# Ministry of Children and Family Development

# KEY WORKER AND PARENT SUPPORT PROGRAM

# Time 2 Formative Evaluation Report

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# 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;
- 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 family-centred model of practice 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

[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

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

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multiple areas of function including development and learning, mental health, and adaptive and social skills

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.

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

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

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.

# SECTION 1 INTRODUCTION

> *[The Key Worker and Parent Support Program] is raising awareness, shifting perceptions, empowering parents, connecting families with community and one another, assisting families with education and other systems, [and has] no time limit of length of time spent with family*. (Agency Manager)

As described in the *Time 1 Formative Evaluation Report* (March 2007), 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 Strategic Plan, which involved nine provincial ministries, outlined in the following priorities for addressing FASD in BC:

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

The Ministry of Children and Family Development (MCFD) chose to implement a family support program that was inclusive of children with FASD and complex developmental-behavioural conditions[3] (CDBC) similar in impact to FASD, rather than a dedicated FASD intervention program. The ***Key Worker and Parent Support program*** were chosen as the models of service delivery.

MCFD is committed to the development of programs based on evidence of successful strategies and interventions, thus in order to know whether the Key Worker and Parent Support approaches work for families, MCFD decided from the outset to include an independent and ongoing evaluation of the program. The goals of the evaluation are to:

- ***learn*** about how the Key Worker model and parent to parent support approach works with families with children with FASD
- ***learn*** whether and how program improvements can be made each year
- ***learn*** about the strengths and challenges of the program
- ***learn*** what difference the program makes for families and communities
- ***inform*** evidence-based ongoing funding decisions

The evaluation is comprised of both a ***formative*** or process, and ***summative*** evaluation***.*** The formative evaluation examines and documents the development and actual implementation of the program, to

assess whether the activities were implemented as planned, and whether the expected outputs were produced. Given MCFD's regional model of program development and service delivery, the formative evaluation also describes regional variations in the Key Worker and Parent Support Program. The summative evaluation looks at whether the program's intended outcomes have been achieved.

The evaluation has the following deliverables*:*

- Development of an Evaluation Framework (logic model)
- Three annual Formative Evaluations (February 2007; February 2008; February 2009)
- Two Summative Evaluations, one 18 months after start up of the program (February 2008) and one at completion of the evaluation (February 2009)
- A plan for MCFD to conduct regular in-house evaluations of the regions' new FASD services (February 2009)

The first of the three Formative Evaluations was completed in March 2007 and presented findings related to the early stages of implementation. The Key Worker and Parent Support program has now been in place for 12-18 months throughout the province. The *Time 2 Formative Evaluation Report* presents findings and reflections relevant to the operation of the Key Worker and Parent Support program since its inception and focuses on the time frame from April - November 2007. The report is divided into several sections:

- **Section 2:** Why a Key Worker/Parent Support Program?
- **Section 3**: Evaluation Research Questions and Process
- **Section 4**: Who is the Key Worker program serving?
- **Section 5:** What are the Key Worker program's activities?
- **Section 6**: How is the Key Worker program working?
- **Section 7:** What are parents' and caregivers' perceptions of the program?
- **Section 8:** Discussion and Recommendations

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[3] 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

## SECTION 2 WHY A KEY WORKER/PARENT SUPPORT PROGRAM?

The Key Worker and Parent Support program was initially based on research and practice evidence from four areas: FASD research 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. These origins are discussed in more detail in the *Time 1 Formative Evaluation Report* and are summarized briefly below.

**Literature**

The Key Worker and Parent Support program is grounded in an understanding of FASD as a brain-based physical disability, and, further, that the associated underlying neuro-cognitive impairments are contra-indicative of a learning theory approach. Following the lead of and conceptual framework articulated by Diane Malbin (www.fascets.org/conceptualfoundation.html), the BC program is based on the notion that finding the right environmental accommodations is an apt framework for working with children and families affected by FASD.

As well, research from the disabilities field also contributed to the development of the Key Worker and Parent Support program, especially studies demonstrating that families caring for a disabled child benefited from having a multi-agency 'key' worker, along the lines of the model in place in the United Kingdom (Greco and Sloper, 2003; Liabo et al, 2001). In this model, families are assisted by Key Workers to help negotiate the many service sectors that play a role in families' life (Joseph Rowntree Foundation, 1999). While the key worker model of service delivery for children with special needs is not common in Canada, family support workers and family liaison workers can play a similar role. Other areas such as mental health and cancer care can also have comparable roles/functions (Drennan et al, 2005).

Further, studies in the disabilities field have also shown the effectiveness of parent support and parent self-help in producing better outcomes for children and their families, including reduced stress (Singer et al, 1999; Santelli et al, 1996; Santelli et al, 1997; Kerr & McIntosh, 2000). The support parents offer each other is invaluable because it is based on experiential knowledge that is difficult to capture through any other means or sources (Kerr & McIntosh, 2000; Armstrong, 2003). This was confirmed in a State of the Evidence review of the literature on interventions with children and youth with FASD that also identified parent support groups as being useful, particularly in helping parents to understand their child's needs and behaviours, obtaining services, and networking with other parents (Premji et al, 2004).

According to Seligman and Darling (1989), support groups for parents have four positive functions:

- alleviating loneliness and isolation;
- providing information;
- providing role models; and
- providing a basis for comparison (p. 44).

Support programs exist in many forms and differ in terms of their eligibility requirements, types of services offered, and administration, but generally, are either structured or unstructured. Characteristically, structured support groups are facilitated by a professional such as a nurse, social worker, or counsellor, whereas non-structured support groups are more often facilitated by a parent or someone with personal knowledge and experience of the particular topic (Livingston, 2005). More recently the Internet has been used to good effect as a venue for parent support. For example, a study of internet support groups for caregivers of children with special health care needs conducted by Baum (2004) found parents' level of stress was reduced and that they rated their experience positively, reporting high rates of satisfaction with respect to finding people with similar challenges (79%), receiving guidance and information (59%), and feeling understood and accepted (50%) (p. 387).

**BC Key Worker and Parent Support Program**

The BC Key Worker and Parent Support 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

Draft Key Worker and Parent Support program Practice Standards recently developed by MCFD (September 2007, p. 3), described the function of Key Workers in part as follows:

> *Key workers assist families in understanding FASD by providing education and information specific to the needs of the child and family. They are familiar with community resources, assist families in accessing support, health and education services and are involved in the development of local support services…… Key workers supplement and enhance, but do not replace, existing community resources.*

**Relationship to literature**

In addition to key workers, the BC program also offers parent support services through facilitation of education workshops and support groups. In keeping with the literature noted previously, MCFD anticipated that parents/caregivers of children with FASD/CDBC would come together through parent support groups, or other mechanisms, such as the Internet or a 'warm' phone line, to actively support each other and exchange ideas and information. At the same time, provision of FASD specific parent support groups presents some unique challenges not often addressed by the literature. Specifically, much of what is written about support groups is directed towards adoptive and foster parents, but groups comprised primarily of these types of caregivers may not meet the needs of birth families and grandparents raising grandchildren; both groups present a unique set of issues and support needs. It has been noted, for example, that a significant barrier to participation in programs by women who have addictions issues, or who are birth parents, is the fear of being judged and shamed about their behaviour (Legge, Roberts & Butler, 2000; Canadian Centre on Substance Abuse, 2001). A mixed group can further exacerbate feelings of guilt and remorse (Ontario Federation of Indian Friendship Centres, 2002). Along these lines, being associated with an FASD program may be yet another barrier for birth families, particularly in small, rural, or isolated communities, a situation that prompted one service in Ontario to change the name of its FASD program in order to promote a more holistic approach and reduce the stigma connected with FASD (Canadian Centre on Substance Abuse, 2001).

Grandparents who are raising their grandchildren with FASD may face similar feelings and emotions as birth parents, that is, feelings of failure, guilt and embarrassment (Brown, no date). Canadian research (Fuller-Thompson, 2005) has also found that grandparent headed households are disproportionately female (59%), First Nations (17%), out of the labour force (57%), and living in poverty (>30%). Grandparents are often also socially isolated because they no longer fit with their peer group (Brown, no date). For these reasons, Leslie and Roberts (2001) recommend creating different peer groups to meet specific needs, including those of birth parents as well as a group for parents that have FASD themselves.

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# SECTION 3 EVALUATION RESEARCH QUESTIONS, FRAMEWORK & PROCESS

**Research Questions**

The overarching research question for the Time 2 Key Worker and Parent Support formative evaluation was:

- *How are the Key Worker and Parent Support program being implemented in the province?*

Additional key evaluation questions included:

- *Who is the program serving?*
- *What activities have been carried out, and/or services have been implemented, and how?*
- *What are the key milestones of the program activities?*
- *How do families/caregivers, Key Workers and other community partners perceive the program?*
- *What are the program's strengths and successes?*
- *What are some of the challenges to implementing program activities?*
- *How are these challenges being addressed to date?*
- *What improvements could be made to improve the program?*

**Evaluation Framework**

In spring 2006, the evaluators developed an Evaluation Framework and an Evaluation Plan. The Evaluation Framework depicted the relationships between the project activities (e.g. Key Worker services and Parent to Parent Support mechanisms) and anticipated outcomes, as well as the indicators of outcomes and program outputs. The Evaluation Plan contained the evaluation research questions, study design, as well as the data collection methods, instruments and approaches to data analysis.

The evaluators developed the Evaluation Framework using a consultative, iterative process. This process is described at length in the Evaluation Plan (which is available as a stand-alone document), and involved: interviewing MCFD Provincial Office staff regarding the program model and desired outcomes; reviewing program documents and relevant literature; developing a draft Evaluation Framework and then obtaining feedback on the framework from regional MCFD and agency staff; and consulting with researchers and experts who have conducted intervention and evaluation research with similar populations. Feedback on the Evaluation Framework and data collection plan was received from all MCFD regions.

The Evaluation Framework, including short-term, intermediate and long-term formative and summative outcomes for the program, is provided in **Appendix A**.

## Overview of Evaluation Process

The Time 2 formative evaluation employed a process study and case study methodologies, and involved qualitative and quantitative methods of data collection. As well, the Time 2 formative evaluation involved both province-wide data collection and more intensive data collection in two communities in each of the five MCFD regions.

Data collection methods for both the formative and the summative components of the Key Worker and Parent Support evaluation are summarized in **Appendix B**. Multiple methods were used, including:

- Annual Agency Questionnaires
- Monthly output data, collected electronically
- Intake Questionnaires for parents/caregivers
- Qualitative, semi-standardized interviews with key informants (e.g. MCFD regional managers and regional coordinators)
- Qualitative, semi-standardized interviews or focus groups with samples of program participants, staff and community partners (e.g., parents/caregivers, Key Workers, supervisors, agency managers, community service providers and/or partners)
- Documentary review

This triangulation of methods helped to ensure the evaluation's rigour and validity.

### *Province-wide data collection process*

Province-wide evaluation data for the Time 2 Formative Evaluation Report were comprised of:

- **Annual Agency questionnaires -** The Time 2 Annual Agency Questionnaire was mailed to the all agencies in September 2007 with a request that the program manager responsible for the Key Worker/Parent Support services complete it. This questionnaire was the primary means of collecting input data, including information about funding, staffing, staff training, other resources and activities. A copy of the Time 2 Annual Agency Questionnaire is provided in **Appendix C.**

  As of December 15, 2007, the evaluators had received 42 out of the 57 Time 2 Agency Questionnaires that were sent out, which represents a response rate of 75%[4]. To achieve this response rate, the evaluators telephoned and/or e-mailed all agencies that had not mailed their Agency Questionnaires by late October 2007; calls and/or e-mails were repeated in mid November and early December if necessary. These contacts with agencies were quite useful as they often

[4] 51 different agencies held 57 contracts to delivery Key Worker and/or Parent Support services in 2007/2008.

enabled agency staff to discuss issues or ask questions regarding the evaluation. Nevertheless, in keeping with conventions of research, if an agency did not send its questionnaire by December 15, following 3-4 phone calls and/or e-mail messages, it was determined that the Agency Questionnaire was not available for this report. A list of all agencies from whom Agency Questionnaires were received is presented in **Appendix D**.

- **Key Worker Program Output data** – In keeping with Time 1, all Key Worker and Parent Support agencies were asked to provide output data electronically to MCFD Child and Youth with Special Needs Managers; these output data were then forwarded to the evaluation team. Following the *Time 1 Formative Evaluation Report* and as a means to improve clarity, in spring 2007 several modifications were made to the template for the output data. **Appendix E** contains the 2007/2008 template for the output data reported by the agencies.

  As of December 15, 2007, the evaluators had received (partial or complete) program output data for Time 2 (April – October 2007) from 54 out of 57 communities/contracts in the five MCFD regions; this represents a 95% response rate. Six agencies submitted very limited or no output data.

- **Intake Questionnaires for Parents/Caregivers** were to be administered by program staff in the agencies delivering the Key Worker and Parent Support program and returned to the evaluation team upon completion. This questionnaire was to be administered at intake and again when the family left the program (exit), or annually (Time 2 and Time 3). In the Time 2 formative evaluation, the data from these questionnaires were used to provide descriptive, socio-demographic information regarding the parents/caregivers accessing the programs.

  As of December 15, 2007, 161 Parent/Caregiver Intake Questionnaires had been submitted to the evaluators. These came from 32 agencies (or 56% of the total number of Key Worker agencies). The 161 parent/caregiver respondents represented 31% of family intakes for Year 2.

- **Key Informant interviews** also were conducted in fall 2007 with all five MCFD Children and Youth with Special Needs Managers and with the Regional Project Manager in one region and with the program's three Regional Coordinators.

- Lastly, **document review** was undertaken as part of data collection for the Time 2 formative evaluation. Relevant documents included: drafts of practice-related documents (e.g. practice standards for Key Workers) from MCFD Provincial Office, contracts, minutes of regional meetings; training agendas, training evaluation summaries, and public announcements/brochures about the service(s).

***Community-based data collection process***

Ten communities – two per MCFD region - were selected in consultation with each region and with MCFD Provincial Office staff to ensure that diverse communities, including Aboriginal, rural/remote, metropolitan, and small urban centres, were represented in the community-based component of the evaluation.

In the communities selected for intensive data collection, there were a total of 12 Key Worker or Parent Support agencies. In one community, one agency had the Key Worker contract and another agency had the Parent Support Coordinator contract; in another community, an Aboriginal and a non-Aboriginal agency each held a contract for a part-time Key Worker. The 12 agencies included:

- 4 Child Development Centres
- 4 Aboriginal multi-service agencies
- 2 community multi-service agencies
- 1 FASD-focussed agency
- Ministry for Children and Family Development

To create the sample of community-based interview participants, the evaluators requested that the Key Worker(s) in these communities informed parents/caregivers and community partners about the evaluation, and sought their assent to take part in face to face or telephone interviews. The sampling process was guided by purposeful sampling (Patton, 1990, p. 171), an approach to sampling that is particularly suited to program evaluation because it involves the selection of "information-rich" informants who are knowledgeable about the program and/or about their own experience of the program and can voice or articulate their experiences and observations[5]. Thus, parents/caregivers that were interviewed for this evaluation were a diverse group, including parents/caregivers of children with suspected and confirmed FASD, as well as parents/caregivers with children with other CDBC diagnoses. After parents/caregivers and community partners had provided their assent to the Key Worker to share their contact information with the evaluators, the evaluators scheduled interviews with participants. An informed consent process was followed prior to commencing the interviews.

No parents/caregivers declined outright to participate in the evaluation; however, in many of the communities there were a few parents/caregivers who either could not be reached to schedule the evaluation interview or who were unable to participate due to high stress or unforeseen family circumstances.

[5] At the same time, in order to minimize the possibility of "selection bias", Key Workers were asked to provide the evaluators with information regarding: the overall number of families with whom they were currently actively working; whether any families had refused to participate in the evaluation interviews; and the range of circumstances under which the Key Worker had elected not to approach the family to seek their participation in the evaluation interview.

A total of 135 people took part in community-based interviews or focus groups. Table 1 provides a summary breakdown of the community-based interview participants, by community and type of interview participant.

**Table 1: Summary of Community-based Interview Participants 2007/2008**

| | Fraser | | Interior | | North | | VC | | VI | | Total |
|---|---|---|---|---|---|---|---|---|---|---|---|
| **# of interview participants** | Com. #1 | Com. #2 | Com. #1* | Com. #2 | Com. #1 | Com. #2** | Com. #1*** | Com. #2 | Com. #1 | Com. #2**** | |
| Key Worker / P2P Coordinator | 1 | 2 | 3 | 2 | 2 | 1 | 1 | 1 | 2 | 2 | **17** |
| Key Worker supervisor | 1 | 1 | 1 | 1 | 0 | 1 | 0 | 1 | 1 | 2 | **9** |
| Agency manager | 0 | 1 | 0 | 1 | 1 | 1 | 2 | 1 | 1 | 2 | **10** |
| Parent/Caregiver | 6 | 8 | 4 | 6 | 6 | 3 | 0 | 9 | 6 | 1 | **49** |
| Community Service Partner | 2 | 3 | 3 | 7 | 7 | 11 | 0 | 5 | 4 | 8 | **50** |
| School-based | 0 | 1 | 0 | 1 | 1 | 2 | 0 | 1 | 0 | 1 | |
| MCFD or SW | 0 | 1 | 0 | 1 | 2 | 2 | 0 | 1 | 4 | 1 | |
| Other | 2 | 1 | 3 | 5 | 4 | 7 | 0 | 3 | 0 | 6 | |
| **Total** | **10** | **15** | **11** | **17** | **16** | **17** | **3** | **17** | **14** | **15** | **135** |

* In this community, one agency provides KW services, and another agency provides Parent Support services.
** In addition to conducting interviews, the evaluators met with a youth group, known as the "Boys Group", that was initiated by the Key Worker and was facilitated by a male Youth Probation Officer.

*** In addition to conducting interviews, the evaluators observed a Circles of Elders group in this community.

**** Two Key Workers, employed out of two agencies, spilt a Key Worker position (1.20 FTE in 2007/2008) in this geographic community. One of the Key Workers was based in an Aboriginal agency and the other in a non-Aboriginal agency.

In all 10 communities, qualitative interviews were conducted with the Key Worker(s) and/or Parent Support Coordinator in the community. Similarly, in eight of the 10 communities, qualitative interviews were conducted with the Supervisor of the Key Worker(s), and/or with the agency's Executive Director. As at Time 1, these interviews focused on all facets of project implementation from staff's perspectives. A copy of these interview guides is provided in **Appendix F**, **Appendix G** and **Appendix H**.

In nine of the 10 communities, qualitative interviews/focus groups were conducted with parents/caregivers. Across the 10 communities, the sample of parents/caregivers included birth, foster and adoptive parents, and grandfathers and grandmothers. Interviews with parents/caregivers focussed

on aspects of satisfaction with the program as well as perceived outcomes for parents/caregivers and for their child(ren). See **Appendix I** for a copy of this interview guide.

Finally, in all communities, interviews were conducted with multi-disciplinary service providers. These interviews focussed on community partners' knowledge of the goals and activities of the program, their perspective on program implementation issues, and perceived outcomes for families, and for themselves and their organization. See **Appendix J** for a copy of the interview guide with community partners. As well, a listing of the types of community partners that participated in the Time 2 evaluation interviews is provided in **Appendix K**.

In all communities, interviews were conducted in a private setting of the informants' choice. The majority of the interviews were conducted face to face, frequently with one member of the evaluator team assuming the role of interview and another member of the team recording interview notes, as verbatim as possible. Telephone interviews were conducted with participants who were not available for face-to-face interviews. At Time 2, a focus group with parents/caregivers was conducted in two communities, and a focus group with multi-disciplinary service providers was conducted in one community.

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# SECTION 4 WHO IS THE PROGRAM SERVING?

## Highlights - Who is the Program Serving

- The majority of families accepted into the Key Worker and/or Parent Support Services (i.e. family intakes) involved a child/youth with confirmed or probable FASD.
- Nevertheless, in all regions, the percentage of family referrals with a child with confirmed or probable FASD was lower at Time 2 than at Time 1.
- About two-thirds of the child/youth intakes in all regions were males.
- Vancouver Island had more child/youth intakes that were older youth, relative to other regions.
- Vancouver Island and Vancouver Coastal had more child/youth intakes that identified as Aboriginal, relative to other regions.

**Introduction**

The question of WHO the Key Worker and Parent Support program is serving is related to an important early formative outcome: that *Families/Caregivers are engaged with Key Workers*. At Time 1, the evaluation report noted that for many key worker agencies, receiving referrals and beginning to engage and work with families had been identified by agencies as the program's biggest milestone in 2006/2007. In keeping with this finding, at Time 2, receiving referrals - and indeed, receiving higher numbers of referrals relative to the previous year – was named as a milestone of the 2007/2008 fiscal year.

At Time 2, agency questionnaire and output data showed that an increasing number of families were engaging with Key Workers. Key Workers' roles and activities with families are described more fully in Section 5. Findings regarding who the Key Worker and Parent Support service has been serving follows.

***Number of families referred to the Key Worker program***

There were dramatic increases between Time 1 and Time 2 in the number of families referred to the Key Worker service in all MCFD regions, particularly in the North and Fraser regions, giving rise to capacity issues. At the same time, there were striking differences between regions in the number of new family referrals. Table 2 provides output data on the number of families referred for service at Time 1 (June 2006 – January 2007) and at Time 2 (February – October 2007).

**Table 2: Number of new family referrals, by region, Time 1 & Time 2**

| Region | Time 1 June 2006 – January 2007 | Time 2 February – October 2007 |
|---|---|---|
| **Fraser** | 43 | 134 |
| **Interior** | 56 | 94 |
| **North** | 62 | 221 |
| **Vancouver Coastal** | - | 89 |
| **Vancouver Island** | 71 | 138 |
| **TOTAL** | **232*** | **676** |

Source: Key Worker and Parent Support program agencies' monthly output data.

* Total in 2006/07 was based on 4 MCFD regions.

***Family referrals with children with confirmed or probable FASD***

In order to more fully describe who the Key Worker and Parent Support program is serving, output data regarding the number of new family referrals with children with confirmed or probable FASD, as well as the number of new family referrals following CDBC diagnosis other than FASD, have been collected on an ongoing basis.

Table 3 provides output data at both Time 1 and Time 2 for the number and percentage of family referrals with a child with confirmed/suspected FASD, relative to each region's total number of family referrals to the Key Worker program. At Time 1, the majority of families referred to the Key Worker program had a child with confirmed or probable FASD. This finding was obtained in all regions, though the percentage of FASD-related referrals was highest in the North and Vancouver Island regions. At Time 2, however, the percentage of family referrals with children with confirmed or suspected FASD decreased in most regions, relative to the region's total number of referrals. These findings were most striking in the North, where at Time 2 about half of the families referred to the Key Worker program had a child with confirmed or probable FASD compared to Time 1 when 82% of the families referrals had a child with a confirmed or probable FASD diagnosis.

**Table 3: Number of new family referrals with children with confirmed or probable FASD, and percentage of total referrals, by region - Time 1 and Time 2**

| Region | Time 1 June 2006 – Jan. 2007 # of referrals w/ suspected FASD | Time 1 June 2006 – Jan. 2007 % of total referrals | Time 2 Feb 2007 – Oct. 2007 # of referrals w/ suspected FASD | Time 2 Feb 2007 – Oct. 2007 % of total referrals |
|---|---|---|---|---|
| **Fraser** | 29 | 65% | 74 | 55% |
| **Interior** | 39 | 70% | 69 | 73% |
| **North** | 51 | 82% | 114 | 52% |
| **Vancouver Coastal** | - | - | 56 | 63% |
| **Vancouver Island** | 62 | 87% | 93 | 67% |
| **TOTAL** | **181*** | | **406** | |

Source: Key Worker and Parent Support program agencies' monthly output data.

*Total in 2006/07 was based on 4 MCFD regions.

***Family referrals with a child with a diagnosis other than FASD, following CDBC assessment***

In a similar vein, Table 4 provides output information for the number of new family referrals with a child with a diagnosis other than FASD, following a CDBC assessment, relative to each region's total number of referrals, at both Time 1 and Time 2. Although there were relatively few family referrals with a child assessed with CBDC/CCY, this varied by region, at both Time 1 and Time 2. For example, in the Fraser region, substantially more of the referrals to the program came from families whose child had been assessed as having CCY/CDBC, relative to all other regions. This pattern of findings is consistent with that reported in the *Time 1 Formative Evaluation Report*. Please note, however, that findings shown in Table 4 relate to family referrals, rather than intakes; it is unknown what percentage of these referrals were admitted to the Key Worker and Parent Support Program.

**Table 4: Number of new family referrals with a child with a diagnosis other than FASD, following CDBC assessment, and percentage of total referrals, by region, Time 1 and Time 2**

| Region | Time 1 June 2006 – Jan. 2007 # of referrals following CDBC assessment other than FASD | Time 1 June 2006 – Jan. 2007 % of total referrals | Time 2 Feb 2007 – Oct. 2007 # of referrals following CDBC assessment other than FASD | Time 2 Feb 2007 – Oct. 2007 % of total referrals |
|---|---|---|---|---|
| **Fraser** | 18 | 42% | 37 | 28% |
| **Interior** | 11 | 20% | 9 | 10% |
| **North** | 2 | 3% | 8 | 4% |
| **Vancouver Coastal** | - | - | 10 | 11% |
| **Vancouver Island** | 5 | 7% | 12 | 9% |
| **TOTAL** | **36*** | | **76** | |

Source: Key Worker and Parent Support program agencies' monthly output data.

* Total in 2006/07 was based on 4 MCFD regions.

Based on Time 2 Agency Questionnaire data, there was a wide range of CDBC/CCY "diagnoses" made for children who were assessed with a condition other than FASD and whose family was referred to the Key Worker program. These conditions included (in order of frequency):

- Attention Deficit Hyperactivity Disorder (ADHD)
- Autism
- Anxiety disorders
- Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS).

In addition to these conditions, "FAE suspected" was included as a response in three regions, and "Static Encephalopathy" was a response in two other regions; possibly, these "diagnoses" were made by the CDBC assessment teams in situations in which prenatal consumption of alcohol could not be confirmed. Diagnoses reported only once, but in different regions in the province, included: Tourette's Syndrome; Mild Intellectual Disability; Mood Disorder; Cerebral Palsy; and Apraxia. A listing of the most frequently reported CCY diagnoses is shown in Table 5; for a more complete breakdown, see **Appendix L**.

**Table 5: CDBC/ CCY "diagnoses" other than FASD, by region, at Time 2**

| | Fraser | Interior | North | VC | VI | Total |
|---|---|---|---|---|---|---|
| Attention Deficit Hyperactivity Disorder | 3 | 2 | 1 | 3 | 3 | **12** |
| Autism | 6 | 1 | 0 | 3 | 0 | **10** |
| Anxiety disorders | 2 | 1 | 0 | 0 | 3 | **6** |
| Neurobehavioural condition / neurodevelopmental disorder | 3 | 2 | 0 | 0 | 1 | **6** |
| FAE suspected | 3 | 2 | 1 | 0 | 0 | **6** |
| Pervasive Developmental Disorder | 3 | 0 | 0 | 0 | 2 | **5** |
| Neonatal Abstinence Syndrome (NAS) | 4 | 0 | 0 | 0 | 0 | **4** |
| Down's syndrome | 3 | 1 | 0 | 0 | 0 | **4** |

Source: Time 2 Annual Agency Questionnaire

***Number of families accepted for the Key Worker program***

In addition to tracking the number of new family referrals, the output data provided information on the number of families **accepted** to receive Key Worker services; this is also known as the number of **intakes** for the Key Worker program.

In keeping with findings reported in the *Time 1 Formative Evaluation Report*, at Time 2 the majority of Key Workers were providing Key Worker services to at least one family.

Table 6 provides output data on the cumulative number of new families accepted for service (i.e., intakes) at both Time 1 (June 2006 – January 2007) and at Time 2 (February – October 2007). As shown, there were substantial increases over time in the number of families accepted for service in all MCFD regions. Indeed, in three of the MCFD regions (Fraser, North and Vancouver Island), the number of intakes more than doubled between Time 1 and Time 2.

At the same time, there was variability between regions in the number of intakes between Time 1 and Time 2. Moreover, in all regions there was substantial within-region variability (i.e., variability between the agencies in the region) in the number of families that were accepted for key worker services.

**Table 6: Number of new families accepted for service, by region Time 1 and Time 2**

| Region | Time 1 June 2006 – January 2007 | Time 2 February – October 2007 |
|---|---|---|
| **Fraser** | 43 | 104 |
| **Interior** | 49 | 66 |
| **North** | 51 | 129 |
| **Vancouver Coastal** | - | 82 |
| **Vancouver Island** | 63 | 133 |
| **TOTAL** | **206*** | **514** |

Source: Key Worker and Parent Support program agencies' monthly output data.

* Total in 2006/07 was based on 4 MCFD regions.

In addition, relative to Time 1, when all but three Key Workers from the four regions that reported information to the evaluation had begun providing Key Worker services to at least one family, at Time 2 there were more agencies (n=6) that had not had any new intakes. Another seven agencies reported having a total of 1 or 2 new intakes. Three more agencies did not participate in reporting for the evaluation. Information regarding the number of agencies with two or fewer new intakes is presented by region in Table 7. Reasons for low intake numbers and/or lack of information include:

- lack of qualified candidates in communities
- high staff turnover, resulting in lengthy periods with no staff
- the emergence of new agencies receiving contracts midway through the 2007/2008 fiscal year.

As well, seven of the 13 agencies that reported fewer than three new family intakes were Aboriginal agencies; this finding may reflect reporting practices but may also have implications regarding program implementation and/or the family engagement process in Aboriginal communities. (This is discussed further in Section 5 of this report.)

**Table 7: Agencies reporting two or fewer new intakes, or that provided no output information, by region, at Time 2**

| Region | Time 2 |
|---|---|
| **Fraser** | 1 |
| **Interior** | 2 |
| **North** | 2 |
| **Vancouver Coastal** | 7 |
| **Vancouver Island** | 4 |
| **TOTAL** | **16** |

Source: Key Worker and Parent Support program agencies' monthly output data

***Demographic information about the children and youth served by the Key Worker program***

Demographic information about the children/youth accepted as 'intakes' to the Key Worker program was reported in the *Time 1 Formative Evaluation Report* and is updated in Tables 8-10.

***Gender of child/youth intake***

At Time 2, approximately 60% of the children/youth referred to the Key Worker program were male. The gender breakdown was more even at Time 2 than Time 1, when approximately twice as many intakes were males. At Time 2, Vancouver Island was the region with the highest percentages of intakes involving a female child or youth.

**Table 8: Gender of child and youth intakes to Key Worker program, by region Time 1 and Time 2**

| Region | Time 1 | Time 2 | Time 1 | Time 2 |
|---|---|---|---|---|
| | Total # and % of male child/youth | Total # and % of male child/youth | Total # and % of female child/youth | Total # and % of female child/youth |
| **Fraser** | 29 (66%) | 90 (66%) | 15 (34%) | 47 (34%) |
| **Interior** | 30 (63%) | 62 (60%) | 18 (37%) | 42 (40%) |
| **North** | 40 (70%) | 106 (68%) | 17 (30%) | 51 (32%) |
| **Vancouver Coastal** | - | 123 (64%) | - | 70 (36%) |
| **Vancouver Island** | 58 (72%) | 114 (56%) | 23 28%) | 89 (44%) |
| **TOTAL** | **157** | **495** | **73** | **299** |

Source: Key Worker and Parent Support program agencies' monthly output data

***Age of child/youth intake***

At both Time 1 and Time 2, the breakdown of child/youth intakes by age groups varied substantially by region, especially the percentage of intakes that were young children (age 0-6) and older youth (16-19). For example, at Time 2, Vancouver Coastal, followed by the Fraser, had a relatively large number/percentage of intakes involving young children, while on Vancouver Island, a relatively high number of intakes involved older youth. At the same time, the output data presented in Table 9 show that there was flux in the ages of children/youth served by the program between Time 1 and Time 2.

**Table 9: Age of child and youth intakes to Key Worker program, by region Time 1 and Time 2**

| Region | TIME 1 | | | | TIME 2 | | | |
|---|---|---|---|---|---|---|---|---|
| | # and % of total for region, age 0-6 | # and % of total for region, age 7-10 | # and % of total for region age 11-15 | # and % of total for region, age 16-19 | # and % of total for region, age 0-6 | # and % of total for region, age 7-10 | # and % of total for region, age 11-15 | # and % of total for region, age 16-19 |
| **Fraser** | 22 (50%) | 11 (25%) | 7 (16%) | 4 (7%) | 55 (40%) | 36 (26%) | 36 (26%) | 10 (7%) |
| **Interior** | 5 (10%) | 13 (27%) | 26 (54%) | 4 (8%) | 32 (31%) | 32 (31%) | 29 (28%) | 11 (11%) |
| **North** | 17 (30%) | 23 (40%) | 14 (25%) | 3 (5%) | 59 (38%) | 51 (32%) | 41 (26%) | 6 (4%) |
| **Vanc. Coastal** | - | - | - | - | 96 (50%) | 31 (16%) | 50 (26%) | 16 (8%) |
| **Vanc. Island** | 22 (27%) | 18 (22%) | 28 (35%) | 13 (16%) | 30 (15%) | 60 (30%) | 58 (29%) | 55 (27%) |
| **TOTAL** | **66** (29%) | **65** (28%) | **75** (33%) | **24** (10%) | **272** (34%) | **210** (27%) | **214** (27%) | **98** (12%) |

Source: Key Worker and Parent Support program agencies' monthly output data

***Cultural heritage / ethnicity***

At both Time 1 and Time 2, the percentage of child/youth intakes who identified as Aboriginal varied widely by region (see Table 10, below). At Time 2, the region with the highest percentage of child/youth intakes who identified as being Aboriginal was Vancouver Island (73%); indeed, the percentage of Aboriginal children/youth intakes was three times higher in Vancouver Island relative to the Fraser, in which 25% of the child/youth intakes to the program were Aboriginal. A similar pattern of findings was obtained at Time 1.

Findings regarding the number/percentage of intake who identify as Aboriginal may correspond with the fact that there are more Aboriginal agencies awarded Key Worker contracts in Vancouver Island, relative to other regions in the province.

As also shown in Table 10, there were very few child/youth intakes that identified as being from a visible minority. (Further analysis of output data at Time 2 revealed that 28 of the 31 "visible minority" intakes on Vancouver Island were from one of the region's Aboriginal agencies, so it is likely that this agency's Aboriginal children/youth intakes were reported as "identifying as a visible minority").

**Table 10: Heritage/ethnicity of child and youth intakes to Key Worker program, by region Time 1 and Time 2**

| Region | Time 1 | Time 2 | Time 1 | Time 2 |
|---|---|---|---|---|
| | Total # and % of child/youth intakes who identify as Aboriginal | Total # and % of child/youth intakes who identify as Aboriginal | Total # and % of child/youth intakes who identify as visible minority | Total # and % of child/youth intakes who identify as visible minority |
| **Fraser** | 9 (20%) | 35 (26%) | 2 (5%) | 20 (15%) |
| **Interior** | 25 (50%) | 48 (46%) | 1 (2%) | 0 (0%) |
| **North** | 33 (58%) | 76 (48%) | 0 (0%) | 1 (0.1%) |
| **Vancouver Coastal** | - | 92 (48%) | - | 3 (2%) |
| **Vancouver Island** | 55 (68%) | 148 (73%) | 3 (4%) | 31 (15%) |
| **TOTAL** | **122 (53%)** | **399 (50%)** | **6 (3%)** | **55 (7%)** |

Source: Key Worker and Parent Support program agencies' monthly output data

***Family type***

Finally, in order to provide some information on the types of families (e.g. birth, adoptive, and foster families, as well as grandparents raising their grandchildren) that have been involved in the Key Worker program, data from the Parent/Caregiver Intake Questionnaire were examined[6]. As shown in Table 11, in all regions, birth, foster, adoptive and extended families were receiving Key Worker and/or Parent Support services. Moreover, overall, foster parents comprised a slightly higher percentage of the families who had accessed the program (33%), relative to birth parents (25%), adoptive parents (18%), and grandparents (15%). At the same time, the relative percentage of each type of family varied by region. For example, in the Fraser, Vancouver Coastal and Vancouver Island regions, birth parents comprised about 25% of the sample of families completing the Intake Questionnaires, yet in the North, birth parents comprised 40% of the sample, and in the Interior, birth parents comprised only 11% of the sample. Another striking finding was that on Vancouver Island, 29% of the sample that completed the Intake

[6] Please note that not all of the families involved in the Key Worker or Parent Support program have completed the Parent/Caregiver Intake Questionnaire (i.e., to date, 161 of the reported 490 'family intakes' have completed the Parent/Caregiver Intake Questionnaire). Therefore, caution is advised in generalizing these findings regarding the percentages of different types of families accessing the program.

Questionnaire were grandmothers raising their grandchild(ren), although there were grandparents who were the primary caregivers and questionnaire respondents in all regions.

**Table 11: Parent/Caregiver Intake Questionnaire respondents' relationship to first child involved in Key Worker program, by region**

| | Fraser (n=46) | Interior (n=36) | North (n=29) | VC (n=24) | VI (n=24) | Total (n=159) |
|---|---|---|---|---|---|---|
| Birth mother | 10 (22%) | 3 (8%) | 10 (35%) | 4 (17%) | 5 (21%) | **32 (20%)** |
| Birth father | 1 (2%) | 1 (3%) | 2 (7%) | 3 (13%) | 1 (4%) | **8 (5%)** |
| Adoptive mother | 9 (20%) | 7 (19%) | 5 (17%) | 1 (4%) | 4 (17%) | **26 (16%)** |
| Adoptive father | 2 (4%) | 1 (3%) | 0 (0%) | 0 (0%) | 0 (0%) | **3 (2%)** |
| Foster mother | 11 (24%) | 16 (44%) | 8 (28%) | 9 (38%) | 3 (13%) | **47 (29%)** |
| Foster father | 0 (0%) | 1 (3%) | 0 (0%) | 4 (17%) | 1 (4%) | **6 (4%)** |
| Grandmother | 7 (15%) | 4 (11%) | 3 (10%) | 1 (4%) | 7 (29%) | **22 (14%)** |
| Grandfather | 1 (2%) | 0 (0%) | 0 (0%) | 0 (0%) | 0 (0%) | **1 (1%)** |
| Other primary caregiver | 5 (11%) | 3 (8%) | 1 (3%) | 2 (8%) | 3 (13%) | **14 (9%)** |
| **TOTAL** | **46 (100%)** | **36 (100%)** | **29 (100%)** | **24 (100%)** | **24 (100%)** | **159 (100%)** |

Source: Parent/Caregiver Intake Questionnaires received as of December 15, 2007

***Timing of new family referrals***

A description of who it is the Key Worker program has been serving also relates to the issue of <u>when</u> referrals are received relative to the CDBC assessment/diagnostic process.

As shown in Table 12, the output data revealed that at Time 2, in nearly all regions, a higher number/percentage of referrals were made to the Key Worker program <u>prior</u> to CDBC assessment, relative to the number of referrals made at Time 1. This shift in the timing of referrals was likely due to the long waiting lists and backlogs in accessing CDBC assessments across the province - families are waiting many months in most regions. Or, it could be in response to greater community awareness about the Key Worker program, and people are not waiting for referral for assessments. As well, since the Time 1 report, the Interior region changed its policy so that families could be referred prior to assessment.

In addition, the Time 2 data revealed that, on Vancouver Island, a high percentage of the family referrals came with previous assessments (not completed by the Regional CDBC assessment teams). Another striking finding at Time 2 was that in the Vancouver Coastal region, a high percentage of referrals came post-assessment. Assuming that Key Workers interpreted this to mean that referrals came following and possibly as a result of a completed CBDC assessment, this is of note because three of the five MCFD regions had very low numbers of referrals that were categorized as being post-assessment.

At Time 2, there continued to be variability in the extent to which Key Workers were involved in helping families to be informed of assessment findings. Overall, Key Workers' variable involvement reflected the reality that many families were still awaiting, or were not seeking out, an assessment. As well, in some regions the Key Workers were not well connected to the CDBC assessment teams. Thus they were not necessarily invited into the process largely because the assessment teams, and families, were not aware of how to involve Key Workers or what they could offer to the process. At the same time, some Key Workers were assisting families at various stages of the assessment process; findings relating to this and other types of practical, emotional and informational support are presented in more detail in Section 5 of this report.

**Table 12: Timing of new family referrals, by region, Time 1 and Time 2**

| | Fraser Valley | Interior | North | VC | VI | Total * |
|---|---|---|---|---|---|---|
| **Time 1 (June 2006 – Jan 2007) Total # of referrals** | **44** | **54** | **70** | **No data available** | **81** | **249** |
| When the family was referred to Key Worker program: | | | | | | |
| Prior to FASD/CDBC assessment by the Health Authority Assessment Team (% of region's total referrals) | 14 (32%) | 12 (22%) | 51 (73%) | No data available | 42 (52%) | **119 (48%)** |
| At time of commencing the FASD/CDBC assessment process (% of region's total referrals) | 0 (0%) | 5 (9%) | 10 (14%) | No data available | 8 (10%) | **23 (9%)** |
| During the assessment process (% of region's total referrals) | 3 (7%) | 6 (11%) | 0 (0%) | No data available | 3 (4%) | **12 (5%)** |
| Post assessment (% of region's total referrals) | 15 (34%) | 22 (41%) | 0 (0%) | No data available | 9 (11%) | **46 (18%)** |
| With previous assessment (not from Health Region Assessment Team) (% of region's total referrals) | 12 (27%) | 9 (17%) | 9 (13%) | No data available | 19 (23%) | **49 (20%)** |
| **Time 2 (February – Oct 2007) Total # of referrals** | **129** | **102** | **211** | **81** | **117** | **640** |
| When the family was referred to Key Worker program: | | | | | | |
| Prior to FASD/CDBC assessment by the Health Authority Assessment Team (% of region's total referrals) | 72 (56%) | 40 (39%) | 188 (89%) | 28 (35%) | 48 (41%) | **376 (59%)** |
| At time of commencing the FASD/CDBC assessment process (% of region's total referrals) | 8 (6%) | 6 (6%) | 15 (7%) | 3 (4%) | 6 (5%) | **38 (6%)** |
| During the assessment process (% of region's total referrals) | 9 (7%) | 8 (8%) | 0 (0%) | 5 (6%) | 4 (3%) | **26 (4%)** |
| Post assessment (% of region's total referrals) | 17 (13%) | 33 (32%) | 1 (0.4%) | 37 (46%) | 21 (18%) | **109 (17%)** |
| With previous assessment (not from Health Region Assessment Team) (% of region's total referrals) | 23 (18%) | 15 (15%) | 7 (3%) | 8 (10%) | 38 (32%) | **91 (14%)** |

Source: Key Worker and Parent Support program agencies' monthly output data. *Totals for Time 1 reflect data from 4 regions, while the totals for Time 2 reflects data from all 5 MCFD Regions

A final set of findings that may be connected to the question of who the program is serving relates to the source of the referrals to the program. As shown in Table 13, there continued to be substantial between-region differences in referral source; to some degree, these differences reflect regional differences in the timing of the referrals relative to the FASD/CDBC assessment process. For example, in the North, the primary referral source has been the Health Authority assessment team, which is in keeping with that region's service model for the Key Worker program (i.e., having the Key Workers serve as the Intake worker on the assessment teams).

A notable shift in these referral source data between Time 1 and Time 2 was that a higher percentage of referrals in Time 2 came from MCFD social workers; this finding was particularly striking in the Interior. This likely reflects work undertaken in that region to promote the availability of the Key Worker program to social workers, and to review all the files of children-in-care in order to identify children who may be eligible, and whose families/caregivers might benefit from the Key Worker and parent support program. As well, in the North, there was a modest increase in the number of self-referrals as well as increased diversity in the referral sources relative to Time 1. According to interviews with managers in this region, the growing diversity in referral source was an indicator of growing community awareness about the Key Worker program.

Table 13 also shows that in several regions there was a higher percentage of families who self-referred to the program, relative to Time 1. This finding was most striking for the Vancouver Island region, where self-referrals and referrals from "other" sources each comprised 23-25% of all referrals to the Key Worker program. Self-referrals, and referrals from "other" sources, including other service providers may reflect growing awareness about the program in communities. These findings, in turn, may be linked to an early formative outcome: that *Communities are informed about the Key Worker and Parent Support programs.*

**Table 13: Number of new family referrals received, by referral source/region Time 1 and Time 2**

| | Fraser Valley | Interior | North | VC | VI | Total |
|---|---|---|---|---|---|---|
| **Time 1 Total # of new family referrals received** | **43** | **56** | **62** | **No data available** | **71** | **232** |
| Referrals received from: | | | | | | |
| Health Authority Assessmt | 12 (28%) | 14 (25%) | 41 (66%) | No data available | 16 (23%) | **83 (36%)** |
| School/School District | 2 (5%) | 4 (7%) | 1 (2%) | No data available | 5 (7%) | **12 (5%)** |
| MCFD Social Worker | 2 (5%) | 9 (16%) | 1 (2%) | No data available | 7 (10%) | **17 (7%)** |
| Other Service Provider | 12 (28%) | 16 (29%) | 18 (29%) | No data available | 24 (34%) | **70 (30%)** |
| Self referral | 10 (23%) | 12 (21%) | 0 (0%) | No data available | 11 (15%) | **33 (14%)** |
| Other | 4 (9%) | 1 (2%) | 1 (2%) | No data available | 8 (11%) | **14 (6%)** |
| **Time 2 Total # of new family referrals received** | **134** | **94** | **230** | **106** | **138** | **702** |
| Referrals received from: | | | | | | |
| Health Authority Assessmt | 47 (35%) | 12 (13%) | 111 (48%) | 13 (12%) | 12 (9%) | **195 (28%)** |
| School/School District | 5 (4%) | 4 (4%) | 2 (1%) | 10 (9%) | 2 (1%) | **27 (4%)** |
| MCFD Social Worker | 13 (10%) | 34 (36%) | 17 (7%) | 13 (12%) | 23 (17%) | **108 (15%)** |
| Other Service Provider | 36 (27%) | 23 (24%) | 84 (37%) | 28 (26%) | 35 (25%) | **201 (29%)** |
| Self referral | 20 (15%) | 15 (16%) | 14 (6%) | 26 (25%) | 32 (23%) | **114 (16%)** |
| Other | 13 (10%) | 6 (6%) | 2 (1%) | 6 (6%) | 34 (25%) | **60 (9%)** |

Source: Key Worker and Parent Support program agencies' monthly output data. *Totals for Time 1 reflect data from 4 regions while the totals for Time 2 reflects data from all 5 MCFD Regions

# SECTION 5 WHAT ARE THE PROGRAM'S ACTIVITIES?

## Highlights - Program Activities

- Key Workers' main activities *with families* included providing practical and emotional support, helping families advocate for themselves and/or advocating on behalf of families, and offering current and relevant information about FASD.
- At Time 1 the parent support component of the Key Workers' role was in the developmental stage; at Time 2 most Key Workers had begun to facilitate parent support.
- Implementation of parent support remained uneven; many Key Workers struggled with establishing viable and sustainable parent support options.
- Use of a family-centred model of practice was identified as a strength of the program.
- Limited information from Aboriginal agencies meant that it was difficult to know how the program was unfolding or being received in these communities.

**Introduction**

This section describes the role and activities of Key Workers, along with the program's strengths, challenges, and participant satisfaction.

**Key Worker Role and Activities**

In the *Time 1 Formative Evaluation Report*, we noted that the Key Worker role was evolving as the implementation of the initiative progressed. We also commented that agency responses to the first Annual Agency Questionnaire reflected some confusion about the role of the Key Worker both between and within regions.

By contrast, responses to the Time 2 Annual Agency Questionnaire along with qualitative interviews with agency staff revealed noticeable consolidation and agreement about the Key Worker role. The majority of respondents described the role of the Key Worker principally in terms of:

- 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.

**Key Worker Role and Activities: Providing families with support, advocacy and education/information**

Broadly speaking, providing support to families, which encompassed both practical and emotional support, was a major focus for Key Workers. Common ways in which respondents described this aspect of the Key Workers' role/function included:

- assisting families to identify goals that will move them forward in some way;
- providing emotional support to manage the parenting/caregiving role;
- empowering parents/caregivers by providing them with support, resources, and information;
- helping parents/caregivers know they can ask questions and have opinions about their child; and
- helping families to access community resources.

In the words of Key Workers and agency managers:

> *The role is to support the people around a child – family members, caregivers – so that they can have a better understanding of the child's needs.*
>
> *We link families up with services, help them find supports*
>
> *We support children and families to have as 'normal' a life as possible.*

In addition, several Key Worker agencies included the notion of 'supporting families as they proceed through the assessment process' as part of the Key Workers' support to families. However, because this theme/type of support to families was raised by only a subset of agencies, it is discussed at the end of this section, as a variation of the Key Worker role.

**Spotlight on Key Worker Activities: Providing Families with Support**

The types of activities undertaken by Key Workers as they fulfilled this aspect of their role were numerous and varied and included:

***Helping families with whatever they needed (family-centred service),*** including helping them through crisis situations:

> I support families by helping brainstorming ideas, linking them to services, attending meetings if they want me and being available for crises. (Key Worker)
>
> I provide a lot of family support – parenting education, exchange of information, trying to support families to deal with/discuss and work through unresolved issues. Families want a solution; they want to hear that FAS will go away but they appreciate the support. I work with them to help celebrate their daily successes. (Key Worker)

***Modelling how to support a child/youth with FASD***:

> One youth wanted a job – I helped him find an employer who was willing and able to support the youth at a work placement. This success helped the foster parent see that he could be successful with appropriate support such as helping him with lunch, getting him up and driving him to work. Then laundry became an issue so I worked with the foster parent about how to help him do the laundry. (Key Worker)
>
> Another youth was running away, not going to school, stealing. I asked what was good about school and the youth said he wanted to be a crossing guard. The parents went to school and worked with the principal to help the youth get the position. There is a lot of support for youth but he no longer runs from school and he is very proud of his job. (Key Worker)

***Helping parents/caregivers be more realistic in their expectations*** of themselves and their child:

> The Key Worker helped change my expectations of L; helped me to reframe them. I am more realistic about him and about my daughter. (Parent)

**Supporting families through the assessment process** and providing follow-up regarding recommendations:

> I explain to the parents/caregivers what the various professionals do, about the assessment tools, what co-morbid conditions are – it gives the families more comfort when they go into the assessment. Having information beforehand helps parents/caregivers prepare for the assessment and develop questions to take with them. (Key Worker)
>
> I encourage parents to follow up on their own [post assessment] and I will liaise with the organization to see if parents followed through…if not then I go back to parents to offer supports and find out what barriers exist. I really emphasize that I am available for support and can help them link to other services such as hearing, counselling, etc. (Key Worker)

Advocacy in relation to families was commonly described as a combination of teaching families how to advocate for themselves, as well as advocating with and on behalf of families across a variety of systems. Some Key Workers described this aspect of the role in the following manner:

> *I support families of children with FASD to navigate the systems, and I support and empower parents to take the lead.*
>
> *The Key Worker's role is to help advocate for more, or more appropriate, services for families.*
>
> *The role is to provide support and educate and advocacy – especially with the education system.*

Because of the need to engage several different institutions and systems, the advocacy function was seen as challenging to do well, particularly while maintaining positive relationships. In the words of one Clinical Supervisor:

> *The Key Worker needs to model how to be a gracious advocate. If they are not, then they can possibly shut the door for the family*.

**Spotlight on Key Worker Activities: Advocacy**

Almost without exception, Key Workers' activities as they related to advocacy included liaising with the education system, a common source of anxiety for most families, in part because of its' potential to impact their lives on a daily basis.

> Interfacing with schools: that is a lot of what parents are looking for from Key Workers. (Key informant interview)

Difficulties associated with the school system often revolved around the learning and behaviour problems of a child or youth and typically resulted in meetings to determine an Individual Education Plan (IEP). Key Workers helped to reduce parents'/caregivers' anxiety and encouraged them to become their own advocates by attending meetings and speaking with school personnel and others on parents'/caregivers' behalf. Sometimes Key Workers were well received at these meetings and sometimes they were not. Thus Key Workers had to be cautious in their approach so as not to close doors for families. Key Workers described their advocacy activities in a variety of ways, including:

> [I] spend a lot of time coaching families about what to say and to self-advocate, particularly with the schools. (Key Worker)
>
> Families need a voice. Sometimes I just go with parents and don't say anything – mainly with the school district, but with MCFD too. I attend meetings to support parents with social workers. (Key Worker)
>
> I attend the IEP meetings as a guest of the parents. Occasionally a Special Education teacher will ask me to attend. I am getting savvier about it. Now, I get the parents/social worker to provide consent to gather information and then I go to the school and say "I'd like to talk" "What can we do?" "Is there going to be an IEP?" …Does it feel adversarial? Initially yes, but less so now. Teachers are afraid I'm seeking a bunch of accommodations that are impossible to do. What seems to happen instead is that my reminders/presence seem to help hold everyone accountable to the IEP, including me. The more people who can be involved the better. (Key Worker)
>
> I have spoken with several teachers, even the karate teacher, mainly advocating for parents as well as coaching and promoting them to be self-advocates. (Key Worker)

With respect to providing <u>education and information</u>, several respondents described the Key Worker role as one of offering parents/caregivers relevant and current information about FASD as well as helping them to understand diagnostic and assessment recommendations and options. Respondents described this aspect of the Key Worker role as:

> *Education is essential for parents, caregivers, the systems involved. ...Parents like the scientific explanation of FASD so they come with an understanding of their issues. (Key Worker)*
>
> *Key Workers assist families in understanding FASD by educating and providing information. Manager)*
>
> *Key Workers assist families' understanding of their child by educating them about FASD as a brain based disability. (Manager)*

Another important component of the education/information role of Key Workers was helping parents and caregivers, along with teachers and others in the community, to identify environmental accommodations and adaptations that addressed the needs and functional capabilities of children and youth. In this respect Key Workers' role was described as "offering knowledge about how the brain process impacts the child's behaviour". One agency said:

> *The Key Worker's role is to work with parents, family members, caregivers and service providers in identifying ways to adapt to child's needs*

**Spotlight on Key Worker Activities: Providing Families with Education and Information**

Key Workers met with parents/caregivers, educators, and others to offer information about FASD as a brain based disability and to help them identify appropriate accommodations given the behaviours and needs of the child/youth with FASD:

> The Key Worker met with one family for two hours. The parents were astounded at the knowledge the Key Worker had. The information really opened them up to new ideas and thinking about FASD. (Community service provider)
>
> The Key Worker helped the foster parent set appropriate boundaries and rules – the child needs more supervision than the foster parent anticipated. The child is 14 but because of dysmaturity, is much younger and the foster parent did not understand this at first. (Community service provider)
>
> Based on information we had received about the child from the previous school, we anticipated a real "problem child". Instead, with the Key Workers' input we were able to anticipate and plan for his needs and behavioural incidents are much reduced. (Community Service Provider)

Key Workers also provided parents/caregivers with other types of information that could make a difference in families' life:

> [I] provide families with information about services and funding such as the child with disability tax benefit. Children with an FASD diagnosis are eligible for a disability tax benefit if they live with their biological family or in the home of a relative. It means $180.00 per month for families. (Key Worker interview)

**Key Worker Role and Activities: Parent Support**

Forty-nine percent of the agencies responding to the Time 2 Annual Agency Questionnaire indicated that the Key Workers were providing Parent Support Services. Moreover, most Key Workers carried both responsibilities (i.e. Key Worker and Parent Support Facilitator). Agency questionnaire data indicated that on average, Key Workers were spending 16% of their time on the development and provision of Parent Support Services. Other agencies offered Parent Support Services through staff and/or volunteers in the agency, or were working in collaboration with organizations in their community that had expertise in parental support. Another approach, adopted by two communities in two regions, was to contract separately for the Parent Support Services.

Thus, whereas at Time 1 this aspect of the Key Worker role was still in the developmental stage, at Time 2 most Key Workers had begun to facilitate parent support or were preparing to do so. Several agencies described this work as involving:

- connecting families to each other;
- providing parents with networking and peer support opportunities through parent support groups; facilitation and coordination of weekly parent to parent support groups; and
- parent mentorship.

At the same time, implementation of parent support was variable. Information from respondents and meeting minutes indicated that parents/caregivers were often very busy and thus did not have time to attend meetings.

> *Three parents did come and provide support to one another, but parents are so busy with the children that they don't have time to come. (Key Worker)*

In some regions of the province, distance was a barrier.

> *Families live 30-40 minutes out of town in different directions; it is hard for them to get in. (Key Worker)*

As well, in some areas, parents/caregivers already had support through other organizations such as their local Foster Parents' Association or Adoptive Parents' Association and perhaps did not see a need for another support group. Along these lines, the heterogeneity of parents/caregivers was a challenge identified by Key Workers in implementing this aspect of their role. This point is illustrated in the quotes below and also was raised as a program challenge (see discussion of program challenges, further in this section of the report). Hence Key Workers spoke of struggling to know how to engage the various parenting subgroups, and having limited success in this regard.

> *Foster parents have the Foster Parent Association and adoptive parents have the Special Needs Adoptive Parents association. The gap is birth parents and newly diagnosed families; they have not yet coalesced as a group. (Key Worker)*

> *Many of the birth parents have FASD themselves and are parents of newly assessed children. (Key Worker)*
>
> *Regarding parent to parent, it is a bit of a struggle. For birth parents and parents with FASD we have to gear materials and adjust the information accordingly, but we are not always sure how. Some information is hard to modify. Parents also range from low functioning to very high functioning. (Manager)*
>
> *One birth parent wanted to start a Birth Parent Support Group. We tried to support her to do this but she could never get this off the ground. (Manager)*
>
> *Grandparents are a significant category and have a host of issues such as age; fatigue; parenting style; finances; inconsistent receipt of services; no respite; feeling out of sync with their peers. (Manager)*

Nonetheless, by trying out a variety of approaches, Key Workers were finding ways to fulfill the parent support component. In one community, parenting education workshops were found to be more successful than parent support groups:

> *When we offer eight-week education sessions, parents/caregivers will attend. When it is a parent-to- parent group, just two or three people come out. But the parent education groups have 12-14 people. Parents want a beginning and an end to the groups. (Key Worker)*
>
> *I tried to get a parent support group of the parent education groups but getting parents to come out to a parent support group is really hard. (Key Worker*)

In another community, a parent-to-parent support group emerged from a six week education group. In still another community, the Key Worker had not organized a parent support group, but had set up a girls group as a way of connecting with the girls and providing them with safe support while they waited for an assessment. In this same community the Key Worker had also established a Boys' Group.

Others found success by pairing up with someone else in the community with group facilitation and parenting education skills. In the words of one supervisor:

> *Before pairing up with N at the family resource centre, the Key Worker had a hard time getting a parent-to-parent group off the ground. It is hard to get parent uptake on that, but it is working better now*.

In Vancouver, Key Workers from four agencies banded together to offer parent support groups for the families they serve. Through experience they have learned that it is important to offer separate groups for caregivers and birth parents and for parents/caregivers of older children and of younger children. At the time of data collection for the evaluation the Key Workers were facilitating a caregivers' support group every other week. As a way to entice caregivers to attend they offered dinner and an activity program for the youths: two workers would meet with the parents and two workers would engage the youths in activities. A birth parents group was also offered earlier in the fall 2007 but the numbers were small so the

Key Workers were in the process of promoting the group and hoped to have a birth parents group available in the New Year (2008).

**Key Worker Role and Activities: Networking with and educating communities and service providers**

In relation to educating communities and service providers, responses to the Time 2 Annual Agency Questionnaire described this in terms of educating professionals in the community about the 'status' of the Key Worker program as well as providing current information about FASD to a range of health, educational, and social service organizations. In the words of a couple of supervisors:

> *The role is to raise awareness of FASD amongst service providers, to give an FASD lens to the discussion and to provide community education.*
>
> *Expertise in FASD is really needed in the communities, and Key Workers provide a focal point for this.*

**Spotlight on Key Worker Activities:**
**Educating Communities & Service Providers**

Activities associated with this role primarily involved meeting with community service providers, most often about a specific child/youth, but also within the context of offering training to staff of other organizations. In the words of several community service providers:

> I've found that staff struggle with how to apply FAS-related information from trainings. The Key Worker helps staff to understand what 'invisible disability' means.
>
> The Key Worker has given information about FASD – and that has been helpful. I found that having the meaning of FASD spelled out into 'developmental age' is helpful. It changes how we work with these students as teachers. We work with students as a three year old rather than a seven year old. Intellectually we know this, but it's important to be reminded and to see it in practice. (Community service provider)
>
> At our organization, people are treated as adult learners who benefit from making decisions for themselves. Recently, I've learned that for people with FASD, support in making decisions is needed because of the brain-based nature of disability. (Community service provider)
>
> The Key Worker educates me constantly about new findings in FASD. For instance, exercise is good for kids with FASD. So I take the kids swimming and get them involved in mountain biking, and other pro social activities. (Community service provider)

Key Workers were also proactive in networking and getting to know people in the community, seeking opportunities to provide them with FASD-related information sometimes without reference to a specific child or youth. As elaborated by several Key Workers:

> I spend a lot of one on one time with different professionals, for example, a new worker at the

> Boys and girls Club who knows nothing about FASD. I will meet with her a number of times over coffee to provide information and support about working with youth with FASD. (Key Worker)
>
> I have attended education fairs, done by the school board and Success by 6. I am just starting to get to know MCFD social workers. I did presentations at Income Assistance and MCFD guardianship team. It really helps to get to know them outside of the crisis situation. (Key Worker)
>
> I go with families to appointments so I get to meet people; that way I can explain the role. As a result I have done some presentations at schools for teachers and Learning Assistance teachers – this becomes particularly important for follow up work. (Key Worker)

Educating and networking with community service providers could also serve a dual purpose. Some Key Workers sought out professionals in the community who could inform them about a variety of topics so that they could in turn better support the families. As described by one Key Worker:

> The Occupational Therapist helped me to understand sensory issues for children with FASD – such as putting a curtain around the bed so that the child sleeps better. I have tried this with a couple of families and it makes a difference. Community partnerships are vital to practice and problem solving – getting guidance from the right person is key. (Key Worker)

**Variations to the Key Worker Role and Activities**

As discussed at Time 1, regional variation and differences in service delivery models continued to influence the role of Key Workers, leading to both intra and inter region variability. This was most noticeable in the North region where Key Workers coordinated the CDBC intakes and assessments. According to responses to the Time 2 Annual Agency Questionnaire, in the North, the Key Worker role/function involved: completion of the intake process; facilitation of assessments as needed; and coordination of professionals involved in assessment process.

Unlike at Time 1, however, when coordination of intakes and assessments consumed the majority of Key Workers' time, at Time 2, questionnaire responses from Key Worker agencies in the North revealed a more equitable approach to the combined role (see Section 7). For example, one agency described the role in this way:

> *The Key Worker has three interrelated functions: coordinate intake and assessment for CDBC referrals; provide ongoing support to families referred and accepted into the program; and assist communities to build up capacity to support families who have children with CDBC (i.e. strengthen community supports).* (Agency questionnaire)

As one Key Worker in the North elaborated:

> *Thirty percent of my time is now spent doing intake/assessment coordination, and 70% is spent supporting families post assessment.* (Key Worker)

Further to this, several agencies both in the North and in other regions included the theme of 'helping families to understand the diagnostic/assessment information and implications for follow up' as part of the Key Worker role. However, the link between the assessment process and Key Workers is variable throughout the province, hence there was not widespread agreement about this aspect of the their role.

Another area of difference between Key Worker agencies concerned whether the Key Worker role included doing individual work with children and youth. Indeed, a few agencies described the role in ways that suggested a direct intervention approach with children and youth or taking on a case manager role. Along these lines, some respondents described the role as providing: counselling; individual family case work; observation and corrective feedback; working one to one with children, youth, and families; and, one to one support. In the same vein, at least one Key Worker expressed frustration with the perceived limitation of the role, stating a preference instead for providing direct intervention with children and youth rather than having to refer them to community resources that may not be either available or accessible. As this Key Worker said:

> *What families really need is a relationship with someone who can provide direct support services. The Key Worker should offer more than support and advocacy. It is not fair to create a relationship and build trust only to refer the family onto programs that have long wait lists. (Key Worker)*

Another Key Worker stated:

> *Families want us to do more. I am asked to do one to one (intervention) with a child or help a youth find a job. I have to say this is not our role. Hard if the parent has FASD too. (Key Worker)*

Finally, some differences in interpretation of the Key Worker role were also evident in the Time 2 data from Aboriginal agencies. Although not all Aboriginal agencies holding Key Worker contracts have participated fully in the evaluation, as stated by one program director, "how the Aboriginal community perceives the service itself is different". This was evidenced by the Time 2 Annual Agency Questionnaire data, wherein a number of Aboriginal agencies described the Key Worker role broadly and in terms of community development and community capacity building, as well as family support. For example, Aboriginal agencies stated that the Key Worker role was to:

- offer support within the life areas and honouring change
- help to reduce personal and public shame around FASD
- build relationships with the aboriginal community/childbearing women
- reduce the stigma for biological families so that they wanted to explore FASD as a possible diagnosis
- offer mentorship and leadership
- support families wherever their needs are….in school, law, community
- provide community development involving families, elders, and community resources

- offer FASD awareness/education/intervention/prevention

Not surprisingly, the activities of Aboriginal Key Workers reflected this broader approach. As described for example, by one Aboriginal Key Worker, the focus was on:

- helping families get to appointments;
- helping families get housing;
- helping families deal with housekeeping, (e.g. dishes and laundry);
- providing crisis intervention; and,
- helping families with organizational tasks and schedules.

Respondents also spoke of the need for Key Workers to use a variety of approaches to reach out and connect with Aboriginal families, such as: teaming up with other service providers (e.g. Healthiest Babies facilitator, Native Youth Group; health clinics) to do joint community presentations and identify children for referral for assessment; meeting and building trust with families by socializing with them during family nights at the Friendship Centre; being visible at community gatherings such as Baby Blanket Night; getting to know grandparents and other family members who are parenting through social and community events; and using traditional knowledge. In one agency, for example, additional funding was obtained to develop an Elders group that will take a leadership role in providing FASD-related knowledge, information and support for grandparents who are raising their grandchildren, thereby ensuring cultural relevance. The plan was for the Key Worker to connect with grandparents and extended family members through the Elders group.

Respondents spoke as well of the need for the program to be flexible about the people with whom they worked, that is, to allow for the possibility of working with young adults with FASD who did not yet have children – as a preventative measure - as well as with parents who themselves had FASD.

In addition, some Aboriginal agencies reported that the association between the Key Worker role and FASD was a disincentive for families wanting to access the service. Families were described as being wary of being labelled and of the stigma associated with FASD. As an alternative, agencies were considering incorporating the role and function of the Key Worker into already existing family serving positions within the communities.

**Events that have contributed to development of Key Worker role**

Despite some of these nuances and differences, there is general agreement as to the role and function of Key Workers. Several factors that were discussed at Time 1 have continued to provide a basis for developing a common understanding of the role. Additional events designed to facilitate common language and framework for practice also have had an impact. These factors include:

1. Delivery of ongoing province-wide training by the same FASD expert as provided training in 2006/2007 (Diane Malbin). Level 1 (for new staff) and Level 2 (for existing/continuing staff) training was offered to Key Workers in October and November 2007, and discussions at these provincial training sessions helped support continued development and understanding of the role;
2. Delivery of Parent Support training in June 2007 provided Key Workers with a framework as well as ideas for implementing this aspect of their role;
3. Regularly scheduled, ongoing regional meetings of Key Workers (both by teleconference and face to face) that have continued to help promote clarity in and common understanding of the role in those regions;
4. The presence of a Regional Key Worker Program Coordinator in some regions has provided a mechanism for networking amongst Key Workers so that they can continue to discuss their role and activities, as well as their successes and challenges. In one region the Regional Key Worker Program Coordinator has also scheduled conference calls specific to provision of parent support that has allowed Key Workers to brainstorm ideas and problem solve ways of delivering this aspect of their role.
5. Development, by MCFD Provincial Office, of 'Key Worker and Parent Support Guidelines' in the fall of 2007. This document was created in response to a recommendation from the *Time 1 Formative Evaluation Report* to help clarify the Key Worker role and function and to provide a common framework for practice. The document also contains guidelines for the provision of parent support. A series of regional consultations regarding the Guidelines allowed for additional input and created a basis for common understanding of the BC program amongst regional managers and Key Workers.

**Program Strengths**

Additional information pertinent to the question of WHAT are the Key Worker and Parent Support service's activities, and information that is central to the formative evaluation, relates to the program's strengths and challenges. A presentation of the themes associated with program milestones can be found in **Appendix M.**

Respondents to the Time 2 Annual Agency Questionnaire were asked an open-ended question about the strengths of the program. Analysis of their responses revealed a similar pattern of themes as was found in the previous year. At Time 1, program strengths were described as:

- Employs a family-centred model/philosophy of practice
- Provides advocacy, service navigation & promotes family empowerment
- Provides families and & communities with FASD-related expertise
- Promotes a wrap-around approach with families
- Promotes community development and capacity-building

At Time 2, these same themes were reiterated, with the following additions:

- Emergence of parent support and education component of program
- Positive outcomes for families
- Key Worker's expertise and skills

Brief elaboration of these findings follows.

**Employs family-centred model/philosophy of practice**

As at Time 1, the most frequently occurring theme at Time 2, which was noted by the majority of agencies in all regions, was the Key Worker's use of a family-centred approach. Related sub-themes, almost all of which were voiced by agencies at Time 1, included:

- Use of an outreach approach and/or making home visits
- Respecting parents as experts
- Key Worker as "someone who listens"
- Strengths-based approach
- Being flexible

As stated by Key Worker agencies, the program strengths included:

> *Respecting parents as the experts on their child and family situation*.
>
> *Responsiveness – meeting the client where they're at in a natural environment.*
>
> *Family-centred, strengths-based philosophy works in the best interests of families.*
>
> *Acceptance on both parts; non-judgemental.*
>
> *Family-centred; individualized; the flexibility of the Key Worker to visit the family or school, etc, to provide service.*

**Provides advocacy, service navigation & promotes family empowerment**

Another frequently noted strength of the Key Worker program was that it provided families with advocacy and assistance in navigating service systems and in accessing services and supports. Along these lines, one agency in the Interior stated:

> *Assisting families with finding Child with a Disability Tax Credit, and Kidsport funding, which keeps kids active.*

Another agency, in speaking of advocacy and family empowerment as a strength of the program, linked this with families' enhanced knowledge of FASD, which was said to come through involvement with the Key Worker and the parent support program:

> *Families being more empowered to advocate for themselves and the strengths gained in the knowledge of FASD.*

**Provides family & community with FASD-related expertise**

The above quote also links with another strength: that the Key Worker program provided families and communities with information and education about FASD. Related sub-themes, which also emerged at Time 1, included:

- provides families with information/understanding regarding FASD
- provides community service providers with information/understanding regarding FASD
- emphasis on and use of an 'environmental accommodation' approach

In speaking of providing families and communities with FASD-related expertise, several agencies emphasized that their Key Worker's particular knowledge base and skill level was also a strong point. For example:

> *Specific knowledge re: accommodations.*
>
> *The skill level of the Key Worker – ECE background and administrative experience with a family centred daycare – extensive FASD education and experience make the service to families and their children effective.*

**Promotes a wrap-around approach with families**

As at Time 1, a few agencies in different regions noted that the program was helping to promote a more integrated or wrap-around approach to serving families with a child with FASD. Some responses suggested that Key Workers' networking helped enable the creation of an individualized, wrap-around approach to service delivery. As one agency noted:

> *Ability to work collaboratively with many diverse entities to bring FASD lens to light for family/community.*

**Promotes community development and capacity-building**

Similar to Time 1, at Time 2 several agencies noted that the program was well-received in the community, and that there was growing interest, as reflected in the increased number of workshops, FASD-related events, and community-based referrals, as well as an increased number of participants in these events and activities.

> *Lots of community interest and participation.*
>
> *Building relationships, networking (events, workshops).*

**Parent support and education component of program**

Whereas at Time 1, a number of agencies stated that they hoped that the parent support component, once launched, would result in reduced parent isolation and stress, at Time 2 a number of agencies across the province indicated that the parent support component of the program had been launched and

was now one of the program's strength and/or successes. Agencies' comments reflecting this theme included:

> *Providing education to parent and connecting parents to each other.*
>
> *[The program is] fostering relationships between families, fostering mentorship of one parent to another.*
>
> *Group is regular, once a week with a minimum of four families, [and is] parent-driven.*

**Positive outcomes for families**

Several agencies listed positive outcomes for families among their discussion of program strengths. Outcomes mentioned included families' reduced social isolation, families' improved connection with services and resources, families' improved relationships with professionals and service providers, and families' increased sense of hope:

> *Families feel support and empowerment – more hopeful.*
>
> *Having this [Key Worker] position that holds the knowledge for support workers to call, has been instrumental in consistency in services to families referred to these services*

**Key Worker's expertise and skills**

As noted above, several agencies considered their Key Worker's knowledge of FASD as an asset of the program. Along with this, at least one agency in all regions spoke of their Key Worker's expertise and skills in working with families as a strong point. Several agencies linked their Key Worker's skills with the worker's use of family-centred approach. The emergence of this theme reflects agencies' appreciation of the high level and diverse skill set required for Key Workers:

> *The ability of the Key Worker to respond to the very individual needs of each family.*
>
> *The Key Worker's warm and welcoming approach, appropriate use of language and ability to build relationships with parents.*

In summary, one agency's response to the Time 2 Questionnaire regarding the Key Worker program's strengths encapsulated many of the themes presented above:

> *Raising awareness, shifting perceptions, empowering parents, connecting families with community and one another, assisting families with education and other systems, [and] no time limit of length of time spent with family.*

**Program Challenges**

In contrast with questionnaire data regarding program strengths, findings concerning program challenges differed from Time 1 to Time 2. For example, at Time 1 the most frequently named challenge concerned

the referral process and the relationship between the CDBC assessment teams and the Key Worker program. At Time 2, however, the theme that emerged most frequently concerned the lack of services or resources for families and/or youth in communities; a related and also frequently cited challenge was lack of understanding about FASD in communities. Another frequently named challenge at Time 2 concerned issues in implementing the parent support component of the program (e.g. difficulties in getting a group of parents/caregivers to come consistently to the support group). As well, at Time 2, there was a much broader range of issues cited as challenges, relative to the number/types of themes that emerged at Time 1. A brief discussion of challenges identified at Time 2 follows.

**Limited resources or services for families in communities**

Numerous agencies in all regions except the North (n=17) noted that limited resources or services for families with a child//youth with FASD represented a challenge. Many agencies emphasized the need for families to have greater access to respite services, while agencies in Vancouver Coastal and Vancouver Island spoke of the need for more community resources for youth with FASD. In addition, agencies spoke of the need for resources that could help families – and perhaps in particular parents who themselves had FASD – with transportation and/or other assistance to ensure they accessed the services that did exist in the community.

> *Lack of additional community support (e.g. respite).* (Fraser region)
>
> *Limited [by having] no resources and direct support for youth 13-19. This is a prime time when youth need critical support and mentorship beyond the role of the Key Worker.* (Vancouver Coastal region)
>
> *Offering the families with transportation to make appointments, childcare when it is available to them, when accompanying them to appointments.* (Vancouver Coastal region)

**Lack of understanding of FASD in the community**

Agencies from all regions commented that limited understanding of FASD in their community was a challenge for the program. For example, several agencies expressed some frustration that other service providers had not yet started to use a FASD-lens when planning or providing services for families with a child/youth with FASD:

> *Still a challenge to get everyone to agree or make a paradigm shift – from behaviours to brain disability.*
>
> *Other systems not using FASD/brain function lens.*

Similarly, in the North and Vancouver Coastal regions, agencies indicated that educating their communities about the existence of the Key Worker program continued to be a challenge:

> *As always with new programs, educating communities about the service is a long but useful process.*

**Low referrals, particularly from certain referral sources (e.g. self-referrals)**

As a related point, several agencies noted that FASD still was highly stigmatized. This was raised as an issue for the program and was linked to the challenge of low referrals, as it meant that families were less inclined to self-refer and to attend parent education or support activities. Similarly, one agency conjectured that their ongoing struggle with a low number of referrals may have been because the community in which the agency was located was affluent and less likely to accept the existence of FASD. In another region, Key Worker agencies identified a low number of referrals from social workers as a related challenge. Issues relating to low referrals to the program were named as challenges in four regions.

> *Not seeing self-referrals. Parents find it very difficult to come.*
>
> *Reducing stigma so biological families will come forward.*

**Parent support program**

At Time 2, agencies from all regions (n=9) identified various facets of implementing the parent education and support component of the program as being a challenge. Some agencies spoke of difficulties in getting a consistent group of families to come to parent support meetings; other agencies indicated that so far there was relatively little interest amongst parents/caregivers in actively participating in a parent/caregiver support group. A few other agencies noted that providing parent support for birth families or for parents who themselves possibly had FASD gave rise to other particular challenges that had to be considered, such as development of appropriate levels and types of information. Agencies also identified logistical challenges associated with launching parent support groups, including large geographic distance and families' high level of stress.

> *Getting people together – people are either in such high need that they cannot attend groups, or their schedules are so busy that it is difficult to bring them together at the same time.*
>
> *Parent to parent supports do not work well due to many parents exhibiting characteristics and behaviours associated with FASD; parents are too stressed or stretched, and geographic distances.*

**Large catchment area of the Key Worker to cover**

Along similar lines, agencies in three regions identified that the large catchment area served by their agency was a challenge for the program; Key Workers found it difficult to cover the distances and to travel to work with families living in outlying and/or isolated communities within the catchment area. In the words of one agency:

> *Limited hours / lots of geography.*

**Insufficient time to carry out demands of the Key Worker position**

The previous challenge relates to an issue that several agencies (n=6) across three regions named as an issue at Time 2: that they did not have enough time to carry out the activities and demands related to the Key Worker role. Another sub-theme related to the theme of "insufficient time", voiced by one agency, was the challenge of having insufficient time/money for the administrative demands associated with Key Worker program. Along these lines, one agency stated that there was "too much paperwork" and another noted that the evaluation Intake Questionnaire was too long and intrusive.

A similar challenge, noted by another two agencies in the North region, was that they spent too much time with CDBC Assessment intake activities – leaving them too little time for "key working".

**CDBC assessment related issues and/or intersection between Assessment teams and Key Worker agencies**

In contrast with Time 1, when one of the most frequently reported challenges concerned the intersection between the Key Worker agencies and the CDBC assessment teams, at Time 2 relatively few agencies (n=5, from 2 regions) cited issues associated with the assessment teams as a challenge. Nevertheless, the issues raised by Key Worker agencies warrant reporting; including concerns about long waiting lists for CDBC assessments, inconsistencies regarding the FASD "diagnosis", concerns about the referral process for assessments, and challenges with communication between the assessment team and the Key Worker agency. In the words of one agency:

> *Many referrals are not identified and could not be identified as having FASD. CDBC continues to be a vague term.*

**Developing Key Worker program focus**

At Time 2, a few agencies (n=3, from 2 regions) reported that they were still working to develop the focus of the Key Worker program and that this was identified as a challenge. Interestingly, all of the agencies that named this as a challenge either had had staff turnover the in preceding year or were organizations that only received funding for a Key Worker in the past fiscal year:

> *Developing focus/direction for program.*
>
> *Lack of clarity around the Key Worker role and whose needs are being met.*

From a more experienced agency, another aspect of this challenge was voiced: a concern that the focus of the Key Worker program could be diluted by too broad a mandate and/or by the lack of other community-based programs for other 'invisible disabilities'. In the words of this program manager:

*We are watering down something that was meant for FASD. Really every child with special needs could benefit from this accommodation adaptation approach. …..Nothing else picks up the slack so the pressure is on for the Key Worker to be catchall. This is not going to work.*

**Staff turnover and burnout**

Three agencies in two regions indicated that staff burnout and staff turnover were challenges for the program in the past year:

*Turnover, burnout, ever-changing demographics.*

**Engaging (birth) families**

Developing relationships and trust with families so that they felt at ease were processes that took time, yet these were named by two agencies as challenges for their program. These issues may also be linked to challenges associated with launching the parent support component of the program, discussed above.

*Parents find it difficult to come to our centre and discuss family concerns, particularly for birth parents.*

**Engaging with Aboriginal communities**

Finally, in keeping with a theme voiced by two agencies at Time 1, two agencies at Time 2 spoke of challenges in either providing a culturally relevant service or in developing collaborative relationships with the local Band:

*Collaboration with the Band has been challenging.*

*Difficulty providing culturally relevant service to some Aboriginal families/community.*

In summary, the strengths and challenges raised by agencies at Time 2 further confirmed and expanded on the role and activities of Key Workers. Responses to the Time 2 Annual Agency Questionnaire showed that the agencies and Key Workers were clearly further along the process of program implementation than they were at Time 1. At the same time, several of the strengths that were identified also contained some challenges. For example, at Time 2, introduction of the parent support component was seen as a definite strength of the program, yet issues relating to its implementation were also quite evident at Time 2. As well, despite recognition of Key Workers' growing knowledge regarding FASD, effecting a shift in perspective (i.e. a paradigm shift) amongst service providers and educators in the community in keeping with an understanding of FASD as a neuro-behavioural disability, was also a challenge. Although issues associated with the referral processes and engaging with birth families continued to be of importance, these issues were raised less frequently as current challenges. Similarly, issues regarding the intersection between the CDBC assessment teams and Key Worker agencies were voiced less frequently.

# SECTION 6 HOW IS THE KEY WORKER PROGRAM WORKING?

## Highlights - How the Program is working

- 66% of Key Workers were in dedicated positions, an increase of 6% over Time 1.
- A significant number of Key Workers continued to be in non-dedicated positions and performed different job functions under different mandates in addition to their Key Worker functions.
- Staff turnover was an ongoing concern in some regions, with 19 out of 42 agencies reporting turnover.
- Reasons for Key Worker turnover included: lack of knowledge and skills necessary for the position; staff discomfort with the role; non-competitive pay scale; maternity or medical leave; and pursuit of advanced education.

This section addresses the key inputs for program delivery including funding, staffing, regional coordination, training and provincial supports.

**Agency Profiles**

At Time 2, 51 agencies around the province were awarded 57 contracts to deliver Key Worker and Parent Support Program; two of these agencies are providing Parent Support only and one agency had not yet begun to implement the Key Worker program. This was an increase of three contracts compared to Time 1.

As can be seen in the table below, the profiles of the agencies delivering the Key Worker services remained very similar to the profiles at Time 1. According to the 42 responses to the Agency Questionnaire received at Time 2, the majority of the agencies continued to be non-profit organizations governed by Boards of Directors. Over 66% of the agencies are accredited or accreditation is pending. The following table summarizes the agency profiles by region.

**Table 14: Agency Profiles – Time 1 and Time 2**

| Region | # of Agencies with contracts | | Governance | | | | Accreditation | | | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Time 1 | Time 2 | Time 1 N=39 contracts | | Time 2 N= 42 contracts | | Time 1 N=39 contracts | | Time 2 N= 42 contracts | |
| | | | Non Profit | For Profit | Non Profit | For Profit | CARF /COA | Pending/No Accreditat'n /Other | CARF /COA | Pending/No Accreditat'n /Other |
| Fraser | 9 | 9* | 11 | - | 9 | - | 11 | - | 9 | - |
| Interior | 9 | 10 | 4 | 2 | 6 | 1 | 5 | 1 | 5 | 2 |
| North | 6 | 6** | 4 | 1 | 4 | 3 | 2 | 3 | 3 | 2 |
| Vancouver Coastal | 13 | 14*** | 5 | 1 | 7 | 2 | 6 | - | 7 | 2 |
| Vancouver Island | 11 | 12**** | 11 | - | 9 | 1 | 2 | 9 | 2 | 8 |
| Total | 48 | 51 ***** | 35 | 4 | 35 | 7 | 26 | 13 | 28 | 14 |

Source: Time 1 and Time 2 Annual Agency Questionnaires
* One agency holds 3 contracts and another has 2 contracts, each contract for different communities
** One agency holds 3 contracts for 3 different communities
*** One agency holds a contract but has not implemented the Key Worker program
**** MCFD internal service site included
*****Total number of contracts/communities = 57

Fifteen of the 51 agencies were Aboriginal agencies that offered services on and off reserve. In addition, some communities continued to develop partnerships with local Aboriginal programs to ensure culturally sensitive delivery of the Key Worker and Parent Support Program.

### Funding

In 2005, funding to each of the MCFD Regions was approved, following the submission of a regional plan that outlined how the Key Worker and Parent Support program would be implemented. Regional funding required that the regional plans included new Key Worker positions and that Parent Support initiatives be developed. The Regional funding allocation is shown in Table 15.

**Table 15: Regional Funding Allocation 2005 to 2008 - Three Year Plan**

| Region | 2005/06 | 2006/07 | 2007/08 |
|---|---|---|---|
| Fraser | $672,000 | $944,610 | $1,489,610$ |
| Interior | $414,000 | $588,240 | $936,240 |
| North | $295,000 | $420,820 | $672,820 |
| Vancouver Coastal | $431,000 | $595.970 | $925,970 |
| Vancouver Island | $388,000 | $550,360 | $875,360 |

Source: MCFD Planning Documents

As can be seen in the table above, the regions received funding increases each year. Based on recommendations from the Time 1 Formative Evaluation, the regions used the 2007/2008 increases to the boost the funding to the agencies so that they could top up existing Key Worker positions rather than fragment the service delivery through creation of additional part time positions.

During 2007/2008, funding for the agencies ranged from $9,996 to $163,224 with the majority receiving between $50,000 to $100,000. The range of funding varied slightly from that reported in the *Time 1 Formative Evaluation Report*. In part, the variation in the value of the contracts reflects the fact that different agencies completed questionnaires at Time 2, e.g., the agency that received $9,996 did not complete an Agency Questionnaire at Time 1 but did so at Time 2. As well, the increase in the value of the upper level of the contract range, from $75,000 at Time 1 to $100,000 at Time 2, was a result of the increased funding allocated to agencies in 2007/2008.

The funding levels for individual agencies depended on the amount of service the agency was expected to deliver. The varying amounts also reflected the diversity of work environments and expectations in relation to unionized and non-unionized agencies, full time and part time positions, and geographical areas to be covered. Of the 39 agencies that provided information about the duration of their contracts, the majority (62%) had contracts lasting one year, with 10 agencies (26%) reporting they had signed contracts of two years' duration and four agencies (10%) reporting they had signed contracts of 3 years' duration. One contract was of greater than 3 years' duration. (See Appendix Q for a comparison of the agencies' budgets from Time 1 and Time 2.)

In addition to funding through their contract with MCFD, seven agencies reported receiving additional funds for the Key Worker and Parent Support programs from other organizations. Similar to Time 1, at Time 2 the eight agencies in the North Region received funding from the Northern Health Authority (NHA) to support the CDBC assessment intake role performed by Key Workers in those agencies. The amounts from NHA ranged from $8,000 to $26,400, depending on demand for CDBC assessments in the communities. Another agency from the North Region received an additional $25,000 from its host organization in order to pay the Key Worker salary, according to the union agreement, and to cover increased levels of service beyond the amount contracted through MCFD. A Vancouver Island agency received $17,000 from a charitable organization in order to purchase materials for the parent library.

Thirty-nine percent of the agencies at Time 2, compared with approximately two thirds of the agencies at Time 1, indicated that they provided or received in-kind contributions (indirect costs[7]) associated with the

[7] Indirect costs, or in-kind contributions do not involve an exchange of funds but include such things as donations, volunteer time, contributions of food or provision of meeting space and so on (Robinson, Millson & Stringer, 2005).

implementation and operation of the Key Worker and Parent Support Program. The most frequently mentioned items of in-kind contributions were for office space, clerical support, administration, materials and clinical supervision. As noted in the previous report, provision of clinical supervision was a requirement of the Key Worker program; however, several agencies indicated that this activity was not adequately funded through the MCFD contract. Six of 42 agencies that responded indicated that they were supporting clinical supervision through a combination of contract dollars and/or in-kind contributions. Of these six agencies, four reported that they were providing clinical supervision through in-kind contributions only. Staff training, transportation and consultation were other areas in which agencies provided or received in-kind support. A number of agencies in the North indicated that, due to the large geographical areas that they covered, transportation would be a growing area of cost to the agencies, which would present difficulties in getting their clients to the centres for assessment.

The evaluation's second Annual Agency Questionnaire asked the agencies to identify any issues with funding. The responses to the question varied from "no issues" with funding, to "The funding does not meet the needs of families and there is already a shortage of services in the community." Each region reflected a similar range of responses whereby some agencies were satisfied with the level of funding and others reported concerns. Common issues with funding across all regions that were identified through interviews and/or with Agency Questionnaires included:

- Funding did not cover full operating costs, including time for supervision and transportation costs.
- Caseload growth was placing more demands on administration time, which was not fully covered in the contract

At the same time, several agencies identified the lack of flexibility in the current funding levels to handle future growth in caseloads and pay increases, as Key Workers moved up the pay grids within their organizations. However, overall there were far fewer issues raised regarding funding in the Time 2 Agency Questionnaires compared to Time 1 responses. Some agencies noted that the contract increases received in 2007/2008 "supported the value and presence of the service in the community and supported the retention of our staff", and "allowed us to increase the FTE to full time".

**Key Workers**

The Key Worker and Parent Support program envisioned that most areas of the province would hire Key Workers who would provide the key worker services in conjunction with parent support 'mechanisms,' e.g., parent support groups. MCFD has consistently recommended that Key Workers possess an undergraduate degree in health or human services (social work, nursing, psychology, child and youth

care) with extensive knowledge of FASD (MCFD, RFP Resource for Regions, 2005, p.9; Draft Key Worker and Parent Support Program Guidelines, Sept 2007, p. 10). Hiring of Key Workers took place throughout 2006 as contracts were signed in the regions. By the end of October 2007, despite staff turnover and hiring difficulties in some areas, Key Workers were in place in all but a few of the contracted agencies.

According to data submitted by the agencies, at Time 2, the level of staffing ranged from 2.5 full-time-equivalent positions (FTE) to 0.28 of an FTE. The majority of Key Workers to date had at least a Bachelor Degree in Social Work or Arts. Tables 16 and 17 below summarize the FTEs and Key Worker qualifications by region.

**Table 16: Summary of Key Worker Positions by Region**
**(n = 42 of 54 Agency Contracts)**

| Region | Number of Agencies with FTEs Time 2 | | | Total Key Worker FTEs Per Region 2006/2007 | Total Key Worker FTEs Per Region 2007/2008 |
|---|---|---|---|---|---|
| **FTEs** | **≥ 1.0** | **0.6 to 0.9** | **≤0.5** | | |
| **Fraser (n = 9)** | 7 | - | 1 | 7.5 | 8.5 |
| **Interior (n = 7)** | 3 | 3 | - | 4.4 | 6.0 |
| **North (n = 7)** | 7 | - | - | 4.6 | 8.0 |
| **Vancouver Coastal (n = 9)** | 7 | 1 | 1 | 6.0 | 9.3 |
| **Vancouver Island (n = 10 )** | 7 | 1 | 2 | 7.5 | 9.3 |
| **Total** | **31** | **5** | **4** | **30.0** | **41.1** |

Source: Time 2 Annual Agency Questionnaire

**Table 17: Summary of Key Worker Qualifications by Region**
**(n = 42 of 54 Agency Contracts)**

| Region | Key Worker Academic Qualifications | | |
|---|---|---|---|
| | **BSW/BA** | **MSW/MA** | **Other** |
| **Fraser (n = 9)** | 6* | 4 | 3** |
| **Interior (n = 7)** | 5 | 2 | 3** |
| **North (n = 7)** | 3** | - | 5* |
| **Vancouver Coastal (n = 9)** | 2 | 3 | 5* |
| **Vancouver Island (n = 10)** | 9 | - | 2 |
| **Total** | **25** | **9** | **18** |

Source: Time 2 Annual Agency Questionnaire
* Agencies in region have more than one key worker
** More than one degree listed for key worker

According to Time 2 Agency Questionnaire data, 66% of the Key Workers were in dedicated positions, that is, their caseload was entirely made up of Key Worker and Parent Support program clients. This is up 6% from the previous reporting period. The Fraser region had a higher percentage of Key Workers in non-dedicated positions. However, many of the agencies reporting from the Fraser region had more than one Key Worker; thus, this trend may reflect sharing of duties with other programs. Funding levels in other agencies only allowed for the creation of part-time Key Worker positions. Approximately 34% of the agencies combined funding from different programs to augment existing part-time positions between compatible programs, i.e. early childhood development, mental health programs, alcohol and drug counselling, youth justice, family support services. Thus, at Time 2, a significant number of Key Workers continued to hold non-dedicated positions and perform different job functions under different mandates in addition to their Key Worker functions.

Fourteen out of 42 agencies reported Key Worker and Parent Support staff changes from April 2006 to October 2007. As can be seen in the table below, Vancouver Coastal and Vancouver Island had the highest Key Worker turnover rates, with 67% and 60% turnover respectively. (See **Appendix N** for a summary of staffing changes per region). It is not possible to assess the turnover rate specifically for the Parent Support positions because the vast majority of the Key Workers fulfil the both roles, meaning that a change in one leads to a change in the other. It should be noted that not all agencies submitted agency questionnaires, thus it is likely that the turnover rate was higher in some regions than indicated in the table below.

**Table 18: Key Worker Turnover Rate by Region***
**April 2006 to October 2007**

| Region | Turnover Rate |
|---|---|
| **Fraser (n = 10)** | 8% |
| **Interior (n = 7)** | 27% |
| **North (n = 7)** | 25% |
| **Vancouver Coastal (n = 9)** | 67% |
| **Vancouver Island (n = 10)** | 60% |
| **Average Provincial Turnover Rate** | **37.4%** |

Source: Time 2 Annual Agency Questionnaire
*Turnover Rate=Total Staff Leaving/Total Number of Positions

One agency had four different people in the Key Worker position from April 2006 to October 2007. Agencies cited the following reasons for Key Worker turnover: lack of knowledge and skills necessary for position, staff discomfort with role, non-competitive pay scale, maternity/medical leave, and pursuit of advanced education. This high turnover is concerning in light of research suggesting that the direct cost of replacing an employee to an agency can be on average three fourths of the employee's annual salary

(Phillips, 1990). The costs of replacing an employee are threefold; (1) direct replacement costs in terms of advertising, interviewing and training a new employee; (2) indirect costs during transition such as workload, morale, and productivity for remaining staff (as well as client satisfaction) and (3) time and energy invested in each new hire is lost for other opportunities that may benefit the agency (McConnell, 2007).

**Key Worker Caseloads and Waiting Lists**

For the Time 2 report, agency directors were asked to identify the average active caseload for the Key Workers in their agency. As can been seen in the table below, the average active caseload per FTE ranged from 17.3 families in the Fraser region to 10.7 families in Vancouver Coastal. Within region variation was more pronounced, with some regions reporting average caseloads that ranged from 1 to 36. Very low caseloads were reported by agencies that have struggled with staffing. While the following caseload information is based on estimates provided by agency directors, it does provide a rough measure of the Key Workers' activity in each region. Nonetheless, results are to be viewed with caution, as there is no standard definition as to what constitutes an active caseload. For example, a very few families may consume the bulk of a Key Worker's time, and yet delays in discharging families may make the caseload appear much larger than it is.

**Table 19: Time 2: Key Worker Caseload per FTE**

| Region | Total KW FTEs 2007/2008 | Range of Active Families per FTE | Average # of Active Families per FTE | Median # of Active Families per FTE |
|---|---|---|---|---|
| **Fraser (n = 8)** | 8.5 | 1 to 31 | 17.3 | 17,5 |
| **Interior (n = 5)** | 5.4 | 9 to 16 | 12.2 | 13 |
| **North (n = 7)** | 8.0 | 8 to 33 | 19 | 20 |
| **Vancouver Coastal (n = 9)** | 9.3 | 2.5 to 26 | 10.7 | 10 |
| **Vancouver Island (n = 10)** | 9.3 | 1 to 36 | 13.2 | 12 |

Source: Time 2 Annual Agency Questionnaire

In addition to caseload information, agency directors were asked to provide information about the average wait time (in days) for families to be assigned to a Key Worker once they had been referred to the Key Worker program. As would be expected, due to increased program participation at Time 2, Table 20 illustrates that there was an overall increase both in the number of agencies reporting waitlists for Key Worker services and the average wait times as compared to Time 1.

Table 20, below, indicates that the Interior Region had a decrease in wait times from Time 1 to Time 2. However, this is due to one agency whose wait time dropped from 11 days at Time 1, to two days at Time

2. This change in wait time could be the result of a measured implementation of the program during the start up phase, whereby the Key Worker had a number of referrals, but due to the newness of the program only took on new families a few at a time, thus creating a short wait list for a brief period of time. Also, the decrease for this one agency could have resulted from increased staffing due to the budget lift during 2007/2008, some of which was allocated to existing programs in order to increase part time Key Worker positions to full time positions.

**Table 20: Wait Times and Waitlist For Key Worker Services, Time 1 and Time 2**

| | Time 1 | | | | Time 2 | | | |
|---|---|---|---|---|---|---|---|---|
| **Region** | **Range of Wait Times (days)** | **Avg Wait Time (days)** | **Median Wait Time (days)** | **# Reporting Active Waitlist** | **Range of Wait Times (days)** | **Avg Wait Time (days)** | **Median Wait Time (days)** | **# Reporting Active Waitlist** |
| **Fraser (n = 8)** | 0 –1.5 | ** | ** | 1 | 0 - 90 | 22.9 | 16.3 | 5 |
| **Interior (n = 6)** | 0 -11 | 3 | - | - | 0 - 2 | * | * | 1 |
| **North (n = 6)** | - | *** | *** | - | 0 - 10 | 3 | 4 | 2 |
| **Vancouver Coastal (n = 8)** | - | *** | *** | - | 0 - 7 | 2 | 1 | - |
| **Vancouver Island (n = 10)** | 0 - 7 | 1.8 | 1 | 2 | 0 - 8 | 2.7 | 2 | 1 |

Source: Time 2 Annual Agency Questionnaire
*Only one agency reported a wait time of 2 days for families to be seen by the Key Worker. Thus, calculating average regional wait times is not appropriate.
**Only one agency reported a wait time of 1.5 days. Thus calculating the average regional wait time was not appropriate
*** No agencies reported wait times thus no average or median times were calculated

**Key Worker Supervision and Regional Coordination**

As discussed in the *Time 1 Formative Evaluation Report*, supervision of Key Workers was considered by the program developers to be an important ingredient in the Key Worker and Parent Support program(Greco et al., 2005). Thus, in the RFP Resource for Regions, developed to assist the MCFD regions in launching the Key Worker and Parent Support Program, the Ministry suggested that, “no Key Worker may practice independently of clinical supervision unless they are a member in good standing of an appropriate professional body” (MCFD, 2005, p.9). Current draft program guidelines reiterate the intention that Key Workers receive clinical supervision from graduate level health or social work professionals (Key Worker and Parent Support Program Guidelines, Sept 2007, p.11).

As mentioned in the previous evaluation report, the requirement from Provincial Office that clinical supervision be provided was reflected in many of the contracts from around the province, however, not all contracts identified the requirement that clinical supervision be available for the Key Worker. As well, as

noted above, some agencies reported that even though clinical supervision was an expectation in their contracts, they did not receive sufficient funds in their contract to cover the clinical supervision costs and thus, they were augmenting the supervision activity with in-kind contribution. Nevertheless, all the agencies responding to the questionnaire stated that the Key Workers were receiving regular (daily, weekly, or bi-weekly) individual supervision with the Executive Director or the program manager. Several agencies offered peer or clinical team supervision opportunities, in addition to regular agency staff meetings in which the Key Workers participated. **Appendix O** provides a summary of the educational qualifications of the Key Workers' supervisors.

A further area of supervision that many of the agencies identified was that of administrative supervision. The administrative supervisor provided support and guidance in the adherence to the appropriate implementation of agency policies and procedures (Kadushin, 1992). Due to funding restraints and/or agency organizational structures, frequently the administrative and clinical supervisors were the same individual.

## Regional and Provincial Supports for Key Workers

### Regional Coordination

A recommendation of the previous report was the establishment of Regional Coordinators for Key Worker services. At Time 1, two regions had established contracts or partnerships with other agencies to provide Regional Key Worker coordination, supervision and mentoring. At Time 2, some form of regional coordination was in place in four regions – the North, Fraser, Vancouver Island and Interior.

In the Interior region, a non-profit agency has held the Regional Coordinator contract. The contract has been funded through surplus funds from the first few years of the Key Worker program, however, the availability of surplus funds was not expected to continue and the region was exploring options to continue the Regional Coordination role.

The Interior Regional Coordinator coordinated the development of, and organized, regional training, acted as a resource and clearing-house for information about FASD and parent support options, and coordinated monthly conference calls with all the Key Workers in the region. The Regional Coordinator also coordinated the collection of output data for the evaluation thereby ensuring consistency in response from the region. As well, the Interior Regional Coordinator worked with the regional CDBC Assessment Team to address the referral process from the Assessment Team to the Key Workers.

Feedback from Key Workers indicated that the conference calls were especially important early on in their role to establish networking and to provide a forum for information sharing between Key Workers. In

addition, the Coordinator included guests who brought specific expertise related to the Key Workers' work with families and communities, e.g. Provincial Outreach Program staff, the evaluation team. In addition, the Key Worker Provincial Consultant, Diane Malbin, has joined the Interior Key Workers' conference calls to provide direct consultation regarding their work. The Interior Regional Coordinator also attended meetings with the Tri-Ministry Alliance, comprised of representatives from the Interior Health Authority, Education and MCFD.

A similar Regional Coordinator position was created in the North region as part of the partnership and Memorandum of Understanding (MOU) between the Northern Health Authority and the MCFD North Region. The Regional Coordinator, a Northern Health employee, was "responsible for data collection, clinical supervision, and overall CDBC program monitoring" (Memorandum of Understanding, 2006). The Coordinator has: provided liaison support for the Key Workers with community resources; funneled referrals to appropriate resources; completed data entry of CDBC referrals and intakes; and aided in policy compliance.

On Vancouver Island, a halftime Regional Coordinator position was created for the Key Worker and Parent Support program in August 2007 and is contracted with a non-profit agency. The Regional Coordinator's role was similar to that of the Interior region whereby she coordinated regular conference calls and/or face-to-face meetings with the region's Key Workers to promote networking, education and information sharing amongst the workers. The intention was to vary the agenda of the conference calls so that meetings regarding case conferencing, information sharing and problem solving were alternated with meetings that included guest speakers, education and consultation. For example the Program Coordinator for the Provincial Outreach Program participated in the December 2007 conference call with the Vancouver Island Key Workers. As well, the Vancouver Island Regional Coordinator provided information and resource materials; supported to new Key Workers in their role; and coordinated the collection of the monthly output data from the agencies.

At a more local level, another model of coordination and mentoring/supervision was created for the agencies delivering Key Worker and Parent Support program in South Vancouver Island. The lead agency has provided "mentoring and leadership to the development of the Key Worker and Parent to Parent Support Services model for South Island." The responsibilities have included liaising with the Vancouver Island Health Authority (VIHA) Assessment Team, acting as the point referral for children and families, tracking and assigning referrals, identifying training needs and mentoring other Key Workers. Contracts for the other three agencies in the South Island area stipulated that they participate with the lead agency assessment team. However, in practice during the past year, only one agency has participated with the mentoring agency. Staff turnover and few referrals at the other agencies have contributed to these agencies' lack of involvement in the mentoring opportunity.

In the Vancouver Coastal region, Key Workers in the Greater Vancouver area have, on their own initiative, formed a peer supervision/mentoring group that meets monthly. The function of the group has been to provide peer support, education and resource networking. They have shared the responsibility for developing the agenda, coordinating the meetings and inviting guest speakers. Additionally, they have collaborated together to deliver biweekly parent support programs. Details regarding the parent support aspects of their work were discussed earlier in this report.

In the Fraser region, the CYSN manager has fulfilled the role of regional coordinator. She has coordinated regular, bi-monthly meetings with the agency staff involved in delivering Key Worker and Parent Support program in the region. Representatives from the Fraser Health Region CDBC Assessment Network and from the School Districts have been regular participants in these meetings as well. The purpose of the meetings has been to promote networking, information sharing, education and problem solving.

Key Workers have reported on the value of the Regional Coordinators' role and how important it was to them in their work:

> *Support from Regional Coordinator has been key – essential. She brings all the information together from the Health Assessment Network, from other Key Workers in the region, from the evaluation team. She is the "eyes and ears" of the program.*
>
> *I have turned to her (the Regional Coordinator) on several occasions when I have been really stuck.*
>
> *Without central coordination, the Key Worker network would fall apart.*

Other Key Workers suggested that they would like to see more opportunities for province-wide networking. As one Key worker stated:

> *[I] wouldn't change the regional network. But I would like more networking across the province. I got to know a couple of Key Workers from other parts of the province through referrals of siblings living in other regions and have since stayed in touch with them.*

## Key Worker Training

Local, regional and provincial delivery training related to FASD and the Key Workers' role continued to be a highlight of the Key Worker and Parent Support Program. As discussed in the previous report, the primary purpose of the training has been to develop common understanding about FASD and the Key Worker role amongst the Key Workers, their supervisors and community service providers. According to the agencies that responded the question in the Annual Agency Questionnaires (n=39), training continued to be available to all Key Workers on an ongoing basis. (See **Appendix P)** for a summary of Training for Key Workers and their supervisors.) Ongoing training in the area of FASD was less available to

supervisors: 10 of the 43 agencies responding to questions regarding training indicated that ongoing training was not available for the supervisors.

At Time 2, local and regional training included: FASD-related conferences that Key Workers attended (e.g. the International FASD conference held in Victoria and a conference held in Kamloops; Parent Support training (North region); foster parent training on FASD; and training about FASD offered by White Crow Village in advance of working at the camp as a volunteer.

Provincial training continued with the delivery of two three-day courses for Key Workers and their supervisors in the fall 2007. Level 1 FASD Key Worker training was designed primarily for recently hired Key Workers and supervisors new to the area of FASD. Level 2 training was intended for Key Workers and their supervisors who had completed Level 1 training the previous year and who had been working in the field. Additional seats in both sessions were made available to community partners from the health and education sectors. Approximately 50 people completed Level 1 in October 2007, and an additional 51 participants completed Level 2 in November 2007. Level 2 training will be offered again in the spring 2008 for those who were not able to attend in the fall.

Level 1 training provided participants with a foundation for understanding FASD as a neurobehavioural disability and a framework for developing and implementing effective strategies for working with families and children with FASD. Level 2 training offered participants an opportunity to deepen their practice through discussions and evaluation of the various approaches and techniques for working with children and youth with FASD/CDBC, and strategies for engaging in collaborative practice with community partners. New content in both Level 1 and Level 2 training for 2007 was a presentation about the CDBC assessment process.

Summaries of the training evaluations were overwhelmingly positive. Participants reported gaining an "increased understanding of the multidisciplinary composition of the assessment teams, the objectives of the assessment process, and strategies for interpreting and implementing the (assessment) reports' recommendations" (Evaluation Summary, Level 2 Key Worker Training Evaluation, November 7-9, 2007).

Further to this, a Key Worker who had completed Level 1 reported in an interview for this evaluation that:

> *Training helped to connect the pieces – how the program came about, where funding comes from, who the players are. The assessment process and explanation of the digit diagnosis was really helpful – the explanation of why things are done the way they are. Also information about the breakdown of Ministry of Education funding was informative. This information will help me in advocating for services. I liked the real stories as illustrations of how to work with the kids with FASD.*

During interviews for this evaluation, one Key Worker reflected on the training she had received the previous year. Her comments exemplified much of the feedback from other Key Workers:

> *Diane's example helped me shift my thinking of FASD as a brain based disability, which responds to accommodations rather than cognitive behavioural approaches. I realized that the way I worked in the school was causing problems. Now I feel better equipped to help parents advocate for more appropriate strategies and accommodations in the school system. I can now describe to schools the differences between accommodations and cognitive behavioural approaches.*

Other training participants talked about the importance of being able to get together with Key Workers from around the province. The comment below echoes those of other Key Workers.

> *The best part was meeting other Key Workers and Intake/Key Workers and talking to them about what they were doing. I got to ask questions and talk about my fears. Meeting them and talking to them really calmed my fears and made me realize that I wasn't way off track, and that everyone was struggling to find the time to get the work done.*

At Time 2, interviews with Key Workers, clinical supervisors, program managers, along with the written evaluations completed by training participants in 2007 offered some suggestions for improvements, primarily for the Level 2 training. Suggestions for future training included:

- Providing opportunities to share or learn about more tools, resources, e.g., booklets, videos, websites, articles
- Focussing on practical aspects around how to access services, how to link with the CDBC assessment teams, how to work with other professionals
- Working with birth parents
- Focussing on advocacy, particularly with the education system
- Focussing on specific case studies
- Increasing Aboriginal input into the training curriculum.

**Expert Consultation**

As noted in the Time 1 Formative Evaluation Report, a hallmark of the Key Worker and Parent Support program was the availability of consultation from a respected expert in FASD, Diane Malbin, MSW, for regions and agencies delivering key worker services. As at Time 1, in 2007/2008 Diane Malbin was available to provide consultation services related to FASD training, program implementation and practice with children and families. Consultation time for agencies, regions or practitioners was approved through the provincial office. The overall contract with the FASD Consultant was for up to 12 hours per month or 144 hours per year.

Relative to 2006/2007, in 2007/2008 there was less demand for expert consultation services. In 2006/2007, a total of 85.2 hours were used; in 2007/2008, as of February 2008, a total of 47 hours had been used. These findings suggest that this expertise is not being utilized to the extent that was initially anticipated. Further comment will be provided in the final formative evaluation report.

### Ministry Website and Program Guidelines

In addition to the provincial training, the MCFD Provincial Office has supported the Key Worker and Parent Support program through the development of the Ministry's website section on FASD and the Key Worker program, and through the development of Draft program guidelines. The website contains information about the Key Worker role, the assessment and diagnosis process, links to the BC Ministry of Education Provincial Outreach Program for FASD (POPFASD) website that provides resources for schools, as well as information regarding research and evaluation initiatives in relation to FASD that are supported by the Ministry. Lastly, the website provides links to relevant publications, and to additional websites that might be helpful for those working in the field (http://www.mcf.gov.bc.ca/fasd/index.htm).

Finally, in response to a recommendation from the Time 1 Formative Evaluation Report, the Provincial Office developed Draft Program Standards for the Key Worker and Parent Support program. These program standards are intended to "clarify the role, function, and framework for practice of key workers" (MCFD Draft Key Worker and Parent Support Program Standards, September 2007, p.4). Once the regional consultation process to review the standards has been completed, a final version will be produced. The final evaluation report will explore how these program standards are utilized in the field.

## REFERENCES

Robinson, D., Millson, W., & Stringer, A. (2005). *Kids 1st – Process and Outcome Evaluation Final Report*. Ottawa: T3 Associates.

# SECTION 7: WHAT ARE PARENTS' & CAREGIVERS' PERCEPTIONS OF THE PROGRAM?

## Highlights - Parents' and Caregivers' Perceptions

- In all regions and almost without exception, parents and caregivers were very positive about the Key Worker and Parent Support program.
- Key Workers' family-centered approach was a key facet of what parents/caregivers liked most about the program.
- Suggestions for changes to the program, from parents' and caregivers' perspective, can be related to emerging program challenges, that is, a need for additional community-based supports and resources, such as respite; a need to strengthen the relationship between Key Workers and schools; and a desire for the Key Worker and Parent Support program to be extended to serve families with young adults, beyond the age of majority.

***She's - what - a lifeline. She's it. (Caregiver interview)***

This section addresses parents' and caregivers' perceptions of and satisfaction with the Key Worker and Parent Support program as well as their dissatisfaction, along with any recommendations for change. The findings in this section are drawn from the community-based interviews with parents and caregivers conducted by the evaluation team in fall 2007. These findings also speak to family-related early and intermediate formative outcomes, including *Families/caregivers are engaged in working with Key Worker* and *Families/caregivers are satisfied with the support they receive.* The program's progress in relation to formative outcomes is discussed more fully in Section 8.

**Perceptions of the Key Worker role**

In discussing how the Key Worker was involved with their family or themselves as well as the range of activities in which they engaged with their Key Worker, parents' and caregivers' descriptions closely mirrored the description of the role voiced by Key Workers themselves. Families reported that the Key Worker provided them with support, advocacy, and education/information, and facilitated parent support activities and networking.

In particular, parents and caregivers emphasized the role that their Key Worker played in:

- Providing emotional support to manage the parenting/caregiving role;
- 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.

**What parents and caregivers liked most about the Key Worker and/or Parent Support Program**

Nearly without exception and in all communities, the parents and caregivers interviewed for this evaluation were extremely positive about the Key Worker and/or Parent Support program. Indeed, 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. In these caregivers' words:

*She's has kept us sane. She has kept me afloat.*

*I don't think I would make it through some days without the Key Worker.*

*Without the Key Worker, my family would have fallen apart.*

Interestingly, in many ways parents' and caregivers' more specific comments about what they liked most about the Key Worker and Parent Support program paralleled the themes that emerged regarding the program's strengths. These are presented below, illustrated by parents' and caregivers' comments.

*I feel supported – I have someone to talk to and to vent with.*

Many parents and caregivers noted that what distinguished the Key Worker program from other services they had received was that the support was for them. For some parents, this experience of having someone whom they could call upon for support was unique. As such, it was valued immensely. A number of parents and caregivers linked their feelings of being supported to other outcomes for themselves and their families, such as not feeling alone or isolated. These outcomes will be explored more fully in the *Time 1 Summative Evaluation Report*.

A small sample of parents' and caregivers' many comments regarding feeling supported is presented below:

*Support! Huge support, which I don't have elsewhere.*

*[The Key Worker] was there for me to vent, bend an ear, get direction about other places to look for services.*

*The biggest thing is just to talk with her.*

*[The Key Worker] is my support. If I have a problem I can't solve, I call her and she helps me.*

*[What do I like best?] That there's support out there. Other than that, there's nothing out there for families with children. There's someone for me, even more so than for the kids.*

Several sub-themes relating to this notion of 'support for me' also may be viewed as dimensions of "best practice" for those engaging in counselling or support with individuals or families. For example, several parents/caregivers noted that: they **felt safe** talking with the Key Worker; **trusted** the Key Worker; felt the Key Worker was **non-judgemental**; and appreciated that there was **confidentiality** when meeting with the Key Worker. A few parents/caregivers stated that they felt they could connect with the Key Worker, and appreciated that the Key Worker was **friendly**, **outgoing**, and **honest**. In parents' and caregivers' words:

*I can unload in such a safe way. When I get so frustrated and upset I can call [Key Worker] and she will help me work through it. Sometimes I call her in tears and she walks me through a plan to help my distress.*

*It has been wonderful to have a safe place to take my frustrations. [The Key Worker] is both safe and knowledgeable. I can't talk with social workers about my parenting frustrations. So having [Key Worker] was wonderful.*

*The office is confidential, which is important. …I feel it's really important to make it safe for birth parents to come forward.*

*I feel comfortable with the [Key Worker].*

*I have a lot of trust in the Key Worker.*

*[The Key Worker} is friendly, easy going, has a positive outlook, and is brutally honest.*

**Family-centred practice**

Also central among the overarching themes of what parents and caregivers liked most was that Key Workers used a family-centred model of practice in providing them with support, advocacy and information/education. Although only one parent used the term 'family-centred', the parents and caregivers spoke clearly about the following elements of this approach, each of which were of considerable importance to families:

Letting families determine the agenda

*She asked me what I needed.*

*She phoned me and asked 'What can I do to help?'*

*She helps me to stand back and decide what are the priorities. Every one of the specialists has his or her own view, but [the Key Worker] helps me identify what is important for me and [my children].*

*What I love about the program: it's completely family-centred. She asks: 'What can I do for you?' Last month I was the only one who showed up at the parent support group. She asked me what I wanted or needed. That's awesome! It's accommodating. You're so used to fighting for things. Then this is like, 'wow'!*

Respectful of parents and their knowledge and expertise about their children

*He respects parents' point of view in what will and won't work with a child.*

*The Key Worker respects parents as "experts" on their children.*

Strengths-based approach

*The Key Worker starts off by telling parents what they are doing right.*

Accessible, flexible and responsive to the family's needs:

*She helps me focus on me, on my self-care.*

*The Key Worker is very responsive – flexible – and is able to pick up on whatever my needs are.*

*The Key Worker is available, flexible and accessible. She follows MY schedule.*

*[The Key Worker} was able to push boundaries a bit in terms of what she was able to do and whom she was able to work with. I think this is a strength of the program.*

*[The Key Worker] has been supportive, resourceful, and helpful. It's huge for me to have some like [Key Worker] available. Knowing that she is there for support; she is so available through phone or e-mail.*

Use of an outreach approach

*She comes to the house, or meets me anywhere I want.*

*She calls me to check on me.*

Follows through

*It's very accessible. [The Key Worker] follows through on everything. She's very flexible. The Parent Support group is always responsive to our input and feedback and ideas and suggestions.*

**Provides advocacy and service navigation**

In addition to liking the support provided by the Key Worker, parents and caregivers spoke about valuing the advocacy and assistance that their Key Worker provided them. With regard to advocacy,

parents/caregivers stated that they appreciated the Key Worker's efforts in trying to find resources for their family (e.g. programs, activities and funding support to enable their child(ren) to participate in programs). Parents and caregivers also emphasized how much they appreciated their Key Worker's presence at meetings with other professionals, especially case conferences at school. In parents' and caregivers' words:

> *[The Key Worker] asked me what my needs were, what would be of benefit. I wanted the school staff to understand how children with FASD think. …[The Key Worker] helps strategize and educate teachers about FASD. The more teachers understand, the more they are able to understand how to work with teens with FASD.*

> *Sunny Hill suggested karate, but I can't afford that. [The Key Worker] is trying to find the funding for this.*

> *What am I hoping for, at the school meeting? I'm hoping that [the Key Worker] can explain better than me what my granddaughter needs. I'm hoping that there's someone to back me up. I can connect with [the Key Worker]. She understands what I'm saying.*

Several parents/caregivers also said that they valued their Key Worker's help in setting up appointments with professionals. Along these lines, a few parents spoke of the importance of their Key Worker's assistance in facilitating the CDBC assessment. According to at least one parent, having a Key Worker to support her family through the assessment process helped ensure that the child and family completed the assessment.

> *It really helps to have someone just for me, to help with phone calls, get information, help set up appointments.*

> *[The Key Worker] went with me to the first interview of the assessment process. He assisted in answering questions and had information that he could provide in a language that doctors understand. He was a translator, and was supportive. Without his presence at the first [assessment] interview, we may have been stopped and not got into the assessment.*

**Provides relevant information and education**

In addition to and intertwined with the themes of support and advocacy, parents and caregivers stated that they loved receiving information from the Key Worker, which they emphasized was highly useful and relevant. Parents/caregivers appreciated information about FASD as a neuro-behavioural disability, and about various strategies, tips, or environmental accommodations that they could try with their child(ren).

> *[The Key Worker] sends me FASD materials on line, which is useful.*

> *[The Key Worker] have me a book that was so relevant to my own life.*

> *She gives me information about conferences and training in the community.*

*She gives me an incredible amount of information that I can utilize. It's calming to know that someone is there.*

*[The Key Worker] provides examples of what may or may not work with children rather than prescribing what has to be done.*

Parents/caregivers whose Key Worker had been part of the CDBC assessment process also valued the worker's involvement as a educator, 'interpreter', and 'sounding board':

*She is a generalist whereas everyone else is a specialist. I get her to review assessments and other information. She is a sounding board for me. She also helps connect what all the other assessments are about.*

*[The Key Worker] is knowledgeable and speaks in layman's terms. She can interpret the child's behaviours.*

Also, as reflected in some of the comments above, parents appreciated the educative role that Key Workers assumed in meetings with multi-disciplinary professionals. Parents recognized that when the community's understanding of FASD was enhanced, their family, along with others, benefited directly.

**Promotes connecting and sharing information with other parents/caregivers**

Finally, several parents/caregivers said that what they liked most about the program was sharing information with other families, and feeling a sense of connection with others who were going through similar issues and experiences.

*The parent network, community events for FASD have been incredibly helpful.*

**Dissatisfaction with the Key Worker Program**

A noteworthy finding was that across all communities there were very few parents or caregivers who identified anything that they did not like about the Key Worker or parent support program.

Comments regarding dissatisfaction focussed on the need for more Key Worker time and/or additional Key Workers in the community, in order to eliminate the time families waited for help. In addition, comments noted the importance of a strong relationship between the Key Worker and the schools, so that families could access all available supports and resources in the classroom and school environment.

**What parents and caregivers would change about the program**

Relatively few parents/caregivers had suggestions for ways to change or improve the Key Worker and Parent Support program. Of the handful of suggestions that were offered, the primary theme that emerged came from parents/caregivers in the North, who emphasized the need for stronger follow–up support from Key Workers, following the CDBC assessment. In parents'/caregivers' words:

> *My relationship with the Key Worker is basically as waitlist manager, not as a person who provides emotional or practical support.*

Interestingly, parents' and caregivers' other suggestions can be linked to the themes that emerged in the agency questionnaire data as program challenges. These included:

- 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.

# SECTION 8 DISCUSSION AND RECOMMENDATIONS

*"The simplicity of the idea of key working stands in stark contrast to the complexity of implementation."* (Drennan, Wagner, Rosenbaum. 2005. p. 3)

The *Time 1 Formative Evaluation Report* highlighted the early stages of the Key Worker and Parent Support program implementation. As noted in that report, the program was an ambitious undertaking, given the unique nature of the program in Canada and the province wide implementation. Based on the first year of operation, a number of strengths and successes of the early implementation were noted. As well, the Time 1 report offered a number of recommendations that were intended to strengthen the program. These recommendations are presented below along with a brief comment as to their status. This update is followed by a discussion of the Time 2 findings. Together, the discussion and companion recommendations summarize the ongoing achievement of formative outcomes and suggest areas that could be strengthened.

**Update on Time 1 Recommendations**

> **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.

**Update:** The first three recommendations have been addressed by the MCFD Provincial Office, through the development of the draft Program Standards for the Key Worker and Parent Support program(MCFD, September 2007). Clarification of the Key Worker's role, function and framework for practice was included in the draft document which was reviewed at regional meetings with staff from agencies holding Key Worker and Parent Support contracts, and with MCFD regional managers with responsibility for the

program area. The program standards acknowledge the need for flexibility to adapt to regional variations throughout the Province. It is expected that the draft standards will be finalized an approved early in 2008.

> **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.

**Update:** The Key Worker role definition has been included in the draft Program Standards. Once these standards are finalized, it is expected that agencies delivering Key Worker services will review and update their Key Worker job descriptions and program brochures to ensure they reflect the newly developed standards.

> **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.

**Update:** As discussed in Section 6 of this report, where possible, the additional funding allocated for the 2007/2008 fiscal year was used to top up the Key Worker positions to create full time positions. Overall the number of Key Worker FTEs increased throughout the province, and some agencies reported that increasing positions to full time helped to attract qualified candidates and to reduce staff turnover.

> **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.

**Update:** Level 1, (i.e., Introductory) training regarding FASD was offered in the fall 2007 for new Key Workers, their supervisors and community partners. This training has contributed to a clearer sense of the role and functions of the Key Worker positions and to the development of a common understanding of FASD as a neuro-behavioural brain based disability.

> **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.

**Update:** Regional Coordination roles were in place in four of the five regions in the province. Key Workers reported that regional coordination played an important role in networking, education, information sharing, support and problem solving.

> **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.

**Update:** This recommendation has not been fully implemented. The rationale for Recommendation #8 was based on research results from the disabilities literature which 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). Some regions have developed strong partnerships with their colleagues in MCFD, Health and Education through a formal structure to enhance the collaboration amongst programs and services at the community level. In other regions, the collaboration was more informal and appeared to be addressing similar issues such as referral processes, follow up to CDBC assessment report recommendations, community education about FASD and Key Worker's role and so on. The value of the formalized approach is that when systemic, partnership and management issues arise, the path for problem solving and dispute resolution is clear.

> **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.

**Update:** This recommendation has been fully implemented with development of curriculum and the offering of one Level 2 Key Worker training session in the fall 2007 and a second session planned for spring 2008.

The follow up on the recommendations from Time 1 during the past year signalled valued support for the program and reflected an ongoing desire to learn and make adjustments to ensure positive outcomes. It is clear from the findings of this report that there has been continued significant progress in relation to achieving the anticipated formative outcomes as set out in the Evaluation Framework (Appendix A). Formative outcomes related to community, key workers and families will now be discussed in turn.

**Early Formative Outcomes: Community-focused**

***Communities are informed about the FASD/CDBC Support Services***

***A shared/common understanding of the role of the Key Worker is developed***

***Through involvement with the KW, service providers and community members are informed about FASD as a brain based disability***

***A locally agreed upon referral process for access to Key Worker service is developed***

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 have also engaged in efforts to provide community education regarding parallel initiatives in Health and Education, i.e., the CDBC assessment process and the Provincial Outreach Program. Community education and information sharing efforts took many forms at the regional, local, agency and individual level. 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. Moreover, with experience, networking through regional coordination mechanisms and core training, the Key Workers, along with their host agencies, community partners and parents had much greater clarity about and confidence in their roles in the community. This was in contrast with Time 1, when the evaluation found that there was confusion about the role and function of the Key Workers.

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. As noted in the Time 1 report, research indicates that effective programs have a strong theoretical base and a clearly articulated model of how interventions lead to change and positive outcomes. 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. While outcomes for children and their families related to these interventions will be discussed in more detail in the *Time 1 Summative Evaluation Report*, it is important to note that, as part of program implementation, the articulation of a theoretical framework for practice and the accompanying training to facilitate skill development have taken hold and were being applied in the field.

Nevertheless, big challenges associated with this shift in the practice framework remain. 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,

particularly the one-to-one consultation with the program's FASD Consultant, around specific cases, noted above, have contributed to progress in this area, the Key Workers and their agencies continue to need support.

Additional regional training would provide much needed support "in getting the message out" about Key Worker program and the effectiveness of environmental accommodations. An example of this type of regional training is being planned in the Interior, whereby a Level 2 community-based FASD training curriculum is being developed to follow up the earlier regional training provided in each of the Key Worker's communities. Similar to the Provincial Level 2 Key Worker training, the focus of the Interior region's proposed community based training will be on the application of environmental accommodations in practice. It is intended to be a more hands on, practice-based level of training.

In addition, in interviews for this evaluation, the Key Workers requested the availability of more specific resources and tools that they could use with families or suggest to other service providers. Ready access to resources such as teaching videos, articles, websites (e.g., for parent support), appropriate toys, tip sheets, reports of successful strategies, and so on, that demonstrate how to work with FASD as a brain based disability was identified as important, especially by the more experienced Key Workers, some of whom had begun to create their own collections. Further, this information needs to be available to a range of family constellations, including parents who themselves may have FASD.

Two recommendations arise from this discussion about the importance of supporting and promoting the developmental process leading to more effective practice with families with a child with FASD or similar neurological conditions.

> **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**.**

The Time 1 report identified the issue of program referrals as being problematic; in particular, the variable practices across the different regions raised questions of equity and accessibility. As reported in Section 4 of this report, however, 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 their 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 output data for this report also indicated that there was a greater demand for Key Worker services in the past year. These findings suggest increased community awareness about the program.

As well, data from the Annual Agency Questionnaires and interviews with Key Workers and their supervisors and managers indicated that Key Workers in many agencies were nearing or have 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. Based on evaluations of the Key Wormer program in Great Britain, Greco and colleagues (2005) found that families potentially achieve better outcomes from Key Workers in dedicated positions, but even Key Workers in non-dedicated positions can match these outcomes so long as they have a much reduced caseload, a generous allocation of time per family, and the flexibility to work within the needs and timeframe of the families they serve.

In recognition of the issues associated with workload and division of intake and key work functions, the executive directors of the North region's Key Worker agencies have created a subcommittee to develop waitlist criteria for the programs in their region and to work through the thorny issues related to

determining how to differentiate between wait listing children for the CDBC assessment process, and accepting or wait listing families for the key worker program.

The increased demand for Key Worker services, the growing pressures of the assessment process on Key Workers' time, and the relatively small financial contribution from the Northern Health Authority, combined with parents' and caregivers' stated desire for more support post-assessment leads to the following recommendation:

> **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.

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 with CDBC diagnoses, who were referred to the Key Worker program. Output data also showed that there was considerable regional variation in these relative numbers.

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, gives 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. At present, regions and individual agencies are responding to referrals as they come, and responses on the Annual Agency Questionnaires do not identify how they decide who to accept for service and who to refer elsewhere.

Not only does the lack of clear eligibility criteria create problems for the agencies in terms of caseloads, program definition and staff training, it also makes it difficult for the evaluation to accurately assess the impact of the program through the summative evaluation process, particularly if inappropriate interventions are being used with children with a range of diagnoses.

Given the increasing demands for service, emerging waitlists and limited resources for program expansion, the following recommendation is offered:

**Recommendation #4:** That MCFD Provincial Office establish 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.

**Early Formative Outcomes: Key Worker-focused**

***Key Worker is hired***

***Key Worker is trained***

***A Key Worker network is created***

***Key Worker is connected to supervision/support (e.g. clinical supervision)***

**Intermediate Formative Outcomes: Key Worker-focused**

***Ongoing training and supervision/supports are available for Key Workers***

***Key Workers have strong relationships with families/caregivers***

The program has made the greatest strides in achieving the formative outcomes related to the Key Workers. With some qualifications, particularly in relation to Aboriginal agencies, the early outcomes listed above 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.

Nevertheless, the Vancouver Coastal and Vancouver Island regions have experienced high rates of Key Worker turnover. Moreover, difficulty finding qualified staff to replace staff who leave, especially in some of the Aboriginal agencies, has hampered program implementation in those communities. The literature indicates that, in order to decrease the likelihood of staff turnover: (1) wages should be increased to at least threshold levels (based on local economic models); (2) sufficient effort should be made to match the applicant's skills to the position; and (3) within-agency support and supervision should be provided for the staff (Ghere & York-Barr, 2007). Findings in the current evaluation indicate that there is merit to these suggestions.

Due the significant turnover in staff throughout most of the province, the following recommendation is offered:

> **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.

As discussed in the findings, the Regional Coordinator positions or mechanisms have 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). To date, the Vancouver Coastal region does not have a formal mechanism in place for regional coordination. Nevertheless, a group of Key Workers in the region have taken the initiative to meet on a regular basis and provide support to one another. While this is a very laudable endeavour, those agencies in the more isolated communities in Vancouver Coastal that are struggling to acquire and maintain staff have not participated, and thus have not had the benefit of the support and networking that could contribute to staff retention.

> **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.

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.

Clinical supervisors function to provide: (1) quality control (including standards of practice and ethics); (2) maintenance and facilitation of supervisees' competence; and (3) development of the supervisees' professional efficacy (including development of personal coping, critical reflection skills and enhanced self-reflection) (Milne, 2007). Many academic programs in the health and social services do not provide clinical supervision as part of the degree criteria and thus, many Key Workers and their supervisors may

not have had prior exposure to this process. Proper clinical supervision allows the supervisee to practice in a safe and empathetic environment that provides the necessary ethical practice boundaries required when providing services to individuals and families with high needs.

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. In practical terms, individuals without the necessary academic and experiential background in a particular domain (e.g., social work, psychology) should not provide clinical supervision in that area. This view is supported by the Draft Key Worker Program Standards. When an on-site supervisor in a particular domain 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.

An additional finding was that many of the supervisors - clinical and administrative - had not had any training in the area of FASD, let alone participated in the Key Worker training. This raises concerns that some Key Workers may not be receiving adequate supervision related to effective interventions with brain-based disabilities. It also suggests that many were not aware of the MCFD Provincial Office's financial support for clinical supervisors to attend the provincial Level 1 and Level 2 training.

There are two recommendations related to clinical supervision. The first addresses the need for Key Workers to understand what clinical supervision is and how to make use of it. The second it intended to support the participation of clinical supervisors in the training and networking opportunities that exist for Key Workers.

> **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.

Finally, with regard to the intermediate formative outcome that *Key Workers have strong relationships with families/caregivers*, 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. Thus there is no recommendation in relation to this discussion.

**Early Formative Outcomes: Family-focused**

**Families/caregivers are engaged in working with KW**

**Families/caregivers are informed about existing services and resources in the community**

**Families/caregivers are informed about their child's assessment/diagnosis findings**

**Information about FASD/CDBC and other related topics is available and accessible for families/caregivers**

Families/caregivers are engaged with Key Workers in most of the 57 communities where there are contracts to deliver services. Parents reported being very happy with the Key Worker and Parent Support program. During interviews, parents highlighted the program's flexibility, accessibility and responsiveness. Indeed, parents' and caregivers' reports of their satisfaction with the program, and their appreciation of the support provided by the Key Workers, are among the most positive and significant findings of this formative evaluation report.

Nevertheless, as pointed out in Section 4 of this report, in a number 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. During the next evaluation time period (November 2007 to December 2008), the evaluation team will attempt to engage Aboriginal Key Workers and agencies to explore more fully what is working well, as well as the challenges and barriers to delivering the Key Worker and Parent Support program as it was envisioned.

Certainly where services and resources existed in communities, parents and caregivers were informed about them and received assistance from Key Workers in accessing them. However receiving information about services did not necessarily mean that parents could access the services, or that they were satisfied with the services offered. The education system presented the greatest challenges for many of the parents/caregivers and Key Workers interviewed for the evaluation, though 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.

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. While it is not within the scope of this evaluation to propose additional services, it is worth noting that other evaluations related to the provision of wraparound services to children and families affected by FASD in Alaska found that parents had expressed the same need for respite and individual support for their child(ren) (Hume et al, 2006). 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.

In terms of the early outcome regarding families having obtained accessible information about FASD/CDBC and other related topics, the parent/caregiver interviews showed that families were very pleased with the information they had received from their Key Worker. If implemented, Recommendation #2, above, will ensure acquisition and access to useful resources not only for Key Workers but also for parents and caregivers.

With regard to the early outcome that parents 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. Bearing in mind that not all families involved in the Key Worker program take part in the assessment process, and that availability of the Key Worker and Parent Support program is not based on having a completed assessment, we offer the following recommendation:

> **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.

Finally, while it may be premature to provide lengthy discussion on progress in achieving intermediate formative outcomes relating to families, drawing on findings from parent and caregiver interviews, brief discussion of two intermediate outcomes: *Families/caregivers are satisfied with the support they receive* and *Families/caregivers feel helped* is warranted. Parents and caregivers overwhelmingly reported that they were satisfied with the support they received from the program, and their comments reflected their perceptions of feeling helped. The various ways in which they were helped, and outcomes relating to the support, information/education and advocacy provided by the Key Worker is the purview of the summative evaluation and will be discussed more fully in the upcoming *Time 1 Summative Evaluation Report*.

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# APPENDICES

# APPENDIX A
# KEY WORKER & PARENT TO PARENT SUPPORT SERVICES
# EVALUATION FRAMEWORK

## *Goals*

- *To maintain and enhance the stability of families with children and youth with FASD/CDBC in order to improve the children's long term outcomes*
- *To increase the knowledge of parents and professionals about the neurological nature of conditions such as FASD so that affected children and youth experience less frustration and more success*
- *To ensure that families with children and youth with FAS/CDBC have an ongoing network of support*

## *Formative Outcomes*

| Outputs | | Outcomes | | |
|---|---|---|---|---|
| Activities | Participation (Reach) | Early | Intermediate | Long Term |
| *Key Worker activities*<br><br>Liaise with regional multi-disciplinary assessment team<br>Support families/caregivers through the assessment/ diagnostic process<br>Assist families/caregivers in following through with recommendations of the assessment<br>Assist families to coordinate their care, both within the healthcare system, and across systems<br>Provide advocacy and assist families in accessing existing family support, health and education services | Families/caregivers of children with FASD/CDBC<br><br>Multi-disciplinary service providers involved in FASD/CDBC assessment<br><br>Multi-disciplinary service providers involved in follow-up accommodations (e.g. school, community recreation staff, social workers, legal/justice system workers, etc.) | *Community*<br><br>Communities are informed about the FASD/CDBC Support Services<br><br>A shared/common understanding of the role of the Key Worker is developed<br><br>A locally agreed upon referral process for access to Key Worker service is developed<br><br>Through involvement with the KW, service providers and community members are informed about FASD as a brain based disability<br><br>*Key Worker* | *Community*<br><br>Increased collaboration amongst service providers, and between service providers and family members<br><br>Communities develop a consistent approach to working with children with FASD/CDBC<br><br>*Key Worker* | Shift in practice from Learning Model to neuro-behavioural approach<br><br>Use of an FASD lens when developing programs' goals, philosophies, and best practice approaches<br><br>Knowledge and experience regarding best practices are shared<br><br>Families/caregivers advocate for themselves |

| Outputs | | Outcomes | | |
|---|---|---|---|---|
| Activities | Participation (Reach) | Early | Intermediate | Long Term |
| education services<br><br>Provide information and support to families/ caregivers and to multi-disciplinary service providers and other community members | | Key Worker is hired<br>Key Worker is trained<br><br>A Key Worker network is created<br><br>Key Worker is connected to supervision/support (e.g. clinical supervision)<br><br>*Families*<br><br>Families/caregivers are engaged in working with KW<br><br>Families/caregivers are informed about existing services and resources in the community<br><br>Families/caregivers are informed about their child's assessment/diagnosis findings<br><br>Information about FASD/CDBC and other related topics is available and accessible for families/caregivers | Ongoing training and supervision/supports are available for Key Workers<br><br>Key Workers have strong relationships with families/caregivers<br><br>*Families*<br><br>Meetings involving families/caregivers, Key Worker and other clinicians/service providers are accessible and family friendly (i.e., supports are in place to enable families/caregivers to participate)<br><br>Families/caregivers feel respected and are treated as partners by clinicians/service providers<br><br>Families/caregivers are satisfied with the support they receive<br><br>Families/caregivers feel helped | |

| Outputs | | Outcomes | | |
|---|---|---|---|---|
| Activities | Participation (Reach) | Early | Intermediate | Long Term |
| | | | Key Worker services are responsive to families'/caregivers' individual needs | |
| *Parent to parent support activities*<br><br>Establish and maintain mutual aid support networks, including parent-to-parent support groups | Families/caregivers of children with FASD/CDBC | *Families*<br><br>Parents/caregivers are engaged as support people/mentors to other parents/caregivers<br><br>Information about FASD/CDBC and other related topics is available and accessible for parent to parent support people/groups | *Families*<br><br>FASD/CDBC-specific parent support mechanisms (e.g., groups, buddy system, phone line, list serve) are formed<br><br>Families/caregivers are connected to parent support mechanisms (e.g., groups, buddy system, phone line, list serve)<br><br>FASD/CDBC-specific parent support groups meet and/or connect by phone or electronically on a regular basis | *Families*<br><br>Parents/caregivers continue to be engaged as support people/mentors to other parents<br><br>Parent to parent support groups are self-sustaining |

## *Summative Outcomes*

| Outputs | | Outcomes | | |
|---|---|---|---|---|
| Activities | Participation (Reach) | Early | Intermediate | Long Term |
| *Key worker activities*<br><br>Liaise with regional multi-disciplinary assessment team<br><br>Support families/caregivers through the assessment/ diagnostic process<br><br>Assist families/caregivers in following through with recommendations of the assessment<br><br>Assist families to coordinate their care, both within the healthcare system, and across systems<br><br>Provide advocacy and assist families in accessing existing family support, health and education services<br><br>Provide information and support to families/ | Families/caregivers of children with FASD/CDBC<br><br>Multi-disciplinary service providers involved in FASD/CDBC assessment<br><br>Multi-disciplinary service providers involved in follow-up accommodations (e.g. school, community recreation staff, social workers, legal/justice system workers, etc.) | *Communities*<br><br>Professionals and/or community people working with the child can identify the child's strengths<br><br>Professionals and/or community people working with children/ families are informed about the child's/family's needs<br><br>Professionals and/or community people working with families with FASD feel part of a network<br><br>*Families/Children*<br><br>Families/caregivers are able to identify strengths of their child<br><br>Families/caregivers understand their child's specific challenges and needs (e.g. primary and secondary disabilities)<br><br>Families/caregivers understand the assessment/diagnostic findings and its recommendations | *Communities*<br><br>Care/service/educational plans identify informed, environmental accommodations<br><br>Schools and service providers make accommodations in the environment according to the individual needs of the children<br><br>Multi-disciplinary service providers and/or community members learn new skills in working with children and youth with FASD/CDBC and their families/caregivers<br><br>*Families/Children*<br><br>Families/caregivers and service providers have a common understanding of FASD as a brain-based disability | *Communities*<br><br>Use of an FASD lens when developing programs' goals, philosophies, and best practice approaches<br><br>*Families/Children*<br><br>Families/caregivers have a strong social/support network |

| Outputs | | Outcomes | | |
|---|---|---|---|---|
| Activities | Participation (Reach) | Early | Intermediate | Long Term |
| caregivers and to multi-disciplinary service providers and other community members | | Families/caregivers understand FASD as a brain-based disability<br><br>Families/caregivers feel less stressed | Families/caregivers are connected to community resources appropriate to their needs.<br><br>Families/caregivers have confidence in their parenting<br><br>Families/caregivers are socially connected and have support systems<br><br>Families/caregivers feel less stressed<br><br>Children's secondary disabilities are reduced<br><br>Children feel less stressed | Children's secondary disabilities are reduced |
| *Parent to parent support activities*<br><br>Establish and maintain mutual aid support networks, including parent-to-parent support groups | Families/caregivers of children with FASD/CDBC | *Families/Children*<br><br>Families/caregivers are able to identify strengths of their child<br><br>Families/caregivers are able to identify FASD/CDBC related behaviours that are problematic<br><br>Families/caregivers understand FASD as a brain-based disability | *Families/Children*<br><br>Families/caregivers are socially connected and have support systems<br><br>Families/caregivers have confidence in their parenting<br><br>Families/caregivers use parenting skills and | *Families/Children*<br><br>There is (increased) family stability (i.e., fewer family breakdowns and/or breakdowns in adoption or foster placements)<br><br>Children's secondary disabilities are reduced |

| Outputs | | Outcomes | | |
|---|---|---|---|---|
| Activities | Participation (Reach) | Early | Intermediate | Long Term |
| | | | approaches grounded in knowledge about FASD/CDBC<br><br>Families/caregivers feel less stressed<br><br>Children's secondary disabilities are reduced | |

# APPENDIX B

# SUMMARY OF DATA COLLECTION METHODS

## Summary of Data Collection Methods for Time 2

| **Province Wide Data Collection** | | | | |
|---|---|---|---|---|
| ***Information to be collected*** | ***Intended Respondent*** | ***Completed by whom*** | ***Implementation Date*** | ***Time Frame*** |
| **Output data**<br>• Demographic info<br>• Referral info<br>• Program info | All Key Worker Agencies | Key Worker agency staff | Commencing November, 2006 | Monthly, as per MCFD requirements |
| **Agency questionnaire** | All Key Worker Program Managers | Key Worker Program Manager | Due October 31, 2007 | Submitted to Evaluation Team annually |
| **Parent/Caregiver Questionnaire** | All Parents/ Caregivers | Parents/ Caregivers, with assistance from KW agency staff, as needed | Commencing December 2006 and ongoing throughout the evaluation | At intake (Time 1), and upon exiting program or annually (Time 2) |
| **In-depth evaluation in a sample of 10 communities** | | | | |
| ***Information to be collected*** | ***Intended Respondent*** | ***Completed by whom*** | ***Implementation Date*** | ***Time Frame*** |
| **Interviews and/or focus groups with**:<br>• Youth with FASD/CDBC<br>• Parents/caregivers<br>• Community service providers<br>• Key Workers<br>• Program Managers<br>• Clinical Supervisors<br>• MCFD Managers | In 10 BC communities, a sample of: Youth with FASD/CDBC; Parents/ caregivers; Community service providers; Key Workers; and MCFD Managers | Evaluation team | Commencing September 2007 through to November 2007 | Annually |

# APPENDIX C

# ANNUAL AGENCY QUESTIONNAIRE

## ANNUAL AGENCY QUESTIONNAIRE

The following questionnaire is designed to capture information about the agencies offering Key Worker and Parent Support programfor Families of Children with FASD and other CDBC and about the program inputs and activities. Please only provide information specific to **Key Worker and Parent-to-Parent Support Services program**. The questionnaire is to be completed ***annually***, beginning in the winter 2006 by each agency contracted by MCFD to deliver the Key Worker and Parent Support Program.

We are recommending that a program manager with knowledge of the program and its budget complete this questionnaire.

If you have any questions or wish to discuss any items on this questionnaire please contact any one of us:


| | | |
|---|---|---|
| Sharon Hume | sharhume@shaw.ca | 250 592-4822 |
| Carol Hubberstey | carolmarie@shaw.ca | 250 595-3469 |
| Deborah Rutman | drutman@uvic.ca | 250 370-6087 |


---

Date:

| *D* | *M* | *Y* |
|---|---|---|
| | | |

1. Full Name of Organization/Agency: □ □ □ □ □ □ □ □ □ □ □ □ □ □ and Contact person's name and email address _____

2. Community: □ □ □ □ □ □ □ □ □ □

3. MCFD Region:

- ☐ North
- ☐ Interior
- ☐ Fraser
- ☐ Vancouver Coastal
- ☐ Vancouver Island

**Background information**

4. Is your organization: (please check appropriate box)

- ☐ Non profit society
- ☐ For profit organization
- ☐ Part of a larger organization or local governance organization such as Band Council, Health region: Please specify □ □ □ □ □ □ □ □ □ □
- ☐ Other _____

5. Is your organization an accredited agency with:

- ☐ The Commission on Accreditation of Rehabilitation Facilities (CARF)
- ☐ Council on Accreditation for Children and Family Services (COA)
- ☐ Accreditation pending
- ☐ Other □□□□□□□□□□□□□□□
- ☐ Not accredited

**PROGRAM MILESTONES, STRENGTHS AND CHALLENGES**

6. What do you see are the **key components** of the Key Worker's role? Feel free to answer in point form.

_____
_____
_____
_____
_____
_____

7. What do you think are the **strengths and/or successes** of the Key Worker and Parent-to-Parent Support Services?

_____
_____
_____
_____

8. What are some of the **challenges** you have faced in implementing the Key Worker and Parent-to-Parent Support Services in the second year?

_____
_____
_____
_____

9. How have the Key Worker and Parent-to-Parent Support Services impacted your agency and the other programs and services you offer?

_____
_____

_____
_____

10. Please describe any suggestions you have for how the services could be improved.

_____
_____
_____
_____

11. What are some **key milestones** for the service in your community during the second year of program implementation?

_____
_____
_____
_____

**KEY WORKER INPUTS**

**Funding**

12. What is the term of your contract with the Ministry of Children and Family Development?

__ 1 year __ 2 years __ 3 years __ over 3 years

13. What is the annual amount of funding you receive from MCFD for the Key Worker and/or Parent-to-Parent Support Services?

Year 1 $_____ Year 2 $ _____ Year 3 $_____

14. Please provide information about the budget for the Key Worker and/or Parent-to-Parent Support Services for the **fiscal year 2007/2008**

| Category | Budget 2007/08 | Any comments? |
|---|---|---|
| Key Worker Salary & Benefits | | |
| Supervision | | |
| Parent-to-Parent Supports costs | | |
| Clerical Support | | |
| Communications | | |
| Travel | | |
| Office Supplies | | |
| Rent | | |
| Activities/Resources | | |
| Administration | | |
| Other | | |

15. Did you receive an increase in funding for 2007/2008?

☐ Yes

☐ No

☐ Not applicable (i.e. did not have a contract in 2006/2007)

16. Are you receiving funding for the Key Worker and/or Parent-to-Parent Support Services from elsewhere (i.e. a funding source other than MCFD)?

__ Yes __ No

17. If yes, from where, and how much?

From:_____ Amount $_____

18. Is your agency (or other agencies) making an in-kind contribution to the Key Worker and/or Parent-to-Parent Support Services?

__ Yes __ No

19. If yes, has the amount of in kind support increased since 2006/2007?

☐ Yes

☐ No

☐ Not applicable (i.e. did not have a contract in 2006/2007)

Please explain the reasons for the increase or decrease. _____

_____

_____

_____

20. Please indicate the value of the in-kind support for the Key Worker/ Parent Support services in the following categories:

| Category | Value of In-Kind Support 2007/08 | Any comments? |
|---|---|---|
| Administration | | |
| Supervision | | |
| Clerical Support | | |
| Office/meeting space | | |
| Training | | |
| Materials/resources | | |
| Transportation | | |
| Child Care | | |
| Consultation | | |
| Other | | |

21. Have there been any issues with regard to funding? Please provide details.

_____

_____

_____

**STAFFING**

22. How many Key Workers currently work in your organization? Please indicate the number of FTEs or the proportion of an FTE, e.g., 1.0 FTE; 0.25 FTE.

_____

_____

23. Has there been a change in the number of FTEs allocated to the Key Worker position?

- ☐ An Increase from _____ FTE to_____FTEs
- ☐ A decrease from ___ _____FTE to _____ FTEs

If there has been a change, please explain reason why

_____

_____

24. What are the qualifications of the Key Workers in your organization? Please indicate the number of Key Workers with the following qualifications.

- ☐ BSW
- ☐ BSN/BN
- ☐ MSW
- ☐ MSN/MN
- ☐ BA
- ☐ MA
- ☐ Other □ □ □ □ □ □ □ □ □ □ □ □ □ □ □

25. Within your agency are the Key Worker(s) in dedicated Key Worker positions or do they have other duties in addition to those associated with the Key Worker role (i.e., more diverse caseload)?

__ Dedicated Key Worker __ Part of larger caseload or other duties

26. Has the role/duties of the Key Worker position changed in the past year? If so, please explain.

_____

_____

27. Please describe the duties of the Key Worker, other than those associated with the Key Worker role.

_____

_____

***For dedicated Key Workers, please answer Question 28, then skip to Question 30:***

28. How many families is the Key Worker(s) <u>actively</u> providing Key Worker services to (e.g. average caseload for Key Worker)? _____

***Key Workers with additional roles or duties:***

29. How many families is the Key Worker actively providing Key Worker services to (e.g. average caseload for Key Worker)? _____

30. Does the Key Worker also provide the Parent-to-Parent Support Services?

__ Yes __ No

31. For each Key Worker in your agency, on average, what percentage of their time do they spend on Parent-to-Parent Support Services? ____%

32. If the Key Worker does not provide Parent-to-Parent Support Services, who provides these services in your agency? Indicate the **number** of staff, volunteers, or "others" who provide the services. Complete all that apply.

__ Staff member(s) _____(title(s))

__ Volunteer(s)

__ Other _____

__ N/A

33. What are the qualifications of this/these person/people?

_____

34. On average, how many hours a week does this person (people) spend facilitating Parent-to-Parent Support services?

_____ hours

35. Have there been any changes in the Key Worker staff since the program began?

__ Yes __ No

36. How many Key Workers have occupied the position since your agency first hired a Key Worker? (we are trying to assess the rate of Key Worker turnover here) _____

37. Reason for changes

_____

_____

38. Have there been any changes in the Parent-to-Parent Support staff since April 1, 2006?

__ Yes __ No

39. Reason for changes

_____

_____

40. Do you have any vacant Key Worker positions at this time?

__ Yes __ No

41. If so, how many positions are vacant?

__ positions

42. How long has the position(s) been vacant?

__ weeks

43. How is/are the Key Worker(s) supervised?

_____

_____

_____

44. Who provides the supervision? (name, title) _____

45. How often does the Key Worker meet with her/his supervisor?

46. What are the supervisor's qualifications?

- ☐ BSW
- ☐ BSN/BN
- ☐ MSW
- ☐ MSN/MN
- ☐ BA
- ☐ MA
- ☐ Other_____
- ☐ Additional certification (e.g., AAMFT Supervisor etc.) _____

47. Is any training provided for the Key Worker upon appointment?

__ Yes __ No

48. If yes, please provide a description of this training. (Feel free to attach any relevant descriptions.)

_____
_____
_____

49. Is ongoing training provided for the Key Worker?

__ Yes __ No

50. If yes, please provide a description. (Feel free to attach any relevant descriptions.)

_____
_____
_____

51. If the person delivering the Parent-to-Parent Support Services is different from the Key Worker, is there any training provided for the Parent-to-Parent Support person upon appointment?

__ Yes __ No

52. If yes, please provide a description. (Feel free to attach any relevant descriptions.)

_____
_____
_____

53. Is ongoing training provided for the Parent-to-Parent Support person?

__ Yes __ No

54. If yes, please provide a description. (Feel free to attach any relevant descriptions.)

_____
_____
_____

55. Has the Key Worker's supervisor attended any training in relation to provision of Key Worker services to children and families affected by FASD/CDBC?

__ Yes __ No

56. If yes, please provide a description. (Feel free to attach any relevant descriptions.)

_____
_____
_____

**Referral Process**

57. Please describe how families are referred to the Key Worker program in your agency. (Please attach any written information about the referral process).

_____
_____
_____

58. On average, how long does a family wait to be assigned to a Key Worker once the referral has been received? _____days

59. Is there a waiting list of families referred to the Key Worker?

__ Yes __ No

60. If you have a waiting list, what happens to families while they are on the waiting list?

_____
_____

61. Is there a waiting list of families for Parent-to-Parent Support Services?

__ Yes __ No

62. If you have a waiting list, what happens to families while they are on the waiting list for Parent-to-Parent support?

_____
_____
_____
_____

63. On average, how long does a family wait to access Parent-to-Parent Support Services? ____ days

64. Do families have a choice as to who their Key Worker is?

__ Yes __ No __ N/A

65. If there is more than one Key Worker in your agency, how are Key Workers and families matched?

_____
_____
_____

66. Do Key Workers regularly visit families in the home?

__ Yes __ No

67. From April 1 to September 30, 2007, how many families have been referred for Key Worker services but did not receive services because they did not respond to calls to set up appointments? _____

68. From April 1 to September 30, 2007, how many families have been referred for Key Worker services but did not receive services because they made appointments but did not show up? _____

69. From April 1 to September 30, 2007, of the total closed files for Key Worker services, what number have been closed because the families have stopped attending appointments and/or discontinued services for unknown reasons, i.e., are not responding to contacts or the Key Workers is now unable to locate the client?

Total files closed_____

# of families that have discontinued service for unknown reasons _____

**CDBC CLASSIFICATION**

70. How many children have been referred to the Key Worker with a classification of CDBC other than FASD? _____

71. Of the children who have been referred with a CDBC classification, what diagnosis have they received? (e.g. acquired brain injury, Fragile X, dual diagnosis – specify – etc). Please list:

_____
_____
_____
_____

**ACCREDITATION REPORTING**

72. If your agency is accredited, what information about the Key Worker and/or Parent Support Services are you collecting and reporting for accreditation purposes? Please provide samples of your reports if possible.

_____

_____

_____

_____

_____

73. Do you have any additional comments?

_____

_____

_____

**Please attach a copy of the Key Worker's job description.**

**THANK YOU FOR COMPLETING THIS QUESTIONNAIRE!**

# APPENDIX D

# AGENCIES COMPLETING TIME 2 ANNUAL AGENCY QUESTIONNAIRE

# Agencies that Completed Time 2 Annual Agency Questionnaires.

| | Agency Code | Agency /Contract |
|---|---|---|
| **Fraser Region** | | |
| 1 | A01 | BC Centre for Ability - Burnaby |
| 2 | A02 | Delta Association for Child Development - Delta |
| 3 | A03 | Fraser Valley Child Development Centre – Abbotsford |
| 4 | A04 | Fraser Valley Child Development Centre – Mission |
| 5 | A05 | Fraser Valley Child Development Centre – Chilliwack |
| 6 | A06 | Pacific Community Resources Society - Surrey |
| 7 | A08 | Peach Arch Community Services – White Rock |
| 8 | A 09 | Lower Mainland Purpose Society – New Westminster |
| 9 | A12 | Ridge Meadows Child Development Centre – Maple Ridge/Pitt Meadows |
| **Interior Region** | | |
| 10 | B01 | ARC Program |
| 11 | B02 | Cariboo Chilcotin Child Development Centre |
| 12 | B03 | Cariboo Family Enrichment Centre |
| 13 | B05 | NONA Child Development Centre |
| 14 | B06 | Penticton District Community Resources Society |
| 15 | B08 | Freedom Quest Regional Youth Services |
| 16 | B09 | Okanagan Metis Children and Family Services - Kelowna |
| **North Region** | | |
| 17 | C01 | Axis Family Resources Ltd. – Prince Rupert |
| 18 | C02 | Axis Family Resources Ltd. – Dawson Creek |
| 19 | C03 | Axis Family Resources Ltd. – Quesnel |
| 20 | C04 | College of New Caledonia – Burns Lake |
| 21 | C05 | Bulkley Valley Child Development Centre Smithers |
| 22 | C06 | Child Development Centre of Fort St John |
| 23 | C09 | Northern Family Health Society – Prince George |
| **Vancouver Coastal Region** | | |
| 24 | D01 | Vancouver Native Health Services - Vancouver |
| 25 | D02 | Hollyburn Family Services – West Vancouver |
| 26 | D03 | Powell River Association for Community Living |
| 27 | D04 | Sea to Sky Community Resources - Squamish |
| 28 | D05 | Sunshine Coast Community Service Society |
| 29 | D07 | Touchstone Family Association - Richmond |
| 30 | D08 | YWCA Crabtree Corner – Vancouver |
| 31 | D09 | Connexus Family & Children Services - Vancouver |
| 32 | D14 | The Children's Foundation - Vancouver |
| **Vancouver Island Region** | | |
| 33 | E01 | Campbell River and District Association for Community Living |
| 34 | E02 | Cowichan Valley FASAT Society - Duncan |
| 35 | E03 | Dist 69 Family Resources Association - Qualicum |
| 36 | E04 | FASD Community Circle - Victoria |

| | Agency Code | Agency /Contract |
|---|---|---|
| 37 | E05 | Metis Society - Victoria |
| 38 | E06 | Nil/Tu,O Child and Family Services Society - Saanich |
| 39 | E08 | Victoria Native Friendship Centre - Victoria |
| 40 | E09 | Wachiay Friendship Centre - Courtney |
| 41 | E10 | West Coast Resources Society - Ucluelet |
| 42 | E12 | MCFD - Nanaimo |

# APPENDIX E

# TEMPLATE FOR 2007/2008 OUTPUT REPORTING

# KEYWORKER EVALUATION OUTPUT DATA TEMPLATE

**Agency:**
**Contract Number:**
**Community:**
**Contact person:**

**For the Evaluation please provide data for items 1 to 18.**
The additional data fields, items 19 to 28, are for your own records.

| | Reporting Indicators | Total | Apr-07 | May-07 | Jun-07 | Jul-07 | Aug-07 | Sep-07 | Oct-07 | Nov-07 | Dec-07 | Jan-08 | Feb-08 | Mar-08 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | | | | | | | | |
| | **Demographic information** | | | | | | | | | | | | | |
| 1 | # of male children and youth intakes | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| | 0 to 6 years | 0 | | | | | | | | | | | | |
| | 7 to10 years | 0 | | | | | | | | | | | | |
| | 11 to 15 years | 0 | | | | | | | | | | | | |
| | 16 to 19 years | 0 | | | | | | | | | | | | |
| 2 | # female children and youth intakes | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| | 0 to 6 years | 0 | | | | | | | | | | | | |
| | 7 to10 years | 0 | | | | | | | | | | | | |
| | 11 to 15 years | 0 | | | | | | | | | | | | |
| | 16 to 19 years | 0 | | | | | | | | | | | | |
| 3 | # intakes who identify as Aboriginal | 0 | | | | | | | | | | | | |
| | % intakes who identify as Aboriginal | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! |
| 4 | # intakes who identify as visible minority | 0 | | | | | | | | | | | | |
| | % intakes who identify as visible minority | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | 0.0 | #DIV/0! | #DIV/0! | #DIV/0! |
| | | | | | | | | | | | | | | |
| | **Referral and Waitlist Information** | | | | | | | | | | | | | |
| 5 | # of new family referrals received | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| 6 | # of new family referrals received from | | | | | | | | | | | | | |
| | Health Authority Assessment Team | 0 | | | | | | | | | | | | |
| | School/School District | 0 | | | | | | | | | | | | |
| | MCFD Social Worker | 0 | | | | | | | | | | | | |
| | Other Service Provider | 0 | | | | | | | | | | | | |
| | Self referral | 0 | | | | | | | | | | | | |
| | Other | 0 | | | | | | | | | | | | |
| 7 | When was the family referred to Key Worker program? | | | | | | | | | | | | | |
| | # prior to FASD/CDBC assessment by the Health Authority Assessment Team | 0 | | | | | | | | | | | | |
| | # at time of commencing the FASD/CDBC assessment process | 0 | | | | | | | | | | | | |
| | # during the assessment process | 0 | | | | | | | | | | | | |
| | # post assessment | 0 | | | | | | | | | | | | |
| | # with previous assessment (not from Health Region Assessment Team) | 0 | | | | | | | | | | | | |
| 8 | # of new family referrals with child(ren) with confirmed or probable FASD "diagnosis" | 0 | | | | | | | | | | | | |
| 9 | # of new family referrals with child(ren) following CCY/CDBC assessment (other than FASD) | 0 | | | | | | | | | | | | |
| 10 | # of new families accepted for & receiving service (intakes) | 0 | | | | | | | | | | | | |
| 11 | # of families receiving service for the first time | 0 | | | | | | | | | | | | |

| | | | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| 12 | # of families waitlisted on last day of month who have been deemed eligible for service | 0 | | | | | | | | | | | | |
| 13 | #of families receiving service within 90 days | 0 | | | | | | | | | | | | |
| | % of families receiving service within 90 days | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! |
| 14 | # of families whose files have been closed (as of the last day of the month) | 0 | | | | | | | | | | | | |
| | | | | | | | | | | | | | | |
| | **Program Data** | | | | | | | | | | | | | |
| 15 | # of families receiving individual service | 0 | | | | | | | | | | | | |
| 16 | # of parent to parent group sessions | 0 | | | | | | | | | | | | |
| 17 | # of sessions of group intervention | 0 | | | | | | | | | | | | |
| 18 | # of sessions of public / provider sessions | 0 | | | | | | | | | | | | |
| | | | | | | | | | | | | | | |
| | **Additional Agency Data** | | | | | | | | | | | | | |
| 19 | # of hours of family intervention | 0 | | | | | | | | | | | | |
| 20 | # of hours of parent to parent group sessions | 0 | | | | | | | | | | | | |
| 21 | # of attendees at parent to parent group sessions | 0 | | | | | | | | | | | | |
| 22 | average number of attendees at parent to parent group sessions | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! |
| 23 | # of hours of group intervention sessions | 0 | | | | | | | | | | | | |
| 24 | # of attendees of group intervention sessions | 0 | | | | | | | | | | | | |
| 25 | average number of attendees at group session | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! |
| 26 | # of hours of public / provider sessions | 0 | | | | | | | | | | | | |
| 27 | # of attendees of public / provider sessions | 0 | | | | | | | | | | | | |
| 28 | average number of attendees per public/provider sessions | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! | #DIV/0! |

# DEFINITIONS OF INDICATORS FOR EVALUATION OUTPUT DATA

**For the Evaluation please provide data for items 1 to 18.** The additional data fields, items 19 to 28, are optional for your own records.

**Referrals** - all referrals should be documented regardless of whether the family or youth continues on to receive service

**Intakes** - all referrals accepted for and receiving service

| | | |
|---|---|---|
| | **Demographic information** | |
| | | |
| 1 | # of male children and youth intakes | Total number of male children **intakes** for the month - **Formula embedded in spreadsheet** |
| | 0 to 6 years | Provide number of **new** male children according to each age category for each month |
| | 7 to10 years | |
| | 11 to 15 years | |
| | 16 to 19 years | |
| 2 | # female children and youth intakes | Total number of female children **intakes** for the month - **Formula embedded in spreadsheet** |
| | 0 to 6 years | Provide number of **new** female children according to each age category for each month |
| | 7 to10 years | |
| | 11 to 15 years | |
| | 16 to 19 years | |
| 3 | # intakes who identify as Aboriginal | Number of new intakes (children/youth) during the month that identify as Aboriginal. 'Aboriginal' includes North American First Nations, Metis and Inuit people. (Other indigenous people, e.g children/youth from Central/South America, would not be included in this category, but should be included in the visible minority category). |
| | % intakes who identify as Aboriginal | **Formula embedded in spreadsheet** |
| 4 | # intakes who identify as visible minority | Number of new intakes during the month that identify as a visible minority. In accorrdance with Stats Canada, 'visible minority' applies to people who are non-Caucasian in race or non-white in colour. These output data should not include Aboriginal people, who are counted above. |
| | % intakes who identify as visible minority | **Formula embedded in spreadsheet** |
| | | |
| | **Referral and Waitlist Information** | |
| | | |
| 5 | # of new family referrals received | Total Number of new family referrals received from all sources -**Formula embedded in spreadsheet** |
| 6 | # of new family referrals received from: | Total Number of new family referrals received each month according to each of the referral sources listed below |
| | Health Authority Assessment Team | |
| | School/School District | May include school counsellor. |
| | MCFD Social Worker | |
| | Other Service Provider | E.g. Infant Development program, Supported child care, youth worker. May also include physicians or nurse practitioners outside of the Health Authority Assessment Team. |
| | Self referral | |
| | Other | |
| 7 | When was the family referred to Key Worker program? | The assessment referred to in this section is the assessment provided through the Health Region under the new FASD/CDBC funding. |

| | | |
|---|---|---|
| | # prior to FASD/CDBC assessment by the Health Region | Number of referrals where the child(ren) does not have a formal medical, neuro-psychological or psycho-educational assessment. Families whose child(ren) are on the waiting list for the assessment should be included in this category. |
| | # at time of commencing FASD/CDBC assessment process | |
| | # during the assessment process | |
| | # post assessment | |
| | # with previous assessment (not from Health Region Assessment Team) | These may be children who have a diagnosis from another jurisdiction or who have had a previous diagnosis, e.g. before the Health Authorities set up their assessment teams. |
| 8 | # of new family referrals with child(ren) with confirmed or probable FASD "diagnosis" | We want to be able to differentiate between those referrals with a confirmed or probable diagnosis of FASD from those with another CCY/CDBC diagnosis. We recognize that not all children whose families are referred for services will have a confirmed FASD diagnosis but you will be working with them as if they did, thus the reference to "probable" FASD diagnosis. |
| 9 | # of new family referrals with child(ren) following a CCY/CDBC assessment (other than FASD) | Please include the number of families who have been referred because their children have received an assessment that falls under the CCY/CDBC definition. Do not include those who have been counted under Item 7 regarding FASD diagnosis/assessment. |
| 10 | # of new families accepted for & receiving service service (intakes) | The total number of families accepted for and receiving service during the month - also could be called intakes. This would also include youth who may be living independently and who have been accepted for and are receiving service. |
| 11 | # of families receiving service for the first time | The total number of families receiving Key Worker or Parent to Parent Support Services **for the first time**. Many agencies are anticipating that the use of the service may be episodic in nature such that families will make use of the service as needed, returning from time to time for additional help/service. Thus, only include new families receiving service each month. |
| 12 | # of families waitlisted on last day of month who have been deemed eligible for service | The number of families for whom intake has been completed but who have received no serivces to date and are waiting for service. Enter the number of families that are on the waitlist on the last day of the month. |
| 13 | #of families receiving service within 90 days | The number of families who have been referred, accepted for service and receiving service within 90 days of referral for the Key Worker or Parent to Parent support services. |
| | % of families receiving service within 90 days | **Formula embedded in spreadsheet** |
| 14 | # of families whose files have been closed (as of the last day of the month) | The total number of files closed during the month up to and including the last day of the month. |
| | | |
| | | |
| | **Program Intervention Data** | |
| | | |
| 15 | # of families receiving individual intervention | The total number of families seen on an individual basis each month. Includes telephone and face to face contacts. This is **not** the number of contacts but the actual number of families you worked with in the past month. For example, you may have 25 families active on your caseload but actually provided individual service to 23 different families during the month. |
| 16 | # of parent to parent group sessions | The total number of parent support groups held during the month. |
| 17 | # of sessions of group intervention | The total number of group intervention sessions other than for parent support groups. Many agencies envision serving youth and may use peer to peer support groups as a way of providing service. |
| 18 | # of sessions of public / provider sessions | The total number of hours delivering public presentations. These would include public education sessions, workshops, conference presentations, education of other service providers and so on. This does not include parent support groups or group sessions with other clients. |
| | | |
| | **Additional Data** | |
| 19 | # of hours of family intervention | The total number of hours spent working with individual families. Includes time spent with any member of the family and caregiver(s). |
| 20 | # of hours of parent to parent group sessions | The total number of hours of parent support groups. This is meant to capture hours of direct service delivery, not total staff hours, which would likely be more than actual direct service hours due to prep time and so on. |
| 21 | # of attendees at parent to parent group sessions | The total number of participating parents/caregivers attending the group sessions, not including staff and guest speakers. |

| | | |
|---|---|---|
| 22 | average number of attendees at parent to parent group sessions | **Formula embedded in spreadsheet** |
| 23 | # of hours of group intervention sessions | The total number of hours of groups sessions. This is meant to capture hours of direct service delivery, not total staff hours, which would likely be more than actual direct service hours due to prep time and so on. |
| 24 | # of attendees of group intervention sessions | The total number of participants attending the group sessions, not including staff and guest speakers. |
| 25 | average number of attendees at group session | **Formula embedded in spreadsheet** |
| 26 | # of hours of public / provider sessions | The total number of hours spent delivering presentations. This is meant to capture hours of direct service delivery, not total staff hours, which would likely be more than actual direct service hours due to prep time and so on. |
| 27 | # of attendees of public / provider sessions | The total number of participants attending the group sessions, not including staff making the presentation and guest speakers. If the sessions include a presentation at a conference the number should reflect the number of people attending the particular session not the number of overall conference atttendees. |
| 28 | average number of attendees per public / provider sessions | **Formula embedded in spreadsheet** |

# APPENDIX F

# KEY WORKER INTERVIEW GUIDE

## INTERVIEW GUIDE - KEY WORKER

### Goals and objectives

How would you define the goals and objectives of the *Key Worker and Parent Support program*program?

Have any of the goals or objectives changed as the *Key Worker and Parent Support program*program has been implemented?

### Staffing, training, supervision

How did you hear about your job?

What kind(s) of Key Worker training or development have you taken part in? What difference do you think this training has made for you in your work as a Key Worker?

***Probe:***

to your understanding of the Key Worker role? Explain.

to your understanding of FASD as a brain-based disability? Explain.

in the work you do, how you practice (i.e., the types of accommodations/interventions you provide). Explain.

What ongoing support or supervision do you receive? (Probe: What are examples of specific topics covered during supervision?)

How does this supervision help you in your work? Explain.

What additional support would be helpful?

Do you participate in local or regional networking with other Key Workers? If yes, is this a helpful process for you? Explain.

***Probe:*** Is there anything you would like to change about the regional/local networking process?

**Key Worker activities**

What do you consider to be your primary activities as a Key Worker?

How would you describe your role vis a vis:

- Parents/caregivers
- Other family members
- Child/youth with FASD/CDBC
- Other community agencies or systems such as MCFD, education system, health system
- Development of Parent Support Services

How do you engage families/caregivers?

- ***Probe:*** How do you inform them about your role? Issues you encounter in relation to engaging families?

How do you engage other professionals and/or community members?

- ***Probe:*** How do you inform them about your role?

Are these activities consistent with your understanding of the Key Worker role? Are there ways in which the activities have shifted? If so, how? What has prompted the shift(s)?

What do you consider are your major successes with this program?

In the past few months have there been any issues or challenges that have occurred regarding the implementation of the *Key Worker and Parent Support program*activities? Examples?

If so, how are the challenges being addressed? Is there anything else that would help resolve these challenges?

***Perceived participant satisfaction***

How do you think families/caregivers perceive the program? What difference do you think it has made to them? Can you think of an example or story that illustrates how families/caregivers perceive the project or what difference it has made?

What do you think families/caregivers like most or think is most important to them about the program?

Is there anything that you think families/caregivers would like to change about the program?

***Community involvement/partnerships***

What other agencies do you work with or access, in your role as Key Worker?

What is your role, in helping families accessing these agencies/organizations? (e.g., facilitator, educator, advocate, referral source)

What difference has defining FASD as a neurobehavioural disorder made to these agencies/organizations? to families/caregivers? Can you think of an example or story that illustrates how the information you have provided regarding FASD as a neurobehavioural disorder has made a difference to other agencies/organizations in the community, or to families/caregivers?

Do you have anything else to add?

# APPENDIX G

# CLINICAL SUPERVISOR INTERVIEW GUIDE

## INTERVIEW GUIDE - CLINICAL SUPERVISOR of the KEY WORKER

### Goals and objectives

How would you define the goals and objectives of the *Key Worker and Parent Support program*program?

Have any of the goals or objectives changed as the *Key Worker and Parent Support program*program has been implemented? Examples

### Experience and Knowledge

Could you please describe how you job is structured? E.g. employee, contract, one agency, several agencies etc.

What kind(s) of previous clinical supervision experience and training did you have? Has this previous experience/training helped you in your current role? Explain.

What was your knowledge of FASD/CDBC previously? Has taking on the role of clinical supervisor for this program changed anything in your understanding about FASD/CDBC?

### Supervision

What do you consider to be your primary focus as Clinical Supervisor of Key Workers?

How many Key Workers are you currently supervising?

How do you engage Key Workers in clinical supervision (e.g. individually, as a group, by telephone, in person, upon request only, regularly scheduled, etc.)

How often do you provide clinical supervision to Key Workers? (e.g. weekly, monthly, as needed, etc)

How has your understanding about FASD/CDBC influenced your supervisory work?

How do you determine the supervision needs of Key Workers?

> **Probe**: How do you determine whether interventions recommended by Key Workers reflect understanding of FASD/CDBC as a physical disability?

Is there a process in place to facilitate networking amongst the Key Workers in your area/region? If so, how does this networking relate to your clinical supervision?

What do you consider are your major accomplishments as Clinical Supervisor in the Key Worker and Parent Support Service program?

Is there anything you need that would support you and your work with Key Workers related to FASD/CDBC?

In the past few months have there been any issues or challenges that have occurred regarding the supervision of the Key Workers and/or parent support facilitators? If so, what are they and how have the challenges been addressed?

**Training**

Have you participated in any training about FASD/CDBC since you started in your role as Clinical Supervisor to the Key Worker and Parent Support program? If so, could you comment on the value of that training and how it has impacted your work with the program?

Was there specific training on FASD/CDBC provided to you to support your role as supervisor? Has the training made a difference to your understanding of FASD as a neurologically based disability? Explain.

Do you have anything else to add?

# APPENDIX H

# AGENCY MANAGER/EXECUTIVE DIRECTOR INTERVIEW GUIDE

## INTERVIEW GUIDE FOR AGENCY MANAGERS

### Implementing the Key Worker and Parent Support Initiative

Please describe any changes in the Key Worker and Parent Support Initiative in your agency during the past year. E.G. funding, model of supervision, Key Worker networking, staff turn over etc.

What do you consider to be the primary role and activities of a Key Worker?

What do you consider to be the strengths of the Key Worker and Parent to Parent service(s) in your agency?

What do you consider to be the major successes of the Key Worker and Parent to Parent service(s)?

In your opinion, what have been some of the challenges or barriers to the ongoing implementing the Key Worker and Parent to Parent service(s) in your agency?

How were these barriers addressed? If you were to start again, are there things that you would do differently?

### Training

Have you participated in any training about FASD/CDBC since the launching of the Key Worker and Parent Support Program? If yes, what training workshop(s) did you attend?

What difference did the training make to your understanding of FASD? How has that impacted your work?

What impact if any, has the training made on the work of your staff in your region?

Looking back, are there any changes or additions you think could be made to the training?

### Families'/Caregivers' Perceived Satisfaction

What do you think families like most, or think is the most important aspect for them about the Key Worker program?

Can you think of an example or a story that illustrates how families perceive the program or what difference it has made for them?

Is there anything that you think families would like to change about the Key Worker and Parent to Parent service(s)?

**Outcome Evaluation Interview Questions**

As a result of the Key Worker and Parent to Parent service(s) have you made any changes in the way your agency addresses issues related to FASD/CDBC, either at an individual child and family level or at a community level,? Can you give me some examples?

Has the Key Worker contract made a difference in your relationships with other agencies in your community? Please explain.

Do you have anything else to add?

# APPENDIX I

# PARENTS/CAREGIVERS INTERVIEW GUIDE

## INTERVIEW GUIDE FOR PARENTS/CAREGIVERS

Tell me about your KW and the kinds of things that he/she does with or for you and your family.

Was this role described to you before you started to receive the service?

**Probe:** If so, how was this role described? and what was your feeling at the time?
Does the Key Worker look at the needs of the whole family? If so, in what ways?

Who in your family meets with the Key Worker?

What do you like best about the Key Worker program?

Have you come across any barriers to receiving the Key Worker services? Is so what are they?

What changes, if any would you make to kinds of things that the Key Worker does, or to the Key Worker program?

Have you participated in anything similar to the Key Worker program elsewhere in the community? If so how did it compare to the Key Worker program?

What do you think is the most important thing that you have learned through this program?

What do you think is the most important thing that your Key Worker has learned through this program?

What difference do you think having a Key Worker has made for you? Made for your family? Made for your child with FASD? Can you think of an example or story that illustrates this impact?

Probe: For example, as a result of the Key Worker, do you understand your child differently? Has this made a difference in how you handle things with your child?
Is your Key Worker able to meet the needs of you and your family?
If so, what needs have been met? Tell me more…
If not, what needs are not met?

Do you have anything else to add?

# APPENDIX J

# COMMUNITY PARTNERS AND SERVICE PROVIDERS INTERVIEW GUIDE

## INTERVIEW GUIDE FOR COMMUNITY PARTNERS AND SERVICE PROVIDERS

### Referrals, Roles and Relationships

How did you first learn about the Key Worker service in your community?

What is your understanding of the role of the Key Worker?

Has your agency/organization referred families to the Key Worker and Parent to Parent service(s)? If so, what was involved in the referral process?

Are the referral process and the eligibility criteria for families clear?

How are you or how have you been involved with the Key Worker and Parent to Parent service(s) in your community?

- ☐ meet with Key Worker and the family to talk about how things are going with (child/family)
- ☐ attend training or information sessions sponsored by MCFD's FASD support initiative
- ☐ attend case conference meetings involving Key Worker and the child/family
- ☐ refer families to Parent to Parent support
- ☐ Other _____

Has your involvement with the Key Worker changed in the past year, since the service started up?

### Strengths, Challenges and Milestones

In your opinion, what are the strengths of the Key Worker and Parent to Parent service(s) in your community?

What do you consider to be the major successes of the Key Worker and Parent to Parent service(s)?

In your opinion, what have been some of the challenges or barriers to implementing the Key Worker and Parent to Parent service(s) in your community?

How were these barriers addressed?

**Training**

Have you participated in any training about FASD/CDBC since the launching of the Key Worker and Parent Support Program? If yes, what training workshop(s) did you attend?

If yes, could you comment on the value of that training and how it has impacted your work?

Has the training made a difference to your understanding of FASD as a brain-based disability? Explain.

Looking back, are there any changes or additions you think could be made to the training?

**Families'/Caregivers' Perceived Satisfaction**

How do you think families perceive the Key Worker service? What difference do you think it has made to them? Can you think of an example or story that illustrates how participants perceive the project or what difference it has made?

What do you think families like most or think is the most important aspect for them about the Key Worker?

Is there anything that you think families would like to change about the Key Worker and Parent to Parent service(s)?

**Outcome Evaluation Interview Questions**

In the past year, what kind of support have you received from the Key Worker? For example,

- ☐ talk to Key Worker on the telephone when you need advice
- ☐ meet with Key Worker to problem solve in relation to FASD/CDBC-affected child and/or their family/caregivers
- ☐ get help from Key Worker in finding and accessing other resources in the community that can help you with the child?
- ☐ Other _____

As a result of the Key Worker service have you made any changes in the way you handle things with children affected by FASD/CDBC? Can you give me some examples?

**Please circle the number that best reflects your experience:**

The information I have received about FASD/CDBC through the Key Worker service is useful.

| Not at all true | | Moderately true | | Very true |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

My understanding of the child's behaviours has changed.

| Not at all true | | Moderately true | | Very true |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

My interventions in working with the child have changed in the past year.

| Not at all true | | Moderately true | | Very true |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

I have a clear understanding of the meaning of the term 'environmental adaptations to provide a good fit' for children with FASD/CDBC.

| Strongly disagree | | Agree Somewhat | | Strongly agree |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

In general I am seeing a decrease in the frequency of the child's secondary behaviours.

| Strongly disagree | | Agree Somewhat | | Strongly agree |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

As a professional, I receive enough personal and professional support to work effectively with children who have FASD/CDBC.

| Strongly disagree | Agree Somewhat | Strongly agree |
|---|---|---|

| | | | | |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

The Key Worker has been helpful in supporting the development of techniques and strategies that are effective with children with FASD/CDBC with whom I work.

| Strongly disagree | | Agree Somewhat | | Strongly agree |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |

# APPENDIX K

# AFFILIATION OF COMMUNITY PARTNERS PARTICIPATING IN THE EVALUATION

## Time 2 Community-based Interview Participants - Community Partners

| Affiliation of Community Partner | # of informants |
|---|---|
| Social worker | 5 |
| Family Support, Aboriginal agency | 5 |
| School-based Student Support Worker / teacher | 3 |
| Family Support / Intervention | 4 |
| MCFD Child and Youth Mental Health | 3 |
| Child and Youth Care worker | 3 |
| (Supported) Child care worker | 2 |
| School District Counsellor | 2 |
| School Vice Principal | 1 |
| Clinical Counsellor | 2 |
| Boys and Girls Club program manager | 1 |
| Manager, Aboriginal agency | 1 |
| Manager, non-Aboriginal agency | 2 |
| Play therapist | 1 |
| Occupational therapist | 3 |
| Psychologist | 1 |
| Physiotherapist | 1 |
| Speech Language therapist (1 school based) | 3 |
| Lawyer | 1 |
| College literacy worker | 1 |
| Youth probation officer | 2 |
| MCFD Aboriginal Family Services | 1 |
| First Nations Health Personnel | 2 |
| **Total interview** | **50** |

As nominated by the KWs, these community partners were the service providers with whom the KW has worked on behalf of families in the KW's caseload.

# APPENDIX L

# CCY DIAGNOSES FOR CHILDREN/YOUTH REFERRED TO KEY WORKER PROGRAM

**DIAGNOSIS OF CHILDREN, OTHER THAN FASD WHO HAVE BEEN REFERRED TO THE PROGRAM -**

| Region | Reporting Year | Classification and number of sites in region reporting classification |
|---|---|---|
| Fraser | October 2007 | ADHD – 3<br>Anxiety Disorders – 2<br>Autism – 6<br>VATERS Syndrome – 1<br>Tourettes Syndrome – 1<br>PDD-NOS – 3<br>Down Syndrome – 3<br>Neurobehavioural Condition – 3<br>Complex Behavioural Disorder – 3<br>NAS (Neonatal Abstinence Syndrome) – 4<br>FAE suspected – 3<br>Fragile X – 1<br>Acquired brain injury – 1<br>Unknown - 4 |
| Interior | October 2007 | ADHD – 2<br>Anxiety Disorders – 1<br>Autism – 1<br>Neurobehavioural Condition – 2<br>FAE Suspected – 2<br>Trisomy 21 – 1<br>Chromosomal Inversion – 1<br>Duane Detraction Syndrome – 1<br>Reactive Attachment Disorder – 1<br>Disruptive Behaviour Disorder – 1<br>Mild Intellectual Disability – 1 |
| North | October 2007 | ADHD – 1<br>FAE Suspected – 1<br>Acquired brain injury – 1<br>Mood Disorder – 1 |
| Vancouver Coastal | October 2007 | ADHD – 3<br>Autism – 3<br>Mild Intellectual Disability – 1<br>Apraxia – 1<br>Learning Disabilities – 1<br>Static Encephalopathy – 2<br>Oppositional Defiant Disorder – 1 |
| Vancouver Island | October 2007 | ADHD – 3<br>Anxiety Disorders – 3<br>PDD-NOS – 2<br>Fragile X – 1<br>Static Encephalopathy – 1 |

| Region | Reporting Year | Classification and number of sites in region reporting classification |
|---|---|---|
| | | Sensory Processing Disorder – 1<br>Communication Disorder – 1<br>Neurodevelopmental Disorder – 1<br>Cerebral Palsy - 1 |

# APPENDIX M

# PROGRAM MILESTONES – TIME 2

## Time 2 Program Milestones

Thematic analysis of the open-ended Time 2 Annual Agency Questionnaire data in relation to program milestones showed a pattern of responses in keeping with, yet extending, those of Time 1. The most frequently reported themes were:

- Increasing community awareness about the program and/or about FASD; having an increased number of referrals come from community service providers
- Receiving (an increased number of) referrals and intakes
- Inter-sectoral partnership discussions and/or collaborative planning (e.g. with the Health Assessment teams, school personnel, Aboriginal community, and so forth)

In addition, several new themes were identified at Time 2. These included:

- Development of parent education sessions and/or parent to parent support
- Key Worker stability and/or expertise
- FASD Day event

**Increasing community awareness and referrals from community service providers**

This was the most frequently reported theme, and was noted by the majority of the agencies (n=21) responding to the Time 2 Agency questionnaire. Many agencies combined the ideas of "increased community awareness about the program" and/or "increased referrals from community service providers" with "increased understanding about FASD" in their responses.

> *We have been running for 10 months and have a very successful program. The community is aware of the program and has helped families with referrals.* (Vancouver Coastal region)

> *Good in-roads with other services: mental health, education, especially Aboriginal services in the school system. More understanding of FASD as a neurological disorder.* (Vancouver Coastal region)

> *More awareness; attitudes shifting. Paradigm shift in the community and among services working with high risk populations.* (Vancouver Island region)

**Receiving (an increased number of) referrals and intakes**

Agencies in all regions reported that having an increase in referrals and/or in intakes was a program milestone of the past year. For some agencies, this year's milestone in relation to referrals and intakes related to getting referrals from a wide range of sources, including self-referrals from families:

> *Word is out! [We're] receiving more referrals. We're a low barrier service.* (Interior region)

> *[We're] now getting calls, requests for services from a wide range of service providers and directly from families.* (Vancouver Island region)

**Inter-sectoral partnership discussions and/or collaborative planning**

In keeping with a theme from Time 1, at Time 2 about one third (n=10) of the agencies responding to the Annual Agency Questionnaire stated that a milestone was their involvement in some type of inter-sectoral partnership discussion sessions (e.g. partnership meetings, workshops, and so forth). In many cases, these inter-sectoral discussions were seen as means to improve collaborative planning and practice-related change across service systems in working with families with a child/youth with FASD. Examples of these partnership-related milestones included:

> *The partnership between MCFD, Northern Health, and the community. The growing partnerships with First Nations communities, organizations and programs.* (North region)
>
> *The creation of the FASD Round Table by the Vancouver School Board is a key milestone in implementing lasting change in the schools and community.* (Vancouver Coastal region)

**Development of parent education sessions and/or parent-to-parent support**

At Time 2, the most frequently occurring new theme regarding program milestones was the implementation of parent education activities and/or parent (to parent) support. Agencies in all regions except the North stated that the launching of parent or peer support had been a program milestone; for some of these agencies, refining these parent education/support activities in order to best meet families' needs became a focus of Key Worker program activities:

> *Tailoring groups to the times and needs of smaller clusters of caregivers is our current focus*. (Fraser region)
>
> *Parent education offered in [Key Worker] communities; positive parent feedback.* (Fraser region)
>
> *Developing a parent to parent Newsletter.* (Vancouver Island region)

**Key Worker stability and/or expertise**

A few Key Worker agencies noted that the hiring of a new Key Worker in the past year provided their agency with stability that had been missed previously. Similarly, a couple of agencies noted that their Key Worker's commitment and/or expertise represented a milestone for the agency. In agencies' words:

> *Expertise of staff and team.* (Interior region)
>
> *Another milestone for our program is the stability of the Key Worker, as we now have had some stability to the program.* (North region)
>
> *Finding a worker who was committed to working with First Nations people.* (Vancouver Coastal)

**FASD Day event**

At Time 2, three agencies noted that International FASD Awareness Day events, organized and/or facilitated by the Key Worker program staff, represented a program milestone in the past year.

Finally, at Time 2, there were several agencies in the North region that stated that the implementation of the CDBC assessments was a milestone for the Key Worker program.

In addition, there were several agencies that provided other noteworthy responses to the questionnaire item regarding program milestones. These included:

- Implementation of clinical supervision;
- Increased program funding;
- Hiring of a second Key Worker;
- Discovering information regarding disability tax benefits for families; and
- Positive outcomes for families.

# APPENDIX N

# SUMMARY OF STAFFING CHANGES BY REGION

## Summary of Changes in Key Workers and Parent Support Staff Since April 1, 2006

## (N= 42 of 57 contracts)

| Region | Agencies reporting Key Worker Turnover | Agencies reporting Key Worker Position Increases | Agencies reporting Parent Support Staff Turnover | Agencies reporting Parent Support Staff Increases |
|---|---|---|---|---|
| Fraser | - | 6 | 1 | - |
| Interior | 2 | 5 | - | 1 |
| North | 2 | 2 | - | - |
| Vancouver Coastal | 5 | 2 | 2 | 1 |
| Vancouver Island | 4 | 2 | 1 | - |
| **Total** | **13** | **17** | **4** | **2** |

Source: Time 2 Annual Agency Questionnaire

# APPENDIX O

# SUMMARY OF QUALIFICATIONS OF CLINICAL SUPERVISORS

## Time 2 - Summary of Key Worker Clinical Supervisor Qualifications
## (N = 42 of 57 Agency Contracts)

| Region | Worker Clinical Supervisor Academic Qualifications | | | | | | |
|---|---|---|---|---|---|---|---|
| | **BSW** | **BA/BSc** | **BSN** | **MSW** | **MA** | **Other** | **Additional** |
| Fraser (n=9) | 3 | 1 | - | 1 | 3 | 1 (PsyD) | 1 (CCC) |
| Interior (n=6) | - | 2 | - | 1 | 2 | 1 (CGA) | 1 (RCC, CCC) |
| North (n=7) | 1 | 2 | - | - | 3 | - | 1 |
| Vancouver Coastal (n=8) | 3 | 1 | - | - | 2 | - | 2 (ECE, RCC) |
| Vancouver Island (n= 9) | 1 | 3 | - | - | 3 | - | 2 |
| Total | **8** | **9** | **-** | **2** | **13** | **2** | **5** |

Source: Time 2 Annual Agency Questionnaire

# APPENDIX P

# SUMMARY OF TRAINING FOR KEY WORKERS AND THEIR SUPERVISORS

**Time 2 - Summary of Provision for Ongoing Training**
**Key Workers & Parent to Parent Staff**

**(N=43 out of 57 Contracts)**

| REGION | Ongoing Training Available for Key Worker | | | Ongoing Training Available for Parent to Parent Staff | | |
|---|---|---|---|---|---|---|
| | Yes | No | No response | Yes | No | No Response |
| **Fraser (n=9)** | 8 | - | 1 | 2 | 1 | 6 |
| **Interior (n=7)** | 6 | - | 1 | 6 | - | 1 |
| **North (n=7)** | 7 | - | - | - | - | 7 |
| **Vancouver Coastal (n=10)** | 8 | - | 2 | 2 | - | 8 |
| **Vancouver Island (n=10)** | 10 | - | - | 2 | 2 | 6 |
| **TOTAL** | **39** | **0** | **4** | **12** | **3** | **28*** |

Source: Time 2 Annual Agency Questionnaire

*** The high number of "not applicable" responses (and non responses) for this question could result because most Key Workers also deliver the Parent to Parent Support aspects of the service. Thus the question regarding ongoing training has already been answered in relation to Key Workers.**

**Time 2 - Summary of Provision Training for Key Workers Supervisors**

**(N=43 out of 57 Contracts)**

| REGION | Ongoing Training Available for Key Worker Supervisors | | |
|---|---|---|---|
| | Yes | No | No Response |
| **Fraser (n=9)** | 6 | 3 | - |
| **Interior (n=7)** | 4 | 2 | 1 |
| **North (n=7)** | 6 | 1 | - |
| **Vancouver Coastal (n=10)** | 8 | 1 | 1 |
| **Vancouver Island (n=10)** | 7 | 3 | - |
| **TOTAL** | **31** | **10** | **2** |

Source: Time 2 Annual Agency Questionnaire

# APPENDIX Q

## AGENCY BUDGETS - COMPARISON OF REPORTING BETWEEN TIME 1 AND TIME 2

## Agency Budgets - Comparison Of Reporting between Time 1 and Time 2

| Budget Category | Region | Time 1 # of Agencies reporting* | Time 2 # of Agencies reporting* | Time 2 Notes |
|---|---|---|---|---|
| Supervision | Fraser | 4/12 | 8/9 | 3 agencies reported an increase; 5 reported for the first time |
| | Interior | 4/7 | 4/7 | All indicated significant increases |
| | North | 3/5 | 1/7 | Only one agency reported a budget line for supervision. The amount had more than tripled compared to Time 1. |
| | Vancouver Coastal | 5/8 | 8/9 | 1 reported an increase; 2 agencies reported similar levels to Time 1; 5 reported for the first time |
| | Vancouver Island | 7/11 | 5/11 | 1 reported an increase; 3 reported similar levels to Time 1; 1 reported decrease |
| Parent to Parent Support | Fraser | 3/12 | 6/9 | 1 agency reporting both years reported decrease; 5 agencies reported for the first time |
| | Interior | 6/7 | 6/7 | 1 reported an increase; 2 reported similar levels to Time 1; 2 reported decreases; 1 reported for the first time |
| | North | 1/5 | 2/7 | 1 reported an increase; 1 reported for the first time |
| | Vancouver Coastal | 3/9 | 5/9 | 1 reported an increase; 2 reported decreases; 2 reported for the first time |
| | Vancouver Island | 6/11 | 4/10 | 2 reported an increase; 2 reported similar levels to Time 1 |
| Clerical Support | Fraser | 3/12 | 6/9 | 3 reported significant increases; 3 reported for the first time |
| | Interior | 1/7 | 2/7 | 1 reported increases at 9x the amount at Time 1; 1 reported for the first time |
| | North | 4/5 | 4/7 | The same 4 agencies reported significant increases – from 1.5x to 10x the amounts at Time 1. |

| Budget Category | Region | Time 1 # of Agencies reporting* | Time 2 # of Agencies reporting* | Time 2 Notes |
|---|---|---|---|---|
| | Vancouver Coastal | - | 4/9 | All 4 agencies reported for the first time |
| | Vancouver Island | 4/11 | 2/11 | 1 reported increases at 7x the amount at Time 1; 1 reported for the first time |
| Communications | Fraser | 4/12 | 8/9 | 1 reported significant increases; 7 reported for the first time |
| | Interior | 5/7 | 5/7 | 2 reported increases; 1 reported a decrease; 2 reported for the first time |
| | North | 2/5 | 2/7 | 1 reported an increase; 1 reported for the first time |
| | Vancouver Coastal | 4/9 | 6/9 | 2 reported an increase, 1 reported a decrease; 3 reported for the first time |
| | Vancouver Island | 6/11 | 4/11 | 3 reported similar budgets to Time 1; 1 reported for the first time |
| Travel | Fraser | 7/12 | 9/9 | 3 reported increases; 1 reported a decrease; 5 reported for the first time |
| | Interior | 6/7 | 6/7 | 1 reported an increase; 2 reported decreases; 1 reported similar budget to Time 1; 2 reported for the first time |
| | North | 5/5 | 7/7 | 3 reported an increase; 1 reported a slight decrease; 3 reported for the first time |
| | Vancouver Coastal | 5/9 | 9/9 | 3 reported an increase; 2 reported a slight decrease; 4 reported for the first time |
| | Vancouver Island | 10/11 | 8/11 | 2 reported increases; 2 reported decreases; 1 reported for the first time |
| Office Supplies | Fraser | 6/12 | 9/9 | 3 reported increases; 6 reported for the first time |
| | Interior | 5/7 | 5/7 | 3 reported an increase; 1 reported a slight decrease; 1 reported for the first time |
| | North | 5/5 | 7/7 | 2 reported an increase; 2 reported a slight decrease; 3 reported for the first time |

| Budget Category | Region | Time 1 # of Agencies reporting* | Time 2 # of Agencies reporting* | Time 2 Notes |
|---|---|---|---|---|
| | Vancouver Coastal | 6/9 | 6/9 | 2 reported an increase; 1 reported a slight decrease; 1 reported similar budget to Time 1; 2 reported for the first time |
| | Vancouver Island | 9/11 | 5/11 | 2 reported an increase; 2 reported a slight decrease; 1 reported similar budget to Time 1; |
| Rent | Fraser | 7/12 | 9/9 | 4 reported an increase; 1 reported a slight decrease; 4 reported for the first time |
| | Interior | 5/7 | 6/7 | 4 reported an increase; 1 reported similar budget to Time 1; 1 reported for the first time |
| | North | 4/5 | 4/7 | 3 reported an increase; 1 reported for the first time |
| | Vancouver Coastal | 5/9 | 5/9 | 2 reported similar budget to Time 1; 3 reported for the first time |
| | Vancouver Island | 7/11 | 4/11 | 2 reported a decrease; 2 reported similar budget to Time 1; |
| Activities & Resources | Fraser | 6/12 | 8/9 | 2 reported an increase; 1 reported a decrease; 5 reported for the first time |
| | Interior | 6/7 | 4/7 | 1 reported an increase; 2 reported a slight decrease; 1 reported similar budget to Time 1; |
| | North | 3/5 | 2/7 | Both agencies reported a decrease |
| | Vancouver Coastal | 6/9 | 7/9 | 4 reported an increase; 1 reported a slight decrease; 2 reported for the first time |
| | Vancouver Island | 7/11 | 4/11 | 1 reported an increase; 1 reported a slight decrease; 1 reported similar budget to Time 1; 1 reported for the first time |
| Administration | Fraser | 8/12 | 4/9 | 3 reported an increase; 1 reported for the first time |
| | Interior | 6/7 | 5/7 | 4 reported an increase; 1 reported for the first time |

| Budget Category | Region | Time 1 # of Agencies reporting* | Time 2 # of Agencies reporting* | Time 2 Notes |
|---|---|---|---|---|
| | North | 4/5 | 6/7 | 2 reported an increase; 1 reported a decrease; 3 reported for the first time |
| | Vancouver Coastal | 5/9 | 7/9 | 4 reported an increase; 3 reported for the first time |
| | Vancouver Island | 9/11 | 5/11 | 3 reported an increase; 2 reported a slight decrease; 1 reported similar budget to Time 1; |

*These columns report the number of agencies that reported a budget figure in each category at Time 1 and/or at Time 2.