May 2018

CanFASD ISSUE PAPER: CURRENT STRATEGIES AND EDUCATIONAL SUPPORTS FOR STUDENTS WITH FASD

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ISSUE:

Students with Fetal Alcohol Spectrum Disorder (FASD) can benefit both their educational and personal lifestyles with the help of educational supports and individualized program plans/individualized education plans (IPPs/IEPs) while attending school.[1] Educational supports include readily available strategies and resources, such as teachers, educational assistants (EAs), administration, and repetitive visual and verbal cues,[2] that help improve the learning outcomes of students with various disabilities. IPPs are student-specific plans designed to implement these educational supports effectively.[1]

Despite educational supports being available in most school systems, current educational strategies are often outdated, too generalized, and lack the accessible information teachers need to prepare ideal IPPs for students with FASD.[1,3-4] Moreover, Millar and colleagues[5] observed that children with FASD who received insufficient supports were at risk for a number of secondary adverse outcomes, including dropping out of school, involvement with the criminal justice system, mental health issues, and substance use problems. Additionally, community support is generally very poor for individuals with FASD and their caregivers, with many parents lacking the knowledge, understanding, and resources to handle the developmental disabilities associated with FASD.[3,6] Despite these inadequate resources, most diagnoses, supports, and interventions come from within school systems, strengthening the importance of improving and revising educational supports to enhance learning outcomes for students with FASD.[3,5]

BACKGROUND:

General symptoms and educational effects – Individuals with FASD present with a wide variety of symptoms as a result of the complexity of factors contributing to such variable developmental outcomes.[7,8] While there are usually no overt physical symptoms, individuals with FASD are uniquely impacted by deficits in their communication, social, behavioural, academic, and executive functioning skills.[8,9] For this reason, children with FASD are often perceived as defiant and having behavioural problems while at home and in school.[6,9] Caregivers and teachers often report feelings of frustration and failure, as they lack an understanding of FASD and the unique identifiers of this disability, and are often not fully prepared to handle the complexity of the child's behaviours and emotions.[3,6,10]

Children with FASD are also known to struggle with mathematics, abstract thinking, and language comprehension,[9,11] though it is not uncommon for individuals with FASD to have IQs within the normal range based on standardized testing, and they will often appear academically sound.[2,5] This discrepancy, in turn, can lead to delayed diagnosis and intervention, as well as perceived family stress,

for a student with FASD if their caregivers and teachers are unaware of how to properly identify the complex and individualized set of symptoms.[4,9,12]

Prevalence and underreporting – Because of the complex nature of the diverse set of symptoms children with FASD present with, it is no surprise that teachers struggle to identify students with FASD, or are wary of identifying students or raising concerns out of a fear of potential backlash or criticism, as individuals with FASD have a number of unique behavioural styles and learning deficits that differ from other developmental disabilities.[5] Consequently, there tends to be a delay in diagnosis and an underrepresentation of the prevalence of students with FASD in the education system.[5,9] As of 2018, research conducted in the United States suggests that the prevalence of FASD in school-aged children ranges from 1.1% - 5%, and that this number is underreported because of the complexity of symptoms and succeeding misdiagnoses, as well as the stigma associated with a FASD diagnosis.[9,13] Beyond the wrongful identification of FASD as a behavioural problem, Koren et al.[9] highlighted how stigmatization has been shown to be a very influential factor of underreporting in schools, as disclosing FASD is linked to the fear of labelling children and having them be exposed to bullying. Furthermore, the disclosing of FASD may lead to further bias and judgment propelled onto parents and caregivers of individuals with FASD, as a result of the lack of knowledge and awareness of the disability.[9]

Provincial and Territorial Recognition – While FASD remains prevalent in the school system, not all provinces and territories within Canada recognize it as a fundable disability in education and there is great variability in FASD education policy across Canada.[5] Currently, Manitoba, Yukon, Ontario, and Nunavut do not recognize FASD as a disability for educational purposes, restricting both diagnosed and undiagnosed students from having proper access to the various educational supports and IPPs/IEPs needed to excel academically.[i] Explicit FASD education policy is often lacking within the Canadian education system; this policy falls within the purview of provincial special educational programming and can include FASD-specific classrooms and/or guidelines for supporting students with FASD in the classroom from an integrated, inclusive, or interdisciplinary model.[5,14]

Both the Manitoba and Yukon education branches do not work with a funding model for specific disabilities, but rather operate on block funding, where school divisions receive a certain amount of money based on the previous levels of special needs students exhibited.[ii] It is important to note that while funding is offered to students with or without a diagnosis, the level of funding is determined solely on the severity of the child's behaviour. Therefore, FASD is not a specific fundable disability in these Western Canada education acts. Rather, the main source of funding for supports and resources in the classroom comes from students demonstrating, and being classified as having, severe violent or reactive behavioural issues.[iii, 15,16]

Meanwhile in Ontario, The Legislative Assembly is currently tabling Bill 191 which will come into force on September 1, 2018, declaring FASD as a fundable disability in the Education Act.[17] This bill aims to: (1) promote awareness and understanding of FASD within school systems, including best practices to support students who are, or may one day, be diagnosed with this disability; and (2) emphasizes school boards to collaborate and communicate with the parents and caregivers of students with FASD, along with FASD support groups, to help provide optimal care for children with FASD.[17] Likewise, the Nunavut Education Act is still under review and is likely to be revised. Currently, FASD is not specifically identified within the Education Act, and the act itself is quite vague surrounding inclusive and special education. These gaps leave support and accommodation planning up to

[i] Family Advisory Committee, personal communication, March 2018; April 2018
[ii] Family Advisory Committee, personal communication, March 2018; April 2018
[iii] Family Advisory Committee, personal communication, March 2018; April 2018

individual educators, only some of whom are FASD informed; though it is important to note that since 2011, the ministry has made strong progress and efforts to support learners with FASD, and positive outcomes are being achieved.

Fortunately, British Columbia and Alberta school systems do recognize FASD as a fundable disability in education and are one-step closer to providing the educational supports and resources needed for these students to excel.[iv] However, it is important to note that while FASD is becoming more recognized in British Columbia, school boards allot funding based on the designation categories the child qualifies for via their IQ test results, which previous studies have identified as being inconclusive determinants of FASD.[2,5]

Henceforth, it is important for all Canadian provinces and territories to pass such bills that recognize FASD as a fundable disability in education acts, to ensure students receive the proper supports and resources they need to improve their academic outcomes. Additionally, the use of proper diagnostic tools and procedures to identify such disabilities correctly, instead of misidentifying these students as having behavioural issues, should not be overlooked.

CURRENT STRATEGIES AND PROBLEMATIC ISSUES OF EDUCATIONAL SUPPORTS:

The general themes across all literature pertaining to educational supports for students with FASD were clear: current strategies are not allowing children with FASD to effectively learn and grow within school systems. Three main concepts were identified across all literature as being the root cause for poor educational support and IPPs for students: ineffective functional assessments and psychoeducational reports; a lack of FASD education and training for teachers; and disjointed communication between all parties.

INEFFECTIVE FUNCTIONAL ASSESSMENTS & PSYCHOEDUCATIONAL REPORTS

One of the first steps moving towards educational supports and IPPs for students with FASD is getting an early and correct diagnosis of the disability.[1,9,18] Children with FASD can have normal IQs, combined with symptoms mistakenly identified as behavioural problems. Consequently, these variations often result in diagnoses being delayed, and only occurring when more severe deficits are visible in the classroom.[2,4-5] Psychologists use functional assessments to diagnose FASD and suggest educational supports for these students, with psychoeducational reports being produced afterwards to relay the assessment results to teachers who then make appropriate IPPs.[1,4,19] However, the current functional assessment has been cited to have substantial problems over the past 40 years, making it extremely difficult for the teachers to find value with its information.[4] Teachers claim the functional assessment lacks comprehension, and focuses more on the diagnosis, only highlights the weaknesses of the students, and is far too generalized and disconnected to create individual program plans.[1,4] As well, the psychoeducational reports summarizing the assessment are far too long, filled with technical jargon, and the assessment questions often do not match the recommendations for the IPPs, making these papers difficult for the teachers to understand and implement.[4,9,19]

POOR TEACHER EDUCATION AND TRAINING ON FASD

Teachers have noted in research studies that the long, technical, psychoeducational reports, written at a graduate level, are the main mode of communication between the psychologist conducting the functional assessment and the educational support personnel planning the IPP for the student with FASD.[4,19] Because of the ineffective reports, teachers have noted feeling frustrated and misguided while trying to fully understand these write-ups, and have trouble obtaining recognizable information that can be used in the student's IPP.[4,19] Because of these challenges, teachers reportedly modify IPPs

[iv] Family Advisory Committee, personal communication, March 2018; April 2018

based off of their own knowledge and training experience with students with FASD, rather than relying on the students' specific report recommendations.[3-5,9,19] Unfortunately, most teachers are not fully educated on, or do not have the proper resources on, FASD, and report having not previously worked with students with FASD. Therefore, teachers cannot soundly make an appropriate IPP that pertains to the child's unique and complex learning styles and behaviours, further compromising their learning outcomes.[3-5,9,19] It is also important to note the role of educational assistants (EAs) in classrooms as a means to address the needs of students with FASD, as these workers are often heavily relied on to support such learning styles, despite these professionals often having minimal FASD training and knowledge.[14] This lack of knowledge, in effect, can lead to inefficient educational supports, as EAs commonly remove students from the classroom to work on specific assignments, not only reducing the opportunity for trained teachers to directly transmit critical curriculum to the student, but also contributing to the stigmatization of isolating students with FASD from their peers. Furthermore, emphasis should be given to caregivers, parents, administrators, physicians, and students influenced by FASD, who have widely expressed their lack of knowledge, awareness, and understanding of the disability, and blame inadequate and inaccessible education and training sources for their ineffective diagnosis and intervention techniques.[1,3-4,6,9,12]

DISJOINTED COMMUNICATION BETWEEN ALL PARTIES

In addition to psychoeducational reports being an ineffective communication tool between psychologists and teachers, research on educational supports has demonstrated an overall collaboration disconnect between all parties involved with the intervention for students with FASD.[1,3-4] Teachers claim their voices and perspectives should be considered during the diagnosis and functional assessment, as they have their own set of experiences and knowledge that could be useful at the beginning stages.[3-4] Likewise, parents have also expressed difficulty advocating on their child's behalf in an educational setting even when they are equipped with proper knowledge, as their expertise is discounted by other professionals involved.[12,20] Parents have also expressed that educational supports should provide the caregivers with more resources for FASD to help them better understand and prepare for their child's complex needs, if they require additional knowledge.[1] Furthermore, the literature shows that when collaboration is sparse between psychologists, teachers, administrators, guardians, and the community, expertise and resources become restricted, individualized program planning becomes disjointed, and the complex needs of the student with FASD are not met.[1,3-4]

SUMMARY:

Evidence shows the need for revised strategies and improved educational supports for students with FASD through all levels of diagnosis, assessment, and intervention planning if positive learning outcomes are desired.

- Functional assessments are too generalized and focus on students' weaknesses, resulting in psychoeducational reports that are too technical and disconnected.[1,4,19]
- Teachers find psychoeducational reports too difficult to understand. Consequently, teachers modify IPPs based off their own knowledge of FASD, without having the proper education or training to identify the unique learning styles of students with FASD, and without the consideration of individual differences among these students (e.g., each individual students' strengths and limitations).[3-5,9,19]
- Communication is limited between all respective parties, leading to disjointed intervention planning and restriction of resources and expertise.[1,3-4]
- Caregivers are perceived to have limited understanding, knowledge, and available resources regarding FASD, creating difficulties coming to terms with their child's unique behaviours and emotions, and subsequently how to identify FASD and support their disability.[4,6] Consequently,

when parents and caregivers do have knowledge of their child's strengths and limitations, they often face difficulties advocating on their child's behalf in an educational setting, as teachers and school administrators may discount the parents' expertise about their child.[12,20]

RECOMMENDATIONS:

Based on current studies, the research evidence regarding supports, including teachers, aides, administration, and caregivers, demonstrates several effective improvements that can be made to enhance the learning opportunities of students with FASD.

- Early diagnosis is essential to acquire the proper tools and resources to meet the complex needs of individuals with FASD, and so all respective parties should play an active role in watching for these multifaceted symptoms.[1,9,18]
- Improving functional assessments is required to optimize IPPs/IEPs, and psychologists should gather a more comprehensive overview of the student, individualizing the assessment, highlighting the strengths and skills of the student, and noting how to use and apply these strengths in the classroom setting.[1,4,19]
- Psychoeducational reports should be shorter and filled with less technical jargon, following the C.L.E.A.R. approach to help teachers bridge the educational gap between reports and IPPs: (C) child-centered perspective; (L) link referral questions, assessment results, and recommendations; (E) enable the reader with concrete recommendations; (A) address strengths as well as weaknesses; and (R) readability.[4,19]
- Teachers and other educational supports should be provided with the proper resources, education, and up-to-date training on FASD to ensure that they are equipped to make sound decisions on the best learning styles for individualized student program plans.[3-5,9]
- Efforts should be made to encourage maximized curriculum delivery to students with FASD in classroom settings, considering the most effective roles of teaching staff. FASD trained and knowledgeable teachers should directly provide students with the proper curriculum in the classroom setting, while EAs should receive more FASD training and help facilitate the learning of the students who are more independent.
- Stronger communication and collaboration between psychologists, teachers, educational aides, parents, and the community will lead to a more enhanced IPP/IEP, as various levels of experience and expertise will be shared amongst all parties.[3-5,9]
- An interdisciplinary team approach is best suited to meet the complex needs of individuals with FASD, and students are more likely to have consistent intervention planning and positive learning outcomes if they are continuously supported from all avenues.[3-4]
- Allocating more educational resources and communicating more effectively with community supports will better prepare parents and guardians with an understanding of FASD.[1,4-5]
- Parents and caregivers should have access to educational resources regarding FASD to enhance their knowledge and understanding of the disorder, and to better serve the unique needs of their child at home.[6,20] Previous literature has alluded to successful parental adaptations of raising a child with FASD via understanding the disorder, and focusing on family integration, cooperation, and optimism, ultimately lowering parental stress levels and increasing family functioning.[20]

Henceforth, educational supports do have the ability to enhance the learning outcomes of students with FASD, so long as current strategies are improved and revised to better suit the complex needs of the individual, equip teachers and educational assistants for individualized program planning, and implement constant communication. Attention should also be placed on educating parents and caregivers and increasing their awareness and understanding of FASD.

Currently, effective classroom teaching strategies for students with FASD are being implemented, focusing on individualized strength-based approaches, and utilizing resources such as visual aides, assigned seating, colour-coordinated calendars, setting routines, and reinforcing ideas.[1-2,4] Given the wide cognitive range of students with FASD, in addition to the variance in executive functioning, there is a need to adopt an approach that best supports the individual with FASD. While most educational philosophy operates from a principle of inclusive education, it is critical to address the specific learning needs of students with FASD, acknowledging the continuum of supportive policies, funding, and evidence-informed practices that are needed.[5] In order to maximize effective classroom teaching strategies, perhaps more specialized FASD classrooms pertaining to the exact needs of these students should be created, much like the first FASD primary level classroom created in the City of Toronto in 2011[5,21] or the FASD classrooms created in Winnipeg, Manitoba.[5] Educational specialists also support this concept, stating that an IPP/IEP created for the learning environment rather than the learner will provide better outcomes for the students; that said, there should also be focus on creating an educational environment that best fits the needs and strengths of the learner, rather than expecting the learner to fit the expectations of the educational environment.

Furthermore, it is important to note that the literature and concepts presented here apply to all levels of education; supporting students through their transitional periods, including the changing of teachers and educational assistants, changing school years, and transitioning into adulthood, will only further the successes of students with FASD. Research has identified that students with FASD tend to succeed more in elementary school, where the teachers, classroom settings, routines, and expectations remain relatively consistent all day. In comparison, students with FASD tend to find high school difficult because of the changing teachers, classrooms, routines, and expectations, and tend to struggle academically. Therefore, it is important to address inefficient educational supports for students with FASD in all school systems and to continue to make changes across Canada. Focus should also be given to the educational structure across all systems and improving the transitional supports that are readily available for these students. Henceforth, while students with FASD are more than capable of having successful and accomplished academic and personal lifestyles, drastic steps and system remodelling will need to be undertaken in order to reach such efficiency and improve educational outcomes for students with FASD.

For more information on educational supports for students with FASD and current teaching strategies, please refer to the following resources:

Engaging All Learners! Supporting Students with Fetal Alcohol Spectrum Disorders
http://www.engagingalllearners.ca/il/supporting-students-with-fasd/

What Educators Need to Know about FASD
https://www.gov.mb.ca/healthychild/fasd/fasdeducators_en.pdf

Understanding FASD: A Comprehensive Guide for Pre-K – 8 Educators
https://sites.duke.edu/fasd/files/2016/04/FASD_Guide.pdf

Teaching Students with FASD: Building Strengths, Creating Hope
https://education.alberta.ca/media/385139/teaching-students-with-fasd-2004.pdf

Making a Difference: Working with Students who have FASDs
http://www.education.gov.yk.ca/pdf/publications/fasd_manual_2007.pdf

POPFASD, the Provincial Outreach Program for FASD
https://www.fasdoutreach.ca/

REFERENCES:

1. Pei, J., Tremblay, M., Pawlowski, A., & Poth, C. (2015). *Best practices for FASD service delivery: guide and evaluation tool kit.* Retrieved from http://www.acds.ca/images/training/external/2015_best_practices_for_fasd_service_delivery_final.pdf
2. Blaschke, K., Maltaverne, M., & Struck, J. (2009). *Fetal alcohol spectrum disorders education strategies: Working with students with a fetal alcohol spectrum disorder in the education system.* South Dakota, SD: National Organization of Fetal Alcohol Syndrome.
3. Job, J. M., Poth, C. A., Pei, P., Caissie, B., Brandell, D., & Macnab, J. (2013). Toward better collaboration in the education of students with fetal alcohol spectrum disorders: integrating the voices of teachers, administrators, caregivers, and allied professionals. *Qualitative Research in Education, 2*(1), 38-64. doi:10.4471/qre.2013.15
4. Pei, J., Job, J. M., Poth, C., & Atkinson, E. (2013). Assessment for intervention of children with fetal alcohol spectrum disorders: perspectives of classroom teachers, administrators, caregivers and allied professionals. *Psychology, 4*(3), 325-334. doi:10.4236/psych.2013.43A047
5. Millar, J. A., Thompson, J., Schwab, D., Hanlon-Dearman, A., Goodman, D., Koren, G., & Masotti, P. (2017). Educating students with FASD: linking policy, research and practice. *Journal of Research in Special Educational Needs, 17*(1), 3-17. doi:10.1111/1471-3802.12090
6. Baskin, J., Delja, J. R., Mogil, C., Gorospe, C. M., & Paley, B. (2016). Fetal alcohol spectrum disorders and challenges faced by caregivers: clinicians' perspectives. *Journal of Population Therapeutics and Clinical Pharmacology, 23*(2), 114-130.
7. Kalberg, W. O., & Buckley, D. (2007). FASD: what types of intervention and rehabilitation are useful? *Neuroscience and Behavioural Reviews, 31*, 278-285. doi:10.1016/j.neubiorev.2006.06.014
8. Miller, D. (2006). Students with fetal alcohol syndrome: updating our knowledge, improving their programs. *Teaching Exceptional Children, 38*(4), 12-18. https://doi.org/10.1177/004005990603800402
9. Koren, G., Fantus, E., & Nulman, I. (2010). Managing fetal alcohol spectrum disorder in the public school system: a needs assessment pilot. *Canadian Society of Pharmacology and Therapeutics, 17*(1), 79-89.
10. Watson, S.L., Hayes, S.A., Coons, K. D., & Radford-Paz, E. (2013). Autism and fetal alcohol spectrum disorder part II: A qualitative comparison of parenting stress. *Journal of Intellectual and Developmental Disability, 38*(2), 105-113. doi: 10.3109/13668250.2013.788137

11. Edmonds, K., & Crichton, S. (2008). Finding ways to teach students with FASD: a research study. *International Journal of Special Education, 23*(1), 54-73.
12. Coons, K. D., Watson, S. L., Yantzi, N., & Schinke, R. (2018). Adaptation in families raising children with fetal alcohol spectrum disorder part II: What would help. *Journal of Intellectual and Developmental Disability, 48*(2), 137-151. doi: 10.3109/13668250.2016.1267718
13. May, P. A., Chambers, C. D., Kalberg, W. O., Zellner, J., Feldman, H., Buckley, D., … Hoyme, H. E. (2018). Prevalence of fetal alcohol spectrum disorders in 4 US communities. *The Journal of the American Medicine Association, 319*(5), 474-482. doi:10.1002/jama.2017.21896
14. Jonsson, E., Dennitt, L., & Littlejohn, G. (Eds.). (2009). *Fetal alcohol spectrum disorder (FASD): Across the lifespan*. Edmonton, AB, Canada. Institute of Health Economics. Available at https://www.ihe.ca/advanced-search/fetal-alcohol-spectrum-disorder-fasd-across-the-lifespan
15. British Columbia Ministry of Education. (2016). *Special education services: A manual of policies, procedures and guidelines*. Victoria, BC: BC Ministry of Education.
16. Alberta Learning Special Programs Branch. (2004). *Standards for special education*. Edmonton, AB: Crown in Right of Alberta.
17. Kiwala, S. (2017). *Bill 191: an act to amend the education act in relation to fetal alcohol spectrum disorder (FASD).* Retrieved from http://www.ontla.on.ca/bills/bills-files/41_Parliament/Session2/b191_e.pdf
18. Poth, C., Pei, J., Job, J. M., & Wyper, K. (2014). Toward intentional, reflective, and assimilative classroom practices with students with FASD. *The Teacher Education, 49*, 247-264. doi:10.1080/08878730.2014.933642
19. Mastoras, S. M., Climie, E. A., McCrimmon, A. W., & Schwean, V. L. (2011). A C.L.E.A.R. approach to report writing: a framework for improving the efficacy of psychoeducational reports. *Canadian Journal of School Psychology, 26*(2), 127-147. doi:10.1177/0829573511409722
20. Coons, K. D., Watson, S. L., Schinke, R. J., & Yantzi, N. M. (2016). Adaptation in families raising children with fetal alcohol spectrum disorder. Part I: What has helped. *Journal of Intellectual and Developmental Disability, 41*(2), 150-165. doi:10.3109/13668250.2016.1156659
21. Alliance Youth Services. (2014). *Fetal alcohol spectrum disorder*. Retrieved from http://www.allianceys.ca/fetal-alcohol-spectrum-disorder.html