

BMJ Open Fetal Alcohol Spectrum Disorder resources for educators working within primary school settings: a scoping review protocol

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ABSTRACT

Introduction Many children affected by Fetal Alcohol Spectrum Disorder (FASD) exhibit neurocognitive delays that contribute to secondary consequences, including a disrupted school experience. Educators often have limited knowledge or experience in the identification, referral, management and accommodation of students with FASD. Effective resources and tools for educators are crucial to ensure these students are supported in their ongoing learning, development and school participation. This scoping review aims to identify and evaluate resources for educators that aid in the identification, management, or accommodation of students with FASD.

Methods and analysis A search will be conducted in 9 peer-reviewed and 11 grey literature databases, Google search engine, two app stores and two podcast streaming services (planned search dates: November 2020 to February 2021). Relevant experts, including researchers, health professionals and individuals with lived experience of FASD, will be contacted in February and March 2021 to identify additional (including unpublished) resources. Resources will be selected based on registered, prespecified inclusion–exclusion criteria, and the quality of included resources will be critically appraised using a composite tool based on adaptations of the National Health and Medical Research Council FORM Framework and the ICAHE Guideline Quality Checklist. Relevant experts will also be requested to provide feedback on included resources.

Ethics and dissemination Ethical approval for this scoping review was obtained from the University of Sydney Human Research Ethics Committee (2020/825). Results of the review will be disseminated through a peer-reviewed publication, conference presentations, and seminars targeting audiences involved in the education sector.

Trial registration Open Science Framework: osf.io/73pjh.

INTRODUCTION

Fetal Alcohol Spectrum Disorder (FASD) is a diagnostic term that describes the continuum of effects resulting from prenatal alcohol exposure, including neurodevelopmental, physical, emotional and behavioural

Strengths and limitations of this study

- This scoping review will be the first to collate a broad range of Fetal Alcohol Spectrum Disorder (FASD)-related resources relevant for educators to effectively recognise and respond to students with FASD.
- The scoping review will adhere to an established six-stage review framework.
- Following the review, access links for the identified high-quality resources will be made available in an online portal, and based on identified gaps, new resources will be developed to support educators.
- The review will be limited to FASD resources despite clinical presentation overlap with other neurodevelopmental disorders.
- The strength of the conclusions and the use of the scoping review will be limited by the quality of available resources identified.

consequences.¹ The estimated global prevalence of FASD among children is 0.77%,² placing FASD as the leading preventable cause of non-genetic developmental disabilities.³ Factors such as dose and exposure patterns, as well as biological, genetic, epigenetic and accompanying environmental factors contribute to the significant variability in the range and magnitude of adverse outcomes associated with prenatal alcohol exposure.^{4,5}

Many children affected by FASD exhibit neurocognitive delays, including attention and executive functioning difficulties, poor memory, impaired reasoning and judgement, learning disabilities and sensory processing and spatial awareness problems.⁶ These delays contribute to secondary outcomes; for example, 94% of individuals with FASD experience at least one mental health problem and 70% have been suspended, expelled or dropped out of school.⁷ Additionally, some



children with FASD have experienced deprivation or neglect resulting from parental mental health, substance use or social problems.^{8–10} These factors in combination contribute to risk of a disrupted school experience for children affected by FASD, particularly if they do not receive appropriate support and intervention.

Adding to these challenges, children with FASD often attend schools where educators have limited knowledge or expertise in the identification, assessment, management or mentorship of students with developmental, learning, social and behavioural problems associated with FASD.¹¹ To ensure the appropriate referral and management of such students, and to support their ongoing learning, development and school participation, educators must be equipped with effective tools. Previous reviews have synthesised FASD identification tools and behavioural management resources. In 2008, an expert panel review summarised Canadian screening tools for FASD and identified one tool which had potential for use within the school setting.¹² However, a review and comparison of available assessment tools developed outside of Canada and that are suitable for the education sector is not available. Systematic and scoping reviews have also synthesised health, behavioural and educational interventions for individuals with FASD.^{13–16} These reviews included student-focused interventions that aim to address neurodevelopmental delays, self-regulation and social skills. Two of the reviews described professional development training programmes for educators that include management techniques for use with students with FASD.^{13 16} While the identified programmes are important, educators require a broader suite of resources to adequately manage and mentor these students, including access to FASD guidelines and policies that are relevant to the school setting, professional development and information-based tools such as factsheets, workshops and webinars, and outlines of effective strategies for managing behaviour within the classroom. To date, there has been no review which has comprehensively collated FASD-related resources to equip educators to effectively recognise and respond to students with FASD.

To meet this need, we will conduct a scoping review to identify and evaluate the quality of resources suitable for the school setting. We seek to comprehensively identify resources which assist educators in identifying students with developmental, learning, social and behavioural problems consistent with FASD requiring medical referral, as well as tools to support ongoing learning, development and school participation for students with FASD. Although there is significant overlap in neurocognitive impairment, developmental delay, comorbidities and secondary outcomes among students with FASD and other neurodevelopmental disorders and brain injuries,^{17–19} this review will be limited to resources which are explicitly relevant for, or designed to, educate, assist or build capacity among educators in identifying, managing or accommodating students with FASD. This review will focus on resources suitable for educators working with

primary school-aged rather than secondary school-aged students. This is because early identification, diagnosis and intervention are important factors associated with reduced risk of long-term adverse outcomes for individuals with FASD, including disrupted school experience as well as troubles with the law, psychiatric hospitalisation, and drug and alcohol problems.^{18 20}

METHODS

Protocol design

The scoping review is informed by the Arksey and O'Malley framework,²¹ which has been further developed by Levac and colleagues²² and the Joanna Briggs Institute (JBI).²³ This framework organises the review process in six stages: (1) identifying the research questions; (2) identifying relevant resources; (3) resource selection; (4) charting the data; (5) collating, summarising and reporting the results; and (6) consultation with key stakeholders to identify additional resources and gain feedback on results. Below, we provide methodological details of each pre-registered stage (osf.io/73pjh).

Stage 1: identifying the research questions

The primary research question of this scoping review is: What resources and/or guidelines are available for educators that (1) enhance identification, assessment and referral of students with developmental, learning, social and behavioural problems consistent with FASD, and (2) aid management or accommodation of FASD-related symptoms and behaviours in a school setting? Secondary research questions include: (1) What is the quality of existing resources in terms of evidence base, impact and utility, generalisability, applicability, credibility, availability, ease of use and currency? and (2) Are resources designed to improve the management or accommodation of developmental, learning, social, and behavioural problems associated with FASD? If so, what are the effective components?

Stage 2: identifying relevant resources

Selection criteria

As outlined in the JBI manual for evidence synthesis,²³ the source of information will include any existing literature, such as, but not limited to, primary research studies, systematic reviews or meta-analyses, guidelines and policies, books, programmes and professional development and information-based resources (eg, factsheets, videos, podcasts, apps, websites). Herein, all sources and types of information are referred to as resources. Resources will be included in the scoping review if they meet the following inclusion criteria:

1. Population: educators (ie, principals, teachers, education assistants, school psychologists, allied health teams and nurses, Indigenous Liaison Officers or other school staff) who interact with and support primary school-aged children with FASD in a school setting.
2. Concept:

- i. Identify and evaluate resources relevant for, or designed to, educate, assist or build capacity among educators in recognising and referring students with developmental, learning, social, and behavioural problems consistent with FASD; and,
 - ii. Identify and evaluate resources for relevant educators that are designed to aid in the management or accommodation of students with FASD indicators or diagnosis, including resources that provide education and mentoring to these students.
3. Context: International resources will be reviewed.
 4. Time frame: any.
 5. Resource accessibility: the resource must be currently publicly available for educators, including free resources and those available for purchase. Current availability will be determined by online searching, recent publications, or contact with resource creators.
 6. Language: English.

Search strategy

Resources will be identified by searching the peer-reviewed and grey literature (ie, published or unpublished resources in non-commercial form), Google search engine, app stores, podcast streaming services and consultations with relevant FASD experts (see [table 1](#)). The search will be conducted using an iterative process by one member of the research team. First, an initial search of at least one bibliographic database and one grey literature source will be conducted to identify keywords and search terms used in the title, abstract, description and/or index terms of resources (note: this step has been completed). Next, selected databases, grey literature, the Google search engine, app stores and podcast streaming services will be searched using the keywords defined in step 1, summarised below and detailed in the online supplemental file. This stage will take place

from November 2020 to February 2021. International FASD experts will then be contacted via email or phone in February and March 2021 and asked to provide any relevant resources for educators (including unpublished resources) and suggest any colleagues or other individuals who might have knowledge regarding such resources. Finally, all relevant resources will be imported into reference management software and an excel spreadsheet, where duplicates will be removed.

Search terms

In step 1 of the search strategy, the following search terms were entered into MEDLINE, PsycINFO, EMBASE, ERIC and Google: ('fetal alcohol spectrum disorder' OR 'fetal alcohol syndrome') AND (intervention OR program) AND (review OR 'systematic review' OR 'scoping review'). Relevant review articles were retrieved and examined for search terms.^{13–16} Based on this exploratory search phase, the search strings for each database, website, app store, and podcast streaming service were finalised.

FASD-related search terms include: 'fetal alcohol spectrum disorder', 'fetal alcohol syndrome', 'alcohol related neurodevelopmental disorder', 'alcohol related birth defects', 'prenatal alcohol exposure' and 'alcohol use during pregnancy'. Resource-related terms include: 'program', 'intervention', 'management', 'guidelines', 'guide', 'policy', 'factsheet', 'information sheet', 'booklet', 'video', 'screening tool', and 'assessment'. Setting-related terms include: 'school', 'school based', 'teacher' and 'educator'. Where possible, the same search terms and fields will be used in database searches, using the websites' search function. When the capacity of the website does not allow for multiple search terms, singular phrases will be searched (eg, 'fetal alcohol spectrum disorder'). Searches for alternate spelling will also be conducted (eg, fetal vs foetal).

Stage 3: resource selection

Once resources have been imported into reference management software, a three-phase screening and selection process will be undertaken: (1) screen title/abstract/description of resources for eligibility; (2) access data sources/obtain full-text versions of resources considered eligible in step 1 and further screen for eligibility; and (3) search for other relevant resources in the reference lists of identified materials and screen for eligibility by following steps 1–2.

One member of the research team will undertake step 1, where a sample (ie, 20%) of the retrieved resources will additionally be screened by a second team member to ensure consistent application of the eligibility criteria for inclusion in the review. Step 2 will be independently undertaken by two team members, with any disagreement resolved by a third member. One researcher will conduct the search for other relevant resources in step 3. For steps 1 and 2, Cohen's kappa will be calculated to assess the inter-rater agreement between the two reviewers. The process of study selection will be reported in the scoping

Table 1 Information sources to be searched

Peer-reviewed databases	PsycINFO, PubMed, Scopus, Web of Science, ERIC, Cochrane Library, MEDLINE, EMBASE, CINAHL
Grey literature	Google advanced search*, FASD Hub, NOFASD, HealthInfoNet, Australian Department of Education websites, Australian Department of Health websites, Education Services Australia, National Organisation for FASD (UK), The National Organization for Fetal Alcohol Syndrome (US), Children's Healthcare Canada, The Provincial Outreach Program for Fetal Alcohol Spectrum Disorder
Apps	Apple App Store, Google Play
Podcasts	Apple Podcast, Spotify
Consultations	FASD experts

*Guided by previous scoping reviews,²⁷ the screening of the Google advanced search will be limited to the first five pages of results (20 results per page; total=100).

Table 2 Draft of customised data charting tool for FASD resources

Category	Details
Authors/developers	
Title	
Year of publication	
Context	Country of origin
Resource category	Identification/assessment or management resource
Resource type	Screening and assessment measures of FASD, guidelines, interventions or programmes or information-based resources
Resource description	Delivery methods, lengths, objectives etc
Target population	Type of educator (eg, principals, teachers, education assistants, school psychologists, allied health teams and nurses or other school staff)
Has the resource been evaluated? If yes, provide details	Sample size, sociodemographic characteristics of sample, reported outcomes, effectiveness, impact, validation (for screening measures)
Details on evidence base of the resource	Evidence base of resource (eg, formal evaluation or published findings) or evidence base that informed development of resource
Resource costs	
Other information	
Reference/website	

FASD, fetal alcohol spectrum disorder.

review using a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow chart.

Stage 4: Charting the data

Charting

Information on each eligible resource will be charted using a customised data charting tool, developed for this review and informed by the JBI manual (table 2).²³ Two team members will initially chart three resources to test the adequacy of the tool in extracting all relevant data and they will modify the tool as required. The remaining data will be charted by one team member. Data charting will involve an iterative process whereby the charting tool will be continually modified and updated as the team member charts each resource and identifies additional data of interest.²³

Quality appraisal

The quality of included resources will be assessed using a composite of two critical appraisal tools: an adapted version of the National Health and Medical Research

Council (NHMRC) FORM framework²⁴ and the iCAHE Guideline Quality Checklist.²⁵ A composite tool will be used to ensure that all relevant domains in varying types of resources are assessed for quality. Resources will be evaluated on their evidence base, impact and utility, generalisability, availability, currency, ease of use, credibility and applicability (table 3). In line with the NHMRC FORM framework, each component will receive a score ranging from A (excellent) to D (poor). Based on individual component scores, an overall grade for each resource will be calculated. One member of the research team will appraise all resources and a second member will additionally appraise 20% of included resources to ensure consistent evaluation. Disagreements will be discussed by the two reviewers, and if any disagreement cannot be resolved, a third member of the research team will be consulted to arbitrate the decision.

Stage 5: Collating, summarising and reporting the results

The reporting of the scoping review will be informed by the PRISMA extension for Scoping Reviews Checklist.²⁶ The results of the search, and each screening step, will be presented in a PRISMA flowchart. The findings from the charting and quality appraisal will be summarised and presented in table form.

Stage 6: Consultation with key stakeholders to identify additional resources and seek feedback

As outlined above, consultation will be conducted with FASD experts during stage 2 (simultaneously with online searching procedures) to identify additional resources relevant to the scoping review. After collating and summarising results, further consultation with FASD experts will occur during stage 6 to seek feedback on our results and to identify gaps in currently accessible resources for educators.

Patient and public involvement

Patients and the general public were not involved in development of this protocol. However, experts, including researchers, health professionals and individuals with lived experience of FASD, will be consulted during stages 2 and 6 of the scoping review in order to locate additional resources relevant for educators and to seek feedback on identified resources.

Dissemination and ethics

This scoping review will be the first to identify and evaluate a broad range of resources suitable for use in school settings to assist educators in identifying, managing, accommodating and mentoring primary school-aged students with FASD. This protocol reports a comprehensive, rigorous and transparent methodology that has received ethical approval from the University of Sydney Human Research Ethics Committee (2020/825).

A limitation of this protocol is the search strategy is restricted to FASD resources despite students with FASD exhibiting overlap in clinical presentation with other neurodevelopmental disorders. However, a broader focus

Table 3 A composite quality appraisal tool based on an adaption of the NHMRC Evidence Statement Form, the NHMRC Body of Evidence Matrix and the iCAHE Guidelines Quality Checklist.

Component	A Excellent	B Good	C Satisfactory	D Poor
Evidence base	Formally evaluated and findings published	No formal evaluation; developed on the basis of published findings OR some testing among endusers has been conducted	No reference to formal evidence or testing; developed by expert consensus	Developed on the basis of personal opinion only
Impact and utility	Covers a range of relevant issues comprehensively	Covers more than one relevant issue	Covers a single issue of high importance	Brief resource, restricted coverage of issue
Generalisability	Relevant to one or more of the target groups	Some information relevant for the target group		Not relevant for any of the target groups
Applicability	Directly applicable to the Australian context	Applicable to the Australian context with some caveats		Not applicable to an Australian context/ unsure
Availability	Readily available at no cost	Available at low cost	Available at significant cost (\$100+)	Not readily available
Currency	Resource is current/regularly updated	Resource is current but not updated regularly	Resource is not current but contains up-to-date information and terminology (≥ 10 years)	Resource contains out of date information and terminology
Ease of use	Easy to use or navigate			Difficult to use or overly complex
Credibility	University-based or government funded, reputable developers			Developers or organisation not reputable

NHMRC, National Health and Medical Research Council.

on resources for other neurodevelopmental disorders would substantially widen the scope of the review and hinder our ability to directly address the primary and secondary research questions.

The results of this scoping review will be disseminated through a peer-reviewed publication, conference presentations and seminars targeting audiences involved in the education sector and FASD research. Access links for identified high-quality resources will be consolidated in an online portal, and based on identified gaps, new resources will be developed to support educators. It is expected that the scoping review will be completed and disseminated in 2021.

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Supplement File.

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FASD resource scoping**Step 1.****a) Peer reviewed databases:**

Databases: PsycINFO, PubMed, Scopus, Web of Science, ERIC, Cochrane Library, MEDLINE, EMBASE, CINAHL

Search terms: (“fetal alcohol spectrum disorder” OR “fetal alcohol syndrome” OR “alcohol related neurodevelopmental disorder” OR “alcohol related birth defects” OR “prenatal alcohol exposure” OR “alcohol use during pregnancy”) AND (school OR “school based” OR teacher OR educator)

AND relevant resource key words:

- Screening or assessment tools: (screen OR “screening tool” OR assessment)
- Programs or interventions: (program OR intervention OR management)
- Previous reviews: (review OR “systematic review” OR “scoping review” OR “meta-analysis”)
- Guidelines: (guide OR guideline OR guidelines OR policy)
- Information-based resources (factsheet OR booklet OR “information sheet” OR video OR app OR application OR game OR gaming OR virtual reality OR interactive OR podcast)

b) Grey literature:

Websites: FASD Hub, NOFASD, HealthInfoNet, Australian federal, state and territory Department of Education and Department of Health websites, Education Services Australia, The National Organisation for FASD (UK), The National Organization on Fetal Alcohol Syndrome (USA), Children’s Healthcare Canada, The Provincial Outreach Program for Fetal Alcohol Spectrum Disorder

Search terms: Use full search terms where possible, but where the capacity of the website does not allow, reduce terms (e.g., “fetal alcohol spectrum disorder”)

AND relevant resource key words:

- Program, intervention, management, factsheet, information sheet, booklet, policy, video, game, gaming, virtual reality, app, application, interactive, podcast, guideline(s), guide, screen, screening tool, assessment

c) Google Advanced search:

Search terms: “fetal alcohol spectrum disorder” OR “fetal alcohol syndrome” OR “alcohol related neurodevelopmental disorder” OR “alcohol related birth defects” OR “prenatal alcohol exposure” OR “alcohol use during pregnancy”

AND relevant resource key words:

- Program, intervention, management, factsheet, information sheet, booklet, policy, video, game, gaming, virtual reality, app, application, interactive, podcast, guideline(s), guide, screen, screening tool, assessment

Review the first five pages (20 results per page) of Google search results.

d) App Stores

Stores: Apple App store (Australian store) and Google Play.

Search terms: Use full search terms where possible, but where the capacity of the app store does not allow, reduce terms (e.g., “fetal alcohol spectrum disorder”)

e) Podcast Streaming Services

Locations: Apple Podcasts app and Spotify

Search terms: Use full search terms where possible, but where the capacity of the streaming service does not allow, reduce terms (e.g., “fetal alcohol spectrum disorder”)

Step 2.

Peer reviewed databases: Import results into reference management software for screening.

Grey literature/Google/App stores/Streaming services: Import relevant results into an excel spreadsheet for further review.

Step 3.

Remove duplicates