Ministry of Children and Family Development

KEY WORKER AND PARENT SUPPORT PROGRAM

TIME 2 FORMATIVE EVALUATION REPORT

EXECUTIVE SUMMARY

What is the Key Worker and Parent Support program?

The BC Key Worker and Parent Support program, funded by the Ministry of Children and Family Development (MCFD), was initially based on research and practice evidence from four areas: research in Fetal Alcohol Spectrum Disorder (FASD) such as that conducted by Dr. Anne Streissguth and her colleagues (1996, 2004); Diane Malbin's Oregon-based FASD project (www.fascets.org); research in the disabilities field; and community-based, FASD-related parent support projects that were operating in BC at the time of the program's inception. The purpose of the Key Worker and Parent Support program is to provide early intervention and support for families dealing with long term behavioural challenges associated with their children's developmental-behavioural conditions. The program evolved during the early stages of implementation to incorporate the following characteristics:

- Regional service delivery model that allows for regional variation and modifications to meet unique local needs and family circumstances
- Availability of an expert in FASD to provide consultation to regional MCFD offices and contracted agencies, in order to help facilitate learning and strategies related to the notion of environmental accommodations and other shifts in thinking
- The Key Worker as a 'facilitator" who assists parents, family members, caregivers and service providers in the child's environment to come to a similar understanding and to develop supportive environmental accommodations accordingly
- Supervision by a qualified professional
- Training

What was the Key Worker and Parent Support program evaluation studying?

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

The Time 2 formative evaluation involved both province wide data collection and more intensive data collection in ten communities, i.e., two communities in each of the five MCFD regions. Time 2 formative evaluation findings are based on:

Annual Agency Questionnaires (42 agencies out of 57 responded);

Monthly output data (54 out of 57 communities/contracts);

Intake Questionnaires for parents/caregivers (as of December 15, 2007, 161 were submitted out of 490 intakes, from 32 out of 57 communities/contracts);

135 qualitative, semi-standardized interviews with key informants and with samples of program participants (parent and caregivers), staff, and community partners; and

Documentary review

What are the key findings?

The number of referrals to the program increased dramatically over Time 1.

The program is reaching a diverse range of families, including birth parents (25% of referrals) and grandparents (15% of referrals).

About two-thirds of the child/youth intakes in all regions were males.

The overall percentage of family referrals with children with confirmed or suspected FASD decreased relative to Time 1, while the percentage of families with children with a diagnosis other than FASD increased. However, the majority of families accepted into the program had children with confirmed or suspected FASD.

There was an increase over Time 1 in the number/percentage of family referrals made to the Key Worker program prior to the child having a Complex Developmental Behavioural Conditions[1] (CDBC) assessment.

In contrast to Time 1, when Key Workers and others expressed uncertainty and confusion about the role, at Time 2, there was noticeable consolidation and agreement that the Key Worker role involved:

Providing families with support; advocacy; and education/information; and facilitating or overseeing parent to parent support

Networking with and educating community service providers about FASD and families' needs

Nearly without exception and in all communities, parents and caregivers were extremely positive about the Key Worker and/or Parent Support program. In particular, they emphasized the role that their Key Worker played in:

Providing emotional support to manage the parenting/caregiving role;

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[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

Providing very useful educational resources, and information;

Providing advocacy on their behalf and interfacing with various 'systems' (e.g. schools or pre-schools) and/or accessing various services and resources; and

Helping them to access the CBDC assessment and then supporting them through the assessment process.

Furthermore, several parents/caregivers described the support they received from their Key Worker as being of tremendous importance in helping them to manage overall, in their day-to-day lives. A central theme was that Key Workers used a <u>family-centred model of practice</u> in providing families with support, advocacy and information/education.

In relation to what parents/caregivers would change about the program, the following suggestions were made:

There is a need for additional community-based supports and resources, in particular respite, for families with a child with FASD.

There is a need for Key Workers to strengthen their relationship with schools.

The Key Worker program should be extended to serve families with young adults, beyond the age of majority.

The program should be extended to allow for additional hours for Key Workers, or additional Key Workers in the community.

There is a need for someone to work directly with the child, in order to help the child develop social skills.

What were the implications of the findings?

Increased community awareness

Between Time 1 and Time 2, Key Worker and Parent Support agencies undertook major efforts to provide community education about FASD and the Key Worker and Parent Support program; these agencies and community partners also engaged in efforts to provide community education regarding parallel initiatives in Health and Education, such as the CDBC assessment process and the Provincial Outreach Program for FASD. The results of education and information sharing were evident in the increased demand for the Key Worker program and the increased diversity of referral sources, especially the number of self-referrals from families.

Gains were also evident in a growing awareness and understanding of the conceptual framework underpinning Key Workers' practice: that is, that FASD is a brain-based physical disability with behavioural symptoms for which environmental accommodations, rather than cognitive behavioural interventions, were more appropriate. The evaluation heard from many Key Workers and community partners, and especially parents, how the use of environmental accommodations was making a difference for them and for their children.

Nevertheless, it is a daunting task for the Key Workers and their agencies to be the centre of a shift in how families and practitioners from the health and social services sector respond to children and their families affected by FASD or similar neurological conditions. Resources and services that could respond in a consistent manner using environmental accommodations were not widely available for families. While the training efforts, access to 'expert' consultation, and collaborative work around specific cases have contributed to progress in this area, Key Workers and their agencies continue to need support.

Referrals and waitlists

Since Time 1, there have been some notable changes in the referral practices in the regions. All the regions have been working closely with their colleagues in the Health Regions to clarify and articulate referral processes between the assessment teams and the Key Worker program. As well, both the Interior and the Fraser regions no longer require that children have a completed CDBC assessment before families can be referred to the Key Worker and Parent Support program, leading to a more consistent and accessible approach to the program province wide.

The data for this report also indicated that there was a greater demand for Key Worker services in the past year, such that many agencies were nearing or had reached their threshold of workable caseloads. As a result, many agencies were considering implementing waitlists, if they had not already done so.

The issue of waitlists is further complicated in the North region, where the Key Workers also act as intake workers for the Northern Health assessment teams, particularly as the demand for both assessments and key worker services increases in each community. According to the Key Workers, the amount of time spent supporting families in their Key Worker role relative to the amount of time spent on the assessment intake role had increased at Time 2. Nevertheless, the Health Authority was receiving more of the Key Workers' time (approximately 30%) doing

intakes in the assessment process, relative to the approximately 16% of program dollars that the Northern Health Authority was contributing. Moreover, family feedback from parents in the North indicated that, while they appreciated the support they receive prior to and during the assessment, they wanted to have more support and follow-up post assessment.

Closely related to increasing demand, waitlists, and the ongoing development and consolidation of the conceptual framework and model of practice, is the issue of who are suitable referrals to the Key Worker program. Compared to Time 1, at Time 2 there were fewer families with children with diagnoses of FASD or suspected FASD, relative to those who were referred to the Key Worker program with CDBC diagnoses. Output data also showed that there was considerable regional variation in these findings.

Two issues arise from this information. First, CDBC is a vague definition, as can be seen by the range of diagnoses of children referred to the Key Worker program, which included: Fragile X Syndrome, anxiety disorders, Down's Syndrome, autism and cerebral palsy. Second, it is not at all clear that the conceptual framework and model for practice for Key Workers, i.e., neuro-behavioural disability and environmental accommodations, give rise to the most effective interventions for children with CDBC diagnoses other than FASD. Nor do the Key Workers necessarily have the training and expertise to determine the most appropriate interventions for the child and his/her family with a CDBC diagnosis.

Formative Evaluation outcomes related to Key Workers

The program has made the greatest strides in achieving the formative outcomes related to the Key Workers.[2] With some qualifications, particularly in relation to Aboriginal agencies, the early outcomes have been achieved, and the program is well on its way to achieving the intermediate outcomes related to training and supervision. Key workers were in place in all but a few agencies. Ongoing training at the provincial, regional and local level has been available to most Key Workers. With the exception of the Vancouver Coastal region, formal regional coordination and Key Worker networks are in place, and all agencies reported that supervision, albeit not necessarily clinical supervision, was available for their Key Workers.

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[2] Formative outcomes for Key Workers are outlined in the evaluation framework in Appendix A.

Nevertheless, the Vancouver Coastal and Vancouver Island regions have experienced high rates of Key Worker turnover. Difficulty finding qualified staff to replace staff who leave, especially in some of the Aboriginal agencies, has hampered program implementation in those communities.

The presence of regional coordination has played an important role in providing ongoing support and leadership for the Key Workers. Further, the pioneering nature of the Key Worker and Parent Support program, along with evidence from research showing that Key Worker programs benefit from the presence of a coordinator whose mandate is to support Key Workers through facilitation of opportunities for problem-solving, training, networking, and information sharing, suggest that having a Regional Coordinator *or equivalent position or mechanism* is important to the BC program (Rowntree, 1999).

Clinical supervision was highlighted in the British Key Worker evaluation as contributing significantly to positive outcomes for families (Greco & Sloper, 2003). As such, the Ministry of Children and Family Development, in creating the Key Worker program in BC specified that Key Workers in this province should have access to clinical supervision. To date the implementation of this aspect of the program model has been modest. While an analysis of the agencies' budgets indicates that some agencies have increased their budgets for this area since Time 1, lack of resources, both funds and qualified personnel, were the most often mentioned reasons for not providing access to clinical supervision for the Key Workers.

Many of the Key Worker agencies reported that the administrative and clinical supervisors were the same individual. However, one type of supervision should not be substituted for another when an appropriate supervisor is not readily available. This view is supported by the Draft Key Worker Program Standards (MCFD, 2007). When an on-site clinical supervisor in a particular domain (e.g. social work, psychology) is not available, use of tele-supervision is recommended. Several agencies reported that they had made use of individual and group phone-based supervision when necessary.

The findings from the interviews with parents/caregivers and Key Workers indicated that, for the most part, Key Workers had developed strong relationships with the families with whom they are working. However, there was some variation amongst the communities in how strong these relationships were. Previous experience, skill level of the Key Workers, supportive community

partners and availability of knowledgeable supervision made a difference to how well established the relationships were with the families. It is expected that with increased experience, ongoing training, supervision and the networking opportunities through regional coordination, that this intermediate outcome will be fully met within the next year.

Formative evaluation outcomes related to parents/caregivers

With regard to the early outcome that parents/caregivers are informed about their child(ren)'s FASD/CDBC assessment, experience around the province was variable. Many of the parents and caregivers interviewed for the evaluation had not been involved with the CDBC assessment. For those whose child(ren) had been assessed, most often the Key Worker had not been involved in the process, except in the North where the Key Workers are part of the assessment team. In other communities where the connection between the assessment team and Key Workers was distant, several Key Workers spoke of the barriers they experienced in trying to forge a closer working relationship with the local assessment team. And yet, where there was a collaborative relationship between the two programs, qualitative interviews suggested considerable benefits to having the Key Workers involved in supporting parents/caregivers during the assessment as well as for post-assessment follow-up.

Challenges

As pointed out in Section 4 of this report, in a number of communities the Key Workers reported seeing very few or families or no families. A significant number of the agencies that have provided services to few or no families are Aboriginal agencies. It is not entirely clear why this is so. As mentioned earlier, staff turnover and lack of qualified staff accounts for some of the low numbers, but this is only part of the story. The few Key Workers who were working in Aboriginal agencies cited community sensitivity to the topic of FASD, and the stigma associated with FASD, as reasons why low numbers of families had accessed the Key Worker program to date.

At the same time, Key Workers in Aboriginal agencies and/or Aboriginal communities reported adopting more of a community development approach to Key Working, by focusing on information sharing with other service providers in the community, and getting to know parents and families by attending other programs and activities in the communities, e.g., Pregnancy Outreach Programs, family activity nights, school programs and so on. This suggests that the Key Worker model may need to be modified in order to be more effective in Aboriginal communities.

Certainly where services and resources existed in communities, parents and caregivers were informed about them and received assistance from Key Workers in accessing them. The education system presented the greatest challenges for many of the parents/caregivers and Key Workers interviewed for the evaluation. However, where there was knowledge of and support for a different way of working with children with FASD or other neuro-behavioural disorders at the School District level, advocacy and program adjustments often went smoothly.

Overall, however, the evaluation findings indicated that Key Workers and parents/caregivers need help in learning how to successfully advocate within the school system. Similarly, school personnel need guidance and support in how to work in partnership with parents/caregivers and Key Workers to ensure a successful educational experience for children with FASD and similar neuro-behavioural disabilities. Leadership from the school districts, particularly those in Student Support Services, and local level collaboration and training would likely facilitate stronger positive relationships.

Similar to other evaluation studies (Hume et al, 2006), many parents/caregivers commented on gaps in services, particularly respite services and someone to spend individual time with their child. Respite and family support services were available to foster parents but not generally available for adoptive or birth parents and grandparents, unless there was a potential concern related to child protection or parents/caregivers paid for these services themselves. As well, a gap in service was identified by Key Workers working with older youth, and by parents/caregivers who were extremely anxious about the availability of services and supports for their child(ren) as the child(ren) reached the age of 19 and would no longer be eligible for children's services.

What recommendations were made?
The findings led to the following recommendations.

Recommendation #1: That a standardized community based training curriculum, that addresses the use of environmental accommodations and strategies at an in-depth, practice-based level be developed by the MCFD Provincial Office for use and delivery around the province. This curriculum may be similar to that proposed by the Interior region. The

development of this curriculum could involve the support of the Ministries of Education and Health in order to emphasize a broad mandate for community development and change.

Recommendation #2: That resources be dedicated to creating an annotated data base/list of resources that would support the work of Key Workers in the field and would reflect the multidisciplinary aspects of collaborative practice with children and families affected by FASD. This database could be posted on the MCFD website, with a link to the Ministry of Education POPFASD site, and should be in a format that is easily updated to include ongoing suggestions from families, academics, policy analysts and practitioners**.**

Recommendation #3: That the North region explore with Northern Health Region additional funding or other strategies to address the shortfall in funded time for the CDBC assessment intake component of the Key Worker role, in order to ensure that Key Workers have sufficient time to provide ongoing support for families.

Recommendation #4: That MCFD Provincial Office establishes program eligibility criteria that reflect the program focus and training related to neuro-behavioural disabilities and the intent of the program as explained throughout the program standards. Further these criteria should not be so restrictive as to exclude families whose children may not have a confirmed diagnosis.

Recommendation #5: That the Level 1 and Level 2 Key Worker training continue to be offered at a provincial level on an annual basis for new Key Workers and their supervisors. The content for the training could be complementary to the standardized community-based training curriculum in Recommendation #1, but with a focus on Key Workers as the primary audience, hence providing valuable networking and peer support opportunities for the Key Workers at a provincial level.

Recommendation #6: That the Vancouver Coastal region explore creation of a formal mechanism to provide regional coordination, networking and mentoring in that region in order to support the Key Workers and their agencies.

Recommendation #7: That a module on clinical supervision be developed for inclusion in the Key Worker Level 1 and Level 2 training.

Recommendation #8: That there be an expectation that clinical supervisors for the Key Worker program attend, at minimum, the Level 1 and Level 2 Key Worker training or the equivalent. Further, wherever possible they be included in Key Worker networking meetings/case conferences.

Recommendation #9: That Regional Coordinators and/or those involved in regional coordination work with their counterparts within the local CDBC assessment teams in order to facilitate collaborative working relationships between the CDBC assessment teams and Key Workers.

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