BSI-FASD
Biographic Screening Interview for Adults with FASD

Lina Schwerg & Sandra M. Ahlert

8th International Research Conference on Adolescents and Adults with FASD
Review, Respond and Relate
Integrating Research, Policy and Practice Around the World
April 19th 2018
Overview

• Introduction
• Background
• The BSI-FASD
• Translation and Adaptation
• Evaluation
  • BSI-FASD Diagnostic Process Overview
  • Recruitment of Participants
  • Implementation of the BSI-FASD
  • Results
• Discussion: Limitations and Recommendations
Introduction

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- BSc Psychologist
- Master student, University of Potsdam
- FASD-Fachzentrum Sonnenhof, Berlin, Germany
  - Apprenticeship
  - Bachelor thesis on Executive Function in Youth with FASD
  - Assistant to Gela Becker
  - Co-Therapist in Group sessions for Adults and Youth with FASD
  - Neuropsychological Diagnostics

**Sandra M. Ahlert**
- BSc Psychologist
- Master student, University of Potsdam
- FASD-Fachzentrum Sonnenhof, Berlin, Germany
  - Apprenticeship
  - Research on FASD
  - Whitecrow Village FASD Society
    - Continued research on FASD
  - Master Thesis on Factors for a Successful Adaption
Background

2014 – 2015 Research Project

“Development of Group Sessions for Adults with FASD and Risk of Addiction”

A research project funded by the BMG (German Ministry of Health)

Results: 5 Projects

1. Weighting of the Impairments for Interventions, Analysis and Prospects
2. Group sessions for Adults and Youth with FASD
4. Adults with FASD and similar…. 
5. Life History Screen → BSI-FASD
Biographisches Screening-Interview für FASD (BSI-FASD)

Adapted Version of the English Life History Screen (LHS)\(^1\)

BSI-FASD
Biographisches Screeninginterview für FASD

- Structured Interview
- 32 Items – 30 Items rated
- 9 Domains:
  1. Childhood History – 2 Items
  2. Maternal Alcohol Use – 3 Items
  3. Education – 4 Items
  4. Criminal History – 3 Items
  5. Substance Use – 2 Items
  6. Employment and Income – 2 Items
  7. Living Situation – 2 Items
  8. Mental Health – 3 items
  9. Day to Day Behavior – 11 Items
BSI-FASD
Biographisches Screeninginterview für FASD

- Each rated item has a corresponding Red-Flag-Response
- Each category has a minimum amount of Red-Flag-Responses required

![Image of BSI-FASD example question and response]

7. Living Situation
   a. As an adult have you ever lived on your own (paying your own rent, etc.)?
      □ Yes  □ No  [Interviewer note: red flag response is no]
      [If 7a = yes, then go to 7b, if 7a = no go to 8a]
   b. How long have you lived on your own at any one time?
      [Interviewer note: red flag response is less than 1 year]
BSI-FASD
Biographisches Screeninginterview für FASD

Screening Results: Who should be referred for diagnosis?

(1) Red Flags in all three Key Life History Domains

<table>
<thead>
<tr>
<th>Key Life History Domain</th>
<th>Red Flag?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Childhood History</td>
<td>Is 1b. response “more than 2”?</td>
</tr>
<tr>
<td></td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Maternal Alcohol Use</td>
<td>Are 2 or more responses “yes” or “unknown”?</td>
</tr>
<tr>
<td></td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>Day-to-Day Behaviors</td>
<td>Are 5 or more responses “yes”?</td>
</tr>
<tr>
<td></td>
<td>□ Yes □ No</td>
</tr>
</tbody>
</table>

OR
BSI-FASD
Biographisches Screeninginterview für FASD

Screening Results: Who should be referred for diagnosis?

(2) Red Flags in two Key Life History Domains and two or more Red Flags in the other Life History Domains

<table>
<thead>
<tr>
<th>Other Life History Domain</th>
<th>Red Flag?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>Is at least 1 response “yes”?</td>
</tr>
<tr>
<td>Criminal History</td>
<td>Is at least 1 response “yes”?</td>
</tr>
<tr>
<td>Substance Use</td>
<td>Is at least 1 response “yes”?</td>
</tr>
<tr>
<td>Employment and Income</td>
<td>Is at least 1 response “yes”?</td>
</tr>
<tr>
<td>Living Situation</td>
<td>Is at least 1 response “yes”?</td>
</tr>
<tr>
<td>Mental Health</td>
<td>Are at least 2 responses “yes”?</td>
</tr>
</tbody>
</table>
Why bother?

In Germany there is a gap between the **suspected** prevalence of adults with Fetal Alcohol Spectrum Disorder (FASD) and the number of people with **actual** diagnosis of this disorder. BSI-FASD can help identify those who should be referred for medical diagnosis.

**Diagnosis can help:**

<table>
<thead>
<tr>
<th>Service Providers/Families</th>
<th>Adults with FASD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Explain behavioral and functional impairment</td>
<td>✓</td>
</tr>
<tr>
<td>Form more realistic expectations</td>
<td>✓</td>
</tr>
<tr>
<td>Adopt compensatory strategies</td>
<td>✓</td>
</tr>
<tr>
<td>Acquire appropriate therapy</td>
<td>✓</td>
</tr>
<tr>
<td>Receive necessary and appropriate services</td>
<td>✓</td>
</tr>
<tr>
<td>Reduce secondary disabilities and adverse life outcomes</td>
<td>✓</td>
</tr>
</tbody>
</table>

(Grant, Brown, Dubovsky, Sparrow, & Ries, 2013)
Why bother?

Figure 1. Secondary Disabilities in a recent German Study (Fröhlich, 2015)
Translation and Adaptation

Step 1
- Translating the LHS (Grant et al., 2013) into German

Step 2
- Retranslating the German version into English to ensure no information / meaning was lost

Step 3
- Adapting items to the German culture

Step 4
- Making German items comprehensible by consulting with an FASD-expert
- Adding “B-Notes” for hard-to-understand items

Example of a B-Note for Employment and Income:
- Definition of SSI

b. Waren Sie jemals auf staatliche Unterstützung angewiesen?
[B-Hinweis: Geld vom Amt, Grundsicherung, Arbeitslosengeld, Erwerbsunfähigkeit, Früh-Rente]
☐ Ja ☐ Nein [Anmerkung: alarmierende Antwort ist Ja]
BSI-FASD Diagnostic Process:
Staff Training & Participant Recruitment

Staff Training *prior to* participant recruitment:

- In-depth staff training on FASD and the medical diagnosis of FASD
- Training on the administration of the BSI-FASD diagnostic tool
- Sensitivity training on how to respectfully interact with FASD adults regarding difficult topics, such as maternal alcohol use
Recruitment of Participants

*Participants were recruited from four sources:*

1. Paracelsus-Wiehengebirgsklinik Bad Essen: an alcohol and prescription drug rehabilitation clinic
   - $N = 122$ screened with the BSI-FASD
     - $N = 8$ (7.2 %) positive screens
     - 4 released early, 1 declined,
       1 the doctor was not able to see,
       2 completed the diagnostic
Recruitment of Participants

*Participants were recruited from four sources:*

(2) FASD-Fachzentrum Sonnenhof

- \( N = 17 \)
  - 12 with pre-diagnosed FASD
  - 5 with a pre-diagnosed negative result
  - (7 more chose not to participate)

(3) Self-help Group for people with FASD

- \( N = 3 \) with pre-diagnosed FASD
  - (4 more chose not to participate)

(4) Member of FASD-Deutschland

- \( N = 1 \) with pre-diagnosed FASD
Diagnostic Process
for participants without pre-diagnostic

1st Diagnostic Step
- BSI-FASD
- Prenatal Alcohol Exposure
- Facial Dysmorphe

2nd Diagnostic Step
- Growth Abnormalities
- Microcephaly
- CNS-Anomalies

N = 90 completed this process
Overall Participant Demographics

- $N = 111$

**Gender:**
- 74 male (66.7%),
- 37 female (33.3 %)

**Age-Range:** 20 – 74 ($M = 46.2$, $SD = 13.482$)

**Diagnostics:**
- 90 completed the diagnostic process
- 16 were pre-diagnosed with FASD
- 5 had a pre-diagnosed negative result
Implementation of the BSI-FASD

• Each interview lasted between 5 – 8 minutes
• The closer the interviewer stayed to the wording of the interview, the smoother it went
• All items that participants found hard to understand in the initial wording could be explained by using the B-Notes
• Overall the interview was easy to implement
• The option “unknown” as a red-flag-answer to the maternal alcohol use questions proved very helpful, as many did not know

Q: Did your mother drink alcohol while she was pregnant with you?  
A: “I don´t know, I was in the womb you know.”
## Results – Descriptive Analysis

Table 1

*Descriptive Analysis.*

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Sex</th>
<th>FASD Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Negative Screening</td>
<td>91</td>
<td>60</td>
<td>31</td>
</tr>
<tr>
<td>Positive Screening</td>
<td>20</td>
<td>14</td>
<td>6</td>
</tr>
<tr>
<td>Total</td>
<td>111</td>
<td>74</td>
<td>37</td>
</tr>
</tbody>
</table>
Results – Screening

Figure 2. Comparison of Red Flag Responses in the BSI-FASD Categories between Participants with Negative Screening, Positive Screening and Overall (Part 1).
Results – Screening

Figure 2. Comparison of Red Flag Responses in the BSI-FASD Categories between Participants with Negative Screening, Positive Screening and Overall (Part 2).
## Results – Screening

### Table 2

*Comparison of Group 1 (Negative Screening) and Group 2 (Positive Screening) on Categories with Red Flag Responses.*

<table>
<thead>
<tr>
<th>BSI-FASD Category</th>
<th>Group 1 - Negative Screening (N = 91)</th>
<th>Group 2 – Positive Screening (N = 20)</th>
<th>( \phi )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Childhood History</td>
<td>1 (1.1%)</td>
<td>8 (40%)</td>
<td>.548***</td>
</tr>
<tr>
<td>Maternal Alcohol Use</td>
<td>15 (16.5%)</td>
<td>20 (100%)</td>
<td>.691***</td>
</tr>
<tr>
<td>Education</td>
<td>34 (37.4%)</td>
<td>18 (90%)</td>
<td>.405***</td>
</tr>
<tr>
<td>Criminal History</td>
<td>33 (36.3%)</td>
<td>10 (50%)</td>
<td>.108 n.s.</td>
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<tr>
<td>Substance Use</td>
<td>8 (8.8%)</td>
<td>4 (20%)</td>
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<tr>
<td>Employment and Income</td>
<td>53 (58.2%)</td>
<td>16 (80%)</td>
<td>.172°</td>
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<tr>
<td>Living Situations</td>
<td>4 (4.4%)</td>
<td>12 (60%)</td>
<td>.608***</td>
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<td>Mental Health</td>
<td>8 (8.8%)</td>
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\( ^* p < .1, ^* p < .05, ^{**} p < .01, ^{***} p < .001 \)
## Results – Screening

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## Results – Screening

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</tr>
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<td>20 (100%)</td>
<td>.691***</td>
</tr>
<tr>
<td>Education</td>
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</tr>
<tr>
<td><strong>Criminal History</strong></td>
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</tr>
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</tr>
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</tr>
</tbody>
</table>

°p < .1, *p < .05, **p < .01, *** p < .001
Results – FASD Diagnosis

Figure 3. Comparison of Red Flag Responses in the BSI-FASD Categories between Participants without FASD Diagnosis, with FASD Diagnosis and Overall (Part 1)
Results – FASD Diagnosis

Figure 3. Comparison of Red Flag Responses in the BSI-FASD Categories between Participants without FASD Diagnosis, with FASD Diagnosis and Overall (Part 2).
## Results – FASD Diagnosis

Table 3  
*Comparison of Group 3 (No FASD) and Group 4 (Diagnosed FASD) on Categories with Red Flag Responses.*

<table>
<thead>
<tr>
<th>BSI-FASD Category</th>
<th>Group 3 – No FASD (N = 95)</th>
<th>Group 4 – FASD (N = 16)</th>
<th>ϕ</th>
</tr>
</thead>
<tbody>
<tr>
<td>Childhood History</td>
<td>4 (4.2%)</td>
<td>5 (31.3%)</td>
<td>.348***</td>
</tr>
<tr>
<td>Maternal Alcohol Use</td>
<td>19 (20%)</td>
<td>16 (100%)</td>
<td>.605***</td>
</tr>
<tr>
<td>Education</td>
<td>37 (38.9%)</td>
<td>15 (93.8%)</td>
<td>.386***</td>
</tr>
<tr>
<td>Criminal History</td>
<td>35 (36.8%)</td>
<td>8 (50%)</td>
<td>.095 n.s.</td>
</tr>
<tr>
<td>Substance Use</td>
<td>11 (11.6%)</td>
<td>1 (6.3%)</td>
<td>-.06 n.s.</td>
</tr>
<tr>
<td>Employment and Income</td>
<td>55 (57.9%)</td>
<td>14 (87.5%)</td>
<td>.214*</td>
</tr>
<tr>
<td>Living Situations</td>
<td>6 (6.3%)</td>
<td>10 (62.5%)</td>
<td>.562***</td>
</tr>
<tr>
<td>Mental Health</td>
<td>7 (7.4%)</td>
<td>8 (50%)</td>
<td>.438***</td>
</tr>
<tr>
<td>Day-to-Day Behaviors</td>
<td>17 (17.9%)</td>
<td>14 (87.5%)</td>
<td>.545***</td>
</tr>
</tbody>
</table>

*p < .05, **p < .01, *** p < .001
Results – Screening and FASD Diagnosis

• Strong correlation: $\phi = .742$ (p<.001)

• Similarities for people with a positive screening and people with FASD
  • All participants had 3/3 red flag responses in maternal alcohol use
  • More than 40% had 2/2 red flag responses in education
  • 50% had 2/2 red flag responses in living situations
  • More than 50% had difficulties in 7+ day-to-day areas
Results – Sensitivity & Specificity

Table 4

Calculating Sensitivity and Specificity

<table>
<thead>
<tr>
<th></th>
<th>FASD Diagnosis</th>
<th>No FASD Diagnosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive Screening</td>
<td>14</td>
<td>6</td>
</tr>
<tr>
<td>Negative Screening</td>
<td>2</td>
<td>89</td>
</tr>
</tbody>
</table>

- Sensitivity: 87.5%
- Specificity: 93.7%
- False positive: 6.3%
- False negative: 12.5%

Correctly identified: 92.8%
## Results – ROC Analysis

Table 4  
**ROC Analysis – Area under the Curve.**

<table>
<thead>
<tr>
<th>Category</th>
<th>AUC</th>
<th>SE</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Childhood History</td>
<td>.635</td>
<td>.085</td>
<td>n.s.°</td>
</tr>
<tr>
<td>Maternal Alcohol Use</td>
<td>.953</td>
<td>.019</td>
<td>***</td>
</tr>
<tr>
<td>Education</td>
<td>.856</td>
<td>.051</td>
<td>***</td>
</tr>
<tr>
<td>Criminal History</td>
<td>.579</td>
<td>.081</td>
<td>n.s.</td>
</tr>
<tr>
<td>Substance Use</td>
<td>.477</td>
<td>.077</td>
<td>n.s.</td>
</tr>
<tr>
<td>Employment and Income</td>
<td>.707</td>
<td>.070</td>
<td>***</td>
</tr>
<tr>
<td>Living Situations</td>
<td>.777</td>
<td>.075</td>
<td>***</td>
</tr>
<tr>
<td>Mental Health</td>
<td>.803</td>
<td>.063</td>
<td>***</td>
</tr>
<tr>
<td>Day-to-Day Behaviors</td>
<td>.912</td>
<td>.030</td>
<td>***</td>
</tr>
</tbody>
</table>

°p < .1, *p < .05, **p < .01, *** p <.001
## Results – ROC Analysis

**Optimal cut-off values:**

<table>
<thead>
<tr>
<th>Category</th>
<th>LHS</th>
<th>BSI-FASD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Childhood History</td>
<td>1/1</td>
<td>1/1</td>
</tr>
<tr>
<td>Maternal Alcohol Use</td>
<td>2/3</td>
<td>3/3</td>
</tr>
<tr>
<td>Education</td>
<td>1/3</td>
<td>1/3</td>
</tr>
<tr>
<td>Criminal History</td>
<td>1/3</td>
<td>1/3</td>
</tr>
<tr>
<td>Substance Use</td>
<td>1/2</td>
<td>2/2</td>
</tr>
<tr>
<td>Employment and Income</td>
<td>1/2</td>
<td>1/2</td>
</tr>
<tr>
<td>Living Situation</td>
<td>1/2</td>
<td>1/2</td>
</tr>
<tr>
<td>Mental Health</td>
<td>2/3</td>
<td>1/3</td>
</tr>
<tr>
<td>Day-to-Day Behaviors</td>
<td>5/11</td>
<td>5/11</td>
</tr>
</tbody>
</table>
Discussion

Conclusion:

• BSI-FASD is able to correctly identify:
  • 87.5% of the people affected by FASD
  • 93.7% of the people without FASD
  • 92.8% overall

• Areas which illustrate significant and strong connection to both a positive screening and an FASD diagnosis include:
  • Maternal Alcohol Use
  • Living Situations
  • Day-to-Day Behaviors
Discussion

Conclusion:
• Areas which illustrate little or no significant connection to both a positive screening and an FASD diagnosis include:
  • Employment and Income
  • Criminal History
  • Substance Use
Discussion

Limitations and Recommendations:
• Sample size – further evaluation necessary
• Difficult to reach participants with suspected FASD
• Diagnostic challenges:
  • No standard diagnostic guidelines exist for adults in Germany
  • It’s difficult to clearly specify standard facial expressions and growth characteristics
  • Proof of prenatal alcohol exposure is difficult
Discussion

Limitations and Recommendations:

• Cut-off values
  • Using different cut-off values for categories
  • Verify item-based cut-off values

• Consider cultural differences
  • Living situations in childhood
  • School subject which caused the most problems
Thank you for your attention!

Feel free to contact us should any questions arise:
Lina Schwerg schwerg@ev-sonnenhof.de
Sandra M. Ahlert sahlert@uni-potsdam.de

Please take a moment to evaluate us.