

MUTUAL SUPPORT - MORAL SUPPORT



A Mini-Break for Families Raising Youngsters with FASD

**8th International Conference on
Fetal Alcohol Spectrum Disorder
Research, Results and Relevance**

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Presenter Disclosure

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Relationship with commercial interests: None

Managing Potential Bias

n/a (no relationship with commercial interests)

What Are We Going To Talk About?

- **Background Information & Development**
 - **Looking Back - How It All Began**
 - **Numbers**
 - **Where We Are Today**
- **Concept**
 - **Three Basic Elements**
- **What Have We Learned?**
- **Looking Forward**

Background Information & Development

- **Late 90's:**
 - **The first families raising children with FASD "met" via the internet**
 - **Desire to meet face to face**
- **2003: 1st family weekend in Hilchenbach near Siegen, North Rhine-Westphalia (60 people)**
- **2018: 173 attendees (74 adults, 72 children, 27 carers)**
- **2019: 153 attendees (65 adults, 66 children, 22 carers)**
- **2018/2019 plus one external speaker**

The Concept

- **Identify the families' needs**
 - determine the programme (themes, activities, location)

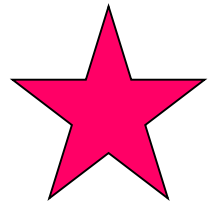
- **Self-monitor, review, modify**
 - different group of people every year

- **Streamline organisation**
 - increase in number of participants!

- **Organise funding**

The Families

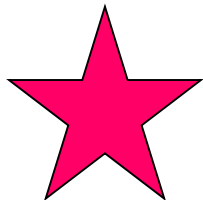
1. Adults = parents
2. "Children" of all age groups
 - a) youngsters who have FASD
 - b) youngsters who don't have FASD



**DIVERSE BACKGROUNDS, PERSONALITIES,
NEEDS!**

Adults' Motivation and Needs

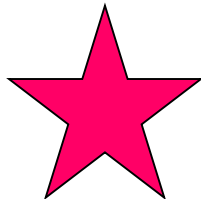
1. Get away
2. Desire to meet like-minded people / connect /
leave isolation
3. Dire need to learn more about FASD



Empowerment

Children's Needs

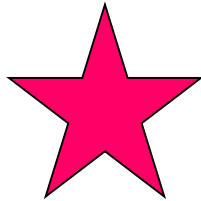
1. Enjoy time away from home (safe environment)
2. Desire to belong / make friends / be "normal"
3. Coping and acceptance of FASD (observe others
"FASD watching", practice social skills)



Empowerment

Three Basic Elements

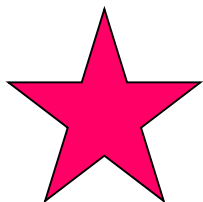
1. Family Time = facilitates well-being
2. Fun (leisure), activities, relaxing
3. Education



"Familienbildungsfreizeit"

Family Education Leisure

Not to forget ...



... the glue

S T R U C T U R E

Family Time

1. Youth hostel + family rooms
2. Morning circle + time-to-go-home circle
3. Fixed meal times, long lunch break
4. Activities as a family:
 - indoor and outdoor games, camp fire, BBQ
5. No obligation to join in

Fun

- **Carer/teamer-child ratio of 1:3**
- **Supervised activities for the children**
 - according to age, capability, likes and dislikes
 - balance: indoor/outdoor; on the move/sitting still
 - for all age groups
- **Educational games, pedagogical value**
 - aim to develop self-confidence, problem-solving skills, cooperation, concentration, stamina

Fun

- **Circus project - children perform**
- **Falconer with his birds of prey**
- **"Drum Magic" - a drum workshop for kids**
- **Quad bikes and trikes**
- **Film project for teens - with Playmobil® figures**

Fun The Film Project

- with Playmobil® figures (2018)
- idea and screenplay developed by the film group
- 10 "film makers" aged 16 - 21
- 3 - 4 people working on the set at any one time
- **750** camera shots / film lasts **30 seconds**



External Professional Speakers

- **trauma and bonding issues**
- **mental health concerns**
- **special educational and pedagogic approaches**
- **various types of therapy**
- **legal issues, sexuality and disability**

Speakers from within our organisation

- **understanding FASD**
Development and behaviour - at kindergarten, at school, as a teenager
- **FASD and education (systems)**
- **Marte Meo**
- **practical tips for everyday**
- **transition into adulthood**

Of an informal nature ...

"Mutual Support - Moral Support"

- learn from one another
- share experience with others
- help one another

What Have We Learned? Conclusions

- **Beneficial for the whole family**
- **The combination of these 3 elements is ideal**
- **We understand more about FASD**
- **We are understood**

And that can make a huge difference!



Looking Forward

We need to

- **continue this work**
- **cover "relatively new" aspects**
 - **FASD across the lifespan**
 - **FASD a whole body diagnosis**
- **remain flexible**
 - **adapt to the needs of our families**

Goodbye and auf Wiedersehen!



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