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Elements for developing community-based interventions for adults with fetal alcohol spectrum disorder: A scoping review

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Abstract

Introduction: Current literature about interventions for adults with fetal alcohol spectrum disorder (FASD) is limited, which is a concern, due to the high prevalence of FASD. FASD creates lifelong physical, mental, cognitive and behavioral deficits, which impacts many aspects of daily living. Community-based interventions are necessary to better support adults with FASD and provide them with the opportunity to achieve success in their daily lives and social participation. This scoping review aimed to identify elements for developing successful community-based interventions for these individuals.

Method: A search was conducted in the MEDLINE, PsycINFO, CINAHL, and EMBASE databases and supplementary gray literature was resourced. Articles were selected based on inclusion–exclusion criteria, and a thematic analysis was completed to identify and present relevant findings.

Results: Seven articles met selection criteria and were included in this review. Six emerging themes were identified: inclusion of a functional context, individualized support, education for service providers, structure and routine, utilizing a strengths-based approach, and environmental adaptations. These themes were used to present the findings related to the elements necessary for developing interventions for adults with FASD.

Conclusion: The results indicate that the identified elements may be necessary to develop successful interventions, especially community-based interventions, for adults with FASD.

Keywords

Fetal alcohol spectrum disorder, adult, community, intervention, occupational therapy, scoping review, occupational therapy

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Introduction and literature review

Fetal alcohol spectrum disorders (FASDs) are a collection of disorders that describe the range of effects that can occur in an individual who was exposed to alcohol in utero (Cook et al., 2016). Found globally, the lifelong physical, neurological, cognitive, and behavioral deficits can occur due to prenatal alcohol exposure (PAE) (Fast and Conry, 2009). A number of alcohol-related diagnoses exist, including fetal alcohol syndrome (FAS), fetal alcohol effects, partial fetal alcohol syndrome (partial FAS), alcohol-related neurodevelopmental disorder, and alcohol-related birth defects (Chudley et al., 2007; Temple et al., 2015).

The global prevalence of FASD among children and youth in the general population is about 7.7 per 1000 population (Lange et al., 2017). Statistics from the World Health Organization (WHO) show that the WHO European region has the highest prevalence (19.0 per 1000 population) and, by country, South Africa has the highest prevalence (111.1 per 1000 population), followed by Croatia at 53.3 per 1000 population and Ireland at 47.5 per 1000 population (Lange et al., 2017). Canada has an estimate of around 10 per 1000 population (Cook et al., 2016). Interdisciplinary diagnostic guidelines for FASD exist and the Canadian version, which was updated in 2014 and had a new dimension 'affect regulation' added to it, is one of the commonly used tools in North America (Cook et al., 2016). In the United Kingdom (UK), there are no formal FASD diagnostic guidelines, and health professionals have adopted the Canadian guidelines (British Medical Association, 2016).

Symptoms of FASD can include growth restriction, intellectual disability, mental health disorders, birth

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defects, and characteristic abnormal facial features, with lifelong deficits in numerous domains of brain function (Chudley et al., 2007; Temple et al., 2015). Deficits in executive function such as cognitive flexibility, inhibition, planning, reasoning, and working memory are common in both children and adult populations (Leung et al., 2016; Rasmussen, 2005). A number of physical disorders are also found in individuals with FASD, making it a complex total body concern for caregivers (Burd and Kerbeshian, 2013). Primary issues experienced by individuals with FASD, are compounded by several secondary factors which include mental health problems, poor social skills, alcohol and drug problems, connection to justice, difficulties with school and employment, and failure to manage basic requirements of daily living (Fast and Conry, 2009). These FASD secondary issue examples reveal how detrimental they are towards one's quality of life and further complicate the provision of effective support services.

Lack of community-based interventions for adults with FASD

What is known about social supports and interventions for adults with FASD is primarily anecdotal. Most of the existing FASD literature focuses on children and prevention of PAE (Rasmussen, 2005). FASD has generally been viewed as a childhood disorder and is therefore linked to children's services (Temple et al., 2015), as well as the concern for early intervention to mitigate existing symptoms (Brintnell et al., 2011). Although prevention is critical in addressing the issues surrounding FASD, interventions must exist and be accessible in the community for individuals already affected by PAE, in particular adults. Many aspects of daily living for adults with FASD require substantial supports; unlike children, they do not have existing institutional structures (schools and families) to support them (Brintnell et al., 2011; Temple et al., 2015).

Developing community-based interventions for adults with FASD

Developing effective community-based intervention programs for adults with FASD is challenging. There is limited research and information about the quality of life, life experiences, and intervention effectiveness for adults with FASD (Brintnell et al., 2011; Chudley et al., 2007). A recent review of the literature found only 11 studies focused on intervention for individuals with FASD, and among them only one study addressed the adult population (Wheeler et al., 2013). Another problem was that previous FASD research had limited exploration of the needs and lifelong support for adults (Chudley et al., 2007).

Although prevention is the ideal method of reducing issues related to the lifelong need for FASD services and supports, interventions must exist and be accessible for those already affected. Unfortunately, nearly all health, justice-related, social, employment, and educational intervention programs have been designed in ways that present challenges for people with FASD (Badry et al., 2015). Practice evidence and research demonstrate that people with FASD do not experience success in typical programs (Dubovsky, 2012). Most programs are based on the behavioral learning models that assume that individuals have the cognitive, memory, and receptive and expressive language skills to comprehend, remember, and conduct what is being required of them (Dubovsky, 2012). Consequently, the failure in those programs is often attributed to the adults with FASD, rather than to the lack of fit between the person's capacities and the program demands, which often leads to these individuals being perceived as uncooperative, noncompliant, unmotivated, lazy, or bad (Badry et al., 2015; Dubovsky, 2012).

Rationale and objectives

In view of the daily living difficulties experienced by adults with FASD, it is necessary that community-based programs are designed and delivered in ways that are a better fit for the necessities of people living with FASD, taking into account their complex needs and challenges. For adults with FASD to ameliorate secondary disabilities and have more successful lives, greater community and more sensitive support and interventions are necessary (Wheeler et al., 2013). With only anecdotal descriptions available on intervention strategies for adults with FASD, it would be beneficial to determining more systematically what exists in the literature for this population to affect the design of more responsive and proactive interventions and services.

Therefore, the objective of this scoping review was to identify existing elements used in developing community-based interventions for adults with FASD. With this information, further research and refinement of interventions can be planned for greater and more subtle support in addressing the needs of adults with FASD to sustain meaningful community living experiences. Furthermore, occupational therapists can make use of the findings to design community programs, intervention services and support groups, with the aim of maximizing functions in adults with FASD.

Method

Given the global nature of FASD, a scoping review allows for identifying the context, the range and variety of elements necessary for developing intervention for adults with FASD, as very limited information exists on interventions/programs. The general purpose of this type of review is to summarize what content and specific research is available on a given topic, with the aim of orienting researchers to current gaps in knowledge (Levac et al., 2010). The five-stage methodological framework described by Arksey and O'Malley (2005) was used as it is currently recognized as best practice for scoping reviews (Colquhoun et al., 2014). This framework allows the synthesis and analysis of a wide range of research and non-research material to provide greater topic conceptual clarity. The five stages are: identifying the research question; identifying relevant

studies; study selection; charting the data; and collating, summarizing and reporting the results. The findings are crucial for occupational therapists to design intervention programs for adults with FASD and develop research directions that enrich evidence-based practice in occupational therapy. Ethics approval was not required for this scoping review after consulting the Health Research Ethics Board at the University of Alberta, Canada.

Stage 1: Identify the research question

The research question guiding this review was, What elements are used in developing community-based interventions for adults with FASD.

Stage 2: Identify relevant studies

The database search took place between September 2016 and July 2017. A health sciences research librarian was consulted to refine, search and develop an efficient search strategy. An occupational therapist with experience in community-based rehabilitation, an occupational therapist specialized in neurology and FASD, an occupational therapy student (RQ), and the research librarian conducted all searches. Electronic searches of the following databases were conducted: MEDLINE, PsycINFO, CINAHL with full text, and EMBASE. Gray literature was also included and was obtained from online searches via Google. Both electronic databases and gray literature searches were conducted using a set of defined keywords as follows: *Elements*: Any aspect or characteristic that contributes to the success of interventions for adults with FASD; *Interventions*: Any type of program or service that adults with FASD participate in to address issues related to FASD and improve quality of life; and *Adults*: Any individual who is 18 years old or older. Table 1 provides the detailed search strategy for this review. The keywords broadly included interventions/programs but did not restrict to community-based interventions; the researchers noticed that some studies addressing community-based intervention did not use these keywords in their abstracts or titles. Exclusion criteria were: Articles focused on children with FASD.

Stage 3: Study selection

Inclusion criteria were articles that were: (a) published in the last 20 years, that is, between 1997 and 2017, (b) published in the English language, (c) published in a peer-reviewed journal, (d) available electronically in full text, (e) based on adults (ages 18+) with FASD, (f) empirical studies including interventions/programs for adults with FASD, and (g) focused on strategies directly for improving the functional level of adults whose function were impacted by FASD. Since empirical studies on adults with FASD were very limited, this scoping review also included two additional sources: (a) review articles that had addressed interventions/programs for individuals with FASD, and (b) gray literature that were identified using the keywords described above. Gray literature was searched via the Google search engine, and only those that was available for downloading in full text or viewing online were included. The access of gray literature included direct retrieval of articles from the Google search engine and browsing of websites that contained the materials by one author (RQ). The inclusion of review studies and gray literature has been reported in previous studies (Levac et al., 2010). The PRISMA flow diagram (Figure 1) outlines the study selection process.

One author (RQ) conducted an initial screening based on the title and abstract of all articles and read all potentially relevant articles in full. Gray literature was further reviewed by an independent researcher, recruited from the Faculty of Rehabilitation Medicine, to determine the appropriateness of selection within the inclusion/exclusion criteria. A second reader, recruited by one of the researchers read all included articles and gray literature in full to confirm that they all met the inclusion/exclusion criteria of the study.

Stage 4: Charting the data

Two authors (RQ and AL) reviewed each article that met inclusion/exclusion criteria. The data were then extracted by one author (RQ) and discussed among all authors to confirm contents. A data-charting table was developed to summarize the following data: author(s), year of publication, title, study population, location of study, aims of the study, methodology, key findings. An additional item was added to chart the relevant element(s) that contribute to the success of intervention for adults with FASD.

Stage 5: Collating, summarizing and reporting the results

Conventional content analysis was used to guide the data analysis process. This methodology is appropriate for this study when existing theory or research literature on a phenomenon is limited (Hsieh and Shannon, 2005). During the process, researchers avoid using predefined categories, instead allowing the categories to emerge from the data. In this scoping review, one author (RQ) independently approached the text by extracting codes, allowing labels for emerged codes that were reflective of more than one key thought. These codes were sorted into categories based on their relationships. The categories were used to organize codes into meaningful clusters that represent elements for successful intervention for adults with FASD. After this process was completed by RQ, the codes and categories were reviewed by two authors (AL and SB).

An initial search identified 634 articles, with two articles extracted through gray literature searches (Table 1). After deleting duplicates, 417 articles were screened by title and abstract using inclusion/exclusion criteria, resulting in 13 full-text articles. These were further examined, resulting in seven articles to be included in this scoping review (Figure 1).

Table 1. Search strategy of the scoping review.

Database:	MEDLINE	PsycINFO	CINAHL	EMBASE
Date searched:	4 March 2017	4 March 2017	4 March 2017	4 March 2017
Search terms/ strategy:	1. (f?etal alcohol or FASD or prenatal alcohol exposure).ti,kf. 2. *Fetal Alcohol Spectrum Disorders/ 3. 1 or 2 4. limit 3 to "all adult (19 plus years)" 5. (adult* adj8 (fetal alcohol or foetal alcohol or fasd or prenatal alcohol exposure)).mp 6. ((adult* adj8 fas) and (fetal alcohol or foetal alcohol)).mp. 7. 4 or 5 or 6 8. Rehabilitation/ 9. exp diagnosis/ 10. (functional capacity or engagement or participation or rehab* or therap* or treat* or intervention* or service* or program* or diagnos*).mp. 11. 8 or 9 or 10 12. 7 and 11 13. 12 not ((child* or youth* or teen* or adolescen* or infant* or neonat* or newborn*) not adult*).ti. 14. 13 not (pregnan* or placenta* or embryo* or midwif* or midwives or stillbirth* or still birth* or still born* or stillborn* or gene* or rat or rats or rodent* or mice or mouse or murine or prevent* or screen* or hair or cost* or economic*).ti. 15. limit 14 to animals 16. limit 15 to humans 17. 14 not (15 not 16) 18. remove duplicates from 17	1. (f?etal alcohol or FASD or prenatal alcohol exposure).ti. 2. *fetal alcohol syndrome/ 3. 1 or 2 4. limit 3 to adulthood < 18 + years> 5. (adult* adj8 (fetal alcohol or foetal alcohol or fasd or prenatal alcohol exposure)).mp. 6. ((adult* adj8 fas) and (fetal alcohol or foetal alcohol)).mp. 7. 4 or 5 or 6 8. rehabilitation/ 9. exp diagnosis/ 10. (functional capacity or engagement or participation or rehab* or therap* or treat* or intervention* or service* or program* or diagnos*).mp. 11. 8 or 9 or 10 12. 7 and 11 13. 12 not ((child* or youth* or teen* or adolescen* or infant* or neonat* or newborn*) not adult*).ti. 14. 13 not (pregnan* or placenta* or embryo* or midwif* or midwives or stillbirth* or still birth* or still born* or stillborn* or gene* or rat or rats or rodent* or mice or mouse or murine or prevent* or screen* or hair or cost* or economic*).ti. 15. limit 14 to animal 16. limit 15 to human 17. 14 not (15 not 16) 18. remove duplicates from 17	S1:(MM "Fetal Alcohol Syndrome") OR TI (fetal alcohol or foetal alcohol or FASD or "prenatal alcohol exposure") S2: (MH "Adult+") S3: (S1 AND S2) OR (adult* N8 (fetal alcohol or foetal alcohol or fasd or prenatal alcohol exposure)) OR ((adult* N8 fas) and (fetal alcohol or foetal alcohol)) S4: (MH "Diagnosis+") OR ("functional capacity" or engagement or participation or rehab* or therap* or treat* or intervention* or service* or program* or diagnos*) S5: TI ((child* or youth* or teen* or adolescen* or infant* or neonat* or newborn*) not adult*) OR TI (pregnan* or placenta* or embryo* or midwif* or midwives or stillbirth* or still birth* or still born* or stillborn* or gene* or rat or rats or rodent* or mice or mouse or murine or prevent* or screen* or hair or cost* or economic*) S6: (S3 AND S4) NOT S5	1. (f?etal alcohol or FASD or prenatal alcohol exposure).ti. 2. *fetal alcohol syndrome/rh, th [Rehabilitation, Therapy] 3. 1 or 2 4. limit 3 to adult < 18 to 64 years> 5. (adult* adj8 (fetal alcohol or foetal alcohol or fasd or prenatal alcohol exposure)).mp. 6. ((adult* adj8 fas) and (fetal alcohol or foetal alcohol)).mp. 7. 4 or 5 or 6 8. Rehabilitation/ 9. exp diagnosis/ 10. (functional capacity or engagement or participation or rehab* or therap* or treat* or intervention* or service* or program* or diagnos*).mp. 11. 8 or 9 or 10 12. 7 and 11 13. 12 not ((child* or youth* or teen* or adolescen* or infant* or neonat* or newborn*) not adult*).ti. 14. 13 not (pregnan* or placenta* or embryo* or midwif* or midwives or stillbirth* or still birth* or still born* or stillborn* or gene* or rat or rats or rodent* or mice or mouse or murine or prevent* or screen* or hair or cost* or economic*).ti. 15. limit 14 to animals 16. limit 15 to human 17. 14 not (15 not 16) 18. remove duplicates from 17
Number of results:	198	128	93	215

FASD: fetal alcohol spectrum disorder.

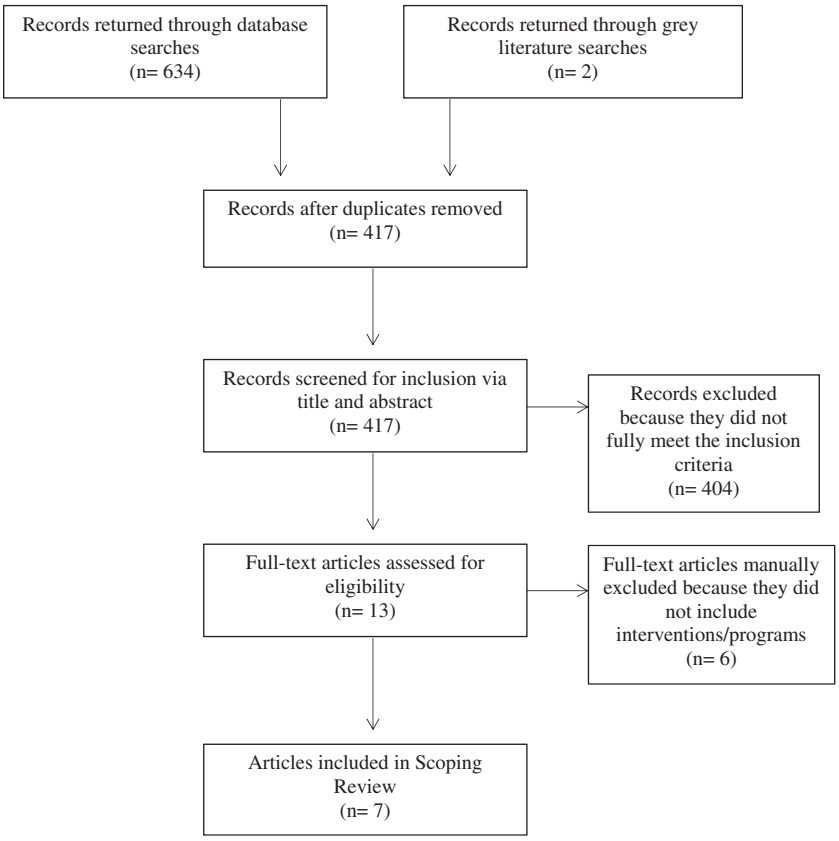

Figure 1. The PRISMA flow diagram showing the study selection process (Moher et al., 2009).

Results

Overall, seven articles aligned with the selection criteria and addressed community-based intervention for adults with FASD (Table 2). A total of five of the articles were published by researchers/service providers based in Canada, two from Ontario (Currie et al., 2016; Temple et al., 2015), two from British Columbia (Community Living British Columbia, 2011; Rutman, 2016), and one from Edmonton (Catholic Social Services – Edmonton, 2017); two of the articles were published in the United States of America (USA) (Birch et al., 2016; Paley and O'Connor, 2009). Of the seven articles, two were extracted from gray literature, one was supported by an external grant, one disclosed a lack of external funding, and three did not provide any information about funding sources. The content analysis revealed six emerging themes: functional context, individualized support, education for service providers, structure and routine, utilizing a strengths-based approach, and environmental adaptations.

Functional context

Overall, five articles discussed functional aspects of everyday living such as managing finances, housing, and employment (Catholic Social Services – Edmonton, 2017; Community Living British Columbia, 2011; Currie et al., 2016; Paley and O'Connor, 2009; Temple et al., 2015). Paley and O'Connor (2009) identified that interventions that provide training in life skills and vocational skills were beneficial for adults with FASD and increased their ability to manage tasks such as finding and maintaining employment and housing, managing their finances, accessing healthcare, and building social networks (Paley and O'Connor, 2009). Currie et al. (2016) reported an unrealized potential for meaningful vocational activities during interviews with adults with FASD when discussing their strengths. Community Living British Columbia (2011) explained the importance of spending time with the individual to determine concrete skills and then matching the individual with work opportunities that are the right fit. According to Temple et al. (2015), many adults with FASD seek assistance in financial support, vocational support, and receiving specialized housing. Catholic Social Services – Edmonton (2017) also found that outreach to support adults living with or suspected with FASD was necessary to connect adults to community agencies and provide assistance in daily living skills such as banking, budgeting, problem-solving, grocery shopping, and crisis intervention.

Individualized support

Overall, four articles identified that individualized support is important for adults with FASD (Community Living British Columbia, 2011; Currie et al., 2016; Rutman, 2016; Temple et al., 2015). Community Living British Columbia (2011) expressed that respectful and individualized support provides individuals with FASD the opportunity to learn and adapt to their disability, meaningfully

Table 2. Charting of the articles used in the scoping review and the elements identified for each article.

Author(s), year of publication, title	Population and location	Aims of the study	Methodology (such as review)	Key findings	Relevant element(s)
Peer reviewed					
Birch et al. (2016) The knowledge of rehabilitation professional concerning FASDs.	111 rehabilitation practitioners (occupational therapy, physical therapy, and speech-language pathology practitioners) - USA	To explore rehabilitation professionals' knowledge regarding signs and symptoms, prevention, and intervention of FASDs.	Quantitative survey design with purposive sampling. Online questionnaire design was utilized to maximize efficiency and meet the needs of busy rehabilitation professionals.	Those participants who received any formal training (such as professional education or continuing education) felt more prepared to recognize deficits of FAS and FASD than those who had received no training. Those with training on the ability to plan and perform relevant interventions reported being more prepared to manage and coordinate intervention plans for those with FASD.	- Educating service providers
Currie et al. (2016) Adults with FASD: Factors associated with positive outcomes and contact with the criminal justice system.	14 adults with FASD and 11 of their 'key support persons' (paid support workers, friend, family members) - Ontario, Canada	To examine the services and supports experienced by a small group of adults with FASD living in both rural and urban locations in Ontario, and their contact with the CJS.	Semi-Structured interviews were conducted, transcribed, and then coded according to key themes.	8 out of 14 participants reported some kind of CJS. Participants reported on: knowledge of their diagnosis and caregiver training and education about FASD; interdependence; routine, structure, and supervision; evidence of a strengths-based approach; effective communication; and collaborative services. All 14 participants could self-identify personal strengths. 10 of 14 participants reported by themselves or their key support to have collaboration or interaction between support workers. 13 of 14 participants acknowledged their need for support. Participants and key support reported that structure, supervision, and routine were very important for optimal functioning.	- Utilizing a strengths-based approach - Collaborative services - Structure and routine - Functional context - Individualized support
Paley B and O'Connor M (2009) Intervention for individuals with FASDs: Treatment approaches and case management.	Individuals with FASD - USA	To review treatment needs and considerations for individuals with FASD and their families, current empirically tested treatment approaches, case management issues, and suggestions for future directions in research on the treatment of FASD.	Research review.	This review highlights the emerging body of research demonstrating that there are a number of treatment approaches that can effectively remediate some of the impairments associated with PAE. Existing evidence-based interventions were successfully adapted for children. Researchers and clinicians must together translate evidence-based interventions into more accessible, community-based services for individuals with FASD and their families.	- Functional context - Educating service providers
Rutman D (2016) Becoming FASD-informed: Strengthening practice and programs working with women with FASD.	Women, young adults, and adults with FASD. - British Columbia, Canada	To provide a conceptualization of the key components of an FASD-informed approach through emerging literature and the author's research, to	Review.	It is imperative that programs are designed and delivered in ways that are FASD-informed, in which take into consideration the needs and challenges of those living with FASD. There are three principles of an FASD-informed	- Educating service providers - Environmental adaptations - Individualized support - Structure and routine

(continued)

Table 2. Continued

Author(s), year of publication, title	Population and location	Aims of the study	Methodology (such as review)	Key findings	Relevant element(s)
		identify the support needs and promising approaches in working with women, young adults, and adults with FASD.		approach: having an awareness of FASD, making person-centered accommodations, and being strengths-based. The author provides FASD-informed accommodations in practice, programming, and physical environment.	- Utilizing a strengths-based approach
Temple et al. (2015) Diagnosing FASD in adults: The development and operation of an adult FASD clinic in Ontario, Canada.	Adults with FASD - Ontario, Canada	To inform readers on the development and operation of an interdisciplinary FASD diagnostic clinic focusing on specifically on adults.	Review.	Issues unique to adult diagnosis are discussed as well as some challenges, including high rates of cancellations/no-shows for appointments, obtaining background and historical information, establishing maternal alcohol history, working collaboratively with other support sectors such as children's protective services and the justice system, and finding appropriate follow up and intervention services in the community.	- Functional context - Individualized support - Structure and routine
Gray literature					
Catholic Social Services – Edmonton (2017) FASD support.	Adults (18 years+) - Alberta, Canada	To support adults living with or suspected with FASD for developing life skills.	Online resource.	Catholic Social Services provides support in areas such as banking, budgeting, grocery shopping, problem-solving and crisis intervention. Supports are provided to connect adults to community agencies such as AISH, income support, PDD, housing programs, FASD assessment, and employment programs.	- Functional Context
Community Living British Columbia (2011) Supporting success for adults with FASD.	Adults with FASD - British Columbia, Canada	To provide an introduction to FASD and suggest accommodations to assist in supporting these citizens.	Information booklet.	This resource provides ways to think about offering support. It provides an understanding of FASD, including the primary characteristics of brain differences and the secondary brain differences and behaviors. Information regarding creating environments that support success includes building on gifts, using proper language, the importance of supportive environments, and the importance of safeguards. Information regarding daily routines, relationships, and community involvement are also discussed.	- Functional context - Utilizing a strengths-based approach - Environmental adaptations - Individualized support - Structure and routine

AISH: Assured Income for the Severely Handicapped; CJS: criminal justice system; FAS: fetal alcohol syndrome; FASD: fetal alcohol spectrum disorder; PAE: prenatal alcohol exposure; PDD: Persons with Developmental Disabilities

contribute to their communities, have positive relationships, and achieve success in many aspects of their lives. Rutman (2016) identified that one-to-one mentorship and outreach-based supports are central to creating opportunities and supporting individuals with FASD using an FASD-informed approach. To better support adults with FASD, Currie et al. (2016) stated that living interdependently, rather than independently was beneficial. They found that most of their participants identified their need for support, however they were ambivalent about receiving support (Currie et al., 2016). Similarly, having consistent service providers are critical in promoting positive outcomes for adults with FASD (Temple et al., 2015). However, in some geographical regions, because some of these individuals do not have a proper screening procedure for psychiatric disorders, many of them do not qualify for long-term case management or support workers (Temple et al., 2015).

Education for service providers

Overall, three articles included information about the importance of education for service providers working with individuals with FASD (Birch et al., 2015; Paley and O'Connor' 2009; Rutman, 2016). As rehabilitation professionals are greatly involved with individuals with FASD, it is necessary that they have the knowledge to correctly identify problems in FASD (Birch et al., 2015). Birch et al. (2015) found that rehabilitation professionals with formal training on management and coordination of intervention plans for individuals with FASD reported feeling more prepared in treating patients with FASD. Providing appropriate FASD education and training can increase professionals' knowledge and thus may allow them to improve the individual's quality of care and subsequently improve outcomes (Birch et al., 2015). Paley and O'Conner (2009) reported that individuals working in healthcare, education, social services, and the criminal justice system need to receive training and education for facilitating diagnosis and treatment. Similarly, Rutman (2016) addressed that service providers must have a strong understanding of FASD to provide effective service. This may be done through participating in face-to-face and/or web-based professional development opportunities, including webinars, communities of practice, and reflective practice discussions with others (Rutman, 2016).

Structure and routine

A total of four articles discussed incorporating structure and routine into the lives of adults with FASD (Community Living British Columbia, 2011; Currie et al., 2016; Rutman, 2016; Temple et al., 2015). Structure emphasizes routines, which helps these individuals to create patterns in their days and weeks and thus increase success and decrease the potential for confusion and frustration (Community Living British Columbia, 2011). In a review by Rutman (2016), consistency of scheduled events was noted to be an important strategy to offset memory difficulties experienced by women with FASD. Another study found that structure, supervision, and routine did not always occur simultaneously in the lives of adults with FASD, however they were identified as being very important factors for optimal functioning by both participants and key support individuals (Currie et al., 2016). Some examples include having signs and checklists posted, as well as using a calendar and alarms (Currie et al., 2016).

Utilizing a strengths-based approach

There were three articles that spoke of the value and utilization of a strengths-based approach when working with individuals with FASD (Community Living British Columbia, 2011; Currie et al., 2016; Rutman, 2016). Rutman (2016) discussed how highlighting the strengths of each individual is an essential means of countering the predominant deficits focus of service systems. Honoring the unique strengths and abilities that people with FASD exhibit is equally as important as recognizing the individualized differences in brain functioning with which people with FASD constantly live (Community Living British Columbia, 2011). Some strengths identified are artistic and musical talent, creativity, curiosity, caring about others. Some individuals experience success with concrete learning experiences, visual cues, and hands-on tasks (Community Living British Columbia, 2011). Using a strengths-based approach allowed participants to self-identify personal strengths and key support persons to change how they worked with these individuals based on the person's identified assets (Currie et al., 2016). Rutman (2016) explained that using a strengths-based approach help reframe problem behaviors into coping mechanisms to address stress, fatigue, or trauma, then honoring these behaviors as reflective of resiliency.

Environmental adaptations

There were two articles that addressed the importance of modifying environments to enhance the potential for success, decreased frustration, and maximized the outcomes of intervention for adults with FASD (Community Living British Columbia, 2011; Rutman, 2016). Stress and distraction can be the result of individuals with FASD being easily over-stimulated by their environment (Community Living British Columbia, 2011). Rutman (2016) found a number of accommodations or modifications for the physical environment that work well for adults with FASD. Some examples include paying attention to lighting and avoiding fluorescent lights and bright colors, decluttering noise/auditory stimuli and visual distractions, using visual aids such as photographs or program staff on the office door, having calm, quiet space for interviews or meetings, and ensuring that the physical space is non-confining (Rutman, 2016).

Discussion and implications

This scoping review aimed to identify elements necessary for developing successful community-based interventions for adults with FASD. As few articles address this focus, it is challenging to design programs that make a difference to these individuals. With seven articles meeting the selection criteria, the results revealed some elements commonly used in developing interventions for adults with FASD. Interestingly, none of them came from Europe and the UK, though FASD research is active; it seems not to be the case on community interventions. The themes identified in the results were: inclusion of a functional context, individualized support, education for service providers, structure and routine, utilizing a strengths-based approach, and environmental adaptations. With limited evidence in treatment and interventions for adults with FASD, the identified elements, though not exhaustive provide a beginning in our understanding of what programming elements may help to develop successful interventions.

Many of the articles indicated that including a functional context into the support provided to adults with FASD might be beneficial (Catholic Social Services – Edmonton, 2017; Currie et al., 2016; Paley and O'Connor, 2009; Temple et al., 2015). A functional context includes practical aspects of everyday living such as developing vocational skills, attaining employment or housing, and managing finances (Paley and O'Connor, 2009). Inclusion of this component within FASD interventions is important as it focuses on the roles of adults and provides individuals the opportunity to develop skills to be contributing members of their communities and reduce connecting with the justice system. The contribution of occupational therapy in promoting the application of functional context is crucial. According to Temple et al. (2015), occupational therapists were part of the clinical outpatient team at an interdisciplinary FASD diagnostic clinic in Ontario, where referrals were accepted for all individuals presenting with functional deficits in daily life activities. There are occupational therapists associated with many of the existing diagnostic teams in the provincial FASD Network sites in Alberta (such as the Northwest Central Alberta FASD Network and South Alberta FASD Network). This broad example demonstrates the involvement that occupational therapy can have in supporting adults with FASD in different functional needs. For example, working on vocational skills can lead to forms of employment, thus building on an individual's unique abilities and encouraging participation and engagement in activities that are meaningful to the individual to sustaining daily living (Currie et al., 2016). Included in a functional focus are actions related to developing skills that allow individuals to increase their confidence and control in their daily lives. Occupational therapy also brings knowledge and expertise on adapting activities and environments to complement clients' strengths (Temple et al., 2015).

Individualized support was identified to be important when providing interventions for adults with FASD (Community Living British Columbia, 2011; Rutman, 2016; Temple et al., 2015). As the effects of FASD are permanent, individuals with FASD will always require assistance to guarantee one lives with dignity within the community (Community Living British Columbia, 2011). Given this, individualized support may entail having medical and health professionals, support workers, mentors, or friends, and family members to provide specific and tailored assistance to individuals (Currie et al., 2016). Occupational therapists collaborate with clients to enable occupation and promote positive health outcomes (Townsend and Polatajko, 2007). With occupational therapist's holistic treatment approach, the individualized support addresses the whole person, while enabling problem-solving and navigating social institutions. It is also suggested that individualized support may be included for transportation, money management, grocery shopping, meal preparation, and house maintenance (Community Living British Columbia, 2011). Flexibility and ongoing support will contribute to success for these individuals and will allow them to feel autonomy and control in their lives (Rutman, 2016).

Structure and routine (Community Living British Columbia, 2011; Currie et al., 2016; Rutman, 2016; Temple et al., 2015) emerged as an element that leads to success in adults with FASD. Structure emphasizes routines, leading to the development of successful daily and weekly patterns (Community Living British Columbia, 2011). For adults with FASD, structure may include planning specific activities at the same times each day and week including intervention sessions. Specifically, occupational therapists can assist in educating individuals in planning and using schedules, signs, checklists, calendars, and alarms and incorporating the strategies in their everyday living routines. This can help them reduce confusion and frustration whenever unexpected events occur, which can lead to impulsive expressions and behaviors. Given the complex functional impairments such as executive dysfunction, impulsivity, and emotional dysregulation in adults with FASD (Leung et al., 2016), the provision of structure and routine in their daily living, together with individualized support, are necessary steps towards successful rehabilitation. Additionally, structure should foster respect, partnership, and participation whenever possible, and is seen as vital to success for adults with FASD living in the community (Community Living British Columbia, 2011).

Educating service providers who work with adults with FASD was identified as being important within three of the articles included in this review (Birch et al., 2016; Paley and O'Connor, 2009; Rutman 2016). Rehabilitation professionals such as occupational therapists, clinical psychologists, and social workers are greatly involved in supporting individuals with FASD, and that the more formal training individuals received led to greater preparedness to efficiently work with these individuals

(Birch et al., 2015). For occupational therapists, more education about the neurophysiological nature and deficits of these adults may be necessary to move forward in creating interventions to better meet the needs of adults with FASD. Education about FASD may be included in basic professional education or continuing education such as webinars and conferences (Birch et al., 2015). Job specific training for occupational therapists who work with adults with FASD may also help ensure optimal support and understanding to maximize the individuals' capacity to live more meaningful lives. Occupational therapists can also equip themselves with knowledge about the strengths-based approach when working with adults with FASD (Rutman, 2016). Encouraging the use of strengths and abilities approaches among occupational therapists who work with these individuals, rather than deficits, is essential for countering the heavy focus on deficits in service systems (Rutman, 2016). Another key area for occupational therapists contributing to the success of interventions is to fashion events that build on and explore the abilities of adults with FASD and provide them with positive experiences and opportunities to live full and happy lives (Community Living British Columbia, 2011).

Adapting the environment (Community Living British Columbia, 2011; Rutman, 2016) in which adults with FASD engage has been found to be beneficial as it can enhance their potential for success, decrease frustration, and maximize support (Community Living British Columbia, 2011). Individuals with FASD can be overwhelmed and over-stimulated by the environment, reducing their successful performance. Examples include being mindful of lighting, visual, tactile and auditory stimuli, and creating a space that is calm, quiet, and non-confining (Rutman, 2016). In the occupational therapy process, deconstructing and understanding the dynamic relationship between person, environment, and occupation is critical for all individuals including people with FASD. This process helps determining the strategies and accommodations to support their strengths and task performances and reducing environmental influences on their ability to meet the demands of their lives (Townsend and Polatajko, 2007).

Implications for occupational therapy

As previously mentioned, permanent long-term physical, mental, cognitive, and behavioral effects result from PAE (Fast and Conry, 2009). Through the use of models such as the Person-Environment-Occupation Engagement model (PEO-E) and Canadian Model of Occupational Performance and Engagement (CMOP-E) (Townsend and Polatajko, 2007), occupational therapists' analysis make them more acutely aware of environmental and social dynamics and stressors, and over-stimulating physical phenomena that add to distractions or changes in emotional regulation. Occupational therapy programs about sensory, motor, and impulse control have also been applied to youths with FASD (Jirikowic et al., 2010). The structuring of successful experiences to increase positive feelings of self and productivity in supportive contexts can all contribute to increased occupational performance and decreased stress. Occupational therapists achieve the latter using various enablement skills such as adapting, advocating, educating, consulting, and designing/building (Townsend and Polatajko, 2007). From a brain–behavior perspective, the richness of neuroscience knowledge in occupational therapy further enhances the understanding of behaviors in adults with FASD, which further guides the selection and applications of intervention content and strategies for specific individuals.

An area that was not addressed in the review articles is programming for adults with FASD who are released from prison and have high recidivism rates. The findings from this review may provide insights for occupational therapists to develop programs that aim at helping young offenders reintegrate into the community. More importantly, keeping these individuals out of the justice system by providing purposeful activity engagement is the key to the success of rehabilitation, which has rarely been addressed in the literature. Related to the identified elements in this review, occupational therapy programs may include providing consultations on the forms of adaptation, designing functional activities such as vocational skills training, educational services for support workers and families, guidance about creating structure and routine, and advice on environmental modification to reduce stress. Given the holistic lens and skills of the profession, occupational therapists are positioned to make a larger contribution in supporting adults with FASD, just as they do for children.

Limitations and strengths

There are limitations in this study. Firstly, not all of the articles included in this review directly address developing interventions for adults with FASD. Other articles may be missed that within their developmental perspective speak to adults programming due to keyword selections. Secondly, three review articles were included in our review. These articles reviewed studies that addressed treatments for both children and adults, with a majority of them referring to children or intervention programs specifically for child care. Therefore, the aims and source of articles were different between our scoping review and those reviews. Thirdly, scoping reviews are not intended to provide favorable evidence towards the effectiveness of results rather the range of evidence, source and focus on topic content where it exists. The content included in the analysis was not investigated for quality. Lastly, scoping reviews cannot identify gaps where poor quality research exists. Included in the Arksey and O'Malley (2005) framework is an optional stage for an external expert consultation, which this review did not include. However, Arksey and O'Malley's framework was chosen specifically to keep this scoping review as systematic as possible, and an external reviewer was able to duplicate the search strategy's results. In terms of strengths, this study specifically focused on adults, with specific emphasis on interventions that are targeted to improving functions of the adults

affected by FASD, rather than individuals like parents of FASD children who might have a different set of complex needs. Adding to that is the target objective to improve functions of the adults affected by FASD. Such specificity should be a benefit to those support workers and caregivers wanting to make use of the findings to develop intervention programs for the adult population.

Conclusion

This scoping review found seven articles and identified elements used for developing community-based interventions for adults with FASD. The six elements that emerged from the reviewed literature were the inclusion of a functional context, individualized support, education for service providers, structure and routine, utilizing a strengths-based approach, and environmental adaptations. With the lack of information about interventions for adults with FASD, it is important first to identify and then understand what core elements are needed in planning interventions that may be beneficial to develop successful interventions in the future. Occupational therapists can also consider implementing these elements into their holistic practice for adults with FASD. Adults with FASD living in the community are mostly autonomous and therefore are collaborators in programming even when they have guardians. Their experience and narrative give insight into which of the theme's elements will be the best fit for them. Together, the relational support and the identified elements may contribute to the development of more successful interventions for adults with FASD living in the community. Individuals will provide greater support opportunities and enable adults with FASD to achieve success and live meaningful lives.

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Research ethics

Ethics approval was not required for this study as there was no human subject recruitment in a scoping review, based on Research Ethics Guidelines from the University of Alberta, Canada.

Consent

Consent was not applicable in a scoping review.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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Contributorship

Ryan Quan searched literature. All authors contributed to the methodology of the project and the interpretation of findings. Ryan Quan wrote the first draft of the manuscript. All authors reviewed, and edited the manuscript and approved the final version of the manuscript.

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