ORIGINAL ARTICLE



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Integrated service delivery for individuals with fetal alcohol spectrum disorder

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Abstract

Background: Individuals with fetal alcohol spectrum disorder (FASD) experience complex needs that often necessitate support from multiple systems. There is growing evidence that people with FASD may benefit from integrated service delivery (ISD), but little is known about ISD elements and processes for this population.

Method: Using a multi-method approach involving a literature review, analysis of programme data, and staff interviews, we examined how ISD is enacted at a rural Canadian FASD centre, and identified facilitators, barriers, and potential impacts of ISD at the centre.

Results: We describe key elements of integrated FASD programming and identify important contextual factors and themes related to ISD barriers, facilitators, and impacts: (1) connection, (2) freedom and autonomy, (3) client-centred care, (4) learning and growth, (5) and reframing expectations.

Conclusions: This study may help to inform a roadmap for enhancing FASD service delivery and guiding FASD research and policy in Canada and beyond.

KEYWORDS

community-based care, diagnosis and intervention, fetal alcohol spectrum disorder, integrated service delivery, prenatal alcohol exposure

1 | INTRODUCTION

Integrated service delivery (ISD) refers to person-centred coordination and linkage of health, social, and/or community services to meet client needs (King & Meyer, 2006; Leutz, 1999). ISD models are particularly useful for enhancing continuity of care, optimising use of resources, and increasing service efficacy for populations with complex and dynamic needs, including those with disabilities (Beasley et al., 2016; Hébert et al., 2003; King & Meyer, 2006). Individuals with disabilities and their families experience diverse needs that often necessitate supports from a wide range of systems. ISD presents a potential model for enhancing these needed supports (Dubuc et al., 2011) and has been applied with people with a range of complex needs

and disabilities, including those with developmental disorders, mental health challenges, chronic diseases, as well as cognitive impairment, and dementia (Hebert et al., 2008). For these groups, ISD models can help bridge systems of care and enhance outcomes by meeting individual and family needs more effectively, increasing client satisfaction and empowerment, and improving health and quality of life (Center JMJ, 2012; Hébert et al., 2010; Schick et al., 2019).

1.1 | Fetal alcohol spectrum disorder and ISD

Fetal alcohol spectrum disorder (FASD) is a neurodevelopmental disability caused by prenatal exposure to alcohol, associated with diverse

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biopsychosocial complexities (Flannigan et al., 2021). Individuals with FASD experience brain- and body-based challenges, including cognitive, behavioural, and social-emotional difficulties (Cook et al., 2016), and increased risk for adversity across the lifespan. Because of the complex and often 'hidden' nature of FASD, the stigma associated with the disability, and a general lack of FASD-informed services, many people with PAE remain undiagnosed or misdiagnosed (Chasnoff et al., 2015). For those who are able to access FASD clinical services, diagnosis requires a comprehensive assessment from a multidisciplinary team (Cook et al., 2016). In Canada, individuals with PAE must experience 'severe and pervasive brain dysfunction' to receive an FASD diagnosis, in at least three of the following neurodevelopmental areas: motor skills, neuroanatomy/neurophysiology, cognition, language, academic achievement, memory, attention, executive functioning, emotional regulation, and/or adaptive and social skills (Cook et al., 2016). These brain- and body-based difficulties, combined with inadequate environmental supports, lead individuals with FASD to face disproportionately high rates of trauma, trouble with school and employment, mental health and substance use needs, and justice involvement (Flannigan et al., 2021; McLachlan et al., 2020; Streissguth et al., 2004).

Importantly, individuals with FASD and their families also have notable strengths, resiliencies, and experiences of success that may be leveraged to improve outcomes (Flannigan, Wrath, et al., 2021). Researchers have suggested that ISD may be well-suited for meeting the complex needs of individuals with FASD and their families (Masotti et al., 2015; Pei et al., 2021). However, despite the promise of such models, few studies have been conducted to examine FASD-specific ISD programmes. Very little is currently known about the barriers, facilitators, and potential impacts of integrated FASD service delivery.

1.2 | Lakeland Centre for FASD

The Lakeland Centre for FASD (LCFASD) is a multidisciplinary integrated FASD service centre in Alberta, Canada. A registered charity and not-for-profit society, the LCFASD has over 50 employees, and offers programmes in FASD prevention, diagnosis, support, and training, serving hundreds of clients each year (Lakeland Centre for FASD, 2022). The LCFASD supports a diverse range of clients and communities, spanning 350 square kilometres and serving one small city, dozens of towns and villages, a military base, seven First Nations communities, and four Métis settlements (McFarlane & Rajani, 2007). ISD at the LCFASD involves both the direct provision of in-house clinical and community-based programmes, as well as the creation and strengthening of connections between clients and support systems outside of the Centre. Throughout its history, the LCFASD has engaged in targeted research and evaluation to measure higher-level progress, process, impacts, and outcomes. Although this work is crucial, previous efforts have most often been related to governance (e.g., review of its operations model, comparison with other service delivery models), focused on a specific aspect of LCFASD's

service delivery rather than a comprehensive exploration across programs (e.g., a targeted study of their addictions recovery programme), and very few incorporated the perspectives of staff and clients.

Given growing evidence to support ISD models for individuals with diverse needs, including those with FASD, more studies are needed to investigate the key processes, facilitators, barriers, and potential impacts of such models. Research in this area is important not only for guiding the ongoing evolution of programming at the LCFASD, but also for informing practice, research, and policy in regions where FASD services are less developed but critically needed. In this study we sought to share knowledge about (1) the ways in which integrated FASD service delivery is enacted at the LCFASD, including history, aims, and scope; and (2) the facilitators, barriers, and perceived impacts of ISD at the LCFASD.

2 | METHOD

For this study we used a multi-method research design, described by Hunter and Brewer as an approach combining several different 'styles of research' in the same study, open to a 'full variety of possible methodological combinations', for example, surveys with interviews, or questionnaires, focus groups, and secondary data analysis (Hunter & Brewer, 2015). Greene and colleagues note that multimethod approaches allow researchers to establish 'an enriched, elaborated understanding of a phenomenon' (Greene et al., 1989, p. 258). In this case, we combined a literature review, secondary data analysis, and semi-structured interviews to help us understand the multifaceted nature and perceived impacts of the LCFASD ISD model. We followed O'Cathain et al. (2008) guidelines for reporting, which involves describing (1) our research approach and justifying its use, (2) the purpose, priority, and sequence of our methods, (3) our approach to sampling, data collection, and data analysis, (4) where, how, and by whom integration occurred, (5) the limitations of our approach, and (6) insights gained from our integration methods. Ethical approval for this study was obtained from the University of Alberta Research Ethics Board. Verbal consent was obtained for virtual interviews whereby a researcher reviewed study information before participants provided consent and began the interview.

2.1 | Data sources

Both qualitative and quantitative data were gathered for this study. We reviewed academic and grey literature, analyzed historical programme data containing client feedback (n = 216), and conducted semi-structured interviews (n = 4) with staff at the LCFASD.

2.1.1 | Literature review

We first conducted a narrative literature review to better understand the ISD process, or how ISD is applied, at the LCFASD. Academic articles were identified through Web of Science, PsycInfo, MEDLINE (1946-present), and PubMed research databases using ('Lakeland' OR 'LCFASD') AND ['fetal alcohol' OR 'FASD' OR 'prenatal alcohol' OR 'PAE'] as MeSH search terms. Commentaries and editorials were excluded. We then searched the grey literature using the same search terms in Google to identify web-based reports and documents not captured in the academic literature. We targeted other specific grey literature sources, such as the Alberta government website, FASD conference archives, and websites of other organisations related to FASD in Canada (e.g., PolicyWise for Children and Families, Kids Brain Health Network, Canada FASD Research Network). We also screened reference lists and asked LCFASD administrators to share any relevant internal reports not publicly available. Within the grey literature, many records had overlapping and redundant content, so when referencing this literature, we selected key sources with the most up-to-date or comprehensive description of relevant information. Sources were included for review if they were written in English and contained any information related to service delivery or programme implementation at the LCFASD.

2.1.2 | Programme data and staff interviews

To learn more about the facilitators, barriers, and potential impacts of ISD at the LCFASD, we examined client feedback data from FASD assessment and diagnosis, support programming, and prevention services. We also conducted semi-structured virtual interviews over Zoom with staff members from multiple LCFASD programmes. Interview questions were centred on the ways in which working at the LCFASD has influenced how staff conduct their job and how being part of the organisation has impacted staff wellbeing (see Appendix for interview script). We also sought feedback from the LCFASD clients and caregivers via a short survey, but this had very little uptake (n=1) and was therefore not included in our analysis.

2.2 Data analysis and synthesis

Relevant academic and grey literature were reviewed and synthesised to produce a narrative overview, generating an integrated summary of existing evidence pertaining to the history, development, aims, and scope of service delivery at the LCFASD. Following Green and colleagues' guidelines (Green et al., 2006), each record was reviewed individually, key findings were summarised, and themes were integrated and organised in relation to our research questions.

Qualitative and quantitative approaches were used to analyze client and staff feedback. Descriptive statistics (i.e., frequencies) were used to present quantitative data collected in client surveys (i.e., Likert-style ratings). A qualitative interpretive description approach was used to analyze data from open-ended client feedback and staff interviews (Thompson Burdine et al., 2021, Thorne et al., 2004). This method was chosen for its applied, flexible nature and emphasis on answering questions from a 'holistic, interpretive,

and relational perspective' (Thompson Burdine et al., 2021, p. 336), which often works best with multiple data collection strategies (Thorne et al., 2004). This approach aligns well with the broader framework of ISD and the specific service model implemented at the LCFASD. Analysis began with one researcher (KF) immersing themself in the data by reviewing transcripts and coding insights into participants' perspectives and cataloguing codes into a chart and looking for categories or patterns. Codes and categories were then refined with continued data engagement and consultation with a second researcher (DE). Finally, categories were interpreted and organised into themes and conclusions addressing our research questions, based on iterative discussion between three researchers (KF, DE, JP) and reviewed by all authors.

Quantitative and qualitative analyzes occurred simultaneously, and findings from both were synthesised and integrated through collaborative interpretation and discussion of findings, led by one author (KF) and reviewed by three others (DE, JP, LM). For client and staff feedback, different questions were asked with respect to experiences at the LCFASD. These perspectives were synthesised into overarching categories again following the qualitative interpretive descriptive approach of analyzing relationships, synthesising patterns, and contextualising categories with reference to our research questions (Thompson Burdine et al., 2021; Thorne et al., 2004) to provide a cohesive and holistic interpretation of perspectives.

3 | RESULTS

Our review of the academic literature yielded 33 records. After removing duplicates (n=15) and titles not related to the LCFASD (n=4), we reviewed 14 full texts, seven of which were ultimately included. Academic papers included a review paper, book chapter, consensus statement, pilot study/model evaluation, toolkit, and two secondary analyzes of programme data. From the grey literature, we identified 27 records, five of which were excluded because they contained no new or relevant information. Grey literature sources included government records (five reports, two newsletters, one discussion paper), LCFASD documents (eight reports, two newsletters, one evaluation), one presentation, one thesis, and one practice toolkit.

3.1 | Model process: History, aims, and scope

Our literature review and synthesis produced a comprehensive overview of the ways in which ISD is enacted at the Lakeland Centre for FASD. The LCFASD began in 1995 as a small committee of four FASD service providers and advocates dedicated to increasing awareness in the community about prenatal alcohol exposure (McFarlane, 2009). The focus of the committee then expanded beyond FASD awareness and education to increasing local capacity for FASD diagnostic services, post-diagnosis outreach, and support for women who may be at risk of using substances during pregnancy. In 2000, the LCFASD received funding for training in FASD

assessment, which opened doors to one of the first community-based FASD diagnostic clinics in Alberta (McFarlane, 2011). Then in 2008, as part of Alberta's FASD 10-Year Strategic Plan, the LCFASD became one of 12 centralized provincial service delivery networks (Government of Alberta, 2023), expanding to three additional satellite offices in the Lakeland region (Lakeland Centre for FASD, 2022). The LCFASD was one of few service networks to employ a *service-based* governance model, whereby the centre itself provided services in the region, rather than a *contract-based* model where networks build capacity in existing community agencies and contract services for clients with FASD (Fridman et al., 2017).

3.1.1 | Lakeland Centre for FASD services

The 'core business' of the LCFASD is to provide FASD assessment and diagnosis across the lifespan; support individuals and families; facilitate prevention and awareness activities; share FASD information; offer education and training; and engage in resource development (Lakeland Centre for FASD, 2017, 2020, 2022). Across programmes, the LCFASD offers a wide range of direct services for clients, families, and community members (see Table 1).

3.1.2 | FASD assessment and diagnosis

The LCFASD diagnostic clinic is open to individuals across the lifespan and was the first clinic in North America to provide FASD assessment services to adults (Stonehocker, 2012). Assessment at the LCFASD follows the current Canadian guidelines, involving a comprehensive medical and neurodevelopmental evaluation by a multidisciplinary team. For many clients, assessment at the LCFASD is the 'first step on a new path of support' (Government of Alberta, 2010). The LCFASD continually evolves its assessment and diagnostic services to meet changing community needs, including offering mobile services to connect with clients in or near their home communities, reduce service barriers, and promote follow through with recommendations made by the clinic teams (McFarlane, 2011, 2013; McFarlane & Rajani, 2007; Stonehocker, 2012). In response to evolving community needs (especially the COVID-19 pandemic), the LCFASD developed a hybrid telehealth model to continue reducing barriers for individuals seeking assessment (Lakeland Centre for FASD, 2022). The LCFASD is one of few service networks to provide services to the Métis Settlements FASD Network (Government of Alberta, 2015).

3.1.3 | Support for individuals and families

In addition to assessment and diagnostic services, the LCFASD offers a range of FASD support programmes facilitated by inter-agency integration, service coordination, and client- and family-based services (Government of Alberta, 2013; Lakeland Centre for FASD, 2020). FASD outreach is offered to all clients with an FASD diagnosis and is

designed to help individuals and families implement strategies and connect with resources to support quality of life (Lakeland Centre for FASD, 2021). For individuals with FASD aged 15 to 24 years, the transition programme supports the transition to adulthood by assisting youth and their families with planning, skill-building, relationships, and connecting with community resources. The LCFASD employment programme provides one-to-one individualised support with a coordinator as well as weekly group skill-building to prepare clients for employment or volunteer work (Government of Alberta, 2015). All clients connected to the LCFASD can access counselling services, which include strengths-based, FASD- and trauma-informed support for a wide variety of challenges and needs (Lakeland Centre for FASD, 2021). The transitional housing programme provides individuals with FASD a safe and stable place to live in the community for up to 3 months. Finally, the LCFASD offers week-long Summer Camps to children with FASD aged 7 to 17 (Lakeland Centre for FASD, 2016; Stonehocker, 2012).

3.1.4 | Prevention and awareness

In line with their mission to reduce the number of alcohol exposed pregnancies, the LCFASD offers three FASD prevention and awareness programmes. The Mothers-To-Be Mentorship programme was established in 2001 and provides long-term non-judgmental oneto-one support for women who are pregnant, planning to become pregnant, or recently gave birth (Lakeland Centre for FASD, 2022). The 2nd Floor Women's Recovery Centre similarly provides live-in support from a harm reduction perspective for women aged 15 years and older who are, or are likely to become, pregnant, and experiencing substance use challenges and other complex needs (Lakeland Centre for FASD, 2022). The 2nd Floor was developed in response to a community gap in residential addictions support for women who are pregnant and/or parenting (Government of Alberta, 2015). Finally, the Prevention Conversation is an FASD awareness programme established by the provincial government and implemented at the LCFASD where facilitators offer virtual and in-person training to professionals, culturally diverse communities, and members of the public across the service region (Lakeland Centre for FASD, 2020). Importantly, the integrated nature of service delivery at the LCFASD allows for resiliency-oriented and relational FASD services with and within Indigenous communities, including outreach, learning sessions, and diagnostic clinics, all contributing to collaborative action on FASD prevention and aligning with efforts towards reconciliation (Wolfson et al. 2019).

3.1.5 | Education and training

In addition to direct service delivery, the LCFASD offers various training opportunities for professionals, schools, parents and caregivers, agencies, organisations, and communities in the Lakeland region and across Canada (Government of Alberta, 2013). Community training

TABLE 1 Core services at the Lakeland Centre for FASD.

Core area and services offered (# clients served to date)	Programme elements and key findings
Assessment and diagnosis	
Paediatric team (735) and adult team (217)	 Diagnostic teams typically comprise a coordinator, physician, neuropsychologist, speech language pathologist, occupational therapist, public health nurse, cultural liaison, mental health worker, social worker, and disability services coordinator, depending on client age and needs (McFarlane et al., 2013; McFarlane & Rajani, 2007). The team has the flexibility to include other service providers depending on individual client needs, such as a psychiatrist, addictions counsellor, legal representative, career counsellor, or post-diagnostic outreach worker (Government of Alberta, 2010; McFarlane et al., 2013; McFarlane & Rajani, 2007). Diagnostic services have been associated with many positive outcomes such as increased financial stability, community responsiveness to FASD best practices, more support for advocacy, better engagement in volunteer or employment opportunities, increased understanding and adjusted expectations among family related to their loved one with FASD (McFarlane et al., 2013). The LCFASD diagnostic model has been described as 'the best way to provide services in a diverse rural geographical area'. (McFarlane, 2011) Caregivers report favourable experiences and high levels of satisfaction with new virtual assessment and diagnostic services. (King et al., 2023)
Support for individuals and families	
Outreach (938)	 Outreach connects clients with education and employment support, medical care, independent living supports, and meal programmes. (LCFASD, 2021)
• Transition (125)	 A transition toolkit was developed to help establish circles of support, facilitating advocacy case work, identifying stable housing and source of income, responding to risky behaviour and crises, promoting supported employment, connecting with the community, and supporting caregivers. (Badry et al., 2009)
Employment (136)	 Employment services provide on-the-job support based on clients' unique strengths and goals. (Government of Alberta, 2015)
Counselling (251)	 Counselling services are offered in both individual and group therapy settings and incorporate arts-based interventions.
Housing (30)	 Staff connect clients to a range of community services, such as mentorship, mental health and addictions support, and medical care, and work with the client to secure permanent housing.
• Summer Camp (~500) ^a	 LCFASD provides opportunities for children to learn about daily living skills, leadership, and social skills; identify their strengths; encourage hobbies and build friendships; and grow respect for self, others, culture, and nature (LCFASD, 2016). Caregivers receive respite from the challenges and stressors associated with supporting a child with FASD (Stonehocker, 2012).
Prevention and awareness	
Mothers-To-Be Mentorship (683)	 Mothers-To-Be helps women to navigate treatment and services in the community to support healthy pregnancies and lifestyles tailored to individual needs, such as substance use treatment, safe housing, financial support, and medical and mental health care (LCFASD, 2020).
• 2 nd Floor Women's Recovery Centre (336)	 The 2nd Floor provides clients with individual and group counselling, complementary therapy, skill-building, parenting courses, access to healthcare, cultural connectivity, and aftercare planning (Flannigan et al., 2022, 2023). The programme has shown strong social return on investment, whereby programme services were reported to reduce societal costs associated with homelessness, justice contact, undiagnosed and untreated health conditions, pregnancy and birth complications, and FASD-specific care by four times (Government of Alberta, 2018; McFarlane, n.d.).
Prevention Conversation	 The Prevention Conversation raises awareness of FASD and equips trainees with the skills and knowledge to have conversations about alcohol and pregnancy (LCFASD, 2020).
Education and training	
Community training	• In 2021/2022, the LCFASD reached more than 2000 people through community presentations and workshops (LCFASD, 2022).
Diagnostic team training	 Clinic training provides ongoing learning and mentorship, relationship building and collaboration, connection to research, and increased capacity for FASD assessment and diagnosis (LCFASD, 2021).
Resource development	• Numerous resources, such as an FASD diagnosis best practice guide (Green, 2018), clinic manual, online resources (Government of Alberta, 2011), numerous information series (Links, 2010), and recommendations for managing clinic waitlists (Burns, 2019), have been developed by the LCFASD. Relatedly, the LCFASD partnered with Alberta Employment and Immigration to develop resources for employment professionals and agencies supporting individuals with FASD and support a local college to develop a post-diploma FASD programme to strengthen the FASD workforce (Badry & Felske 2013). The LCFASD has also hosted several multidisciplinary.

strengthen the FASD workforce (Badry & Felske, 2013). The LCFASD has also hosted several multidisciplinary

Core area and services offered (# clients served to date)

Programme elements and key findings

conferences to disseminate information about ongoing developments in FASD research, practice, and policy (De Jong et al., 2021).

^aNote: This number is approximate and includes children who return over multiple years.

workshops and sessions are tailored to the needs and goals of groups seeking training (Lakeland Centre for FASD, 2022). The LCFASD also offers FASD diagnostic training for clinicians across Alberta and other provinces, increasing consistency in multidisciplinary FASD assessment across the country in line with the current Canadian guidelines (Lakeland Centre for FASD, 2021). The LCFASD has developed numerous resources to support FASD service delivery and has hosted several multidisciplinary conferences (Lakeland Centre for FASD, 2022). In recognition of its commitment to training and development, LCFASD was nominated in 2013 as a finalist for Alberta's Best Workplaces (Government of Alberta, 2013).

3.1.6 | Synthesising the literature

Synthesis of the evidence identified in our narrative review suggests that the community-based ISD model at the LCFASD helps to improve service delivery, build community capacity, increase coordination of care, and establish strong partnerships in the region. As described in one evaluation report (Stonehocker, 2012, p. 12):

A one-stop-shop is how it should work... Coordinated services are a commitment not a goal. Programs are piloted and adapted to best fit the client's needs. Innovation is encouraged and 'doing whatever it takes' isn't a career risk... Within this integrated service delivery model, clients are less likely to 'fall through service cracks' with a single organization coordinating their supports and programming.

Service integration and diverse partnerships benefit agencies, who may experience increased FASD understanding, access to FASD expertise and service referrals, stronger collaboration and collegial relations, and identification of needed systems change (McFarlane, 2011). Individuals and families benefit through increased service investment and access, reduced travel needs, stronger relational and life-long support, and more relevant recommendations from the clinical team. Communities gain increased understanding of alcohol use during pregnancy and the needs associated with FASD, better referral options, and a sense of involvement and ownership (McFarlane, 2011).

Important contextual factors

Based on our synthesis of the literature, we identified several broader contextual factors relevant to the aims and scope of ISD at the LCFASD. First, the work conducted at the Centre is often described as being highly relational, building strong connections with clients, families, communities, and agencies. Relatedly, the LCFASD is inclusive in aim and scope, both in terms of considering the holistic needs of clients and their families and wider circles of care, and in an eagerness to collaborate with other teams and individuals with vested interest. Multiple records refer to the LCFASD as being responsive to the communities, agencies, and clients with whom they work, with an openness for flexibility guided by identified needs. Similarly, the aims and scope of the Centre are reported to be continuously evolving to accommodate and address changing client and community needs. LCFASD services are described as existing on a continuum, facilitating a pathway of care across a wide spectrum of supports that can be accessed by individuals and families, as needed, across the lifespan.

3.2 | Barriers, facilitators, and impacts: Client and staff perspectives

Our examination of programme data and interviews with staff informed our understanding of the potential impacts of ISD at the LCFASD. In total, we analyzed feedback data from 97 clients (57 paediatric and 40 adult) who accessed assessment and diagnostic services, 16 clients who accessed support services (transition, employment, and housing), and 103 clients who accessed prevention services (2^{nd} Floor Recovery Centre). We conducted four interviews with staff from support (n=3) and prevention (n=1) programmes. Client feedback and staff perspectives were integrated through common patterns and subthemes identified across data sources. Together, data were conceptualised in terms of five themes: (1) building and fostering connection, (2) freedom and autonomy, (3) client-centred care, (4) learning and growth, (5) and reframing expectations.

3.2.1 | Building and fostering connection

Our analysis of staff and client feedback highlighted **connection** as being at the forefront of ISD at the LCFASD. Connections were described by staff and clients at all levels of service delivery, including client/staff relational connections, consultation between LCFASD

¹For example, client reports of flexible programming, experiences with staff who go above and beyond, and clients feeling increased control over their lives along with staff reports of feeling trusted and valued by supervisors, given space for breaks and self-care, and describing a dynamic and engaging work environment were integrated and conceptualised as the broader theme, *autonomy and freedom*.

staff and supervisors, and bridges across professionals and agencies to create strong circles of support for clients. Many clients expressed their appreciation and gratitude for LCFASD staff, who were described as warm, welcoming, compassionate, non-judgemental, and positive. In this way, staff were able to create a 'safe space' to connect with clients. Similarly, many staff reported strong connections with managers and supervisors: 'My supervisor's been hugely supportive... it's been a really good relationship'.

Clients also reported on the ease with which they were able to connect with LCFASD services; most clients who provided feedback about assessment and diagnosis (n = 92, 94.8%), support services (n = 7, 100%), and prevention programmes (n = 74, 73.3%) noted that the process for accessing the LCFASD services was manageable.

Staff described community connections that are forged across programmes and systems beyond the Centre. In describing their role, one participant noted 'I contact everything from the schools to public health to pediatricians to doctors to community services'. These connections were perceived to increase access to resources for clients and facilitate more integrated and appropriate services: 'I know how to direct clients or service providers to the right, you know, person kind of thing or the right agency, whatever they need'. Most clients (n = 5, 71.4%) who provided feedback about support services agreed that their programme coordinator connected them with opportunities in the community. Regarding the impacts of these community connections, one staff member noted that 'The Lakeland Centre really supports building those relationships in your community, and it actually will move mountains for the women you serve'. Similarly, connections were discussed in relation to enhanced community capacity, with multiple staff describing 'ripple effects' of expanding impacts: 'we're reaching these people... and then they're going to spread the word'. Several staff described their most notable and fulfilling accomplishments in terms of facilitating connections that lead to change for clients: 'when we... inform either a school or a caregiver about a strategy, and they actually follow through, and it's actually successful... that's gold. Those are really happy days'.

Although **connection** was predominantly interpreted as a facilitator for helpful outcomes, participants also discussed relevant barriers, particularly in terms of relational disconnect. Staff noted that, at times, there can be misunderstandings around roles and expectations between programmes, and physical divisions within the workspace that can impede connections between staff. A small number of clients also referred to relational barriers or disconnect with staff. For example, clients from the 2nd Floor reported that 'there needs to be more staff that have personal experience dealing with addictions so we can relate to them better' and that they need 'more staff available to meet with one on one in the evenings'.

3.2.2 | Freedom and autonomy

Another theme identified in participant feedback was **freedom and autonomy**. Staff described feeling valued, respected, and trusted by their supervisors which allowed them the freedom and flexibility to do

their 'best work'. One staff member explained: 'I've been ... fortunate enough that my co-workers and my supervisors trust me that I do colour outside the lines, but always in mind is well-being for the women I serve'. Multiple clients commented on this flexibility with staff 'thinking outside the box', reporting that 'staff went above and beyond to help'. Room for staff autonomy and freedom seemed to promote a sense of confidence and competence, with one staff noting 'When I feel like management trusts me to do my job, I feel like I'm better equipped to do my job'. It also seemed to give staff the freedom to set boundaries and prioritise their self-care and work/life balance when needed: 'I do still try and take the time to find some alone time... and just, you know, just shut everything down. And that I am allowed to turn this [refers to phone] off and try to keep a balance going'.

The notions of *freedom and autonomy* were also apparent within client feedback with mixed responses in terms of how clients felt about the flexibility and choice they had within specific LCFASD programmes. Some clients reported 'it felt like I can have an open mind here' whereas others felt that staff 'should be more lenient... and find ways to actually work around clients' needs and just bending the rules a bit here and there'. On the other hand, many clients (especially those from the 2nd Floor) explained that through their time at the Centre they gained autonomy, choice, and control over their lives: 'Today I take full accountability and responsibility for the negative effects my drug use has had on my life' and 'I have more control of myself, and I have to say I do love and enjoy it very much'.

Barriers related to **freedom and autonomy** were described by several staff, specifically around how system gaps, and limitations in funding, time, and resources left some feeling like their 'hands are tied'. One staff member noted 'I felt really frustrated, given that I had no way to support her. Because the things that she needed, I couldn't provide her, the organization couldn't provide her. She needed food, she needed housing, she needed clothing, and we just were unable to do that'.

3.2.3 | Client-centred care

Our third theme underscored the importance of client-centred care. Staff described a collective responsibility to serve clients with a wraparound and comprehensive approach, ensuring a strong circle of support:

I help them and their supports build a plan to move into adulthood... all areas of their life, their health and wellness, education, employment, finances, culture, parenting, kind of every aspect of their life to make sure kind of everyone that's supporting them is on the same page, and that during this very vulnerable time in their life... they're less likely to fall through the cracks.

Staff interviews revealed that a key element of **client-centred care** at the LCFASD is an individualised and humanistic service approach,

where the uniqueness and inherent value of each client is recognised and appreciated. As one staff member explained, working at the Centre has helped her to learn that people with FASD 'are so vastly unique, and letting them show you who they are and what they need, I think has been really, really important'.

Individualised needs were discussed in terms of varying service priorities, ranging from immediate basic needs such as financial support and housing (e.g., 100% of housing clients who shared feedback reported that they were provided with a safe and clean place to stay) to longer-term goals such as meaningful employment or postsecondary education. The humanistic element of service delivery was further reflected in feedback from 2nd Floor clients, who reported their rights were respected (n = 87, 87.9%), their private information was kept confidential (n = 94, 91.3%), and they felt comfortable asking questions (n = 83, 82.2%). The client-centred aspect of the LCFASD service model also allows for continuous support that, for some clients, may extend over many years. One staff member considered one of her greatest accomplishments to be supporting a longterm client: 'To see this kid that has basically been handed every bad card to him throughout his life. See him succeed, and you know us be the ones to stand by his side along the way was amazing'.

Along with these helpful impacts of client-centred care, some clients also described individualised barriers such as logistical challenges, noting for example that assessment 'was difficult due to transportation and scheduling' and 'it was a long day'.

3.2.4 | Learning and growth

Next, many staff and clients shared their perspectives related to learning and growth. For staff, opportunities for training and ongoing learning facilitated confidence and competence at work: 'A lot of people struggle to find a job... I've not only found one, but I've also been given a lot of responsibility and opportunity to grow along the way'. Experiential learning was described by some staff as especially impactful: 'You not only get trained, but then you will live and breathe it for a whole summer... you're actually applying it, and really seeing the spectrum'. These learning opportunities were associated with increased understanding of the nuances of FASD, and awareness and ability to recognise FASD-related needs across all aspects ISD: 'Getting to sit in on the diagnostic clinic as well... You see the whole diagnostic process, and then also working on the outreach side, you get to see the interventions as well, and then, being in the Center, a lot of the prevention side as well. I am also trained in the Prevention Conversation, so getting the full view of it'.

Learning and growth were also relevant for clients, many of whom reported that their experience at the LCFASD helped them to better understand themselves or their loved ones with FASD: 'the Lakeland Centre is very helpful and information about understanding the diagnosis of FASD and how it affects other people's brain, including myself'. Many assessment clients reported that their experience helped them to better understand FASD (n = 75, 78.1%), and most caregivers reported that it helped them to better understand their

loved one's strengths (n = 76, 86.4%), and to feel more prepared to help (n = 76, 86.4%). Many support service clients who provided feedback (n = 6, 85.7%) reported that they learned new skills to benefit their life. Learning and growth were especially notable among 2nd Floor clients, many of whom reported increased self-understanding and awareness: 'I have learned and grew to look and get to know myself. I understand my traumas... where they came from'. This learning and growth seemed to increase confidence and empowerment for some clients, with one explaining that 'knowing that I have the courage to speak up for myself and have my rights to say NO... for me and better myself'. Several clients recognised growth as a long-term journey and recovery as an ongoing process: 'although I still have a long way to go, I definitely learned a lot of new skills and I also learned a lot about myself' and 'I feel like I can do this and keep on doing what I learned. Because I know it takes time to get through it and to put it into action'.

Several barriers and areas for improvement were identified related to learning and growth. Staff noted that their opportunities for learning were at times limited by funding: 'Obviously working for a non-profit, the money aspect is unfortunately, you know, a part we have to consider. But anytime, especially if there's like free webinars or trainings, anything that's really going to benefit my job and my clients'. Feedback from some clients revealed potential areas for programme improvement, including more focus on certain topics, greater variety of activities, and deeper learning in some areas. For instance, one employment programme client requested 'More group meetings. More job shadowing... More opportunities for hands-on visual learning' and a client from 2nd Floor explained 'I did not do enough selfwork on specific issues... some of the things I wanted to deal with only just got touched on'. Clients also discussed the desire to learn more concrete strategies to translate what they have learned into meaningful change: 'I understand [my daughter] but that doesn't always help when dealing with her'. When discussing the impacts of substance use in her life, one 2nd Floor client noted that 'I feel I already had an understanding of the impact but needed more tools to deal with it'.

3.2.5 | Reframing expectations

The final theme, **reframing expectations**, was apparent in several ways. Staff described adjusting their expectations of themselves and their roles at the LCFASD, and needing to 'expect the unexpected', and accept the good days with the bad:

There are days that... maybe I don't feel like I'm doing the best. But that's... not the actual, you know, overall picture, right? ... Overall, I feel like I try my best. So, you know, I can't be perfect'.

Several staff also highlighted the importance of adopting a positive attitude, recognising that 'success' is relative to each client, and reframing what it means to make an impact:

Maybe I didn't get anywhere in terms of emotional regulation or working on trauma or grief and loss with this client. But I was able to engage with them in a dignified, respectful way where they were treated like a human being... And that being a significant part of the work

Another staff explained that 'how you measure success' really matters:

...If a woman showed up to her doctor's appointment today... Or even showed up at the office at one o'clock when she was supposed to meet me. That's awesome. Texts me back, even though she's been ghosting me for three weeks... You're able to kind of see those small successes, that's huge steps forward.

The notion of **reframing expectations** was also apparent in clients' views about the future. One 2nd Floor client explained that her time with the Centre helped improve her sense of optimism: 'I see more positive in my life now. I found myself again', which also related to increased hope for the future: 'I can choose a better life for myself'.

There were also challenges with **reframing expectations**, especially barriers in terms of bridging gaps for clients and finding common ground with other service providers. One staff member explained: 'I still haven't heard from the person I need to connect with to start offering services to these kids, so they're in limbo. But it's not my fault... that's really challenging... I don't like accepting that, but I have to'.

4 | DISCUSSION

ISD is increasingly recognised as best practice for individuals with disabilities and diverse needs, but very little is known about how this model can be carried out, or what impacts it may have for individuals with FASD and their families. In this study, we aimed to describe the ways in which integrated FASD service delivery is enacted at the Lakeland Centre for FASD, and identify facilitators, barriers, and potential impacts of these services. A multi-method approach was used to integrate and synthesis information from multiple sources, consolidating lessons learned about ISD at the LCFASD. Based on our review of 29 records from the academic and grey literature, as well as analysis of programme data (n=216) and interviews with the LCFASD staff (n=4), we identified five themes relevant to the potential impacts of ISD at the LCFASD, which we embedded within broader contextual factors that may facilitate the implementation and effectiveness of this model.

Broadly, the LCFASD model is described as highly relational, inclusive of diverse needs and perspectives, responsive to community and client needs, continually evolving, and providing a robust continuum of care. Within this environment, ISD is further facilitated by prioritising individualised and client-centred care, building connections

to create strong circles of support and ripple effects in the community, promoting freedom and autonomy to enhance confidence and competence for staff and clients, providing opportunities for ongoing learning and growth, and allowing for reframing expectations about outcomes and success. These themes point towards processes and elements that have contributed to the successes achieved at the LCFASD (Stonehocker, 2012). Our findings also align with factors previously identified by researchers as key components of ISD in general populations (Ross & Greenberg, 2020) as well as those with complex needs (Pei et al., 2021), such as shared understandings and partnerships, strong and long-standing relationships with colleagues and community partners, client/family-centred care, case management, and communication across silos (Center JMJ, 2012). Building on this previous literature, the current study contributes to a potential roadmap with key elements for effective ISD for people with FASD and their families. It also highlights potential priorities for ISD with clients with FASD and other complex needs, underscoring the importance of client-centred, collaborative, inclusive, flexible care, which has implications for guiding clinical practice and policy advancement.

Another aim of this research was to identify potential barriers that may impede effective integrated FASD service delivery, and several areas for growth and improvement were described. First, given the relational nature of work at the LCFASD, interpersonal differences or disconnect may interfere with successful implementation of ISD for both clients and staff. Because relationship-based support can help to increase wellbeing and autonomy for individuals with disabilities (Björnsdóttir et al., 2015; Dowling et al., 2019), including FASD, efforts to maintain strong, supportive interpersonal connections should be a focal priority in ISD. Other common barriers identified in this study included practical and logistical challenges with client access to services (e.g., lack of transportation), as well as staff capacity to provide services (e.g., limited funding). Gaps in resources, sustainable funding, and access to FASD-informed supports are welldocumented for people with FASD (Anderson et al., 2019; Petrenko et al., 2014), indicating a need for authentic commitment from government and policymakers leading to long-term systems-level change. Finally, analysis of client and staff feedback identified experiential, hands-on learning, and tangible strategies to translate learning into practice as a programming-specific area for improvement. Several of these challenges have been noted in past evaluations as barriers to the success of the LCFASD including growing client need; challenges defining success for clients with complex needs; sustained funding; and record management (Stonehocker, 2012), which further highlights specific areas for continued growth and improvement at the Centre.

4.1 | Limitations and future directions

Although this study is an important first step in targeted research around ISD and FASD, several limitations should be acknowledged. First, given that some of the information analyzed in this study was historical programme data, there were numerous gaps with many clients and several programmes at the LCFASD not reflected in the

findings. Relatedly researchers were not involved in the initial collection of programme data, and it is therefore unknown whether there may have been inconsistencies in collection approaches. Since client feedback data was de-identified before analysis, we were not able to characterise demographic information. Similarly, to protect participant anonymity and confidentiality, we did not collect or report on staff demographics. As well, there was no uptake on the survey we designed for past clients and family members, which left a significant gap in terms of our understanding of lived experiences for individuals

receiving services. Nor did we speak with partner agencies or commu-

nities regarding their interactions with the LCFASD, thus we do not

have any data to reflect those important perspectives.

Future research incorporating more systematic data collection, from multiple points of view, following clients and families longitudinally, and investing time to understand how best to engage with and learn from individuals with lived experience would allow us to further understand the widespread impacts and long-term outcomes associated with ISD at the LCFASD. Moreover, future work that compares the process and impacts of service delivery at the LCFASD with other programmes and models will be important for determining effectiveness and identifying common strengths, challenges, and unique contributions of this model and others. Additionally, further research is needed on the ways in which social determinants of health and unmet needs can impact individuals with FASD and their families and may differ for those of varying socio-economic status. For instance, participants in this study spoke of client needs around financial and housing stability, access to education, affordable and high-quality health care, and social inclusion, all of which are known to impact health outcomes, especially for equity-seeking populations such as those with disabilities, including FASD (Organization WH, 2024; Badry & Felske, 2013; De Jong et al., 2021).

Findings from this study regarding the barriers of ISD at LCFASD also reveal important limitations about the model itself. These include logistical limitations of reaching clients in a broad and rural geographic area, limited funding and resources, programming gaps, interpersonal and relational differences, and the difficulties inherent in coordinating and navigating at the interface of multiple systems and agencies to best meet client needs across a wide range of areas. Finally, the LCFASD being in a rural community means that lessons learned from this Centre may not generalise to service networks in other geographic locations, particularly urban centres. Despite these limitations, this research helps to guide the progress of integrated FASD services in Alberta and beyond.

5 | CONCLUSION

What started as an effort to increase FASD awareness evolved over nearly 30 years to become an integrated and wrap-around system of support for individuals with FASD and their families. With its breadth of programming, the Lakeland Centre for FASD provides a continuum of services that can be accessed by clients of any age, at any point, as often as needed. Building on relational strengths and connections,

LCFASD services continue to expand and evolve in response to client and community needs, filling service gaps and reducing barriers to FASD-related support in the Lakeland region. This responsive and inclusive approach to FASD service delivery allows the LCFASD to provide person-centred, integrated services that are fundamentally driven by individual and community needs. Lessons learned at the LCFASD over the last 30 years may inform continued programme development and advancement towards effective and impactful FASD services for individuals, families, and the broader community.

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CONFLICT OF INTEREST STATEMENT

None of the authors has a conflict of interest to disclose.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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APPENDIX A

A.1 | LAKELAND CENTRE FOR FASD SERVICE PROVIDER INTERVIEW SCRIPT

Our goal in this study is to learn about how working at the Lakeland Centre for FASD impacts programme staff. We want to hear about how the experiences you've had at the LCFASD have influenced the way you do your job and how being part of the organisation has impacted your wellbeing.

To start, I would like to know about the role(s) you play at the LCFASD.

- 1. Please briefly share what programme(s) you work in and what type(s) of clients you see.
 - a. Prompts: What are your client(s) ages? Do you work with individuals, families, or both? In what settings do you primarily work (e.g., clinic or 'in the field')?
 - b. Prompt: Do you primarily work as part of a team, or on your own?

Now I will ask you about some of the experiences you've had while working at the LCFASD and how they have influenced the way you work.

- 1. How has your understanding of FASD changed through being a part of the LCFASD?
 - a. Prompt: In what ways has the organisation influenced this change?
- 2. In what ways does the LCFASD influence how you feel about your ability to do your job?
 - a. Prompt: How has the organisation impacted your skill development?
 - b. Prompt: How has it influenced the opportunities and resources available to you?
- 3. Can you tell me about a time when you felt really good about your ability to meet your client(s) needs?
 - a. Prompt: In what ways has the Centre influenced this confidence?
- 4. Can you tell me about a time when you *did not* feel good about your ability to meet your client(s) needs?
 - a. Prompt: How were you able to manage this?

The next questions are about your wellbeing at work.

- 6. What kinds of things have been important for supporting your wellbeing at work?
 - a. Prompt: In what ways has the LCFASD influenced your wellbeing?
- 7. Can you tell me about a time when you felt really, deeply satisfied with your job?

To wrap up, my final question is about what you might change at the LCFASD.

1. If you had a magic wand, what would you change at the LCFASD to make sure that you are at your best and are able to do your best with your clients?