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FAScinating Research

A qualitative interview study focusing the situation of foster parents raising children with FASD

Master Thesis (10EC)

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Abstract

Background: Under the term **fetal alcoholic spectrum disorder** (FASD) several forms of mental disabilities are summarized, characterized by cognitive and behavioural difficulties due to an intoxication with alcohol during pregnancy. A major part of these children lives with foster parents or were occupied by child and youth welfare centres. The behavioural and cognitive deficits contribute to problems in raising and parenting these children and adolescents appropriately.

Goal: Aim of this study is to investigate which strategies foster parents use to bring up these children (1), which sources of help and support they use (2) and what appropriate support should be like from their perspectives (3).

Method: For the present study, an explorative interview design is used. Eight foster mothers of children and adolescents with FASD were reached through snowball and convenience sampling and questioned with the help of a semi-structured interview. Transcriptions were analyzed with the help of *Atlas.ti*. Codes, categories and subcategories were formed following a standardized scheme. Although the total score of the interrater reliability was under the acceptable range, scores for important parts of the results were acceptable.

Results:(1) As important strategy, participants emphasized the importance of **structural elements** in parenting to ease daily life. Additionally, the **adaption** and **reformation** of the own **parental attitude** and **environment** to the difficult circumstances were strategies mentioned. (2) **Institutional forms** of help were used, under which youth welfare services, external forms of care and special schools. There are forms of **private support** described by the participants, like family and friends taking care of their children. Forms of **therapy** were mentioned as support possibilities for the interviewees. (3) There is a high need of **more knowledge about FASD** in public and the society in the view of the interviewed foster parents. They wish for **FASD** as being a **part of medical and social education**, contributing to greater knowledge and understanding, resulting in the creation of more forms of support by public and professional institutions. The interviewed foster mothers described wishes for building up **perspectives** for themselves and their disabled children.

Discussion: This study provided new beneficial insights in the current situation of foster parents raising children with FASD concerning the forms of support they use. Furthermore, it provided insights in the wishes and hopes for the creation of appropriate forms of support in future. This qualitative study should function as a starting point for further quantitative nationwide research aiming the creation of appropriate and suitable forms of support.

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1. Introduction

1.1 Case Example

“Especially during infancy, we noticed the fetal alcoholic syndrome concerning Lisa, because she showed no feeling at all for risks, but followed her impulses. (…) So she climbed on a three-meter-high tower at the swimming pool and jumped down, although she couldn’t swim. Or she rode her balance bike at high speed in a narrow curve, where she fell and got injured several times. This behaviour in conjunction with the missing understanding of cause and effect was conspicuous at an early stage. Her missing or limited feeling for her own body or pain was also conspicuous. She often had a severe inflammation of the middle ear, which we first noticed when the pus ran out of her ear, but by then the eardrum was already cracked. Before that, she had shown no signs of being ill. She had only undefined stomach ache. That was also supposed to be the reason for her not getting dry before the age of seven. Whenever she felt good, it worked age-appropriately, but when she was moved, she wetted her bed until the second year of school.”*

**name changed*

(E-mail contact with a foster mother of two foster children with FASD, 06.03.2017

1.2 Diagnosis

The scientific world first noticed the consequences of drinking during pregnancy in 1968. Paul Lemoine conducted a study with 127 children and observed the developmental differences between alcohol-intoxicated children during pregnancy and those who were not. Based on his findings, he formulated the main characteristics of FAS, which are still valid today. These are conspicuous facial abnormalities, stunted growth, abnormalities of development, psychomotoric abnormalities and behavioural problems (Mitha, 2014).

Nowadays, the term **fetal alcoholic spectrum disorder** (FASD) summarizes diagnoses which are the direct or indirect consequence of the alcohol consumption of the mother during pregnancy. This intoxication of the embryo affects the development of essential parts of the brain and the neuronal network. (WWU, 2014). The full spectrum disorder **Fetal Alcohol Syndrome** (FAS) is broadly characterized by growth deficits, a unique cluster of facial and central nervous system abnormalities. It is the most frequent disability that is fully preventable and without any direct genetic influences (Pfinder, Feldmann, 2011). In the USA one to three cases per one thousand live births were estimated**.** Other studies estimate that two to five percent of the school children suffer from FASD in the USA und Western Europe. A study of Landgraf and others (2013) name an incidence of eight per one thousand live births in Germany. In total numbers, this meant a prevalence of 5457 children in 2013. With respect to the average life span, the total amount of people suffering from FASD in Germany is about 300.000 people (ter Horst, 2015). Beside the physical deficits, there are numerous behavioural problems, ranging from quite normal to pathological behaviour, see point *1.1.2 Cognitive and Behavioural Deficits* (Astley, 2013).

The **4-Digit Code** is an evidence-based diagnostic instrument for the diagnosis of FASD validated by more than 35 studies in ten years. With the help of the code, the key features of FASD are assessed. The four features are growth deficiency (1), FAS facial phenotype (2), Central Nervous System (CNS) structural/functional abnormalities (3) and prenatal alcohol exposure (4). These features are ranked on a four-point likert scale from absence to presence of the classic feature. Following this procedure, four different diagnoses are possible. First the full spectrum disorder FAS could be diagnosed and then a partial FAS, as well as severe or moderate Alcohol Related Neurodevelopmental Disorder (ARND). A severe ARND is also described as static encephalopathy and alcohol exposure (SA/AF). Encephalopathy describes the amount of brain damage caused by alcohol intoxication. Moderate ARND describes neurobehavioural disorder and alcohol exposure (ND/AF) (Astley, 2013). To clarify which features are necessary for the diagnosis, the following table has been created (table 1).

Table 1

Diagnoses 4-Digit Code

	Growth	**FAS face**	**CNS**	**Alcohol**
1. FAS	✓	✓	severe	✓
2. pFAS		✓	severe	✓
3. SE/AE			severe	✓
4. ND/AE			moderate	✓

To diagnose the full spectrum disorder FAS, the typical facial characteristics must be present. Figure 1 illustrates the typical characteristics of a young child, suffering from FAS. For example, short palpebral fissures, a relatively short nose, a flat philtrum, a thin upper lip and a flattened medial face typical for such a face. These characteristics can get less obvious in adolescence and adulthood (Sampson, Streissguth, Bookstein, Little, Clarren, Dehaene, Hanson & Graham, 1997).

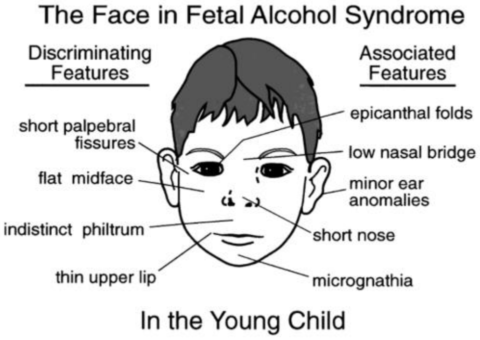

Figure 1: Classical FAS characteristics of the face of a young child (Sampson et al., 1997)

1.2.1 Cognitive and Behavioural Deficits

There is a wide variety of behavioural and cognitive problems resulting from the damage of the Central Nervous System (CNS) and thus of the brain regions. Especially vulnerable to alcohol-related damage are the regions of the prefrontal cortex and the basal ganglia. Therefore, patients have difficulties in processing information from the environment to control their behaviour and their executive functions are limited. This implies that they are not able to plan their behavioural action. In general, the Intelligence Quotient (IQ) is below average. Even if the IQ lies within the mean value, many patients cannot fulfil their potential because of the described brain damage and the resulting behavioural consequences (Becker, 2013).

For daily life with children and adolescents diagnosed with FASD this implies major problems in upbringing and education. Ter Horst (2010) summarizes various cognitive and emotional difficulties. As for their cognitive abilities, children and adolescents with FASD have a retarded language development, intellectual deficits, less brain performance and only a slight ability to concentrate. The average IQ does not rise above 75 points. Especially the low memory performance of people with FASD impairs their learning abilities. Furthermore, ter Horst (2010) states that there are some emotional and behavioural difficulties that people with FASD face. They have difficulties organizing themselves or solving problems and coping with social situations tends to mean trouble for them. In general, they are naive and cannot assess risks. So they often get into trouble committing risky or illegal acts without learning from experience. Consequently the described cognitive and behavioural deficits may lead to an exploitation by others. They are highly vulnerable to manipulation and therefore they are often victims of criminal acts ranging from theft to sexual abuse (ter Horst, 2010).

1.3 Caregiving

Because of the described deficits, 70.5 percent of the adults suffering from FASD can not live independently or finance their own life (Spohr, 2014). A study estimates that in childhood and adolescence, 22.9 percent of the FASD-affected children live with foster parents or in child and youth welfare centres (Nordhues, Weischenberg, Feldmann, 2013). In a Canadian study, researchers conducted sixty interviews with caregivers and twenty-six with clinicians concerning the most challenging behaviour and the most successful parenting strategies concerning people suffering from FASD. Caregivers reported that *Externalizing Behaviors*, *Cognitive Difficulties* and *Social Difficulties/Maladjustment* are the most challenging behavioural issues. In addition, they reported that *Parental Reflection*, *Routine/Structure/Consistency* and *Environmental Modification* are the most successful parenting strategies. The interviewed clinicians claimed that *Insufficient Support/Knowledge from Health and Social Professionals and Agencies* and *Behavioural Difficulties/Challenges* are the most frequent concerns of caregivers (Green, Roane, Hewitt, Muhajarine, Mushquash, Sourander, Lingley-Pottie, McGrath, Reynolds, 2014).

Ter Horst (2015) explains that the problems arise in the child and youth welfare centres because of the professionals’ lack of knowledge and the special needs this disability requires. One major problem in the context of child and youth care is that children with FASD do not fit in with the normal process of on-going success and learning. Because there is often no obvious improvement in their skills and facilities, these children frequently change institutions and therefore do not get enough support. According to ter Horst (2015), there is a high need of accurate information on many institutions such as schools and youth welfare services.

Another American study focused on answering the question what the most frequent nursing sensitive problems in a community context are, expressed by caregivers and other persons affected by FASD. The Center for Substance Abuse and Mental Health Services Administration (SAMHSA) recorded 15 Town Hall forums where persons affected by FASD in different ways, caregivers, persons with FASD and policy makers discussed problems arisen in the community. In total, 376 statements were analysed and the researchers concluded that *communication with the community*, *caretaking/ parenting*, *mental health* and *income* were the most challenging problems they faced (Caley, Winkelman, Mariano, 2009). Koponen, Kalland and Autti-Rämo (2009) investigated the socio-emotional development of FASD-affected children living in foster families. They found out that most of the children showed at least one of the different developmental deficits. The most frequent deficits are *concentration, attention, languag*e or *speech problems*. Another study compared the development of FASD-children to a sample of children with a normal development. They found out that FASD-affected children scored significantly lower on scales of *independent behaviour, social interaction* and *communication*, *personal living* and *community living skills*. And they scored significantly higher on *maladaptive behaviour* scales (Jirikowic, Kartin, Carmichael Olson, 2008).

Beside these research studies, there are some guidelines available concerning the handling of FASD. The guidelines are adequate for different fields of daily life and offer practical help for people who give care to children and adolescents with FASD. One guideline that offers help for professional and non-professional caregivers has been published by the Canadian Edmonton and Area Fetal Alcohol Network (EFAN). On more than 50 pages, this organization summarizes strategies for different fields of caregiving such as *sensory dysfunction*, *how to guide behaviour, choice making, impulse control*, *communication, time, money, ownership, storytelling, calming techniques, feelings and emotions, transitions*, the *criminal justice system* and *age-specific strategies*. The detailed guideline was written with the help of scientific literature, different community help services, researchers, physicians, and caregivers and professionals who provided advice and information (EFAN, 2007). Another guideline for professional caregivers and families has been composed by German psychologists and researchers. The “FAS-First-Aid-Kit” offers practical help for the daily life with FASD-children. The guideline focuses on twelve different fields of daily life and contains descriptions of possible problems and methods of solutions. It is about *routines, rules, communication, furnishing an apartment and keeping it in order*, *how to dress, personal hygiene*, *food, sleep, property, sense of time*, *hyperactivity* and *anger* as well as *feelings* (Schmidt, Fietzek, Holodynski, Feldmann, 2013).

The review of the existing studies, literature and guidelines indicated some researcher investigated the situation of children with FASD and their caregiver. It was conspicuous that there were lacking two main issues. First an investigation of appropriate forms of support the foster parents of children with FASD used or wished for and second a lack of studies putting the special needs of foster parents in centre of investigation. Green et al. (2014) for example focused on foster parents investigating parenting and behavioural difficulties but not support possibilities. In contrast to the current studies, this research aims to gain a holistic image about the situation of foster parents raising children with FASD putting their experiences and needs in the centre of the qualitative interview study. Therefore, this investigation aims to answer the question **which strategies foster parents use to bring up children and adolescents affected by FASD**. In addition, it would be useful to gather information about **which sources of help and support the participants use** parenting their children. And in the end investigating **what appropriate support should be like from the foster parents' point of view**.

2. Method

2.1 Design

For this **exploratory interview study**, interviews were conducted face-to-face with foster parents of children and adolescents suffering from FASD.

2.2 Participants

The participants were foster mothers of children suffering from FASD and were reached through **snowball** and **convenience sampling**. The first interviewed foster mother was contacted through a FASD-specific housing group. She made contact with other foster parents who were part of a *FAS counseling group* on the social-media platform *Facebook*. The researcher became a member of the group and posted an inquiry concerning the study the researcher wanted to conduct. After that, many foster parents answered and stated that they would like to take part. The criteria for that were to be a foster parent of an FASD child and to live in North Rhine-Westphalia to minimize the journey costs. Altogether, eight foster mothers of children suffering from FASD were interviewed (table 2).

Table 2

Overview Participants N= 8

Participants	Age	Socially oriented education	Continuing Training FASD	Initial Contact FASD
P 1	54	✓	✓	FP
P 2	43	✓	✗	PC

P 3	40	✓	✗	FPT
P 4	36	✗	✗	FP
P 5	45	✗	✗	FP
P 6	50	✓	✓	PC
P 7	49	✗	✓	FP
P 8	48	✓	✓	FP

The average age of the participants was 45.6 years and they were all female. Five of them had a socially oriented background, so they had studied social education or worked as educators, for example. Furthermore, half of the participants had a continuing training concerning FASD (table 2).

Most of the participants, namely five out of eight, mentioned that they had first come *into contact* with the issue of FASD by receiving foster-children suffering from it (table 2, FP). Only two participants had had some information about FASD because of their profession before hosting a foster child (table 2, PC) and only one said that they had had a foster-parent training before, where FASD had been explained (table 2, FPT). So for the majority, the problems that arise out of this mental disability had been new.

2.3 Procedure

The study took place in various places. All interviews, except for two were conducted at the homes of the participants to minimize their efforts. The appointments were planned via messages on *Facebook*. Once it was held at a youth centre and once at an FASD-specific housing group, because it was logistically advantageous. The interviews were conducted in North Rhine-Westphalia (NRW), Germany. Every foster mother participated voluntarily in this study and had signed an informed consent (see appendix) at the beginning of the interview. The informed consent stated that the data were analyzed in completely anonymized form. The interview was recorded to be transcribed later and the participants had the possibility to drop out after the interview and in that case their data would be deleted. The interview started with a short introduction held by the researcher, explaining the aim and the reason of the study and the procedure of the interview. The researcher emphasized that there were no false answers and if something was unclear, the participants should feel free to ask. The interview was conducted in German and the average length of the interview was 32.5

minutes ranging from 24 minutes to 50 minutes. Due to the inclusion criteria, appointments with the possible participants were made privately. After six participants had been interviewed, signs of saturation were noticed. The researcher analyzed the transcriptions and created a coding list. Statements of the participants and therefore the codes recurred and little new was mentioned. That is why the sampling procedure was stopped after two more interviews and so the overall sample contained eight interviews in the end.

2.4 Instrument

The interview scheme was created based on the literature described in the introduction. Especially the manuals of the EVAN (2007) and the Canadian study which highlighted the difficulties caregivers face, were taken as a guideline for the development of the interview-scheme (Green et al., 2014). After the first interview had been conducted, the structure of the scheme was adapted. The domain *support* and *forms of help* merged because it was noticed that the participants gave similar statements in both domains. After that the structure of the interview was maintained. The semi-structured interview began with demographic information followed by five different domains. Insights into the interviews were given in table three, whereas the full interview scheme can be found in the appendix.

Table 3

Insight Interview Questions

Interview Domain	Example question
Experiences	In your point of view, what are the most important experiences you made with your children suffering from FASD?
Support / Forms of Help	How accessible were these forms of help for you?
Information	Where did you get this information from?
Support Tools	What kind of concrete support tools do you use dealing daily with FASD?
Future Wishes	What do you wish for the future support of foster parents and caregivers?

When a participant gave information about an issue before the question was asked, the structure of the interview was adapted. When a participant did not know what to say about a question, the question was reformulated or an example was given. For example, when an interviewee could not think of any desirable support possibilities, the researcher suggested that they should think about a perfect world where every support needed was given (table 3).

2.5 Data Analysis

After the first six interviews had been conducted, transcriptions were made and analyzed with the help of the programme Atlats.ti (8th version). To generate a coding list, the transcriptions were viewed in Atlas.ti and the first two interviews were coded inductively. On the basis of these two analyses, a coding list was created. With the help of this list, the other four interviews were analyzed. Some codes were adapted or removed because they did not fit with the found data. At the end of this phase, the results of this analysis were discussed with the supervisor. The coding list approached saturation, and the researcher came to the conclusion to conduct two to three more interviews, to investigate if the impression of saturation will be confirmed. The conduction procedure was stopped, after two more interviews were conducted. The analysis of the last two interviews confirmed that saturation was approached.

The analysis of the data was conducted based on the *research line* proposed in the book about qualitative analysis by Hennie Boeije (2005). The first two interviews were coded openly and inductively. With the help of the coding list created based on the first two interviews, the added interviews were analyzed. During axial encoding, the eight interviews were reviewed again. The researcher analyzed the transcriptions to see if there were codes that could be merged because of the same meaning or if codes could be deleted. Furthermore, the units of meaning were examined to see if they could rather be described with a different expression. After a discussion with the supervisors, unclear definitions were further defined and explained to simplify the understanding of the results. In the following table, difficult or possibly unclear subcategories were defined (table 4).

Table 4

Definition Unclear Subcategories

Domain	Subcategories	Definition
Behavioural Difficulties		
	Aware of *being different*	These children know that they are different in comparison with other children of their age and are in a state to name what is different.
	No learning	These children do not learn from experience and quickly forget something they have learned.
	Sexualized behaviour	These children are not able to adapt their behavior or control their impulses and therefore behave in a more sexualized way.
Parenting Strategies		
	Dependability	Stability concerning the caring person and the environment.

	Strengths	Giving these children the chance to discover their own talents, to feel positive and confident about themselves and strengthen their self-esteem.
	Making consequences understandable	Making consequences directly visible for these children, because they are not able to understand abstract concepts.
Support and Forms of Help		
	Family Aid Services	Special ambulant care service for disabled persons who live at home.
	External Care	Possibilities of external care, for example leisure activities during the holidays.
	Prevention Care	When the caring person is unable to give care because of illness for example, the care is guaranteed by nursing staff.
	Level of Care	Judged by the HIC to make sure the person is well taken care of
Support Tools		
	Weight Cover / Vest	Therapeutic tool that provides the disabled persons with a better body feeling and helps them to calm down and sleep at night.
Source of Information		
	Clinic *Walstedde*	Child and youth psychiatry housing a FASD counselling center.

2.6 Interrater Reliability

To examine the **interrater reliability**, one interview transcript was given to a fellow master psychology student. The student got the anonymized transcript, the coding list with definitions, created and used by the first researcher (Hanna Kösters=HK), the interview scheme and an introduction to the task. The fellow student coded the interview transcript independently and assigned the codes of the list to the statements of the interview. After that, the coded interview was sent back to the first researcher (HK) to compare the results with her own analysis. The goal of this procedure was to gain insight in the extent of overlap between the two analyses and thus to enable the researcher to come to a conclusion about the interrater reliability. For the presentation of the overlap between the analyses, the researcher has chosen to give the percentages of agreement between the two raters (table 5).

Table 5

Results Interrater Reliability

Category	**Percentage of Agreement**
Behavioural Difficulties	*66.67*
Parenting Strategies	*36.36*

Support and Forms of Help	**81.81**
Support Tools	*66.67*
Sources of Information	**88.89**
Future Wishes	**88.89**
Total	*71.15*

unacceptable agreement
acceptable agreement

The **total agreement** of all codes in this interview transcript between the two researchers was 71.15 percent. According to Altman (1991) an acceptable level of agreement should be located between 75 and 90 percent. In conclusion to this rule, the found overall agreement did not seem acceptable.

But three of the sections coded by the two raters, had agreement percentages which are located within the range of acceptance. First, the *source of information* and the *future wishes* parts hold interrater percentages of agreement near to the upper end of acceptance (90%) proposed by Altman (1991), indicating an agreement of 88.89 percent. The third section, *support and forms of help*, holds a percentage of agreement of 81.81 percent, which also indicated an acceptable agreement to Altman's rule (1991). It is conspicuous that these three parts (*source of information, future wishes, support and forms of help*) played a major role in answering the research questions (cf. Results) and contributed to a great extent to the conclusion drawn from this study. In conclusion, acceptable interrater percentages in these sections indicated reliable results for the answering of the research questions.

Furthermore, two of the three sections indicating no acceptable percentages of agreement have no direct influence on the answering of the research questions. The *behavioural difficulties* (66.67%) and the *parenting strategies* (36.36%) part of the interview functioned as an introduction to the issue of FASD and dealt with a better understanding of the circumstances raising a child suffering from FASD. When the analysis of the interrater reliability had been finished, the researchers discussed the possible reasons for the low agreement percentages of the *parenting strategies* part. A closer look revealed that most of the variance could be explained because of different units of meaning assigned to the same codes by the two raters. The interview analyzed by the two raters was longer in comparison to others and the participant had explained her position in detail. In comparison to other parts of the interview, the *parenting strategies* were discussed in detail. Consequently, the chance of assigning different units of meanings to the same codes was higher. After having discussed the differences, the second rater understood why the first researcher had sometimes chosen different units. In addition to that, there had been some confusion about the code of *dependability*. The second rater had also used it for codes which were assigned to statements concerning *rituals* by the first researcher. After the differences had been discussed and the definitions clarified, the two raters agreed that *dependability* in this context referred to caring persons and *rituals* referred to acts.

3. Results

3.1 Behavioural Difficulties of Children with FASD

As described in the method section, the interview had a certain structure that enabled the participants to talk about their daily life and the problems they experienced by raising a child with FASD. To get an overview of the behavioural difficulties the participants described, results about these will be summed up in the following section.

Half of the participants named problems with the sleeping habits of these children. One of them (8) mentioned that *"(...) because he was running around, (...) we couldn't find rest anymore."* The children have problems to fall asleep or to sleep through the night. The same number of them claimed that their foster-children were not able to learn, for example from experience or they quickly forgot what they had already learned. Therefore, one interviewee (2) stated *"(...) that the normal educational strategies aren't effective (...) they won't learn from punishment, I would say. So, punishing them doesn't make any sense, (...).".* Three participants named problems with *feeding*, the *inability to assess risks*, *motoric problems*, the respect of other people's *property* and the *lack of empathy* for others. One foster mother (6) explained: *"I remember for example, that he had difficulties in understanding what's mine and what's yours, so I often got trapped and didn't put things away in time or something like that."* Another participant (1) found that her children often lacked a feeling of empathy: *"What's conspicuous, too, is that many children don't recognize your feelings. Yes, when you are unhappy or sad, it doesn't mean a thing to them."*

In conclusion, the interviewed foster mothers described two main issues that were related to difficulties in behaviour. Firstly, they described difficulties in understanding or learning complex constructs such as property, empathy, consequences or risks. That emphasizes the limited cognitive abilities these children have. Secondly, they described basic needs, such as sleep or food that are directly related to their children's difficulties.

3.2 Parenting Strategies

The interviewees described *parenting strategies* they used to raise their children (table 6). The detailed table can be found in the appendix. The most frequent strategies they named was providing *structure* in daily life. Most of the participants explained that they followed a weekly or daily plan to structure the daily life for their children. Moreover, four participants emphasized that *exact instructions* contributed to a higher level of structure in in the FAS-children's life. To make the instructions for FAS-children easier to understand, it was considered as important to name clearly and explicitly what was expected of them. That contributed to an understandable and structured daily life and prevents disorientation. *Dependability* is defined as "*stability concerning the caring persons and the environment"*. The category *dependability* means that these children do have a high need for constant environmental factors concerning the caring persons but also the living-environment. One participant (1) described for example that when she had an accident and could no longer take care of her foster daughter, the girl faced vast problems. *Rituals* were also named by three interviewees as an important aspect of structuring their daily life. One participant (2) stated that when her foster children knew that every morning they first had to put their jackets on the same hook before starting their activities at the kindergarten, it helped them to get smoothly through the morning with less problems and interruptions. Another structuring element named by the participants was *avoiding excessive demands*. The interviewees emphasized that it was important to sometimes think for these children. FAS-children have problems to understand complex social situations. Sometimes it might be helpful to prepare the situation for them in order to ensure that they feel secure and thus avoid their suffering from any kind of strain. One participant (1) emphasized that every *excessive demand* would produce behavioural problems. So she keeps her foster children's life strictly in order to avoid any form of strain.

Another important aspect they named was related to their own *parenting attitude*. Three of them emphasized for example the importance of enhancing the children's strengths in life such as their self-esteem telling them that they were good the way they were – all that being the result of the caregiver's own positive attitude towards life. *Strengths* are defined in this context as *"giving them the chance to find their own talents, feel positive about themselves and strengthen their self-esteem"*. Another important aspect of the caring person's educational attitude is to *stay patient* facing recurring problems. One foster mother (6) gave the example of her children wetting the bed again and again even at an age beyond that stage. She emphasized that she had tried to stay patient and had not dramatized the situation, because that would not have changed anything. In her opinion, this attitude contributed to a stress-free relationship with her children. The same mother also used another educational strategy: *facing the consequences*. Whenever she used this strategy, she tried to make it *understandable* to her children. So she explained: *"One method is to say, well, windscreen wipers are expensive, you will have do without your chocolate pudding until the new wipers are paid off. So I went to REWE*[1] *with him and showed him four tubs of chocolate pudding and said (...) all these chocolate puddings cost as much as the windscreen wiper and now you must do without for one month to pay it off."*

Another important aspect of *parenting strategies* is to adapt *environmental factors.* Two participants mentioned that *avoiding sugar* in *food* was important because these children were prone to become addicted to such substances. According to them, too much sugar contributes to behavioural restlessness. Another environmental aspect is to have less stimuli such as within the reach of these children. *"Especially with FAS we have noticed that actually an environment with poor stimuli (...) helps to achieve relaxation (...)",* one foster mother (2) stated. A highly stimulating environment which encourages these children to do sports has the same effect. One participant (6) pointed out that she had had good experience with a trampoline as a remedy for motoric restlessness.

Concerning the research question, which strategies foster parents used to bring up their children and adolescents with FASD, the importance to implement a *structure* in their life could be described as most important. Nearly every interviewed foster mother stressed the importance of a *daily or weekly planning* related to *dependability* and *predictability*. Another important aspect concerning the research question was an adaption of their own *parenting attitude* and the *environment* that contributed to less behavioural difficulties in the eyes of the interviewed participants.

Table 6

Codes for **Parenting Strategies** (N=8)

Categories	**Subcategories (Definition)**	**Participants**	**Quotations**
Structure			

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[1] REWE is a German supermarket chain

	Weekly/Daily Plan	1,2,3,4,6,7,8	*“They need a precise, they need a very clear daily plan, because they can’t organize themselves. She forgets a lot of things.” (P3)*
	Dependability (Stability concerning the attachment figures and the environment)	1,3,5,6,8	*“I think, that the dependability. Yes, for my oldest daughter with FASD, she couldn’t stay alone in the apartment, after I had had an accident (...)” (P1)*
	Exact introductions	1,4,5,6	*“(...) My husband always names in simple and concise words what he wanted the kids to do. (...) children with FAS need an exact instruction (...) that works!” (P1)*
	Rituals	2,4,7	*“When I know, in kindergarten my jacket always hangs on this/the same hook, then it becomes a ritual, and it has to be that way every morning, before doing the next step (...)” (P2)*
	Avoid excessive demands	1,6	*“Trying not to demand too much from them (...) because then X won’t go to school. I’m in the position to say, X’ll stay at home. Because it’s clear/obvious that the situation could escalate in school. (6)”*
Parenting Attitude			
	Strength (Giving them the chance to find their own talents, feel positive about themselves and strengthen their self-esteem.)	1,2,6	*“(...) that’s what I always try to communicate, that they are great, the way they are. And I love you just the way you are. You are a very great child (...) they have a lot of self-esteem. (...)” (P6)*
	Being patient	4,6,7	*“(...) staying cool and saying, it’s okay, go upstairs, put your wet laundry into the washing machine (...) don’t dramatize that (...)” (P6)*
	Make consequences understandable (Make consequences directly visible for these children, because they are not able to understand such abstract concepts)	6	*“One method is to say, well, windscreen wipers are expensive, you will have to do without your chocolate pudding until the new wiper is paid off. So, I went to Rewe with him and showed him four tubs of chocolate pudding and said, (...) all these chocolate puddings cost as much as the windscreen wiper and now you must do without for one month to pay it off. (...)” (P6)*
Environment			
	Food	2,6	*“(...) and sugar is what is very obvious in my opinion, it’s the first addictive drug they consume and they feel a great desire for it and it causes conspicuous behavior and restlessness.” (P2)*

Poor-stimuli environment	1,6	*“Especially with FAS we have noticed that actually an environment with poor stimuli (…) contributes to relaxation (…)” (P2)*
Activity	6	*“A lot of exercise to avoid motoric restlessness, that means trampoline, playing outdoors most of the time.” (P6)*

N= Number of participants,
P^N= Participant cited,
X= anonymized name of a child

3.3 Support and Forms of Help

Asked about *support* and *help opportunities* they used, there were possibilities for *daily life* indicated by the foster mothers (table 7). Most of them named *Family Aid Services* as forms of help they made use of. Some of them also took of *external* on holiday. One participant (6) mentioned the possibility to have her children externally looked after for up to three weeks in holidays. Half of the interviewees also emphasized that they used *private support*, for example the possibility that their children were looked after by family members of friends. Two participants also named the possibility of *prevention care* to make use of when they themselves were incapable of taking care of their children. *Prevention care* can be assured by every person who takes care of a family lid at home when the generally caring person is unable to care for them so that their care is guaranteed. Three of the interviewed foster mothers sent their children to *special schools* so that they receive individual support. One interviewee (4) reasoned: *“The classes were too big, I mean, there are eleven children in one class now, and even then, they sometimes get separated during the lessons. While one teacher is doing languages with five pupils, the other is doing math.”* Furthermore, two participants stated that they made use of a *home help*. They reasoned that often their children could not be taken care of externally because they had behavioural difficulties or an attachment disorder.

The foster mothers also mentioned *institutional forms of help* they used. Half of them indicated that they got support from the *child and youth welfare services*. “*So therefore, I really have the feeling of being supported, and that there is some interest in the issue.”* one interviewee (8) stated. Another opportunity for getting support is the *severely handicapped pass* and the *level of care* defined by the *health insurance companies*. The interviewed foster mothers stated that receiving this *severely handicapped pass* or *level of care* helped them to take advantage of more support possibilities. In conclusion, many foster mothers stated to fall back on some *institutional forms of help* to receive *daily support*. For example, a certain *level* *of care* is often necessary to be entitled to *prevention care.* These two categories are related to each other in the eyes of the participants.

Most of the interviewed foster mothers also indicated that they used or had used some forms of *therapy*. It was conspicuous that they assessed some of them as constructive, whereas other forms were considered as not effective. *Constructive forms of therapy* mentioned by most of the participants were *developmental therapies*, like speech therapy or ergo therapy. Another *constructive* form of therapy was the *riding therapy* in the eyes of three participants (1,2,6). *„The interaction between the horse and the human being. The horse notices immediately when the child makes a mistake or when she can't concentrate and it shows that to the child.“* reasoned one participant (1) to explain why the riding therapy was effective from her point of view. Three of the interviewees mentioned *medicine* as a *constructive form of therapy* they used. One participant (8) explained: "*We were looking for a psychological practice then, because after the situation had got worse, X had to take medicine, just to protect herself."* A therapy that only one participant (5) mentioned was a form of *video-taping* therapy called *Marte Meo.* She described that the mother and her daughter had been filmed in a certain situation that had been analyzed afterwards but only the positive sequences had been shown to the mother and according to the foster mother that had had a highly effective impact on her. Another participant (4) mentioned that she had chosen a *psychological therapy* for her child. This therapy had a positive influence on the child's attachment disorder and that way it was possible to help her in difficult situations.

But there were also *non-constructive forms of therapy* described by the interviewees. In contrast to one foster mother, another participant (3) valued a *psychological therapy* as *non-constructive*, because her foster child had not been able to adapt the learned behavior to her daily life. Another ineffective form of therapy described by one foster mother was a *play therapy* in the context of *special therapies* they had followed. She (5) explained: *"Because you never know your exact role in therapy, so you feel uncomfortable and you don't like to do it. (...) I never really knew what my part was. And yes, they played with X, working on colors and animals, something like that."* Even though some participants stated that they felt supported by the *child and youth welfare service*, three interviewees (1,3,6) considered the support as *insufficient*. They reasoned for example that the employees did not have enough knowledge about FASD, so that they could not be supported adequately. Five participants (1,2,6,7,8) criticized that there was not enough knowledge about FASD in nearly every institution. *"Even though it is an integrative school where special teachers work, they don't* *know anything about that issue. Just like the child and youth welfare service."* explained one foster mother (2). Another difficulty described by two participants (1,6) was the *missing feeling of being part of a group*. They reasoned that it was hard for them to find a self-help group for example, because they felt so different compared to other foster parents.

Concerning the research question which sources of help and support the participants used simplify parenting, *institutional forms of help* were related to *daily support forms* according to the participants. As described, the foster mothers needed institutions like the *child and youth welfare services* to obtain approval for daily help forms like the possibility of making use of *external care*. According to the analysis, *private support* through family and friends was only a small proportion compared to the professional forms of help like *special schools* or *family aid services*. It also stands out that some forms of therapy were assessed as effective and others as ineffective. So one foster mother (4) considered psychological therapy as constructive, whereas another one (3) thought it was non-constructive. The amount of named forms of therapies that were used by the participants indicate that there is a wide variety of useful and effective forms of therapy, individually depending on the needs of the children with FASD.

Table 7

Codes **Support and Forms of Help** (N=8)

Categories	**Subcategories (Definition)**	**Participants**	**Quotations**
Daily Life			
	Family Aid Services (Special ambulant help service for disabled persons who live at home)	1,4,5,7,8	*"She comes here about once a week for two hours, then they play something or they go on small trips." (P4)*
	Private Support	1,3,4,6	*"And we have our, my mom and my parents-in-law, they also take care of the children." (P3)*
	Special school	4,5,8	*"The classes were too big, I mean, there are eleven children in one class now, and even then, they sometimes get separated during the lessons. While one teacher is doing languages with five pupils, the other is doing math." (P4)*
	External care (Possibilities of external care, e.g. leisure activities.)	4,6	*"(...) yes, and then there is the possibility to have them looked after for up to three weeks in holidays (...)" (P6)*
	Prevention care (When the caring	3,6	*"We use the option of prevention care. The prevention care of the Life Aid*

	person is unable to give care, because of illness for example, the care is guaranteed by care staff.)		*Services, and yes, at the moment we are getting a monthly support of two afternoons on weekends (...).” (P6)*
	Home help	1,2	*“That’s a home help. Because the little one has such a vast attachment disorder, that she cannot be looked after externally. So she comes and takes over whenever I have to do something else (P2)*
Institutional Help			
	Child and Youth Welfare Services	1,3,5,8	*“(...) she asked for information material, she busied herself with the issue intensively, she couldn’t understand everything in daily life but she tries. So, therefore I really have the feeling of being supported and that there is some interest in the issue.” (P8)*
	Severely Handicapped Pass	1,2,7	*“(...) we applied for the care level and the severely handicapped pass. Well, actually we got to know about that because of other foster parents, and via the internet, we didn’t know that before (...).” (P7)*
	Level of Care (Valued/Assessed by the HIC to estimate the care a person needs to be well provided)	2,7	*„So we applied for the level of care quickly, that was no problem. Then we got a relieve support) (...).“ (P2)*
	Health Insurance Company /HIC	2	*“Then we got the relieve support paid by the health insurance company (...).” (P2)*
Therapy			
➔ constructive	Developmental Therapies	1,2,4,6	*“(...) both go to a special school, so they aren’t at home that much. And therapy possibilities like speech therapy (...)” (P6)*
	Riding Therapy	1,2,6	*“And then there was the possibility to combine riding therapy and ergo therapy. So that’s what she is doing now and then they sometimes do ergotherapy on the horse. That’s pretty good for her. It increases her awareness of herself and the limits of her body.” (P1)*
	Medicine	6,7,8	*“We were looking for a psychological practice then, because after the situation had got worse, X had to take medicine, just to protect herself.” (P8)*
	Video-taping	5	*“(...) We were filmed in special situations. These situations were analyzed, but only the positive sequences were shown and reviewed in the end.” (P5)*
	Psychological Therapy	4	*“There is a difference when I want her to do something, she does it more often. Or*

			she stops for moment when she wants to run away or insult me. Now she holds her tongue more often. I have noticed that something has changed, there is some attachment now." (P4)
➔ non-constructive			
	Psychological Therapy	3	*"But that kind of therapies are difficult for X because she cannot adapt them to her daily life." (P3)*
	(Special Education) Play Therapy	5	*"Because you don't know your role in therapy, so you feel uncomfortable, and you don't like that. (...) I never knew my part. And yes, they played with X, worked on colors and animals, something like that." (P5)*

N= Number of participants,
P^N= Participant cited,
X= anonymized name of a child

3.4 Support Tools

Related to *forms of help and support* the interviewed foster mothers make use of, they also described some *tools* they used (table 8). Four of them used tools for *visualisation* to make complex sequences or abstract concepts understandable for their children. Three participants (2,4,7) stated that they used *picture cards* to simplify daily procedures for their children. One foster mother (4) described their fixing cards in the bath room, so that her foster daughter knew what to do there. Another *visualisation tool* used by two participants (2, 3) was a *timer* or *an hourglass*. One foster mother (3) explained: *"We have such a timer for X, because she doesn't know how to use a watch and never remembers the time or remember it."*.

To enable their children to *rest*, some participants use *support tools*. Two foster mothers (7,8) stated that they made use of a *weight cover* or, to enable their children to feel their bodies. With the help of the weight, the children were able to stay in bed at night and sleep or to sit at the table during their meals. A *weight cover* is a therapeutic tool used for different forms of disability. This way, they are able to calm down and rest or sleep at night. Furthermore, two interviewees (1, 8) mentioned that they used an *acoustic door signal* to make sure they would notice their children leaving their rooms at night. One foster mother (8) explained: *"Like X, he has an acoustic door-signal, because he runs around at night and we don't come/can't come to rest at night."* But the door-signal also enables the child to stay in its room at night. The mother (8) explained that because her foster son knew that he could not leave his room without being noticed, he lost interest and could sleep more easily. In order to get *some sleep*, one interviewee (7) mentioned that they had bought a *nursing bed* for their daughter. It was a special kind of bed, which she could not leave easily.

For better *orientation*, one participant mentioned the possibility of *GPS-tracking* systems. The foster mother (1) explained that if a child got lost or ran away, they could use a smartphone tracking system to find it. Another interviewee (2) indicated that they used *light-strips* in their house to enable her foster daughter to find her way around, because she never found the light switch at night.

For their *parenting*, the foster mothers made use of different tools. A tool that was mentioned by half of the participants was the *FAS-First-Aid-Kit*. The *FAS-First-Aid-Kit* is, as described in the introduction, a tool that summarizes important daily aspects of parenting a child suffering from FASD, ranging from rituals and rules to personal hygiene and sleep. This first-aid-kit contains useful tools which the caregiver of FASD-children can use. For example, one foster mother (3) said that she used the material not only to understand things better but also to make use of its picture cards to make their daily life easier. Another tool that was used by two foster mothers (5, 8) was a *reinforcement plan*. One mother (8) explained, that it was highly motivating for her children when goals were formulated together and positive behavior was rewarded.

The analysis of support tools used by the participants contributes to answering the research question which sources of help and support the participants used to simplify parenting. The categories indicate which daily life support the foster mothers used and therefore offered an insight in the used support forms. But the described help tools can also be attributed to the parenting strategies the participants used and therefore contribute to the answering of the research question, which strategies foster parents used to bring up their children and adolescents with FASD. Within the category of *visualisation*, they named the use of *picture cards*. This is related to the *parenting strategy* of implementing a strict *structure* and of making use of *rituals* in daily life. The use of *hourglasses* or *timers* could be related *avoiding excessive demands*. Furthermore, the *support rest tools* could also be attributed to *structure*, because they enable the foster parents to stick to a strict *day daily schedule* that is necessary for children with FASD. The point of *orientation* could be related to the *parenting strategy* of *adapting environmental factors* to enable their children to orientate themselves, for example. The tools of the category *parenting* could be attributed to the *parenting attitude* of strategies described by the interviewees. The *FAS-First-Aid-Kit*, for instance, enables the foster mothers to gather a better understanding for different important issues concerning

FASD, for example that these children are not in state to estimate *the consequences of their behaviour*. The *reinforcement plan* contributes to the *parenting attitude* of enhancing their children's strengths (cf. table 6). So in conclusion, a connection could be drawn between the described support tools (table 8) and the parenting strategies (table 6).

Table 8

Codes for **Support Tools** (N=8)

Categories	**Subcategories (Definition)**	**Participants**	**Quotations**
Visualisation			
	Picture Cards	2,4,7	*"So,) for example, in the bath room, we have these pictures. So that she knows what to do there." (P4)*
	Hourglass / Timer	2,3	*"We have such a timer for X, because she doesn't know how to use a watch she can't read the time and she never remembers the time/it. (...)." (P3)*
Support Rest			
	Weight Cover / Vest (Therapeutic tool that provides the disabled persons with a better body feeling and helps them to calm down and sleep at night.)	7,8	*"Then we have a weight cover and a weight vest, so that the child gets a better body feeling." (P7)*
	Acoustic Door-Signal	1,8	*"Like X, he has an acoustic door-signal, because he runs around at night and takes things out. We didn't find rest at night." (P8)*
	Nursing Bed	7	*"And then she has a nursing bed (...) an "Emperor-Bed". Do you know that?" (P7)*
Orientation			
	GPS-Tracking	1	*"Yes, we don't need that at the moment, a watch with a GPS transmitter so that we can find the child. (...) We used to have that. But now we use the smartphone, we use the Apple-function "Track my Phone"." (P1)*
	Light-Strips	2	*"We use light for orientation so that she can find her way around, because she can't find the light switch (...)." (P2)*
Parenting			
	FAS-First-Aid-Kit	2,3,4,7	*"And we got this FAS-Kit, do you know that?" (P3)*

	Reinforcement Plan	5,8	*"(...) Every child gets its own individual points for the behavior that we want to change. If they behave well, they'll get a sticker. If they don't behave as expected, they'll get a warning in the form of a yellow mark. When they have two yellow marks, these marks will be deleted. In the end, they get reward-boxes, depending on how many stickers they have got. That's a great motivation for them (...)." (P8)*

N= Number of participants,
P^N= Participant cited,
X= anonymized name of a child

3.5 Sources of Information

The interviewed foster mothers were also asked about their *sources of information* to understand what exactly helped them to make use of certain support forms or tools described in table seven and eight. Table nine shows the results of the *sources of information* mentioned by the participants.

Firstly, many participants searched for information *autonomously*. Therefore, almost every participant (except P1) used the *internet* to gather information. One participant (8) explained: *"Firstly, I searched on the internet. Without end. To see if there were possibilities of further training."* Other participants stated that they had just searched on the internet, because at the beginning they had not known anything about this issue. Another *source of information* that was used by the majority of the interviewed foster mothers was the contact with other *foster parents*. One interviewee (4) said that she used a schedule because of a tip she had got from another foster family. Three participants (1,2,3) stated that they read *books* to gather information. One foster mother (1) also mentioned a scientific book about FASD to be her *"Bible"* as well as *articles* that had offered her information about FASD back in the year 1995 and 1996.

Secondly, many participants had searched for information on a *professional* level. Therefore, most of them contacted the *Clinic of Walstedde* to gather information about FASD. It is a clinic near Münster in North Rhine-Westphalia and it has specialized on child and youth psychiatry. It houses an FASD counselling center. Three foster mothers (1, 5, 8) stated that they had got information from *medical scientists*. One of them (8) explained that a *medical scientist* had expressed her suspicion that the tested child was possibly suffering from FASD. Three foster mothers (2, 6, 7) mentioned *FASD Deutschland e.V.* as an important source of information they used. One mother (2) explained: *"Yes, I found the brochures of FASD Deutschland very helpful, also to hand them over to others."* Only one participant (3) stated that she gathered information from a *specialist counselor* who visited her once a month to talk about FASD-specific issues.

Overall, three interviewees (2, 4, 5) indicated that the information they had found was *not sufficient*. One mother (5) explained it this way: *"For some first information, yes. But in the case of having a child suffering from FAS, no."* In addition, two interviewees (2, 4) also stated that they had had vast problems to gather useful information.

The described *sources of information* contributed to the answering of two research questions, namely which strategies foster parents used to bring up their children and adolescents with FASD and which sources of help and support the participants used. It highlights the understanding for the process of gathering *support* gained by the participants. Many foster mothers pointed out that they had first got information through institutions like the *clinic* to make use of tools like the *FAS-First-Aid-Kit*. In conclusion, the search for *information* on FASD is necessary in the eyes of the interviewees to gather the needed *forms of help* or the special *support tools which are* useful for children suffering from FASD. For example, one mother said that she used a schedule for her children just because of another foster mother's tip. For a better understanding it is also necessary to adapt one's own *parenting strategies*, for example to keep the *environment less stimulating* than normally while caring for a child suffering from FASD.

Table 9

Codes for **Sources of Information** (N= 8)

Categories	**Subcategories (Definition)**	**Participants**	**Quotations**
Autonomous Search			
	Internet	2,3,4,5,6,7,8	*"Yes, I informed myself on the internet, because there are so many possibilities. And then I called them, and asked them about it, and then I got appointments." (P4)*
	Exchange foster parents	2,3,4,6,7,8	*"Well, the schedule for example, that I received from another foster mother from the facebook group." (P4)*
	Books	1,2,3	*"So Herman Löser's book was my Gospel, my Bible, at that time. From that book, /I picked up a lot*

			of information. There was a second book by Ms Steiner. That was the first I) read for information." (P1)
	Journals /Articles	1	*"Only through Professor Löser, who tested the children and a journal for foster parents, where an article was published in the year 95-96." (P1)*
Professional			
	Clinic Walstedde (Child and youth psychiatry housing a FASD counselling center.)	2,3,4,5,6,7	*"Then we contacted the outpatient department in Walstedde of course." (P4)*
	Medical Scientists	1,5,8	*"There was this scientist who expressed some suspicion suspected something." (P8)*
	FASD Deutschland e.V.	2,6,7	*"Yes, I found the brochures of FASD Deutschland very helpful, also to hand them over to others." (P2)*
	Specialist Counseling FASD	3	*"There is this specialist counselor who comes to our home once a month and would also come if there) were a problem, he is available twenty-four hours a day. In any case of an emergency, too." (P3)*

N= Number of participants,
P^N= Participant cited,
X= anonymized name of a child

3.6 Future Wishes

At the end of the interview, the participants were asked about their *wishes for the future* (table 10). Many interviewees mentioned that *FASD in public education* was an important issue. Nearly every foster mother felt the need to explain FASD as a disability to other people. One mother (3) explained: "*I'd prefer other people to know more about FAS. I know a lot. I know what my kids are like. And I know that they are okay just the way they are, but the others don't."* Two other participants (2, 4) stated that they would like to have more possibilities of *further and ongoing education and training* for foster parents. Other foster mothers (6, 7) wished FASD to be a *part of every professional education*. One interviewee (6) reasoned: *"Firstly, I'd wish medical scientists for children and young people to learn how to diagnose FAS in an early stadium of their education. (…) Then, I'd wish them to discuss this issue early in school, in biology, sex education, whatsoever, and point out that the consumption of alcohol during pregnancy may cause irreversible harm to the unborn child. (…)".* They denounce the missing knowledge of FASD in many professions. One foster mother (2) even expressed the wish to develop an FASD-specific *manual* to make coping with children suffering from FASD easier.

Concerning life *perspectives*, the participants named more wishes. Firstly, they mentioned hopes for *perspectives* of their *foster children*. A majority (2,3,5,7,8) expressed hopes concerning the *professional* education of their children. One foster mother (5) explained that she wished her son to be able to fulfil one of his *professional* aims, no matter what the future might bring. Others (1,3,7,8) expressed wishes about their foster children's *living* perspective. One mother (3) explained: *"I hope if these children move out of our home, that they will be housed well and well provided for."* Four participants (3,5,6,7) wanted their children to find a balance between seeking support and living independently. Therefore, an interviewed foster mother (3) explained: "*Yes, right. That she gets support when she needs it, but that she also has the possibility to deal with some things independently."* Two other interviewees (1,3) stated that they wished their children to find satisfaction in life. A mother indicated: *"Actually, it's important for us to see our children happy, no matter what happens."* One foster mother (4) wished her foster daughter to be able to develop some *social competence* and to find an effective *"miracle therapy"* for her.

Secondly, the participants also named some wishes for their own *perspectives* as *foster parents.* Four of them (2,4,7,8) wished for more *daily support*. One of them (8) explained that it had taken her one year to find additional help staff and months to train them. Three participants (1,2,4) hoped to receive more *societal respect* in future. They explained that they often felt misunderstood, for example when their children behaved badly and thus made them react strictly. So they wished for more respect through better understanding for the challenging task of raising a disabled child. Two other foster mothers claimed more *self-help groups on-site*. One interviewee (3) wished every foster family to be supported by a a specialist in counselling. She reasoned: *"For every child. or foster families who have disabled children. This specialist in counseling is needed."* Another foster mother (2) mentioned the issue of *financial hedging.* She pointed out that the mother of a disabled child was not able to work anymore and so should have the right to obtain a pension later.

Concerning the last research question what appropriate support should be like in the eyes of foster parents, the analysis of their *future wishes* provided an insight for the answer to this question. An important issue is FASD as a disability in *public education.* For the future the participants considered it important to inform society about FASD and its impact on these children and their parents. This was related to the wish for *societal respect*. The foster mothers stated that they often felt misunderstood because of their special children and parenting styles. In conclusion, they claimed more understanding of the disability and respect for their task of raising a disabled child. An interesting aspect that the participants did not only wish for perspectives for their children, but also for their own future. It was conspicuous that they expressed as *normal* wishes as many most parents do. This included hopes for their *professional* future, their *living perspectives* and *life satisfaction*. Other hopes were more special and related to raising a disabled child. They included finding a *balance between support and independence* as well as an *effective form of therapy* and the possibility to develop some *social competence*. The wishes for the future perspectives of the foster parents were all very special and related to their uncommon situation. Claiming *social respect* or *more self-help groups* is typical for parents who raise a disabled child, but not so important for parents in general.

Table 10

Codes for **Future Wishes** (N= 8)

Categories	Subcategories	Participants	Quotations
Public Education FASD			
	Explaining Disability	2,3,4,6,7,8	*"(…) I'd prefer other people to know more about FAS. I know a lot. I know what my kids are like. And I know that they are okay just the way they are, but the others don't know that." (P3)*
	Continuing Training Foster Parents	2,4	*"Firstly, I would like to have more possibilities of continuing training…also compulsory." (P2)*
	FASD part of the professional education	6,7	*"Firstly, I'd wish medical scientists for children and young people to learn how to diagnose FAS in an early stadium of their education. (,,,) Then, I'd wish them to discuss this issue early in school, in biology, sex education whatsoever, and point out that the consumption of alcohol during pregnancy may harm the unborn child.(…)" (P6)*
	Development of a Manual	2	*"Basically a manual for FAS, dealing with FAS or maybe to inform those who don't know anything about it." (P2)*
Perspective			
➔ Foster Children			

	Professional	2,3,5,7,8	*“So I’d wish X to fulfill his professional aims, no matter what…” (P5)*
	Living	1,3,7,8	*“I hope if these children move out of our home, that they (are) will be housed well and well provided for.” (P3)*
	Balance between Support and Independence	3,5,6,7	*“Yes, right. That she gets support when she needs it, but that she also has the possibility to deal with some things independently (…).” (P3)*
	Satisfaction	1,3	*“Actually, it’s important for us to see our children happy, no matter what might happen.” (P3)*
	Developping social competence	4	*“That’s what I really hope. That she can work on her social competence in some way. And that this will be successful.” (P4)*
	Finding forms of therapy	4	*“(…) that we will find a miracle therapy that is effective.” (P4)*
➔ Foster Parents			
	More daily support	2,4,7,8	*“No, not at all. It took one year to find the additional care staff and also four to five months to train them for the issue, because they didn’t know anything about FAS. (…)” (P8)*
	Societal Respect	1,2,4	*“(…) That doesn’t work at all. That has to be respected by society. That’s what I really hope (…).“ (P2)*
	More self-help groups on-site	4,5	*“In the first place, I would say self-help groups.” (P5)*
	Nationwide Specialist Counseling	3	*“For every child or foster families with disabled children. This specialist counseling is needed (…).” (P3)*
	Financial Hedging	2	*Yes, of course. That isn’t easy. If you have a disabled child at home, then theoretically you should (have) be entitled to obtain a pension, because it isn’t realistic at all to work (…)” (P2)*

N= Number of participants,
P^N= Participant cited,
X= anonymized name of a child

4. Discussion

4.1 Conclusion

The goal of the study was to gain a greater insight in the special situation of foster parents raising children with FASD by interviewing them about difficulties and support possibilities used and necessary for parenting these children appropriately. For the answer to the first research question concerning strategies foster parents used to bring up their children and adolescents suffering from FASD, the results of the *parenting strategies* were informative. Firstly, the participants emphasized the importance of structural elements in parenting to make daily life easier. Secondly, the adaption and reformation of their own parental attitude an as well as that of the environment towards the difficult circumstances produced by the behavioural problems of their children played a major role in the strategies the foster parents used.

Concerning the second research question, which sources of help and support the participants used to facilitate their daily life, their answers contributed to give an answer. At first, institutions of help were used, among them child and youth welfare services, external forms of care and special schools. Then, the participants named forms of private support like family and friends taking care of their children. Finally, different forms of therapy were mentioned as support possibilities for the interviewees. It was conspicuous that some forms were evaluated as constructive such as the riding therapy whereas other forms were valued as non-constructive. In conclusion, the results indicate that there is a need for guidance through effective forms of therapy facing the difficulties of children and adolescents with FASD.

As for the third research question what appropriate support should be like in future, the part of the interview dealing with the *future wishes* provided informative aspects. In the first place, there was a high need of more knowledge about FASD in our society in the eyes of the interviewed foster parents. The participants hoped that more knowledge and understanding would result in more respect and recognition for their task in future. Secondly, they wished for FASD to be part of medical and social education, thus contributing to greater knowledge and understanding and resulting in the creation of more forms of support by public and professional institutions. At last, the interviewed foster mothers described wishes for building up perspectives for themselves and their disabled children. Especially concerning their own financial hedging and the living and working perspectives of their children, they wish for more future assistance.

4.2 Research Value

Studies focusing on the support possibilities, putting the experiences of these special foster parents in its centre, were missing within the scientific literature about FASD. Olson et al. (2009) reviewed the role of family factors in the outcome of individuals with FASD and how the foster family was affected by the task of raising a disabled child. The review indicated that good quality caregiving and stability of the home environment contributed directly to positive outcomes for children suffering from FASD. In addition, Streissguth (1997) emphasized the special role of foster parents of FASD children. She described their role as being a lifelong *advocate* for the needs and rights of these children. In conclusion, these implications highlighted the importance of stable and psychologically balanced foster parents raising children with FASD. Furthermore, Plant and Sanders (2007) drew a connection between feelings of stress of the of caregivers and negative family factors, such as *coercive parent-child interaction, increased risk of family maladjustment* and *parental depression*. That contributed to the implication that a stable, stress-free environment with psychologically balanced foster parents was necessary for the creation of a secure home where growing up in a carefree atmosphere was possible, especially for children suffering from these major behavioural difficulties. Nevertheless, there is little research putting the needs of these caregivers in its centre and examining the forms of help and support used and needed. Green et al. (2014) started focusing on foster parents next to professionals aiming to investigate behavioural difficulties and parenting strategies. This in-depth research of the situation of foster parents aimed to clear up which support possibilities were effective and how appropriate support could be build up in future. Especially the results of the answers to the two research questions which sources of help and support the participants used what appropriate support should be like provided new insights. Furthermore, this study held a unique status because it focused on the perceptions, experiences and views of the foster parents and emphasized their special role raising children with a disability which is not much known in society. With the help of the detailed interview and the thorough analysis of its results, a clear picture of the support being used as well as the support being needed could be drawn whereas literature and scientific studies mainly focus on these children’s neuronal damages and behavioural difficulties (cf. Ter Horst, 2010; Becker, 2013).

4.3 Critical Reflection

Reflecting critically on this study, some limitations should be discussed. The sample of the study was mainly reached through a self-help group on a social media platform. The self-help group is a place for foster or adoptive parents, persons suffering from FASD, professionals and interested parties. The participants involved were highly committed, well informed and prepared to raise their children. Interviewing the foster mothers, the researcher realized that the participants did probably not account for the vast majority of foster parents raising children with FASD. For future research, it is recommended to try to reach a sample that accounts more for the average foster parents’ population. This will contribute to a less biased insight in the needs of the foster parents.

In addition to the limitations of the sampling procedure, the places of the interviews were sometimes not optimal. The interviews took mainly place at interviewees’ homes. Sometimes, young children were present, family members entered the room or there was an interruption because of a ringing mobile phone. Thus, the procedure of the interview was quite often disturbed and therefore some chances for further questioning or explanation were seized, a conclusion drawn only after the transcriptions had been done. During undisturbed interviews, the researcher had the chance to pose additional questions, when something was not clear and then the interviewees explained circumstances in detail. Because of the recognition of the differences between the interviews, the researcher would now propose to try and standardize the interview circumstances more narrowly. Besides the places, the focus on NRW also implied some limitations. The Clinic of *Walstedde*, hosting an FASD counseling service, was named by many participants as an important *source of information*. Furthermore, the *FAS-First-Aid-Kit* inter alia developed by Dr. Feldmann, was described by some of the interviewees as a support tool they used regularly. The relation between the clinic of *Walstedde* where Dr. Feldmann leads the FAS-ambulance center, the support tool of the *FAS-First-Aid-Kit* and the limitation to NRW for the interviews seemed obvious. For future research it would be interesting to get more insight into which tools foster parents use in other federal states.

Furthermore, the researcher reflected critically on her own role during the interviews. As an employee of FASD-specific housing groups for children and adolescents, the researcher possesses some practical and theoretical knowledge gained during her work. Potentially, this could have influenced the formation of the codes. But being an employee with knowledge about FASD contributed to the researcher’s status of an expert, the seriousness of the study and the trust the participants put in taking part in this study. All this had a positive influence on their willingness to take part in the research as well as on the atmosphere during the interviews.

4.4 Implications for Future Research

First of all, the described results of this qualitative study should be confirmed or, if applicable, expanded through the implementation of a quantitative study questioning a greater sample size. A quantitative study would be a necessary basis on which to build up appropriate support possibilities for these foster parents. This interview study could function as an indication for a study focusing on a greater and thus more representative sample. Furthermore, it would be beneficial to compare the support situation of foster parents with the situation of professional caregivers. The conducted interview study focused on the needs of foster parents putting the fact aside that many children with FASD are raised in a professional youth health context (Nordhues, Weischenberg, Feldmann, 2013). In conclusion, the comparison of the two situations concerning the forms of support would contribute to an improvement of support possibilities for professional and non-professional caregivers.

Secondly, the results of this study indicated that there was the strong wish for more societal and public knowledge about FASD as well as for more respect and recognition for their task. The participants compared the role of their children to the role of children with *Down's Syndrome*. Some interviewees wished for the same acceptance as people with *Down's Syndrome* get. As this disability is well-known and thus accepted in society, these children and their (foster) parents have less problems in the participants' point of view. *Google* search for the German term *Fetales Alkoholsyndrom* resulted in 25,200[2] hits, whereas *Down Syndrom* provided 1,300,000[3] hits. Relating the hits of this *Google* search to the level of awareness in public, it indicates the difference between these two types of disabilities. The question arises why *Down's Syndrome* is obviously better known than FASD. A great German organization named *Aktion Mensch* has implemented a lot of advertising for the inclusion of disabled people. Among others they have created advertisements showing children or adolescents with *Down's Syndrome* (Aktion Mensch, 2017). Nationwide campaigns like that have possibly increased the knowledge and recognition of *Down's Syndrome* in our society and also strengthened the acceptance of these people. The cause of FASD is markedly different to *Down's Syndrome*. While *Down's Syndrome* is caused by a genetic defect, FASD originates due to an external factor, namely intoxication as a consequence of alcohol consumption during pregnancy. It is not only one hundred percent

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[2] https://www.google.de/?gws_rd=ssl#q=Fetales+Alkoholsyndrom; 10.07.2017

[3] https://www.google.de/?gws_rd=ssl#q=Down+Syndrom, 10.07.2017

preventable, but also related to guilt and shame. But simultaneously, alcohol is a socially accepted drug. The statistics of 2013 show that people in Germany drank 9.7 liters of alcohol per person per year and that 2.6 million children were raised in a household with at least one member being addicted to alcohol (Kenn dein Limit, 2017). Obviously, alcohol plays an important part in our society and a disability caused by it is possibly still negated by some people. The question remains how society could can gain greater knowledge and awareness of FASD.

To increase the public awareness of FASD, campaigns like the ones for *Down's Syndrome* function as an effective example. Posters and TV spots emphasizing the consequences of drinking during pregnancy and supported by prominent persons approving the *9-month abstinence rule* could contribute to an increased publicity of FASD and the consequences of drinking during pregnancy. To implement such a great campaign, further research would be necessary to confirm the need of increased public knowledge and recognition.

4.5 Message

The interview study conducted and analyzed in this paper has offered beneficial insights in the situation of a special social group: foster parents of children suffering from FASD. It has examined especially the forms of support used by this group and the wishes for more appropriate support in the foreseeable future. As described, the results of the study could function as a starting point for further research: (1) quantitively confirming and broadening the results concerning the support forms and indicating (2) how to increase the societal publicity of FASD.

As a societal appeal, the results indicate a strong wish for more tolerance towards the behaviours and thus the special needs of children suffering from FASD. Their foster parents often go unheard but highly deserve to be listened to and taken more seriously.

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6. Appendix

- Complete Tables

Behavioural Difficulties of Children with FASD

Codes for Behavioural Difficulties (N= 8)

Categories	**Subcategories**	**Definition**	**Participants**	**Quotations**
Behaviour				
	Aggression	Physically aggressive against others (beating, kicking etc.)	7,8	*(...) "So she beats and kicks, she insults me, that's not daily for this child (...)" (P7)*
	Nutrition		5,7,8	*"Yes, because she didn't chew her food. She didn't want to chew and she still not wants to. Yes of course she chews, but than she also chews yoghurt." (P7)*
	Sleeping habits	The sleeping behaviour is different from normal sleep in comparison to peers.	2,5,7,8	*"(...) because he was running around, (...) we couldn't find rest anymore." (P8)*
	Inability to estimate risks	Risks are taken without thinking about the possible consequences.	2,7,8	*"Always. When a normal child touches a hot plate, it notices, that's hot, and won't do it again. If an FAS child touches a hot plate, oh that's hot, but on the next day, it will touch it again." (P8)*
	Auto-Aggression		3,5	*"(...) She hurts herself...then she becomes a danger for herself and others (...) (P3)*
	Steal (property of others)	Are not able to respect and understand the property of others.	2,6,8	*"(...) I remember for example, that this is a difficulty, too. That's mine and that's yours (...)" (P6)*
	Missing empathy	Difficulties in putting themselves in position of others.	1,2,4	*"What's conspicuous, too, is that many children don't recognize your feelings. Yes, when you are unhappy or sad, it doesn't mean a thing to them." (P1)*
	Aware of *being different*	These children know that they are different in comparison with other children of	1,3	*"And she X notices, that she is so. She then asks: Why am I this way? Why do I forget so much? (...)" (P3)*

Developmental Delay		their age and are in a state to name what is different.		
	No learning	These children do not learn from experience and quickly forget something they have learned.	2,3,4,6	*“(…) that the normal educational strategies aren’t effective (…) they won’t learn from punishment, I would say. So, punishing them doesn’t make any sense, (…).”. (P2)*
	Sexualized	These children are not able to adapt their behaviour or control their impulses and therefore behave in a more sexualized way.	2	*“(…) Immediately meant immediately, two weeks later, she went with a boy to the school toilet to get a cigarette.” (P2)*
	Social Competence	Difficulties in social situations and in finding friends.	4	*“Yes especially, yes, our foster daughter does have vast difficulties with her social competence. She has no empathy (…)” (P4)*
	Delayed Growth		7	*“(…) that’s when we noticed the thing with her head. That we tried three to four riding helmets, and the we bought a children’s helmet, a bicycle helmet, with a lot of padding in it (…).” (P7)*
	Motoric Problems		4,6,8	*“This girl was three when they came to us, and she was not able to walk stairs, she could not touch sand, she was so traumatized when she saw a man,” (P8)*

N= Number of participants,
P^N= Participant cited,
X= anonymized name of a child

Initial Contact FASD

Codes for Initial Contact (N= 8)

Subcategories	**Definition**	**Participants**	**Quotations**
Admission Foster Parents	First contact through the admission of an affected foster child.	1,4,5,7,8	*“That was actually before we should get our first foster child, that should have FAS. That’s when I informed myself (…).” (P5)*

Professional contact	First contact through the own profession.	2,6	*"The very first time while my past professional praxis as social-pedagogic family aid (...)." (P6)*
Foster Parent Education	First contact through a special education for foster parents.	3	*"The first time we heard about FAS as we prepared for becoming foster parents. We had that special course, where they told us, that there are these children and also what it means to raise them." (P3)*

N= Number of participants,
P^N= Participant cited,
X= anonymized name of a child

Parenting Strategies

Codes for Parenting Strategies (N= 8)

Categories	Subcategories	Definition	Participants	Quotations
Structure				
	Weekly/Daily Plan	Days and weeks are strictly structured and leave no place for spontaneity.	1,2,3,4,6,7,8	*"They need a precise, they need a very clear daily plan, because they can't organize themselves. She forgets a lot of things." (P3)*
	Dependability	Stability concerning the caring person and the environment.	1,3,5,6,8	*"I think, that the dependability. Yes, for my oldest daughter with FASD, she couldn't stay alone in the apartment, after I had had an accident (...)" (P1)*
	Exact introductions	Complex sentences and instructions should be avoided to ease understanding.	1,4,5,6	*"(...) My husband always names in simple and concise words what he wanted the kids to do. (...) children with FAS need an exact instruction (...) that works!" (P1)*
	Rituals		2,4,7	*"When I know, in kindergarten my jacket always hangs on this/the same hook, then it becomes a ritual, and it has to be that way every morning, before doing the next step (...)" (P2)*
	Avoid excessive demands	Holding high demands result in behavioural problems.	1,6	*"Trying not to demand too much from them (...) because then X won't go to school. I'm in the position to say, X'll stay at home. Because it's clear/obvious that the situation could escalate in school. (6)"*
Parenting Attitude				
	Strengths	Giving these children the	1,2,6	*"(...) that's what I always try to communicate, that they are*

		chance to discover their own talents, to feel positive and confident about themselves and strengthen their self-esteem.		*great, the way they are. And I love you just the way you are. You are a very great child (…) they have a lot of self-esteem. (…)" (P6)*
	Being patient		4,6,7	*"(…) staying cool and saying, it's okay, go upstairs, put your wet laundry into the washing machine (…) don't dramatize that (…)" (P6)*
	Making consequences understandable	Making consequences directly visible for these children, because they are not able to understand abstract concepts.	6	*"One method is to say, well, windscreen wipers are expensive, you will have to do without your chocolate pudding until the new wiper is paid off. So, I went to Rewe with him and showed him four tubs of chocolate pudding and said, (…) all these chocolate puddings cost as much as the windscreen wiper and now you must do without for one month to pay it off. (…)" (P6)*
Environment				
	Nutrition	Adapting the food to the abilities and needs of the children.	2,6	*"(…) and sugar is what is very obvious in my opinion, it's the first addictive drug they consume and they feel a great desire for it and it causes conspicuous behavior and restlessness." (P2)*
	Poor-stimuli environment	Less stimuli in the environment contribute to rest and calmness.	1,6	*"Especially with FAS we have noticed that actually an environment with poor stimuli (…) contributes to relaxation (…)" (P2)*
	Activity		6	*"A lot of exercise to avoid motoric restlessness, that means trampoline, playing outdoors most of the time." (P6)*

N= Number of participants,
P^N= Participant cited,
X= anonymized name of a child

Support and Forms of Help

Codes for Support and Forms of Help (N= 8)

Categories	Subcategories	Definitions	Participants	Quotations

Daily Life				
	Family Aid Services	Special ambulant care service for disabled persons who live at home.	1,4,5,7,8	*“She comes here about once a week for two hours, then they play something or they go on small trips.“ (P4)*
	Private Support		1,3,4,6	*“And we have our, my mom and my parents-in-law, they also take care of the children.” (P3)*
	Special school	Special schools for handicapped children having problems with different aspects of learning.	4,5,8	*“The classes were too big, I mean, there are eleven children in one class now, and even then, they sometimes get separated during the lessons. While one teacher is doing languages with five pupils, the other is doing math.” (P4)*
	External care	Possibilities of external care, for example leisure activities during the holidays.	4,6	*“(...) yes, and then there is the possibility to have them looked after for up to three weeks in holidays (...)” (P6)*
	Prevention care	When the caring person is unable to give care because of illness for example, the care is guaranteed by nursing staff.	3,6	*“We use the option of prevention care. The prevention care of the Life Aid Services, and yes, at the moment we are getting a monthly support of two afternoons on weekends (...).” (P6)*
	Home help		1,2	*“That’s a home help. Because the little one has such a vast attachment disorder, that she cannot be looked after externally. So she comes and takes over whenever I have to do something else (P2)*
Institutional Help				
	Child and Youth Welfare Services		1,3,5,8	*“(...) she asked for information material, she busied herself with the issue intensively, she couldn’t understand everything in daily life but she tries. So, therefore I really have the feeling of*

				being supported and that there is some interest in the issue.” (P8)
	Severely Handicapped Pass		1,2,7	*“(...) we applied for the care level and the severely handicapped pass. Well, actually we got to know about that because of other foster parents, and via the internet, we didn’t know that before (...).” (P7)*
	Level of Care	Valued by the HIC to estimate the care a person need to be well provided.	2,7	*„So we applied for the level of care quickly, that was no problem. Then we got a relieve support) (...).“ (P2)*
	Health Insurance Company /HIC		2	*“Then we got the relieve support paid by the health insurance company (...).” (P2)*
Therapy ➔ constructive	Developmental Therapies	For instance, ergo therapy or speaking therapy.	1,2,4,6	*“(...) both go to a special school, so they aren’t at home that much. And therapy possibilities like speech therapy (...)” (P6)*
	Riding Therapy		1,2,6	*“And then there was the possibility to combine riding therapy and ergo therapy. So that’s what she is doing now and then they sometimes do ergotherapy on the horse. That’s pretty good for her. It increases her awareness of herself and the limits of her body.” (P1)*
	Medicine		6,7,8	*“We were looking for a psychological practice then, because after the situation had got worse, X had to take medicine, just to protect herself.” (P8)*
	Video-taping		5	*“(...) We were filmed in special situations. These situations were analyzed, but only the positive sequences were shown and reviewed in the end.” (P5)*
	Psychological Therapy		4	*“There is a difference when I want her to do something, she does it*

				more often. Or she stops for moment when she wants to run away or insult me. Now she holds her tongue more often. I have noticed that something has changed, there is some attachment now." (P4)
➔ not-constructive				
	Psychological Therapy		3	*"But that kind of therapies are difficult for X because she cannot adapt them to her daily life." (P3)*
	(Special Education) Play Therapy		5	*"Because you don't know your role in therapy, so you feel uncomfortable, and you don't like that. (...) I never knew my part. And yes, they played with X, worked on colors and animals, something like that." (P5)*

N= Number of participants,
P^N= Participant cited,
X= anonymized name of a child

Support Tools

Codes for Support Tools (N= 8)

Categories	Subcategories	Definitions	Participants	Quotations
Visualisation				
	Picture Cards		2,4,7	*"So, for example, in the bath room, we have these pictures. So that she knows what to do there." (P4)*
	Sand Glass / Timer		2,3	*"We have such a timer for X, because she could not use watches or remember the time. (...)." (P3)*
Support Rest				
	Weight Cover / Vest	Therapeutic tool that provides the disabled persons with a better body feeling and helps them to calm down and sleep at night.	7,8	*"Then we have a weight cover and a weight vest, so that the child gets a better body feeling." (P7)*

	Acoustic Door-Signal	A signal that indicates when someone leaves a room.	1,8	*“Like X, he has an acoustic door-signal, because he runs around at night and takes things out. We didn’t find rest at night.” (P8)*
	Nursing Bed	A special bed, that bounds children within it and could not easily left.	7	*“And then she has a nursing bed (...) an “Emperor-Bed”. Do you know that?” (P7)*
Orientation	GPS-Tracking		1	*“Yes, we don’t need that at the moment, a watch with a GPS transmitter so that we can find the child. (...) We used to have that. But now we use the smartphone, we use the Apple-function “Track my Phone”.” (P1)*
	Light-Strips		2	*“We use light for orientation so that she can find her way around, because she can’t find the light switch (...).” (P2)*
Parenting	FAS-First-Aid-Kit		2,3,4,7	*“And we got this FAS-Kit, do you know that?” (P3)*
	Reinforcement Plan		5,8	*“(...) Every child gets its own individual points for the behavior that we want to change. If they behave well, they’ll get a sticker. If they don’t behave as expected, they’ll get a warning in the form of a yellow mark. When they have two yellow marks, these marks will be deleted. In the end, they get reward-boxes, depending on how many stickers they have got. That’s a great motivation for them (...).” (P8)*

N= Number of participants,
P^N= Participant cited,
X= anonymized name of a child

Sources of Information

Codes for Sources of Information (N= 8)

Categories	**Subcategories**	**Definitions**	**Participants**	**Quotations**

Autonomous Search				
	Internet		2,3,4,5,6,7,8	*“Yes, I informed myself on the internet, because there are so many possibilities. And then I called them, and asked them about it, and then I got appointments.” (P4)*
	Exchange foster parents		2,3,4,6,7,8	*“Well, the schedule for example, that I received from another foster mother from the facebook group.” (P4)*
	Books		1,2,3	*“So Herman Löser’s book was my Gospel, my Bible, at that time. From that book, /I picked up a lot of information. There was a second book by Ms Steiner. That was the first I) read for information.” (P1)*
	Journals /Articles		1	*“Only through Professor Löser, who tested the children and a journal for foster parents, where an article was published in the year 95-96.” (P1)*
Professional				
	Clinic Walstedde	Child and youth psychiatry housing a FASD counselling center.	2,3,4,5,6,7	*“Then we contacted the outpatient department in Walstedde of course.” (P4)*
	Medical Scientists		1,5,8	*“There was this scientist who expressed some suspicion something.” (P8)*
	FASD Deutschland e.V.		2,6,7	*“Yes, I found the brochures of FASD Deutschland very helpful, also to hand them over to others.” (P2)*
	Specialist Counseling FASD		3	*“There is this specialist counselor who comes to our home once a month and would also come if there) were a problem, he is available twenty-four hours a day. In any case of an emergency, too.” (P3)*
Evaluation				
	Insufficient	The found information was evaluated as insufficient.	2,4,5	*“For the first information, yes. But for the case of having a child suffering from FAS, no.” (P5)*
	Difficulties finding information	Difficulties finding	2,4	*“(...) If you attempt to search the internet, that will take hours (...)” (P4)*

information was not useful.

N= Number of participants,
P^N= Participant cited,
X= anonymized name of a child

Future Wishes

Codes for Future Wishes (N=8)

Categories	Subcategories	Participants	Quotations
Public Education FASD			
	Explaining Disability	2,3,4,6,7,8	*“(...) I’d prefer other people to know more about FAS. I know a lot. I know what my kids are like. And I know that they are okay just the way they are, but the others don’t know that.” (P3)*
	Continuing Training Foster Parents	2,4	*“Firstly, I would like to have more possibilities of continuing training…also compulsory.” (P2)*
	FASD part of the professional education	6,7	*“Firstly, I’d wish medical scientists for children and young people to learn how to diagnose FAS in an early stadium of their education. (,,,) Then, I’d wish them to discuss this issue early in school, in biology, sex education whatsoever, and point out that the consumption of alcohol during pregnancy may harm the unborn child.(...)” (P6)*
	Development of a Manual	2	*“Basically a manual for FAS, dealing with FAS or maybe to inform those who don’t know anything about it.” (P2)*
Perspective			
➔ Foster Children			
	Professional	2,3,5,7,8	*“So I’d wish X to fulfill his professional aims, no matter what…” (P5)*
	Living	1,3,7,8	*“I hope if these children move out of our home, that they (are) will be housed well and well provided for.” (P3)*
	Balance between Support and Independence	3,5,6,7	*“Yes, right. That she gets support when she needs it, but that she also has the possibility to deal with some things independently (...).” (P3)*
	Satisfaction	1,3	*“Actually, it’s important for us to see our children happy, no matter what might happen.” (P3)*
	Developping social competence	4	*“That’s what I really hope. That she can work on her social competence in*

			some way. And that this will be successful.” (P4)
	Find forms of therapy	4	*“(…) that we will find a miracle therapy that is effective.” (P4)*
➔ Foster Parents			
	More daily support	2,4,7,8	*“No, not at all. It took one year to find the additional care staff and also four to five months to train them for the issue, because they didn’t know anything about FAS. (…)” (P8)*
	Societal Respect	1,2,4	*“(…) That doesn’t work at all. That has to be respected by society. That’s what I really hope (…).“ (P2)*
	More self-help-groups on site	4,5	*“(…) That doesn’t work at all. That has to be respected by society. That’s what I really hope (…).“ (P2)*
	Nationwide Specialist Counseling	3	*“For every child or foster families with disabled children. This specialist counseling is needed. (…)” (P3)*
	Financial Hedging	2	*Yes, of course. That isn’t easy. If you have a disabled child at home, then theoretically you should (have) be entitled to obtain a pension, because it isn’t realistic at all to work (…)” (P2)*

N= Number of participants,
P^N= Participant cited,
X= anonymized name of a child

- Informed Consent

Einverständniserklärung

Hiermit erkläre ich mich einverstanden, an dem Interview mit dem Thema **„Der alltägliche Umgang mit FAS(D) - Hilfen und Unterstützung“** teilzunehmen.

Ich wurde ausreichend darüber informiert, zu welchem Zweck meine Angaben verwendet werden und dass die Informationen anonym und vertraulich behandelt werden.

Mir ist bewusst, dass ich das Interview jeder Zeit abbrechen kann und meine Bereitschaft zur Bearbeitung der Angaben zurückziehen darf.

Des Weiteren bin ich damit einverstanden, dass die Tonspur des Interviews aufgenommen wird, um die Analyse des Inhalts zu ermöglichen.

Name Teilnehmer/in: ____

Datum: ____

Unterschrift Teilnehmer/in: ____

Name Interviewleitung: ____

Unterschrift Interviewleitung: ____

Interview Scheme

Demografische Angaben

Geschlecht: ☐ weiblich

☐ männlich

Alter:

Ausbildung/Beruf:

Weiterbildung FAS(D): ☐ nein ja: ____________________

Funktion: ☐ Pflegemutter/Pflegevater

☐ Betreuer_in

• Wie sind Sie persönlich mit dem Thema FASD in Kontakt gekommen?
• Wann haben sie zum ersten Mal ein Kind mit FASD betreut? Über welchen Zeitraum hinweg?
• Wie viele Kinder insgesamt?
• Was waren die wichtigsten Erfahrungen, die sie mit diesen Kindern gemacht haben?
• Was ist ihrer Meinung nach das wichtigste im Umgang mit Kindern mit FASD?
• Und warum ist das so?

ZUSAMMENFASSUNG:

• Haben sie sich Unterstützung gesucht?
• Wie sah diese Unterstützung genau aus? In welcher Form hatten sie Unterstützung? ➢ Ärzte / Kliniken ➢ Jugendamt ➢ Vereine ➢ Psychologen / Therapeuten
• Gab es noch andere Hilfen, die sie in Anspruch genommen haben?
• Wie sahen diese Hilfen genau aus?
• Wie gut zugänglich waren diese Hilfen für sie?
• Wie einfach zu erreichen waren diese Hilfen für sie?
• Wie ausreichend ist ihrer Meinung nach das Angebot an Hilfen?
• Was wäre ihrer Meinung nach noch nötig an konkreten Hilfen?

ZUSAMMENFASSUNG

• Haben sie Informationen speziell zu dem Thema FASD erhalten? • Wie sahen diese Informationen konkret aus? ➢ Broschüren ➢ Artikel ➢ Bücher ➢ Internet ?
• Woher haben sie diese Informationen erhalten? ➢ Offizielle Stellen: Kliniken, Jugendamt, Beratungsstellen, Therapeuten ➢ ?
• Wie gut zugänglich waren diese Informationen für sie?
• Wie ausreichend ist aus ihrer Sicht die Versorgung mit Informationen?
• Wo sehen sie noch Informationsbedarf?

ZUSAMMENFASSUNG

• Gibt es konkrete Hilfsmittel, die sie im täglichen Umgang mit ihrem Kind nutzen?
• Was sind das für Hilfsmittel? ➢ Strukturpläne ➢ Piktogramme ➢ Skills bei Wutanfällen
• Wie sind sie darauf gekommen, dieses Hilfsmittel zu nutzen?
• Was hilft dabei aus ihrer Sicht am meisten?

ZUSAMMENFASSUNG

• Was ist ihrer Meinung nach (noch) nötig um Pfelegeltern / Betreuer ausreichend zu unterstützen?
• Wo sehen sie noch Bedarf an konkreten Hilfen?
• Was wünschen Sie sich für die Zukunft bezüglich der Unterstützung von Pflegeeltern und Betreuern?
• Durch wen sollte diese Unterstützung erfolgen?
• Was wünschen sie sich für ihre eigene Zukunft als Pflegemutter /Pflegevater/ Betreuer_in?

ZUSAMMENFASSUNG