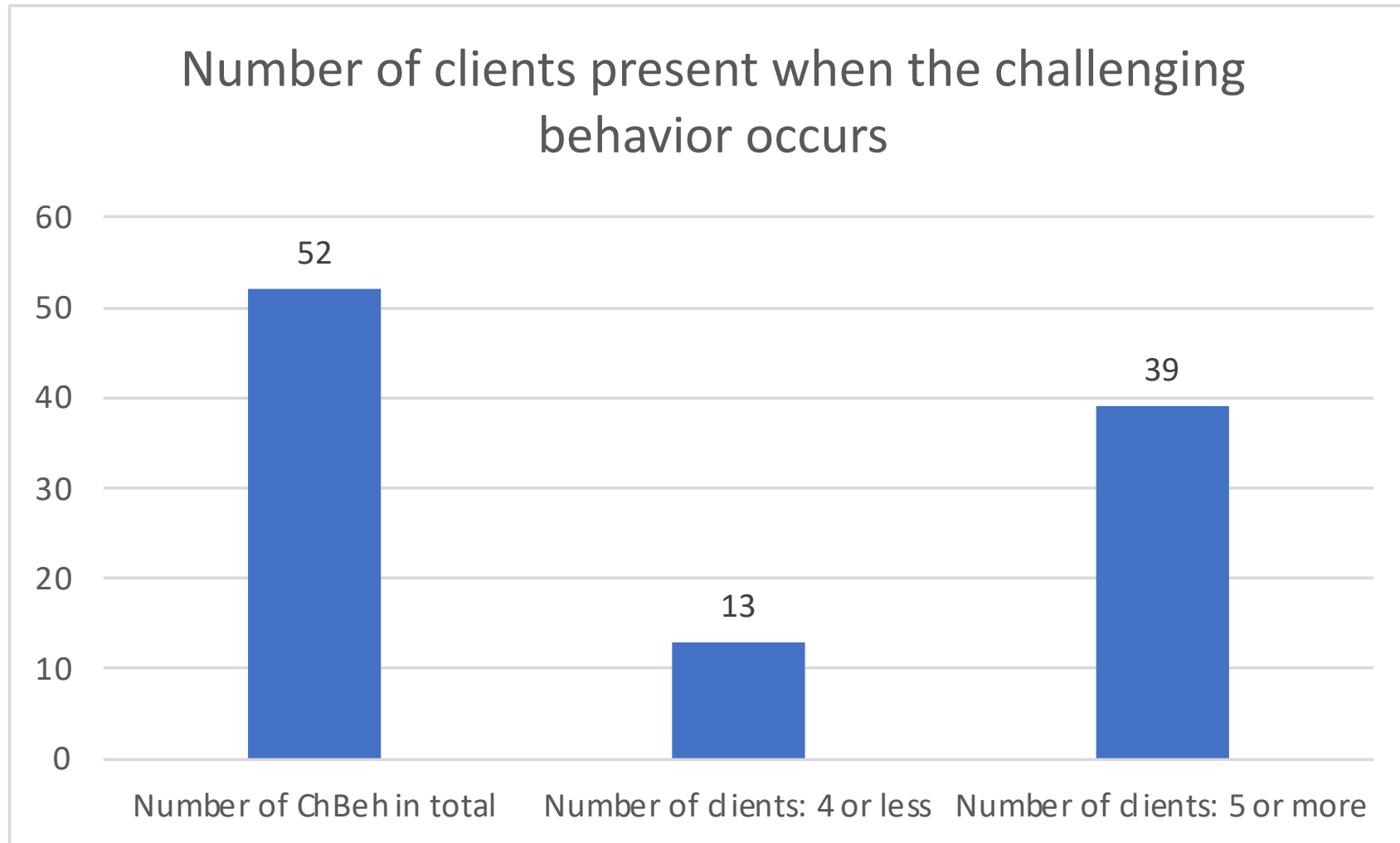
Behavior-Observation-Instrument

- Every challenging behavior in the group home has to be documented
- „When does a challenging behavior occurs and who is present?“
- Period of observation: 4 weeks

	Date	Time	Name of present staff	Number of Staff	Number of clients
1.					
2.					
3.					
4.					
5.					
6.					
7.					
8.					
9.					
10.					
11.					
12.					
13.					
14.					
...					







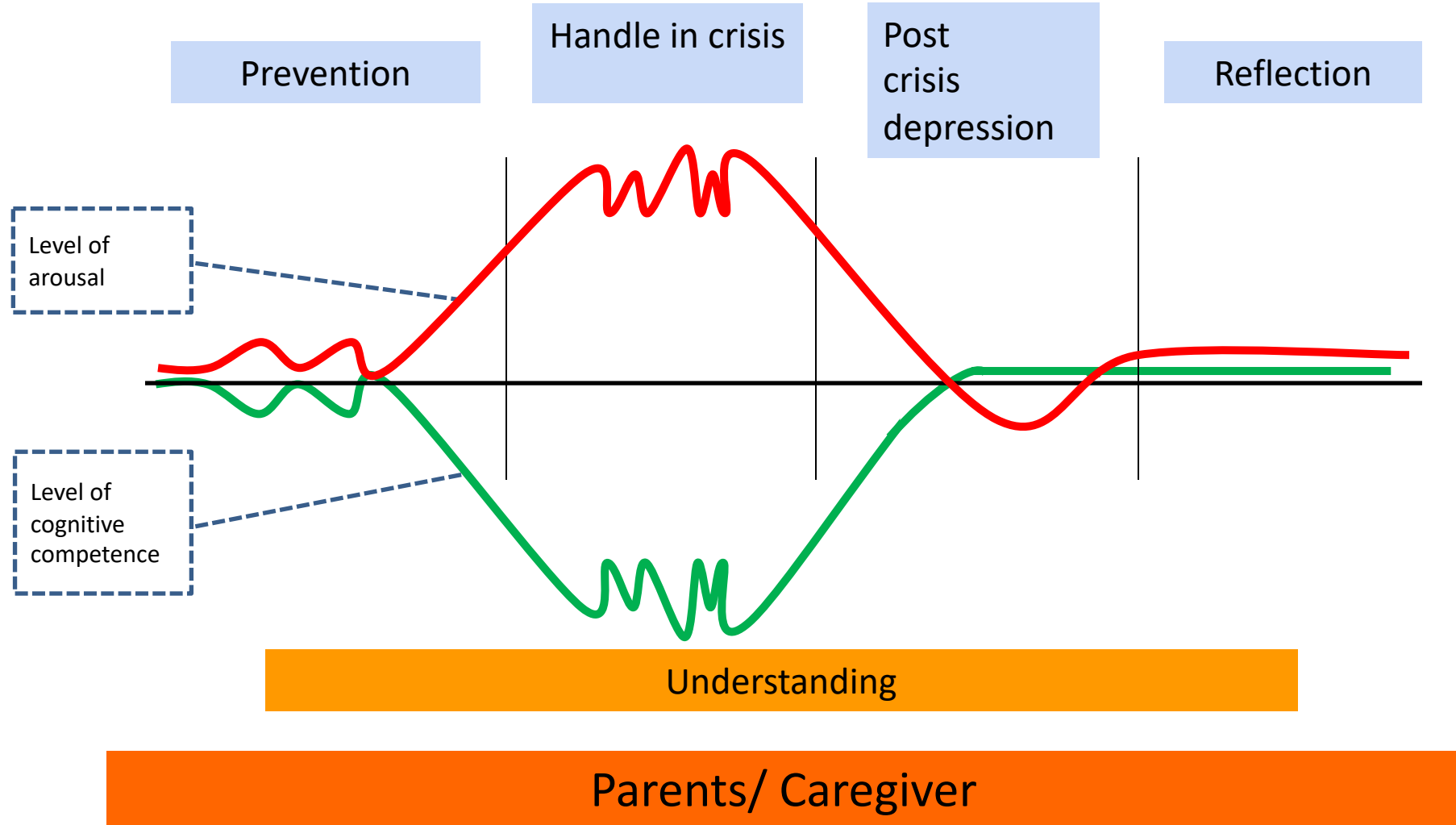
Example Behavior-Observation-Instrument

Result: Focus on Environment aspects – number of staff and clients

Intervention/ Prevention / Treatment on the basis of the result of the test

Course of a crisis

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Egocentrism		Perceiving emotions by others			
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