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Strategies for Supporting the Development of Abilities of Children with FASD in the Family Environment: Possibilities and Dilemmas

Strategie wspierania rozwoju zdolności dzieci z FASD w środowisku rodzinnym możliwości i dylematy

ABSTRACT

Parents or guardians who have full or partial custody of a child with Fetal Alcohol Spectrum Disorder (FASD) witness the child's complex and unique development and accompany them in acquiring competencies in various learning environments. The aim of the study was to explore the opinions of parents and guardians of children with FASD regarding the needs and possibilities for developing their children's abilities. In order to describe strategies for supporting children with

Raporty z badań

KEYWORDS

abilities, Fetal Alcohol Spectrum Disorder, parental support, predispositions, difficulties

SŁOWA KLUCZOWE

zdolności, Spektrum Alkoholowych Zaburzeń Płodu, wsparcie rodzicielskie, predyspozycje, trudności

SPI Vol. 28, 2025/1 e-ISSN 2450-5366

DOI: 10.12775/SPI.2025.1.004 Submitted: 16.09.2024 Accepted: 21.02.2025

Case Reports



FASD, opinions were collected from 39 parents or caregivers. The analysis identified several key aspects of promoting the abilities of children with FASD: the personal involvement of parents and caregivers, positive reinforcement, financial support, and the use of social and cultural resources. Respondents also highlighted a number of challenges in the care and education of children with FASD in Poland, particularly the insufficient knowledge among educational staff about both the difficulties and strengths of these children. Based on this analysis, it seems crucial to provide caregivers with appropriate support, practical guidance, and tools to help them consciously nurture the potential of the children in their care.

ABSTRAKT

Rodzice lub opiekunowie posiadający całkowite lub częściowe prawo do opieki nad dzieckiem ze Spektrum Alkoholowych Zaburzeń Płodu (FASD) są świadkami skomplikowanego i niepowtarzalnego rozwoju dziecka oraz towarzyszami zdobywania przez nie kompetencji w różnych przestrzeniach uczenia się. Celem badań było poznanie opinii tych osób na temat potrzeb i możliwości w zakresie rozwoju zdolności u ich podopiecznych. Dla opisania strategii wspierania dzieci z FASD w rozwijaniu ich zdolności zebrano opinię od 39 rodziców lub opiekunów prawnych. Na podstawie materiału zidentyfikowano kluczowe aspekty wspierania zdolności dzieci z FASD: osobiste zaangażowanie w rozwój zdolności dziecka rodziców i opiekunów, pozytywne wzmocnienia, zapewnienie zaplecza finansowego, wykorzystanie kapitału społecznego i kulturalnego. Respondenci wskazywali także na liczne wyzwania w zakresie opieki i edukacji dzieci z FASD w Polsce, m.in. na niedostateczną wiedzę kadry pedagogicznej na temat trudności i możliwości dzieci z FASD. W perspektywie przeprowadzonej analizy kluczowe wydaje się być zapewnienie opiekunom dzieci odpowiedniego wsparcia, poradnictwa rodzinnego oraz narzędzi, aby świadomie mogli wspierać potencjał swoich wychowanków.

Introduction

The term *Fetal Alcohol Spectrum Disorders* (FASD) was introduced in 2004 by the National Organization on Fetal Alcohol Syndrome and the FASD Center of Excellence in Washington, D.C., to define the spectrum of developmental effects caused by alcohol exposure

during prenatal life. However, it is not intended for use in clinical diagnostics. This term has been recognized and adopted by international organizations and researchers worldwide (Hargrove et al. 2024; Eliason et al. 2024; Gault et al. 2023; Popova et al. 2023; Astley Hemingway et al. 2020).

In the international DSM-5 classification, FASD has been recognized as one of the Other Specified Neurodevelopmental Disorders. This category "specified" is used in cases where symptoms characteristic of neurodevelopmental disorders cause clinical distress or deficits in occupational, social, or other areas of life functioning but do not meet the criteria for other disorders in this group (Gałecki et al. 2018). In Poland, since 9 September 2020, following the introduction of new diagnostic standards within the FASD spectrum, diagnoses of two syndromes have been made: FAS (Fetal Alcohol Syndrome), coded LD2F.00 in the ICD-11 classification, and ND-PAE (Neurodevelopmental Disorder Associated with Prenatal Alcohol Exposure), coded 6A0Y in the ICD-11 classification (Okulicz-Kozaryn et al. 2020).

This is one of the reasons why the term children with FASD has been adopted in this article as an umbrella term to describe all children with neurobehavioral disorders resulting from prenatal alcohol exposure. The diversity of terminology surrounding this syndrome reflects the complexity, extent, and ambiguity of the deficits caused by the teratogenic effects of ethanol. The negative effects of prenatal alcohol exposure are observed in children across cognitive domains (e.g., problems with memory, concentration, abstract thinking, and executive function disorders), emotional domains (e.g., difficulty regulating mood, emotional immaturity in adolescence), and a wide spectrum of socially unacceptable behaviors—ranging from antisocial tendencies to withdrawal and anxiety disorders (Palicka 2023a, 2023b). As Małgorzata Stopikowska (2016: 204) emphasizes, "individuals with FASD are at greater risk of developing serious disorders in the psychosocial domain than the rest of society and therefore require a well-functioning support system."

While working with a child with Fetal Alcohol Spectrum Disorder (FASD), a scaffolding strategy derived from Lev S. Vygotsky's concept of developmental teaching is used, among other approaches. Krzysztof Liszcz adapted this strategy for working with children affected by FASD (Liszcz 2011). This specific type of interaction



consists of numerous *Joint Involvement Episodes* (Filipiak 2015), where learning is treated as a social process—a dialogic interaction with others in which support is structural and procedural, guiding the child forward with the help of a more competent *other* (a teacher, parent, or peer).

The caregiver who provides the scaffolding initiates the activity and sets the direction for the learner, while the nature and extent of support are determined by the child's capabilities at the time (Filipiak 2011). Such structured efforts allow for a deeper insight into the child's level of functioning, as well as the supervision and adjustment of interventions. Ewa Filipiak (2015: 17), reflecting on Vygotsky's theory, notes that in order to work more effectively with the child, it is necessary to "base the work with the learner on their evolving developmental needs and knowledge, as well as new experiences, and take into account their potential abilities and emerging interests."

These measures take on particular significance when working with children with specific learning difficulties, as changes in a student's functioning, behavior, and actions are often subtle (Wiśniewska 2015). Often, within the FASD-affected child-teacher-parent triad, it is the parents who provide the most essential scaffolding for the child's development (Karasowska 2006). Parents have developed strategies for handling difficult situations, are aware of their children's needs, and are uniquely positioned to provide effective protection and support (Banach, Matejek 2016).

In the context of therapy for a child with FASD, it is the caregivers who become the experts, thus becoming informal consultants and advisors to the teachers and professionals working with the child (Liszcz 2011). At the same time, individuals with FASD are often perceived primarily in terms of their difficulties, making it challenging to recognize their potential and abilities. However, studies on the subject (Kleinfeld, Wescott 1993; Duquette, Stodel 2005; Duquette et al. 2006) and research exploring parental observations and experiences (Klecka 2006; Liszcz 2011) reveal that individuals with FASD, among other things, learn quickly through experience, possess musical and artistic talents, perform well in various sports, are capable of caring for children and animals, and have vivid imaginations.

Another article (in press) identified the abilities demonstrated by children with FASD, as described by their parents, along with the

Research method

in children with FASD.

Survey studies conducted using an electronic questionnaire focused on the observations of parents or guardians of children with FASD regarding the opportunities and challenges related to developing their abilities. The aim of the exploratory research was to identify the factors that foster the development of abilities in children with FASD, as well as the limitations that accompany these processes, according to their relatives. The study sought to answer the following research question: What strategies do parents or guardians use to support the abilities of children with FASD, and what factors hinder their development, according to the respondents?

The research problem and objectives determined the use of purposive sampling of respondents (Konarzewski 2000; Rubacha 2011). The responses obtained through an electronic survey questionnaire constituted the analytical material. Fifty-four parents or guardians of children with FASD living in Poland participated in the study. The participants were primarily women acting as adoptive parents (61%), guardians in foster care (24.1%), or close or distant relatives with legal custody of the children (11.1%). Due to the diversity of the research group, a major challenge during the analysis of the results was adopting appropriate terminology to describe the respondents' roles in relation to the child with FASD. This raised the question of whether the respondents should be referred to as "parents" or "guardians." Considering the terms used in the respondents' statements such as "as a parent," "being a parent," "my son," and "my daughter" which omit legal or biological distinctions, the term "parents and legal guardians" was chosen.

Given the quality and completeness of the data obtained from the survey questionnaires, as well as the fact that parents most frequently described strategies for supporting the development of abilities in children of early school age (9 boys and 10 girls) and in students of grades 4–8 (13 boys and 7 girls), 39 survey responses were selected for further analysis. The obtained results were systematized and analyzed



according to the division by sex and age of the children, identifying differences and similarities in the strategies declared by parents and guardians. Reaching the sample group proved to be the most difficult stage of the research. The lack of uniform diagnostic standards before 2020 (Okulicz-Kozaryn et al. 2020) and the insufficient number of facilities diagnosing individuals with FASD spectrum disorders may contribute to an underestimation of the actual number of people with this condition in Poland.

An electronic survey was sent out to groups connecting parents of children with FASD on social networks. However, in the initial phase of data collection, this strategy did not yield the expected results. Only the so-called "negotiation with the doorkeepers," as referred to by Mariola Racław (2018: 171)¹—specialists in the field of FASD in Poland and their recommendation of the project—enabled the researchers to gain the trust of respondents and, in many cases, obtain declarations of willingness to participate in other projects concerning FASD. The research results were analyzed based on word frequency and dominant themes in the material. Factors were organized into groups, followed by data interpretation and discussion of the findings. The data obtained was illustrated with excerpts from participants' statements presented later in this paper.

Results

Due to the wide range of difficulties and deficits, the process of raising and nurturing the abilities of a child with FASD is a path without a consistent coordinate system. Identifying abilities—along with the strategies adopted to nurture them—remains a challenge for both the home environment and education, and the outcomes of these efforts are not always in line with expectations. In seeking answers to the research question, it was found that parents or guardians of children with FASD engage in numerous activities that require personal commitment to their child's proper development and to enhancing their potential.

¹ The author defines this term as conversations with people who facilitate entry into the research environment by recommending a project or researcher, or by indicating the first respondents.

The majority of respondents (69.2%) emphasized the need for frequent involvement and full attention to the child's development, as well as ongoing efforts to improve their skills. The child's abilities can be enhanced by creating an educational atmosphere, including engaging the child in additional household activities, discussing interesting topics, or explaining surrounding phenomena and human relationships. According to parents and guardians, providing emotional support and accompanying the child to important events, such as sports competitions or music auditions, were also key factors in supporting their development. The data analysis indicates that parents were particularly involved in providing emotional support, especially for boys in grades 4–8. Accompanying children to events, such as competitions or performances, was also more prominent for boys in this age group. Respondents frequently mentioned that they acted as initiators, guides, and first teachers, introducing their children to the intricacies of various fields of knowledge.

One parent of a 13-year-old described their child's skills in mechanical skills and construction: *My son loves to make modifications*, for example, to a quad, with improvements carried out under his dad's guidance. He works on it systematically, several times a week (R3). Parents of children in early elementary education also engaged in joint exercises to enhance their child's abilities, which may have significant therapeutic and compensatory value for children with FASD. The time spent together with the child served the respondents not only to develop their abilities but also to discover them—particularly when, in addition to high ability, the child had multiple cognitive dysfunctions and concurrent disorders. In this context, abilities appeared in parents' descriptions as a form of therapy, compensation for deficits, and a way to enhance the child's self-esteem. A representative statement in this regard came from a mother describing her 9-year-old daughter:

My daughter has been diagnosed with mild intellectual disability in addition to FAS (she scores at the upper limit in tests—I think it's right on the borderline between mild disability and the lower end of the normal range). Intellectually, she develops more slowly than her peers, so I look for skills and abilities that fall within her capabilities and give her the opportunity to excel beyond other children. She has already started noticing her deficits and feels self-conscious about them, so I try to find activities she is good at, where she can feel proud of her achievements. (R32)



In the context of joint exercises, skill improvement, and motivation to take on new challenges, the data show that, in grades 4–8, parents and guardians of boys were more involved in encouraging their children to take on challenges, providing more intensive support in this area compared to parents of younger boys. These data and descriptions illustrate how parents tailor their involvement in the development of children with FASD to the individual needs and abilities of the child. They focus not only on intellectual growth, but also on emotional and social development by introducing new challenges and areas in which the child can feel competent and valued. Detailed information on how parents and guardians support the abilities of children with FASD is presented in Chart 1.

According to parents and guardians, positive reinforcement was an indispensable factor in boosting a child's abilities. The importance of positive motivation in developing the abilities of school-age children at risk of social maladjustment was also reported by Ewelina Winiarczyk-Waleniak (2023), who emphasized that situations in which children's successes are recognized and appreciated by others are key motivators for further improvement. In the study described in this article, this type of support was declared by 46.6% of respondents.

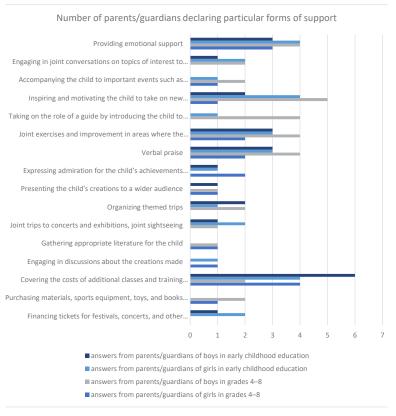
Most often, parents and guardians used verbal praise, but they also expressed admiration for the child's achievements, initiative, and engagement through messages and gestures. Verbal praise was the dominant form of reinforcement, particularly for boys in grades 4–8. In early school education, both boys and girls received similar levels of praise, which suggests equal use of this type of motivation in younger age groups. Showcasing their creations to a wider audience was another source of gratification for children. Although used less frequently, it was observed in parents of both younger and older children. Expressing admiration through nonverbal messages and gestures was another reinforcement method, more commonly directed toward girls in the older grades. The following statements exemplify the importance of positive reinforcement in nurturing a child's abilities:

noticing their work, praising and expressing admiration, providing positive reinforcement, encouraging further development, taking an interest in the child's work, activities, and in what makes them happy. (R25)

We motivate him by praising him, showing his work to others who also praise him. He attended drawing classes (though he does not go anymore because he does not want to). We even organized an exhibition of his work at the local cultural center. (R50)

despite occasional failures, I try to comfort and motivate him. (R12)

Chart 1. Types of support provided by parents and caregivers in developing the abilities of children with FASD



Source: Authors' own elaboration.

The socio-economic status of a gifted child's family may be an important factor in the support strategies they adopt (Sitek 2020). Results from the TIMSS 2019 study show that the higher the parents' education level and financial status, the better the grades achieved by students—especially in larger towns, where the availability of cultural venues and extracurricular activities allows parents to allocate more financial resources toward their children's education, thus kindling a desire to undertake various activities (Sitek 2020).



Equally important, according to respondents, was the use of the family's social and cultural capital, as noted in 20.5% of the survey responses. Parents and guardians created various opportunities to develop their child's talents, such as themed trips and explanations of everyday phenomena and interpersonal relationships. To introduce their children to the worlds of culture and science, respondents provided relevant literature, initiated outings to concerts and exhibitions, and engaged in discussions about the resulting experiences. However, this form of support was relatively less common, especially among early school-age children.

For students in grades 4–8, parents more frequently acquired books, which may indicate a greater interest in and need for developing skills through literature in a specific field. Meanwhile, activities such as attending concerts, exhibitions, and other cultural events were more common among younger children. Among older students, shared experiences like attending concerts together appeared to be more sporadic. Additionally, only a few parents or guardians reported engaging in conversations about the works their children created.

Analysis of the survey questionnaires also revealed the topic of financial investment in the development of the child's abilities, appearing in as many as 60% of the responses. Respondents described their family's financial resources as often being crucial in the decision to continue supporting the child's abilities in a particular discipline. They reported covering the costs of extracurricular activities and master classes, as well as purchasing materials, toys, and books necessary for developing their child's hobbies and skills. In addition, they paid for tickets to festivals, concerts, and other cultural and sporting events. This perspective is well reflected in the following statement: I pay for and drive him to football classes. I create space to develop his creativity—LEGO, art supplies, origami tutorials, etc. (R39).

Regarding expenses for developing the abilities of children with FASD, the results indicate that, in the early childhood education group, additional classes and workshops (especially for boys) and tickets for concerts and other cultural events were more frequently funded. In this same age group, there were no instances of financing the purchase of development-supporting materials. In contrast, for older students (grades 4–8), families not only covered the costs of additional classes but also purchased books, sports equipment, and

other necessary materials. Some respondents mentioned allocating significantly larger funds to support their child's abilities, such as purchasing and maintaining a horse. However, financial constraints were also reported as a barrier to a child's ability development.

At times, respondents' accounts revealed that the decision to support a child's abilities was fraught with difficulties and dilemmas. Participants stated that the biggest obstacles to developing abilities in children with FASD were the physical, social, and cognitive disorders associated with the spectrum. This concern was shared by 38.46% of respondents. The most frequently cited difficulties included cognitive deficits, poor memory, concentration issues, language difficulties, psychomotor agitation, poor fine motor skills, psychological effects of past trauma, and behavioral disorders. These challenges were reported by both parents and guardians of children in grades 1-3 and grades 4-8. Many of the aforementioned disorders persist throughout the lives of individuals affected by FASD. As a result, when deciding to nurture their child's talents, parents or guardians had to carefully consider which areas were within the child's mental and physical capabilities. This awareness is reflected in the following statement: *Unfortunately*, there are domains that cannot be developed due to innate issues, such as problems with abstract thinking (R17). Another significant theme described by respondents was the low and fluctuating motivation observed in these children. One guardian referred to this as "short-lived enthusiasm." Similar difficulties were reported by 20.5% of respondents, who noted issues such as aversion to effort, rapid fatigue, burnout from challenges, fear of failure, and a lack of self-confidence. These struggles—characterized by giving up quickly and being afraid to fail-were more frequently observed in boys, particularly in the higher grades. This mindset made it much more difficult for children with FASD to persevere in their aspirations and improve their skills. Even with full family support, maintaining a child's interest in a particular discipline can be exceptionally difficult—and sometimes even impossible—as one parent summed up:

I sign my child up for training classes, but the longest they'll participate is six months. What follows is a categorical refusal—crying, reluctance, demanding to stay at home, and coming up with excuses to stay at home (a reluctance to engage in physical exercise and intellectual effort, keeping their head down, and a fear of drawing attention to themselves—freezing up). (R43)



From the perspective of parents and guardians, an extremely important factor correlating with the development of their children's abilities was the external environment. The responses primarily concerned the education of children with FASD. A total of 38.46% of respondents identified numerous shortcomings in the current education system and the work of school staff. One respondent described these concerns in detail:

An overly fast pace of work imposed by the system, a lack of appreciation for creativity—teachers often just want it to be exactly as it is in the textbook. There are no laboratories in schools, no work with technological tools that could help them learn faster. No reference to real-world facts. Classes are boring—just writing in a notebook and reading from a textbook. No experiments, no presentations, no teaching children how to apply knowledge in practice. Our system is outdated, stuck in the Prussian model. Education is terribly neglected. Special education is almost nonexistent in schools with integrated classes. These classes should be structured differently. In my opinion, they make no sense, at least not at the school my son attends. First of all, a profound reform is needed—among teachers, in their approach, and in their understanding of various disorders. I get the impression they don't even care. It's very sad. (R34)

This view was also shared by other respondents who questioned the effectiveness of the school environment in improving their children's abilities. More than half of these responses came from parents and guardians of boys in grades 4 to 8. In this regard, the primary concerns of parents and guardians were the level of knowledge that educators had about children with FASD and the commitment of teachers and specialists to supporting students with deficits. Some respondents even felt that school staff were reluctant to work with their child. Additionally, parents and guardians criticized the Polish education system, which, in their opinion, relies on inadequate teaching methods, ineffective work strategies, and an excessively demanding curriculum. According to the respondents, the large volume of homework and the overwhelming amount of material to be learned hindered their children's ability to develop their skills.

According to the respondents, low public awareness regarding the functioning of individuals affected by FASD also hampered their progress. However, this relationship was observed by only a small percentage of parents and guardians in both age groups (5.1%). The respondents also pointed out that professionals, sports coaches, and instructors often lacked knowledge about the mental and physical

capabilities of these children, which posed a significant barrier to nurturing their abilities. As one survey participant observed, most organizations do not adapt their extracurricular activities to be accessible to individuals with neurodevelopmental disorders.

One foster parent highlighted the many challenges faced by large families. In such situations, according to the respondent, caregivers had to divide their time, organizational efforts, and financial resources among a large number of children in their care. When children with neurobehavioral disorders were part of the household, the focus of those around them shifted toward managing behavioral difficulties, while strengthening their abilities became secondary. The statement below illustrates this perspective:

When such a restless child is in a large foster family, the entire household switches to survival mode. There is no focus on developing the child's interests, passions or abilities (even if the child has them) because these are often overshadowed by the difficulties. (R44)

The final part of the study focused on the measures that educational institutions take to support the abilities of children with FASD. According to 41.3% of respondents, such efforts do not target their dependents. Under Polish law, children diagnosed with Fetal Alcohol Spectrum Disorder are not granted a special educational needs decision, despite experiencing significant developmental deficits. Their inclusion in mainstream education presents both opportunities and challenges for children, parents or guardians, and teaching staff alike.

In most cases, parents and guardians of children on the FASD spectrum noted deficiencies in how teaching staff approached their development, as they tended to concentrate only on weaknesses. However, respondents observed a positive trend in the growing interest of educational staff in FASD, which has led to gradual improvements in teachers' skills and the tools that they use when working with children affected by neurodevelopmental disorders. A key request from parents and guardians was the opportunity to participate in school life and be actively involved in designing their child's educational environment.



Conclusions of the study

The results support the claim that parents and guardians play a crucial role as both creators and companions in the development of their children's abilities. To keep their child motivated to continue working on their skills, respondents frequently allocated time and financial resources while also seeking creative and unconventional solutions to emerging difficulties and problems. They recognized the importance of supporting their child's development, particularly given the numerous limitations associated with FASD, as well as barriers related to education, finances, and service accessibility. The strategies described in this study may serve as a guide for other parents and caregivers of children with FASD, offering possible solutions and building a sense of connection with others in similar circumstances.

Moreover, it appears that many parents and guardians see themselves as partners to their children's teachers, consultants, and special therapists, continuing and reinforcing the knowledge and skills their children acquire at school. This study is oriented around the pedagogy of development or growth (Szmidt 2013), which assumes that, alongside wisdom and creativity, abilities are among the fundamental resources of every individual and should be the foundation of educational curricula. Such a strategy allows for a more holistic perspective on people with disabilities or deficits—one that does not define them solely through their limitations. For parents and guardians of children with FASD, this approach can be valuable in designing strategies to support their child's abilities. It also helps them understand that developmental deficits and difficulties do not preclude their children from being recognized and excelling in a particular field.

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