EVERYDAY LIFE AND FASD
A Weekend Break for Adults Affected by FASD
Peer-to-Peer Exchange, Led by Professionals

8th International Research Conference on Adolescents and Adults with FASD
Review, Respond and Relate

Vancouver, BC, Canada
April 18 - 21, 2018

FASD Deutschland e.V.
Background

- Dramatic increase in the number of adults diagnosed with FASD seeking help from our organisation
  - left alone, isolated, ignored, forgotten
  - fallen through the cracks

- Need for support (peer-to-peer exchange, coaching and/ or mentoring)
**Decision:** Board meeting Summer 2015
Organise a weekend break for adults with FASD and their immediate caregiver

**Hurdles:**
- Sponsor required
- Location?
First Steps

- Applications for grants
- Develop concept
- Find the right professionals
- Find a suitable location
- Spread information
First Achievements
29 people

- First event of this type: July 2016, Fulda youth hostel
- Sponsor = health insurance company

- 15 adults diagnosed with FASD
  20 - 58 years old
- 6 caregivers/ life partners,
  4 children, 1 childminder
- 1 social worker (FASD experienced)
- 2 other experienced speakers
Key Questions

Moderated Discussion "Life Circumstances"
(led by social worker)

- What can or can't I manage well?
- Where/when do I need help?
- How can we help each other?
- What do we need?

First Weekend Break for Adults
15 - 17 July 2016
First Results

Mission Statement: "First and foremost we want justice ..."
- Clarify the legal status of the unborn child (person)
- Ask to be respected and to be met at eye level
- Demand of us, we act NOW.

Questionnaire about medical conditions developed
(similar to the beginnings of "The Lay of the Land")

First adult FASD self-help group, Berlin
- Overall positive response
  - request for a repeat weekend 2017
  - one extra day
  - focus on "Emergency Plans" and "FASD pass"
26 adults with FASD; 15 caregivers/ life partners
4 speakers plus 1 moderator
12 children and 2 childminders

- 2 FASD groups: "high-functioning/ "low-functioning"
- group for caregivers/ life partners
  (own moderator)
- additional accommodation booked
- costs: € 12,700 incl. travel expenses (DAK)
Group Rules

- **Secrecy**: Nothing said here leaves this room
- **Voluntariness**: Only tell as much as you feel happy to
- **Value**: No judgement of what others say
- **Interaction**: Be respectful, hear others out
- **Questions**: Dealt with in order of priority
Subjects of Discussion

Key words:

- Household
- Dealing with the authorities
- Family planning
- Help with daily routine

- Work (incl. sheltered workplace)
- Living accommodation
- Legal issues *
- Pensions

* People with FASD don't qualify for compensation under the German OEG (Victims' Compensation Statute)
Results

Individuals with FASD

- realised potential to help each other
- improved confidence (self-esteem)
- developed a feeling of "belonging"

Caregivers/Partners

- recognized need for "road maps" "What do I do if/when ...?"
- first ideas put together
  - unique
  - simple
  - practiced
  - updated

"A trouble shared is a trouble halved"
Conclusions

We need:

- knowledge/ awareness about FASD; how adult lives are affected
- practical help
- political awareness/ readiness > legislation

We have:

- a wealth of knowledge and experience
- courage to stand up and be counted

We're worth it!!!
Goodbye and auf Wiedersehen!

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EUFASD 2018
24 - 26 September

H4 Hotel Berlin
Alexanderplatz
(formerly Ramada)