Chapter 16
Educating School-Aged Children with FASD

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Introduction

Fetal alcohol spectrum disorders (FASD) is a descriptive term encompassing the range of physical abnormalities and neurobehavioral deficits associated with the effects of prenatal alcohol exposure (PAE) [1–4]. The clinical diagnosis of fetal alcohol syndrome (FAS), partial fetal alcohol syndrome (pFAS), neurodevelopmental disorder associated with prenatal alcohol exposure (ND-PAE), and alcohol-related neurodevelopmental disorder (ARND) is included within the term of FASD [2, 4]. In the United States, approximately 1–5% of school-aged children may be affected by PAE [5]. While the estimated prevalence of children and youth with FASD in other countries is similar to the United States, meta-analysis and review studies have suggested significantly higher prevalence rates in South Africa, Croatia, and estimated for Ireland [6, 7]. The prevalence of FASD among school-aged children may be an underestimation due to differences in study methodologies and diagnostic models [8, 9]. Nevertheless, based upon the estimates, it is probable that most school systems in the United States and other nations educate children and youth with FASD [10, 11].

The effects of PAE include a range cognitive and functional impairments that may be compounded by other in-utero exposures, genetic factors, and pre-and-postnatal environmental stressors that disrupt development and learning [12] Though some individuals with FASD share similar traits, research has not yet identified a consistent cognitive or behavioral phenotype associated with the disorder [1, 13]. Some children and youth affected by PAE have global developmental delays, while others may exhibit specific deficits in one or more cognitive domains that

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interfere with learning [1, 13]. Irrespective of cognitive impairments, some children and youth with FASD have problems with behavior regulation, emotional regulation, and adaptive functioning [14–16]. Also, among individuals with FASD, there is a high rate of reported co-occurring medical conditions [17]. Many affected by PAE have experienced social and environmental challenges, such as multiple caregiving placements, deprivation, or involvement in foster care that may impact learning readiness [12, 18, 19]. The variable presentation of FASD coupled with common adverse experiences place many children and youth at risk for learning and school problems, especially if they do not receive intervention [20, 21]. Though not all school-aged children with FASD exhibit the same cluster of characteristics, it is important for educators to understand the scope and nuances of the disorder and consider PAE as an indicator that the student may require support or interventions to address potential learning and school problems [22].

However, there are barriers obtaining information about FASD that pose challenges to educators to understand and meet the needs of school-aged children affected by PAE. Many children are not screened or evaluated for the effects of prenatal exposures potentially leading to overlooked or misdiagnosis and ineffective treatment planning [23, 24]. This may occur more often among minoritized populations, children living in poverty, or children in foster care because of disparities in access to healthcare and mental health services [23–26]. Negative stereotypes and misperceptions about FASD may hinder collaboration between caregivers, educators, and allied service providers. Because of misperceptions, such as beliefs that children with FASD have severe behavioral problems due to poor parenting, some caregivers may not disclose information about their children's diagnosis out of concern of being judged by teachers or ostracized by classmates' families [27]. Other misinformed beliefs, such as children with FASD are unable to learn because of permanent brain damage, may inadvertently influence some teachers' interactions and effort with students [28]. Access to accurate information is necessary to counter stigma and respond to the needs of school-aged children with FASD [28, 29].

The neurobehavioral deficits associated with FASD fall within the classification of developmental disabilities, defined as a group of life-long conditions related to physical and or neurocognitive impairments that impact language, learning, and behavior [30, 31]. However, studies examining prevalence and outcomes of different conditions classified as developmental disabilities often do not specify FASD as a subset, contributing to the marginalization of the disorder [30, 31]. Furthermore, few studies have surveyed the number of school-aged children with FASD receiving special education services [32]. Currently, in the United States, there is no long-term coordinated surveillance effort to examine the special education services and educational outcomes of students with FASD in public schools [9, 32]. These and other barriers interfere with understanding and disseminating accurate information about FASD to guide educational policy and best practices to offset potential school problems.

Qualitative studies examining experiences of students with FASD, their caregivers and teachers, provide insight into key components to support students with FASD in schools despite existing barriers [33, 34]. From these studies, increasing awareness through training and dissemination of accurate information about the effects from PAE were associated with improved student–teacher interactions and countering misperceptions [35, 36]. Studies showed that collaboration between school personnel, caregivers, allied services providers, and when developmentally appropriate, individuals with FASD, was associated with better interactions with families and support of students at school [37, 38]. In addition, studies have shown that effective individualized interventions following a habilitative approach improved learning, academics, and functioning at home and at school [39, 40].

This chapter provides an overview of the educational needs of school-aged children with FASD. The chapter presents a review of the literature regarding school functioning, educational experiences, and outcomes of school-aged children affected by PAE. Next, the chapter discusses regulations, school-based services, and best practices in public education that apply to school-aged children with FASD in the United States. Lastly, the chapter concludes with a proposal for an integrative approach that focuses on building and applying skills to promote active engagement, learning, and participation at school so that children and youth with FASD can reach their potential.

School Functioning

School functioning refers to the academic, behavioral, and social skills needed to meet the expectations of an educational setting [41]. Efficient school functioning relies on the interplay between multiple cognitive processes and personal characteristics to engage, maintain motivation, and learn in a school setting [42, 43]. These cognitive processes and personal traits are sensitive to biological, genetic, social, and environmental factors [22, 44, 45].

In the general population, intellectual abilities, language, attention, executive functioning, working memory, and visuospatial processing are associated with scores on standardized academic achievement measures of word reading, reading comprehension, written expression, and mathematics [42, 46, 47]. Also, studies of children have shown associations between graphomotor skills and performance on standardized measures of written expression and mathematics [42, 48, 49]. In school-aged children, better developed executive functioning and self-regulation are associated with higher grades and fewer behavioral problems in the classroom [50–52].

Attention, executive functioning, and self-regulation are interlinked constructs that contribute not only to scores on academic achievement tests but also to traits needed to manage the social demands of a school setting [51–54]. In broad terms, executive functioning refers to a set of cognitive processes that includes inhibition, updating working memory, and shifting that interact to complete goal directed behavior [55, 56]. Neural models of executive functioning suggest that these processes are associated with activation of the prefrontal cortex and basal ganglia [55]. According to this definition of executive functioning, inhibition is the ability to suppress dominant, automatic, or proponent responses when completing a task [55]. The definition defines updating working memory as the ability to monitor, add, and delete information as new content is acquired [55]. Lastly, shifting is the ability to switch between task goals and sets of information [53, 55]. These processes work in coordination to support learning and problem-solving tasks that are critical for the school environment.

Self-regulation, defined as the unconscious and conscious control of one's emotions and behaviors across contexts, shares cognitive resources with executive functioning [57, 58]. As children increase in conscious control of their behavior and emotions, they draw upon the cognitive processes related to executive functioning and other domains, such as language to modulate their responses [53, 57]. In school, self-regulation may be observed by students' focusing, staying on task, coping with frustration, self-monitoring, and maintaining self-control across school settings [43, 57]. Specifically, studies have shown that self-control is associated with changes in grades, increased task completion, and use of prosocial behaviors in the classroom [43, 51]. In the long-term, better developed executive functioning and self-regulation are associated with higher educational attainment and decreased risk of later substance abuse and involvement with the judicial system [43, 59].

Along with cognitive processes, individual learning traits such as self-efficacy contribute to school success [33, 43, 60]. Self-efficacy is one's belief in one's ability to understand, learn, and apply skills to achieve a goal [61, 62]. It assists with students' effort, motivation, and persistence to complete challenging tasks or to maintain performance in less-than-optimal learning settings [62]. Research examining effort in students with learning disabilities has shown that those with positive self-perceptions about learning were more likely to use strategies to persevere with challenging learning tasks when compared to students with learning disabilities who hold negative self-perceptions [63]. Other studies have shown positive relationships between self-efficacy and higher grades in school and reaching goals in the workplace [60, 64]. In school-aged children, self-efficacy is sourced through supportive learning environments with appropriate teacher and parent expectations and positive school experiences [43, 62]. Reviews of strength-based literature suggested that many individuals with FASD exhibit personal traits that align with self-efficacy [65].

FASD, Disrupted School Experiences, and Educational Outcomes

Studies of individuals with FASD referred for clinical services and recruited from the community illustrate the risk for school problems and disrupted school experiences, defined as being suspended, expelled, or dropping out of school in this population [20, 66]. A 1996 summary report from a project examining adverse outcomes and protective factors in individuals with FAS or affected by PAE referred for clinical services indicated that approximately 60% of school-aged children and adolescents with PAE reported difficulties having good relationships with their peers and between 55 and 60% reported exhibiting behaviors that disrupted classes [20]. In addition, approximately 60% of the participants with FAS or affected by PAE indicated having been suspended, expelled, or dropped out of school with only 40% of individuals with PAE between the ages of 21 and 51 having graduated high school or completed the high school general equivalency exam (GED) [20]. Studies of participants with FASD recruited from the community reported somewhat better school experiences and outcomes. For example, a 2006 study examining school functioning with participants recruited from the community in an urban area in the southeastern United States found no differences in conduct problems at school in adolescents with PAE when compared to a special education contrast group, and to a control group of adolescents with no or unknown PAE [67]. A more recent study analyzing the records of adolescents, youth, and adults with FASD from the Canadian National FASD Database indicated that 18% reported school disruptions defined as being suspended or expelled from school [66]. The school disruption rate was lower than reported by participants with FASD referred for clinical services. However, for comparison to a general school-aged population within a Canadian school system, the rate of school disruptions for the adolescents with FASD was higher than the average rate of approximately 3% of students reported to be suspended and expelled in schools under the jurisdiction of the Ontario Ministry of Education [68].

Research suggests that individuals with PAE with more complex cognitive, behavioral, and mental health issues of have poorer educational outcomes [66, 69]. One study, examining the effects of PAE on adaptive functioning in young adults with PAE compared to a control group and a special education contrast group of young adults with no or unknown PAE found that 53% of young adults with facial features and cognitive impairments associated with PAE had graduated high school [69]. For the young adults with cognitive impairments but no facial features associated with PAE, 62% completed high school [69]. The study indicated that 66% of the special education contrast and 81% of the control group reported graduating high school [69]. Except for the group of the more severely impacted adolescents with PAE, the graduation rates for the special education contrast group and the control group were similar to the 2015 graduation rates in the United States in which 66% of students receiving special education and about 84% of all students completed high school [70].

A more recent study conducted in Finland examined the impact of childhood adversity, out-of-home placements or being in foster care, as well as behavioral, mental health, and other diagnoses on secondary school completion in youth with and without prenatal exposure [71]. Individuals were excluded from the study if they had intellectual disabilities to match the groups of individuals with and without prenatal exposures. The results indicated that individuals with prenatal exposure to alcohol and drugs without cognitive impairment were less likely to complete secondary school [71]. For those that completed high school in both the non-exposed and prenatally exposed groups, neuropsychological, mental health, and behavioral disorders including psychiatric disorders as well as dual diagnoses were related to a lag or an extended time to complete secondary school [71]. There was no association between the overall score of reported childhood adverse experiences and out-of-home placements to completion of secondary school [71]. The study indicated that regardless of history of prenatal exposures, those who had more behavioral, mental health, and medical diagnoses fared worse than those without the complications transitioning into adulthood [21, 69, 71]. An earlier study out of Sweden reported that all individuals with FASD completed the compulsory years of education as mandated by the Swedish Education Act that prohibits dropping out of school and allocates special education and other services to ensure completion of education [21]. Overall, these studies reflect the variability in presentation of FASD, individuals' intervention needs, access to services, and policies that have long-term implications.

FASD, Cognitive Processes, and School Functioning

Over the years, studies have shown that neurodevelopmental impairments associated with PAE combined with other medical, environmental, and social factors have detrimental impacts on most aspects of school functioning [1, 19]. Some with FASD exhibit global developmental delays with scores on standardized measures of intellectual and adaptive functioning falling more than 2 standard deviations below the mean when compared to the normative sample [1]. Yet, most individuals affected by PAE do not exhibit global developmental delays but have impairments in one or more specific cognitive domains [1].

Imaging and behavioral studies have identified that brain structure and white matter integrity are susceptible to the effects in-utero alcohol exposure influencing processes drawn upon for learning [13, 72–74]. For example, neuroimaging studies have shown associations between alterations in the prefrontal cortex and frontoparietal region and heavy PAE [72, 75]. Atypical development in one or more of these areas would impair executive functions such as inhibition, planning, and shifting [74, 76, 77]. Decreased white matter integrity and connectivity related to PAE is associated with poorer cognitive efficiency [74, 76, 78]. This would impact academics, behavior, and managing the expectations of a school setting.

Behavioral studies have identified impairments with verbal learning and recall in school-aged children with PAE due to inefficient use of strategies for encoding or deficits with word retrieval [79, 80]. The impairments with verbal learning and recall have remained after accounting for influence of intellectual abilities in children with PAE [80]. In addition, research has indicated that children with FASD show poorer performance encoding spatial information needed for place learning when compared to typically developing, non-exposed peers [81, 82]. Problems with visual and spatial coding not only would interfere with academics but also with navigating a school or classroom layouts, organizing, and locating materials, judging social distance, and following classroom routines [83]. Other studies have indicated aspects of attention, working memory, and executive functioning impacting effective communication, spelling, and written language skills [84, 85].

Across age-groups, studies have found differences in brain activation patterns in individuals with PAE compared to nonexposed individuals and others with behavioral diagnosis such as Attention-Deficit Hyperactivity (ADHD) during mental tasks of numerical processing [86, 87]. Specifically, studies have shown that children with FASD showed less activation in areas of the intraparietal sulcus and activated additional regions to support processing numerical information including determining magnitude, judging proximity of numbers, and basic arithmetic when compared to non-exposed controls [87, 88]. Deficits with number processing combined with weakness in visuospatial abilities, executive processes, and working memory associated with the effects from PAE would impact learning mathematics [89, 90].

Clinically, caregivers and teachers often report children with FASD exhibit difficulties with behavior and self-regulation that interfere with school functioning. Many children and adolescents with FASD are reported as having problems with attention and may be described as unfocused, easily distracted during instruction, and frequently making careless errors when completing assignments or test [91]. Based upon the results of parent and teacher behavioral reports of attention problems, many school-aged children affected by PAE often meet the criteria for or have a diagnosis of Attention-Deficit Hyperactivity Disorder (ADHD) [17, 92]. However, a description of attention problems may mask weaknesses in other cognitive processes that impact learning and classroom functioning.

Studies using cognitive measures in addition to traditional parental and teacher behavioral checklists have found differences in attentional profiles in children affected by PAE when compared to non-exposed children with ADHD [93, 94]. In a 2011 article, Mattson, Crocker, and Nguyen succinctly summarized the similarities and differences between FASD and ADHD. They indicated that FASD is associated with lower intellectual abilities, and more impaired selective attention, problem-solving, encoding, verbal fluency, and adaptive behaviors than ADHD [93]. In comparison to ADHD, FASD may be associated with less impaired motor control, focused attention, sustained attention, and retrieval of information [93]. The article indicated that FASD and ADHD share similarities regarding parental and teacher reports of behavioral problems, challenges with social skills, as well as weaknesses with cognitive flexibility and execution of complex motor tasks [93]. The reliance on parent and teacher reports or checklists does not capture the other underlying neurocognitive impairments that may contribute to or appear as attention difficulties in classroom settings in children affected by PAE [94]. Awareness of the differences between FASD and other behavioral disorders would be necessary when assessing observed behavioral difficulties to determine appropriate interventions.

Many children and adolescents with FASD exhibit deficits with aspects of executive functioning that interfere with academic performance, social interactions, and classroom behavior [95, 96]. Specifically, studies have shown that children with FASD show difficulties with shifting between mental sets, incorporating feedback to adjust problem-solving approaches, recognizing that a response may be correct for one problem but not for another, and learning to regulate attentional resources when tasks and time demands increase [2, 4]. Problems with executive functioning in school-aged children with FASD often are greater than expected when compared to overall cognitive abilities and may persist into adulthood [2, 4].

In addition, school-aged children affected by PAE are described as having difficulties with emotional and behavioral regulation, which overlap with executive functioning [1, 16, 58]. Often school aged with FASD are described as being easily overwhelmed and overreact to common environmental stressors [58, 97]. Clinically, parent and teacher reports indicated that school-aged children with FASD exhibit difficulties modulating their arousal level that interferes with transitioning from high-level activities to seated work, sustaining engagement during group instruction, and refraining from impulsively responding in class [98, 99]. Also, problems with executive functioning and self-regulation in school-aged children affected by PAE may be described as showing lack of persistence to complete work, avoidance of tasks, commenting out of turn during class discussions, and exhibiting behaviors that may be bothersome to classmates [100, 101]. There are ways to address weakness with executive functioning and self-regulation and skills influenced by these processes to improve academic performance and classroom behavior [102, 103]. Some examples include teaching cognitive control strategies and metacognitive awareness, providing instruction to improve use of prosocial skills, and effective problem-solving approaches through repeated practice across contexts, and using various levels of difficulty or challenges [103, 104].

Some school-aged children with FASD are reported has having difficulties managing social interactions [95]. Studies have shown that adolescents affected by PAE may have difficulties explaining a situation possibly due to poor encoding of the event or challenges organizing language to express ideas in a logical sequence [84]. Also, problems with organizing and expressing verbal information clearly would interfere with meaningful participation during classroom discussions and when working cooperatively in groups [85, 105]. In the classroom, children with FASD are reported to demonstrate prosocial skills such as initiating and engaging in social exchanges with peers; however, they are described as showing variability in sustaining these interactions [106, 107]. Some children with FASD due to impulsivity may make comments that are unrelated to a topic or inappropriate to the social situation [95]. The unpredictability of interactions of school-aged children with FASD may result in avoidance by classmates [95]. Also, teachers may misinterpret problems with impulsivity as purposeful disruptive classroom behavior [95]. Providing instruction to sustain engagement and awareness of the social setting and interactions may improve classroom behavior.

A recent review article by Lees et al. has a table of examples of the cognitive indicators related to FASD and common presentations in the classroom. Not all individuals with FASD have the same neurobehavioral deficits and learning profile. The variability among the neurobehavioral traits associated with effects from PAE in school-aged children shows the need for comprehensive evaluations to identify the learning strengths and challenges to prevent misinterpretation of observed behaviors and to guide appropriate intervention planning [99, 108].

FASD and Individual Traits

Recent articles examining personal traits through a strength-based model have suggested that many school-aged children affected by PAE have personal characteristics that are associated with successful school functioning [65, 109]. In a 2021 review study, Flannigan et al. proposed that many individuals with FASD have affinities in arts, music, and sports [65]. The findings from the review indicated that many individuals with FASD were described as socially motivated, curious and demonstrated perseverance [65]. These traits are associated with self-efficacy and better school functioning [65]. Other studies have suggested that school-aged children with FASD who are socially motivated are more receptive to learn through interactive exchanges with instructors [65, 109, 110]. Interactive instructional approaches have been effective when habilitating mathematic skills and learning readiness in children with FASD [110, 111]. Additionally, individuals with FASD, who are socially motivated, might benefit from support to establish and maintain positive relationships with peers and adults [107]. Stable connections with responsible adults and positive peer networks are found to be protective factors in childhood and related to better outcomes in adulthood [108, 109].

FASD and Academic Achievement

Studies examining the timing and dosage of in-utero alcohol exposure have been found to impact scores on academic achievement measures of reading, spelling, and arithmetic [67, 90, 112]. In a 1996 study, Goldschmidt et al. examined academic skills in children affected by PAE at 6 years of age [112]. After controlling for intellectual abilities, social factors, and other prenatal substance exposure, heavy intrauterine alcohol exposure at the second trimester of pregnancy was associated with lower scores on tests of word reading, spelling, and arithmetic. There was a dose–response relationship between in-utero alcohol exposure during the second trimester and arithmetic test scores. A threshold effect of one drink per day during the second trimester was related to lower scores on tests of word reading and spelling [112]. In a follow-up study when the children were 10 years of age, binge drinking during the second trimester was associated with lower reading scores [113]. Contrary to the earlier study, there was no relationship between PAE and scores on the test of arithmetic; however, scores were generally lower than those in reading and spelling [112, 113]. Furthermore, in-utero alcohol exposure during the first and second trimester was related to poorer teacher's ratings of academic performance across subjects reflecting an association of academic underachievement with PAE [113]. Without controlling for factors that might influence academic performance, a study conducted in Australia found that children with heavy PAE during the first trimester of pregnancy were twice as likely not to meet reading benchmarks on a nationally administered, criterion-referenced academic test [114]. Additionally, the study indicated that maternal binge drinking, defined as consumption of five or more drinks in a single sitting, was related to failing to meet academic benchmarks in expressive writing [114]. The findings demonstrated the of binge drinking and heavy PAE on academic functioning. However, there is little information on the impact of light-to-moderate in-utero alcohol exposure and academic achievement [115].

Other studies have examined the impact of PAE on academic achievement by examining maternal biological factors that may be related to the amount of exposure. Interesting outcomes regarding PAE, and academic achievement came out of a population-based study of pairs of mothers and their children from the United Kingdom participating in the Avon Longitudinal Study of Parents and Children. In a 2013 study, researchers examined the effects of PAE on academic performance using a Mendelian randomization based upon the maternal variant in the alcohol-dehydrogenase gene that is considered to predict higher metabolism of alcohol that may result in lower prenatal alcohol exposure [116]. The results showed that moderate levels of alcohol consumption by women with higher incomes during pregnancy were associated with higher scores on cognitive and academic measures when compared to women who reported light drinking. In this study, women who had higher incomes reported moderate drinking during pregnancy when compared to women who reported light drinking. Additionally, better scores on cognitive and academic standardized tests were noted in children whose mother had the gene variant. The authors concluded that the children of mothers with the gene variant had lower exposure during pregnancy [116]. However, the findings reflected the influence of socioeconomic status and maternal education related to better outcomes on cognitive and academic achievement measures, possibly masking the impact of PAE [45, 116]. A later study examining the dosage, timing, duration, and patterns of maternal drinking during pregnancy applying Mendelian randomization showed clear effects of PAE on academic achievement after accounting for socioeconomic status [117]. These studies point out the need to screen school-aged children for the effects of PAE regardless of social and environmental factors to assess their educational needs. The impact of PAE on cognitive and academic functioning crosses socioeconomic status, race, and other demographic factors [116, 117].

Other studies have shown associations between heavy PAE and impaired cognitive processes impacting spelling and word reading. In 2015, Glass et al. examined spelling and word reading skills of children heavily exposed to alcohol in-utero as compared to a non-exposed contrast group [118]. The results indicated that children with heavy PAE had significantly lower scores on measures of word reading and spelling, phonological processing, and working memory when compared to the contrast group. Comparison of cognitive functioning between the two groups indicated that working memory uniquely contributed to spelling in the children with heavy PAE but not to the contrast group after accounting for the variance of phonological processing and speeded naming. Results indicated that working memory had a stronger relationship to performance on measures of word reading and spelling in children with heavy PAE when compared to the nonexposed contrast group. The authors surmised that a wider range of executive functioning problems may interfere with learning in children affected by heavy PAE [118].

In a recent study, researchers investigated structural and functional brain mechanisms that mediated word reading and phonemic decoding tasks in adolescents with PAE and dysmorphia as compared to a group of adolescents with PAE without dysmorphia, and a control group of typically developing adolescents without reported PAE [119]. The findings showed that adolescents with PAE and dysmorphia showed greater activation in the right precentral gyrus during the phonemic decoding task, and rightward lateralization in the inferior longitudinal fasciculus during both tasks. The study controlled for family socioeconomic status, intellectual abilities, other exposures, and diagnosis of ADHD. In the group of adolescents with PAE and no dysmorphia, activation in the left angular gyrus and white matter organization in the left inferior longitudinal fasciculus was associated with better reading skills; however, the association was weaker when compared to the controls [119]. Overall, the study indicated differences in brain structural characteristics and activation impacting sight word reading and phonemic decoding between adolescents affected by PAE with and without dysmorphia [119].

Across age-groups of children affected by PAE, studies have identified deficits in mathematics. In 2011, Rasmussen and Bisanz examined a range of mathematical skills in young children with and without FASD between 4 and 6 years of age. Children with FASD had lower mean scores on quantitative concepts, applied problems, and math reasoning when compared to a control group of children without FASD [120]. The findings indicated that phonological working memory was associated with performance on the mathematical tests for both groups with children with FASD showing significantly lower scores than the control group [120]. It is not clear from the article if there were group differences in intellectual abilities. The reported correlations suggested that children with FASD drew upon more aspects of verbal working memory that are associated with executive functioning when completing different mathematical tasks when compared to the control group [120]. In this study, there was no association between visuospatial abilities and mathematics.

Other studies have examined associations of cognitive processes and mathematics in children affected by PAE. One study conducted in 2015 examined whether attention, working memory, and aspects of visuospatial abilities would be associated with mathematical abilities in children with and without heavy PAE who were 7–12 years of age [89]. The children with heavy PAE had lower global mathematics achievement scores when compared to the non-exposed control group of children [89]. The findings indicated that after accounting for socioeconomic status and intellectual abilities, spatial attention and memory explained the variance in mathematics achievement scores of children with heavy PAE when compared to the non-exposed controls [89].

The deficits in mathematics associated with PAE continue into adolescence. In a 2006 study, adolescents affected by PAE scored significantly lower on measures of mathematical achievement when compared to adolescents who were exposed but had no effects and to a contrast group of adolescents who received special education services [67]. In a later study, researchers examined academic achievement in correlation with brain surface area in children ages 8–16 with heavy prenatal alcohol exposure to a control group of children with no reported prenatal exposure [90]. The results indicated that atypical brain development was associated with lower scores on mathematics in children with heavy prenatal alcohol exposure [90]. Mathematics is a life skill. Deficits in mathematics would hinder budgeting and managing money, interpreting, and following schedules, measuring for cooking, and other daily tasks [16].

Caregivers, Teachers, and Students with FASD Perspectives on School

Qualitative studies have interviewed caregivers, teachers, and students with FASD regarding their perspectives on school. Biological and non-biological caregivers expressed significant levels of stress advocating for services for their children with FASD. Caregivers reported being hesitant to disclose information about their children's diagnosis of FASD out of fear of being judged or shunned by school staff and classmates' families [27, 121]. Also, caregivers expressed frustration about educators' limited knowledge about the learning needs of their children with FASD [121, 122]. Some caregivers who had obtained school-based services reported they were inadequate addressing the needs of their children with FASD [34, 123, 124].

In other studies, teachers reported having little knowledge about the impact of PAE on learning, school functioning, and available resources [29, 35, 125, 126]. Some teachers stated that reports from clinical or diagnostic evaluations were hard to understand because they were written using medical terminology and provided little information that translated into classroom interventions [29, 122]. Many teachers reported being unaware of having students with FASD in their classes [126]. It is likely that teachers were unaware of students' diagnosis of FASD due to caregivers' reluctance to discuss the diagnosis for fear of stigma, poor communication between school staff, or possible oversight of incorporating medical and other diagnostic reports provided to the school into students' records [127].

Teachers have expressed frustration about having the time and the tools to address learning and behavioral challenges of children with FASD in the classroom [125, 126]. A study conducted in South Africa reported that teachers expressed feeling stressed working with children with FASD in the classroom [128]. Many of the teachers had received information about FASD; however, they stated that the training did not provide enough strategies to address the variability in learning and classroom behavior exhibited by children affected by PAE [128]. Other studies examining training for teachers and school staff about the impact of PAE on behavioral and learning showed positive impacts on supporting children with FASD in the classroom [37]. A quasi-experimental study conducted in British Columbia, Canada showed that teachers who received training about FASD adjusted their approaches to address learning and behavior difficulties of children with FASD in their classroom [37]. The findings showed statistically significant improvement in adaptive functioning in children with FASD. Though not statistically significant, possibly due to the small sample size, the research reported a moderate effect of teacher training on student's academic outcomes [37]. The results suggested that teacher training on the impact of PAE tailored for school settings may improve teacher interactions with students who have learning challenges related to FASD.

Few studies have examined students with FASD views on what helps them to feel successful and motivated at school. In a collective case study of eight adolescents with FASD who received special education instruction, parent support and advocacy, and appropriate academic expectations and instruction, as well as had positive peer or social networks contributed to their motivation to do well and graduate high school [33]. In another qualitative study, high school students with FASD receiving special education reported losing motivation when assignments and materials were either too easy or too difficult, and when the students perceived their teachers to show a limited understanding of their learning needs and were disengaged when providing instruction [123]. The interviews with adolescents with FASD indicated that a social network of peers and parent support were critical in maintaining students' persistence and motivation to complete school [29, 127]. In line with the literature on self-efficacy, realistic expectations, supportive caregivers and teachers, and a positive school environment influenced student motivation and self-efficacy leading to better outcomes in adolescents FASD [33, 35]. The findings from the qualitative studies provide a starting point to examine educational practices to improve the outcomes of children and youth affected by PAE.

FASD and Special Education Services

Survey and review studies have examined the prevalence of children and youth affected by PAE receiving special education services in Canada and other countries. However, there is limited information regarding the type and implementation of special education services and other interventions provided in school settings across nations. In a 2019 study, Popova et al. compared the prevalence of FASD among children and youth classified into special subpopulations, including incarcerated, special education, clinical care, state's care, and Aboriginal populations, to the global estimate of 0.77% from the general population [9]. The study estimated that between 7.58 and 8.81% of children and youth with FASD received special education services. The prevalence of FASD was estimated to be 10–40 times higher in the classified subpopulations when compared to the prevalence of FASD within the general population [9]. In an earlier study, researchers conducted a survey between 2011 and 2012 to estimate the number of Canadian children with FASD, ages 5–14, who received special education in public schools and the cost to provide the services [32]. Based upon completed surveys from two Canadian provinces, 6631 children out of 169,000 were identified as having FASD with an estimated cost of services of 53.5 million Canadian dollars [32]. In a subsequent study, other researchers examined the cost of care for individuals with FASD in Canada, Sweden, New Zealand, and the United States [129]. The estimated mean cost per year for special education services, based upon a review of seven studies, was

7177.00 United States dollars per individual with FASD [129]. The authors stated these are rough estimates in part due to FASD being underrecognized or misdiagnosed impacting surveillance [129].

Studies examining adverse outcomes associated with the effects from PAE have included information about participant's educational placement [20, 67]. In the 1996 summary report by Streissguth et al. 40% of the participants with FAS or affected by PAE reported receiving special education services. The report indicated 65% of the participants with FAS or affected by PAE received interventions to address problems with reading and mathematics, with only 30% receiving interventions to improve functional and life skills [20]. It is not clear in the summary if the reported remedial interventions were special education services or provided through other school programs. In a 2006 study of adolescents affected by PAE, approximately 28% of adolescents with facial features and cognitive impairments, and 16% without facial gestures but cognitive impairments received special education services [67]. For the adolescents with PAE and facial features approximately 11% were eligible for special education services under classification of mild intellectual impairment, 6% were eligible under dual categories, 4% eligible due to identified learning disabilities, 2% eligible for speech or language impairment, and 2% eligible under the classification of moderate intellectual impairment [67]. For the adolescents with PAE without facial features, 5% were eligible for special education services under the classification of mild intellectual impairment, 4% were eligible under emotional or behavioral disorders, 2% were eligible under the classification of learning disabilities, 1% were eligible under the classifications of speech or language impairment or dual category, respectively [67]. A combination of the educational regulations and the variability of needs of school-aged children affected by PAE make it challenging to identify the number of children with FASD who receive special education services and the types of interventions that are effective.

Individuals with Disabilities, Regulations, and Schools

Influenced by civil rights legislation from the 1950s to the mid-1960s, the United States enacted laws to protect the rights of individuals with disabilities. Section 504, Rehabilitation Act, of 1973, as amended in 29 USC § 794 (Section 504), prohibits discrimination against individuals with disabilities by organizations and programs that receive federal assistance [130]. Subsequently, the Americans with Disabilities Act of 1990 and the Amendment Act of 2008 expanded the protection of rights and equal access across public entities of individuals with disabilities and their families regardless of receiving federal funding. These anti-discriminatory laws work alongside the Individuals with Disabilities Education Act (IDEA), which authorizes funding and guides implementation of special education programs and services for infants and school-aged children through secondary school, to protect the rights and ensure services for children and youth with disabilities [130, 131].

Other nations have implemented regulations to protect the rights of individuals with disabilities and provide intervention services. For example, in the United Kingdom, the Special Educational Needs and Disability Act, updated in 2014 outlines the definition of a disability and allocates a continuum of supports for individuals from birth to 25 years of age [132]. However, the implementation of special education services varies within each country of the United Kingdom [132]. Australia passed regulations including the Disability Discrimination Act of 1992 and the Disability Standards for Education in 2005 that provided a definition of a disability, protects the rights of individuals with disabilities, and ensures they receive appropriate instruction and supports to learn in school [133]. Kenya has established policies and frameworks to provide students with disabilities special education services and to remove barriers accessing the services [134]. Due to international efforts of many countries, including Kenya, upholding the United Nations Convention on the Rights of Persons with Disabilities, other nations have established policies to ensure children with disabilities opportunities for equitable and inclusive educational opportunities [135]. For this chapter, the education regulations for the United States in relation to the needs of school-aged children with FASD are discussed.

Definition of Disability

The Americans with Disabilities Act and Section 504 have a similar and broadly defined classification of an individual with a disability [130, 131]. The definition in the Americans with Disabilities Act and Section 504 differs from other legislation granting services and support for individuals with disabilities such as Supplemental Security Income (SSI) or eligibility for special education services. Because Section 504 pertains to entities that receive federal assistance, including the United States Department of Education, schools use their definition when determining whether a student has a disability and is eligible for protections under the law [130].

The disability definition in Section 504 includes physical and mental impairments that significantly impact daily functioning. This would include the effects of PAE. In the law, a physical impairment includes but is not limited to cosmetic disfigurement, or anatomical loss of one or more bodily systems such as neurological, musculoskeletal, cardiovascular, endocrine systems, or impairments with sensory organs [130]. The law provides examples of mental impairments including intellectual disabilities, learning disabilities, mental health disorders, and emotional disorders that substantially interfere with daily activities [131]. The law defines major life activities as actions needed for daily tasks, such as caring for oneself, hearing, seeing, communicating, learning, and working. This includes bodily functions such as breathing and walking [131]. Multiple sources of information are considered to determine if a student has a disability. Medical conditions in remission or improved through treatment or devices does not exclude an individual from meeting the definition of having a disability [130, 131].

Section 504 and Schools

Section 504, 34 CFR Part 104 applies to the education of students with disabilities. The law authorizes students with disabilities equal access to education and opportunities to participate in extracurricular activities with non-disabled peers [130]. To ensure equitable education, Section 504 entitles access to general or special education, support, services, and aides to address the individual needs of students with disabilities [131]. This ensures that students with disabilities have equal opportunities to participate in school-sponsored activities without exclusion, harassment, or bullying because of a disability [131]. Educational entities that receive federal funding are required to comply with Section 504. This includes preschools, public schools, post-secondary schools, adult education programs, and afterschool programs that receive federal assistance from the United States Department of Education [131].

According to Section 504, students with disabilities are to have a free and appropriate education (FAPE) regardless of the severity of the disability [130]. This means that students with disabilities are to be educated with students who are not disabled to the extent possible given their educational needs [130]. The law stipulates periodic evaluations and case reviews to safeguard against misidentification of students with disabilities that might lead to improper educational placement. The law provides students, caregivers, advocates, and monitoring agencies steps to file grievances in cases of noncompliance [131]. The Office of Civil Rights receive the complaints and initiate corrective action [131]. Section 504 does not allocate funding or enforce the implementation of special education programs [130].

In schools, a Section 504 Team is convened to review information when determining if a student's impairment substantially limits functioning in any major life activity regardless of mitigating factors that may offset the impact. A student's high grades or academic performance may not be used to deny 504 accommodations if there are substantial limitations on other life activities [130]. If a student is identified as an individual with a disability under Section 504, then accommodations are provided to ensure equal access to educational opportunities and extracurricular activities. The accommodations, aides, and support must not place undue financial, administrative, or instructional burdens on schools or programs [131]. In some cases, the Section 504 Team may refer the student for consideration for eligibility of special education services as outlined by IDEA [136]. Identification as an individual with a disability does not guarantee that the student is eligible for special education services. If a student is found ineligible for special education services but is identified as having a disability according to Section 504, the student may continue to receive accommodations [130]. Accommodations through Section 504 may be provided throughout an individual's formal educational and into employment [137]. Regarding public education, Section 504 works in coordination with IDEA to meet the educational needs for students until twelfth grade or until their 22nd birthday [137]. A comparison of Section 504 to IDEA is presented in Table 16.1 [138].

Table 16.1 Comparison of Section 504 and IDEA [131, 136–140]

	Section 504 of the Rehabilitation Act of 1973	Individuals with Disabilities Act (2004)
Governmental department	Office of civil rights	United States department of education
Funding provisions	None	Provides federal funding for special education programs for students up to 21 years of age if their 22nd birthday occurs during the summer break, or to their 22nd birthday if it occurs during the school year
Definition of disability	Physical or mental impairment substantially impacting major life activities	Exceptional learners, sometimes including those who are gifted and talented, who exhibit a disability impacting their educational performance
Age-groups	All ages	Infants, children, and youth (0 through to 22nd birthday)
Key elements	Protects the rights of individuals from discrimination based upon their disability Grants access to general education, special education, accommodations, and modifications to ensure equitable educational opportunities of individuals with disabilities Procedures for nonbiased evaluations to determine a disability Safeguards and procedures to ensure appropriate placement and to file grievances	Outlines procedures, including nonbiased evaluations, to identify students in need of specialized instruction, modifications, accommodations, and related services Individualized Education Program (IEP) states the eligible student's instructional goals, objectives, placement for instruction, and related services Provides for instruction in the least restrictive environment Ensures caregiver and when appropriate student participate in decisions Procedural safeguards for caregivers to access to records, participate in school decisions, and provide due process if disagreement or concerns of noncompliance
Free and Appropriate Education (FAPE)	Grants access to general education or special education, accommodations, modifications, services to meet the student with a disability need. Ensures the student with a disability participates with peers without disabilities to the extent possible	Provides special education and related services to eligible students to ensure their educational needs are met to receive a free and appropriate education
Applicable organizations	Educational entities and programs that receive federal assistance. This includes preschools, k-12 public schools, afterschool programs, colleges, and employment	Public schools up to 12th grade, or student's exit from public school if remain until 22nd birthday

The Individuals with Disabilities Education Act (IDEA)

In the United States, special education services for school-aged children are guided by Individuals with Disabilities Education Act (IDEA) Parts B and C and Every Student Succeeds Act of 2015 [141]. Table 16.2 provides a timeline of legislation for school services for children with disabilities.

Table 16.2 Timeline of legislation related to special education services [139, 141–144]

Year	Legislation	Provision summary
1965	Elementary and Secondary Education Act (Pub. L. 89–10)	Funding states to close the achievement gap
1974	The Family Educational Rights and Privacy Act (Pub. L. 93–308)	Commonly referred to as the "Buckley Amendment" established maintain privacy and confidentiality of students and their families. Provided legal guardians the right to examine and challenge school records if they feel they are inaccurate. Protects from release of personally identifiable information to third parties including special education records and Section 504 documentation without consent from legal guardian, parent, or student if reached the age of majority. Transferred rights to the individual with a disability at the age of majority
1975	Education of All Handicapped Children Act (Pub. L. 94–142)	Established free and appropriate education for students with disabilities Mandated Individualized Education Plan (IEP) for students receiving special education services Incorporated caregiver involvement in the education of children with disabilities Established students with disabilities are to be educated in the least restrictive environment. Allocated educational-related services for elementary and secondary school students with disabilities
1986	Amendment to the Education of All Handicapped Children Act (Pub. L. 99–457)	Mandated states to provide services for infants, toddlers, and preschool children with disabilities or at risk for disabilities and not included in the 1975 Education of All Handicapped Children act
1990	Individuals with Disabilities Education Act (Pub. L. 101–336)	Reauthorized the Education of All Handicapped Children Act of 1975. Changed the name to the Individuals with Disabilities Education Act (IDEA). The name used first-person language reflecting changes through advocacy to increase inclusion of individuals with disabilities Expanded the definition of disability and eligibility categories to include autism and traumatic brain injury Mandated transition plans included in IEPs for students with disabilities by age 16
1997	Amendments to the Individuals with Disabilities Education Act (Pub. L. 105–17)	Significant changes regarding disciplining and protecting children with disabilities at school. It is mandated that IEPs must include methods to measure student progress

Table 16.2 (continued)

Year	Legislation	Provision summary
2001	Elementary and Secondary Education Act, no child left behind (Pub. L. 107–110)	Financial resources allocated through Title I for school districts to improve access to quality education for low-income schools. Established schools needed to make Adequately Yearly Progress (AYP) to show student progress with steps provided if AYP was not met. Provided options for parents to move their child to another school if the child attended a school that was considered failing. Allocated supplemental instruction for students who attended schools that were on the "failing list" for 3 years. Linked academic content to standardized testing. Provided criteria for teachers to be considered fully qualified to instruct students Required schools to use scientifically based research to guide programs and instruction. Led to the unsuccessful attempt to establish national academic standards known as Common Core
2004	Individuals with Disabilities Education Improvement Act, (reauthorization of IDEA) (Pub. L. 108–244)	Changed the law to improve the quality of special education and increase academic expectations of students with disabilities to align to the No Child Left Behind Act. Moved to have special education instruction closer to grade level standards. Instruction and interventions must be peer reviewed and scientifically based Data-driven progress monitoring to measure response to the instruction. Allocated steps to prevent overidentification of students in need of special education services because of race or ethnicity. Mandated the IEPs must include measurable annual objectives
2015	Every Student Succeeds Act (Pub. L. 114–95)	Reauthorized the Elementary and Secondary Education Act of 1965, and replaced No Child Left Behind. The law requires every state to measure student performance in reading, mathematics, and science. Each state is required to publish an online report card providing information about each state's educational outcomes, graduation rates, student suspensions, and teacher qualifications. Requires each state to provide the average cost to educate students. Allocates flexibility for states to invest in career and technology education and other student needs. This act is linked to IDEA. It mandates that each state must ensure all children with disabilities are included in state and district assessment programs including those mandated Every Student Succeeds Act. This includes providing appropriate accommodations and alternative assessment

The Individuals with Disabilities Education Act (IDEA) Part B states the provisions of special education services for school-aged children from 3 years of age to 21 years of age. IDEA Part C states the provisions for intervention services for infants and toddlers, from birth to 2-years of age [142]. There are differences between IDEA Part B and IDEA Part C. Some of the differences are described in Table 16.3.

The purpose for IDEA Part B is to ensure that all children with disabilities receive a free and appropriate education with specialized instruction and related services to meet their needs and monitored under public supervision and direction

Table 16.3 Examples of differences between Parts B and C of the Individuals with Disabilities Act [139–143]

IDEA Part B (2006) 34 CFR Part 300 School-aged children 3–21 years of age	IDEA Part C (2011) 34 CFR Part 303 Infants and Toddlers 0–2 years of age
Special education and related services for eligible students	Early intervention services for infants and young children with identified medical, health, and developmental disabilities
Address impact on learning and school through the Individualized Education Program (IEP)	Address impact on development through the Individual Family Service Plan (IFSP)
No mandated coordination of services with community providers	Allocates coordination with community-based agencies and providers
Services provided on a continuum in the least restrictive environment at school	Established minimum of services. Services may be provided in the home, community, or clinic
Both Parts B and C mandate child find, a system to locate and identify children with disabilities in need of services	

[143]. IDEA outlines requirements for use of funding for special education services. It mandates evaluation procedures, eligibility criteria, and exceptions for determining students' eligibility for special education and related services [143]. If a student is found eligible for special education services by the eligibility team, a written plan, the Individualized Education Program (IEP), is developed. The IEP provides an overview of the students' learning strengths and challenges, annual learning goals and coordinated objectives, the types and amount of instructional and related services, settings where the services are provided. Methods to monitor progress, and transition services if the student is at least 16 years of age. The IEP is developed by a team that consists of school personnel, the students' caregivers, and their invitees of other individuals who have knowledge of the students' learning needs. In some cases, the student may be present at the IEP meeting if found appropriate. In addition to program planning, IDEA ensures parental and student rights, procedural safeguards, enforcement to compliance, and steps for due process [141].

The definition of a student with a disability and need for services outlined in IDEA differs from Sect. 504 of the Rehabilitation Act of 1973 and Title II of the Americans with Disabilities Act of 1990. According to IDEA Part B, there are 14 categories used to determined eligibility for special education and related services [141]. A student may be found eligible for services in more than one category. Table 16.4 presents the exceptionalities or eligibility categories, a brief description of each category, and applicable exclusionary factors [138, 141].

To be found eligible for special education services, IDEA mandates that multiple sources of information are considered including students' schoolwork, teacher notes, observation data, performance on school administered assessments, results from psychoeducational evaluations, and medical documentation [141]. Also, evaluations and information from private providers working with a student may be presented for consideration [141].

The law indicates that students would not be considered eligible for special education services if the issues to learning challenges are related to the lack of receiving

Table 16.4 IDEA eligibility exceptionalities [136, 138, 141]

Disability/ exceptionality	Description
Autism	A developmental disability impacting verbal and nonverbal communication and social interaction. Impairments are present before age 3 and impact educational performance. Does not apply if the child has an emotional disturbance that is not related to the disorder
Deaf blindness	Combination of vision and hearing impairments that significantly interfere with communication and other educational needs that cannot be addressed in special education programs for children with only deafness or blindness
Deafness	Impairment in processing linguistic information aurally with or without amplification adversely impacting educational performance
Emotional disturbance	Shows one or more traits of emotional or behavioral disturbance over a long time, harming school functioning. These traits are (1) the inability to learn that cannot be explained by intellectual, sensory, or other health factors; (2) the inability to build or maintain appropriate interpersonal relationships with teachers and classmates; (3) exhibits inappropriate types of behaviors or feeling within every circumstance; (4) shows pervasive depression or unhappiness; and (5) exhibits physical symptoms or fears associated with school problems. Schizophrenia is included within this exceptionality. However, children who are socially maladjusted are excluded unless otherwise identified
Hearing impairment	Fluctuating or permanent loss of hearing impacts educational functioning. This excludes those who meet criteria for deafness
Intellectual disability	Impaired intellectual abilities and adaptive behaviors often noted in early development adversely impacts school functioning
Multiple disabilities (does not include deaf blindness)	Refers to co-occurring impairments (e.g., intellectual disability and blindness) that significantly impact educational performance and cannot be addressed in special education programs that are designed for only one of the impairments
Orthopedic impairment	Severe bone or muscle conditions that often are related to congenital anomalies, disease, or other medical complications adversely impacting educational performance
Other health impairment	Chronic or acute medical conditions that limit strength, vitality, alertness in an educational setting, and impact educational performance
Specific learning disability	A disability in one or more underlying psychological processes that may interfere with listening, thinking, reading, writing, spelling, and mathematics. Students who have learning difficulties related to vision, hearing, motor, intellectual impairment, emotional disturbance, environmental, cultural factors, including limited English language proficiency, or economic disadvantage are excluded
Speech or language impairment	Impairments in aspects of language and communication including articulation, stuttering voice impairment, receptive language, expressive language, that adversely impacts educational performance

(continued)

Table 16.4 (continued)

Disability/ exceptionality	Description
Traumatic brain injury	Brain injury caused by an external physical force resulting in total or partial functional disability, psychosocial impairment or both having a detrimental impact on school functioning. This does not include congenital brain injury, injury from a trauma at birth, or degenerative diseases impacting the brain
Visual impairment including blindness	Impaired vision that adversely impacts educational performance even with correction. Includes partial sight and blindness
Significant developmental delay (only for children ages 3–9)	Young children identified using appropriate diagnostic measures and procedures as having a delay in development in one or more of the following areas: physical development, cognitive development, communication, social-emotional, behavior, and adaptive functioning in need of special education and related services

scientifically based instruction for reading, lack appropriate instruction for math, or if the student has limited English proficiency [141]. In some cases, before determining a student requires special education services, notably for Specific Learning Disability, schools would implement a multi-tiered system of support (MTSS) including response to intervention (RTI) and positive behavioral interventions and supports (PBIS) [141, 145]. This provides multiple tiers of evidenced-based or research-based interventions that increase in intensity according to students' responses to the interventions [145]. Students are referred for consideration for special education services if they show little-to-no progress in response to the interventions [145]. The purpose for MTSS is to prevent misidentification of a student as having a learning disability [143]. There are criticisms about the implementation of MTSS. For example, the implementation of MTSS varies across states and school districts, and often the intervention plans do not clearly define objectives or use appropriate interventions and methods to monitor progress [145].

According to IDEA, special education services are provided on a continuum. Students with disabilities are to be educated within a setting closest to the general education environment to the maximum extent with non-disabled peers [144]. The separation of students with disabilities should only occur when the severity of the disability impedes the student's learning in lesser restrictive settings despite receiving accommodations and other supports [141, 144]. Many students with disabilities are educated in inclusion classes with instruction provided by a general education teacher in coordination with instruction or support through special education [146]. Some critics have suggested that this undermines the purpose for special education by limiting access to specialized interventions and adjustments to materials that some children require [146, 147]. However, many students with disabilities do well in inclusion settings when instruction is on their learning level, and they receive the necessary supports [135].

FASD and IDEA

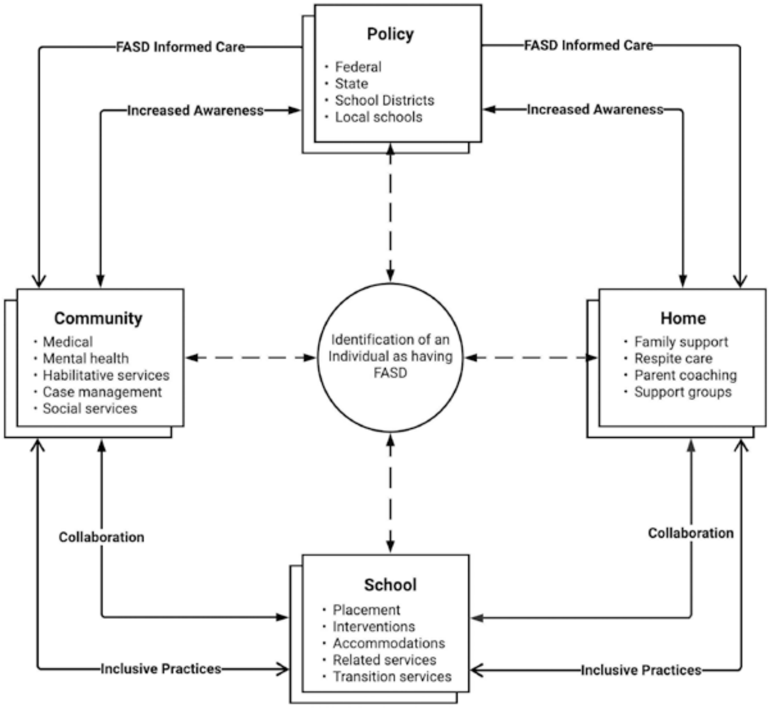
Given that FASD encompasses the medical and clinical diagnoses of FAS, pFAS, ARND, and ND-PAE, some children with an alcohol-related diagnosis are found eligible under Other Health Impairment (OHI). Other school-aged children with FASD may be found eligible under one or more of the other exceptionalities. Children who have a medical diagnosis but found ineligible for special education services may continue to receive support through a 504 Accommodation Plan or receive supplemental instruction or support that is not funded through IDEA such as Title I early intervening services [141]. The availability of supplemental educational programs vary by school district.

At this time, FASD is not a specific eligibility category listed in the federal IDEA regulation. Advocates are working on the national and state levels to increase awareness, change policy, and improve services for individuals with FASD. In 2021, the FASD Respect Act, to reauthorize and expand funding to increase prevention efforts, research, screening, and identification of FASD was introduced to the 117th United States Congress; however, it was not brought before Congress for a vote by the end of session [148].

In Alaska and California, advocates have had success obtaining recognition of FASD as a medical condition under the exceptionality of OHI for their respective states [149–151]. In addition, Alaska has mandated that all new teacher hires are required to receive training about the impact of FASD [151]. These are steps toward increasing awareness and access to services to improve educational care and outcomes of students affected by PAE.

Educational Care for Individuals with FASD

Educational care for individuals with FASD requires collaboration at the national, state, and local levels to increase awareness, training, research, and access to interventions and supports. For example, systematic efforts to increase public awareness and prevention would help to remove barriers such as social stigma. Regarding research, including FASD within studies examining prevalence or other topics related to developmental disabilities would expand the body of research increasing dissemination of information. Also, providing well designed and inclusive research about FASD would aid in dismantling inaccurate perceptions. Changes in policy, public perception, and approaches to research is only one part of inclusive practices to improve educational care of individuals affected by PAE. Collaborative efforts between educators, caregivers, allied health professionals, and individuals with FASD at local levels are needed as well. A conceptualization of educational care for individuals affected by PAE is presented in Fig. 16.1 [38, 152].



Note: Educational care for school-aged children with FASD requires collaborative efforts among policy makers and stakeholders, medical and community providers, caregivers, and with individuals with FASD (35-36, 38). Policy is needed to increase awareness, disseminate accurate information, and expand access to necessary services (27-28, 38,128). To provide FASD-informed care, policy makers, school administrators, educators, community providers, and caregivers would benefit from training related to their roles in the care of individuals with FASD (35, 36, 122, 128). Educational care requires collaboration between educators, caregivers, allied health professionals, and if developmentally appropriate, the individual with FASD are needed (109-110, 123, 125, 153, 155, 157). This is to provide a collaborative effort to ensure appropriate placement, instructional approaches, related services, accommodations, and transitional plans to improve educational outcomes (153, 155, 162).

Fig. 16.1 Educational care for individuals with FASD

Policy for FASD-Informed Educational Care

The success of advocacy efforts in the states of Alaska and California may be blueprints to expand recognition and training requirements for teachers and others working with children with FASD. The inclusion of FASD in educational regulations and recognized by school systems would provide opportunities to survey and monitor educational trajectories and outcomes. In addition, given the reported prevalence of FASD as 1–5% of school-aged children, with some regions having higher rates, the disorder should be included in research and other policy discussions related to developmental disabilities [5, 30]. This would contribute to disseminating accurate information, open discussions about the disorder, and increase funding to expand opportunities for intervention research to improve educational outcomes.

Currently, training and information about resources for FASD provided in college teacher training programs and professional development within school districts is inconsistent [99]. Incorporating information about FASD into teacher training programs and professional development would be critical to ensure that educators are able to provide the necessary instruction and support to students [29, 35, 36].

Training for Allied Health Professionals, School Personnel, and Caregivers

Studies have shown that providing allied health professionals, educators, and caregivers training about the impact of PAE on development improves managing behavioral and learning needs of children affected by PAE [103, 110]. For professionals and caregivers, training would need to include information about the range of neurodevelopmental deficits attributed to PAE, the complexity of needs, and evidenced-based interventions [37, 153, 154]. As part of the training for allied health professionals and educators, it would be important to discuss how to maintain confidentiality because of sensitive health information. This includes learning how to discuss educational concerns with caregivers who might be sensitive about their children's diagnosis of FASD [124]. Providing quality training would contribute to dispelling misinformation about FASD and facilitate collaboration between caregivers, educators, and allied health providers [34, 124, 153].

For caregivers, training would need to increase their understanding of FASD and how to advocate for their children's needs. Parent training programs such as Families Moving Forward have been found to help caregivers reframe their perceptions of their children's behavior in relation to neurodevelopmental deficits associated with PAE, facilitate positive interactions with their children, and learn to meet the needs of the family [155]. Other intervention programs have incorporated parent training components. For example, researchers provided caregiver training on FASD and how to advocate for their children as part of the Math Interactive Learning Experience (MILE) [110, 111]. For the study, caregivers attended two workshops covering FASD, neurodevelopment, and managing their children's behavior [110]. Incorporated into the training was an overview of IDEA, types of special education services, and other supports children with FASD may require. Caregivers reported they benefitted from the training [110]. To ensure caregivers have tools to advocate for their children with FASD, training would need to include information about educational regulations, limitations of school-based services, and other avenues to obtain services [110, 155]. Also, training would need to include components on how to communicate effectively with schools and educators [34]. Providing caregivers with tools to understand and describe their children's needs might lessen their feelings of frustration and misunderstandings that could lead to potential conflicts with school personnel [156].

Educational Planning for the Individual with FASD

Educational planning begins with a comprehensive evaluation to discern the effects from PAE from other developmental and learning disorders to provide an accurate diagnosis [24, 154]. The evaluation would need to assess cognitive abilities, adaptive functioning, behavior, social-emotional status, and academic achievement [2]. The report from the evaluation would need to be written using terms that caregivers, educators, and other professionals are able to understand [122]. Also, reports would need to discuss the individuals' relative strengths and deficits impacting learning and school functioning [157]. Discussions about individuals' learning strengths and challenges are necessary to guide educational planning [157]. The report recommendations addressing learning and school functioning need to be applicable to the educational setting [29, 122]. This requires the evaluator to understand educational regulations, schools' implementation of special education services, accessibility to supplemental instruction and accommodations that are not part of special education, and the limitations of school service. In some cases, it may be more appropriate for families to seek services from community providers rather than through the school system [156].

Explaining Learning Needs

It is important for caregivers to understand and clearly describe the learning needs of children and adolescents with FASD when advocating for school services. This would include providing caregivers a framework and terms to discuss abilities, or learning strengths, and challenges of their children with FASD when meeting with educators [157]. One framework is the Functional Abilities Classification Tool (FACT) [158].

FACT was developed to be used by allied health professionals, special educators, other clinicians to summarize information gathered from medical records, developmental and psychological evaluations, school records, and student and caregiver input to describe children's functioning and participation in their educational setting [158]. It is based upon the International Classification Functioning, Disability, and Health, Children and Youth (ICF-CY) that considers abilities in terms of participation and engagement in the environment [10, 159]. The ICF-CY refers to disabilities as impairments that restrict engagement and participation. The ICF-CY views the environment as a source of support or barrier to meaningful participation across settings [159]. FACT integrated this perspective into a framework to assist with educational planning [157]. It considers student behaviors as signals indicating that the student may not be receiving the necessary level of interventions or supports or may be mismatched to the classroom expectations or setting for learning [158].

The tool defines abilities as the functions needed to complete or execute a learning task, in areas of verbal communication, literacy, visual cognitive, social skills, executive functioning, and self-regulation [158]. These abilities are rated on a scale of 1–4, with 1 indicating abilities within normal limits or similar to age-matched peers, to 4 indicating that significant modifications are required to ensure learning [158]. FACT defines students' participation as meaningful engagement or participation in structured and unstructured settings that commonly occur in schools. The school settings include individual work, multi-stepped tasks, group work, teacher directed group work, unstructured group work, structured physical activity, such as physical education class, and unstructured physical activities, such as recess. Participation is rated on a scale of 1–4, with 1 indicating the individual engages and participates similar to classmates, and 4 indicating very low quality and frequency of meaningful participation to no engagement [158]. Student perspectives about what they find helpful and challenging at school are incorporated into the summary [158]. The ratings and the student input are summarized to described children's quality of engagement and learning across different school settings and activities. Considering students' learning in terms of the quality and frequency of participation is useful to describe the variability of functioning across settings often noted in school-aged children affected by PAE [1]. This would assist in clarifying the needs of the individual with FASD.

Though FACT may be a useful framework when considering the learning needs of school-aged children with FASD and other disabilities, there are reservations. Studies need to be conducted to examine the tool's validity and reliability. Also, the definitions and constructs need to be reviewed. The tool is subjective and relies on the accuracy of records [158]. Regardless of the tool's limitations, it is a useful framework to consider educational needs by focusing on the individuals' abilities and barriers to learning rather than a diagnostic label. Also, it provides common terminology that may be used by caregivers and others to describe children's learning needs to facilitate negotiations to obtain services.

Educational Placement

As outlined in IDEA, eligibility and special education services including class placement are based upon the needs of the individual [141]. Some children and adolescents with FASD who have significant cognitive impairments or emotional and behavioral needs might benefit from placement in a more restrictive setting such as in a small group, special education class [160]. This is to provide the necessary supervision and highly specialized instruction, such as applied behavioral analysis to improve functional skills, or other interventions that could not be implemented in a larger group setting. Others with FASD do well in inclusion settings or general education settings with accommodations [100]. Educational placement of school-aged children with FASD should be based upon the appropriateness of the classroom and learning expectations to ensure they are maintaining meaningful participation, gaining skills, and interacting with peers in their instructional and school settings [152, 160].

Transition Planning

Given the risks for poor educational outcomes and transition to adulthood experienced by many with FASD, specific plans to move from high school to post-secondary school training are necessary [66, 69, 161]. IDEA mandates that by 16 years of age, the IEP must have a transition plan. However, best practices suggest that it is beneficial to begin when a student is 14 years of age or entering the ninth grade [162, 163]. Also, IDEA indicates that individuals with disabilities may remain in school until their 22nd birthday. For students with FASD and other disabilities, transition planning needs to consider if they should remain in school until the age limit [164].

The purpose for a transition plan is to improve academic and functional skills in preparation to enter post-secondary school activities such as furthering education, participating in vocational training, or entering supported employment or other community programs [163]. A person-centered planning model focusing on the students' strengths and interest is implemented when devising transition plans [164]. This approach not only consider the students' affinities and interests, but also their cognitive, academic, and adaptive functioning to create goals and objectives [164]. Often a vocational assessment is required to evaluate these skills [163]. The assessment would need to examine prevocational and functional skills in addition to surveys to determine the students' interests. Based upon the gathered information, realistic goals and objectives need to be developed to not only improve academic skills but also to build self-determination, or the skills to manage daily life [164]. As part of building self-determining, instructors would need to work with students with FASD to become aware of their strengths, challenges, and interests and set their own goals and objectives [164]. Other objectives to improve adaptive functioning, problem-solving, self-advocacy, and making appropriate social judgments would need to be considered [161, 164]. Transition plan objectives need to be clearly defined, systematically reviewed, and adjusted as the student gains skills [162].

In addition to goals and objectives, a range supports provided at school or in the community may be considered to ensure completion of secondary school and preparation for post-secondary school activities [161, 162]. For example, students might work with mentors, graduation coaches, or school liaisons from vocational rehabilitation programs to complete all prerequisites needed to enter post-secondary school activities. The transition planning team might consider if medical, mental health, social services, and legal advice are needed to make sure the necessary paperwork is correctly completed and submitted so that benefits and other services may be accessed when students reach the age of majority [161]. Also, providing information about peer groups and other social and recreational activities should be included as part of developing their support system [162]. Because of the long-term impact of PAE, many individuals with FASD require support throughout adulthood.

Related Educational Services

Some school-aged children with FASD may require educational-related services to address hearing and vision impairments, weaknesses with speech and language, problems with motor functioning, and other areas [1]. In accordance with IDEA, students who are found eligible may be provided educational-related services at no cost to the caregivers [141]. Examples of school-based services include speech and language therapy, occupational therapy, physical therapy, and assistive technology. Also, students with FASD may benefit from school supports that may not be funded through IDEA. These may include social skills training, afterschool tutoring, or participating in afterschool programs [156]. Availability of these programs vary by school district. In some cases, it may be necessary to seek services from the community or private providers [100].

Individualized Interventions for Children with FASD

There are interventions to improve learning readiness, self-regulation and executive functioning, behavior, as well as early literacy and mathematical skills in children affected by PAE [110, 111, 165]. Many of these interventions are for children 3–12 years of age [165, 166]. There has been little research examining learning challenges and interventions for older school-aged children with FASD [166]. Also, there is little research on the impact of FASD and interventions for academic skills such as expressive writing, reading comprehension, notetaking, or content areas such as history and science [99, 165, 166]. Though studies have shown that children affected by PAE have responded to interventions through serious computer games targeting specific skills, there is little information about the impact of virtual or online learning in comparison to traditional classroom instruction [102, 103]. These are areas for future research to understanding and address the learning needs of school-aged children with FASD.

Research showed that that effective interventions for individuals with FASD share similar traits. The focus for interventions was to build skills by addressing the underlying cognitive deficits mediated by the individuals' relative strengths within the context of a learning or an everyday task [110]. The intervention activities were developmentally appropriate and on the children's learning level [166]. The interventions also focused on changing children's inefficient thinking patterns and improving problem-solving approaches rather than recall of isolated skills [165, 166]. Recognizing common elements of interventions effective for individuals with FASD would be useful to select methods found effective from other learning disorders to address learning challenges associated with PAE [156].

Researchers have examined programs to address challenges with self-regulation and executive functioning associated with the effects of PAE. These interventions may be implemented within a school setting. The Alert Program is used by many occupational therapists to improve children's self-awareness of their arousal level and to use strategies to modify their behavior when they become overwhelmed [167]. Results from studies using this program with children with FASD, between 6 and 12 years of age, have shown improvements with regulating emotions, problem-solving, and with attention [156].

Another program specifically designed for children with FASD, 5–10 years of age is GoFAR [102, 103]. The program used a serious computer game, parent training, and therapeutic sessions with caregivers and their children to improve self-regulation and adaptive behaviors [103]. A key component of GoFAR was to teach children to use the Focus/plan, Act, and Reflect (FAR) framework to approach and systematically work through problems. For each task during the computer game and therapy sessions, children were cued to focus and plan before starting the activity. This directed the children to look at all the information, think about what they are to do, and gather the materials needed to complete the tasks. With this information, the children devised a plan to complete the activity. After making the plan, the children work through the task. They verbalized what they were doing as they completed each step of the task. This was to increase engagement and awareness of their actions. Upon completion of the task, the children reflected upon their actions by recall what they did. The results from the GoFAR studies indicated that children who received the training showed decreases in disruptive behavior, made improvements in their sustained attention, and showed gains in their adaptive skills [102, 103]. The FAR approach is based upon the Plan-Do-Review strategy implemented in the High Scope early childhood programs and is reported to improve children's approaches to solving problems [110]. Similar approaches are used in the Strategies for Enhancing Early Developmental Success (SEEDS) preschool program. Results from a recent case study indicated that program has shown promise to improve parent engagement, self-regulation, and early literacy skills in young children with PAE and involvement with the child welfare system [168].

Academic interventions to improve early reading and mathematics in children affected by PAE have been examined. The Language and Literacy Training program was developed to improve early reading and phonetic skills in young children affected by PAE 9 years of age. The study was conducted in South Africa [169]. Findings from the study indicated that children who received the literacy training made gains in letter knowledge, phonemic awareness, sound-to-symbol association or decoding, spelling, and naming objects and categories. However, there were no group difference between children who received the literacy training and the control group on the overall measure of academic achievement [169].

The Math Interactive Learning Experience (MILE) was developed to improve learning readiness and early mathematical skills in children with FASD 3–10 years of age [110, 111]. Specific instructional approaches were used to address weaknesses with visuospatial processing, encoding, graphomotor skills, working memory, and executive functioning. For example, to improve executive functioning and problem-solving approaches, children were taught to use Focus/Plan, Act, Reflect (FAR) approach used later in the GoFAR study [103, 110]. Through mediated exchanges, children were guided to construct their understanding of the mathematical skills. Carefully selected manipulatives, such as small blocks, were used to provide concrete demonstrations of the skill or concept. As children worked through tasks, they verbalized how they solved the mathematical problems. Once children demonstrated proficiency solving problems using the manipulatives, the instructor directed the children to transform the information into written symbols [110]. Parents were provided direction and activities on how to work with their children at home on the mathematical skills. Results from the study indicated that children made gains on standardized measure of mathematical achievement that were evidence 6 months after participating in the intervention [111]. A study in Canada implemented MILE with children with FASD, 4–10 years of age [170]. The researchers did not incorporate the parent training component. The findings indicated that children who participated in the intervention made gains in their mathematical skills. Specifically, children who were prenatally exposed to alcohol but did not have an FASD diagnosis, who were at the older end of the age range of the study, and had lower intellectual abilities showed greater changes in their mathematic achievement score [170]. The results from MILE indicate that teaching approaches were effective to improve learning readiness and a specific skill deficit that associated with the effects from PAE.

Other studies have examined ways to improve skills related to working memory [171]. Children with FASD, 4–11 years of age, were taught rehearsal strategies to retain information. Children were assigned to either the rehearsal training group or to a control group that did not receive training. A digit span measure requiring the participants to remember strings of numbers that gradually increased in length as the items proceeded were administered to children in each group. Results indicated that both groups performed similar on the digit span measure at the pre-test and at the first post-test. The children who received the rehearsal training performed better than those who did not receive training at the second post-test. The authors concluded that teaching children rehearsal strategies would help to support working memory difficulties in school-aged children with FASD [171].

In addition, many children with FASD are reported to exhibit problems with peer relationships that would interfere with school functioning. The Children’s Friendship Training Program was designed for children 6–12 years of age to improve specific skills related to use of prosocial behavior needed to interact with peers [172]. Examples of the skills taught included understanding the rules of social conventions in a group, having conversations, handling teasing, bulling, and unjustified accusations, and negotiating peer conflict. Results from studies conducted in clinical settings and in the community showed children with PAE made improvements in understanding appropriate social skills. Also, parent reports indicated improvement in children’s behavior [172, 173]. It is important to note that teacher reports did not indicate improvement in behavior or social skills [172]. The authors suggested that these skills may not be as observable in a structured classroom setting when compared to less structured environments [172, 173]. Overall, these studies show that children with FASD respond to interventions provided in the community or in educational settings to improve academic, behavior, and social interactions that are necessary to function in school.

Classroom Strategies

Because of the variable presentation of the effects from PAE, selecting support strategies would depend upon the individuals' learning strengths and needs [157]. To address the learning and behavioral needs of school-aged children with FASD, it may be necessary to use strategies or approaches found effective for other developmental disabilities or learning disorders. Based upon studies of interventions for children with FASD, classroom instruction would need to be scaffold carefully to help students build upon previous skills [100]. Instructional pacing or presentation of videos when learning online would need to be adjusted to support children's rate of processing [110]. Classroom instruction as well as online learning would need to ensure that there are opportunities for frequent review of the material. Also, tasks would need to be on the individual's learning level. Tasks that are too difficult or too easy may impact behavior and sustained attention [91]. These adjustments may be applied in special education or in general education settings.

Some school-aged children affected by PAE are reported to exhibit behavioral challenges due to the neurodevelopment deficits, experiences of adversity, or other factors that require supports [108, 161]. To assess their behavioral needs, a comprehensive functional behavioral analysis conducted by a behavioral specialist or a trained psychologist to determine the purpose of the behaviors would need to occur. After the functional behavioral analysis is completed, a positive behavioral intervention plan would need to be developed. The behavioral plan would need to be used as a teaching tool to help children with PAE learn specific skills or replacement behaviors to respond and interact effectively at school [101]. Additionally, students may need increased adult supervision and reminders to help them manage the expectations of a school setting [101].

Conclusion

With the necessary support and services, school-aged children with FASD can be successful in their educational setting. The focus of educational interventions is to habilitate skills and support individuals with FASD to meaningfully participate in their learning environment. It requires collaboration between stakeholders, caregivers, school administrators, educators, allied health professionals, and individuals with FASD to make sure funding, policies, recognition of the disorder, and access to services are available. On the individual level, accurate diagnosis and development of a learning profile that incorporates their strengths, talents, and challenges would be necessary to guide educational planning. School-aged children affected by PAE have variable presentations. Therefore, it would be necessary to have educators who are informed about the impact of PAE on learning, behavior, and school functioning and access to resources to provide the necessary interventions. The goals are to provide the necessary educational instruction for all ages to improve outcomes and subsequently the quality of life.

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