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
March 6-9, 2019 - Vancouver, BC, Canada
Presenter Disclosure

Alison Frieleng and Gisela Michalowski

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
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
1. Adults = parents

2. "Children" of all age groups
   a) youngsters who have FASD
   b) youngsters who don't have FASD

DIVERSE BACKGROUND, 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

STRUCTURE
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!

FASD Deutschland e.V.
Huegelweg 4
D- 49809 Lingen

info@fasd-deutschland.de
www.fasd-deutschland.de
www.fasd-fachtagung.de

Alison Frieling
alisonfrieling@
fasd-deutschland.de

Gisela Michalowski
giselamichalowski@
fasd-deutschland.de