

A photograph of a man with a beard and a red plaid shirt over a white t-shirt, carrying a young girl on his shoulders. The girl is wearing a striped shirt and red pants, and she is holding a colorful kite with a long tail. They are in a field of tall grass with mountains in the background. The kite is flying in the upper left corner of the image.

# ANNOTATED BIBLIOGRAPHY: TOP FASD ARTICLES OF 2019

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# Introduction and Search Methods

The articles below, also summarized in our Top FASD Articles of 2019 list,<sup>1</sup> were selected by a group of Canada FASD Research Network (CanFASD) staff, researchers, and Family Advisory Committee members to highlight some of the work that has been published over the last year in the field of FASD.

A literature search of Web of Science, PubMed, PsycInfo, Scholars Portal, Proquest Nursing and Allied Health, Google Scholar, CINAHL, Ovid, and Ovid Nursing Journals databases yielded over 460 articles published in 2018 on FASD. Many of these were excellent publications (especially in the areas of animal models of FASD, epigenetics, and brain-based research). However, the final list was narrowed down to focus on CanFASD's areas of emphasis in FASD prevention, intervention, diagnosis, social justice, child welfare, and family collaboration. Additional consideration for what constituted the "top" articles included:

- » Generalizability to Canadians
- » Influence on practice or policy
- » Novelty
- » Scientific rigour
- » Media attention

Final selections were categorized by area of focus, and limited to 5 articles or less per category. All articles are published in peer-reviewed journals. They are arranged in alphabetical order by first author's surname, and those marked with an asterisk (\*) are available in open access.

Top selected articles were sorted into 9 categories: assessment, diagnosis, and clinical presentation of FASD; intervention; mental health; prevention and maternal health; child welfare; caregivers/families; justice; research methodology/policy issues; and basic science and epigenetics. For a summary of the prevention and maternal health articles, please refer to the Prevention Network Action Team's Annotated Bibliography of Articles Published in 2019.

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1 <https://canfasd.ca/wp-content/uploads/publications/Top-Papers-of-2019-FINAL.pdf>

# Search Results: Top FASD Articles of 2019

## Assessment, Diagnosis, and Clinical Presentation of FASD

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1. \*Coons-Harding, K. D., Flannigan, K., Burns, C., Rajani, H., & Symes, B. (2019). Assessing for fetal alcohol spectrum disorder: A survey of assessment measures used in Alberta, Canada. *Journal of Population Therapeutics and Clinical Pharmacology*, 26(1), E39-E55. doi: 10.22374/1710-6222.26.1.4 (<https://jptcp.com/index.php/jptcp/article/view/54>)

The current study aimed to provide insight into the specific assessment measures used by FASD clinicians in Alberta, Canada. Two requirements for evaluating the neurodevelopmental domains in an FASD assessment are a multidisciplinary diagnostic team and the use of a battery of assessment measures. Although the current Canadian FASD Diagnostic Guideline provides a list of suggested assessment measures to use in this process, it is unclear how closely clinics providing diagnostic services align with these recommendations. A survey was distributed to all FASD diagnostic clinics in Alberta, with 19 clinics having at least one diagnostic team member respond. Participants reported using a total of 173 unique direct measures (e.g., standardized tests) and indirect measures (e.g., clinical interviews). The results indicated that while most of the measures reported reflect those suggested in the Canadian Guideline, measures beyond those listed in the Guideline are also used in the diagnostic process. The findings of this study provide useful information regarding the assessment process for FASD, and further highlight similarities across the FASD diagnostic process in Alberta. Results support a need for a comprehensive set of neuropsychological tests that is reliable and useful to increase the consistency and accuracy of the FASD diagnostic process.

2. Doyle, L. R., Coles, C. D., Kable, J. A., May, P. A., Sowell, E. R., Jones, K. L., ... Mattson, S. N. (2019). Relation between adaptive function and IQ among youth with histories of heavy prenatal alcohol exposure. *Birth Defects Research*, 111(12), 812-821. doi: 10.1002/bdr2.1463

Though adaptive function (i.e., communication, daily living skills, and socialization) and general intellectual function (e.g., reasoning, memory) are often correlated, the exact nature of their relationship remains unclear, particularly for individuals with prenatal alcohol exposure (PAE) who show impairment in these domains. Therefore, the current study sought to investigate the relationship between adaptive and intellectual function in a group of individuals with PAE compared to controls. 163 youth with PAE and a control group of 274 individuals with and without other conditions completed a comprehensive battery of standardized tests to determine their overall IQ score. Parents of all 473 participants completed a questionnaire related to their child's adaptive functioning. Results showed that the PAE group had lower IQ and total adaptive functioning scores than the control group. A more detailed analysis found that this difference was driven by the PAE group's lower scores on the Communication domain of adaptive functioning. While there were no group differences in communication when only considering individuals with low IQ, having a higher IQ and being in the control group were associated with greater adaptive functioning. The findings suggest that communication deficits reported by caregivers are not fully explained by IQ, with PAE being a contributing factor to this relationship.

3. Garrison, L., Morley, S., Chambers, C. D., & Bakhireva, L. N. (2019). Forty years of assessing neurodevelopmental and behavioral effects of prenatal alcohol exposure in infants: What have we learned? *Alcoholism: Clinical & Experimental Research*, 43(8), 1632-1642. doi: <https://doi.org/10.1111/acer.14127>

The purpose of this review was to summarize the effects of PAE on child development. A search of the literature reporting results from longitudinal studies that measured developmental outcomes of individuals with PAE was conducted. A total of 31 publications were included in this review. 24 studies examined neurocognitive outcomes, 24 studies examined adaptive behaviour outcomes, and 12 studies examined outcomes related to self-regulation. PAE was reported to have significant implications for lower neurocognitive outcome scores in over half of the relevant studies. Young children with PAE were also found to have lower adaptive functioning in one third of studies compared to individuals without PAE and PAE-associated deficits were reported in three quarters of the selected self-regulation studies. The results of this review draw attention to the need for specific research in the area of self-regulation, as results for this domain were the most consistent.

4. Lebel, C. A., McMorris, C. A., Kar, P., Ritter, C., Andre, Q., Tortorelli, C., & Gibbard, B. (2019). Characterizing adverse prenatal and postnatal experiences in children. *Birth Defects Research*, 111(12), 848-858. <https://doi.org/10.1002/bdr2.1464>

The purpose of this study was to create a list of prenatal and postnatal adverse exposures in children with PAE and to then describe the frequency of these adverse events in children with known PAE. A group of experts identified seven adverse exposures: high PAE, other prenatal substance exposure, prenatal stress, postnatal neglect before the age of 24 months, postnatal neglect after the age of 24 months, postnatal threats of harm before the age of 24 months, and postnatal threats of harm after the age of 24 months. Case files of 77 children with PAE were reviewed for evidence of exposure to the identified adverse events. Beyond PAE, nearly all children had additional prenatal adverse exposure. Two-thirds of the sample also experienced postnatal adversity. These children typically experienced more than one type of postnatal adverse exposure. The authors also found that high PAE was related to experiencing more prenatal and postnatal adversity. The results of this study suggest that clinicians assessing and treating individuals with PAE should consider additional prenatal and postnatal adversity for a more comprehensive assessment and in determining the most effective treatment plan.

5. \*Mukherjee, R. A. S., Cook, P. A., Norgate, S. H., & Price, A. D. (2019). Neurodevelopmental outcomes in individuals with fetal alcohol spectrum disorder (FASD) with and without exposure to neglect: Clinical cohort data from a national FASD diagnostic clinic. *Alcohol*, 76, 23-28. doi: <https://www.sciencedirect.com/science/article/pii/S0741832918300065>

The current study employed a case-control design in an effort to compare developmental outcomes across two groups including individuals with PAE without postnatal neglect (PAE-PN) and individuals with PAE with postnatal neglect (PAE+PN). Clinical data from 99 individuals with FASD were reviewed. The groups did not differ on the developmental outcomes of Attention Deficit/Hyperactivity Disorder or Autism Spectrum Disorder diagnoses, though these were most commonly reported among all individuals. In both groups, the total adaptive behaviour score was lower than would be expected of individuals of the

same age. When comparing the groups on scores of the specific adaptive function domains, the PAE+PN group had lower scores on domestic daily living than the PAE-PN group. The results of this study suggest that PAE, and not postnatal neglect, is the primary contributor to additional mental health concerns, lower adaptive functioning, and deficits in sensory perception among individuals with PAE. Therefore, in supporting families with a child with PAE and a history of neglect, it is important that professionals look beyond the home environment when addressing the function of behavioural difficulties.

6. Kapasi, A., Makela, M., Joly, V., Flannigan, K., & Pei, J. (2019). Understanding employment success in adults with fetal alcohol spectrum disorder. *Journal of Vocational Rehabilitation, 51*(3), 377-393. doi:10.3233/JVR-191053.

The aim of this study was to learn about the work experiences of adults with FASD. The authors created a survey that was completed by three groups of people: working adults with FASD, families of working adults with FASD, and support workers of working adults with FASD. 29 surveys were returned, including 20 surveys completed by adults with FASD. Participants reported multiple areas related to successful employment including: finding a fit between their abilities and the job; disclosing that they have FASD; being in a work environment that was supportive and made any necessary accommodations; and having help from family, support workers, and supervisors throughout the day. Successful work experiences improved individuals' self-esteem, increased their sense of independence, and led to more social interactions and friendships. Importantly, participants recognized the importance of educating employers about the abilities of individuals with FASD, leading to more job opportunities for those affected by FASD.

7. Makela, M. L., Pei, J. R., Kerns, K. A., MacSween, J. V., Kapasi, A., & Rasmussen, C. (2019). Teaching children with fetal alcohol spectrum disorder to use metacognitive strategies. *The Journal of Special Education, 53*(2), 119-128. doi:10.1177/0022466919832371

The purpose of this study was to test a computerized intervention meant to improve the attention, response inhibition, and working memory of children with FASD. Seven children with FASD played three different educational games for several hours over multiple weeks. The games were designed so that once a level was mastered, the participant would have access to a more difficult level. A coach was present during each session to provide strategies to children who got stuck on a level. Over the duration of the intervention, participants began using a greater variety of strategies, began using a greater variety of strategies without prompting, and required fewer prompts from their coach. The results of this study show that when individuals with FASD are supported at the beginning of an intervention, they are capable of learning new skills to a point where less support is needed.

8. Quan, R., Brintnell, E. S., & Leung, A. W. S. (2019). Elements for developing community-based interventions for adults with fetal alcohol spectrum disorder: A scoping review. *British Journal of Occupational Therapy, 82*(4), 201-212. doi:10.1177/0308022618790206

The current study aimed to highlight key characteristics that are necessary when developing community-based interventions that successfully meet the needs of individuals with FASD. The authors performed a review of academic and community-based organization publications, including any literature that reported on community-based programs for adults with FASD who target improving daily living skills. A total of seven publications met these inclusion criteria and were reviewed. The following six themes

were identified: inclusion of a functional context; individualized support; education for service providers; structure and routine; utilizing a strengths-based approach; and environmental adaptations. Results suggest that in developing effective interventions for adults with FASD, particularly those that are community-based, the identified components in the current study may be fundamental to providing optimal support and facilitating successful outcomes.

## Mental Health

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9. Dirks, H., Francke, L., Würz, V., Kretschmann, C., Dehghan-Sanij, S., & Scherbaum, N. (2019). Substance use, comorbid psychiatric disorders and suicide attempts in adult FASD patients. *Advances in Dual Diagnosis, 12*(1-2), 6-13. doi:10.1108/add-10-2018-0018

The purpose of this paper was to describe substance use, additional psychiatric disorders, and suicide attempts in individuals with FASD. Participants were 31 individuals diagnosed with FASD following a mental health assessment at a specialized diagnostic FASD clinic in Germany. The mental health assessment obtained information on all substance use, mental health diagnoses, and past suicide attempts. The majority of participants reported having used alcohol at some time in their life and over half had used marijuana. However, for alcohol, marijuana, and all other illicit drugs, a pattern of regular use rarely occurred. Most participants had at least one additional mental health disorder. One in four participants reported at least one suicide attempt. The results of this study suggest that clinicians working with people who have FASD should screen for patients' current and lifetime substance use, the presence of additional mental health disorders, and suicidal ideation, as these are all common among individuals with FASD.

10. Mela, M., Coons-Harding, K. D., & Anderson, T. (2019). Recent advances in fetal alcohol spectrum disorder for mental health professionals. *Current Opinion in Psychiatry, 32*(4), 328-335. doi:10.1097/YCO.0000000000000514

The purpose of the current study was to highlight the unique mental health and medical needs of individuals with PAE/FASD that require both appropriate identification and intervention. The authors provide a review of recent research in the field of FASD and mental health. Specifically, the authors discuss research regarding: the international recognition of FASD; knowledge of Neurodevelopmental Disorder Associated with PAE (ND-PAE) and FASD among mental health professionals; medical advances relevant to mental health professionals; co-occurring mental health concerns; biopsychosocial interventions relevant to mental health professionals; inappropriate sexual behaviour; forensic implications; FASD as a whole body disorder; and the stigma associated with FASD. Mental health professionals should be made aware of the unique considerations relevant to individuals with FASD, such as forensic implications and whole-body impacts. With this recognition, quality of care can be improved while potentially lessening associated stigma.

11. Temple, V. K., Cook, J. L., Unsworth, K., Rajani, H., & Mela, M. (2019). Mental health and affect regulation impairment in fetal alcohol spectrum disorder (FASD): Results from the Canadian National FASD Database. *Alcohol and Alcoholism, 54*(5), 545-550. doi:10.1093/alcalc/agz049

In an effort to explore the relationship between Affect Regulation (AR) impairment and other mental health problems and diagnoses, data were retrieved from the Canadian National FASD Database (<https://canfasd.ca/topics/diagnosis/#nationaldatabase>) of children and adults with FASD. The prevalence of sev-

eral mental health diagnoses (i.e., attention/deficit hyperactivity disorder, post-traumatic stress disorder, conduct disorder, attachment disorder, intellectual disability, and language disorder), as well as a history of suicidality, were compared between individuals with and without AR impairment. Compared to individuals with FASD and no AR impairment, conduct disorder, attachment disorder, and post-traumatic stress disorder were approximately five, six, and eight times more likely to be reported in individuals with FASD and AR impairment, respectively. Individuals with FASD and AR impairment were over eight times more likely to report a history of suicidality. Because AR impairment is closely related to common mental health disorders experienced by individuals with FASD, early interventions targeting AR are likely to have beneficial long-term outcomes.

## Child Welfare

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12. \*Coons-Harding, K. D., Azulia, A., & McFarlane, A. (2019). State-of-the-art review of transition planning tools for youth with fetal alcohol spectrum disorder in Canada. *Journal of Developmental Disabilities*, 24(1), 49-65. (<http://oadd.org/wp-content/uploads/2019/11/41026-JoDD-24-1-v11f-81-98-Coons-Harding-et-al.pdf>)

The purpose of this study was to review the literature on transition planning tools used with Canadian youth who have FASD. Twelve tools from four Canadian provinces were identified. There was significant overlap in the successful characteristics of the 12 planning tools. These characteristics included: a transition plan is deemed necessary and made; this plan should be made early; a timeline for transition should be created and followed; there should be a designated transition plan coordinator; the youth with FASD should be included in creating their transition plan; and the transition plan should include multiple domains (e.g., income support, employment, housing). Despite these common characteristics, different tools place different emphasis on specific aspects of a child's life (e.g., biological and psychosocial) and who exactly is responsible for guiding the transition is often unclear. Future research on the success of using transition planning tools with individuals with FASD will clarify their utility

13. \*Hutton, S., Head, K. J., Lyttle, S., Kenneally, J. N., & Rehou, M. (2019). System kids: Transition-aged youth from foster care to developmental services. *Journal on Developmental Disabilities*, 24(1), 49-65. (<http://oadd.org/wp-content/uploads/2019/11/41026-JoDD-24-1-v11f-49-65-Hutton-et-al.pdf>)

This paper presents the stories of three individuals with disabilities navigating the transition from foster care to developmental care. Overall, the individuals reported a lack of services available to them as they transitioned from foster care to adult developmental services. Sarah, one of the individuals interviewed for this article, was diagnosed with FASD and recounted her experience. Sarah lived in 18 different foster homes before her 18th birthday. Because of her moving multiple times, she rarely made lasting friendships and eventually stopped trying to connect with her foster families, knowing that her stay with them was likely to be brief. Sarah experienced similar instability with her support staff. At 18 years old, this instability made it difficult to connect with the right services, visiting with four different agencies before finding a good fit. Despite these barriers in her life, a poster that hangs on Sarah's wall speaks to her positive outlook on her future: "Don't let anyone hold you back. Take risks. Spread love. This life is your message to the world. Let it be extraordinary."

## Caregivers/Families

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14. \*Brown, J., Kaspi, A., Nowicki, E., & Cleversey, K. (2019). Expectations of youth with fetal alcohol spectrum disorder in adulthood: Caregiver perspectives. *Journal on Developmental Disabilities*, 24(2), 30-42. (<https://oadd.org/wp-content/uploads/2019/12/41028-JoDD-24-2-v11f-30-42-Brown-et-al.pdf>)

The purpose of this study was to explore the perceived service planning needs of caregivers of youth with FASD transitioning to adulthood. Sixteen caregivers were asked the question: “*What kind of adult life do you think they will have?*” The 16 participants gave 57 unique responses to the question, which led to the determination of four concepts: have a purpose; serious problems; continuous challenges; and always needing support. The concept “have a purpose” included themes such as achieving employment and higher education. The concept of “serious problems” included themes such as future involvement with the justice system and preparing for the worst. The theme of “continuous challenges” included themes of worry and lack of hope about the future. The theme of “always need support” included themes of weaknesses that would prevent the individual from taking care of themselves. Caregivers acknowledged that with the right supports their loved one could live a successful adult life. However, caregivers were unable to identify what available resources would be helpful in assisting their loved one during adulthood, indicating the lack of services available.

15. Reid, N., & Moritz, K. M. (2019) Caregiver and family quality of life for children with fetal alcohol spectrum disorder. *Research in Developmental Disabilities*, 94. <https://doi.org/10.1016/j.ridd.103478>.

The purpose of this study was to describe the quality of life of caregivers to children with FASD and to identify which areas of life are most frequently impacted. 109 caregivers completed a measure of their physical, mental, emotional, and cognitive functioning; communication; worry; and how their families are affected in daily activities and family relationships. The most frequently reported strengths were physical and cognitive functioning. The most frequently reported difficulties were worry and their family’s daily activities. Caregivers of children with facial features had better scores on almost all measures compared to caregivers of children without facial features. The caregiver’s own mental health, country of residence, child’s gender, and child’s behaviour all predicted overall quality of life. Providing caregivers with the supports they need may lead to better outcomes for themselves and for their children.

## Justice

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16. \*Freeman, J., Condon, C., Hamilton, S., Mutch, R.C., Bower, C., & Watkins, R. E. (2019). Challenges in accurately assessing prenatal alcohol exposure in a study of fetal alcohol spectrum disorder in a youth detention center. *Alcoholism: Clinical & Experimental Research*, 43(2), 309-316. <https://doi.org/10.1111/acer.13926>

The aim of this study was to assess PAE in a group of youth in an Australian detention center. Information on PAE was collected from the youths’ mothers or a first-degree relative with knowledge of their pregnancy. The informants completed a detailed interview about the youth’s birth, prenatal exposures, and development, as well as a brief questionnaire on patterns of alcohol use specific to the duration of the pregnancy. Information on PAE was available for 88 youth, with mothers providing PAE information for 55 of those cases. The most frequent patterns of alcohol use during pregnancy included drinking 4 or less times

a month and having 7 to 9 alcoholic beverages on days when drinking occurred, with 75% of women consuming alcohol during all three trimesters. However, a number of participants were unable to provide answers or declined to provide answers to some questions, making accurate and thorough information on PAE difficult to obtain. The authors acknowledge that this information is difficult to obtain in any setting, but collecting this information retrospectively is additionally challenging.

17. \*McLachlan, K., McNeil, A, Pei, J., Brain, U., Andrew, G., & Oberland, T. F. (2019). Prevalence and characteristics of adults with fetal alcohol spectrum disorder in corrections: A Canadian case ascertainment study. *BMC Public Health*, 19(1), 43. <https://doi.org/10.1186/s12889-018-6292-x>.

The goal of this study was to estimate the prevalence of FASD among a Northern Canadian correctional population. 80 justice-involved adults completed a comprehensive medical and psychological assessment in accordance with the 2005 FASD Diagnostic Guideline. Information on PAE was obtained from mothers, collateral reports, and case files (e.g., child welfare, education system). PAE was confirmed in 25% of the sample; however, 50% of participants had unknown PAE. The prevalence of FASD was 17.5%. Nearly 95% of the sample displayed at least moderate neurodevelopmental dysfunction in one or more categories. The justice-involved adults also reported a number of other health problems including sleep issues, obesity, poor dentition (i.e., the arrangement or condition of the teeth), and additional mental health concerns. Over 80% of participants reported a history of abuse. The finding that 12 of the 14 individuals diagnosed with FASD were receiving this diagnosis for the first time as part of this study highlights the need for more comprehensive assessments of FASD in the general population, but particularly within the justice system.

## Research Methodology/Policy Issues

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18. \*Aspler, J., Zizzo, N., Bell, E., Di Pietro, N., & Racine, E. (2019). Stigmatisation, exaggeration, and contradiction: An analysis of scientific and clinical content in Canadian prime media discourse about fetal alcohol spectrum disorder. *Canadian Journal of Bioethics*, 2(2), 23-35. (<https://cjb-rcb.ca/index.php/cjb-rcb/article/view/49>)

The aim of this study was to review how the Canadian media reports information on FASD. The authors reviewed over 280 articles from 10 Canadian newspapers published between 2002 and 2015. The authors categorized the content of articles into scientific, clinical or social contents. Six general themes were identified: prevalence of FASD and of women's alcohol consumption; research related to FASD; diagnosis of FASD; treatment of FASD and maternal substance use; primary disabilities associated with FASD; and effects of alcohol exposure during pregnancy. From these six themes, three additional themes were identified that could lead to an increase in the stigma associated with FASD. These included exaggerating the rates of FASD in Indigenous communities, contradicting information on FASD between articles, and scientific information presented without social context. The authors state that these issues in reporting of FASD could lead to a focus on FASD in Indigenous communities while not considering prevalence in the general population, confusion as to if there is a "safe" amount of alcohol that can be consumed during pregnancy, and beliefs that FASD is a result of an addiction despite alcohol consumption being a cultural norm.

## Basic Science and Epigenetics

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19. Holman, P. J., Baglot, S. L., Morgan, E., & Weinberg, J. (2019). Effects of prenatal alcohol exposure on social competence: Asymmetry in play partner preference among heterogeneous triads of male and female rats. *Developmental Psychobiology*, 61(4), 513-524. <https://doi.org/10.1001/dev.21842>.

The goal of this study was to assess how the social environment influences dysfunction in social skills often associated with PAE. Male and female rats were divided into a PAE group and two control groups. Rats were then divided by sex and put into same-sex groups of three. The groups were either comprised of two controls and one PAE or two PAE and one control. Social interactions within the groups were recorded over a ten-minute period. The authors found that when there was only one PAE rat in the group, this rat was less often included in play. However, when two PAE rats were in the group, there was more equal play between all three group members. These findings show that the social deficits often seen in individuals with PAE may not be a direct result of their disability, but may be shaped by the fact that they may not be included in as many social interactions; therefore, not given the opportunity to build on their social skills.

20. McLachlan, K., Vavasour, I., MacKay, A., Brain, U., Oberlander, T., Loock, C., Beaulieu, C. (2019). Myelin water fraction imaging of the brain in children with prenatal alcohol exposure. *Alcoholism: Clinical and Experimental Research*, 43(5), 833-841. <https://doi.org/10.1111/acer.14024>

The goal of this study was to determine if there are different amounts of myelin in the brains of children with PAE compared to 'healthy' children. Myelin is the insulator of nerves and helps quickly pass messages from one area of the brain to another, or to the body. Participants underwent a brain scan that looked at how much myelin was present in 12 different parts of the brain. The two groups had similar amounts of myelin in 11 of the 12 areas of the brain examined. However, it was speculated that there are not as many nerves in each area of the brain among children with PAE compared to controls. The authors also found that children with PAE showed an increase in myelin in the frontal lobe (i.e., the planning and decision-making part of the brain) as age increased. The authors state that this increase may be the way that the PAE-affected brain 'catches up' to the expected concentration of nerves and myelin.

