



An Integrative Systems Approach to Enhancing Service Delivery for Individuals with Complex Needs

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Abstract

Purpose of Review There are a lack of system-wide integrative services for individuals with complex needs and a corresponding demand for advancing cross-disciplinary practices in community settings. This demand is especially acute for individuals with fetal alcohol spectrum disorder (FASD) and a gap we have sought to address.

Recent Findings We present findings from a literature scan to guide service delivery for individuals and families affected by FASD and other complex needs: four overarching guiding principles for policy decision-makers, seven guiding practices for organizations, and 23 guiding practices for service providers.

Summary These identified principles and practices bridge diverse perspectives, with potential for their implementation to provide consistent, evidence-based services to underserved populations with complex needs.

Keywords Fetal alcohol spectrum disorder · Guiding practices · Service delivery · Complex needs

Introduction: FASD and Service Gaps

In this article, we advance strategies for enhancing service delivery for individuals with complex needs with a focus on individuals with fetal alcohol spectrum disorder (FASD). Guiding practices can promote knowledge that is useful to key stakeholders such as public healthcare practitioners, researchers, and evaluators [1], toward the ultimate goal of improving service delivery for individuals with complex needs. The urgency of the need for enhanced service delivery is especially acute for individuals with FASD, who most often have complex needs including challenges in their physical, mental, and behavioral functioning related to prenatal alcohol exposure [2].

Researchers estimate that the global prevalence of FASD is approximately 7.7 per 1000 births, depending on the population [3]. Individuals with FASD may present with a wide range of neuropsychological disabilities that impact their

functioning [4]. Over 90% of individuals with FASD have mental health issues that may include depression, mood and anxiety disorders, attention-deficit/hyperactivity disorder, and conduct disorder and are at a high risk for suicidality and substance abuse problems [5, 6]. The relationship between mental health issues and other individual and environmental factors associated with FASD is complex and likely reciprocal [5, 7]. Individuals with FASD receive mental health services from a variety of care providers, including primary care physicians and nurse practitioners [8]. All mental health and care providers need to consider a network of services, an alignment of service delivery, and an integrated approach to mental health and wellness to support individuals with FASD [7].

Enhancing services to meet the needs of individuals with FASD has been difficult to achieve for two core reasons: first, research informing intervention and service delivery for individuals with FASD is still emerging [9, 10]. Second, individuals with FASD are complex and present with diverse challenges across multiple domains of functioning including behavioral regulation, mental health, and cognition and experience the systemic effects of chaotic family environments and involvement in social services [6]. Consequently, it is difficult to fit individuals with FASD into existing systems of service delivery. Service providers have combined practical wisdom gained from previous experiences and research from the general disability literature in nonsystematic ways in an attempt to

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react to challenges presented in meeting the needs of individuals with FASD. Among the problems revealed by this reactive approach are inconsistency and a lack of evidence-based service delivery practices.

Given the nascent state of research on FASD, the current literature scan provides stakeholders with guidance for providing services to individuals with FASD and their families. In recognition of existing challenges with attaining a diagnosis of FASD, we expanded our population scope to avoid unintentional constraints of requiring a diagnosis for service access. As such, we intentionally present guiding practices that are applicable to individuals and families with complex needs more generally, rather than restricting our focus to individuals and families dealing with FASD. The term “individuals with complex needs” is used to describe individuals whose needs exceed those that a single service provider can address and captures individuals based on functional challenges as opposed to diagnostic categories alone. Our aim is to guide the consistent application of foundational principles that can inform systematic evaluations and enhance outcomes for this population.

Through this literature scan, we advance principles and practices to guide enhanced service delivery for individuals and families affected by FASD and other complex needs. In advancing guiding practices to provide consistent and evidence-based service delivery for underserved populations with complex needs, it was necessary to take a systems perspective. This is because of the interdependency of the embedded societal, organizational, and individual contexts in which service delivery takes place. By applying a systems perspective, we can better recognize the dynamic and multiple embedded systems involved in serving individuals with complex needs. Accordingly, individuals, families, agencies, staff members, and broader systems are all represented, and their perspectives are considered throughout the guiding practices. The literature scan offers an essential starting point for bridging diverse perspectives and building shared understandings among stakeholders to support consistent and evidence-based service delivery to underserved populations with complex needs.

Method

A literature scan was completed to identify, describe, and integrate current practices for working with individuals and families with FASD, recognizing that this may extend to those who have complex needs more broadly speaking. The literature scan was guided by the following question: What evidence exists in the literature to guide effective service delivery practices for individuals with complex needs and their families? The databases searched during the literature scan included Academic Search Complete, PsycINFO, Education

Resources Information Center (ERIC), and Cumulative Index to Nursing and Allied Health Literature (CINAHL). The initial search involved using the term “Fetal Alcohol Spectrum Disorder” paired with any of the following terms: service delivery, best practices, promising practices, evidence-based practices, services, and intervention. Initially, we focused on identifying peer-reviewed studies to increase understanding of the scientific research on current practices. However, we found the scientific literature to be limited in this area. Therefore, our search was expanded to include gray literature including program evaluation reports, conference presentations, and government documents.

Once the literature was identified, we were guided by Roberts and Nanson’s promising practices [11] in our identification, descriptions, and ranking of the guiding practices. Our ranking system distinguished among four categories to support each guiding practice, using the following criteria:

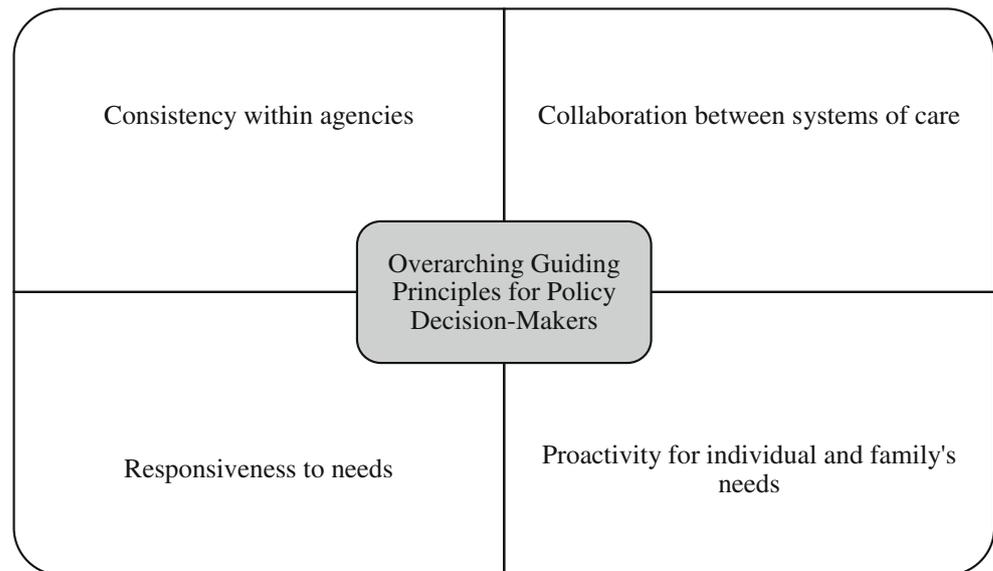
- Good evidence: two or more controlled studies (i.e., randomized control trial).
- Moderate evidence: two or more quasi-experimental studies or one controlled study (i.e., randomized control group).
- Some evidence: two or more case studies or evaluations that do not have control or comparison groups or one quasi-experimental study (i.e., nonrandomized comparison group).
- Expert consensus: including the perspectives of expert practitioners, educators, other stakeholders, and government documents; this level of evidence lacks formal research or evaluation.

Finally, we carried out a thematic analysis [12] of the literature to identify themes and subthemes to provide practical guidance for policy decision-makers, organizations, and individuals whose work involves individuals with complex needs. Two graduate students (one is the third author of this paper) generated subthemes in consultation with the first author. Both reviewers then hand-coded subthemes and generated rich descriptions. Where there was disagreement in coding, the reviewers consulted with the first author to reach consensus. Next, themes were generated through multiple discussions with the first and second authors.

Results and Discussion

The literature scan resulted in the identification of practices for guiding enhanced service delivery for individuals and families affected by FASD and other complex needs at three levels (see Fig. 1). These include four overarching guiding principles for policy decision-makers, seven guiding practices for organizations categorized into three

Fig. 1 Four overarching guiding principles for policy decision-makers



domains, and 23 guiding practices for service providers categorized into nine domains. These are discussed below.

Overarching Guiding Principles for Policy Decision-Makers

Four overarching guiding principles were generated that permeate the guiding practices for organizations and service providers (see Fig. 1). As described below, these principles include consistency, collaboration, responsiveness, and proactivity; they represent an overarching philosophy of practice and therefore can be considered guiding principles. These are intended to be high-level principles for which more specific examples are provided in the organizational-level domains and guiding practices that follow.

- **Consistency:** this principle includes a shared understanding of the needs of complex populations, such as those with FASD, within systems, as all points of care should be similarly educated in order to promote common goals. Consistency within agencies, from management through frontline service delivery, enhances delivery of structured and stable services across systems and can be realized through establishing shared understandings.
- **Collaboration:** truly collaborative and integrated systems require organizational support to facilitate effective interaction between agencies. This allows employees to engage in complex case management, coordination of referrals, and intentional planning between types of services. Collaboration across agencies enhances the integration and efficiency of services across systems.
- **Responsiveness:** this principle reflects the balance between dependency and complete independence; achieving interdependence in this way entails matching expectations

to the individual, and sometimes their families as well, and then providing and adapting services in response to outcomes. Responsiveness to individual needs enhances the outcomes of services across systems.

- **Proactivity:** anticipation of individual and family needs fosters personal and familial control in which some challenges or difficulties may be anticipated. This reduces the need for reactive response and promotes success-focused planning. This increases awareness of transition periods and facilitates clear and early planning to navigate change across systems.

Guiding Practices for Organizations

Thematic analysis produced seven guiding practices for organizations, categorized into three organizational-level domains: (1) the nature of support service delivery, (2) content for continuing education for service delivery support workers, and (3) areas for targeted hiring practices. These three domains and seven guiding practices are discussed below and summarized in Table 1.

Nature of Support Service Delivery

A *collaborative service delivery approach* was ranked as having some evidence of being an efficacious practice. Service providers have identified a need to streamline care for individuals and families affected by FASD [13]. Centralized services help parents and caregivers conserve time and energy [14] but are not always feasible because of funding barriers and geographical distance. Approaches that have been proposed to facilitate increased integration of care include electronic medical records, a client-centered medical home, and

Table 1 Organizational-level domains and ranked guiding practices for organizations

Organizational-level domains	Guiding practices for organizations	Ranking of evidence
Nature of support service delivery	1. Collaborative delivery approach	Some evidence
	2. Transition service focus	Expert consensus
Content for continuing education	3. FASD-competent workforce	Expert consensus
	4. Disability context framing training	Expert consensus
	5. Vicarious trauma-focused content	Expert consensus
Areas for targeted hiring practices	6. High interpersonal and work skills	Expert consensus
	7. Familiarity with complex case management	Expert consensus

multidisciplinary primary care group practice models [13]. Providers of support services are described as working with community partners toward achieving common goals, delivery of interventions, and consistent messaging [15, 16].

A *transition service focus* was ranked as having expert consensus. As young people with FASD reach the legal age of majority, they are likely to experience challenges as their vulnerabilities clash with a new set of socially imposed expectations and responsibilities. This represents a compelling case to provide more intensive support in daily living activities for youth transitioning into adulthood, instead of the conventional drop-off of care [17, 18, 19, 20]. An extension of care beyond age 18 to aid in the development of daily living supports is recommended for vulnerable individuals who are working toward independent living [21].

Content for Continuing Education for Service Delivery Support Workers

Having an *FASD-competent workforce* within systems of care was ranked as a practice for which there is expert consensus. Experts consistently describe how services for people with FASD and their families should have staff with specialized training in serving individuals with FASD. Support workers who utilize an FASD-informed approach are more likely to be understanding when addressing challenges that individuals with FASD experience have stronger relationships with individuals and their families, experience less frustration, use problem solving approaches that are more constructive and effective, and have higher job satisfaction [22, 23].

Support worker training should be situated within a disability context; this practice was ranked as having expert consensus. Understanding FASD as a brain-based disability can inform expectations, in turn shaping interpretation of behavior and goodness of fit of supports [15]. Developing core competencies is the key to effective training [24], and support workers should have the opportunity to practice these skills

in their work. This may entail engaging in consultations and developing case planning strategies [15].

The necessity of *vicarious trauma-focused training content* was a practice ranked as having expert consensus. Working with children, adults, or families who have experienced trauma may cause a support worker to experience personal thoughts and feelings of trauma, referred to as vicarious trauma [25]. When providing support for individuals and families with complex needs, exposure to challenging events or behaviors is possible, and therefore, training and support for vicarious trauma have been recommended [25, 26]. Support workers should have embedded opportunities for supportive debriefing and supervision, as well as access to mental health services to address experiences of burnout and stress [27].

Areas for Targeted Hiring Practices

High interpersonal and work skills were ranked at the expert consensus level. Experts describe the personal characteristics of workers as the key in avoiding client dropout when working with individuals with complex needs [28, 29]. They describe an attitude of possibility, in which creative solutions to challenges are explored, complemented by a nonjudgmental, noncondescending perspective [28, 30]. Experts also describe trustworthiness, empathy, availability, and maturity as important staff characteristics that may aid in successful service delivery.

Familiarity with complex case management was ranked as having expert consensus for its value. Workers should be familiar with complex case management, as in addition to individual developmental needs, environmental factors such as exposure to trauma or adversity may also impact families dealing with FASD or other complex needs [15]. This approach allows for consideration of multiple factors simultaneously, including ways to be aware of and responsive to communication, learning styles, and cultural and socioeconomic circumstances of families [24], in addition to

recognizing developmentally appropriate approaches and interventions for every individual.

Guiding Practices for Service Providers

Thematic analysis resulted in 23 guiding practices for service providers, categorized into nine domains guiding service delivery at the service provider level: diagnosis, individual support, education, health, employment, housing, family support, financials, and navigating the legal system (Table 2). These nine domains and 23 guiding practices are discussed below and summarized in Table 2.

Diagnosis

Early diagnosis was ranked as having good evidence. Although some professionals have expressed a reluctance to diagnose children due to concerns that there are no known effective treatments [31], it is well established that early diagnosis is associated with better outcomes for individuals with complex needs such as FASD [32–34]. Timely diagnosis is critical to accessing the proper services and funding, which

can help prevent adverse outcomes such as mental health problems, homelessness, inappropriate sexual behaviors, alcohol and drug addictions, and incarceration [35]. “Early diagnosis” has been defined as occurring before age six [36]; others emphasize that it is never too late for a diagnosis to be beneficial, as diagnosis improves access to interventions and helps reframe challenging behaviors [37].

Individual Support

Early intervention was ranked as having some evidence for its usefulness. Early intervention is frequently recommended; for children with FASD, this is reported to improve children’s developmental trajectory [6, 31, 35, 38•, 39]. Early intervention is identified as an important opportunity to leverage neural plasticity in early childhood, as this is a time during which there is significant opportunity for growth [40]. Similar to early diagnosis, “early” appears to mean intervening as soon as possible.

A positive strength-based approach was ranked as having some evidence for its use. Clinical expertise combined with current evidence shows that positive perceptions and strength-

Table 2 Service delivery domains and ranked guiding practices for service providers

Service delivery domains	Guiding practices for service providers	Ranking of evidence
Diagnosis	1. Early diagnosis efforts	Good evidence
Individual support	2. Early intervention	Some evidence
	3. Positive strength-based approaches	Some evidence
	4. Age appropriate services	Expert consensus
	5. Interdependence focus, not independence	Expert consensus
	6. Consistency in staff supports	Expert consensus
	7. Sensory processing disorder awareness and supports	Moderate evidence
	8. Functional assessments	Expert consensus
Education	9. Use of a unique learning profile	Moderate evidence
	10. Parent-assisted adaptive functioning training	Moderate evidence
Health	11. Preventative mental health services	Expert consensus
	12. Supported access to medical care	Expert consensus
	13. Supported recreational activity	Expert consensus
	14. Sexually exploitive situations and risky behavior management	Expert consensus
Employment	15. Client-centered approach	Expert consensus
Housing	16. Safe and secure housing	Some evidence
Family support	17. Stability of the home environment assessment	Good evidence
	18. Caregiver well-being emphasis	Good evidence
	19. Provision of educational resources by support workers	Moderate evidence
	20. Training in parenting strategies focused on caregiver attitudes	Moderate evidence
	21. Planning for the future	Expert consensus
Financials	22. Aid accessing financial funding	Expert consensus
Legal system	23. Supported dealings with the justice system	Expert consensus

based activities are related to improvements in personal development, individual satisfaction, and resilience, as well as family flexibility [41, 42]. Caregivers of youth with FASD have emphasized a desire to acknowledge their child's strengths rather than their deficits [43, 44]. A positive, strength-based approach promotes the existing resources of individuals and their families in order to improve functioning and overall well-being and in turn minimize the likelihood of adverse outcomes that have been associated with FASD [24]. This approach reframes dysfunctional behaviors as the result of unique brain functioning and cognitive challenges rather than willful non-compliance; activities and opportunities that build on the unique personal characteristics and skills of each individual are emphasized [41].

Age-appropriate services were ranked as having expert consensus for their use. Experts agree that the effects of complex disorders, such as FASD, are present across an individual's lifespan [45] and that needs evolve as individuals age [32, 37]. For instance, supports must adapt and evolve to respond to needs that commonly emerge in adulthood, such as those associated with becoming a parent [46]. Experts believe that age-appropriate supports reflect the combination of an individual's social and adaptive needs along with their cognitive capacities.

Support with a focus on interdependence, not independence, was ranked as having expert consensus supporting its practice. As individuals with FASD transition out of adolescence, experts concede that independence may look different as compared to their nonaffected peers [41]. Most people with FASD will require some degree of lifelong assistance with a full continuum of services to support their success [41, 42]. Thus, interdependence appears to be a more reasonable aim than independence [47]. Interdependence has been defined as "a relationship in which both persons are valued, respected and each one contributes equally; and where no one person is required or expected to have all the answers" [48]. This relationship may describe interactions between individuals and their caregivers, support workers, or others in their lives and underscores the absence of a power imbalance—the individual with FASD feels they have equal voice.

Consistency in staff supports from support services was ranked as having an expert consensus level of evidence. Experts call upon service delivery to provide the needed consistency and structure for individuals with FASD [41, 49]. This is described as essential by clients, caregivers, and service workers [14, 50]. Staff turnover can be detrimental to client success, and conversely, consistency in supports can create the security and stability necessary for successful relationships that facilitate service delivery [14, 46, 51]. Consistency also extends to the use of a similar approach by staff within different systems of support. This could include agreement regarding goals, priorities, and interventions, which creates consistency across environments [15].

Awareness and support for sensory processing disorders were ranked as having moderate evidence of being a beneficial practice. Sensory processing disorders impact an individual's ability to interpret and organize sensory information from their body or environment [52] and are often reported for people with FASD [53, 54]. Awareness of the potential impact of sensory processing disorders on behavior and performance can help reframe difficult behaviors and limited functional skills [55].

Education

Completion of a *functional assessment* was ranked as having expert consensus supporting its efficacy. Experts believe that a functional assessment can facilitate development of a well-balanced individualized education plan (IEP) [56, 57]. Functional assessments can provide a balanced portrait of a student's strengths and challenges and allow for collection of a broad range of information rather than becoming overly focused on a single piece of information [46, 51]. Functional information can help identify environmental conditions and supports which will enhance a youth's performance and may serve as a checklist to monitor progress [49].

The use of a *unique learning profile* was ranked as having moderate evidence. Derived from information collected through both educational and functional assessments, a learning profile is a portrait which can be used to identify programming needs to be reflected in education plans. Customized education plans have been demonstrated to enhance learning and development within a number of larger interventions for individuals with FASD [14, 52]. In fact, an individualized program plan or education plan (IPP or IEP) provides an opportunity for teachers, caregivers, students (when possible), and service providers to communicate and plan together [58]. Ideally, this plan should include operationally defined goals and objectives which are functional and meaningful to all involved [56, 58, 59]. Training on writing quality goals and objectives, as well as collaboration between academic and health professionals, has been highlighted by researchers as important to the success of education plans [39, 58, 59].

Parent-assisted adaptive functioning training was ranked as having moderate evidence for being a beneficial practice. Individuals with FASD may struggle with activities of daily functioning [41]. Researchers have reported that adaptive skill interventions, such as programs aimed at social interaction and communication, produce positive, lasting impact for youth and may reduce the occurrence of adverse outcomes [14, 53, 55, 57]. Many evidence-based interventions also reveal that caregivers are important to intervention initiatives and should be included as facilitators, as parent-assisted activities are the key to the maintenance and generalization of newly learned skills [31, 60, 61].

Health

Preventative mental health services were ranked as having expert consensus for being a valuable practice. Individuals with complex needs, such as those with FASD, experience higher than typical rates of mental health problems, including suicidal behavior and mood and substance abuse disorders [2, 61–63]. Provision of appropriate preventative services and early treatment of these conditions may reduce occurrence and impact of these problems and ultimately support healthy outcomes for complex populations [61].

Although evidence for treatment practices for complex populations, and particularly for those with FASD, is still emerging, interventions reported as helpful in addressing children’s mental health disorders have also proven successful for youth with FASD [64]. Experts additionally report that along with supported, regular access to mental health and substance abuse programming, mentorship programs for adults are also helpful for sustaining mental health. Within the therapeutic context, inclusion of a third party and use of hands-on tools and techniques that engage multiple senses are reported to aid in success for clients with FASD [65].

Support for accessing medical care was ranked as having expert consensus. Individuals with FASD may require help accessing medical services such as attending medical appointments, navigating the health system, and following up with health professionals [13, 17, 66•].

Supported recreational activity was ranked as having expert consensus. Regular physical activity provides physical, psychological, and emotional benefits to all individuals, including those with complex needs [67]. Experts believe that engagement in recreational activities provides opportunities for “teachable moments” and experiences of success that may not be experienced elsewhere [20, 68]. Experts recommend programs which are prosocial and noncompetitive; for which, appropriate developmental and social supports are provided [69].

Managing sexually exploitive situations and risky behavior was a practice for which there is expert consensus. Individuals with FASD may be at higher risk for sexual exploitation, due to increased impulsivity, a lack of inhibition, lower abstracting abilities, and poor social skills [70]. To manage this need, teaching and planning by a trusted individual is recommended, in particular promoting a “planned versus crisis approach to sexual activity” [21, p. 8]. Support workers are encouraged to help clients better understand their vulnerabilities, identify supports to address these issues, and develop safety plans. Discussions of reproductive health, including birth control and sexually transmitted infections (STIs), are recommended [20], with consideration for approaches that are best suited for each individual. For instance, discussion regarding use of a long-acting, injectable medication as a method of birth control may be warranted if a client has difficulty remembering to take birth control pills [20].

Employment

Client-centered employment services were ranked as having expert consensus supporting their use. Experts believe that job preparation programs which combine individually tailored vocational counseling with supportive employment supervision and training produce the most stable, successful placements [20, 71]. Service providers also promote positive employment outcomes by considering individual sensory issues, activity and lifestyle preferences, and stress management abilities [39, 72]. Balancing structure and flexibility in the work environment, with an informed and understanding supervisor, is also important in obtaining and sustaining employment [73, 74].

Housing

The importance of *safe and secure housing* was ranked as having some evidence of being a beneficial practice. Adults diagnosed with FASD may struggle to live independently [6], and many individuals with FASD end up homeless [75, 76]. Stable housing facilitates the provision of mental health and other support services [77, 78]. That said, because mental health and housing services in Canada often lack coordination, individuals with complex needs require assistance in navigating these often complicated systems and barriers [78•]. Nonetheless, having a place to live that is safe and secure is essential to stability, a first step in navigating these systems. Within housing initiatives, it is critical that the unique needs of the individual are understood so that supports may be responsive. For instance, individuals might feel threatened by the behavior of other residents in recovery housing, experience threats from strangers, and/or encounter threats related to loss of self-control [79]; understanding this will allow for reframing and supportive response. Researchers emphasize that service providers continuously monitor and address safety and security issues [79] in the context of long-term services that are responsive to needs that intersect systems [80].

Family Support

Stability of the home environment was ranked as having good evidence for its significance in FASD support. Stability is associated with a number of positive outcomes, including a reduction in the frequency and severity of behavioral and social problems [35, 36]. For youth in care, this entails reducing the number of times they experience placement changes. This may be accomplished by providing training, support services, and funding for biological, foster, and adoptive parents [81], as well as implementing a dedicated support team to maintain contact with the family and proactively address challenges that may arise [82].

Emphasis on caregiver well-being was ranked as having good evidence supporting its practice. Caregivers report challenges managing the economic impact, emotional stress, and fatigue that may come with raising a child with complex needs [83]. Self-care has been emphasized as critical for caregivers [42] and includes maintaining a positive outlook and practices for stress management. The use of respite care, counseling services, and peer parent support networks are recommended [42, 81, 84], and support workers are encouraged to assist caregivers in accessing these services and funding sources to reduce additional burden [85].

Support workers should provide educational resources; this practice was ranked as having moderate evidence. Understanding the neurodevelopmental nature of FASD and gaining confidence in their parenting are reported as critical for caregivers. When caregivers understand the roots of their child's needs, they recognize that behaviors are not the result of willful disobedience and can reframe responses to better address concerns while also increasing their focus on their child's strengths [31, 42]. Overall, this can result in reduced frustration and increased successes [24]. Unfortunately, many parents report feeling that they have incomplete information on their child's disorder [42, 86] and therefore support workers can help parents by providing easy access to this information [87] such as reading material, information sessions, and parent mentoring [24].

Training in parenting strategies which focus on caregiver attitudes was ranked as having moderate evidence supporting its practice. Clinicians report that caregivers of children with FASD may struggle in their role [31]. Even with clearer understandings of their child, caregivers benefit from provision of effective behavioral parenting strategies, along with positive caregiver cognitions; these are associated with lower parenting stress levels and better outcomes for children [42, 88].

Exercises that target cognitive appraisals have been demonstrated to improve parental efficacy in the general disability literature and for some FASD interventions [31, 42, 89]. This might involve coaching, mentoring, or cognitive behavioral strategies, all of which should include in-person practice of skills [31, 84]. Parent training must also be tailored at least somewhat to unique circumstances of families who raise youth with FASD, as some parents may need comprehensive behavioral training, while other parents may require only supervision and assistance with monitoring their children's behaviors [31, 42].

Planning for the future was a practice ranked as having expert consensus. The future is a significant concern for many caregivers of children with FASD; they worry about their children's ability to live safely and independently. Many caregivers hope that family, friends, or support services will be available to support their children in the future [43], yet they feel unsure of how to engage in this planning. Support workers can help parents plan for the future and develop a network of supports [41].

Financials

Aid to access funding was ranked as a beneficial practice having expert consensus. Caring for a child with complex disabilities can take a significant financial toll on families that does not ebb with the transition to adulthood. Ongoing support is often needed as individuals struggle to find and maintain employment to cover the costs of their basic needs [90]. Support services are essential to assisting clients and their families in proactively accessing income support.

Legal System

Supported dealings with the justice system were a beneficial practice ranked as having expert consensus. A disproportionate number of individuals in the Canadian criminal justice system have FASD [91]. People with FASD often struggle to receive appropriate care and treatment within the justice system [39], including accessing mental health services while in custody and probation [92]. Researchers report that adults with FASD may have diminished capacity and require assistance to navigate the complexities of the legal system, including access to guardianship and trusteeship programs [93]. Provision of comprehensive mental and physical health assessments, and FASD assessment services for those at risk of having neurocognitive deficits, is also needed to enhance rehabilitative outcomes and decrease recidivism for individuals with FASD in the criminal justice system [91].

Practice Implications

It is clear from our analysis that the majority of practices involving individuals with FASD has been informed by expert consensus and is not yet consistently embedded within systems of support. Consequently, it appears that service delivery activities are ahead of the research literature, possibly reflecting the urgent need for services in this complex population. With the absence of a comprehensive evidence base to support service delivery for individuals with complex needs such as FASD, service providers are called upon to respond to individual and family needs in the best ways they know how. As we continue to evolve in the field, it is necessary to seek evidence to understand if services are having meaningful impacts and view programming through an evaluation lens. Furthermore, it is necessary to engage and direct research initiatives that bridge back to existing service delivery activities. Our findings support a continued emphasis on investing in formal research and the evaluation of existing practices currently used for service delivery with individuals with FASD and other complex needs.

Limitations and Future Directions

This literature scan is an important initial step toward building a shared understanding among stakeholders. Nonetheless, the findings should be considered in light of the following three limitations: firstly, the current rankings of the practices are emerging; they are not yet evidence-based. The practices outlined in this paper establish a starting point to hone an approach for measuring outcomes in universal ways that allow us to think between service delivery programs rather than simply within programs. Secondly, the lack of evidence to inform the identified practices to date is a limitation of the current literature scan (as described above). There may be practices that have not been identified, or have been overstated because they exist currently in service of necessity, instead of reflecting evidence. More systematic approaches are needed to assess and evaluate the practices currently being used by service providers. Finally, specific keywords and databases were used in the present literature scan, which bounded the scope of the resources reviewed. Stakeholders will need to pay attention to changing terms in the literature when reviewing and evaluating guiding practices for individuals with FASD and other complex needs.

Conclusions

Our scan identified four broad principles of consistency, collaboration, interdependence, and proactivity that permeate the identified guiding practices. It is intended that these overarching guiding principles may inform decision-making and promote effective service delivery for individuals with complex needs. We identified organizational- and service provider-level domains for enhanced service delivery and actionable guiding practices, as well as the level of evidence to support each practice. The overarching principles, domains of service delivery, and guiding practices together comprise a framework for working with individuals who have complex needs, bridging policy-level thinking to organizational and service provider domains and practices. Recognizing the evolving nature of guiding practices, this document offers opportunities to monitor, evaluate, and refine our approaches to service delivery. Organizations are anticipated to use the findings from the suggested principles, domains of service delivery, and guiding practices to improve their services and programs and provide a more integrated and holistic approach to supporting healthy outcomes. Optimally, agencies and programs that align with the identified practices will be well positioned to provide high-impact services to clients and families with complex needs.

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Declarations

Conflict of Interest The authors declare that they have no conflict of interest.

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