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Commentary

Transforming FASD Diagnosis in Newfoundland and Labrador: A Community Collaborative Approach for Capacity Building and Network Development

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Abstract

This commentary delves into fasdNL's innovative work in establishing a comprehensive diagnostic network for fetal alcohol spectrum disorder (FASD) in Newfoundland and Labrador (NL). Although unparalleled in its complexity, FASD remains a persistently underdiagnosed and under-resourced lifelong condition. fasdNL, a community-based non-profit organization in NL, has significantly enhanced diagnostic capabilities and training for healthcare professionals, streamlined referral assessments, and addressed persistent gaps in FASD evaluation. The creation of fasdNL's Diagnostic Network represents a significant step forward in improving FASD diagnosis and support within the province. fasdNL's training program is grounded in the principles of Inter-Professional Health Education (IPHE), designed to foster collaboration among diverse health professionals. By emphasizing the importance of a multi-disciplinary approach to FASD diagnosis, the initiative enhances clinicians' capacity to work collaboratively in line with the Canadian FASD Diagnostic Guidelines. This training model not only improves diagnostic capacity but also promotes inter-professional practice by encouraging knowledge exchange and collaborative decision-making among healthcare providers. Further, it underscores the crucial role and potential of community organizations in addressing collaborative assessment and diagnostic processes by building on existing capacities within their regions.

Keywords: fetal alcohol spectrum disorder; diagnosis; community innovation; interprofessional health education

Introduction

Fetal alcohol spectrum disorder (FASD) is a lifelong neurodevelopmental disability caused by prenatal alcohol exposure (Cook et al., 2016). FASD affects individuals throughout life and poses a public health challenge. With an estimated prevalence rate of 4% among the general Canadian population, with higher rates in child welfare and justice systems that often lack appropriate services, the need for effective FASD diagnosis and support in both urban and rural areas is critical (Popova et al., 2019). The connection to alcohol use during pregnancy and its stigma complicates access to support and diagnosis (Bell et al., 2016; Choate & Badry, 2018; Dunbar Winsor, 2021).

Individuals with FASD often face challenges with motor skills, physical health, learning, memory, attention, communication, emotional regulation, and social skills (Cook et al., 2016). Individuals with FASD are at increased risk of mental health challenges (Wilhoit et al., 2017). Unique strengths and variability among how FASD presents across individuals makes accurate diagnosis essential but difficult. Therefore, enhancing diagnostic capacity and providing early assessments enable timely interventions and support, crucial for individuals with FASD (Doak et al., 2019; Reid et al., 2015). Additionally, specialized training for healthcare professionals improves the provision of care for those with FASD.

fasdNL, a pan-provincial non-profit organization, has been at the forefront of FASD work in Newfoundland and Labrador since 2013. Focused on increasing awareness through education, networking, knowledge mobilization, and resource development, fasdNL has made significant strides in developing FASD diagnostic training and a provincial diagnostic network.

Rationale for Initiative

Newfoundland and Labrador, with 510,550 residents (Statistics Canada, 2021), has faced challenges in FASD diagnosis, including limited training, low awareness, minimal funding, and inadequate diagnostic capacities (Dunbar Winsor & Morton-Ninomiya, 2018). This has led to underdiagnosis, long waitlists, and high costs for private evaluations, leaving many individuals and families without timely and affordable diagnoses. Since 2013, fasdNL has been developing and delivering FASD training, resources, providing family supports, and engaging in community-based research (fasdNL, 2025). Recognizing gaps in FASD assessment, fasdNL launched an initiative to improve diagnosis across the province. For example, access to FASD assessments for adults has been a persistent challenge as some geographic regions face limited access due to provincial health zone requirements.

Central to this effort was the creation of a collaborative training course for healthcare professionals involved in FASD assessment and diagnosis. Leveraging its internal expertise and network of knowledgeable researchers and clinicians in the province, fasdNL developed a comprehensive training program to train clinicians in a multi-disciplinary team approach in line with the Canadian FASD Diagnostic Guidelines (Cook et al., 2016). This training, delivered via Zoom at minimum cost[1] to ensure accessibility across NL, targeted active clinical practitioners, including physicians, speech-language pathologists, occupational therapists, and psychologists. To be eligible to register for the training, clinicians had to conduct diagnostic assessments as part of their professional duties and sought to add FASD assessments into the scope of their existing practice. The initiative evolved beyond training to create a provincial diagnostic network as planned. By collecting information from trained individuals who consented to be part of a diagnostic network database

[1] Historically, obtaining diagnostic training has been an expensive endeavour paid for by provincial governments and health authorities, mainly relying on expertise from western Canada.

(such as location, population served, cost of assessment, etc.), fasdNL created a system to connect professionals to individuals seeking FASD assessments or support.

The initial training delivery equipped 75 professionals with the necessary skills and resources to diagnose FASD, a first step to accessing supports and services and formed the basis of the fasdNL Diagnostic Network database. These professionals committed to being part of the network for at least a year, permitting the creation of diagnostic team assessments as recommended by Canadian guidelines. Clinicians or individuals who wish to seek an FASD assessment contact fasdNL who compile information such as region and age and assemble a diagnostic team. The network, maintained by fasdNL, enables coordinated diagnostic efforts and provides a centralized resource repository for continuous professional development. The creation of fasdNL's diagnostic network exemplifies Inter-Professional Collaborative Practice (ICP) by enabling healthcare professionals from different fields to work together in diagnosing FASD. Through this network, clinicians from diverse disciplines form diagnostic teams that function in alignment with ICP principles. By centralizing resources and facilitating communication across professions, this network bridges gaps in diagnosis

Implications and Future Directions

fasdNL's Diagnostic Network represents a transformative approach to FASD diagnosis in NL. The network works collaboratively with existing public and private assessment options to fill FASD gaps in more rural regions, provide alternates to lengthy waitlists, and increase assessment options province wide for adults. fasdNL targets underserved populations, including isolated areas, by improving access to FASD assessments. This addresses long-standing disparities in diagnostic services, particularly for adults who have historically faced challenges in receiving timely and affordable evaluations. By enhancing training and creating a network, fasdNL has improved access to FASD assessments and support. This model demonstrates the potential for similar community-based approaches to the assessment of other neurodevelopmental disorders, such as ADHD and autism, particularly in regions with limited healthcare capacities.

The network also offers valuable data-sharing opportunities, providing insights into the number of individuals seeking assessments, wait times, and barriers to diagnosis and support. This information can guide future organizational strategies and funding priorities, ensuring that community needs are met effectively.

Conclusion

fasdNL's innovative initiative represents a shift in the healthcare landscape of Newfoundland and Labrador. By addressing longstanding gaps in FASD diagnosis and support, this community-driven approach offers a blueprint for enhancing diagnostic capacities for various neurodevelopmental conditions. Ongoing evaluations of fasdNL's Diagnostic Network and training program will provide valuable insights into the effectiveness of this inter-professional approach. Data on the number of individuals trained, wait times for assessments, and regional diagnostic capacity will inform future improvements. These evaluations are critical for understanding how inter-professional collaborative models can be scaled and adapted to other neurodevelopmental disorders, such as ADHD and autism, in resource-limited settings. The success of this model underscores the importance of professional training, collaborative networks, and community engagement in improving healthcare outcomes.

Declarations

The authors have no conflict of interest or funding to declare. No research involving humans or animals was conducted. Ethics clearance was not sought.

Author Contributions

KDW drafted this commentary manuscript. HCP and LSW reviewed and provided input on the commentary manuscript. KDW, HCP and LSW are involved in fasdNL as staff or board members and worked collaboratively to develop fasdNL's Diagnostic Network as described in the commentary.

References

Bell, E., Andrew, G., Di Pietro, N., Chudley, A. E., Reynolds, J. N., & Racine, E. (2016). It's a shame! Stigma against fetal alcohol spectrum disorder: Examining the ethical implications for public health practices and policies. *Public Health Ethics, 9*(1), 65-77.

Choate, P., & Badry, D. (2018). Stigma as a dominant discourse in fetal alcohol spectrum disorder. *Advances in Dual Diagnosis, 12*(1/2), 36-52.

Cook, J. L., Green, C. R., Lilley, C. M., Anderson, S. M., Baldwin, M. E., Chudley, A. E., Conroy, J. L., LeBlanc, N., Loock, C. A., Lutke, J., Mallon, B. F., McFarlane, A. A., Temple, V. K., & Rosales, T. (2016). Fetal alcohol spectrum disorder: A guideline for diagnosis across the lifespan. *Canadian Medical Association Journal, 188*(3), 191-197. https://doi.org/10.1503/cmaj.141593

Doak, J., Katsikitis, M., Webster, H., & Wood, A. (2019). A fetal alcohol spectrum disorder diagnostic service and beyond: Outcomes for families. *Research in Developmental Disabilities, 93,* 103428.

Dunbar Winsor, K. (2021). An invisible problem: Stigma and FASD diagnosis in the health and justice professions. *Advances in Dual Diagnosis*, *14*(1), 8-19.

Dunbar Winsor, K., & Morton Ninomiya, M. E. (2018). The past, present, and future of fetal alcohol spectrum disorder work in Newfoundland and Labrador: A landscape paper for change. *Birth Defects Research*, *110*(16), 1215-1222. https://doi.org/10.1002/bdr2.1378

fasdNL. (2025). What we do. http://www.fasdnl.ca/whatwedo.html

Popova, S., Lange, S., Shield, K., Burd, L., & Rehm, J. (2019). Prevalence of fetal alcohol spectrum disorder among special subpopulations: A systematic review and meta-analysis. *Addiction, 114*(7), 1150-1172. https://doi.org/10.1111/add.14598

Reid, N., Dawe, S., Shelton, D., Harnett, P., Warner, J., Armstrong, E., & O'Callaghan, F. (2015). Systematic review of fetal alcohol spectrum disorder interventions across the life span. *Alcoholism: Clinical and Experimental Research, 39*(12), 2283-2295.

Statistics Canada. (2021). Census Profile, 2021 Census of Population. https://www12.statcan.gc.ca/census-recensement/2021/dp-pd/prof/details/page.cfm?Lang=E&SearchText=Newfoundland%20and%20Labrador&DGUIDlist=2021A000210&GENDERlist=1,2,3&STATISTIClist=1,4&HEADERlist=0

Wilhoit, L. F., Scott, D. A., & Simecka, B. A. (2017). Fetal alcohol spectrum disorders: Characteristics, complications, and treatment. *Community Mental Health Journal, 53,* 711-718. https://doi.org/10.1007/s10597-017-0104-0