Early Intervention Programs for Alberta’s Children with a Fetal Alcohol Spectrum Disorder (FASD): Characteristics of Service Delivery

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Executive Summary

Purpose of the Study

The purpose of this research was to describe the characteristics of early intervention programs for Alberta’s children age zero to 12 years with a FASD and their families. An attempt was made to identify those factors that facilitate program efforts, effectiveness, efficiency and adequacy, and those that positively influence the health status of the children and their families. The aim of this study was to facilitate beginning understanding of how services are meeting the complex health determinants of children with a FASD and their families; identify potential health disparities or gaps in services provided; identify facilitators and barriers to early intervention programs; and guide policy decision-making and enhance service delivery programs for Alberta’s children.

Methods

Design:

A non-experimental descriptive survey design was used to summarize essential characteristics of early intervention programs for Alberta’s children from birth to 12 years of age with a FASD and their families. A theoretically-based questionnaire was developed using an overarching framework for program evaluation in public health (Health Canada, 2001) and a framework for building a system of strategies to promote early childhood development (Federal/Provincial/Territorial Advisory Committee on Population Health and Health Security, 2003). Several models (e.g., health promotion model, and socio-ecological model) were used to organize the essential elements of the program (Hamilton and Bhatti, 1996; Stokols, 1996) including target population and need, expected effects, activities, resources, and stages of program development. The questionnaire was piloted in two early intervention programs, as well as reviewed by two experts in the field. The questionnaire predominantly used dichotomous questions, multiple choice questions and Likert-type scale questions in order to facilitate completion of the questionnaire by respondents.

Sample and Data Collection:

44 intervention programs in Alberta were identified and all were contacted. Only those programs that provided services to children under 12 years of age, provided intervention services defined as an action(s) or strategy(ies) that address core features of a FASD and specifically targeted children with a FASD were included in the study. 23 programs were identified that met
these inclusion criteria. During the study, one program was terminated and another could not be contacted. The Directors or Supervisors of an identified program completed the questionnaire. Questionnaires were hand-delivered to local programs and were couriered to all other programs. A maximum of two reminder phone calls were made to help ensure completion of the questionnaire. 21 questionnaires were sent out; however one was returned as the program was not an intervention program. Of the 20 remaining questionnaires, 12 were completed and returned, a response rate of 60%.

Data Analysis:

A master coding scheme was developed for the closed-ended questions in the questionnaire and used to enter survey data into Statistical Package for the Social Sciences (SPSS) version 16. Data were entered by a statistical consultant and the principle investigator cross-checked 3 questionnaires (25% of the sample), identified using a random number table, for accuracy of data entry. An incorrect entry was made for the other category in reference to question #3 that was corrected; otherwise there was complete agreement. Frequencies were generated for multiple-choice questions. For open-ended questions which generated a numerical response, data were not normally distributed even after log transformation; hence medians and inter quartile ranges have been reported. For 7-point Likert-type scale questions the negative scores implied the factors were barrier (scores of -3 associated with a strongly negative influence and -1 indicating mildly negative influence), positive scores implied the factors were facilitators (scores of 3 associated with a strongly positive influence and 1 indicating mildly positive influence), and zero implied no influence. Reported for each response were a frequency and percentage, as well as a median value. Descriptive statistics were used to highlight similarities and differences between programs. In instances where open-ended questions were used to elicit subjective responses, content analysis was used to objectively, and systematically identify themes that emerged in the written responses (Polit & Beck, 2008). The principal investigator conducted the content analysis.

Findings

Please refer to the report for findings. Key findings are presented in the discussion which follows.
Discussion

An initial perusal of the resource directories suggested that there are numerous programs, 44 in total, which attend to Alberta’s children age zero to 12 years with a FASD and their families. However, only approximately half provided services to children age zero to 12 years who are suspected of or have a diagnosis of a FASD. A little over 10 percent of the programs could not be reached and the remaining provided services to older children. During the time period between screening and mailing of questionnaire, which was approximately 14 months, one program was terminated, and another changed its name or contact information and could not be reached. Therefore, a challenge relates to maintaining accurate and updated information about programs, which provide services to Alberta’s children age zero to 12 years with a FASD, and ensuring this information is updated in a timely way every year.

Early intervention programs participating in this study serve Alberta’s children age zero to 12 years with a FASD and their families residing in 7 of the 9 regions as delineated by Alberta Children’s Services. Two regions most represented were Calgary and area (42%) and Southern Alberta (25%) and two regions not represented were North Central Alberta and North West Alberta regions. Given the lack of understanding about the true prevalence of a FASD and the geographical distribution of children age zero to 12 years with a FASD, as well a response rate of 60%, it is difficult to appraise whether appropriate program distribution exists in Alberta.

Health care disparities defined as “the mismatch between need and access associated with membership in one socially identifiable and disadvantaged group compared with their non-disadvantaged counterpart” (Franks & Fiscella, 2008; p. 672) may be associated with geographical distribution of early intervention programs. Disparities associated with geography may create inequities in access and use of services among alcohol-affected children and their families who are a group already at risk. An important area for future study is the identification of factors that influence access and utilization of early intervention programs for alcohol affected children and their families who reside in Alberta.

Nine (75%) of the early intervention programs reported that the location of their program (i.e., setting) had a positive influence on facilitating their services; however the degree varied from mildly positive (17%), moderately positive (25%), to strongly positive (33%). Three (25%)
indicated the location of their program had no influence on facilitating their services. A program's ability to provide services and support health may be influenced by policy decisions, political mandates, funding, particularly cutbacks in funding (Raphael, Phillips, Renwick, & Sehdev, 2000). Funding sources were variable in that 6 (55%) were funded provincially and 5 (45%) were funded by multiple sources including provincial government (100%), federal government (20%), non-government agencies (20%), corporate sector (20%) and other such as fee for service, donations, and fund raising (40%). As well, the annual program budget differed; the median being $315,856 (quartile range of $97,345 to $500,000). Despite these differences, the degree of influence of financial support for program was rated to be strongly positive and moderately positive by 8 (67%) and 3 (25%) of early intervention programs, respectively. Only 1 (8%) early intervention program rated the influence of financial support for program to be strongly negative. Early intervention programs varied in their rating of the degree of influence of the political climate (provincial and national) on facilitating the services of the program. The influence of the political climate on early intervention programs was rated as strongly positive by 2 (17%) program, moderately positive by 5 (42%), mildly positive by 2 (17%), no influence by 1 (8%) and moderately negative by 1 (8%). The findings suggest that it is important to explore the Directors or Supervisors perceptions of opportunities and challenges experienced by early intervention programs when examining characteristics.

Early intervention programs target multiple levels such as individual, community, society, and involve multiple systems (i.e., two or more service providers or community stakeholders). Although programs attend to multiple needs of affected children and families, few attend to all needs of children and families, 30% and 40% respectively. Two (22%) of the early intervention programs indicated that they provide the affected child ongoing support and three (33%) indicated that they provide families “continuous” or “ongoing” support. A majority of programs (75%) use a multidisciplinary approach. The multi-level, multi-strategy, and multidisciplinary approach described by early intervention programs is consistent with: a) the themes of the expected effects extracted from the data on missions, goals, and objectives, and b) the myriad of problems experienced by alcohol affected children and their families as highlighted in the literature. A multidisciplinary team should work together to attend to all needs of the child with a FASD and their families (Premji et al., 2004). Alcohol impacts functioning throughout the lifespan of an affected individual (Streissguth et al., 1994); hence early
intervention programs should extend across the lifespan of the individual focusing on life-long management (Premji et al., 2004).

The eligibility criteria for affected children to enter and receive services were dissimilar across programs and suggested that some early intervention programs serve a more general population. One may postulate that differences in eligibility criteria may be related to maturity of program (Dick et al., 2003). However, the twelve early intervention programs have been operational for a median duration of 6.7 years; lower and upper quartile of 6 years and 9 years, respectively. Hence, duration of program may not account for differences in eligibility criteria noted across early intervention programs. How FASD fits into the mandates of these more general programs requires further exploration, as well as how eligibility impacts enrollment of alcohol affected children and their families.

Programs directing services to the child affected with a FASD also varied with respect to other characteristics such as particular family members targeted, number of programs offered, and their length, activities, and process of determining priority areas of needs and referral. Program characteristics have been reported to be associated with client engagement (Broome, Flynn, Knight, & Simpson, 2007), outcomes, and health status of those enrolled in the program (Mukamel, Peterson, Temkin-Greener, Delavan, Gross, Kunitz et al., 2007). Early intervention programs reported that only 80 to 90% of both affected children and their families completed their program. The current study did not measure health outcomes nor assess health status of those enrolled in the program. A better understanding is required of the relationship between early intervention program characteristics and client engagement, and outcomes for the affected child and his/her family. Identifying key program attributes will help identify effective model(s) of care, as well help focus resources and services to attain specific outcomes (Mukamel et al., 2007).

Children with a FASD, as well as their families, are often affected by a myriad of difficulty. Early intervention programs attend to multiple needs of the child and family and have multiple strategies that are directed at multiple levels in multiple settings. Additionally, early intervention programs indicated that the care for children with a FASD and their families falls within the purview of many service providers or community stakeholders. How well these multifaceted programs are integrated within and between levels, settings, and strategies, requires
evaluation. Explicating an evidence-based conceptual framework to guide the development of such multifaceted programs for Alberta Children’s age zero to 12 years with a FASD and their families will facilitate appraisal of effectiveness.

An organization’s effectiveness may be enhanced by their capacity to engage in research (Majchrzak, 1982); however most measures of research capacity were rated by early intervention programs as either fairly poor, no influence, or fairly good. Academic preparations (e.g., higher degrees such as Doctor of Philosophy) or research-related education was identified as a barrier to developing research capacity. Increasing motivation to undertake research, and strengthening the culture and support for research may positively influence a programs capacity to engage in research thereby improving effectiveness.

Early intervention programs focus predominantly on “downstream” interventions directing activities or strategies toward the care of the affected child and their families (Bekemeier, 2008). Even community strategies tended to focus more on provision of support to parents (e.g., respite program), training of health professionals, caregivers, and hosting conferences. At the community level some strategies included health promotion programs about FASD and were directed at the community or specific groups (e.g., post-secondary classes) and were thereby classified as “midstream” interventions (Orleans, Gruman, Ulmer, Emont, & Hollendonner, 1999). However these type of interventions were not a dominant theme in the findings (i.e., mentioned by only 2 early intervention programs). “Upstream” interventions entail directing efforts to improve population health by addressing underlying social determinants of alcohol exposure during pregnancy through changing national public policy, shaping social norms, etc. (Bekemeier, 2008; Orleans et al., 1999). These structural interventions were not evident in the data shared. For instance, none of the early intervention programs indicated formal involvement at the political system (e.g., government) level. A successful population health perspective requires implementation of downstream, midstream, and upstream interventions.

Conclusions

Overall, early intervention programs for Alberta’s children from birth to 12 years of age with a FASD and their families are multi-level and multi-system, they differ in key elements of program (e.g., eligibility criteria, number of programs, and duration of program). At present we
do not have an understanding of the essential attributes of early intervention programs. Early intervention programs need to implement midstream, and upstream interventions to promote a population health perspective. Developing research capacity was identified as a need by respondents and may be important to improving effectiveness of programs.

**Recommendations for Healthcare Policy Makers**

- An accurate resource directory should be developed and maintained so that it is easy to identify early intervention programs which are specific to children age zero to 12 years with a FASD.

- Create a provincial strategy for early intervention programs for children age zero to 12 years with a FASD.

- Early intervention programs should implement downstream, midstream, and upstream interventions and appropriate resources should be allocated to facilitate this.

- To enhance effectiveness of early intervention programs, develop research capacity within these programs.

**Recommendations for Healthcare Researchers**

- Identify appropriate means (e.g., standard definitions, methodologies, surveillance systems) to determine the true prevalence of a FASD. Mapping the distribution of children age zero to 12 years with a FASD against where early intervention programs are currently located, will enable identification of service delivery gaps (e.g., no programs or too few programs to meet the needs children age zero to 12 years with a FASD).

- Identify the current demand for services by children with a FASD and their families, and determine the extent to which existing early intervention programs are able to meet these demands.

- Explicate an evidence-based conceptual framework to guide the development and evaluation of an integrated multifaceted early intervention programs for alcohol-affected children and their families who reside in Alberta.
• Evaluate how well current multifaceted early intervention programs are integrated within and between levels, settings, and strategies.

• Develop a better understanding of the facilitators and barriers to delivery of service by early intervention programs as this enable identification of strategies to strengthen existing early intervention programs.

• Identify factors that influence access and utilization of early intervention programs for alcohol-affected children and their families who reside in Alberta.

References


