

Parental Coaching to Help Reduce the Effects of Stress





My Only Conflict of Interest ...

... arises when trying get through red tape, deal with the authorities and access services for people with FASD.

Unfortunately, this happens quite frequently !



Learning Objectives

- Recognize and understand the key stress factors for parents raising youngsters with FASD
- Learn about stress-relief factors to better cope
- Importance of holistic approach to FASD including educating caregivers



Background

"They're kind and they're sweet but they have boundary issues, they're destructive, aggressive and out of control; they appeal to our maternal instincts ... and sometimes they almost drive us to despair.

What on earth will become of them? Will they ever grow up? I mean, can we let them live on their own ...? After an absolute odyssey I just long to meet a doctor who understands my child and knows what FASD means."

(Foster Mother Quote)

Foster and adoptive parents raising a child with FASD have a stressful life. Their subjective perception is characterized by the feeling of having too little support and too few resources. In addition, because FASD is generally not well-known or understood, they frequently face extremely hurtful comments or reactions from the social environment

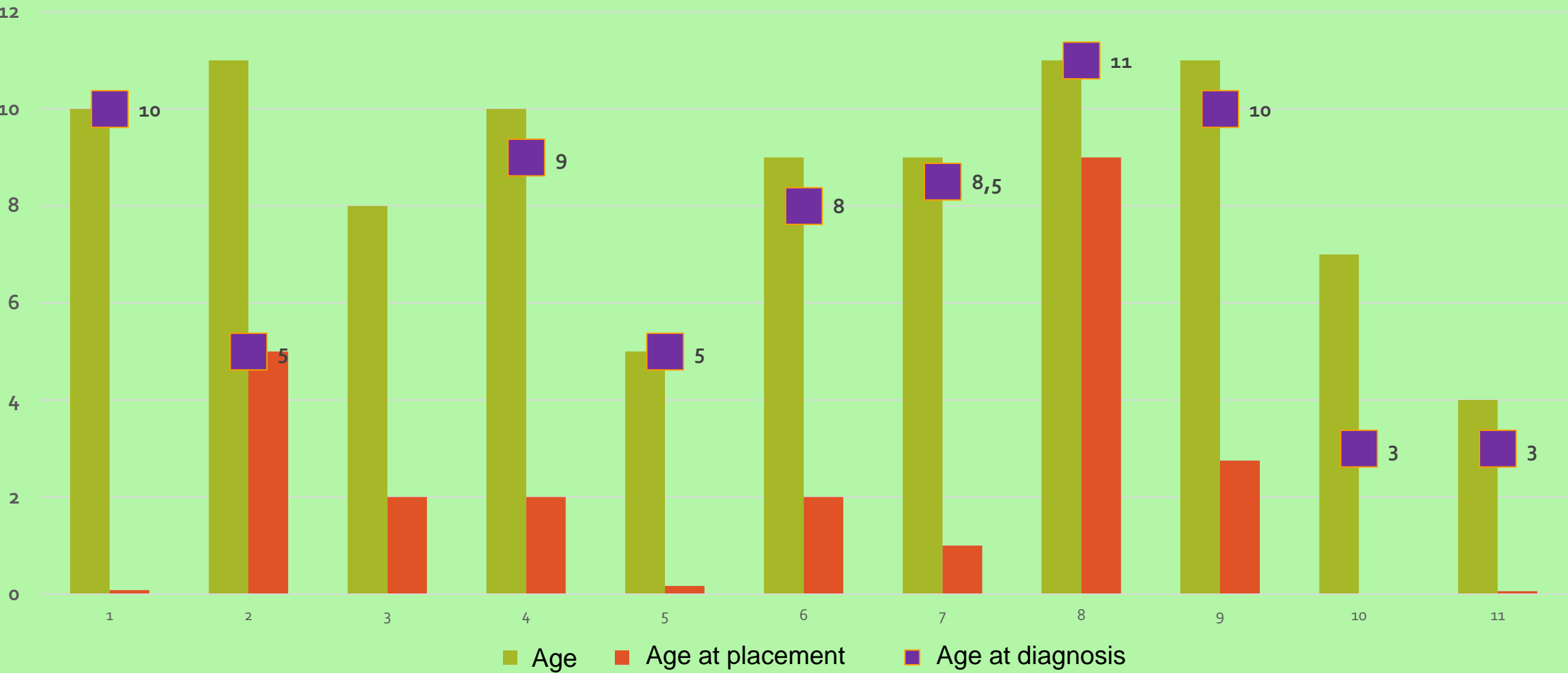


Target Group: Parents (Caregivers) of FASD Kids Treated at SPC Leipzig

- number of participants:** 12
- age of children:** 3 - 11 years
(3 preschool children, 9 children of school age)
- average age at time of placement:** 2 years
- average age at diagnosis:** 6 years

Age at Placement / Age Received FASD Diagnosis

- 8 out of 11 children were age 2 or under at the time of placement in foster or adoptive family
- 8 out of 11 children received the diagnosis before the age of 2 (as of August 21st 2016)



Questionnaires and Timing



- **Methods:**
 - Perceived levels of stress were determined before and after the course using the Parental Stress Questionnaire (PSI or ESF) by *H. Domsch, A. Lohaus* ***published by Hogrefe, Goettingen***
 - Special questionnaire for foster/adoptive parents; developed at SPC Leipzig and specifically related to FASD to determine the needs and assess experience of participants
- **Reference Period:**
 - PSI before parental coaching began (to)
 - PSI after the last regular meeting (t1)
 - Interview immediately after parental training finished and follow-up 5 months later

Questionnaires developed by the team at SPC Leipzig and specifically related to FASD



- **Questionnaire completed at the end of the course, covered:**
 - the most common problematic areas
 - diagnostic procedures
 - benefit of offers of support/assistance
 - the parents' needs
 - important "discoveries" (realisation/awareness)
- **Follow-up questionnaire after 5 months, course evaluation:**
 - did content prove valuable? Benefit gained
 - sustainability, lasting value -> practicable in everyday life?
 - positive effects of measures offered
 - qualities and skills adoptive/foster parents must have
 - spontaneous questions / current issues

Intervention Plan

Start of
parents'
course

Follow-up meetings

Previously diagnosed

1. Basic knowledge about FASD

3. Personalized advancement, avoiding overstrain

5. How to reduce stress for everyone, using role-play to help handle difficult situations

6. Discussion: problems, every day situations; Special Questionnaire

February 2016

March 2016

**April
2016**

May
2016

June
2016

November 2016

January
2017

February 2017

T0

T1

Parental Stress Questionnaire

2.Strategies for everyday life, emergency plans

4. Questions pertaining to social law, suitable schooling and job outlook

Parental Stress Questionnaire; Special Questionnaire

7. Discussion:
problems, every
day situations,
follow-up,

Treatment at SPC

Regular medical check-ups (also for co-morbid conditions, medication)

**Neuro psychological
diagnostics, trauma
therapy**

Organisation and co-ordination of treatment/therapies

Education for patients + caregivers including important aspects of social law; help gain access to integration assistance programmes

Advance social participation at all ages: kindergarten, school, accommodation, work

"Dealing with Anger"



Emergency Plan FASD - Questions to Ask

What? (Identify conflict situation/s)

When? (Situation that triggered it off/what time?)

Why ... did it happen?

Who ... was involved?

What can I/we do to change that?

Do we have resources we can activate?

Who?

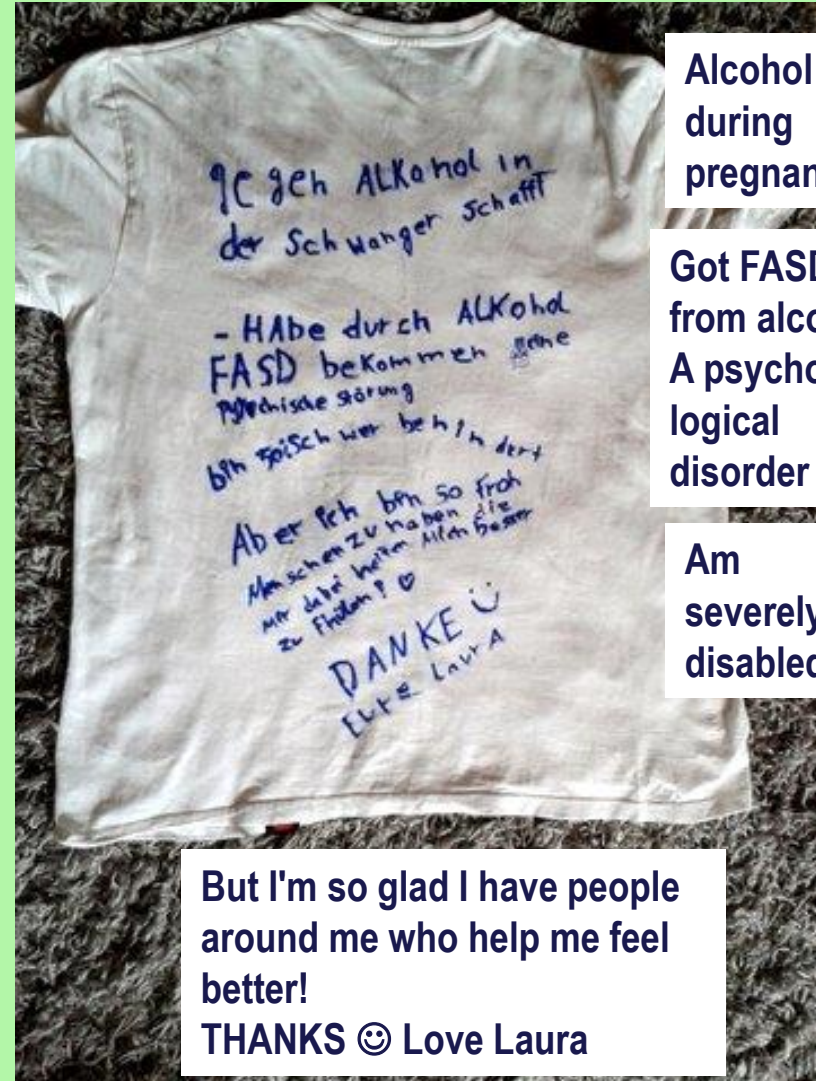
How?

What helps?

Use an "emergency" card

Use a "stop" card

What do I/we have to learn to accept?



Alcohol during pregnancy

Got FASD from alcohol. A psychological disorder

Am severely disabled

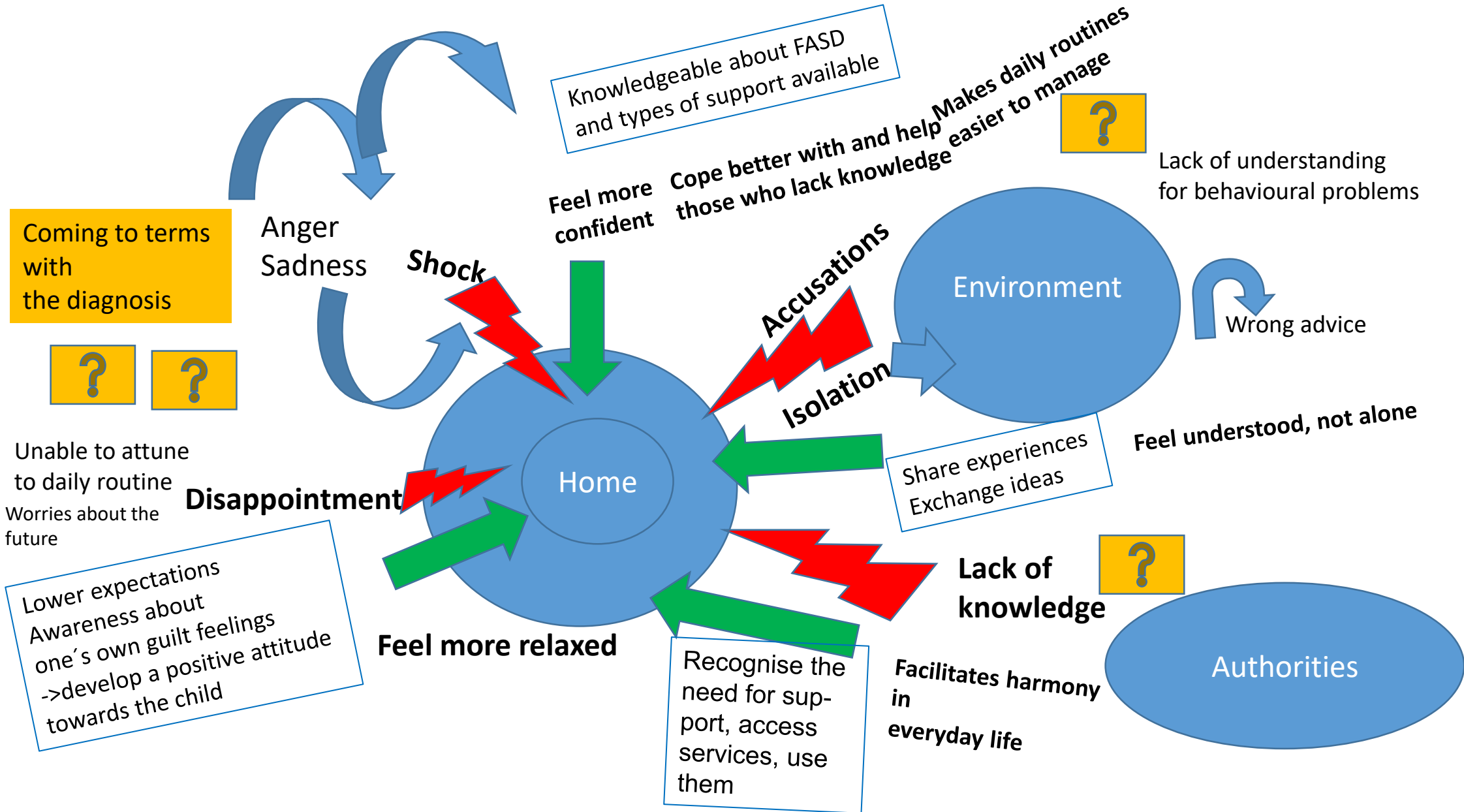
But I'm so glad I have people around me who help me feel better!
THANKS ☺ Love Laura

Results

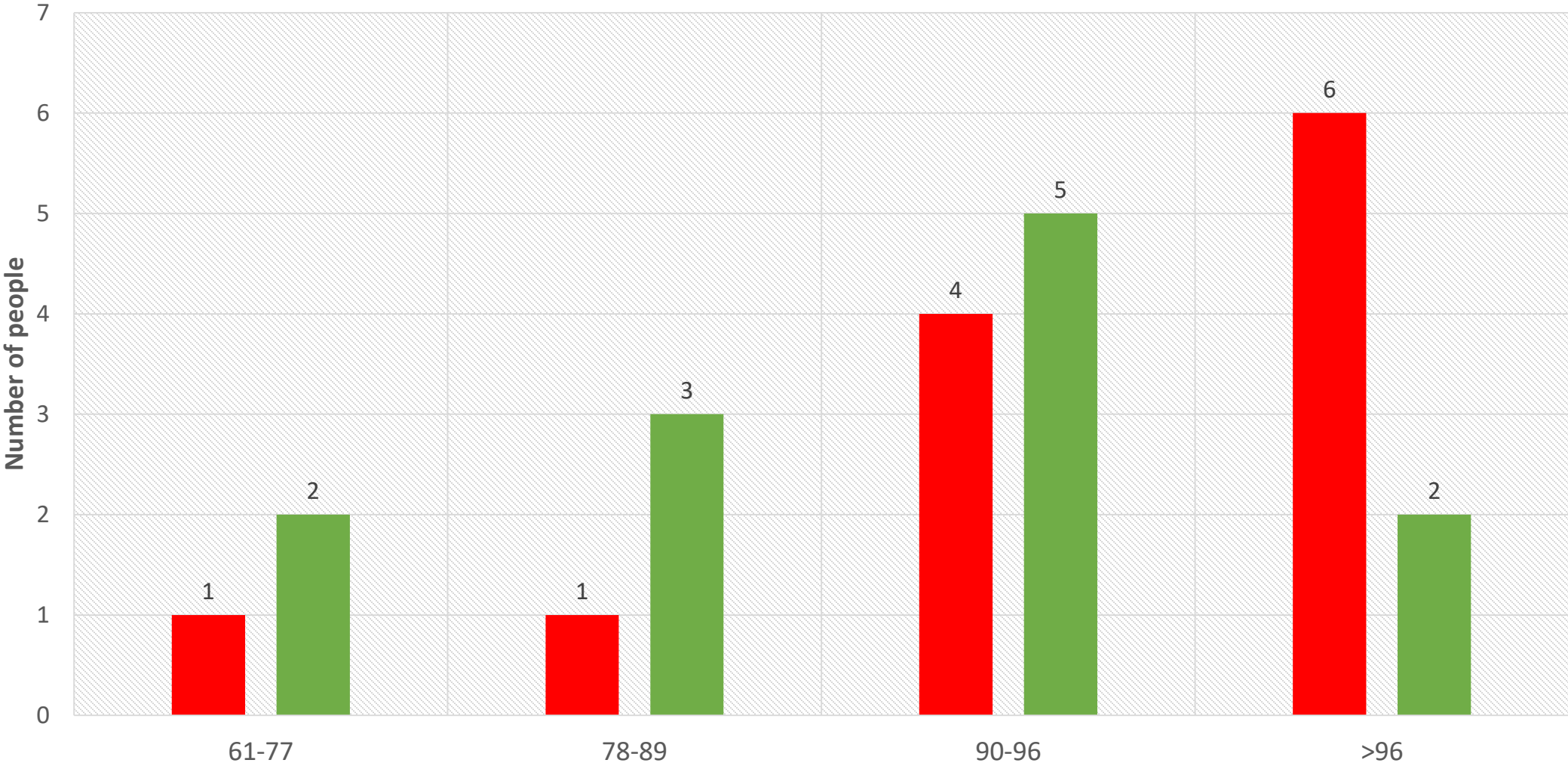


- Identification of primary stress factors
- Substantial reduction in stress levels
- Parents perceived improvement
- Daily routine became more manageable; effects of stress reduced by a change of attitude and implementation of (new) strategies (**Support Circle**)
- Developed awareness of structural preconditions

Primary Stress Factors



The graph shows the levels of parental stress perceived at the beginning and at the end of the training course (t0 and t1 respectively)



N= 12,
(10 foster / 2 adoptive parents)

■ to ■ t1

The x-axis shows the percentile rank whereby the values
61 - 77 are within the average range
78 - 96 are above the average range
> 96 are well beyond the average range

Results: How does the training course help ?



It facilitates

- **reality testing** which means learning to accept the disability; that takes the pressure off, reduces stress
- **a change of strategy**; that **changes expectations** (learn about distraction as a way of coping with difficult situations)

It teaches and explains how to

- **identify resources** and **talents** and **utilise** them
- **protect the child from stress** and **avoid overload**
- **access support**

The participants

- are given **useful tips for everyday life**
- are able to **reduce stress levels** by **learning how to deal with the authorities** and **acquiring knowledge about how to deal with FASD**
- **gain a better understanding of behaviour, certain habits and the problems** that make everyday life a challenge when raising children with FASD

The most important "discovery" was: it's not our fault, it's not the kids' fault, and other people have the same problems.

Support Circle

- Behavioural issues
- Temper tantrums
- Learning difficulties
- Constant supervision needed, support required to get through daily routine

Lack of understanding from social surroundings, finger pointing/blame, frequent conflict in social situations

Diagnosis FASD

Relief and / or shock?

?

?

- **Consultation: Explaining the diagnosis**
- Impart knowledge about FASD

Adjust expectations

- Share experience and stories with others in the same situation (no longer feel alone, feel understood)

Eradicate sources of stress

Explain FASD to social surroundings, develop strategies and share with others

- Educate and explain behaviour specific to FASD, exchange ideas, share
- Receive advice and useful tips
- Apply knowledge to the case in question

Acquiring knowledge and understanding

Stress-relief, "letting it out"

Developing confidence in dealing with FASD

Strengthening emotional health
Mindfulness

- Off-set anxiety and fear with the help of a professional who can answer your questions
- Consistent contact person

Self-care, seek help and support

Acceptance of FASD and coping

(family context, environment)



Foetal Alcohol Spectrum Disorder

Job Description for a Foster Mother

Working hours: 24 / 7 / 365-366

Salary: € 1.57 / per hour (highest salary)

Personal requirements / skills: marathon runner, kick-boxer, expert in self-defence, double decathlon athlete

Qualifications: Medical Doctor, Diplomat, Ambassador, Defence Lawyer

Additional qualifications in: therapeutic pedagogy, teaching, social education, trauma pedagogy and social law

Structural preconditions: "Game reserve" mentality, dedication, chaos and frustration tolerance, sense of humour (preferably black!), flexibility, patience, courage, assertiveness

No-one can manage that on their own - what you need is a network of people

Conclusion



- Professional trainer is necessary to lead the group and guide/steer positive group dynamics → solution-oriented discussion → methods for **coping and dealing** with FASD.
- Reduced stress levels lead to a more positive view of children.
- Parental coaching is only **one element of the master plan** and it is imperative it be continued.
- The participants call for support and demand that FASD be recognized as a lifelong disability
- One goal was to encourage parents to learn to accept help and to understand the importance of any opportunity for respite in order to have some "time off" to regenerate.
- It is planned to publish results in the form of a **coaching manual**. The manual will be designed for use by FASD experts who will be trained before they use the manual and become a multiplier.

Skills Our Parents Need

Patience, calmness,
composure, endless
stamina, capable of
showing
understanding,
unconditional love for
us (FASD Kids)

Results from
questionnaire



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