Responsibility from the Start!

Fetal Alcohol Spectrum Disorder

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Federal Ministry for Family Affairs, Senior Citizens, Women and Youth

Foreword by Lisa Paus, MdB and Federal Minister for Family A airs, Senior Citizens, Women and Youth, for the Brochure 'Responsibility from the Start! – Fetal Alcohol Spectrum Disorder' published by the Working Group on Alcohol and Responsibility


Laurence Chaperon

Dear Reader,

Drinking alcohol can have severe consequences, not just for drinkers but for their children as well. Drinking even small amounts of alcohol during pregnancy can harm a child's development for the rest of its life.

Fetal alcohol spectrum disorder (FASD) is among the most frequent congenital disabilities in Germany. It can lead to physical, intellectual and social impairments. While FASD cannot be cured, it can be avoided. This makes it all the more important to raise awareness about the consequences of drinking alcohol not just during pregnancy, but at all times. Knowledge about the causes of fetal alcohol spectrum disorder and its many and diverse forms can provide tangible relief for those a ected, their relatives and friends. As a society, we must make it a priority to help them overcome the hurdles of everyday life and ensure that their special abilities are promoted.

This is why I ask that you read ‘Responsibility from the Start!’. It provides detailed information on fetal alcohol spectrum disorder (FASD) which you can also share with your families, friends and other people you know.

Lisa Paus MdB
Federal Minister for Family A airs, Senior Citizens, Women and Youth

Introduction

If an expectant mother consumes alcohol while pregnant, her child can su er a wide range of physical and intellectual impairments. In Germany, this a ects some 7,000 newborns every year.

The very di erent changes seen in the child are collectively known as fetal alcohol spectrum disorder (FASD). FASD is disability for which there is no cure. While some de cits can be treated, signi cant developmental delays persist into adulthood.

In addition to physical impairments, cognitive de cits and behavioural disorders are often related to FASD.

Children, adolescents and also adults with FASD lack concentration and forget things, they are innocent or guileless, naive and easily misled. They tend not to learn from their own experiences and make the same mistakes over and over again. They are quickly seen as either cheeky or lazy.

When repeatedly confronted with such accusations, be it at school or elsewhere, children and adolescents with FASD begin to believe what they hear. They ask themselves: 'What's wrong with me? Why do I keep making the same mistakes? That's not how I want to be.'

It can often be a great relief for those a ected when they realise that, despite receiving endless reprimands, they are not the bad people they believe themselves to be and their di culties in learning and following rules can have a completely di erent cause. Even carers who have long doubted their own parenting or childrearing skills can be relieved when they are informed

about the actual cause of their adolescent's recurring undesirable behaviour.

An early diagnosis is important in order to ensure that children and adolescents with prenatal alcohol damage get the help they need and are able to manage their everyday lives in the best way they can. Once a diagnosis has been made, parents, nursery school teachers and teachers can better understand a child and its special needs. And with an early diagnosis, the responsible child welfare and healthcare authorities are better able to identify the kinds of assistance needed.

This lea et explains the diverse characteristics of children, adolescents and adults with FASD. It contains practical tips for use in helping them meet the recurring challenges they face in their daily lives. And it provides details of potential treatment, therapy and educational and welfare assistance for those affected, their families and friends.

A sense of understanding along with appropriate forms of assistance can ensure that children, adolescents and adults with FASD can develop their abilities despite their disabilities and be proud of who they are.

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Terms and de nitions

Maternal consumption of alcohol during pregnancy can have lifelong consequences for children. As symptoms can be highly variable, the term 'fetal alcohol spectrum disorder' (FASD) is now used. This brings together all alcohol-related in uences on the development of the embryo and the fetus. FASD thus encompasses the full fetal alcohol syndrome (FASD), partial FASD (pFASD) and alcohol-related neurodevelopmental disorder (ARND). In pFASD, the physical changes are less pronounced or absent, but as with FASD there are a wide range of embryo-fetal brain function and behaviour di culties as a result of the neurotoxic e ects of alcohol. pFASD is not to be regarded as a mild form of FASD, as a ected children display equally great social and emotional restrictions and a similar degree of su ering to children with full-blown FASD. This also applies to ARND, in which there are no visible physical changes, but the child's brain function and behavioural disorders can be traced back to the con rmed consumption of alcohol during pregnancy.

In everyday diagnostic practice, the following distinction has proved useful:

- **FASD with con rmed maternal alcohol exposure**
- **Partial FASD with con rmed maternal alcohol exposure**
- **Alcohol-related neurodevelopmental disorder (ARND)**

E ects of alcohol on the unborn child

Alcohol easily crosses through the placenta. The unborn child is therefore exposed to the same blood alcohol level as the mother. The developing fetal liver has little or no ability to break down alcohol. Alcohol interferes with cell division and stunts growth. It also causes organ damage. Primarily, it disrupts the development of the brain.

Physical features of FASD

Despite adequate nutrition and good support, many children with FASD stay smaller and lighter than healthy peers, and their head circumference is smaller as well. This growth de - ciency is sometimes made good later on, but in many cases the children only attain below-average height. The typical features of FASD include facial malformations. The upper lip is thin. The philtrum – the groove between nose and upper lip – is extended and attened. The nasal bridge is shortened and widened, and the nostrils tend to be prominent. The eyes appear smaller and further apart; the ears are low-set and turned slightly to the back of the head. These facial changes mostly normalise in the course of childhood. In adulthood, only the thin upper lip and small eyelid openings tend to remain. Alongside the typical facial changes, there may also be skeletal changes, heart defects, and genital and kidney malformations. Many a ected children, however, either have no noticeable de cits (pFASD) or appear perfectly healthy (ARND). Thus, in many cases, their intrusive behaviour which results from alcohol-related brain damage may seem both inexplicable, willful and determined.

FASD – from child to adult

Children with FASD

In the first few years, children with FASD display speech development defects. While speaking ceases to present any difficulty over time and FASD children can cause astonishment with a wide vocabulary and a highly talkative nature, their ability to understand often stays within narrow limits.

Sight and hearing may be affected, as may the sense of touch. Many children are thus oversensitive to even the slightest touch (and hence to seams in clothing or water on the skin). Yet, many FASD children have a remarkably high pain threshold. Temperature sensitivity is also impaired. There is often an inability to sense appetite and satiety.

Motor development may be delayed. In some cases, children are marginalised because of their poor fine motor skills. Not infrequently, however, they develop exceptionally good gross motor skills, although they easily overestimate their abilities in this regard.

The intellectual deficits are most evident in logical thinking. Abstract reasoning and the capacity to learn rules and logical relationships are impaired. There is low ability to retain learned solutions and apply them to other situations. Most alcohol-damaged children show severe attention deficits. They only have a short attention and interest span, and are easily distracted. Accordingly, they are unable to keep arrangements and are poor at carrying out assigned tasks.

Children with FASD are unable to sit still and quickly switch from one type of play to another without seeing games through to the end. They have difficulty controlling their own emotions and find frustrations hard to tolerate. The children are unable to assess the risks of their own conduct, for example in play. Natural fear of danger is generally lacking. The children are consequently reckless and high-spirited. They get into dangerous situations in road traffic or when climbing. In con-

trast to other children, FASD children fail to learn even from bad experiences. Aside from this, a ected children are mostly exceptionally willing to help, but naive, gullible and easily led; they are often unable to judge the social consequences of their actions. They are all-too trusting towards other children and even strangers. As a result, they repeatedly nd themselves in unpleasant situations to their own disadvantage. This also applies to children with FASD who score normally in intelligence tests.

Adolescents with FASD

Adolescents with FASD are also naive towards strangers and unable to see through others' intentions. Given a friendly word, they are happy to do others' bidding without being able to realise what is happening or that their trust is being misused. Girls with FASD who respond gullibly to attention from others and in some cases seek contact in a sexualised form themselves are especially at risk. Boys wanting to get in with others of their own age are similarly easily misled. Approaches such as 'If you want to be my friend, then ...' are often enough. Adolescents with FASD are hangers-on rather than leading the action. Held to account by adults, they can neither understand nor explain their own conduct. As a result, they soon get into similar difficulties again. In most cases, a vicious circle develops, with increasingly outraged sanctions from authority going hand in hand with growing helplessness and desperation on the part of the adolescents and young adults concerned.

Adults with FASD

Adults with FASD are underdeveloped for their age. They are not su ciently independent or accountable to live independent lives. They need ongoing instruction and control (for example with bodily care, planning the day and attending work). Problems likewise persist with regard to social contacts, understanding of time and money, adhering to rules, and placing themselves and others at risk through inattentiveness.

Statutory support is generally needed in respect of nances and healthcare.

Even where adolescents with FASD attain a school leaving quali cation, di culties arise at the latest during vocational training, where the scope for assistance from parents and teachers is no longer available, placing a heavy burden both on the young adults and their initially well-meaning instructors. Failure and dropping out of training may result.

An institutional living and working environment gives adults with FASD a predictable and thus fear-reducing setting in which they can show their capabilities and skills.

Everyday assistance

General

Children and adolescents with FASD react very emotionally to assigned tasks – not because they are unwilling or lazy, but because they themselves feel they are unable to do what is asked of them. Once an over-demanding situation is brought to an end and tasks are assigned to t their level of ability, the children liven up and become calmer and easier to deal with.

Children and adolescents with FASD need very clear structures and simple instructions on how to behave. A prescribed structure to the day with ritualised activities of daily living, a steady pattern and regular control should be ensured on a lasting basis without spontaneous change. Children and adolescents with FASD nd this very helpful and it leads to improvements in social behaviour. In this kind of environment, they feel secure and protected from demands they cannot cope with. In most cases, prescribed structures and instruction remain necessary through adolescence and young adulthood.

Provocations

Those around children with FASD often perceive the behaviours they show as a form of provocation. They 'provoke' with noises and tics, they are unable to sit still and succumb to the smallest of distractions, or they cease to perform tasks they have previously carried out with ease. Parents of children with FASD are likely to be able to name a host of 'provocations' they face on a daily basis. Here again it is important to understand that children with FASD do not deliberately aim to provoke people around them. Such behaviours are attributable to the alcohol damage, not to wanton misconduct. Undesirable behaviour should lead to clear consequences to give the child guidance. Children with FASD may not be able to judge for themselves whether their conduct is right or wrong, and therefore needs feedback from others on their behaviour.

Lying and stealing

Due to cognitive impairments, children and adolescents with FASD do not understand things that have happened or that they have experienced, and forget chains of events. When asked, memory gaps are readily lled with invented tales. The children themselves often believe the tales they tell. Simply enquiring whether it is true or thought up can halt the child mid-tale and prompt them to re ect and think.

Children and adolescents with FASD nd it hard to tell between 'yours' and 'mine'. They are often careless when it comes to their own property and tend to do things like giving away or forgetting their toys. They also take items from others without thinking it wrong. Here, carers' support and supervision is key. At the same time, it is important for the child or adolescent not just to be pulled up for taking something, but to be clearly told that it belongs to someone else. Likewise, it should be explained how it feels to have something taken away. It is helpful to have simple, xed rules when it comes to dealing with things that belong to others. The child's own things can all be marked in the same way, for example. Items of value around the home should always be kept where the child or adolescent cannot get at them.

Anger and aggression

People with FASD do not deal well with frustration and situations where they are over-challenged. They often have aggressive outbursts. Such outbursts can be stemmed by avoiding over-challenging situations day to day, repeatedly explaining how things are done and setting rules.

In acute situations, it can be helpful to have a calm room – not for use as a punishment, but as somewhere to calm down by cutting out overpowering outside stimuli.

Promoting strengths

People with FASD often feel 'inadequate'. They see for themselves that they are unable to do what is asked of them, that they forget assigned tasks and that those around them react to their behaviour with irritation. In some areas, though, children and adolescents with FASD are gifted. They may be talented in things such as music or sports. Many children with FASD are responsible and caring in dealings with animals. Parents and teachers should work patiently to uncover and promote those abilities.

At school

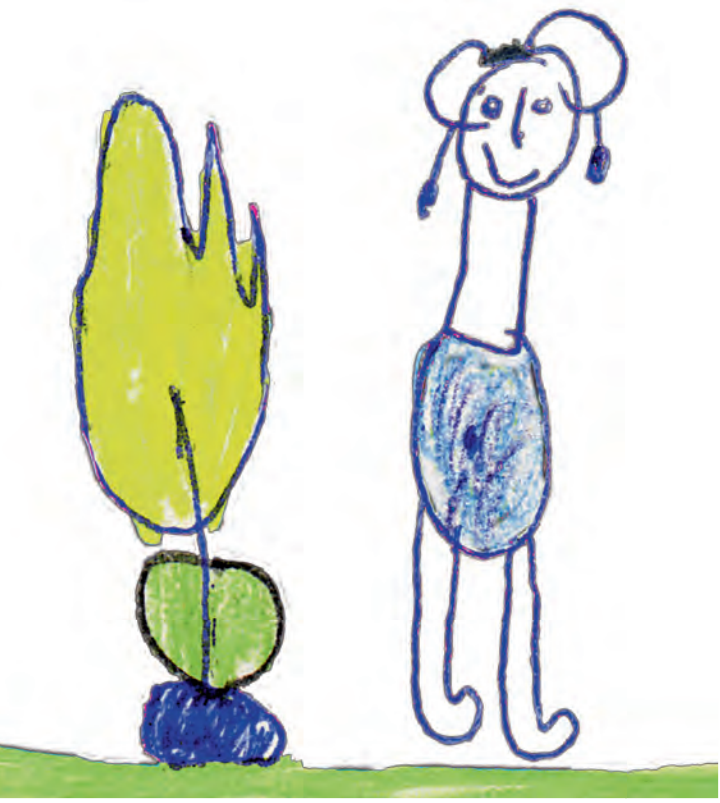
Placed in ordinary schooling, a ected children often nd themselves constantly over-challenged. They develop anxieties because every day brings changing circumstances and new demands. They have problems at school despite normal or only slightly reduced intelligence. Individual instances or phases of good performance fail to re ect what FASD children 'could achieve if they only exerted themselves'. Phases of good performance are just as much part of FASD as 'bad' phases. An FASD child who completed an exercise one day can be clueless faced with the same exercise the next. Aggression after being asked to do something or avoiding homework are almost never proof of 'laziness' in a child with FASD, or of parental failure, but are sure signs that the child is over-challenged.

FASD children who do keep up in class tend not to come up to the social standards of their peers. They are taunted, taken advantage of and given the blame for pranks – at times without them noticing that they are being played with and used, and without being able to dissociate themselves.

The choice of school should therefore not only be based on the child's 'school performance'. Many behavioural and social anomalies in the FASD child soon disappear after switching from an over-demanding to an appropriate type of school. Special schools are reluctant to accept FASD children who do well in intelligence tests. As the children's problems relate to coping

with everyday life and social interaction, a special school is nonetheless often the more appropriate choice. The change of school should be made before a child ceases to enjoy learning and 'switches o '.

In many cases, the desire to provide an FASD child with a calm learning environment can only really be satis ed at home. In the classroom, a FASD child should not sit at the back. FASD children cope better in small classes. The teacher should make a point of asking if the child has understood a set task or noted what has to be done for homework. It is not always possible to provide such conditions. However, speci c forms of assistance can be discussed in direct consultation with the teacher.



ADHD-focused therapies are not helpful with FASD. Even good training cannot prevent the performance ups and downs seen with FASD children. Many training elements are still useful, however: Children with FASD need to revisit the same subject matter more times than other children. Long explanations are less helpful than demonstrating the desired behaviour and practising it with the child. Instructions should be clear and simple, and should always relate to one thing at a time. Likewise, tasks should be assigned one at a time – a second task only when the first is properly completed. Eye contact should be made while giving instructions. Explanations are sometimes better given in pictures rather than words. When starting a new or even a known task, providing assistance can sometimes be just as necessary as reminding the child of the task in hand.

At work

Adults with FASD very quickly come up against their limits in the workplace. In particular, vocational training in the primary labour market poses challenges that people with FASD perceive as highly stressful and over-demanding. This is because they are expected to work independently and master steps in a process; instructions are given only once and then taken as understood. These are all things that a person with FASD cannot do. The result is high drop-out and dismissal rates. Trainers, supervisors and colleagues of people with FASD should be aware that they need wide-ranging assistance even in adulthood.

Adults with FASD are neither lazy nor lethargic. In many cases they are motivated and like to show what they can do. This can work if tasks are clearly and simply worded and instructions are explained and repeated several times. Support is needed with starting both new and known tasks.

Given clear structures and routines that give guidance, people with FASD are quite capable of being eager and willing. It may be necessary to provide for frequent breaks or to restrict the length of the working day. A suitable working environment is often found at workshops for people with intellectual disabilities and in other forms of assisted employment.

FASD and addiction

Prenatal alcohol exposure does not in itself heighten addiction risk for people with FASD. The fact that some of them develop addiction problems has to do with adolescents and adults with FASD being both open to stimulus and easily led. This calls for a watchful eye and early intervention from carers.

Forms of treatment

Medication

Many parents are concerned that medication such as methylphenidate may alter their child's personality. In fact, medication generally allows FASD children to live out the personality they actually have, without the attention de cits and behavioural anomalies caused by FASD. Aggression and impulsive outbursts can be signi cantly reduced with risperidone. Medication is often the only way to open the door to learning and to enable children to have friendship-based contact with peers.

Other forms of therapeutic assistances

The developmental impairments in children with FASD call for early support and in some cases therapeutic measures (such as early intervention, occupational therapy and speech therapy). Children with FASD generally learn slowly and forget what has already been learned. Parents and professionals need to take that into account in their expectations regarding therapy outcomes. Psychotherapeutic and psychiatric measures should be behaviourally oriented with the main focus on the children's behaviour in everyday con ict situations. Children and adolescents with FASD are willing and cooperative in psychotherapy. They are mostly unable to keep promises, however, because they soon forget them or do not understand what is expected. Consequently, children or adolescents with FASD are sometimes assumed to be therapy-resistant or to intentionally disappoint the therapist. Therapy is then broken o by the professional, adding yet another experience of personal failure and rejection for the child.

Parents of children with FASD often face tremendous stress and strain. They need to think of their own welfare, make sure they have time and space for themselves, and seek timely help to relieve the burden they face. The rst place parents nd understanding and support is from others in the same situation, for example in FASD self-help groups.

Useful tips

Integration assistance *(Eingliederungshilfe)* for children and adolescents with or at risk of psychological disability

Children and adolescents in Germany are entitled to integration assistance from the public youth welfare services on account of psychological disability if there is a strong probability of their psychological health being at variance from what is typical for their age for longer than six months and in consequence their ability to participate in society is or can be expected to be impaired (German Social Code Book VIII (SGB VIII), section 35a).

Integration assistance for children and adolescents with a physical or intellectual disability; integration assistance for adults

Anyone who as a result of a physical, psychological or intellectual disability is ... signi cantly restricted in their ability to participate in society is entitled to integration assistance under the SGB Book IX (section 99). This means that child and youth welfare services only have special responsibility for young people with a psychological disability. This can result in jurisdictional problems when it comes to FASD, because it is not always clear from the symptoms of FASD whether a disability is psychological or intellectual.

It is not up to applicants to clarify this, however. The problem is resolved by the jurisdiction rule in SGB IX, section 14. This states that if an agency receives an application for integration assistance, the agency must decide if it is responsible. If it considers itself not responsible, it must forward the application to the responsible agency within two weeks. The second agency must then provide the assistance, regardless of which agency is actually responsible.

Disabled person's pass

Children, adolescents and adults with FASD are entitled to a disabled person's pass depending on the severity of their disability. The pass can be applied for by parents or legal guardians. The level of disability and the applicable categories are decided by the pensions o ce *(Versorgungsamt)*. The categories that can be assigned in connection with FASD are B, G and H (SGB IX, section 146).

Care grades

Many children, adolescents and adults with FASD are unable to carry out basic care activities without instruction and control. Basic care includes assistance with bodily care, eating and drinking, and mobility.

The assignment of a care grade *(Pflegegrad)* of at least Grade 2 makes it possible to provide assistance such as short-term care in an approved institutional facility. Half of the short-term care rate, can, however, be used towards respite care. This can then be used to pay for care provided by neighbours and, to a certain extent, by family members.

Appointing a legal guardian for adults with FASD

For a wide range of reasons, young adults with FASD are often unable to take on responsibility for themselves and their lives. Many cannot handle money or live independently. Everyday activities are forgotten, or they neglect bodily care and their health. It can thus make sense to apply for the appointment of a legal guardian beyond the age of 18. As the appointment of a legal guardian should ideally take place in mutual agreement with the young FASD adult, it helps to initiate such an arrangement with them early on.

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