

Ministry of Children and Family Development

KEY WORKER AND PARENT TO PARENT SUPPORT PROGRAM

Time 1 Formative Evaluation Report

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EXECUTIVE SUMMARY

In September 2003, the Premier of British Columbia released *Fetal Alcohol Spectrum Disorder: A Strategic Plan for British Columbia*, the first comprehensive plan related to Fetal Alcohol Spectrum Disorder (FASD) in Canada. The FASD Strategic Plan identified the following priorities:

- Diagnosis and assessment
- Public awareness and education
- Early intervention and prevention
- Life long support for those affected
- Research and evaluation

Based on these priorities, the following activities received funding:

2005/06

- The Ministry of Health was funded to develop new integrated assessments and diagnosis capacity for children with FASD and other similar conditions
- The Ministry of Children and Family Development (MCFD) was funded to provide a new support program specifically for families of children and youth (birth to 19 years of age), with FASD and/or other complex developmental behavioural conditions (CDBC) similar in impact to FASD

2006/07

- The Ministry of Education committed ongoing funding to establish a new FASD provincial outreach program hosted by the Prince George school district

The funding that was provided was new, ongoing, and increases over the first three years of program development (2005 to 2008).

Key Worker and Parent to Parent Support

After extensive research and provincial consultations with a variety of stakeholders, MCFD decided to implement a family support program that is inclusive of children with FASD and complex developmental-behavioural conditions¹ (CDBC) similar in impact to FASD, rather than a dedicated FASD intervention program. The *Key Worker* and *Parent to Parent Support* approaches were chosen as the models of service delivery. The Key Worker program is based on research from other jurisdictions that shows that children and families with disabilities benefit from the presence of a key worker. As well, input from

¹ The Complex Developmental Behavioural Conditions (CDBC) Network offers assessment services for children and youth who have biomarkers such as substance exposure, dysmorphic features and growth retardation as well as significant difficulties in multiple areas of function including development and learning, mental health, and adaptive and social skills

families along with evidence from already existing FASD programs throughout BC indicated that parents/caregivers valued the support they received from other parents with circumstances similar to their own. This knowledge gave rise to inclusion of parent to parent support as part of the overall service.

The program was funded provincially but delivered through the five MCFD regions. Regional variations in program delivery and implementation were expected.

The purpose of the BC Key Worker and Parent to Parent Support Services is to provide early intervention and support for families dealing with long term behavioural challenges associated with their children's developmental-behavioural conditions. The goals and objectives of the program are to:

- Maintain and enhance the stability of families with children and youth with FASD and other complex developmental-behavioural conditions in order to improve the children's long term outcomes.
- Increase the knowledge of parents and professionals about the neurological nature of developmental-behavioural conditions such as FASD so that the affected children and youth experience less frustration and more success.
- Ensure that families of children with FASD other complex developmental-behavioural conditions have an ongoing network of support.
- Evaluate the various program component impacts on child and family outcomes such as improved access to services, behavioural progress, family stress reduction and family stability.

An independent and ongoing formative and summative evaluation is included as part of the programs' implementation. Appendix A contains the Evaluation Framework; Appendix B summarizes the evaluation data collection methods.

Initial formative evaluation findings are based on:

- 39 responses to the Agency Questionnaire, representing a 74% response rate², and;
- 41 key informant interviews including in-depth qualitative interviews in two communities representing two different MCFD regions and a joint qualitative interview in a third MCFD region with the two Key Workers who split the FTE position for their geographic community³.

Forty-eight agencies around the province were awarded 53 contracts to deliver Key Worker and Parent to Parent Support Services; two of these agencies are providing Parent to Parent Support only. One agency holds three contracts and another has two contracts, each contract for a different community. Fifteen of

² Appendix D lists agencies by region that completed the Time 1 Agency Questionnaire

³ This interview was conducted at the end of the Time 1 formative evaluation data collection period. More extensive data will be collected in this community for subsequent evaluation reports.

the 48 agencies are Aboriginal agencies that offer services on and off reserve. In addition, some communities developed partnerships with local Aboriginal programs to ensure culturally sensitive delivery of the Key Worker and Parent to Parent Support Services.

Findings, Discussion and Recommendations

Hallmarks of the Key Worker and Parent to Parent Support Services are the availability of consultation from a respected expert in FASD (Diane Malbin, MSW) for regions and agencies delivering key worker services, along with province wide training and support, and inclusion of a process and outcome evaluation from the outset. Other notable features of the program are that it is a province-wide service that has increasing funding over the first three years of implementation, and that the program links assessment and support services.

In addition, early formative evaluation findings have revealed a number of strengths of the program to date. These include:

Summary of program strength 2006-2007:

- There has been **multi-sectoral and inter-ministry collaborative planning**, as well as, in several regions, ongoing collaborative activities to promote better coordination of the province's current FASD-related initiatives.
- There has been **common, province-wide training of all Key Workers**, provided by the program's expert consultant. The training was extremely well-received: among the strengths of the training was the quality of the curriculum and expertise of the facilitator; the consistency of the information provided to all Key Workers; and the opportunity to have Key Workers come together to network and exchange information.
- As of March 2007, **Key Workers were in place** nearly all contracted KW agencies in the province
- As of March 2007, **nearly all Key Workers were seeing families**; for Key Workers, beginning to receive referrals was noted as a major milestone to date.
- Key Workers' use of a **family-centred approach to practice** was seen as a program strength by Key Workers and families alike.
- **Regional Coordinators** were in place in two regions, and another region planned the hiring of a Regional Coordinator for spring 2007. As well, coordination/mentoring of Key Workers by a "lead" Key Worker, was taking place in one metropolitan community.

The Key Worker and Parent to Parent Support program is at an early stage of implementation, with Key Workers just being introduced into most communities in BC during the latter half of 2006. At all levels -

provincial, regional, and local – there is a strong desire to learn from what is working and what is not, so as to make the adjustments that are needed to ensure positive outcomes for families and communities.

This first formative evaluation highlights areas where implementation of the program is going well, as well as areas where adjustments are needed. These are addressed below.

Inputs: Key Worker role, funding, training, regional coordination

The BC Key Worker and Parent to Parent Support Services were initially based on a model that was developed in the UK. However, involvement of expert consultation and FASD training based on a model developed by the expert consultant and provincial trainer (Malbin, 2002) influenced how the BC program was conceptualized and gave prominence to the notion of appropriate environmental accommodations.

The language related to the Key Worker's role and function subsequently changed. Key Workers were now seen as "facilitators" and were expected to help a wide range of people to understand FASD as a brain-based physical disability with behavioural symptoms, with a goal of helping to identify ways that the child's environment could be adapted in response to the child's needs. This was a subtle yet important shift in emphasis that did not appear to be broadly understood. Missing was an appreciation or understanding that the concept of *environmental accommodations* offered a lens through which the child's and/or family's needs might be identified.

MCFD's regional delivery structure introduced regional variations, as was noted by differences in the Key Worker's job descriptions and responsibilities. For example, in the Northern region, Key Workers were functionally integrated with the health region's intake process for the CDBC Assessment Teams. As a result, in some communities the task of gathering documentation in support of the assessment process has taken precedence over other activities envisioned for Key Workers, such as engaging families prior to or outside the assessment and engaging the community. Access to Key Worker services was not originally intended to be predicated on being referred for assessment, yet some contracts specified that referrals were to come from regional CDBC assessment teams. In the Interior and Fraser Regions, some contracts with agencies limited the time a Key Worker could spend with families to six months. Again, such constraints were not originally envisioned as part of the service.

Time 1 formative evaluation findings found that there was considerable confusion about the Key Worker's role and function. This is a concern, since the literature from the disabilities field on key workers is clear that key worker services were most effective and outcomes for families better when the Key Worker has a clearly defined role that both the worker and the families understand (Greco et al, 2005; Rowntree Foundation, 1999). The literature further notes that implementation of the key worker model of service delivery begins with establishment of:

- general principles,
- service specific principles (i.e. family centered; flexible; individualized approach; formalized program that is recognized by professionals/practitioners across all agencies) and
- role-specific principles (i.e. clearly defined job descriptions; roles; responsibilities; limitations).

These factors help make transparent the expectations for Key Workers by giving them a framework for practice (Drennan et al, 2005, p. 4). The same can be said of the Parent to Parent Support services, which have not yet been fully developed in most regions. Several sources (i.e. key informants, Agency Questionnaires) expressed uncertainty as to what the role of the Key Worker is with respect to the Parent to Parent support function, as well as to how to develop this aspect of the service if it is not part of the Key Worker's role.

These findings give rise to the following recommendations related to defining the Key Worker role and establishment of minimum standards for practice:

Recommendation # 1: That the Provincial Office of MCFD take a lead role in facilitated discussions to clarify Key Worker's function, role, and framework for practice. These discussions should involve Key Workers and supervisors.

Recommendation # 2: That the Provincial Office of MCFD take a lead role in establishing a collaborative process whereby minimum provincial standards, best practices guidelines, and eligibility criteria for the Key Worker and Parent to Parent Support services program are developed, along with mechanisms to ensure that there is accountability in meeting these standards and guidelines.

Recommendation #3: Further to #2, that this collaborative process - involving provincial, regional and community-level participants from multiple sectors - consider where the balance lies between regional variability and provincial standards.

Recommendation # 4: That once definition of Key Worker role is developed, it be included as part of the Key Worker's job description and be used to provide information for families about the Key Worker role.

Funding of the Key Worker and Parent to Parent Support Services was another concern that emerged through the evaluation. Funding allocations to contracted agencies were such that over half the Key Worker positions were part time. Further, key informants noted on more than one occasion, that the position required a high level of practice knowledge and experience but was not as highly compensated

as other locally posted positions, making it difficult to attract and retain Key Workers. Consequently, several agencies encountered problems finding or keeping qualified personnel, particularly in communities where the position was part time.

Additional FASD funding will be made available to the regions for 2006/07. Nevertheless, given the early findings with respect to hiring and retaining Key Workers, the following recommendation is cautiously offered:

Recommendation # 5: That where possible, additional funding be used to top up existing Key Worker positions rather than fragment the service delivery through creation of additional part time positions.

All Key Workers are receiving supervision from a variety of sources. Provincial training provided by Diane Malbin to Key Workers, program managers, clinical supervisors and others associated with the program, was well received and is considered a major achievement of the program. The training was instrumental in helping to establish common ground amongst Key Workers and clinical supervisors and in introducing the concept of FASD as a brain based disability as well as the notion of finding appropriate accommodations. This leads to the following recommendation.

Recommendation # 6: That the Provincial Office of MCFD oversee ongoing introductory training on FASD and the role of the Key Worker, for new Key Workers, clinical supervisors and program managers.

Furthermore, some regions, such as the Interior, North, and south Vancouver Island, have benefited from having a Regional Coordinator who adds consistency, focus, and direction for Key Workers in the regions. For Key Workers, the Regional Coordinator position provides a point of contact and facilitates information sharing and opportunities for networking and development of best practices. While we recognize that a regional coordinator is not the only means by which these activities can be achieved, where possible and/or practicable, this aspect of a service delivery model should be considered and leads to the following recommendation.

Recommendation #7: That Regional Coordinator positions *or other* mechanisms for regional coordination, such as a list-serve and peer mentoring groups, be implemented for each MCFD region and that it be an expectation that Key Workers will participate in networking with their regional colleagues in order to share and promote best practices in relation to their work.

Engaging Families and communities

The referral process to the Key Worker program and between the Key Worker program and the health assessment teams have been problematic in the early days of implementation. As the issues have been identified, the regions have worked with their partners in the health regions to address the barriers. Nevertheless, there remains variation amongst communities and regions as to when and how families are referred, which may reflect a lack of overarching service delivery and practice principles, such as accessibility.

All of the regions spoke to these issues, noting the fragmentation that exists between and within the various service sectors. Some regions such as Vancouver Island have had success with interagency planning through establishment of regional planning committees that have enabled Key Workers to work together with schools to address assessment recommendations. The Fraser region has likewise had success in working out differences in understanding, expectations, and language related to the assessment and referral process and other aspects of the Key Worker program, such as finding physicians or paediatricians who will refer families for assessment, through regional partnership meetings. The Interior region is still working on creating partnerships, and there is a designated Regional Coordinator in this region that helps facilitate this process. In the North, MCFD and NH have formalized their relationship with a MOU including joint funding. In other regions and communities, creating collaborative working relationships between Key Workers and regional assessment teams needs to be addressed.

Again, results from the disabilities literature indicate that the Key Worker services are most beneficial when they “are effectively managed and when health, education, and social services are all committed to the service and provide adequate resources with respect to funding, staff, and managerial support” (Greco et al 2005, p. iv). In the UK model, having a multi-agency steering group, including senior managers from each agency with decision making abilities, was recommended to oversee the service and facilitate information sharing, gaining consent from families, and so forth. They further recommended that parents should be involved to help keep the focus on the needs of families.

The need to address systemic, partnership and management issues at the community or regional level gives rise to the following recommendations.

Recommendation #8 –That regional collaborative steering committees that parallel the provincial FASD committee, be established and resourced to enable the participation of MCFD, Health, Education, the Regional Coordinator, agency personnel, and families.

At the same time, a challenge noted during the evaluation was the lack of awareness about FASD in communities and perhaps more importantly, differing understandings about what is needed in response to

those living with FASD. Without an awareness or common understanding of FASD, there is less need to identify it as an issue and likewise, no need to develop necessary community-based resources or responses.

Related to this, some key informants expressed concerns about the feasibility of expecting Key Workers to facilitate congruent application of the concept of environmental adaptations across the various systems that impact on families, children and youth with FASD/CDBC, when there is no agreement between the various sectors about FASD as a brain-based disability or the efficacy of environmental adaptations. Recasting FASD as a brain-based disability changes assumptions about the types of responses that might make sense. This type of paradigm shift is neither easily nor quickly accomplished. Community-based training in FASD, similar to that which has been provided in the Interior (and planned for the in North) offers an opportunity to help facilitate achievement of common understandings, and gives rise to the following recommendation.

Recommendation #9 – That FASD training that articulates the concept of environmental adaptations and builds on the existing introductory training be offered at a regional or community level; this training may be viewed as “Level 2”, and wherever possible should be cross-discipline with invitations to parents and caregivers to attend.

Finally, a major achievement in implementation of the Key Worker and Parent to Parent Support Services has been the collaboration between MCFD and the Ministries of Health and Education. At the same time, key informants have stated that it has become increasingly apparent that each ministry has interpreted the thrust of the Key Worker program slightly differently and has used a different set of assumptions to guide its practice, particularly in relation to application of the terms FASD and CDBC, the concept of environmental accommodations, and the use of functional assessments. Absence of common understanding or use of commonly agreed upon language at a provincial level has complicated implementation at a regional level. A case in point is the CDBC label/terminology. As it is used within the health system, CDBC encompasses autism, FASD and complex children and youth. MCFD's focus initially was FASD, not the broader CDBC umbrella term. Many key informants had difficulty explaining or defining CDBC or knew of its origin.

These differences in language and assumptions are being addressed through development of a provincial framework involving all three ministries. This should help to add clarity to the overall program focus.

Evaluation

In the first year of implementation, the evaluation team has worked to develop relationships with the agencies that are providing the data. Overall agency participation in the evaluation has been strong. Limitations to the evaluation include:

- Lack of output data and a limited number of Agency Questionnaires from one region
- Small sample size for in-depth community data gathering.

The data have been supplemented by the evaluation team's participation in Key Worker conference calls, and provincial and regional meetings, as well as through ongoing contact with agency staff and managers throughout the province, regarding the evaluation. It is expected that with full program implementation, all regions and agencies will participate in the evaluation.

The evaluation also noted the need for a closer look at eligibility criteria for the Key Worker program, particularly with respect to referrals. Thus in the future, the evaluation will collect data not only with respect to the number of referrals that are categorized as "probable FASD" but also with respect to the breakdown of the referrals that are categorized as "other CCY/CDBC diagnosis" in order to better understand the range of diagnoses for which children and their families are being referred to the Key Workers.

References

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