

# Rapid Synthesis

Identifying Effective Approaches to Support  
Parents and Caregivers of Children with  
Fetal Alcohol Spectrum Disorder

12 October 2018



EVIDENCE >> INSIGHT >> ACTION



**Rapid Synthesis:  
Identifying Effective Approaches to Support Parents and Caregivers of Children with Fetal Alcohol  
Spectrum Disorder**

**60-day response**

12 October 2018

#### McMaster Health Forum and Forum+

The goal of the McMaster Health Forum, and its Forum+ initiative, is to generate action on the pressing health- and social-system issues of our time, based on the best available research evidence and systematically elicited citizen values and stakeholder insights. We aim to strengthen health and social systems – locally, nationally, and internationally – and get the right programs, services and products to the people who need them. In doing so, we are building on McMaster’s expertise in advancing human and societal health and well-being.

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#### Timeline

Rapid syntheses can be requested in a three-, 10-, 30-, 60- or 90-business-day timeframe. This synthesis was prepared over a 60-business-day timeframe. An overview of what can be provided and what cannot be provided in each of the different timelines is provided on McMaster Health Forum’s Rapid Response program webpage ([www.mcmasterforum.org/find-evidence/rapid-response](http://www.mcmasterforum.org/find-evidence/rapid-response)).

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#### Conflict of interest

The authors declare that they have no professional or commercial interests relevant to the rapid synthesis. The funder played no role in the identification, selection, assessment, synthesis or presentation of the research evidence profiled in the rapid synthesis.

#### Merit review

The rapid synthesis was reviewed by a small number of policymakers, stakeholders and researchers in order to ensure its scientific rigour and system relevance.

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## KEY MESSAGES

### Questions

- What approaches have been found to be effective for parent support groups of children with fetal alcohol spectrum disorder (FASD) and other neurodevelopmental conditions?
- In Ontario, Canada, what approaches have been successful in parent support groups for parents and caregivers of those with FASD, what is needed to further tailor or enhance support groups and other supports available through its health and social systems, and what is needed to make these approaches sustainable?

### Why the issue is important

- Fetal Alcohol Spectrum Disorder (FASD) is used “to describe a broader spectrum of presentations and disabilities resulting from alcohol exposure in utero.”
- FASD affects between 2% and 3% of elementary school students in the greater Toronto area.
- There has been increasing evidence that the right information, supports and services provided in a timely manner can significantly reduce the burden of this condition on individuals, families and caregivers.
- Given this potential it is timely to consider the evidence and stakeholder insights about what approaches are effective for supporting families and caregivers of those with FASD, and any critical components that should be integrated into these models to tailor them to the Ontario health and social systems.

### What we found

- To inform this rapid synthesis, we identified 15 documents including five systematic reviews, one scoping review, and five primary studies, and undertook 11 key informant interviews with managers, researchers, caregivers and representatives from advocacy groups.
- One recent low-quality systematic review and two primary studies examined support groups for FASD and autism, and these documents found mixed levels of effectiveness for support groups.
- In addition to support groups, literature on FASD and other neurodevelopmental conditions noted a number of other approaches that could be integrated alongside support groups to help parents or caregivers, including therapy, counselling, coaching, education, respite, mindfulness and meditation, and care coordination, which were found to be effective in supporting family and caregivers of those with neurodevelopmental disorders.
- The most frequently described approach in the included literature was education, which focused on teaching caregivers about FASD (or other neurodevelopmental disorders), parenting skills, or how they can play a therapeutic role in the treatment of FASD.
- The second question was informed from findings from one scoping review, one primary study, and insights from 11 key informant interviews, and while key informants described some of the attributes and successes of support groups, there was a tendency throughout interviews to also discuss successes or gaps in supports in general, for parents and caregivers, and for those with FASD.
- Support groups were frequently described by key informants as having been established in their communities, however they noted that they differed substantially in their level of formality.
- Key informants noted the importance of support groups in providing a space for peer-to-peer support, and when asked about the success factors that led to the establishment of support groups, key informants highlighted that the groups’ existence often hinged on a single person or a small organization.
- With respect to broader services, key informants stressed that existing approaches could be better tailored to meet the needs of those with FASD, and emphasized the need for more services and supports for those with FASD, explaining that parents and caregivers are best able to manage when their child is understood, well supported and has consistency from programs and from their interactions with health and social-service professionals.

## **QUESTIONS**

- What approaches have been found to be effective for parent support groups of children with fetal alcohol spectrum disorder and other neurodevelopmental conditions?
- In Ontario, Canada, what approaches have been successful in parent support groups for parents and caregivers of those with FASD, what is needed to further tailor or enhance support groups and other supports available through its health and social systems, and what is needed to make these approaches sustainable?

## **WHY THE ISSUE IS IMPORTANT**

Fetal Alcohol Spectrum Disorder (FASD) is used “to describe a broader spectrum of presentations and disabilities resulting from alcohol exposure in utero.”(1) FASD affects fetal and brain development and may result in limitations to any of an individual’s: memory; sensory integration; social communication; language processing; emotional regulation; adaptive functioning; and other executive functions that may make conforming to social, behavioural and cognitive expectations difficult.(2; 3) These effects may mean that individuals affected by FASD are unable to live independently, have difficulty securing employment, and experience behavioural challenges that increase their risk of being in conflict with the law.(2)

Approximately 130,000 Ontarians are living with FASD at a national cost-estimate of between \$1.8 and \$6.2 billion annually in direct and indirect costs.(2) However, other estimates place this number significantly higher, between two and three per cent among elementary school students in the greater Toronto area.(4) This issue represents a significant public health challenge, with recent data showing it spanning across geographic communities and socio-economic groups.(4)

There has been increasing evidence that the right information, supports and services provided in a timely manner can significantly reduce the stress that this condition has on individuals, families and caregivers.(3) Given this potential, the previous provincial government undertook a series of 16 roundtables with service providers, advocates, families, caregivers and individuals affected by FASD across five Ontario regions, as well as eight roundtables with First Nations, Métis, Inuit and Indigenous peoples living in urban communities, and one dedicated roundtable for those with lived experience. Discussions at the roundtables provided feedback on the following five areas:

- awareness and prevention;
- screening, assessment and diagnosis;
- programs, services and supports for individuals and caregivers;
- training for front-line staff and professionals; and
- evidence-based service-delivery models.(2)

### **Box 1: Background to the rapid synthesis**

This rapid synthesis mobilizes both global and local research evidence about a question submitted to the McMaster Health Forum’s Rapid Response program. Whenever possible, the rapid synthesis summarizes research evidence drawn from systematic reviews of the research literature and occasionally from single research studies. A systematic review is a summary of studies addressing a clearly formulated question that uses systematic and explicit methods to identify, select and appraise research studies, and to synthesize data from the included studies. The rapid synthesis does not contain recommendations, which would have required the authors to make judgments based on their personal values and preferences.

Rapid syntheses can be requested in a three-, 10-, 30-, 60- or 90-business-day timeframe. An overview of what can be provided and what cannot be provided in each of these timelines is provided on the McMaster Health Forum’s Rapid Response program webpage ([www.mcmasterforum.org/find-evidence/rapid-response](http://www.mcmasterforum.org/find-evidence/rapid-response))

This rapid synthesis was prepared over a 60-business-day timeframe and involved five steps:

- 1) submission of a question from a policymaker or stakeholder (in this case, Health Nexus);
- 2) identifying, selecting, appraising and synthesizing relevant research evidence about the question;
- 3) conducting key informant interviews;
- 4) drafting the rapid synthesis in such a way as to present concisely and in accessible language the research evidence; and
- 5) finalizing the rapid synthesis based on the input of at least two merit reviewers.

Feedback on these five themes ultimately informed a \$26-million commitment (in the 2017-2018 provincial budget) to be distributed over four years on the following seven FASD-specific initiatives:

- create one stop access to information and training resources;
- provide funding for over 50 FASD workers to support approximately 2,500 Ontarians with FASD;
- support parent support networks;
- increase access to FASD initiatives developed by Indigenous partners;
- establish a consultation group to provide advice and feedback to inform implementation planning and prioritization of efforts;
- create a research fund to learn more about FASD and how to prevent it; and
- support public awareness initiatives targeting at-risk groups, including women of child-bearing age.(5)

Additional investments in FASD diagnostics and more general supports were also made through the Ontario Special Needs Initiative.(6)

To further inform these efforts as well as any changes or new initiatives pursued by the new provincial government, it is timely to consider the evidence and stakeholder insights about what approaches are effective for supporting families and caregivers of those with FASD, and any critical components that should be integrated into these models to tailor them to the Ontario health and social systems

## **WHAT WE FOUND**

From the searches we conducted (see Box 2 for details about our search strategy), we only identified one recent low-quality review and two primary studies that were directly relevant to support groups for parents or caregivers of children with FASD and other neurodevelopmental conditions.(7-9) Given the paucity of literature, we expanded the scope of our search and of this rapid synthesis to include an additional 12 documents, including four systematic reviews,(3; 7; 10-12) one scoping review,(13) and seven primary studies (8; 9; 14-21) that provided details on other supports and services for parents and caregivers of those with FASD and other neurodevelopmental conditions. We complemented the findings from the research evidence with 11 key informant interviews, including four managers, two researchers, and five caregivers and representatives from advocacy groups, who shared their experiences running and participating in support groups, as well as more broadly the success factors of existing programs and the needs for additional supports in the FASD community.

It should be noted that the intention of this review is to focus specifically on approaches designed to assist families and caregivers of those with FASD and other similar life-long neurodevelopmental conditions, and not on the effectiveness of treatments for individuals with these conditions. Systematic reviews and single studies were included only if they described approaches directed at parents, families or caregivers. We provide more details about each systematic review and single study in Appendix 1 and 2, respectively.

### **Box 2: Identification, selection and synthesis of research evidence**

We identified research evidence (systematic reviews and primary studies) by searching (in July 2018) Health Systems Evidence ([www.healthsystemsevidence.org](http://www.healthsystemsevidence.org)); Social Systems Evidence ([www.socialsystematicsevidence.org](http://www.socialsystematicsevidence.org)) and PubMed. In HSE and SSE, we used the following three keyword search: 1) fetal alcohol spect\*; 2) autism; and 3) neurodevelop\*. In PubMed, we used the following three search strategies: 1) fetal alcohol spectrum\* AND (caregiver OR parent) [limited to the last 10 years]; 2) (autism OR neurodevelop\*) AND (caregiver OR parent) [limited to the last five years and systematic reviews]; and 3) (((caregiv\*) AND support group\*)) AND (alcohol OR neurodevelop\* OR cognit\* or autism).

The results from the searches were assessed by one reviewer for inclusion. A document was included if it fit within the scope of the questions posed for the rapid synthesis.

For each systematic review we included in the synthesis, we documented the focus of the review, key findings, last year the literature was searched (as an indicator of how recently it was conducted), methodological quality using the AMSTAR quality appraisal tool (see the Appendix for more detail), and the proportion of the included studies that were conducted in Canada. For primary research (if included), we documented the focus of the study, methods used, a description of the sample, the jurisdiction(s) studied, key features of the intervention, and key findings. We then used this extracted information to develop a synthesis of the key findings from the included reviews and primary studies.

**Question 1: What approaches have been found to be effective for parent support groups of children with fetal alcohol spectrum disorder and other neurodevelopmental conditions?**

We identified 14 documents (five systematic reviews (3; 7; 10-12) and nine primary studies (8; 9; 14-21)) that described key findings from specific approaches designed to support families and caregivers. A short summary of these findings has been provided in the narrative below, while additional details can be found in Table 1.

Of these documents, three (one recent low-quality systematic review and two primary studies) examined support groups for fetal alcohol spectrum disorder and autism.(7-9) The documents found support groups had mixed levels of effectiveness, with one study suggesting that a Facebook-based support group was used by parents and caregivers to provide various types of support (e.g., informational, emotional, network, validation and tangible assistance) to caregivers, with informational support being the most frequently exchanged posts on the Facebook group. Another primary study found semi-structured support groups produced no difference in psychological well-being and found a reduction in the well-being of some parents and caregivers of those with autism.(7-9) However, authors of this primary study noted that these findings may reflect an adjustment period among parents.(8)

In addition to support groups, literature on FASD and other neurodevelopmental conditions noted a number of other approaches that could be integrated alongside support groups to help parents or caregivers. The first is to provide parents or caregivers of those with neurodevelopmental conditions with counselling or therapy, which may also be an effective support. For example, two studies conducted in Ontario found that Acceptance and Commitment Therapy improved depression and stress among caregivers, self-reported health status and psychological flexibility.(20; 21) In addition, ACT reduced cognitive fusion and increased the consistency of caregivers' behaviours with their reported values. Another primary study found cognitive behavioural therapy when combined with motivational support improved the ability of caregivers to reframe problem behaviour through a neurodevelopment lens.(15) Similarly, coaching approaches were found to be effective in reducing caregiver stress and helping them to identify needs across a number of domains.(3; 14)

The most frequently described intervention in the included literature was education, which largely focused on teaching caregivers about FASD (or other neurodevelopmental disorders), parenting skills, or how they can play a therapeutic role in the treatment of FASD.(3; 7; 12) Generally, education improved the well-being and self-efficacy of caregivers, as well as helping them to understand the behaviours of those with FASD.(3; 7; 12; 17) None of the reviews provided information on the comparative effectiveness of different educational approaches.

Respite care was also examined in one primary study, which found a significant correlation between informal social support (e.g., friends and family members able to provide respite care) and levels of burden reported by parents and caregivers.(18) In addition, the study found health status was an important mediator between reported burden and levels of informal support, indicating that those most in need may not be receiving the informal social support and respite that they require.

One medium-quality review and one single study found that engaging in mindfulness and meditation lowered parental stress and improved psychological well-being for parents of those with neurodevelopmental conditions.(3; 19) However, it had no significant effect on other measures such as empowerment, burden, self-help, or compassion.

One primary study examined a multi-intervention program which integrated many of the approaches described above including psychoeducation, mindfulness exercises and education resources. The study found caregivers enrolled in the program had a better understanding of the behaviour of, and better communication with, those with FASD.(16)

Though not related to the effectiveness of interventions for families and caregivers, one review investigated the costs of FASD in Canada, including all direct costs relating to healthcare, education and social services for both affected individuals and their families.(11) The review provided varied estimates on annual individual costs ranging from \$14,342 to \$21,642.(11) Three other studies included in the review provided a nation-wide annual cost-estimate of between \$344 million and \$5.3 billion.(11) However, it remains uncertain whether or how providing parents with enhanced supports affects costs.

**Table 1. Summary of key findings related to approaches to support families and caregivers of those with neurodevelopmental disorders**

Interventions	Key findings
Support groups	<ul style="list-style-type: none"> <li>• One recent low-quality review aimed to identify programs targeted at families of those with physical disabilities and/or intellectual impairments, and identified support groups as one such approach.(7)</li> <li>• One primary study examined two Facebook-based autism support groups and found they were used by parents and caregivers to:               <ul style="list-style-type: none"> <li>○ provide informational support, including sharing advice and experiences as well as requesting information;</li> <li>○ provide emotional support;</li> <li>○ establish a network, which includes posts and comments that connected members;</li> <li>○ provide esteem support by providing validation to the experiences of other members; and</li> <li>○ provide tangible assistance by offering specific help.(9)</li> </ul> </li> <li>• One primary study found no significant difference in the psychological well-being or quality of life of caregivers or parents participating in a semi-structured support group of those with autism, one month following the intervention.               <ul style="list-style-type: none"> <li>○ The study found that subjective well-being and employment were significant mediators for quality-of-life measures.</li> </ul> </li> <li>• Authors of the study suggested that the findings may reflect an adjustment period of parents learning to share their feelings, build trust within their group, and learn new coping mechanisms.(8)</li> </ul>
Counselling and therapy	<ul style="list-style-type: none"> <li>• One recent low-quality review aimed to identify programs targeted at families of children with physical disabilities and/or intellectual impairments and found education and counselling services delivered either online and in group settings as one possible approach.(7)</li> <li>• Two primary studies conducted in Ontario found Acceptance and Commitment Therapy (ACT) improved depression and stress among caregivers, reported health status, and psychological flexibility, as well as reduced cognitive fusion (e.g., attaching a thought to an experience), and increased caregivers’ engagement in behaviours that are consistent with their values for parents or caregivers of children (under 3) with autism.               <ul style="list-style-type: none"> <li>○ However, ACT did not have a significant effect on improving social isolation scores.(20; 21)</li> </ul> </li> <li>• One primary study examined a program combining cognitive behavioural therapy and motivational support of those with FASD. and reported improvements in caregivers’ knowledge of FASD and ability to reframe problem behaviour through a neurodevelopment lens.(15)</li> </ul>
Coaching	<ul style="list-style-type: none"> <li>• An evaluation of a coaching program included in a recent high-quality review found that participating caregivers showed a reduction in identified needs and stress, as well as an improvement in the caregiver’s well-being.(3)</li> <li>• A single study of a coaching program in Alberta for families and caregivers of those with FASD resulted in a reduction in 13 of 14 identified areas of family need including: housing and transportation; family parenting; community development; community resources; relationship and peers; family situational; grief and loss; immediate family and marital conflict; health issues; motivation; extended family contact and relationships; family neglect; and other needs.</li> </ul>

	<ul style="list-style-type: none"> <li>• In addition, caregivers that participated in the study reported a reduction in stress and improved confidence in their parenting.(14)</li> </ul>
Education	<ul style="list-style-type: none"> <li>• One recent high-quality review found education on parenting skills improved caregivers' well-being and ability to care for those with FASD.             <ul style="list-style-type: none"> <li>○ The same review found an education and training program on FASD for foster parents reduced placement changes for children.(3)</li> </ul> </li> <li>• One recent medium-quality review found centre-based parent education improved self-efficacy, but had inconclusive effects on reducing stress among parents with autistic children.             <ul style="list-style-type: none"> <li>○ By comparison, relatively little evidence was found on home-based education, but one study found that parents with low baseline levels of self-efficacy experienced improved confidence and efficacy from these programs.(12)</li> </ul> </li> <li>• One recent low-quality review aimed to identify programs targeted at families of those with physical disabilities and/or intellectual impairments and found education was the most frequently cited intervention, with most programs focused on training parents to play a therapeutic role.             <ul style="list-style-type: none"> <li>○ The review did not provide information on the effectiveness of educational interventions.(7)</li> </ul> </li> <li>• One older high-quality review examined parent-assisted child friendship training, which included parental education, improved the social skills of children and parents.(10)</li> <li>• Finally, one primary study noted that the opportunity to increase caregivers' knowledge of FASD through education helped them to access supports and not to blame their child for non-compliant behaviours.(17)</li> </ul>
Respite	<ul style="list-style-type: none"> <li>• One recent primary study found a significant negative correlation between a caregiver's level of informal social support from friends and family (who could provide respite care and emotional assistance) and their reported levels of caregiver burden.</li> <li>• In addition, the caregiver's health status was found to be a significant mediator between their reported burden and levels of informal support.(18)</li> </ul>
Mindfulness and meditation	<ul style="list-style-type: none"> <li>• Limited evidence included in one recent medium-quality review suggested that mindfulness, relaxation and meditation may improve stress, affect and satisfaction among parents with autistic children.(12)</li> <li>• One primary study conducted in Ontario found parents and caregivers of adults (16 and over) with autism reported significant and sustained (at a 20-week follow-up) improvements in psychological well-being following six two-hour mindfulness sessions.</li> <li>• However, the study found no significant changes to other parent measures including empowerment, burden, self-help or compassion.(19)</li> </ul>
Care coordination	<ul style="list-style-type: none"> <li>• One recent low-quality review found that care coordination for children with complex care needs reduced health care utilization and improved parental engagement with care.(7)</li> </ul>
Multi-component interventions	<ul style="list-style-type: none"> <li>• One primary study examined a multi-component program (psychoeducation, mindfulness exercises and education resources) for parents and caregivers of children with FASD.             <ul style="list-style-type: none"> <li>○ Caregivers enrolled in the program reported a better understanding of their child's behaviour and their role in supporting their child, as well as improved communication and behaviour of the child.</li> <li>○ While caregivers reported enjoying the flexibility of the program, they reported desiring a more structured support system.(16)</li> </ul> </li> </ul>
Mindfulness and meditation	<ul style="list-style-type: none"> <li>• Limited evidence included in one recent medium-quality review suggested that mindfulness, relaxation and meditation may improve stress, affect and satisfaction among parents with autistic children.(12)</li> <li>• One primary study conducted in Ontario found parents and caregivers of adults (16 and over) with autism reported significant and sustained (at a 20-week follow-up) improvements in psychological well-being following six two-hour mindfulness sessions.             <ul style="list-style-type: none"> <li>○ However, the study found no significant changes to other parent measures including empowerment, burden, self-help or compassion.(19)</li> </ul> </li> </ul>

**Question 2: In Ontario, Canada, what approaches have been successful with parents and caregivers of those with FASD, what is needed to further tailor or enhance supports available through its health and social systems, and what is needed to make these approaches sustainable?**

Findings from one scoping review,<sup>(13)</sup> one primary study,<sup>(17)</sup> and insights from 11 key informant interviews informed the second question. While key informants described some of the attributes and successes of support groups, there was a tendency throughout interviews to also discuss successes or gaps of supports in general, both for parents and caregivers and for those with FASD.

Support groups were frequently described by key informants as having been established in their communities, however they noted that they differed substantially in their level of formality. One key informant described that the peer-to-peer interaction provided by support groups was particularly important given that many parents and caregivers experience feelings of being overwhelmed along with feelings of isolation and guilt, and that these sentiments are not often considered by the other supports and services in place. When asked about the success factors that led to the establishment of support groups, key informants highlighted that the groups' existence often hinged on a single person or a small organization who took it upon themselves to plan semi-regular meetings and any additional efforts that grew from the group. Key informants described how other initiatives grew out of the support groups, such as a family meal club where families of those with FASD join together two nights a week to make dinner and help each other with the after-school routine - a time in the day that most key informants commented was particularly stressful. Other more formal initiatives also grew out of the support group, such as an advocacy day for parents and caregivers at the Ontario legislature.

In relation to broader supports and services, the scoping review, which focused on adults and was developed to inform the quality indicators for intellectual and development services in Ontario,<sup>(13)</sup> found that the most used services by families were respite and daytime care supports, financial support services, and informational services about programs and supports.<sup>(13)</sup> This is generally consistent with what key informants described as being other supports and services (apart from support groups) that were successful in helping parents and caregivers in their communities.

A significant focus of interviews was on how the supports that already exist can be better tailored to parents and caregivers of those with FASD, and made more effective through better design. In relation to this, key informants stressed that the right services and supports exist for other neurodevelopmental conditions and disabilities, but that eligibility criteria for accessing these services should be tailored to consider FASD and the challenges that accompany it. For example, key informants described the need for flexibility in the eligibility criteria for tax benefits, such as requiring a diagnosis (and in some cases repeated proof of the diagnosis), which may take up to two years to obtain. In addition, key informants described that supports and services need to move away from a one-size-fits-all approach (e.g., one set of services for everyone with FASD) and instead move towards a "menu" approach, where parents and caregivers could pick and choose the supports that would be most helpful to them and most suited to their own routines. In considering the tailoring of approaches, one key informant noted that there has been a trend towards achieving flexibility by offering services online, which will help to reach those who might otherwise not have access to supports. However, the key informant stressed that while there are many advantages to online services, it is critical to the well-being of parents and caregivers to maintain some degree of peer-to-peer contact with a social-support network.

Both the scoping review and primary study also identified caregivers' perceptions about the services they need.<sup>(13; 17)</sup> The scoping review identified a gap in supports and services both for caregivers and those with FASD that span the life course.<sup>(13)</sup> This was also raised by key informants who stressed that the gap in supports that exists when those with FASD turn 18 is extremely stressful for caregivers who scramble to understand the changes in eligibility criteria and in what services are available. In addition, the primary study identified the need for different approaches to address uncertainty among caregivers about what supports exist, as well as the need for greater public awareness and knowledge about FASD.<sup>(17)</sup> The study also found

that caregivers emphasized the importance of a diagnosis, indicating that a diagnosis validated their concerns regarding their child's behaviour, helped them to convey their needs to health professionals, and was a requirement for accessing some benefits and supports for their children (e.g., financial support through tax benefits).(17) These perceptions were mirrored in key informant interviews that emphasized the need for many of the same services, including echoing the need for more diagnostic and navigation services, both within the health system as well as in the education and justice sectors.

Key informants also called for broader supports and services for those with FASD. Specifically, they described that while supports and services tailored to parents and caregivers are important, they are best able to manage when their child is understood, well supported and has consistency in programs and health and social-service professionals. One example that was provided was the need for educational supports and awareness from teachers. Key informants stressed that if better education supports were available, parents and caregivers could use the time their children are at school as a form of respite, both to take care of themselves as well as to maintain employment without the worry of being called to pick their child up from school.

When asked about what is needed to create sustainable supports and services for FASD in Ontario, the key informants focused on one or all of the following three elements: 1) the need for consistent and reliable funding, with renewals based on long-term outcome evaluations; 2) provincial education policy on FASD; and 3) flexibility in eligibility criteria for disability funding and tax returns both at a provincial and federal level. When asked about barriers for moving forward with these elements, participants emphasized two key barriers. The first was the stigma around FASD stemming from a lack of knowledge about FASD among educators, managers, policymakers and the public, and the second was a lack of time for caregivers and parents to advocate for change. Key informants highlighted that with relatively few supports available, they spent the majority of their time and energy on ensuring their child has the service and supports they need, and as a result do not always have sufficient time to engage in advocacy work.

Finally, two key informants identified two potential windows of opportunity that could be used to facilitate efforts to enhance approaches to support parents and caregivers of children with FASD. The first is to collaborate with FASD organizations across the country. The key informants highlighted how Ontario fell behind many other provinces in effectively supporting those with FASD and could learn from the experiences of FASD networks in Alberta and Saskatchewan. The second window of opportunity is to learn from the experience of other neurodevelopmental conditions. For example, most key informants mentioned the discrepancy between FASD supports and services and those available for those with autism. Key informants described that while they did not think it was appropriate to combine services, the FASD community may be able to learn from the advocacy and championing efforts of the autism community and adopt some of the same strategies that have led to their policy successes.

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## APPENDICES

The following tables provide detailed information about the systematic reviews and primary studies identified in the rapid synthesis. The ensuing information was extracted from the following sources:

- systematic reviews - the focus of the review, key findings, last year the literature was searched, and the proportion of studies conducted in Canada; and
- primary studies - the focus of the study, methods used, study sample, jurisdiction studied, key features of the intervention and the study findings (based on the outcomes reported in the study).

For the appendix table providing details about the systematic reviews, the fourth column presents a rating of the overall quality of each review. The quality of each review has been assessed using AMSTAR (A MeaSurement Tool to Assess Reviews), which rates overall quality on a scale of 0 to 11, where 11/11 represents a review of the highest quality. It is important to note that the AMSTAR tool was developed to assess reviews focused on clinical interventions, so not all criteria apply to systematic reviews pertaining to delivery, financial or governance arrangements within health systems. Where the denominator is not 11, an aspect of the tool was considered not relevant by the raters. In comparing ratings, it is therefore important to keep both parts of the score (i.e., the numerator and denominator) in mind. For example, a review that scores 8/8 is generally of comparable quality to a review scoring 11/11; both ratings are considered “high scores.” A high score signals that readers of the review can have a high level of confidence in its findings. A low score, on the other hand, does not mean that the review should be discarded, merely that less confidence can be placed in its findings and that the review needs to be examined closely to identify its limitations. (Lewin S, Oxman AD, Lavis JN, Fretheim A. SUPPORT Tools for evidence-informed health Policymaking (STP): 8. Deciding how much confidence to place in a systematic review. *Health Research Policy and Systems* 2009; 7 (Suppl1):S8).

All of the information provided in the appendix tables was taken into account by the authors in describing the findings in the rapid synthesis.

**Appendix 1: Summary of findings from systematic reviews about effective models to support parents and caregivers of children with fetal alcohol spectrum disorder**

Type of review	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
Systematic review	To review a range of interventions for individuals with fetal alcohol spectrum disorders across all age groups (3)	<p>Fetal alcohol spectrum disorders can have negative impacts on individuals and families, so effective interventions are required to ensure healthy development and family dynamics.</p> <p>The review included 32 studies. Of these 32, seven studies were focused on supporting and educating parents or caregivers.</p> <p>Three studies focused on building parenting skills. These programs were effective at improving parents' well-being and ability to care for their children. Furthermore, children displayed improvements in their behaviour. One study found that group workshops and information packets targeted at parents were more effective than internet-based training programs for improving behaviour, but all three modes of educating were able to improve parents' knowledge of behavioural learning principles.</p> <p>Four studies of support, education, and advocacy initiatives were included. Coaching families, a program targeted at supporting parents, showed a reduction in the needs and stress of caregivers and improved caregiver well-being; greater time in the programs was linked to greater improvements. A program aimed at workers and foster caregivers for children in out-of-home care found that specialized fetal alcohol spectrum disorder training was associated with a significant decrease in placement changes for children. Finally, the Key Worker and Parent Support Program in British Columbia, which supported families affected by fetal alcohol spectrum disorders, showed some qualitative evidence of improved well-being and skills in caregivers; however, there were no statistically significant changes.</p>	2014	8/10 (AMSTAR rating from McMaster Health Forum)	Not reported
Systematic review	To review the effectiveness of interventions aimed at children with fetal alcohol spectrum disorders (10)	<p>Greater insight into the effectiveness of interventions for fetal alcohol spectrum disorders can improve outcomes for children and families.</p> <p>The review included 12 studies, and one study described an intervention that involved supporting parents/caregivers.</p> <p>The intervention described a 12-week program of parent-assisted child friendship training. These sessions were accompanied by educational sessions for parents, teaching them about fetal alcohol spectrum disorders and social skills. This program was found to improve the social skills of the children and</p>	2009	10/10 (AMSTAR rating from McMaster Health Forum)	3/12

McMaster Health Forum

Type of review	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
		parents, and problem behaviours decreased among the children. These improvements were found to persist at three months follow-up.			
Systematic review	To review available family-oriented services for families of children with disabilities and/or impairments and develop a framework based on the findings (7)	<p>This review aimed to identify programs and services targeted at families of children with physical disabilities and/or intellectual impairments. The search covering 2009 to 2014 included 36 studies. The researchers identified four groups of services: educational; support groups; psychosocial interventions; and care coordination.</p> <p>Fourteen articles focused on educational interventions for families. Educational interventions were grouped into two broad groups: 1) educating parents about their child's condition (either in person or online); and 2) training parents to provide some service to their child. Most education interventions were focused on training parents to have a therapeutic role, likely due to the importance of this type of intervention. Although educational programs were aimed at providing parents with information, they also were noted to be places for psychosocial support. It was also noted that many educational programs were targeted at specific disabilities.</p> <p>Four articles focused on support groups for parents. Three of the described groups were peer-led (by parents) and the roles for parents varied from being a facilitator to a participant within the group. One article described a provider-led group for parent support.</p> <p>Twelve articles described psychosocial interventions. Counselling and psychological interventions were run online and in group settings, and they focused on strengthening parents' competencies and coping skills. Respite programs were also identified and frequently involved some intervention for children to participate in. Finally, coaching programs were identified and involved empowering parents to help their child achieve a goal or perform in a natural context.</p> <p>Finally, six articles discussed care coordination which was provided by medical homes and clinics. These services were targeted at ethnic minorities and children with complex care needs. Some studies found that care coordination was found to reduce healthcare utilization and improve parental engagement with care.</p> <p>The framework developed by the authors outlined a range of family-oriented services that a pediatric rehabilitation centre could offer to advance familial wellness. The framework identified three major areas to target: the needs of parents; enabling parents to assist in care; and educating parents. To address the</p>	2014	3/9 (AMSTAR rating from McMaster Health Forum)	9/28

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Type of review	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
		needs of parents, care coordination and psychosocial services and supports were identified. Training parents to take on a therapeutic role was identified to enable parents to assist in care. Finally, general information provision and individualized educational services were noted as ways to educate parents.			
Systematic review	To report on costs associated with fetal alcohol spectrum disorders on the individual, system and societal level (11)	<p>Fetal alcohol spectrum disorders cause difficulties throughout the lifespan and patients often require support from many sectors. These factors make estimating the cost of fetal alcohol spectrum disorder difficult. Nonetheless, the current review included 13 studies that estimate the costs of fetal alcohol spectrum disorders in Canada and the United States.</p> <p>Three studies investigated the costs of fetal alcohol spectrum disorders in Canada. All costs were reported in Canadian dollars and converted to May 2010 values. All studies included direct costs relating to healthcare, education and social services. Indirect and other costs were also incorporated in all three studies. The data informing the estimates was drawn from a sample and may not accurately reflect the broader Canadian context. All three studies used a conservative prevalence of three cases per 1000, although one study conducted a second analysis with an upper-range prevalence rate at nine per 1,000. Annual costs per person varied significantly, with estimates ranging from \$14,342 to \$21,642 per person. This led to nation-wide annual costs estimates ranging from \$344 million to \$5.3 billion. It is worth noting that the lower estimates only reflect the costs for those between one and 21 years of age, while the upper-range estimate incorporates an age range from birth to 53 years old and has a few more cost components. Another study estimated lifetime costs associated with fetal alcohol spectrum disorders to be approximately \$1.1 million by using an annual cost of \$15,812 and an average life expectancy of 71.6 years.</p> <p>Ten studies estimated the cost of fetal alcohol spectrum disorders in the United States. All costs for these studies were reported in U.S. dollars as of June 2010. These studies incorporated various combinations of healthcare, home care, special education, indirect, and other costs. The prevalence rates used in these studies was usually lower than those used in the Canadian studies, with most studies using a rate around two per 1,000. Three studies investigated costs from the perspective of the healthcare system only and reported cost estimates of \$74.6 million, \$321 million, and \$1.6 billion. Residential care costs were noted as a main cost driver. Studies that reported on lifetime costs reported estimates of \$2 million and \$1.374 million. Societal cost estimates ranged from \$1.944 billion to \$5.4 billion.</p> <p>The authors noted that all estimates are likely to be low due to a lack of data for several cost components. Important cost areas that were not addressed include</p>	2010	6/9 (AMSTAR rating from McMaster Health Forum)	3/13

McMaster Health Forum

Type of review	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
		child-welfare system costs, law-enforcement costs, and intangible costs such as pain and suffering. The significant differences in cost estimates were attributed to methodological differences.			
Systematic review	Examining the impacts that interventions for children with autism spectrum disorder have on parents (12)	<p>Having a child with autism spectrum disorder (ASD) in a family can increase demands on parents and requires parents to commit a significant amount of time and effort towards their child. Therefore, this systematic review sought to determine what impact interventions for children with ASD can have on parents' stress and self-efficacy. The review included 34 articles that had some measure of family outcomes. Most of the children with ASD were males between one and 17 years of age. Most caregivers were mothers. The findings were grouped according to the intervention type and the setting of the intervention (either home- or centre-based programs).</p> <p>Centre-based parent education and coaching programs were found to have a moderate level of evidence supporting their ability to improve parental self-efficacy. The evidence was not conclusive regarding whether these interventions were effective at reducing parental stress.</p> <p>Home-based (and combined setting) parent education and coaching interventions had limited evidence. There was limited evidence suggesting that these interventions can decrease stress. Some evidence suggested that parents with low levels of self-efficacy at baseline benefited from improved confidence and efficacy.</p> <p>Centre-based behavioural interventions were found to have moderate to strong evidence supporting their ability to improve parental confidence and self-efficacy. The evidence related to improvements in stress levels and quality of life was mixed.</p> <p>Home-based behavioural interventions were found to have no impact on parental self-efficacy and confidence. The evidence was mixed with respect to parental stress and quality of life.</p> <p>Finally, interventions aimed at relaxation, mindfulness and strengths were also discussed. Few evaluations of these interventions were found. The very limited evidence suggests that these interventions may improve parental stress, affect and satisfaction.</p> <p>Overall, the evidence regarding family outcomes is limited. Centre-based interventions were found to be more effective at improving parental confidence</p>	2013	6/9 (AMSTAR rating from McMaster Health Forum)	1/34

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Type of review	Focus of systematic review	Key findings	Year of last search/ publication date	AMSTAR (quality) rating	Proportion of studies that were conducted in Canada
		and self-efficacy. The researchers suggested this may be because centre-based programs are more intensive and have an emphasis on research.			
Scoping review	To inform the development of quality indicators for intellectual and developmental disabilities (I/DD) services in Ontario which are relevant to families (13)	<p>A scoping review of 80 articles aimed to inform the development of quality indicators for I/DD services in Ontario through mapping and examining research in this area. The results of the review were organized into three main themes: service use, service need (including waiting for services), and permanency planning.</p> <p>A general service-use pattern was identified; respite and daytime activities, financial support services, and informational services about future programs and supports are the most widely used. Residential services are used less frequently, which may be attributed to the lack of availability of such services, and many families' unwillingness to receive residential supports. Service use was related to the presence of challenging behaviours among individuals with I/DD, as well as carer demographics and health status.</p> <p>Recent attention has been given to the unique service needs of families. The needs of adults with I/DD have been shown to be different from those evident in childhood, with children needing more developmental and medical services. Furthermore, evidence suggests that families' need for respite care seems to be rising, with several studies highlighting increasing respite need patterns despite its decreasing availability. In addition, studies have shown that carers need more information about support services for their children, and a need for proactive as opposed to crisis-driven service. Service need, like service use, was associated with challenging behaviours among individuals with I/DD, as well as carer demographics and health status. Carers' perceptions of how well they can provide for the child in the future was also a key determinant of service need.</p> <p>Planning for the future care of adults with I/DD is important; however, research suggests that the majority of carers do not take proactive steps towards future planning. Permanency planning was found to be associated with child level of functioning, parent income, social support, and caregiving demands.</p> <p>This review outlined the importance of measuring family carers' mental and physical health status, as well as their perceptions of service quality. However, methodological limitations, including reliance on cross-sectional data, warrant considerations for future system monitoring efforts.</p>	2011	n/a	7/87

**Appendix 2: Summary of findings from primary studies about effective models to support parents and caregivers of children with fetal alcohol spectrum disorder**

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
Evaluating the impact of the coaching families program (14)	<p><i>Publication date:</i> 2012</p> <p><i>Jurisdiction studied:</i> Alberta</p> <p><i>Methods used:</i> Retrospective analysis using case file data</p>	<p>The sample included 186 families with a child having a fetal alcohol spectrum disorder. Most caregivers in contact with the program were female and their average age was 46. Parent/caregivers were 30% foster parents, 23% adoptive parents, 19% biological parents, 15% biological relatives, and 9% were permanent guardians. Seventy-eight per cent of caregivers were Caucasian, 18% were First Nations Canadian, and the rest were from other ethnocultural groups. Most of the households had only one child, and 67% of the children involved had a fetal alcohol spectrum disorder diagnosis.</p>	<p>The studied intervention was the coaching families (CF) program run by Catholic Social Services in Alberta. CF pairs families with mentors who support the family and help them identify services. Mentors help educate families about fetal alcohol spectrum disorders, caring for children with fetal alcohol spectrum disorders, and advocating for their children. Mentors also work with families to help them access respite care. The goal of the program is to help families cope, lengthen child placements, and reduce family breakdown.</p>	<p>The time families spent in the CF program was an important indicator of the reduction in their needs and the attainment of their goals. So, the longer they spent in the program the more their needs were reduced and the greater their achievement of goals.</p> <p>The researchers grouped families' needs into 14 categories and found significant reductions in 13 of these groups when comparing pre- and post-program needs. Families' goals were grouped into six categories, and all six categories of goals showed significant improvements after the intervention.</p> <p>Overall, satisfaction with the CF was very high (98%), and caregivers reported a significant decrease in stress. Caregivers also reported feeling more confident in their parenting and more aware of the needs of their child with a fetal alcohol spectrum disorder. Most of the caregivers (65.6%) reported having no issues with CF, but some complaints centred around mentors lacking empathy, having difficulty accessing services, and that the program lacked long-term support.</p> <p>The CF program was found to be quite effective at addressing the needs and goals that it focused on. However, certain issues, such as caregivers' mental health, were not explicitly addressed by the program.</p> <p>The findings from this study are important due to the large sample size employed, but methodological strength was limited because there was no control group.</p>
To evaluate the Families on Track Intervention Pilot for child and family outcomes (15)	<p><i>Publication date:</i> 2017</p> <p><i>Jurisdiction studied:</i> New York, U.S.</p> <p><i>Methods used:</i> Randomized controlled trial</p>	<p>Thirty children with a fetal alcohol spectrum disorder were recruited for this trial. The children ranged in age from four to eight. Forty per cent of the children were diagnosed with fetal alcohol syndrome or partial fetal alcohol syndrome, with the rest having confirmed prenatal alcohol</p>	<p>Families on Track is a 30-week program combining home-based parent consultations with weekly skills groups for the children. The branch of the program targeted at caregivers was the Families Moving Forward (FMF) program. The FMF program combines motivational, cognitive behavioural, and behavioural strategies to modify parenting attitude, responses to child</p>	<p>The Families on Track Intervention pilot was fairly successful at retaining participants, and caregivers reported high levels of satisfaction with the program. Satisfaction was high for the caregivers' learning outcomes, their relationship with their specialist, and their enjoyment of the program. However, caregivers reported that their children had a bit more trouble applying what they learned and thus improved only moderately.</p> <p>Pre- and post-testing revealed that caregivers made significant improvements in their knowledge of fetal alcohol spectrum disorders because of the intervention. Families in the intervention group also showed a large decrease in their needs, while families in the active control group showed only a small-to-medium effect. Caregivers in</p>

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Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
		<p>exposure. Families enrolled in the study were allowed to concurrently access other interventions.</p> <p>The enrolled families were placed into either the Families on Track program or an active control group. By the end of the trial, 15 families were part of the intervention group, and 12 were part of the active control.</p>	<p>behaviours, and reduce parents' aggression towards their children. FMF works to reframe children's problem behaviour into a neurodevelopmental lens so that parents can understand these behaviours and be more supportive and effective in their parenting.</p> <p>The FMF program was delivered bi-weekly at the families' homes. Sessions lasted 90 minutes, and the specialist delivering the sessions was usually the same person leading the child through their skill-building program.</p>	<p>the intervention group were more likely to be able to reframe their child's problem behaviour through a neurodevelopmental lens, and they were more likely to employ antecedent strategies. Parents in the intervention group also demonstrated some gains in self-efficacy and social support, but these improvements were not statistically significant. Small improvements in parental self-care, satisfaction, and distress were noted, but these improvements did not reach statistical significance.</p> <p>With respect to outcomes for children, improvements in self-regulation and self-esteem were the most significant effects.</p>
<p>Collecting participants' perspectives regarding their experience with a family-focused intervention for fetal alcohol spectrum disorders (16)</p>	<p><i>Publication date:</i> 2017</p> <p><i>Jurisdiction studied:</i> Australia</p> <p><i>Methods used:</i> Mixed methods study utilizing a phenomenological approach and single-case experimental design</p>	<p>Three families of children having a diagnosis of neurobehavioural disorder were recruited. Children ranged in age from nine to 12, were female, and they were assessed to have extremely low adaptive behaviour. Parents ranged in age from 43 to 57, had at least a high school education, and four out of six parents had an existing mental health diagnosis. Families were recruited from a fetal alcohol spectrum disorder diagnostic service.</p>	<p>The researchers tested an adaptation of the Parents under Pressure (PuP) program, a home-based intervention. PuP focuses on ensuring that parents can manage their own emotional state so that they can provide their child with appropriate care. PuP begins with an assessment so that a tailored care plan can be developed for each family. Each family received some combination of psychoeducation regarding fetal alcohol spectrum disorders, mindfulness exercises, modules on managing emotions, and resources (such as books and apps) to help manage emotions and provide care. Sessions with therapists were held fortnightly for one to two hours and involved talking about issues</p>	<p>Two of the three families completed all sessions and follow-up assessments (the third family withdrew for reasons unrelated to the intervention).</p> <p>Overall, the participants found the intervention procedure and time commitment to be acceptable. Parents found that the intervention helped them understand their child's behaviour and their role in supporting their child. Furthermore, they felt supported by the therapist and parents felt more inclined to support one another. Parents also mentioned that their family was communicating better, their child's behaviour improved, and they had hope for their child's future. Parents appreciated having a therapist with knowledge of fetal alcohol spectrum disorders, seeing positive changes in their child's behaviour, and having the therapist meet with school staff. The intervention was applauded for being flexible, but parents desired a more structured follow-up support system. Parents also noted that more work needed to be done to support their child's social skills, the family's communication skills, their own emotional regulation, and to use the intervention's strategies.</p> <p>A measure of parent-reported child psychosocial distress showed that there was a medium-to-high degree of improvement over the course of the intervention. A different measure of parent-reported child executive function did not provide conclusive evidence of improvement. Both children who completed the intervention showed</p>

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
			from the past week and developing new skills.	improvements from pre- to follow-up in how accurately they performed in a neuropsychological test; however, both children also performed the test slower in follow-up assessments. Respiratory sinus arrhythmia measurements (which measure self-regulatory processes and emotional control) showed no improvements from pre- to follow-up. However, the timing of these measurements may have skewed the results.
<p>Surveying caregivers of children with fetal alcohol spectrum disorders regarding their perception of the diagnosis and the changes that followed the diagnosis</p>	<p><i>Publication date:</i> 2017</p> <p><i>Jurisdiction studied:</i> Australia</p> <p><i>Methods used:</i> Audiotaped interviews and qualitative analysis</p>	<p>Primary caregivers of children with a fetal alcohol spectrum disorder were recruited from a diagnostic service (part of Queensland Health’s Child Development Service) in mid-2015. Ten families participated in the study. Caregivers included foster parents, adoptive parents, and legal guardians. Interviews took place two months following a diagnosis and lasted 30 to 40 minutes.</p>	<p>No intervention.</p>	<p>The researchers identified six recurring themes from the parents’ interviews.</p> <p>The first theme was a desire to enhance their child’s future. Caregivers wanted to ensure that their child was well supported and able to mature into a happy person. Caregivers believed they had to advocate for their child because they know about their child’s abilities.</p> <p>Caregivers also felt significant uncertainty. Many caregivers had accessed and exhausted all available resources, but the child did not show improvement. This led to more uncertainty regarding their child’s future, and uncertainty regarding the importance of a diagnosis given the lack of resources to help.</p> <p>The third theme pertained to caregivers’ knowledge and understanding of fetal alcohol spectrum disorders. Caregivers made attempts to learn more about fetal alcohol spectrum disorders by accessing resources, and therefore had a greater understanding of the child’s difficulties. This understanding allowed caregivers to not blame their child for non-compliant behaviours.</p> <p>A fourth theme was a lack of societal understanding regarding fetal alcohol spectrum disorders. Caregivers found that the condition was not widely acknowledged as a disability, so their children were often wrongly blamed or held to unrealistic standards – especially at school. Furthermore, caregivers felt they were being blamed and perceived as bad parents due to their child’s behaviours.</p> <p>The importance of the diagnosis itself also emerged as a theme as it validated caregivers’ previous concerns regarding their child’s behaviour. Furthermore, caregivers were grateful because the diagnosis clarified their child’s needs and allowed caregivers to convey this information to health professionals.</p> <p>Finally, all caregivers found the experience with the Child Development Service to be positive and empowering. They reported</p>

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Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
				<p>that the staff were very accommodating and showed more respect than previous professionals had. Furthermore, the specific diagnosis of a fetal alcohol spectrum disorder was more valuable to caregivers than a more general developmental-behavioural diagnosis, and it allowed caregivers to access more specific supports.</p>
<p>Assessing caregivers' perceptions of burden, social support, their own health, and the interactions between these factors (18)</p>	<p><i>Publication date:</i> 2018</p> <p><i>Jurisdiction studied:</i> U.S.</p> <p><i>Methods used:</i> Quantitative correlation research with a web-based survey</p>	<p>A total of 328 parents (aged 50 or older), with adult children (aged 18 or older) who have been diagnosed with autism spectrum disorder, were recruited through support organizations.</p> <p>The parents were mostly female, white, affluent, and had at least one university degree.</p>	<p>No intervention.</p>	<p>This study sought to determine the relationship between caregiver burden, informal social support, and caregivers' self-reported health status. Specifically, the aim was to determine if health status moderates the relationship between informal social support and caregiver burden.</p> <p>Informal social support refers to the family and friends who may assist caregivers in taking care of their adult child with autism spectrum disorder. This may take the form of respite, emotional support, or other assistance. The measure of caregiver burden provides an assessment of the challenges associated with providing care for an adult child with autism spectrum disorder. The authors of this study separated caregiver burden into four groups: time dependence, financial, emotional, and developmental (which assesses the extent to which caregivers may lead very different lives than their peers who are not taking care of an adult child with autism spectrum disorder).</p> <p>On average, parents rated their own health somewhere between "good" and "very good", and they experienced caregiver burden on aggregate, and in the time, developmental and financial domains. Furthermore, most parents reported receiving a moderate level of social support.</p> <p>When statistical analysis was run on the data, a significant negative correlation was found between caregiver burden and informal social support, signalling that higher levels of social support are associated with lower levels of caregiver burden. Furthermore, the self-reported health of caregivers was found to be a significant moderator of the relationship between their burden and level of informal social support.</p> <p>This study was limited because the participants had a relatively high degree of advantage and access to caregiving resources. Furthermore, caregiver health status was the moderating variable being studied; however, it was only assessed by a single question on an electronic survey.</p>

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
<p>Assessing how parents and caregivers use a Facebook-based autism support group (9)</p>	<p><i>Publication date:</i> 2015</p> <p><i>Jurisdiction studied:</i> Online/Malaysia</p> <p><i>Methods used:</i> Activity in two Facebook groups was analyzed using deductive content analysis and sorted by frequency of occurrence</p>	<p>Two Facebook groups for caregivers of children with autism spectrum disorder were used in this study: Autism Malaysia (3,972 members) and Autism Children Club (4,094 members). Data from August to November 2013 were analysed resulting in 3,637 total posts and comments being included in the analysis. Eighty per cent of the members in these groups were parents of children with autism spectrum disorder. The remaining members were mostly teachers, health professionals, and suppliers of relevant supplies and services.</p>	<p>No intervention.</p>	<p>Parents were the most engaged in these Facebook groups, having exchanged 99% of all posts and comments. The posts and comments were sorted into five themes and 25 sub-themes.</p> <p>The most common theme was informational support, with more than 30% of posts and comments being coded with this theme. Posts and comments that fell into this theme involved sharing advice and experiences, recommending experts and resources, and requests for suggestions. Overall, over 70% of informational posts and messages offered information, while less than 30% requested information.</p> <p>The second most common theme was emotional support. Emotional support posts and comments included those building relationships, conveying feelings (positive or negative) about parenting a child with autism spectrum disorder, and offering encouragement. Posts and comments offering empathy, sympathy and congratulations were also included in the emotional support theme. Emotional support messages were most common in comments rather than posts.</p> <p>The third most common theme was network support, which included posts and comments that connected members and reaffirmed the presence of support. Esteem support, which included validation and complimentary posts and messages, was the fourth most common theme. Finally, messages coded under tangible assistance (offering specific help or unspecified assistance) was the fifth and least commonly coded theme.</p> <p>This study helps to understand how users use Facebook as a platform to receive and share social support; however, the findings were limited to two groups and there were no assessments of how parents and caregivers perceived this type of support.</p>
<p>Evaluating the mental health and quality of life of mothers who took part in a support-group program for mothers of children with autism (8)</p>	<p><i>Publication date:</i> 2005</p> <p><i>Jurisdiction studied:</i> Taiwan</p> <p><i>Methods used:</i> Quasi-experimental pre-post control group design</p>	<p>Twenty-seven mothers of children with autism took part. Eight mothers took part in the intervention, and 19 were in the control group. The children of these mothers had all been diagnosed with autism by a psychiatrist, the mothers were the primary caregivers, and</p>	<p>The intervention involved 10 sessions of a support group program. The sessions occurred weekly for 90 minutes. Each session was semi-structured and focused on a theme. The themes, such as “coping strategies” or “community resources”, were intended to guide the discussions, but the members were welcome to discuss other items as well. All sessions were</p>	<p>Of the eight mothers who took part in the intervention, the average attendance at the support group sessions was 89%.</p> <p>After analyzing the survey results, it was found that there were no statistically significant differences in psychological well-being or quality of life between the control and intervention groups at any of the three time points. For the intervention group, psychological well-being and quality-of-life ratings were found to be lower post-intervention than they were prior to the intervention. However, this decline was recovered from at the one-month follow-up.</p> <p>A Generalized Estimating Equation analysis was carried out and revealed that subjective well-being and employment had a significant</p>

*Identifying Effective Approaches to Support Parents and Caregivers of Children with Fetal Alcohol Spectrum Disorder*

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
		<p>they did not have any chronic diseases.</p> <p>Participants ranged in age from 30 to 51, and 30% had a high school diploma or higher level of education.</p>	<p>led by a psychiatric nurse specialist.</p> <p>The Chinese Health Questionnaire-30 (used to assess psychological well-being and quality of life) and World Health Organization Quality of Life-BREF Taiwan version surveys were administered pre- and post-intervention, as well as at one-month follow-up. Demographic characteristics were also gathered prior to the intervention.</p>	<p>effect on the psychological well-being score at one-month follow-up. Subjective well-being was the only factor found to have a significant effect on quality of life.</p> <p>The authors suggested that employment may have had a significant effect because of the additional support network that it provides. Furthermore, they suggested that the decline in psychological well-being and quality of life for the intervention group may be because the mothers needed time to adjust to sharing their feelings, build trust within their group, and learn coping strategies.</p> <p>This study was limited by a small sample size and short duration of the intervention. Furthermore, only mothers were involved, limiting the applicability to other parents and caregivers.</p>
<p>Examining two community-based interventions for parents of adults with autism spectrum disorder and other developmental disabilities (19)</p>	<p><i>Publication date:</i> 2017</p> <p><i>Jurisdiction studied:</i> Canada</p> <p><i>Methods used:</i> Pseudo-randomization approach including two arms</p>	<p>Parents who have a child with Autism Spectrum Disorder and are aged 16 and above were recruited through Developmental Services Ontario (DSO). Fifty parents and children participated in the study. Parents ranged in age from 37 to 81, and children ranged in age from 16 to 40.</p>	<p>The two interventions of interest are mindfulness, and support and information. Each group involved an orientation session followed by six two-hour weekly sessions. The mindfulness-based intervention was co-led by two clinicians with group mindfulness facilitation experience. Mindfulness sessions introduced clients to various meditation techniques. The parent support and education intervention was co-led by two clinicians employed by DSO Toronto. Each week, there was an initial check-in, followed by a guest presentation on a topic selected by group members and some facilitated discussion about the weekly topic. Topics that were addressed through discussion included: getting to know adult developmental services and how to access resources; person-directed planning; caregiver issues and respite; specialized clinical</p>	<p>Session participation in both interventions varied amongst the sample of 50 parents involved in the study. Although the majority of parents attended at least four out of the six sessions, the most commonly stated reasons for irregular attendance included: child issues (e.g., childcare, child health problems); parent issues (e.g., health problems); and transportation. Total satisfaction scores were similar across the mindfulness and support and information groups.</p> <p>With respect to the primary outcome (psychological distress), only parents in the mindfulness group reported significant reductions in psychological distress, which were sustained at follow-up at 20 weeks.</p> <p>In terms of secondary outcomes, there was no significant effect of group assignment on the Five Facet Mindfulness Questionnaire (FFMQ) – a questionnaire that measures five key component skills of mindfulness. Similarly, there was no significant effect of group assignment on the other parent measures (empowerment, burden, self-compassion and positive gain).</p> <p>Thus, the results suggest that the psychological components of the mindfulness group intervention were more effective than the non-specific effects of the support and information group. However, the authors acknowledge that there were several limitations which should be accounted for when interpreting study findings (e.g., small sample size and incomplete data at post-intervention, as well as 20 weeks follow-up).</p>

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
			services; crisis supports; and residential alternatives.	
Evaluating the impact of a brief Acceptance and Commitment Therapy (ACT) group intervention led by parents for mothers of children with autism (20)	<p><i>Publication date:</i> 2018</p> <p><i>Jurisdiction studied:</i> Canada</p> <p><i>Methods used:</i> Process measures were evaluated at pre-, post-, and three months following the intervention</p>	<p>Mothers of school-age children with autism (i.e., age &lt; 22 years) were recruited from autism service organizations across the Greater Toronto Area (GTA) through flyers. Thirty-three mothers participated in one of three ACT groups held from June 2015 to February 2016. The age of participating mothers ranged from 26 to 59, and the age of their children ranged from three to 20.</p>	<p>The basic format of this brief workshop consisted of general ACT group experiential exercises followed by debriefing. In addition to this general format, some changes were made to this mothers-only group compared to earlier mixed parents ACT groups, based on feedback from the two mother co-facilitators, including: providing a more welcoming environment (e.g., hosting the groups in a community rather than clinical setting); adding new ACT exercises such as reviewing video clips and poems related to ACT processes; and including the use of the ACT matrix as a simplified conceptual tool for introducing and understanding the ACT model.</p>	<p>Three standardized measures were used to evaluate the impact of the intervention in improving ACT processes: Acceptance and Action Questionnaire Version II (AAQ-II), which measures overall psychological flexibility; Cognitive Fusion Questionnaire (CFQ), which assesses cognitive fusion versus defusion; and Values Living Questionnaire (VLQ), which assesses the perceived importance of values across 10 different areas of life (e.g., work, family, friends, etc.) from “not at all important” to “very important”, and the consistency of one’s actions with their own values in each of these life areas from “completely inconsistent” to “completely consistent.”</p> <p>The results of the AAQ-II suggest that participants demonstrated improved psychological flexibility between pre- to post-, and pre- to follow-up, with no significant change between post and follow-up.</p> <p>Analysis of the CFQ revealed that there was a significant decrease in cognitive fusion from pre- to post-, and pre- to follow-up. There was also a significant decrease from post- to follow-up.</p> <p>There was considerable change in VLQ across time, with a large increase between pre- to post-, and pre- to follow-up. Such findings represent increased engagement in behaviours more consistent with their values after the workshop. However, there was no significant change from post- to follow-up.</p> <p>This study offers supporting evidence of improvement in various ACT processes (i.e., psychological flexibility, cognitive fusion, and values) following participation in a brief ACT workshop. However, there are several study limitations that need to be considered when interpreting the results, including the absence of an active treatment control group, as well as a relatively short follow-up period.</p>
Reporting on the clinical outcomes of a brief parent-facilitated Acceptance and Commitment Therapy (ACT) intervention for mothers of children with autism spectrum disorder (ASD) (21)	<p><i>Publication date:</i> 2018</p> <p><i>Jurisdiction studied:</i> Canada</p> <p><i>Methods used:</i> Outcome measures were collected via questionnaires completed at pre-treatment, post-treatment, and follow-up</p>	<p>Participants were recruited through autism service agencies and autism family organizations in a large urban setting and surrounding areas in Toronto. Thirty-three mothers of school-age children and adolescents</p>	<p>The ACT intervention involved the use of experiential group exercises with the goal of increasing defusion and acceptance of difficult emotions that can be attributed to parenting. The intervention was delivered in a group format consisting of one evening session followed by a</p>	<p>The following measures were collected to assess the clinical outcomes of the ACT intervention: Depression Anxiety Stress Scale (DASS-21) scores, which were used to assess perceived depression and stress; Isolation and health subscale scores from the Parenting Stress Index 4<sup>th</sup> edition (PSI-4), which were administered to measure perceived social isolation and physical health; and Intervention satisfaction feedback forms.</p> <p>The results of the DASS-21 suggest that depression and stress significantly improved from pre- to post- and from pre- to follow-up.</p>

Focus of study	Study characteristics	Sample description	Key features of the intervention(s)	Key findings
		<p>(&lt;22 years) participated in one of three ACT groups held from June 2015 to February 2016.</p>	<p>full-day session and a second “refresher” evening session one month later. The intervention group was co-led by a father of a child with ASD, as well as two mothers of children with ASD.</p>	<p>However, no significant improvements were identified between post- and follow-up. Therefore, a significant change was observed post-assessment and maintained at follow-up.</p> <p>Analysis of isolation and health subscale scores revealed that health significantly improved from pre- to post- and from pre- to follow-up, although not between post- and follow-up. However, changes were not significant for social isolation scores.</p> <p>In terms of intervention satisfaction, feedback forms suggest that the majority of participants agreed or strongly agreed with positively worded statements (e.g., “I thought the workshop content was interesting”). Analysis of the open-ended items revealed that mothers perceived the workshop atmosphere as a welcoming, safe space to share their experiences. Furthermore, several mothers reported that ACT concepts were presented in a comprehensible fashion.</p> <p>This study suggests that ACT for parents is practical and beneficial, as evidenced by its ease of recruitment, high adherence rates, and positive satisfaction ratings. Moreover, improvements were observed from pre- to post- and maintained at follow-up for all but one of the clinical outcomes examined. However, there are several limitations that need to be considered when interpreting the study results, including a short follow-up period and the absence of an active treatment control group.</p>





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