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Establishing a multidisciplinary specialist centre for fetal alcohol spectrum disorders—Lessons learned from a model project in Germany

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Abstract

Background: Inadequate coordination between relevant professionals hampers the provision of appropriate care for individuals with fetal alcohol spectrum disorder (FASD). Integrated, multidisciplinary care is thus urgently required. Hence, we aimed at establishing the first university-bound, interdisciplinary specialist centre for FASD in Germany, systematically collecting data on its utilisation and evaluation by attendees.

Methods: After our centre started to provide consultation and support services in July 2019 until May 2021, we collected 233 questionnaires on the centre's utilisation (including attendees' sociodemographic characteristics and the topics on which they requested consultation, e.g., general information about FASD, consultation on therapy options, and educational consultation). Ninety-four of 136 individuals who received consultation at our centre submitted an evaluation questionnaire that recorded attendees' satisfaction with the support they had received (e.g., the extent to which the consultation met their needs).

Results: Of 233 participants who completed the utilisation questionnaire, 81.8% were female, and 56.7% were aged 40 to 60 years. Moreover, 42% were foster parents, while 38% were professionals. Most attendees had questions on FASD in general as well as on a specific child or adolescent with FASD. Almost three quarters of the attendees requested consultation on adequate therapies for FASD patients, while 64% had questions on parenting issues. The overall quality of the consultation was rated very well.

Discussion: Our service was used by both caregivers and professionals who reported numerous and complex concerns and needs. Professionally sound and multidisciplinary services are viable instruments to meet those needs, bearing the potential for quick and notable relief among individuals affected. We propose further advancement of networking and coordination between care providers, the expansion of multidisciplinary services, and securing early diagnosis and consistency of care as relevant steps to even better support children and adolescents with FASD and their families in the future.

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KEYWORDS

fetal alcohol spectrum disorders, fetal alcohol syndrome, health services, integrated care, interdisciplinary communication

1 | INTRODUCTION

Worldwide, fetal alcohol spectrum disorder (FASD) is the most frequent congenital, chronic disorder leading to birth defects, developmental and neurocognitive disability, and life-long impairment of independent living (Landgraf et al., 2020; Smith et al., 2017). The term FASD is an umbrella term for three different conditions: Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome, and Alcohol Related Neurodevelopmental Disorder (Landgraf et al., 2013; Wozniak et al., 2019). Symptoms include but are not limited to developmental, intellectual, and behavioural impairment (Chokroborty-Hoque et al., 2014; Kodituwakku & Kodituwakku, 2014; Mattson et al., 2011). Moreover, FASD has been shown to be associated with a range of comorbidities such as psychiatric conditions, congenital malformation, or chromosomal abnormalities (O'Connor & Paley, 2009; Popova et al., 2016).

The prevalence of FASD varies between different regions of the world with the highest numbers (19.8 per 1.000 population) being reported for the WHO European Region (Lange et al., 2017), where also the highest numbers of women consuming alcohol during pregnancy are observed (Popova et al., 2022). Calculations for the global prevalence of FASD lead to an estimate of 7.7 per 1000 population (Lange et al., 2017). A recent study from the United States came up with estimates between 11.3 and 50.0 per 1000 first-grade children, concluding that those figures may be more precise estimates than the lower numbers from earlier studies (May et al., 2018). A reason for discrepancies in reported numbers may be that FASD are utterly underdiagnosed, either because they are misdiagnosed or because they are not recognised (Chasnoff et al., 2015; Lange et al., 2018). In fact, evidence from various studies suggests that clinicians and health professionals have considerable knowledge gaps with respect to FASD and often do not feel well equipped to diagnose disabilities related to prenatal alcohol exposure (Howlett et al., 2019; Payne et al., 2005; Vagnarelli et al., 2011). As a result, affected individuals frequently receive no or inappropriate treatment (Burd & Popova, 2019; Popova et al., 2020). Proper professional support and interventions as early in life as possible are, however, crucial to ameliorate affected individuals' quality of life and everyday functioning (Paintner et al., 2012; Wilhoit et al., 2017).

To ease this situation, a specific guideline describing detailed criteria for diagnosing FASD has been published in Germany in 2016 (Heinen & Landgraf, 2016). However, this has not led to sufficient betterment in terms of adequate care for individuals with FASD and their families (Weinmann et al., 2021). A lack of appropriate care for children and adolescents with FASD was observed also in other locations (Popova et al., 2020).

One of the main reasons for these shortcomings in providing appropriate care for affected youngsters and their families seems to be inadequate coordination between relevant professionals (Adebiyi et al.,

Key messages

- We founded Germany's first interdisciplinary specialist centre for FASD that is tied to a university, run based on scientific evidence, and combine expertise from paediatrics, neuropaediatrics, psychology, social pedagogy, and health services research.
- More than 200 individuals registered for consultation with our centre, about half of them indicating to be foster or adoptive parents and more than a third being professionals caring for children and adolescents with FASD.
- Attendees' concerns and information needs were numerous and diverse with educational and therapy issues being the most frequent ones.
- Individuals caring for children and adolescents with FASD are facing complex and multilayered problems and challenges.
- Highly experienced, multidisciplinary consultation services have the potential for quick and notable relief among families and professionals.

2018; Masotti et al., 2015). As a consensus statement from 60 experts concluded, improved integration of care for children and adolescents with FASD and their caregivers is urgently required (Masotti et al., 2015). This could include, among other things, better information sharing between medical and nonmedical service providers, for example, as to ensure that teachers gain a better understanding of the medical reasons for the behavioural deficits of their pupil with FASD. Furthermore, as individuals with FASD often need life-long care, efforts are needed to ensure smooth transition between different areas of care (e.g., acute and follow-up care, paediatrics, and adult medicine) (Masotti et al., 2015). Ideally, such integration of care should be realised through the implementation of multidisciplinary teams encompassing various relevant occupations (Ordenewitz et al., 2021).

To the best of our knowledge, such specialist centres with different health professionals (e.g., paediatricians, psychologists, and pedagogues) and high FASD experience hardly exist, especially outside North America. This shortage may be explained by the fact that the complexity of the clinical picture of FASD and the resulting enormous impairment of everyday functions are still underestimated by both medical and political actors in the health and social system (Landgraf et al., 2018).

Based upon these considerations, we aimed at establishing an interdisciplinary specialist centre for FASD as a model project for the improvement of care for children and adolescents with FASD in Germany. The specific objectives were as follows:

- To establish suitable FASD care infrastructures by formation of a multiprofessional team;
- To establish an interdisciplinary specialist centre with high FASD expertise as a contact point for families and professionals caring for children and adolescents with FASD;
- To provide low-threshold (i.e., free of charge, short waiting times, quick and unbureaucratic registration, and independent from individuals' socio-economic background, ethnicity, or gender), case-specific, and general consultation regarding FASD based on scientific evidence;
- To document the centres' utilisation by collecting data on the characteristics of the attendees and their primary concerns and information needs; and
- To validate the centre by collecting systematic evaluations from its attendees.

2 | METHODS

2.1 | Formation of the centre

The “German FASD Competence Centre Bavaria” was launched in October 2018 in the city of Munich as a model project for the entire country. The centre was integrated within the existing structures of a university hospital, assembling a multidisciplinary team (paediatrics, neuropaediatrics, psychology, social pedagogy, and health services research). From July 2019 onwards, the centre offered professional consultation and support for caregivers of children and adolescents with FASD and professionals in the field. While the centre is tied to the university hospital (e.g., using the hospitals' IT infrastructure), it is running its services independently and has its own third-party funding. Its staff is employed both with the hospital and the legal carrier of the centre. With respect to diagnostics, the “German FASD Competence Centre Bavaria” is not performing FASD diagnostics itself but is located in the same building as the university hospitals' social paediatric centre, where FASD diagnosis takes place. The centre's services were provided as a voluntary option to anyone seeking support, that is, attendees were not recruited by our centre. Instead, attendees actively contacted our centre to make an appointment. What we did, however, was to spread information about the opening of our centre among various stakeholders in the state of Bavaria such as youth welfare offices, youth care facilities, or clinics.

As possible ways of communication, telephone, video, and face-to-face appointments were offered. The consultation was then carried out by one (usually) or several members (i.e., disciplines) of the team, depending on the topics on which the attendee requested consultation during registration at the centre (see Section 2.3) and further questions arising during the consultation. All requests and consultations that took place were discussed in the entire team and any further needs of the attendees were identified and met, if possible, that is, the number of appointments was case-specific and depended on the attendees' needs.

Knowledge about the project was disseminated by contacting all relevant stakeholders such as patient support groups, children's and child psychiatric hospitals, social paediatric centres, youth welfare offices, or addiction consultation centres. Moreover, information about the centre was spread via relevant professional associations.

2.2 | Data collection

As to systematically collect data on the utilisation and evaluation of the centre, two specific questionnaires were administered to the centre's attendees. A translation of the full wording of each questionnaire item is provided in Data S1 and S2. Before completion of the questionnaires, participants gave informed consent that their data will be used for scientific purposes.

2.3 | Utilisation of the centre

All attendees were asked to complete an online questionnaire when they contacted the centre the first time. The questionnaire collected the following information:

- Gender (female, male, or diverse);
- Age (<20, 20–40, 40–60, or >60 years);
- Role (birth parent, foster parent, adoptive parent, paediatrician, psychologist, teacher, etc.);
- Highest level of education (e.g., middle school, A levels, or university degree); and
- Place of employment (only for professionals, e.g., hospital, youth welfare office, nursery, etc.).

In addition, the topic of the attendees' concern was recorded, differentiating between the following categories:

- General consultation regarding FASD;
- Educational consultation (e.g., consultation on dealing with the child as parent/guardian);
- Care services (e.g., advice on occupational options for adolescent with FASD);
- Intervention (e.g., consultation on crisis intervention in the family);
- Social law (e.g., consultation on applying for a care degree);
- Therapy options (e.g., consultation on family therapy services);
- Support services (e.g., information regarding self-help groups); and
- Other concerns as free text.

Additionally, attendees were asked how they became aware of the centre (e.g., clinic/experts, congress/training, parents/friends/self-help group, and newspaper/radio/TV). Finally, we recorded the communication channel (phone, video, or face to face) and number of appointments per attendee.

2.4 | Evaluation of the centre

After their last consultation, the attendees were asked to complete an additional questionnaire to evaluate the consultation they received at the centre. This tool recorded attendees' satisfaction with the support according to German school marks (from 1 = *very good* to 6 = *insufficient*) regarding the following items:

- Staff's understanding of the attendee's situation;
- Staff's understanding of the essence of the attendee's problems;
- Improvement of the child's problems as a result of the consultation;
- Improvement of attendee's own understanding of the child's problems;
- Positive change in attendee's behaviour towards the child;
- Overall quality of the support;
- Extent to which attendee's needs were met;
- Helpfulness of the support;
- Importance of the interdisciplinary nature of the centre;
- Ease of contacting the centre and making an appointment;
- Waiting time for an appointment; and
- Sufficiency of time for questions.

In addition, individuals were asked whether they would approach the centre again, whether they would recommend the centre to other families/professionals, and whether they were satisfied overall with the services offered (answer options yes/no).

The selection and formulation of the individual items of the questionnaires were based as far as possible on existing instruments such as the Patient's Experience Questionnaire (Pettersen et al., 2004), the Questionnaire for Measuring Patient Satisfaction (ZUF-8) (Juergen & Nübling, 2002), the Patient Satisfaction Questionnaire Short Form (PSQ-18) (Marshall & Hays, 1994), and the Picker Patient Experience Questionnaire (Jenkinson et al., 2002). Both questionnaires were provided as online questionnaires via LimeSurvey (LimeSurvey GmbH, Germany).

2.5 | Statistical analysis

We summarised the variables regarding the utilisation of the centre (sociodemographic characteristics of the attendees, types of concerns, number of appointments, and support channel) by calculating the absolute (*n*) and relative (%) frequency of the respective answer categories. Furthermore, we calculated mean, standard deviation (*SD*), and minimum (*Min*) and maximum (*Max*) for each item of the evaluation questionnaire. This was performed for all submitted questionnaires as well as stratified by role of the attendee (caregiver vs. professional) and by the number of appointments the attendees had (one appointment vs. two or more appointments). To test for differences between the respective categories with respect to the evaluation provided, *t*-test statistics for independent samples with an alpha level of .05 were calculated. Analyses were carried out with SPSS 26 (IBM Corp., USA).

3 | RESULTS

3.1 | Utilisation

Between July 2019 and May 2021, 233 individuals completed the utilisation questionnaire. More than 80% of them were female, and slightly more than half of the attendees were between the ages of 40–60 years. In terms of their role, foster parents were the largest group (42%), while biological parents accounted for less than 10% of the attendees. More than one third of the visitors were professionals. Among these, employees from youth welfare offices (20%), youth care facilities (19%), and social paediatric centres (13.5%) represented the largest groups. The other professionals came from a wide range of different settings (Table 1). More than half of the individuals reporting a degree from a university or a university of applied sciences. As this was likely to be due at least partly to the large proportion of professionals, the educational level was calculated additionally only for those that contacted the centre as non-professionals (i.e., caregivers). In this group, the number of graduates was slightly smaller (Table 1).

Concerning their concerns, most attendees stated that they required consultation on FASD in general (71%) as well as on a specific child (81%). Almost three quarters of the attendees wished to receive consultation on adequate therapies for the child/adolescent with FASD, while 64% had questions on how to deal with their child as parent/guardian. Consultation on therapy with drugs was another frequently stated topic (55%) (Table 2). Most individuals found out about the centre through institutions, clinics or professionals (23%), and the internet (21%).

Out of 233 individuals who registered, 136 requested and received direct consultation. The remaining 97 participants did not receive direct consultation but were sent FASD-related materials, including links to websites and contact details of other service providers. Among the 136 individuals who received consultation, 65.4% needed only one appointment for support, about 25.8% attended two to four appointments, and 8.8% five to nine appointments. Eighty-four per cent of the appointments were performed via phone, while only 4% occurred face to face (Figure 1).

3.2 | Evaluation

Ninety-four of 136 individuals who received consultation (69%) submitted an evaluation questionnaire. Out of 12 items to be rated according to school marks (1 = *best* and 6 = *worst*), nine received an average grade of “very good” (mean ≤ 1.5). Only the item “Improvement of the child's problems as a result of the consultation” was rated mediocly. The overall quality of support was rated as “very good” (mean: 1.18). For none of the variables, there was a meaningful difference in the evaluation given by caregivers compared with professionals. Caregivers (mean: 1.45) and professionals (mean: 1.22) alike indicated that they found it important that an interdisciplinary team was available for consultation (Table 3). Likewise, there were no meaningful differences in the evaluation provided by those attendees

TABLE 1 Sociodemographic characteristics of the individuals completing the utilisation questionnaire ($N = 233$).

Variable	Missing	No answer	Number (n)	Per cent (%)
Gender	2	0		
Female			189	81.8
Male			42	18.2
Diverse			0	0.0
Age group (years)	7	0		
<20			7	3.1
20–40			70	30.0
40–60			132	56.7
>60			17	7.3
Role	6	3		
Biological parent			21	9.4
Foster parent			93	41.5
Adoptive parent			26	11.6
Individual with FASD			1	0.4
Social pedagogue			37	16.5
Paediatrician			10	4.5
Psychiatrist/psychotherapist/psychologist			12	5.3
Teacher/educator			6	2.6
Nurse			1	0.4
Others			17	7.5
Highest level of education	8	11		
Secondary school			9	4.2
High school			28	13.1
A levels			23	10.5
Apprenticeship			30	14.0
University of applied sciences			39	18.2
University			80	37.4
Others			5	2.3
Highest level of education (only parents, $n = 140$)	1	4		
Secondary school			6	4.5
High school			24	17.8
A levels			19	14.1
Apprenticeship			29	21.5
University of applied sciences			16	11.9
University			37	27.4
Others			4	3.0
Professional	0	0		
Yes			89	38.2
No			144	61.8
Place of employment of professionals	0	0		
Youth welfare office			18	20.2
Youth care facility			17	19.1
Social paediatric centre			12	13.5
Hospital			6	6.7
Support centre			6	6.7
Freelancer/self-dependent worker			5	5.6

(Continues)

TABLE 1 (Continued)

Variable	Missing	No answer	Number (n)	Per cent (%)
Medical practice			4	4.5
Nursery/kindergarten			3	3.4
Child guidance agency			1	1.1
Addiction consultation centre			1	1.1
Regular school			1	1.1
Others			15	16.9

Note: No answer: Number of individuals indicating "I do not want to answer this question."

Abbreviation: FASD, fetal alcohol spectrum disorder.

with only one appointment compared with those attendees with two or more appointments (Table S1). Moreover, 93% of the attendees were satisfied with the centre's offerings.

4 | DISCUSSION

The present project aimed at establishing Germany's first interdisciplinary FASD competence centre tied to a university, serving as an easily accessible coordination and case management centre for families and professionals caring for children and adolescents with FASD. Since its opening, the centre was approached by a relevant number of individuals, predominantly foster parents of children with FASD, but also many professionals. Their concerns and information needs were numerous and diverse with educational and therapy issues being the most frequent ones. The evaluation of the centres' services through its attendees was very positive.

There are a couple of lessons that can be learned from these data and from the first years of our centre. The fact that about half of our clients were foster or adoptive parents while only slightly more than 10% were biological parents supports the perception that the vast majority of individuals with FASD are placed in out-of-home care (Rangmar et al., 2015). At the same time, there is indication that foster and adoptive parents of children and adolescents with FASD have numerous and complex demands that are often unmet (Weinmann et al., 2021). Consequently, those families need continuous support from professionals, not only in order to reduce stress levels among the caregivers but also to ensure that the affected children and adolescents can live in a stable environment (Doak et al., 2019; Pelech et al., 2013; Skorka et al., 2020).

About a third of our clients were professionals from miscellaneous disciplines. Our question to the professionals whether they found it valuable that an interdisciplinary team was available for consultation was answered extremely positively. They stated that they found it very helpful that the consultation was carried out by an interdisciplinary team. In our opinion, this results in the following implications for further support. First, even institutions such as social paediatric centres, which already carry out interdisciplinary diagnostics and care for children and adolescents with FASD, need an "expert back-up." Supporting institutions such as youth welfare offices even

have a higher demand regarding knowledge about FASD. Second, depending on the issue, discipline-specific consultation, where the communication partners have the same educational background and speak the same language, is extremely helpful. Third, interdisciplinary knowledge building is necessary for networking, ideally coordinated by an interdisciplinary coordination centre aiming to establish networks, to help network partners and parents overcome communication difficulties and to coordinate support for the families.

Moreover, it is striking that the parents and professionals approached the multidisciplinary team of our centre with a wide variety of concerns. This indicated that families with children and adolescents with FASD very often have complex, multilayered needs that have not been met so far and that could be covered by an interdisciplinary competence centre (Bobbitt et al., 2016; Weinmann et al., 2021). It also reflects the very high burden and numerous challenges for families caring for children and adolescents with FASD (Bobbitt et al., 2016; Chamberlain et al., 2017). This interpretation is to some extent supported by the numbers of consultation appointments we recorded. About 26% attended two to four appointments, and some clients need at least five and up to as much as 15 appointments. This very often very intensive need for support implies that the individuals caring for children with FASD, especially caregivers, are sometimes very stressed and have extremely complex problems.

When launching the project, we did not expect that we would perform most consultations via telephone. This may be to some extent explained by the large catchment area of our centre (not only Munich but the entire state of Bavaria, with several attendees coming even from other regions of Germany, especially from regions where no FASD experts are available). The main reason for the low number of requests for in-person consultations is most likely the COVID-19 pandemic as during this time, many people were very cautious and hesitant to meet others in person. However, phone consultations have limitations in which they do not allow observations of facial expressions, body language, and behaviour of those seeking help and are thus, in our experience, less effective and more prone to misunderstandings than consultations that are performed in-person. Hence, new ways of providing support should be established, such as video-based interventions and online training. Consequently, the digitisation of our centres' services will be a top priority for the future. The importance of digital services is underlined by the fact that a marked

TABLE 2 Summary statistics for the topics of concerns indicated by the individuals completing the utilisation questionnaire ($N = 233$).

Variable	Missing	Number (<i>n</i>)	Per cent (%)
General consultation	25		
Consultation regarding FASD in general		148	71.2
Consultation regarding a specific child/adolescent		188	80.7
Educational consultation	26		
Consultation on dealing with the child as parent/guardian		132	63.8
Consultation on dealing with the child as professional		76	36.7
Consultation to inform the child about his or her FASD condition		114	55.1
Care services	27		
Advice on preschool offers, kindergarten, or school forms		76	32.6
Advice on occupational options for the adolescent		69	33.5
Advice on the transition of care from paediatrics to adult medicine (transition)		42	20.4
Intervention	27		
Crisis intervention at family level		83	35.6
Crisis intervention at kindergarten level		21	10.2
Crisis intervention at school level		47	22.8
Structured intervention for child/adolescent		109	52.9
Intervention/training for parent		102	49.5
Social law	28		
Application for an inclusive kindergarten or a curative day care centre		24	11.7
Application for an integration helper/a school companion		48	23.4
Application for a care degree		58	28.3
Application for a disabled person's pass		54	26.3
Other social law issues		87	42.4
Therapy options	28		
Consultation on adequate therapies for the child/adolescent		151	73.7
Consultation on family therapy		100	48.8
Consultation on therapy practices		112	54.6
Consultation on therapy with drugs		113	55.1
Consultation on rehabilitation options		92	44.9
Support services	28		
Consultation on other focal points		95	46.3
Consultation on family support services/family relief measures		103	50.2
Information regarding self-help groups		72	35.1
Advice on partial/full inpatient accommodation options		58	28.3
Wish for additional network partners (therapy facilities, self-help, regional centre, specialists, and coordination centre)		39	19.0

Abbreviation: FASD, fetal alcohol spectrum disorder.

proportion of our attendees declared that they became aware of our service via the internet. Having said that, the most frequently reported way how people heard about the centre were recommendations from professionals in hospitals and other institutions. This underlines the importance of networking between professionals. For future projects and similar endeavours, this means that the main way to publicise support measures should be via collaborating professionals and institutions as well as via web-based tools (websites, social media, apps, etc.).

The support provided by the team of the “German FASD Competence Centre Bavaria” was consistently rated as very helpful and positive, with an overall average mark of 1.35 (scale from 1 = best to 6 = worst according to German school marks). It should be emphasised that the parents apparently very much appreciated the understanding of their own situation and the sufficient time for questions. The improvement of their own understanding of the clinical picture was rated by the parents with 1.66, the change in their own parental behaviour with 2.17, and the improvement of the child's

problems with 3.00. These scores imply that a professionally sound and interdisciplinary intervention, even if it only took place once and by telephone, was already perceived as partially relieving the family. It also needs to be mentioned that we did not expect that the respective children's problems would improve immediately after the appointment with our centre as such changes usually require long-term intervention.

When interpreting our findings, some caveats need to be kept in mind. The reported sociodemographic characteristics of our clients should not be taken as a general description of the traits of caregivers and professionals caring for individuals with FASD. As we did not actively recruit them and thus do not have a sampling frame, we are not able to estimate the representativeness of our attendees for the entire population of FASD caregivers and professionals in Germany. What we provide is a description of those actively seeking help. Additionally, not all individuals registering for an appointment completed an evaluation sheet, opening the door for the possibility of bias in our

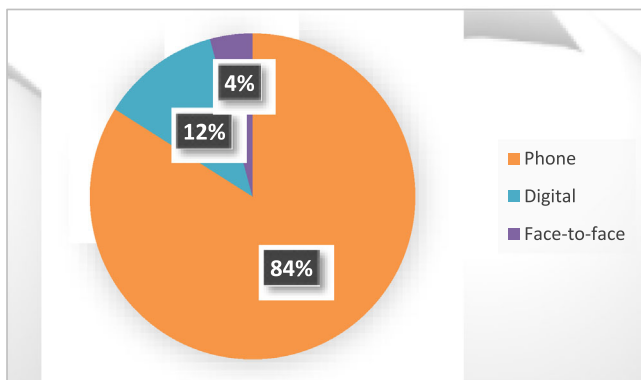


FIGURE 1 Proportion of appointments performed via different support channels (phone, digital, and face to face).

evaluation results. In terms of basic traits such as gender, age, or role, we could, however, not identify any meaningful differences between the respondents and the nonrespondents to the evaluation questionnaire. Furthermore, a competence centre like ours should not be confused with a diagnostic centre. What we describe is rather some form of a contact point where patients can direct to after they received their diagnosis. In the case of ideal networking between health care services, diagnostic centres or clinics would send their patients to a centre such as the one described here. The centre would then start to implement integrated care or case management as to ensure adequate and continuous management of the disease (e.g., by identifying adequate therapy options and giving advice on how to apply for social benefits). We are also aware that this report contains some terms that are specific to the social and healthcare system in Germany and may thus be a little bit difficult to grasp for international readers. For instance, a “social pedagogue” is an occupation that is quite common in Germany but may not exist in this form in other countries. According to the European Skills, Competences, Qualifications and Occupations (ESCO) classification provided by the European Union, social pedagogues

provide care, support, and education to children and young persons with different backgrounds or capabilities. They develop educational processes for young persons to be in charge of their own experiences, using a multi-disciplinary approach set to the learning experience. Social pedagogues contribute to the individuals' learning, welfare, and societal inclusion, and put an emphasis on building self-reliance.

The major strength of our centre is its multidisciplinary character, its affiliation with one of Germany's top-ranked universities, the

TABLE 3 Evaluation of the centre by attendees according to school grades (from 1 = very good to 6 = insufficient).

Variable	Total (N = 94)		Caregivers (N = 53)		Professionals (N = 39)		P-value
	Mean	SD	Mean	SD	Mean	SD	
Staff's understanding of attendees' situation	1.07	0.26	1.04	0.19	1.10	0.31	.218
Staff's understanding of the essence of attendee's problems	1.12	0.32	1.15	0.36	1.08	0.27	.304
Improvement of the child's problems as a result of consultation	2.89	1.53	3.00	1.55	2.50	1.52	.490
Improvement of attendee's own understanding of child's problems	1.68	1.09	1.66	1.13	1.72	1.05	.815
Positive change in attendee's behaviour towards the child	1.98	1.18	2.17	1.08	1.63	1.30	.110
Overall quality of the consultation	1.18	0.42	1.16	0.37	1.20	0.47	.667
Extent to which attendee's needs were met	1.33	0.56	1.28	0.50	1.41	0.64	.278
Helpfulness of the consultation	1.32	0.77	1.33	0.88	1.29	0.61	.795
Importance of centre's interdisciplinarity	1.37	0.79	1.45	0.90	1.22	0.58	.251
Ease of making an appointment	1.47	0.84	1.35	0.60	1.62	1.07	.139
Waiting time for appointment	1.28	0.66	1.28	0.62	1.29	0.73	.930
Sufficiency of time for questions	1.08	0.31	1.08	0.28	1.05	0.32	.635

Note: For two individuals, role is unknown. P-value is calculated via two-sided t-test for independent samples. Abbreviation: SD, standard deviation.

longstanding FASD expertise of its staff, and the fact that its activities are performed on the basis of scientific evidence while, at the same time, constantly reassessed through evaluation questionnaires. An example of the centre's evidence-based approach is the systematic literature review that was performed as a foundation for the planning of intervention programmes (Ordenewitz et al., 2021). Another example is a survey that we performed among professionals and caregivers to systematically collect data on the needs and demands of families caring for children and adolescents with FASD and to adapt our services accordingly (Weinmann et al., 2021). For instance, as this survey yielded clear indication of the caregivers' (largely unmet) demand for in-patient therapy options for their children, we initiated quarterly cooperation and coordination meetings between all child and adolescent psychiatry clinics in Munich, cooperatively defined responsibilities, and performed training on FASD. Furthermore, we made sure that all consultation was based on the evidence-based German guideline for FASD (Landgraf et al., 2013). Because of those features, the FASD competence centre can be regarded as a high-quality institution that is the first of its kind in Germany and a pilot project for the entire country. To the best of our knowledge, also at European level, there are few highly experienced nationwide FASD coordination and care centres. One example of another interdisciplinary specialised FASD centre comes from Norway, where such a service was established in 2015 (Løhaugen et al., 2015). Nevertheless, as a recent commentary from experts in the field concluded, a lot of work is still to do to enhance diagnostic and care services for individuals with FASD (Popova et al., 2020).

Based on our experiences and the data collected during the first years of the "German FASD Competence Centre Bavaria," we propose several measures to improve care for children and adolescents with FASD in Germany (and possibly beyond, depending on country-specific circumstance like the national health system, local infrastructure, etc.). First, it is of uppermost importance to equip health professionals with sufficient awareness and knowledge to diagnose dysfunctions and deficits related to prenatal alcohol exposure as early as possible. In fact, there is clear indication that an early diagnosis is one of the key factors for a positive long-term development of patients with FASD (Benz et al., 2009). Second, we suggest a further expansion of networking and coordination between medical and nonmedical care providers. As outlined initially, better integration of care is vital to make sure that FASD patients receive continuous support across the lifespan. A way of achieving improvements in coordination and integration of care may be the expansion of multidisciplinary services by building of additional regional specialist centres as the one presented in this report. Moreover, consistency of care may also be fostered by the development of FASD-specific integrated care pathways (Weinmann et al., 2021).

To conclude, the present paper highlighted several lessons learned from the initial phase of a FASD competence centre in Germany, drawing implications for future action. These include the complex and multifaceted character of the problems and needs of

individuals with FASD, the demand for expert consultation not only among caregivers but also among professionals working with individuals with FASD, and the necessity of professionally sound, highly experienced, evidence-based, and interdisciplinary services to meet these numerous and challenging needs. Encouragingly, our findings imply that such services have the potential for quick and notable relief among families affected.

AUTHOR CONTRIBUTIONS

Tobias Weinmann: Conceptualization; methodology; investigation; validation; data curation; writing—original draft; formal analysis. **Lisa K. Ordenewitz:** Methodology; investigation; project administration; writing—original draft. **Julia A. Schlüter:** Investigation; project administration; methodology; writing—original draft. **Jessica Jung:** Investigation; project administration; writing—original draft. **Katharina Kerber:** Investigation; project administration; writing—original draft. **Lukas Finkeldey:** Data curation; project administration; formal analysis; writing—original draft. **Florian Heinen:** Conceptualization; methodology; funding acquisition; writing—original draft; supervision. **Mirjam N. Landgraf:** Conceptualization; methodology; investigation; formal analysis; funding acquisition; validation; supervision; writing—original draft.

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CONFLICT OF INTEREST STATEMENT

Apart from the funding described above, the authors declare no competing interests.

DATA AVAILABILITY STATEMENT

The data are available from the corresponding author upon reasonable request.

ETHICS STATEMENT

The project "German FASD competence centre Bavaria" was approved by the Ethics Committee at the Medical Faculty of Ludwig-Maximilians-University Munich (project number: 19-121).

INFORMED CONSENT STATEMENT

Informed consent was obtained from all participants.

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