Ministry of Children and Family Development

KEY WORKER AND PARENT TO PARENT SUPPORT PROGRAM

Time 1 Formative Evaluation Report

March 2007

Prepared by:

Sharon Hume and Associates
Sharon Hume, MSW, Deborah Rutman, PhD
Carol Hubberstey, MA, Doreen Johnson, BSW

Table of Contents

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

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

Based on these priorities, the following activities received funding:

2005/06

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

2006/07

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

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

Key Worker and Parent to Parent Support

After extensive research and provincial consultations with a variety of stakeholders, MCFD decided to implement a family support program that is inclusive of children with FASD and complex developmental-behavioural conditions[1] (CDBC) similar in impact to FASD, rather than a dedicated FASD intervention program. The *Key Worker* and *Parent to Parent Support* approaches were chosen as the models of service delivery. The Key Worker program is based on research from other jurisdictions that shows that children and families with disabilities benefit from the presence of a key worker. As well, input from

---

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

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

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

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

- Maintain and enhance the stability of families with children and youth with FASD and other complex developmental-behavioural conditions in order to improve the children's long term outcomes.

- Increase the knowledge of parents and professionals about the neurological nature of developmental-behavioural conditions such as FASD so that the affected children and youth experience less frustration and more success.

- Ensure that families of children with FASD other complex developmental-behavioural conditions have an ongoing network of support.

- Evaluate the various program component impacts on child and family outcomes such as improved access to services, behavioural progress, family stress reduction and family stability.

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

Initial formative evaluation findings are based on:

- 39 responses to the Agency Questionnaire, representing a 74% response rate[2], and;

- 41 key informant interviews including in-depth qualitative interviews in two communities representing two different MCFD regions and a joint qualitative interview in a third MCFD region with the two Key Workers who spilt the FTE position for their geographic community[3].

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

---

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

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

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

Findings, Discussion and Recommendations

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

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

Summary of program strength 2006-2007:

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

Engaging Families and communities

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

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

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

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

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

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

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

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

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

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

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

Evaluation

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

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

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

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

References

Drennan, A., Wagner, T., & Rosenbaum, P. (2005). *The Key Worker Model of Service Delivery.* , Hamilton, ON: Can Child Centre for Childhood Disability Research. Institute for Applied Health Sciences

Greco, V., Sloper, P., Webb, R., & Beecham, J. (2005) *An Exploration of Different Models of Multi-agency Partnerships in Key Worker Services for Disabled Children: Effectiveness and Costs.* York, UK: Department for Education and Skills. Research Report 656. University of York.

Joseph Rountree Foundation. (1999). *Implementing key worker services: a case study of promoting evidence-based practice.* York UK: The Homestead. www.jrf.org.uk

Malbin, D. (2002). *Trying Differently Rather Than Harder, 2nd Edition,* Portland, Oregon: FASCETS

SECTION 1   INTRODUCTION AND BACKGROUND

Introduction

In September 2003, the Premier of British Columbia released *Fetal Alcohol Spectrum Disorder: A Strategic Plan for British Columbia,* the first comprehensive plan related to Fetal Alcohol Spectrum Disorder (FASD) in Canada. The FASD Strategic Plan built on work that had been going on in BC for over 10 years and reflected the involvement and input of a wide range of interested groups, including parents, caregivers, people with FASD, advocates, teachers, health and other service providers, professionals, community leaders, and all levels of government (http://www.mcf.gov.bc.ca/fasd/pdf/fasd_strategic_plan-final.pdf). A cross-ministry Assistant Deputy Ministers' Committee on FASD, that also included federal representatives, helped to oversee development of the strategic plan and to ensure implementation of key priorities for action.

The FASD Strategic Plan provided direction for policy makers, service providers, community groups, and researchers and was meant to generate discussion amongst these groups as to the parameters and priorities for action over the next three years, from 2003-2006. Employing a collaborative and integrated approach, the FASD Strategic Plan identified the following priorities:

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

Following release of the FASD Strategic Plan, in 2004, the Ministry of Children and Family Development (MCFD) submitted a request to Treasury Board for funding for development of new FASD services.

Background

In 2005 the Ministry of Health and Ministry of Children and Family Development received funding to implement cross-ministry initiatives in support of the FASD Strategic Plan and that would improve screening, diagnosis, assessment, intervention, and support for children and youth with FASD. The Ministry of Health was funded to develop new integrated assessments and diagnosis capacity for children with FASD and other similar conditions and MCFD was funded to provide a new support program

specifically for families of children and youth (birth to 19 years of age), with FASD and/or other complex developmental behavioural conditions (CDBC) similar in impact to FASD. In 2006/07 the Ministry of Education committed ongoing funding to establish a new FASD provincial outreach program hosted by the Prince George school district.

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

In order to determine how best to address the identified priorities, upon receiving the funding in 2005, the Children and Youth with Special Needs division within MCFD immediately undertook the following activities:

- Stakeholder consultations with parents, service providers, Ministry partners, and experts in the FASD field
- Environmental scan of existing FASD-related resources within the province
- Preparation of a discussion paper on supporting children with developmental-behavioural conditions
- Review of best practices (ongoing).

These activities yielded the following information (MCFD, 2005)

- Stakeholders said that they expected the government to build an integrated approach to services for children and youth with special needs
- Parents said that they wanted support and help negotiating the service systems that they routinely encountered
- All groups noted the importance of early intervention, the value of linking services to assessments, and the need to create a province wide program, not a pilot project

Creation of Key Worker and Parent to Parent Support Program

In light of this information, as well as research that "indicated that family supports produce better outcomes for children with disabilities and their families as a whole" (MCFD, 2006 FASD conference notes), MCFD decided to implement a Family Support Program that was inclusive of children with FASD and complex developmental-behavioural conditions[4] (CDBC) similar in impact to FASD, rather than a dedicated FASD intervention program. The *Key Worker* and *Parent to Parent Support* approaches were chosen as the models of service delivery.

---

[4] 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

The Key Worker service, as originally discussed within MCFD, was based on the UK model of key working with families with children with serious disabilities. Program developers within MCFD envisioned Key Workers as working with families by: providing education and information relevant to FASD and/or CDBC and the needs of the child and family; empowering families to become advocates for their children; providing emotional and practical support; assisting families in accessing support, health, and education services; helping to develop local supports; and finally, working with community resources to meet the needs of children and youth with FASD and/or CDBC. Key Workers could also inform families who suspected that their child had FASD about the process by which they could be referred for an assessment by a multidisciplinary assessment team, while providing appropriate interim support.

The Key Worker model was selected for several reasons. First, it took into consideration existing community resources and programs, as well as feedback from parents that they were exhausted from having to do all the education, service coordination, and advocacy on their own, and that they needed support and help to negotiate the various service systems. As well, the overall funding did not allow for creation of a province-wide stand-alone program. Co-ordination of existing programs, as part of a Key Worker function, was seen as a means of leveraging the initial investment/funding. The intent was for the Key Worker and Parent to Parent Support Services to augment and coordinate existing services, not duplicate what already existed for children with special needs at a community level.

Second, in developing the new services, the Ministry wanted to move to a needs-based approach so that any children or youth with suspected or diagnosed alcohol-related neuro-developmental disabilities and their families would be eligible for service. This meant that having an FASD assessment was not the sole criterion for service since this would leave out children under age four who otherwise were too young to fully take part in an assessment. The needs-based approach also allowed for the inclusion of children and youth with brain damage of various etiologies yet similar to that caused by FASD, who could "benefit from specialized FASD supports" (MCFD, 2005).

Finally, the Key Worker model complemented the Ministry of Health's plan to develop a provincial diagnosis and assessment system for FASD. Although the Key Worker program allowed for self-referrals, it was nonetheless important that families be linked to the assessment process. Since the Key Worker program was going to be based on needs not diagnosis, incorporation of a functional assessment was also seen as essential (MCFD, 2005). It was the Ministry of Health's intention to make the assessments more accessible and useable by families, in part through use of functional assessments[5]. Through close collaboration with the Ministry of Health at the provincial and regional levels, a stronger link was

---

[5] Functional assessments or assessments of adaptive functioning cover a number of domains such as cognitive functioning, executive functioning, motor functioning, ability to focus, and social skills. Research has shown that, for people with FASD, assessments of adaptive functioning provide a more accurate picture of the individual's overall capacity or functioning level relative to IQ assessments (Alberta Learning, 2004; Russell, 2003; 2007).

envisioned between the diagnosis, assessment, and support components of the new inter-ministry initiatives.

In response to parents of children with FASD who identified that having support from other parents was one of the most valuable forms of family support, MCFD also included Parent to Parent Support in the new program service delivery design. This aspect of the new service was not well defined, in part to allow for regions to respond to the needs of parents and/or to allow for innovative approaches to emerge in terms of linking together parents of children with FASD/CDBC in isolated communities.

In 2005/06 regional consultations were conducted by the five MCFD regional offices; local FASD resources were mapped and each region submitted a plan for incorporating the Key Worker and Parent to Parent Support program into their service delivery structure. Following approval of their service plans, the regions focused on building capacity for the new services with an emphasis on education and training. In support of the regions, evaluation, training support, and expert consultation were provided at a provincial level.

In concert with the activities undertaken by MCFD and Ministry of Health, in September 2006 the Ministry of Education established a Provincial Outreach Program for Fetal Alcohol Spectrum Disorder (POPFASD). The POPFASD is intended to build capacity in school districts by providing teachers with a network through which they can ask questions, as well as share current FASD research, resources, successful practices, and strategies for working with students with FASD.

Evaluation

MCFD is committed to development of programs based on evidence of successful strategies and interventions. In order to know whether the Key Worker and parent to 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

There are two main components to the evaluation: *formative* or process, and *summative.* The process 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 will also describe regional variations in the Key Worker and Parent to Parent 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)

This Year 1 Process Evaluation Report presents findings related to the early stages of implementing the Key Worker and Parent Support Services, from April to February 2006. The report is divided into several sections:

- **Section Two:** Provincial Vision – Key Worker & Parent to Parent Support
- **Section Three**: Evaluation Framework and Methodology
- **Section Four**: Inputs and Outputs
- **Section Five:** Formative Findings
- **Section Six**: Discussion and Recommendations

References

Ministry for Children and Family Development (2005). *A Project Plan Draft: Supporting Families with Children and Youth with FASD and other Complex Developmental-Behavioural Conditions.* MCFD. Victoria, B.C.

SECTION 2   BC'S KEY WORKER AND PARENT TO PARENT SUPPORT SERVICES

According to MCFD documents, British Columbia's **Key Worker and Parent to Parent Support Services** are guided by research and practice evidence from four areas: Dr. Anne Streissguth's groundbreaking research in FASD; Diane Malbin's Oregon-based FASD project (www.fascets.org); research in the disabilities field; and existing community-based, BC parent support projects related to FASD. MCFD's model of program service delivery added *regional variation and modifications* to the core concepts.

Literature

Milestone research conducted by Streissguth et al in 1996 conceptualized the difference between primary and secondary disabilities associated with FASD. In Streissguth and colleagues' research, secondary disabilities were defined as not being characteristics that a person was born with (i.e. not primary characteristics), but that can arise over time "as a function of a chronic poor fit between the person and his or her environment" (www.fascets.org). The secondary behavioural problems that Streissguth et al (1996) examined included difficulties in school, trouble with the law, substance abuse problems and mental health problems. Secondary disabilities can be reduced if not prevented from occurring given improved community and professional understanding as well as adequate and appropriate interventions.

Longitudinal work by Streissguth and her colleagues (2004) has shown that children diagnosed with FAS/FASD have better outcomes if they are diagnosed early and appropriately, have stable home environments, and receive services before age six. Nevertheless, until recently there has been relatively little academic literature that has identified or documented what types of 'interventions' work best for children and youth with FASD. The Centres for Disease Control and Prevention in Atlanta noted for example, that "limited information is available regarding strategies for interventions specific to persons with FAS" (http://www.cdc.gov/mmwr/preview/mmwrhtml/rr5411a1.htm). Similarly, Premji et al (2004) conducted an extensive literature search of FASD interventions, and found few peer-reviewed studies that offered reliable evidence of effective intervention strategies, although a growing body of 'gray literature' (reports and information available through the internet, and unpublished or self-published documents) has been amassing in relation to strategies that support learning and positive social development for children and youth with FASD.

One 'intervention' identified by Premji et al (2004) as effective in supporting families and in helping to reduce secondary disabilities for children and youth with FASD is explicitly grounded in a conceptual model of FASD as a brain-based physical disability (Malbin, 2002). An important implication of this model

is that our society's prevailing treatment models (i.e., learning approaches including behaviour modification) are a "poor fit" for people with FASD or other neuro-developmental conditions, because the underlying neuro-cognitive impairment associated with FASD is contraindicated for a learning theory approach. Malbin's approach, to shift the focus from the child, to the child-in-the-environment, brought to the forefront the notion of finding the right environmental accommodations rather than imposing a cognitive-behavioural intervention (http://www.fascets.org/conceptualfoundation.html).

In contrast with the relative dearth of academic literature on interventions having demonstrated effectiveness for children/youth with FASD, there is a significant body of literature that has identified that families caring for a disabled child benefit 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). Key working models of service delivery for children with special needs are not common in Canada, although family support workers and family liaison workers can play a similar role, as do others in areas such as mental health and cancer care (Drennan et al, 2005).

A Key Worker is a 'named' person whom the family can approach for advice, advocacy, and assistance for any problem related to the disabled child. This approach uses a community capacity building model with an interagency steering committee and external facilitator who work together to break down barriers and improve interagency collaboration. The Key Worker also assists families by providing information; identifying and addressing the needs of all family members; providing emotional and practical support as required; assisting families in their dealings with agencies and acting as an advocate if required (Greco & Sloper, 2003; Greco et al 2005). Evaluation of this model has shown that consistent training and supervision for Key Workers, along with a clearly defined role/job description is associated with better family outcomes (Greco &ß Sloper, 2006; Sloper et al, 2005).

Finally, parent self-help has been used to good effect with parents of children with physical disabilities. Studies in the disabilities field have indicated that family supports produce better outcomes for children and their families as a whole, including reduced stress (Singer et al, 1999; Santelli et al, 1996; Santelli et al, 1997; Kerr & McIntosh, 2000). The support that parents offer each other is based on experiential understanding that is hard to capture through other sources (Kerr and McIntosh, 2000). Seligman and Darling (1989) identified four positive functions of support groups for parents: alleviating loneliness and isolation; providing information; providing role models; and providing a basis for comparison (p. 44). Similarly, 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). Support programs exist in many forms and differ in terms of their eligibility requirements, types of services offered, and administration.

Purpose - BC Key Worker and Parent to Parent Support Program

MCFD assumes that the "family is the most vital ecological context for early child development" (MCFD 2005) and that parents are the "experts". Within this context, the purpose of the BC Key Worker and Parent to 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 so as to help improve their stability. The goals and objectives of the program are:

- To maintain and enhance the stability of families with children and youth with FASD and other complex developmental-behavioural conditions in order to improve the children's long term outcomes.

- To increase the knowledge of parents and professionals about the neurological nature of developmental- behavioural conditions such as FASD so that the affected children and youth experience less frustration and more success.

- To ensure that families of children with FASD other complex developmental-behavioural conditions have an ongoing network of support.

- To evaluate the various program component impacts on child and family outcomes such as improved access to services, behavioural progress, family stress reduction and family stability.

Regional service delivery model

The Key Worker and parent to parent support services are being delivered within MCFD's regional service delivery structure. This method of service development and delivery recognizes the presence of unique local needs and family circumstances. Thus, MCFD anticipated that regional variation and modifications to the core concepts of the Key Worker and Parent to Parent Support Services would occur (see Section 4 for a brief discussion of the regional Key Worker and Parent To Parent Support Services).

Relationship to the literature

Over the first year of implementation of the Key Worker and Parent to Parent Support Services (i.e. 2006/07), some of the language and thinking related to the role and function of the Key Worker changed. Provincial training provided for Key Workers, based on the FASCETS program, resulted in some modification of the original approach, as well as grounding the program in the understanding of FASD as a brain-based physical disability with presenting behavioural symptoms. Similar to the FASCETS program, the Key Worker is regarded 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. As part of the BC program's approach, an expert in FASD is available to regional MCFD offices and contracted agencies to help facilitate learning and strategies related to these concepts. At the same time, the BC Key Worker model assumes several elements of the UK model, including supervision and training.

In the BC approach, Key Workers assists families by:

- providing education and information specific to their needs
- being familiar with community resources and helping families to access support, health and education services
- informing development of local support services
- providing emotional and practical support to families
- helping families to become their own best advocates
- liaising with the Health multidisciplinary assessment team
- helping families access services appropriate to the needs of the child
- attending school meetings and case conferences with the parent (Luettgen, 2007).

Finally, parent to parent support is another important feature of the B.C. FASD strategy. Parent to parent support has been "identified by parents of children with FASD as one of the most valuable forms of family support" (MCFD 2005), in part because families with children with special needs are in a unique position to understand what others in similar situations may be experiencing. In keeping with the above literature, MCFD anticipated that parents/caregivers of children with FASD/CDBC would come together through parent to parent support groups, or in more isolated communities, through other more innovative approaches such as the internet or a 'warm' phone line. Although this aspect of FASD/CDBC support program is still in early stages of development, there are examples of parent to parent Support already in place in conjunction with other community programs in BC including:

- local parent and grandparent FASD trainings
- parent mentoring
- parent support groups

References

Alberta Learning (Special Programs Branch) (2004*). Teaching Students with FASD: Building Strengths, Creating Hope.* Edmonton Alta: Alberta Learning. Publication on line: http://www.learning.gov.ab.ca/k_12/specialneeds/fasd/fasd9.pdf

Baum, L. (2004) Internet Parent Support Groups for Primary Caregivers of a Child with Special Health Care Needs. *Pediatric Nursing. Vol. 30*, (*5).* 381-401.

Drennan, A., Wagner, T., & Rosenbaum, P. (2005). *The Key Worker Model of Service Delivery*. , Hamilton, ON: Can Child Centre for Childhood Disability Research. Institute for Applied Health Sciences

Fetal Alcohol Syndrome Consultation, Education and Training Services, www.fascets.org

Greco, V. & Sloper, P. (2003). *Care co-ordination and key worker schemes for disabled children: Results of a UK wide survey.* York, UK: Social Policy Research Unit, University of York.

Greco, V., Sloper, P., Webb, R., & Beecham, J. (2005) *An Exploration of Different Models of Multi-agency Partnerships in Key Worker Services for Disabled Children: Effectiveness and Costs.* York, UK: Department for Education and Skills. Research Report 656. University of York.

Joseph Rountree Foundation. (1999). *Implementing key worker services: a case study of promoting evidence-based practice.* York UK: The Homestead. www.jrf.org.uk

Kerr, S.M. & McIntosh, J.B. (2000). Coping when a child has a disability: exploring the impact of parent to parent support. *Child: Care, Health and Development, 26.* (4). 309-322.

Liabo, K., Newman, T., Stephens, J., & Lowe, K. (2001). *A review of key worker systems for children with disabilities and development of information guides for parents, children and professionals: summary*. www.barnardos.org.uk/resources

Luettgen, J. (2007) *Supporting Families with Children and Youth with FASD: An Overview of British Columbia's Family Support Initiative and Evaluation.* Presentation at the 2nd International Conference on Fetal Alcohol Spectrum Disorder: Research, Policy and Practice Around the World. UBC Interprofessional Continuing Education.

Malbin, D. (2002). *Trying Differently Rather Than Harder , 2nd Edition,* Portland, Oregon: FASCETS

Ministry for Children and Family Development (2005). *A Project Plan Draft: Supporting Families with Children and Youth with FASD and other Complex Developmental-Behavioural Conditions*. MCFD. Victoria, B.C

Premji ,S., Serrett K., Benzies RN, & Hayden, K.A (2004). *State of the evidence review: Interventions for children and youth with a fetal alcohol spectrum disorder (FASD*) Unpublished manuscript, Alberta Centre for Child, Family and Community Research

Russell, D. (2003). *IQ – It just doesn't matter: The role of adaptive functioning in individuals with FAS/FAE/ARND*. Conference presentation made at "*Fetal Alcohol Spectrum Disorder – Doing What Work*s" Vancouver, BC.

Russell, D. (2007) IQ Versus Adaptive Functioning in Individuals with FASD: The Saga Continues. Conference presentation made at "*Fetal Alcohol Spectrum Disorder – Research, Policy and Practice Around the World*" Victoria, BC.

Santelli, B., Turnball, A., Marquis, J & Lerner, E. (1997). Parent to Parent Programs: A Resource for Parents and Professionals. *Journal of Early Intervention. 21*, (1), 73-83

Santelli, B., Turnball, A., Sergeant, J., Lerner, E & Marquis, J. (1996). Parent to Parent Programs: Parent Preferences for Support. *Infants and Young Children. 9*, (1), 53-62

Seligman, M. & Darling, R.B. (1989*). Ordinary families, special children: A systems approach to childhood disability*. New York. Guilford Press.

Singer, G., Marquis, J., Powers, L., Blanchard, L,.,Divenere, N., Santelli, B., Ainbinder, J. & Sharp, M. (1999). A Multi-Site Evaluation of Parent to Parent Programs for Parents of Children with Disabilities. *Journal of Early Intervention. 22*, (3) 217-229

Sloper, P., Greco, V., Beecham, J. & Webb, R. (2006) Key worker services for disabled children: what characteristics of services lead to better outcomes for children and families? *Child Care, Health & Development*, *32 (2).* 147-157.

Streissguth AP, Bookstein FL, Barr HM, Sampson PD, O'Malley K & Young JK. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effect*s. J Dev Behav Pediatrics, 25(4),* 228-38

Streissguth, A.P., Barr, H.M., Kogan, J. & Bookstein, F. L., (1996). *Understanding the Occurrence of Secondary Disabilities in Clients with Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE),* Final Report to the Centers for Disease Control and Prevention (CDC), August, 1996, Seattle: University of Washington, Fetal Alcohol & Drug Unit, Tech. Rep. No. 96-06,

SECTION 3   EVALUATION RESEARCH QUESTIONS, FRAMEWORK & PROCESS

Research Questions

Key research questions for the Key Workers and Parent-to-Parent Support formative evaluation included:

- *How are the Key Worker and Parent Support Services being implemented in the five regions of the province?*
- *How are families/caregivers engaged in the program?*
- *How do families/caregivers, Key Workers and other community service experience the program?*
- *What activities have been carried out, and/or services have been implemented, and how?*
- *What are the program's strengths?*
- *What are the key milestones of the program activities?*
- *What are some of the barriers to implementing program activities?*
- *How are these barriers being addressed to date?*
- *What improvements could be made to improve the quality of the program?*

Evaluation Framework

As an early step in the evaluation, 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.

Evaluation Process

The formative evaluation employed a process study and case study methodologies, and involved qualitative and quantitative methods of data collection. As well, the formative evaluation involved both province-wide data collection and more intensive data collection in a sample of BC communities. Ultimately, two communities in each of the five MCFD regions will participate in community-based data collection; however, for the Time 1 formative evaluation, we 'piloted' the community-based data collection process in three communities and three regions. Communities were selected in consultation with each region and with MCFD Provincial Office staff to ensure that diverse communities including Aboriginal, rural/remote, metropolitan, small urban, were represented in the qualitative component of the evaluation.

Appendix B summarizes the data collection methods for both the formative and the summative evaluations; multiple methods were used, including:

- Agency Questionnaires
- Output data collected electronically
- Qualitative, semi-standardized interviews with a sample of program staff, supervisors and other key informants (e.g. MCFD regional managers)
- Qualitative, semi-standardized interviews/focus group with a sample of program participants (i.e., parents/caregivers)
- Documentary review

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

For this Time 1 Formative Evaluation Report, the **province-wide evaluation data** was comprised of:

- **Annual Agency questionnaires -** The Agency Questionnaire was sent to the all agencies in December 2006 with a request that the program manager responsible for Key Worker/Parent-to-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 this questionnaire is provided in **Appendix C.**

As of March 15, 2007, the evaluators had received 39 out of the 53 Agency Questionnaires that were sent out, which represents a 74% response rate[6]. The evaluators telephoned and/or e-mailed all agencies that had not mailed their Agency Questionnaires, but In keeping with conventions of research, if an agency did not send in its questionnaire following three 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.

---

[6] 48 different agencies hold 53 contracts to delivery Key Worker and/or Parent to Parent Support services

- **Key Worker Program Output data** - In December 2006, 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. Appendix E contains a template for the output data reported by the agencies.

  As of March 15, 2006, the evaluators had received program output data from four out of five regions and 37 out of 53 agencies, which represents a 70% response rate[7].

- **Key Informant interviews** also were conducted with all five MCFD Children and Youth with Special Needs Managers and with the program's two Regional Coordinators.

In addition, community-based data were collected in one community in each of two MCFD regions. Community-based data collection involved:

    In Region 1, qualitative interviews were conducted with:

- o Key Worker and the Key Worker Supervisor serving three communities in the region. These interviews focused on all facets of project implementation from staff's perspectives; a copy of these interview guides is provided in Appendix F.
- o 3 multi-disciplinary service providers in the community, including a member of one of the region's well-established Assessment teams; see Appendix G for a copy of the interview guide;
- o Manager of the region's Health Assessment Network; and
- o 5 parents/caregivers (comprised of 2 birth parents, 1 foster parent, 2 grand-parents). See Appendix H for a copy of this interview guide.

    In Region 2, the Key Worker program served several outlying communities. Qualitative interviews were conducted with:

- o 3 Key Workers and 2 Key Worker Supervisors serving three communities in the region. Two of these Key Workers and one supervisor were based in Aboriginal Agencies.
- o 6 multi-disciplinary service providers in one community and 7 service providers in another community; and
- o 5 parents/caregivers in one community (comprised of 1 birth parent, 1 adoptive parent and 3 foster parents).

---

[7] In one MCFD region, delays in confirming approval of the items/indicators included as part of the output data meant that the agencies in this region did not receive the template for submitting their output data until March 1, 2007. Thus, output data were not included from this region in the Time 1 Formative Report.

As well, to augment the community-based data collection, a joint qualitative interview was conducted in a third MCFD region with the 2 Key Workers who spilt the FTE position for their geographic community[8]. One of the Key Workers was based in an Aboriginal agency and the other in a non-Aboriginal agency.

In Region 1, community-based interviews were conducted in a private setting of the informants' choice; all but 4 were conducted face to face (4 were telephone interviews), 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. In Region 2, a focus group with five parents/caregivers was held in the sponsoring agency's meeting room. As well, two focus groups with multi-disciplinary, multi-agency community service providers took place in meeting rooms in local agencies; one focus group involved three participants and the other involved eight participants. in addition, individual face-to-face meetings took place in private settings of the informants' choice. An informed consent process was adhered to with all interviews with parents/caregivers.

A total of 41 people took part in interviews and focus groups. See Appendix I for a listing of the key informants who took part in the Time 1 formative evaluation.

Lastly, document review was undertaken as part of data collection for the Time 1 formative evaluation. Relevant documents included: initial project proposals and work plans, contracts, and public announcements/brochures about the service(s).

---

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

Sharon Hume & Associates

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

Agency Profiles

Forty-eight agencies around the province were awarded 53 contracts to deliver Key Worker and Parent to Parent Support Services; two of these agencies are providing Parent to Parent Support only. According to the 39 responses to the Agency Questionnaire, the majority of the agencies contracted to deliver the services are non-profit organizations governed by Boards of Directors. Over two thirds of the agencies are accredited or accreditation is pending. The following table summarizes the agency profile by region.

Table 1: Agency Profiles

Region	# of Agencies with contracts	Governance N=39 contracts		Accreditation N=39 contracts	
		Non Profit	For-Profit/ Other	CARF/ COA	Pending/No Accreditation
Fraser	9*	11	-	11	-
Interior	9	4	2	5	1
North	6**	4	1	2	3
Vancouver Coastal	13	5	1	6	-
Vancouver Island	11	11	-	2	9
TOTAL	48***	35	4	26	13

Source: Time 1 Annual Agency Questionnaire

* One agency holds 3 contracts and another has 2 contracts, each contract for different communities.
** One agency holds 3 contracts for 3 different communities.
*** Total number of contracts =53

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

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 to Parent Support Services would be implemented. It was a

requirement that the regional plans included new Key Worker positions and that Parent to Parent Support initiatives be developed. The Regional funding allocation is shown in Table 2.

Table 2: Regional Funding Allocation 2005 to 2008

Region	Funding Formula [1]	2005/06 actual	2006/07 actual	2007/08 estimated
Fraser	30.55%	$672,000	947,000	$1,497,000
Interior	18.83%	$414,000	$584,000	$923,000
North	13.42%	$295,000	$416,000	$658,000
Vancouver Coastal	19.58%	$431,000	$607,000	$959,000
Vancouver Island	17.62%	$388,000	$546,000	$871,000

[1]Socioeconomic Model   Source: MCFD Planning Documents

Although the MCFD regions developed different approaches to contracting for the services within their regions, in 2005/2006 nearly all regions had planning discussions and processes that involved multi-sectoral networking and collaboration, involving representatives from community agencies and from the regional health authorities and CDBC assessment teams. For some regions, the collaborative relationships developed or strengthened through these planning processes set the stage for ongoing multi-sectoral, cross-Ministry collaboration and coordination activities in 2006/2007; the Fraser Valley's Partnership Group meetings and the North's development of a Memorandum of Understanding are illustrations of 'products' or outcomes of these collaborative activities in the regions.

In terms of decisions regarding the disbursement of funding, two of the regions (Fraser Valley and Vancouver Island) disbursed the funds to community agencies through a collaborative decision making process, whereby community agencies came together and determined which agency would be best suited to deliver the Key Worker and Parent to Parent Support Services: those selected were awarded the contracts through a *Notice of Intent* process. These two regions were the first to begin implementing the Key Worker and Parent to Parent Support Services in the early spring of 2006. The remaining three regions employed a competitive bidding process, with Key Worker and Parent to Parent Support Services coming on stream throughout the late summer and fall 2006 and winter of 2007.

Funding for the agencies ranged from $28,000 to $241,000 with the majority receiving between $50,000 to $75,000. The funding levels 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. The majority of the contracts (66%) were for one year, with six agencies (15%) reporting they had signed contracts of 2 years' duration and six agencies (15%) reporting that they had signed three-year contracts.

In addition to funding through their contract with MCFD, nine agencies reported receiving additional funds for the Key Worker and Parent to Parent Support programs from other organizations. All eight of the Key Worker agencies in the North Region received funding from Northern Health Authority (NHA) to support the CDBC assessment intake role performed by the Key Workers in those agencies. The amounts from NHA ranged from $4,700 to $24,000 depending on the anticipated demand for CDBC assessments in the communities. A Vancouver Island Region agency fundraised to support their Key Worker and Parent to Parent Support programs beyond the level for which they were contracted through MCFD. This agency had submitted grant applications to a number of foundations and other levels of government, e.g. Federal Government, in order to acquire additional funding.

Additional direct costs in at least two agencies in the North Region included agency contributions for the Key Worker positions in order to increase the amount of service available in the areas they served (from 0.8 FTE to 1.0 FTE). The value of this additional staff time was approximately $18,800 per year. One of the agencies reported that it would not be able to sustain this level of contribution beyond the term of its two-year contract.

Approximately two thirds of the agencies indicated that they provided or received in-kind contributions (indirect costs[9]) associated with the implementation and operation of the Key Worker and Parent to Parent Support Services. The most frequently mentioned items of in-kind contributions were for administration, supervision and clerical support. The provision of clinical supervision was a requirement of the Key Worker program, yet several agencies indicated that this activity was not adequately funded through the contract. Thus, they were providing it through an in-kind contribution. Fourteen of the 39 agencies that responded indicated that they were supporting clinical supervision through a combination of contract dollars and/or in-kind contributions. Of these 14 agencies, five reported that they were providing clinical supervision through in-kind contributions only – that there were insufficient funds in the contract to cover clinical supervision. Office space, materials and resources, meeting spaces, training and consultation were other areas where agencies provided or received in-kind support. A number of agencies also reported that they anticipated that childcare would be a growing area of in-kind support as the Parent to Parent Support initiatives became more active.

---

[9] 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).

The evaluation's 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 adequately support the expectations of the contract". 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 the regions that were identified through interviews and/or the Agency Questionnaires included:

- Funding did not cover full operating costs. Caseload growth would require more funding.
- Limited funds for education, training, resources and travel. Some agencies stated that they were able to use start up funds to support training, education and developing group resources but that these funds were not available on an ongoing basis.
- Some agencies were topping up the funding to cover additional staff time, training, child care costs, transportation and thus were worried about the sustainability of the services over the long term.
- Funding allocations within regions impacted hiring. Many agencies had difficulty attracting qualified staff because limited funding meant only part time positions were available or funding levels did not match salary levels for qualified staff.
- Specific to the North Region, some agencies found it a challenge to allocate the Key Worker funding between the intake and support services role.
- The funding did not allow for adequate coverage for all communities. Many communities have no access to the Key Worker and Parent to Parent Support Services because of remote locations and limited resources.

Key Workers

The Key Worker and Parent to Parent Support Services 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. A MCFD document recommended that Key Workers possess a "minimum of 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). Hiring of Key Workers took place throughout 2006 as contracts were signed in the regions. By the end of February 2007, Key Workers were in place in all but one of the contracted agencies. Throughout the province, the level of staffing ranged from 2.0 full-time-equivalent positions (FTE) to 0.2 of an FTE. According to data submitted by the agencies, the majority of the Key Workers that had been hired to date had at least a Bachelor Degree education. Tables 3 and 4 below summarize the FTEs and Key Worker qualifications by region.

Table 3: Summary of Key Worker Positions by Region
(N=39 out of 53 Agency Contracts)

REGION	NUMBER OF AGENCIES WITH FTEs IN RANGE			TOTAL KEY WORKER FTEs PER REGION
FTEs	≥ 1.0	0.6 to 0.8	≤ 0.5	
Fraser (n=11)	4	3	4*	**7.5**
Interior (n=6)	1	2	3	4.4
North (n=5)	3	2	-	4.6
Vancouver Coastal (n=6)	4	-	2	5.95
Vancouver Island (n=11)	5	2	4	8.45
TOTAL	17	9	13	30.9

Source: Time 1 Annual Agency Questionnaire

Table 4: Summary of Key Worker Qualifications by Region
(N=39 out of 53 Agency Contracts)

REGION	KEY WORKER ACADEMIC QUALIFICATIONS	KEY WORKER ACADEMIC QUALIFICATIONS	KEY WORKER ACADEMIC QUALIFICATIONS
	BSW/MSW	BA/MA	Other
Fraser (n=11)	3	1	6**
Interior (n=6)	3	3	1
North (n=5)	4	2***	-
Vancouver Coastal (n=6)	2	4	-
Vancouver Island (n=11)	3	5***	4
TOTAL	15	15	11

Source: Time 1 Annual Agency Questionnaire

* 1 agency contracted to provide Parent to Parent Support only
** 1 agency had not hired at Key Worker at time of writing
*** 1 Key Worker listed 2 degrees

According to the respondents, 60% of the Key Workers were in dedicated positions, that is, their caseload was entirely made up of Key Worker and Parent to Parent Support Services clients. In other agencies, funding levels only allowed for the creation of part time Key Worker positions. Approximately 40% 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, a significant number of Key Workers were in non-dedicated positions and were performing different job functions under different mandates in addition to their Key Worker functions.

Some agency managers identified Key Worker recruitment as a significant issue, particularly in the larger urban areas where well-qualified health and human service workers were in high demand. This factor,

combined with limited funding resulting in part time positions, further exacerbated the hiring process for some.

> *In a tight labour market candidates with this level of education and sufficient experience are hard to come by (Agency Questionnaire)*

> *This is further made difficult by disparate wage grids between Child Development Centres (CDC's) under HEABC collective agreements and agencies such as ours under CSSEA collective agreements. CDC's in neighbouring communities operate under a health sector collective agreement that pays significantly higher wages than the social services sector collective agreement we operate under. With few candidates to be found in general, those who are available are understandably choosing employment with higher wage rates. (Agency Questionnaire)*

Staff turnover was high is some regions as well, with 12 of the 39 agencies reporting Key Worker staff changes in the relatively brief period of time from May 2006 to February 2007. Appendix K contains a breakdown of the staffing changes by region. One agency had three different people in the Key Worker position between September 2006 and February 2007. Reasons for the turnover in Key Workers included: part-time nature of the work was not satisfactory, maternity leave, poor fit between employee's expectations and the nature of the work, and lack of clarity about the role. As one respondent stated:

> *(We are) not funded at high levels - qualifications are high and not in line in salaries, so these people getting snapped up by health/education/etc. So (we) have lost several Key Workers who have found better paying jobs. (Agency Questionnaire)*

As envisioned by the early program developers, 27 agencies reported that the Key Worker was ultimately going to provide Parent to Parent Support Services. Many agencies indicated that this aspect of the program had not started, primarily because the Key Workers had only been in place and accepting referrals for a short period of time. Thus, they had not had time to promote this aspect of the service. Other agencies offered the Parent to Parent Support Services through other staff and/or volunteers in the agency, or were working in collaboration with other agencies in their community that had expertise in parent support. Another approach, adopted by two communities in two regions, was to contract separately for the Parent to Parent Support Services. At the time of writing, the parent to parent aspect of the program was very much in the developmental stages. Some key informants indicated that they were unsure how to develop this aspect of the service and were hoping for more guidance from the provincial office. Development of the Parent to Parent support service will be explored in more depth in future reports.

Key Worker Supervision and Regional Coordination

Based on research evidence, supervision of Key Workers was considered by the program developers to be an important ingredient in the Key Worker and Parent to Parent Support Services (Greco et al, 2005). Thus, in the *RFP Resource for Regions,* developed to assist the MCFD regions in launching the Key Worker and Parent to Parent Support Services, 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). This recommendation was reflected in many of the contracts from around the province, although not all the contracts identified the requirement that clinical supervision be available for the Key Worker, especially those that were signed early in 2006/2007 fiscal year. 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 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 (weekly or bi-weekly) individual supervision with the Executive Director or with 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 K provides a summary of the educational qualifications of the Key Workers' supervisors.

In addition to clinical supervision, two regions have established contracts or partnerships with other organizations to provide Regional Key Worker coordination, supervision and mentoring. In the Interior Region, a non-profit agency holds the Regional Coordinator contract. The Regional Coordinator organized regional training, acted as a resource and clearinghouse for information about FASD and parent support options, and coordinated monthly conference calls with all the Key Workers in the region. She also coordinated the collection of output data for the evaluation thereby ensuring consistency in response from the region. As well, she worked with the regional CDBC Assessment Team to address the referral process from the Assessment Team to the Key Workers. The focus of the conference calls was on networking and information sharing amongst the Key Workers about their work, including the strengths and challenges. 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. MCFD Regional staff stated that they valued the Regional Coordinator position because it brought focus, consistency and energy to a very new program, as it was being implemented across the region.

- 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). Weekly conference calls with Key Workers focused on building relationships amongst the Key Workers, developing a consistent approach and standardizing information packages, forms and processes to support the dual roles of the Northern Key Workers, (i.e. also fulfilling the intake role for the Regional CDBC Assessment teams). Key workers reported that this network was very supportive and an important component of developing their new positions. As one Key Worker said:

The teleconferences help because they provide info and clarify processes. It helps to hear from other Key Workers and how they deal with situations. It also really helps to hear where others are in the process. It makes me feel better to hear that others are at about the same stage.

During the early months of program development, some agency managers in the North Region expressed concern about the duplication and/or confusion of supervision roles and responsibilities between the North Region's Regional Coordinator and the agency managers and supervisors who would normally provide supervision to their Key Workers staff. Because Key Workers were the only ones from their agencies participating in the weekly conference calls, there was potential for them to receive conflicting direction or they would receive important program information that their agency managers were unaware of, e.g., referral process, or evaluation requirements. The 'outside' clinical supervision also raised questions of liability for some of the agencies. In order to address these concerns, regular conference calls with the program managers were established. They 'meet' every few months to share information, plan and problem solve. These calls were recently implemented, thus little data were available about the specific content and impacts.

On Vancouver Island, another model of coordination and mentoring/supervision was created for the agencies delivering Key Worker and Parent to Parent Support Services in South Vancouver Island. As set out in the contract, the lead agency provided "mentoring and leadership to the development of the Key Worker and Parent to Parent Support Services model for South Island". The responsibilities 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 mentorship of the lead agency in developing a consistent model for the Key Worker and Parent to Parent Support Services. Key Workers from the four agencies have met regularly to assign cases that have been referred, to develop and deliver training to parents and community service providers, and to provide peer supervision to one another. The agencies also jointly developed a brochure to be given to parents. The Key Workers found this to be a very helpful process in orienting themselves to a new role, not only in their agencies and communities, but also in the province.

At least one MCFD regional manager, who had not developed a Regional Coordinator role, was hoping to do so in order to ensure there was greater support for the emerging role of the Key Workers, close connection with the health assessment teams in order to strengthen the referral process, and greater visibility, consistency and accountability for the Key Worker role in the communities. This region had posted positions for a part-time Regional coordinator and a part-time Clinical Coordinator and was awaiting classification of the positions.

Both the Fraser Region and the Vancouver Island region have held one-day regional meetings with Key Workers and/or their supervisors/managers. In the Fraser Region, members of the Fraser Health Assessment Network also attended the two, one-day meetings. The primary purpose of these meetings was for information sharing, problem solving and networking. Beyond these meetings, there was no formal mechanism to connect Key Workers in these regions. Nevertheless, Key Workers in the Fraser Region have met together on their own for information sharing and peer supervision and plan to continue this approach.

Similarly, in the Vancouver Coastal Region, there is no mechanism to bring Key Workers together, either formally or informally. However, at the Vancouver Coastal Key Worker training offered through the Justice Institute of BC, participants expressed an interest in having a forum to get together to share ideas about practice, policies and issues they were facing.

Training for Key Workers

Training for Key Workers and their supervisors/managers has taken place at the provincial, regional and local levels. The primary focus of the training has been to develop a common base of understanding about FASD and the key worker role amongst Key Workers and their supervisors; and to provide some initial skill building opportunities in community FASD education (train the trainer model) and advocacy. All the agencies (n=39) that responded to the Annual Agency Questionnaire reported that the Key Workers had received training upon appointment, and all but two indicated that training would be provided on an ongoing basis. (See Appendix K for a summary of Training for Key Workers and their supervisors.)

At the provincial level, in late spring 2006 Diane Malbin was retained to deliver training to the Key Workers and their supervisors. Two sessions were completed, one in September 2006 and a second in January 2007. Approximately 130 participants completed the training sessions. The majority of those attending were newly hired Key Workers and their supervisors. In the second session, some seats were made available to other community service providers working in the area of FASD.

According to the training syllabus, the three-day sessions were designed to provide:
- A foundation for understanding neurobehavioral disorders

- A framework for developing effective techniques
- A framework for support for implementation of these techniques in different settings.

Evaluations from the initial training session in September 2006 were overwhelmingly positive. Nevertheless, the evaluations indicated that the participants wanted more specific information about the role of the Key Worker: "that they left the conference (training) feeling confused about how to proceed" (Evaluation Summary of Three Day FASD Key Worker Training, September 2006, MCFD). This sentiment was echoed by some of the key informants interviewed for this formative evaluation report. Adjustments were made for the second provincial training in January 2007 in order to place greater emphasis on defining the role of the Key Worker. Evaluation comments from this training suggested that participants gained a solid appreciation for the role as a Key Worker. In contrast to the expressions of confusion from the first training session, participants in the second training session "indicated that they felt prepared and ready to implement the new ideas and techniques that they learned in working with clients" (Evaluation Summary of Three Day FASD Key Worker Training, January 2007, MCFD). As one key informant stated, the training "provided clarity about Key Worker role and a deeper understanding of FASD as brain based disability and how to work with children".

The following quote from one key informant characterizes training participants' appreciation for the provincial training and at the same time, the importance (for her) of developing a common language and conceptual framework upon which to base the role of the Key Worker.

> I've seen huge growth - Ahas! - in some people. They've experienced the paradigm shift. This is such a key strength for the provincial initiative overall. In the long run, that makes a huge difference.... I'm just so happy that everyone is speaking the same language, especially with Diane being the Consultant.

Regional level training specifically for Key Workers included:
- Key Worker training - Vancouver Coastal Region (developed and facilitated by the Justice Institute of BC)
- Aboriginal Key Worker training - Vancouver Island region (facilitated by BC Aboriginal Network for Disability)
- CDBC Assessment Team training[10] – North Region (facilitated by Northern Health Authority)
- Train the Trainer to build community capacity to develop integrated approach to service delivery for children and families affected by FASD – North Region (developed and facilitated by College of New Caledonia, Burns Lake Campus)

---

[10] Key workers participated in this training because part of their role includes the coordination of the intake for the CDBC Assessment process in the North.

- Advocacy Skills for Key Workers – Vancouver Island (facilitated by Foster Parents Support Services Society)

In addition to the Key Worker training, MCFD managers, Key Workers and their supervisors have identified the need for training and resources for Parent to Parent Support activities. For many agencies and their staff this was a new field of endeavour. For example, one Key Worker expressed the need for Parent to Parent Support training: she had questions about how to present the information about FASD, about mixing families with children with FASD with families with children with other CDBCs. As well, she did not have experience with running a parent support group so was interested in learning more about the facilitation skills and structures that work for parent groups.

In response to the emerging desire expressed for Parent to Parent Support training and/or resources, several regions undertook planning and/or committed funds for regional training in this area. For example, the Fraser Region provided funding for Parent Education training as an initial step to developing the Parent to Parent Support Services. The intent behind the parent education training was that parents would benefit from information and understanding about FASD and/or other CDBCs first, as part of a Parent to Parent Support Services continuum. Similarly, in the North Region, a 3.5 day "Parent to Parent Support Services" training for Key Workers, delivered by Self-Help Resource Association of BC, was planned for late spring 2007.

The various training initiatives were well received around the province. One MCFD manager considered the availability of training as a key success for the program and the region. One Agency Director felt that the amount of training available reflected the priority placed on addressing FASD. She stated that she really appreciated the level of training support available for this new initiative, however, that it was hard to fit it all in. For many of the Key Workers, who worked only part-time, the training took them away from their work and communities, sometimes for significant periods of time.

Key Worker Role

As discussed in Section 2, the Key Worker role is evolving as the implementation of the initiative progresses. Agency responses on the Annual Agency Questionnaire reflected a range of interpretations about the role of the Key Worker across the province and within regions. Some respondents saw the role as providing "case management" and "developing service plans which keep families at the centre of decision making". Education, information and resource sharing with families and community service providers; advocacy and acting as a referral source; supporting families during and after the assessment process; "providing opportunities for parents to seek and find support with each other"; community

development and compiling an inventory of services were among the other roles identified by respondents. Still others described the work as:

> *Helping parents learn how to navigate and advocate through the system of care for their children*

> *Becoming the key contact in the community for strategies for behaviours and information on how to work effectively with children with FASD and their families.*

Job descriptions provided by a small sample of agencies also reflected a range of understanding about the Key Worker role. Some key worker job descriptions were based on standard agency job descriptions, most commonly Family Support Services Workers, in order to meet job classification criteria in unionized settings. Others reflected contract information provided by MCFD in the *RFP Resource for Regions* (2005), which was developed to assist the MCFD regions in launching the Key Worker and Parent to Parent Support Services in the regions.

MiCFD documents reflect an evolution in understanding of the role. As can be seen in the table below, the description of the role of the Key Worker has changed from the early conceptualization in the *RFP Resource for Regions* (2005) to a more recent posting on the Ministry's Website.

Table 5: Comparison of Key Worker Roles in MCFD Documents

RFP Resource for Regions (2005)	MCFD Website (2007) (http://www.mcf.gov.bc.ca/fasd/support.htm)
• Liaise with a regional Health multidisciplinary assessment team that identifies children and adolescents with FASD and similar behavioural developmental conditions. • Support parents at the time of first diagnosis by a multidisciplinary assessment team. • Assist families in following through with recommendations and in accessing existing family support, health and education services. • Assist families whose children already have the formal diagnosis of FASD. • Refer suspected or self-referred cases of FASD to a multidisciplinary assessment team while providing appropriate interim support. • Does not provide therapy, but will work under supervision of a skilled professional.	• Understand their role as one that builds on a family's strengths. Children with FASD do best when their individual strengths are recognized and built upon in a supportive environment adapted to meet their needs. • Assist families in understanding FASD by providing education and information specific to the needs of the child and family • Be familiar with community resources, assist families in accessing support, health and education services and are involved in the development of local support services • Provide emotional and practical support to families. • Work with parents, family members, adoptive parents, caregivers and service providers in identifying ways to adapt the child's environment in response to the child's needs. • Strives to empower the family to become their own best advocates for their child (Advocacy).

Additional aspects of the Key Worker role were described in a Ministry presentation developed for the *2nd International Conference on Fetal Alcohol Spectrum Disorder: Research, Policy and Practice Around the World* in March 2007. According to the presentation, the BC Key Worker may also:

- Liaise with the Health multidisciplinary team assessment team
- Explain the range of programs, services and resources available to parents, and help them access the ones most appropriate to the needs of the child
- Attend school meetings and case conferences with the parent
- Assist in starting then acting as a resource to parent support approaches (groups, mentoring)
- Assist affected youth living independently
- Act as a community resource for FASD information and prevention

Regardless of the job descriptions some Key Workers expressed confusion regarding their role.

> *I'm a bit confused about role of Key Worker as a "change agent" within community. Therefore, if it's a family's choice that limits who/how you can go. e.g. family in (community) who declined Key Worker involvement in advocating for services in school.*

> *The Key Worker role is confusing if you are not doing intake.*

Based on Agency Questionnaires and key informant interview data, reaching a common understanding, not only within MCFD and the agencies but also in the community, the Key Worker role was a significant challenge during the past year. For example, in describing implementation challenges, one agency spoke of the low numbers of referrals received yet linked this to the lack of clarity regarding the Key Worker's role:

> *A key challenge has been the low number of referrals to date. A contributing factor may have been confusion regionally and provincially regarding the role of the key worker (i.e., behavioral intervention vs. linking and liaising) and the population to be served.*

Challenges associated with achieving a shared understanding of the Key Worker role may partly stem from the multiple or evolving models underpinning the Key Worker program discussed above. Similarly, differences amongst staff working within MCFD regions as well as FASD/CDBC Assessment managers, in conceptualizations of the Key Worker role initially resulted in confusion regarding the Key Worker's role.

Different service delivery models, such as those In the North Region and in two agencies in the Vancouver Island Region, where the Key Worker positions combined CDBC Assessment intake with the Key Worker and Parent to Parent Support services may also have contributed to the confusion. This

combined role, partially funded by the respective health authorities, was designed to facilitate access to both CDBC assessments and key worker services in smaller communities. Intake functions included:

- Coordination of referral information for the CDBC assessment teams
- Liaising with assessment team and community health services/agencies to ensure needs of child and family are met
- Coordinate CDBC assessment appointments with the child and family
- Support the family through the assessment process

Key Worker functions included:

- Providing the families with tools, resources, support and guidance;
- Ensuring that specific information sharing regarding the child's health or special needs takes place;
- Fostering community integration across all community systems, including Aboriginal communities, in order that the child or youth will access comprehensive services;
- Providing respectful and supportive care through emotional support, encouragement and linking to community supports; and
- Establishing and maintaining mutual aid support networks, including parent-to-parent support groups (Memorandum of Understanding MCFD North Region and Northern Health Authority, 2006)

Interviews with North Region Key Workers and their supervisors/managers, and data from the Annual Agency questionnaires indicate that at this early stage in implementation of the assessment and Key Work programs in the North, the focus has been on the intake process for the CDBC Assessments and on community education. While the data do not speak to all communities, actual support to families, beyond the CDBC assessment process has been limited. In at least one community, this has led to turnover of Key Worker staff who felt their skills in working with families were not being used. The following responses from some northern communities reveal a focus on the assessment process. The role of the Key Worker is to:

- *Coordinate assessment, support families/children throughout the assessment, community education, gather reports for assessment, education for families/others caring for/teaching child, parent to parent support, documentation of gaps in services.*
- *Support families through the assessment/diagnosis process*
- *Establish the administrative framework for the program with the funders*
- *Develop partnerships in the community.*

However, not all communities with the combined role emphasized the CDBC assessment process. Others had another perspective of the Key Worker role as:

- *Liaison to school district and community partners*
- *Primary contact for families*
- *Organizing and finding resources relating to a particular child's disability, developmental delay, diagnosis or level of functioning*
- *Assisting with parents who may have FASD to understand and access diagnosis.*
- *Supporting parents who may have FASD in parenting children who have been diagnosed.*
- *Providing linkage and advocacy for all parents who need support.*

Those interviewed expected that a shift in emphasis would occur once the families had completed the assessment process and the Key Workers began to work with the families on interpreting and implementing the recommendations of the assessment reports. At the same time, however, key informants in the North reported that referrals for assessment were increasing which increased their workloads in relation to their intake duties.

Nevertheless, despite the differences, several factors have contributed to developing a shared understanding of the Key Worker role in some areas of the province:

- Foremost among these factors was the delivery of province-wide Key Worker training by Diane Malbin in September 2006 and January 2007. Discussion of the Key Worker role at provincial trainings led to increased understanding of the role, and promoted the importance of a shared vision/understanding of the role.
- Second, having regularly scheduled, ongoing regional meetings of Key Workers (both by teleconference and face to face) helped promoted clarity in and common understanding of the role in those region.
- Finally, in some regions, having a regional program coordinator both helped to ensure that there were mechanisms for Key Workers to network and discuss their role and activities, as well as their emerging successes and challenges.

MCFD Provincial Office Inputs

The Children and Youth with Special Needs Branch of MCFD has supported the development and implementation of the Key Worker and Parent to Parent Support Services in the regions through funding, research, access to information and training support. Initially there was firm guidance regarding the parameters of the program, especially the requirement for key worker and parent support components, followed by resources such as RFP templates, suggested job descriptions, resources related to recent relevant research, and training for the regions to draw upon as they planned and implemented the program. More recently a section on FASD and the Key Worker and Parent to Parent Support Services has been added to the MCFD website.

As well, Provincial Office support has been provided through a three-year contract for consultation services with Diane Malbin, a recognized authority in FASD and FASD-related interventions. These consultation services are available to all MCFD regional staff working in the area of FASD, contracted Key Worker and Parent to Parent Support agencies and the Key Workers. At the time of writing, the consultation services had been used primarily to support curriculum development for various provincial and regional FASD training initiatives and program development. It is anticipated that as program implementation proceeds, more Key Workers and their supervisors will use the 'expert' consultation for case consultation.

For the most part, the support from the Branch has been well received, especially the training for Key Workers and their supervisors, the consultation services and the website. However, responses to open ended questions on the Agency Questionnaire and key informant interviews, including regional staff, suggested that more support was desired in the form of policies, job descriptions and clearer articulation of language and referral processes for both the Key Worker activities and the Parent to Parent Support component.

This section has addressed some of the key inputs and formative outcomes related to the key worker positions. In the next section formative outcomes in relation to engaging families and the communities will be discussed.

References

Greco, V., Sloper, P., Webb, R., & Beecham, J. (2005) *An Exploration of Different Models of Multi-agency Partnerships in Key Worker Services for Disabled Children: Effectiveness and Costs.* York, UK: Department for Education and Skills. Research Report 656. University of York.

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

Province of British Columbia. 2005. *RFP Resource for Regions.* Ministry of Children and Family Development.

Engaging Families/Caregivers

Early Formative Outcome: *Families/caregivers are engaged with Key Worker*

As of March 2007, all but three all Key Workers had begun providing Key Worker services to at least one family. Table 6 provides output data on the number of new families accepted for service (i.e., intakes) from June 2006 – January 2007.

Table 6:

Number of new families accepted for service (i.e., intakes), by region, June 2006 – January 2007

	Fraser Valley	Interior	North	VC	VI	Total (4 regions)
Number of New families accepted for service (i.e., intakes)	43	49	51	No data available	63	**206**

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

Numerous Key Worker agencies reported that receiving referrals was a major milestone of the past year. Indeed, 'receiving referrals' and beginning to engage and work with families were identified by agencies as the program's biggest milestone to date.

At the same time, as noted above, agency questionnaire and key informant data indicated that because of initial and in some communities prolonged confusion around the referral process and eligibility criteria for the program, many Key Workers had received fewer referrals to date than anticipated. These findings are discussed in more detail in the section of this chapter on Engaging Communities.

There also was considerable variability within MCFD regions in the number of families who had begun to receive Key Worker services. For example, in one region, one agency had not yet seen families, four agencies were working with fewer than five families, three agencies were working with 5-9 families, and two agencies were working with more than 10 families. Output data from other regions showed comparable variability across agencies and communities with respect to the number of families they were serving.

The ways in which Key Workers first engaged with families (i.e., the types of activities initially undertaken with families) varied between regions. The biggest regional difference was in the North Region, where

Key Workers served as intake workers for the FASD/CDBC assessment process. Thus, the Key Worker role in this region involved coordinating the assessment process and gathering relevant documents for the assessment, and supporting families to be able to access and understand the assessment process. By contrast, in all other regions (i.e., ones that were not as closely linked to the assessment process), Key Workers' initial activities in engaging with families were more varied and likely to focus on parent/caregiver or community education or on accessing appropriate community supports and/or environmental accommodations.

As shown in Table 7, differences were observed between regions in the number/percentage of referrals in which the child had suspected or confirmed FASD, relative to referrals in which the child had a CDBC assessment other than FASD. For example, in the Fraser Valley, referrals to the Key Worker program came from many families whose child had been assessed as having CCY/CDBC, whereas in other regions, referrals from families with suspected or confirmed FASD substantially predominated. In the future, we will explore the breakdown of the CCY assessments and what these CCY 'diagnoses' are in order to explore the need for additional clarification in the eligibility criteria for the Key Worker and Parent to Parent support services program.

Table 7:

Number of new family referrals with children with confirmed or probable FASD
& number of new family referrals following CDBC assessment other than FASD,
June 2006 – January 2007

	Fraser Valley	Interior	North	VC	VI	Total (4 regions)
Number of New Family Referrals with Children with Confirmed or Probable FASD	29	39	51	No data available	62	**181**
Number of New Family Referrals with Children following CDBC assessment other than FASD	18	11	2	No data available	5	**36**

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

Additional demographic information about the children/youth accepted as 'intakes' to the Key Worker program is provided in Table 8. As can be seen, in all regions there were substantially more males referred to the program than females; the percentage of males ranged from 66% to 72% of the total intakes, across the four regions for which output data were available for this report. The breakdown by age groups in intakes was far more variable by region, however, especially the percentage of intakes that were age 0-6 (e.g. in one region, 50% of the total intake were age 0-6, while in another region, 10% of the total intakes were age 0-6). Similarly, the percentage of intakes who identified as Aboriginal varied widely by region: from 20% to 68%. The region in which there was the lowest percentage of intakes who

identified as being Aboriginal (20%) corresponded to that in which there was the highest percentage of families referred with a CDBC (rather than confirmed or suspected FASD) assessment (38%).

Table 8:

**Demographic information for child and youth intakes to Key Worker program, by region
June 2006 – January 2007**

	Fraser Valley	Interior	North	VC	VI	Total (4 regions)
Total number of **male** child/youth intakes	29	30	40	No data available	58	**157**
Total number of **female** child/youth intakes	15	18	17	No data available	23	**73**
• Number of child/youth intakes, **age 0-6**	22	5	17	No data available	22	**66**
• Number of child/youth intakes, **age 7-10**	11	13	23	No data available	18	**65**
• Number of child/youth intakes, **age 11-15**	7	26	14	No data available	28	**75**
• Number of child/youth intakes, **age 16-19**	4	4	3	No data available	13	**24**
Total number of child/youth intakes, **who identify as Aboriginal**	9	25	33	No data available	55	**122**
Total number of child/youth intakes, **who identify as visible minority**	2	1	0	No data available	3	**6**
SUMMARY INFORMATION						
Total number of child/youth intakes	**44**	**48**	**57**	**No data available**	**81**	**230**
Percentage of total child/youth intakes **who are male**	66%	63%	70%	No data available	72%	**68%**
Percentage of total child/youth intakes **who are female**	34%	37%	30%	No data available	28%	**32%**
• Percentage of total child/youth intakes who are **age 0-6**	50%	10%	30%	No data available	27%	**29%**
• Percentage of total child/youth intakes who are **age 7-10**	25%	27%	40%	No data available	22%	**28%**
• Percentage of total child/youth intakes who are **age 11-15**	16%	54%	25%	No data available	35%	**33%**
• Percentage of total child/youth intakes who are **age 16-19**	7%	8%	5%	No data available	16%	**10%**
Percentage of child/youth intakes, **who identify as Aboriginal**	20%	50%	58%	No data available	68%	**53%**
Percentage of child/youth intakes, **who identify as visible minority**	5%	2%	0%	No data available	4%	**3%**

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

Agency questionnaires and interview data revealed that an additional formative outcome and key strength of the program was the Key Worker's family-centred approach and philosophy of practice. Elements of a 'family-centred' approach that were important in the Key Worker program included:

- Use of outreach
- Key Worker as "someone who listens"
- Community-based service
- Strengths-based approach

As noted by Key Worker agencies in two regions:

Being able to start where the client requires (is a strength of the program). (Key Worker) support is flexible, open-ended. (The Key Worker) may support (the family) for a half hour via phone or attend meetings as required. Needs are client-driven.

Build on families' strengths; family centered philosophy: family knows child best.

Formative Outcome:

Families / caregivers are engaged with Key Worker

Spotlight on a "Family-centred" approach to engaging with families/caregivers

In keeping with agency questionnaire data, families interviewed as part of the evaluation's community-based data collection spoke consistently of the importance the Key Worker's use of a flexible approach that was guided by the needs of the parent/caregiver. In the words of several parents/caregivers who had engaged with the Key Worker in one community:

(The Key Worker) is great - she's compassionate. She asks what I need. She goes step by step. She doesn't overwhelm you. She validates my feelings. Even if she can't do anything about this - just to listen to me, how I'm feeling.

She calls me - out of the blue. I really appreciate that she calls me. She asks how things are going and what can she do to help. She offered to help get a meeting/referral to a pediatrician.

I'm excited about (the Key Worker): There's someone there. Someone who calls back. Someone who identifies resources and sees the possibilities. This gives my family some hope.

Early Formative Outcome: *Families/caregivers are informed about their child's assessment findings*

In the past year, there has been considerable variability in the extent to which Key Workers have been involved in helping inform families about assessment findings.

In part, this can be related to regional variability in terms of when Key Workers began working with families. For example, as shown in Table 9, in one region, a substantial percentage (41%) of referrals came after the child was assessed.

**Table 9: Timing of new family referrals, by region,
June 2006 – January 2007**

	Fraser Valley	Interior	North	VC	VI	Total (4 regions)
When was the family referred to Key Worker program?				No data available		
# 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%)**
Total number of referrals	**44**	**54**	**70**	**No data available**	**81**	**249**

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

In another region, many of the families referred to the Key Worker either already had a previous assessment, or were seeking the Key Worker's support prior to their involvement in the assessment process. In this region as in others, there is little information to date that speaks to the Key Worker's role in informing the family about assessment findings, since it would be a number of months until the

FASD/CDBC assessment findings became available. Similarly, agency questionnaire data suggested that this aspect of the Key Worker program was still evolving.

Given that the FASD/CDBC assessment teams themselves were still in early days of implementation, and thus as of March 2007 in some regions relatively few assessments had been completed, perhaps a more relevant early outcome to report on is: *Families/caregivers are assisted / supported during their child's assessment.*

Agency Questionnaire data indicated that a number of agencies viewed Key Workers' assistance of families during the assessment process to be both a key facet of the Key Worker role and a strength of the program. This finding emerged strongly in the North, where Key Workers were integrated into the assessment teams. A number of Key Workers/agencies reported that support of families during the assessment process was especially important for parents/caregivers who themselves had FASD or who had limited capacity and resources. In the words of one agency:

> *The Key Worker provides guidance needed for families from pre-assessment through to the ongoing services and support. This is especially pertinent as the majority of the parents display characteristics of FASD and would be unable to access or understand this service.*

Based on the evaluation's community-based interviews, there was some evidence that families valued having a Key Worker's involvement in the presentation and discussion of the assessment findings (see box, below).

Formative Outcome:
Families/caregivers are assisted / supported during their child's assessment
Spotlight on a community-based example of this outcome

In one community, a family had been referred to their Key Worker through the regional FASD/CDBC assessment team, and the Key Worker accompanied the family to the case conference convened by the team to share assessment findings and recommendations. In this situation, the caregiver (who was the child's grandparent) expressed her appreciation of the support that both she and her very ill adult daughter (the child's mother) received from the Key Worker. This caregiver stated:

> *(The Key Worker) came to a meeting in the fall at (the assessment centre). She spent three hours at this meeting - that's a lot of time. …It was a very difficult meeting to take. I wasn't really prepared to hear the news. Yet what I liked*

> *about it was everyone focused on (the child's) behaviour. It's not that L wants to be bad; he just has behaviours. (The Key Worker) also suggested various supports/strategies. She promised to follow up and she did. This doesn't always happen. (The Key Worker) also said, "I can't wait to meet (child). That meant a lot to (my daughter). She perked right up."*
>
> The assessment team Coordinator was similarly positive about the support provided to the family during the post-assessment meeting, and also commented that having the Key Worker present at the post-assessment meeting was helpful to the Coordinator herself, in that she recognized that the family's support needs were being addressed. She noted:
>
> > *(The Key Worker) dropped everything to come and support the (caregiver). She was non-judgmental, and sat near the caregiver, providing support. It was a fantastic and very emotional meeting. I felt great – knowing that (the Key Worker) was there to support the family. Since then, the Key Worker has provided phone support and encouragement to the child's mom.*

Early Formative Outcome: *Families/caregivers are informed about existing services and resources*

Data about this outcome are limited, given the small sample of families/caregivers involved in the evaluation at this time. Nevertheless, based on the community-based interviews, the experience of families/caregivers varied in relation to this outcome.

Some parents/caregivers received information about services and resources that were specific to the needs of both the child and the family.

> *She offered to help get a meeting/referral to a paediatrician.*

> *(The grandmother) wants sole custody and sole guardianship of both the 4 year old and 2 year old. (The Key Worker) is going to talk with MCFD about getting this.*

> *There's someone there. Someone who calls back. Someone who identifies sources and sees the possibilities. This gives her (the mother) some hope.*

More importantly, in addition to providing information about services/resources, the families/caregivers valued offers from Key Worker to facilitate access to services and/or to accompany the parent/caregiver

to meetings. While not stated directly, the impression from the families/caregivers was that without this level of support in accessing services, they might not follow up on their own.

> *She has helped me with the Social Worker (who is a child protection worker and threatening to remove the boy) and with the school. She can word things better than I can. I am not very adept with words.*

> *She has offered to accompany me to take the children to Vancouver for assessment with paediatrician. Taking them to a doctor is a big deal.*

Other parents/caregivers who were more recently involved with a Key Worker as part of the assessment intake process reported that they had not been offered information about services and community resources and others identified the need for assistance in finding services:

> *We need help knowing who and what we can talk to when we come to meetings – we want help to figure out the network of services and who we can turn to for help.*

Consistent across all the regions, the responses of the Agency Questionnaires emphasized providing information about services and resources as an important role for Key Workers. As can be seen from the quotes below, similar to the experience of parents/caregivers, the agency responses stressed a close relationship between providing information, linking to resources and advocacy:

> *Intervention: empower parents by providing them with support, resources and information*

> *Providing linkage and advocacy for all parents who need support*

> *Supporting parents to link with community resources that meet the needs they identify for themselves and their children*

Early Formative Outcome: *Information about FASD/CDBC and other related topics is available and accessible*

This outcome is linked to 'engaging communities' outcome (*communities are informed about FASD as brain-based disability*), discussed later in this section.

In all regions, Key Workers have provided information about various aspects of FASD/CDBC to a variety of groups, including but not limited to parents and caregivers. Key Workers have undertaken

presentations and/or workshops or educational sessions at community-based programs (e.g. parent groups, schools), and participated in networking meetings with other community professionals including schools. For example, one Key Worker agency had facilitated workshops on various aspects of living and working with FASD, including criminal legal system issues, addictions issues, and parenting issues.

In addition, evaluation data suggested that when the Key Worker was based in agencies that offered multiple programs serving families and adults, opportunities sometimes arose organically for Key Workers to share information on FASD/CDBC with agency colleagues and then with the participants of colleagues' programs.

For example, in one House of Friendship that held a Key Worker contract and also offered several programs for adults and/or families, one of the Key Worker's co-workers ran a supported employment program. Following a discussion with the Key Worker about the Key Worker program, the colleague asked the Key Worker to lead a discussion about FASD with her program's clients. This led to at least one client of the employment program following up and accessing additional information about FASD/CDBC, as well as self-referring to the Key Worker and potentially seeking support in accessing a FASD/CDBC assessment for her child.

Engaging with Communities

Early Formative outcome: *Shared understanding of referral process*
Reaching a shared understanding of the referral process was a major task of this first year of program implementation.

In all regions, key informants including Key Workers, program managers and regional Child and Youth with Special Needs managers stated that developing a common understanding of the referral process had been a challenge. Key informants also emphasized that there was substantial within-region as well as between-region variability in the 'typical' or standard process of referring families to Key Workers. This reality contributed to the challenges in achieving this short-term formative outcome.

To illustrate, in one MCFD region, Key Worker agencies in the southern part of the region emphasized that referral or access to the Key Worker was not tied to the assessment process; moreover, there were no stipulations in eligibility criteria in terms of presence or recency of a FASD/CDBC assessment. By contrast, in other parts of this region, referrals to the Key Worker agency were closely linked to the health assessment process. In communities in this area, the referral process typically involved the Health Assessment Coordinator contacting the Key Worker upon receiving parents'/caregivers' consent, and then the Key Worker contacting the parents/caregivers to inform them of the Key Worker program.

Open-ended comments on the Agency Questionnaires in another MCFD region also illustrated the within-region variability in the referral process and/or reflected variability in agencies' understanding of the referral process. In describing their agency's referral process, two agencies noted:

> *Referrals are only accepted through referral from the regional health authority. (Agency Questionnaire)*

> *Referrals can be made by anyone as long as the parent is aware of the referral. (Agency Questionnaire)*

In a different MCFD region, referrals to Key Workers similarly came from and were tied to the FASD/CDBC assessment teams. In this region, however, the vast majority of children and youth who were assessed were children in care; yet because of perceived issues surrounding confidentiality, there was considerable variability in terms of whether and when MCFD social workers referred parents/caregivers to the Key Workers. Key Workers thus spent a lot of time in fall 2006 and winter 2007 informing social workers about the program and building relationships with them in order to facilitate the referral process.

Another primary factor contributing to confusion or to a lack of shared understanding of the referral process was lack of clarity at both a managerial and an agency level regarding eligibility for the program as well as the definition of the target client group(s) (i.e., families with children with Complex Developmental Behavioural Conditions), since the terminology of CDBC was not one that was frequently or consistently used. As one agency noted in its questionnaire:

> *We haven't begun accepting referrals yet; they start February 1, 2007. However, our first challenge has been in defining criteria for qualification for the program, as 'complex behaviour' seems to mean different things to different people.*

In some regions and communities, confusion or lack of shared understanding of the referral process was linked to a difference in perspectives between CYSN managers and Community Services Managers in relation to both the typical referral process and the eligibility criteria for Key Worker services. As one agency manager reported:

> *In developing our brochure, we took from wording of our contract. There was some confusion between May and October regarding where referrals came from, e.g. from health or more broadly. I realize there are variations in language and contracts. I want to be more inclusive.*

Table 10 provides output data for four MCFD regions in relation to the referral source. These data, as well as those shown above in Table 9, show substantial between-region differences in referral source and the timing of the referrals relative to the FASD/CDBC assessment process.

Table 10: Number of new family referrals received, by referral source and region
June 2006 – January 2007

	Fraser Valley	Interior	North	VC	VI	Total (4 regions)
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%)**

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

In all regions, strategies undertaken to address challenges relating to a clearly understood or common referral process included:

- Repeated discussions and meetings between MCFD CYSN managers and Health Assessment managers;
- Ongoing meetings between CYSN managers and Community Services Managers to facilitate amendments in Key Worker contracts to reflect a more open referral process; and
- Relationship building between Key Workers, assessment team members, social workers and other community professionals.

Formative Outcome: Shared understanding of referral process –
Spotlight on the Fraser Valley Region

The standard referral process

According to MCFD CYSN and Health Assessment Networks Managers, the aim in this region was to have 'seamless' connections between FASD/CDBC assessments and the Key Worker program. At the same time, the CYSN Manager stated that there should be an 'open door'

---

approach for families in terms of referrals for the Key Worker program. In fall 2006, Key Workers and the assessment teams believed that referrals to Key Workers were (primarily) to come through the assessment teams.

Year 1 Challenges

Initially, the above referral process created confusion because assessment teams were not clear about what information they could share with the Key Workers or when they could share information and/or make the referral (i.e., at intake or following the completed assessment). Moreover, Community Services Managers in this region initially believed that the Key Worker service should only be accessed by families who were being assessed by the region's health assessment teams, and contracts with the Key Worker agencies had varying language regarding the referral process. Further, initially a number of the Key Worker agencies had developed their own referral forms for use by the region's assessment teams. These agency-specific forms created additional complexity and increased the assessment team's workload in that the teams were not always clear about the geographic catchment areas of the Key Worker agencies or other eligibility criteria for the program, or whether a given agency's Key Worker program was fully operational. As a result of these challenges, a number of agencies in the region were slow to receive referrals for Key Worker services.

Actions taken to address implementation challenges

Ongoing discussions between MCFD and Health Managers have been instrumental in ironing out the bumps in the referral process. These steps included:

- The Health Assessment Network developed a common referral form for Key Worker services to be used by all assessment teams and all Key Worker agencies.
- It was agreed that parents/caregivers would be informed about the Key Worker program upon intake into the Assessment process. With parent/caregiver consent, referrals to the Key Worker agency would be made at intake. Parents/caregivers would be informed/reminded about the Key Worker program when the assessment took place and/or following the assessment.
- The MCFD CYSN Manager clarified and reiterated the intended 'open door' eligibility criteria, and thus the multiplicity of referral processes.

These clarifications led to amendments in the contacts between Key Worker agencies and their Community Services Manager in relation to eligibility criteria for Key Worker service. With these amendments, there was greater clarity that families who had not been assessed or who had 'recently' been assessed were nevertheless eligible for the Key Worker support program. There also was greater clarity that referrals could come from other community professionals or

from families themselves.

Early Formative Outcome: *Shared Understanding of the Role of Key Worker*

In the process of conducting analyses for this report, we have identified the need to re-conceptualize this early formative outcome as two related outcomes:

1. Having a <u>clear</u> understanding of the role of the Key Worker
2. Having a <u>common</u> understanding of the role of the Key Worker (i.e. across Key Worker agencies, and between various divisions of MCFD; between MCFD and the Key Worker agencies; between Key Worker agencies and the FASD/CDBC assessment teams, and so forth).

Formative findings including issues and challenges in reaching a clear and common understanding of the role of the Key Worker are discussed in Chapter 4, in the section on Key Worker role.

Early Formative Outcome: *Communities are informed about the FASD/CDBC support program*

In the past year, Key Workers in all regions spent much of their time meeting with community agencies and service providers, as well as MCFD teams, in order to inform them about the new FASD/CDBC program. As noted above, meetings convened by Key Workers to discuss the program were instrumental in promoting better understanding about eligibility criteria for the program as well as the various possible referrals pathways for Key Worker services.

In addition, many Key Worker agencies developed brochures in order to inform families, community agencies and organizations, MCFD teams and FASD/CDBC teams about the program. Brochures generally included information about the Key Worker and Parent to Parent support role, FASD, and the connections to the CDBC assessment process. In the North, the Key Workers, along with the Regional Coordinator spent time developing common content and format for promotional pamphlets.

Early Formative Outcome: *Through Key Workers, community members are informed about FASD as a brain-based disability*

As of March 2007, progress was made in informing community members about FASD as a brain-based disability. In most regions, sharing knowledge through regional training events and/or through community-based workshops was a focus of Key Workers' activities.

For example, in the Interior Region, the systematic development of regional training curricula and the delivery of workshops on FASD in seven communities across the region were central components of

program implementation in 2006/7. According to key informants, these trainings acted as catalysts for further community development and information sharing regarding the Key Worker and parent-to-parent support services. As well, the training workshops resulted in the creation of 'FASD Tables' in some communities, which began meeting on an ongoing basis with leadership from the Key Workers.

In the Fraser Region, one agency (a Child Development Centre) held Key Worker contracts in three communities. The Key Workers in these communities collaboratively developed a series of educational workshops on FASD/CDBC for parents/caregivers and other community members. In this situation, the Key Workers hoped that the workshops would potentially become the basis or entry point for community-based parent-to-parent support groups. In February 2007, this workshop series commenced, with the workshops being held in the most centrally located of the three communities. Key Workers informed the parents/caregivers on their caseloads about the workshops and supported interested parents/caregivers to attend. The workshops were jointly facilitated by the Key Workers.

On Vancouver Island, there was substantial within-region variability in terms of how Key Workers were involved in developing and delivering community-based information on FASD. For example, one Key Worker agency (a FASD-focussed organization) had received separate funding for FASD-related educational workshops for many months prior to the formal commencement of the Key Worker program. The Key Worker at this agency had been organizing and facilitating these workshops even prior to assuming her role as a Key Worker. In other communities in this region, however, as of early spring 2007 Key Worker agencies had only begun to plan or undertake community education related to FASD.

In the North Region, as mentioned earlier, Key Workers attended two train-the-trainer sessions developed by the College of New Caledonia based on a National FASD training initiative. It was anticipated that Key Workers would then customize the training and deliver it within their communities. At the time of writing not all Key Workers had implemented this strategy; future evaluation reports will track this and report on outcomes associated with the training.

Output data relating to this formative outcome (i.e, "number of hours of public / provider sessions" and the "number of attendees per public / provider sessions") are shown in Table 11. As can be seen, there was variability between regions in the number of sessions and the number of community participants attending the sessions.

Table 11:
Number of hours of public / provider sessions
and number of attendees per public / provider sessions, by region
June 2006 – January 2007

	Fraser Valley	Interior	North	VC	VI	Total (4 regions)
Number of hours of public / provider sessions	31	124	27.5	No data available	174	**356.5**
Total number of attendees at public / provider sessions	216	581	119	No data available	1153	**2069**

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

---

Formative Outcome:

Community members are informed about FASD as a brain-based disability –

Spotlight on the Interior Region

Regional FASD-related training - the implementation process

- In the 2005/6 FY, the region used a portion of its Key Worker program funding to contract Thompson River University (TRU) to develop a training curricula relating to 'FASD 101' including women's issues and addictions (Phase 1) and integrated case management (Phase 2).

- In 2006, Diane Malbin (the FASD Consultant contracted by the MCFD Provincial Office) provided content expertise to ensure that the curriculum was congruent with provincial training on FASD.

- In summer 2006, the Interior region hired a FASD/CDBC Program Coordinator, whose primary activities included assisting the 'roll-out' of the Key Worker program, facilitating ongoing networking and information sharing amongst Key Workers, and overseeing the regional FASD-related training.

- The regional FASD-related training was organized into two phases, with each phase being 3-days (15 hours) in duration, held 7 weeks apart. Phase 1 included having a panel of young adults with FASD speaking about their experiences living with FASD. Similarly, Phase 2 included a parent/caregiver panel.

- The trainings were co-facilitated by the same two instructors in each community; however, the Key Worker based in each host community was closely involved in organizing the sessions.

- For Key Workers, the training sessions provided opportunities to share information

regarding the Key Worker program, to be a visible resource regarding FASD/CDBC, and to engage in relationship building with diverse groups and individuals.

- The training sessions were designed for 30 participants from a variety of sectors and organizations, including MCFD social workers, Aboriginal agencies, school personnel, staff of Child Development Centres and other community agencies, and adoptive, foster and birth parents.
- In 2006/7, the training sessions were offered in 7 communities in the region.
- By March 2007, approximately 240 people had participated in at Phase 1.

Year 1 Challenges

- Community awareness/development regarding FASD takes time!
- Understanding FASD as a brain-based disability often requires a 'paradigm shift'. This shift also takes time and involves reframing previously held conceptions as well as dealing with emotions associated with this reframing process.

Actions taken to address implementation challenges

The presence of the regional Program Coordinator, along with ongoing discussions involving the Coordinator and Key Workers, and program managers in community agencies, and/or Health Assessment teams have been instrumental in helping to promote common information and shared language regarding FASD.

Appendix J provides a summary of the strengths, challenges, and milestones that emerged from the Agency Questionnaires.

Appendix L provides a summary of the remaining Time 1 program output data.

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

The MCFD Key Worker and Parent to Parent Support Services for families, children, and youth with FASD or CDBC is an ambitious undertaking involving inter-ministry collaboration and development, and delivery of a provincial program within MCFD's regional model of service delivery. The Key Worker and Parent to Parent Support Services is the first of its kind in BC and possibly Canada. This puts BC at the forefront of addressing the needs of children and families/caregivers affected by FASD and also makes the province uniquely positioned to contribute to the literature on best practices related to FASD.

The Key Worker program is based on research from other jurisdictions that shows that children and families with disabilities benefit from the presence of a key worker. As well, input from families along with evidence from already existing FASD programs throughout BC indicated that parents/caregivers valued the support they received from other parents with circumstances similar to their own. This knowledge gave rise to inclusion of parent to parent support as part of the overall service.

Hallmarks of the program are the availability of expert consultation for regions and Key Worker agencies, along with province wide training and support, as well as the inclusion of a process and outcome evaluation from the outset. Other notable features of the program are that it is a province-wide service that has increasing funding over the first three years of implementation, and that the program links assessment and support services.

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

Summary of program strength 2006-2007:

- There has been **multi-sectoral and inter-ministry collaborative planning**, as well as, in several regions, ongoing collaborative activities to promote better coordination of the province's current FASD-related initiatives.
- There has been **common, province-wide training of all Key Workers**, provided by the program's expert consultant. The training was extremely well-received: among the

---

strengths of the training was the quality of the curriculum and expertise of the facilitator; the consistency of the information provided to all Key Workers; and the opportunity to have Key Workers come together to network and exchange information.

- As of March 2007, **Key Workers are in place** nearly all contracted KW agencies in the province

- As of March 2007, **nearly all Key Workers are seeing families**; for Key Workers, beginning to receive referrals was noted as a major milestone to date.

- Key Workers' use of a **family-centred approach to practice** was seen as a program strength by Key Workers and families alike.

- **Regional Coordinators** were in place in two regions, and another region planned the hiring of a Regional Coordinator for spring 2007. As well, coordination/mentoring of Key Workers by a "lead' Key Worker was taking place in one metropolitan community.

The Key Worker and Parent to Parent Support program is at an early stage of implementation, with Key Workers just being introduced into most communities in BC during the latter half of 2006. At all levels - provincial, regional, and local – there is a strong desire to learn from what is working and what is not, so as to make the adjustments that are needed to ensure positive outcomes for families and communities.

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

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

The BC Key Worker and Parent to Parent Support Services were initially based on a model that was developed in the UK. However, involvement of expert consultation and FASD training based on a model developed by the expert consultant and provincial trainer influenced how the BC program was conceptualized and gave prominence to the notion of appropriate environmental accommodations. The language related to the Key Worker's role and function subsequently changed. Key Workers were seen as "facilitators", and expected to help a wide range of people to understand FASD as a brain-based physical disability with behavioural symptoms, with a goal of helping to identify ways that the child's environment could be adapted in response to the child's needs. This is a subtle yet important shift in emphasis that did not appear to be broadly understood. FASD/CDBC assessment was viewed by families, community service providers and many Key Workers as the way to access services. Missing, however, was an appreciation or understanding that the concept of *environmental accommodations* offered an additional perspective on what the child and/or family might need.

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

Confusion about the Key Worker's role and function is a concern. The literature from the disabilities field on key workers is clear that key worker services are most effective and outcomes for families better when the Key Worker has a clearly defined role that both the worker and the families understand (Greco et al, 2005; Rowntree Foundation, 1999). The literature further notes that implementation of the key worker model of service delivery begins with establishment of:

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

These factors help make transparent the expectations for Key Workers by giving them a framework for practice (Drennan et al, 2005, p. 4). Research from the parenting field similarly indicates that effective parenting education and support programs have a strong theoretical base and clearly articulated model of how the program interventions lead to change (Hume et al, 2005). The same can be said of the Parent to Parent Support services, which have not yet been fully developed in most regions. Several sources (i.e. key informants, Agency Questionnaires) expressed uncertainty as to what the role of the Key Worker is with respect to the Parent to Parent support function, as well as to how to develop this aspect of the service if it is not part of the Key Workers' role.

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

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

> **Recommendation # 2:** That the Provincial Office of MCFD take a lead role in establishing a collaborative process whereby minimum provincial standards, best practices guidelines, and

eligibility criteria for the Key Worker and Parent to Parent Support services program are developed, along with mechanisms to ensure that there is accountability in meeting these standards and guidelines.

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

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

Funding of the Key Worker and Parent to Parent Support Services was another concern that emerged through the evaluation. Funding allocations to contracted agencies were such that over half the Key Worker positions were part time. Further, key informants noted on more than one occasion, that the position required a high level of practice knowledge and experience but was not as highly compensated as other locally posted positions, making it difficult to attract and retain Key Workers. Consequently, several agencies encountered problems finding or keeping qualified personnel, particularly in communities where the position was part time.

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

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

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

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

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

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

Engaging Families and communities

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

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

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

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

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

At the same time, a challenge noted during the evaluation was the lack of awareness about FASD in communities and perhaps more importantly, differing understandings about what is needed in response to those living with FASD. Without an awareness or common understanding of FASD, there is less need to identify it as an issue and likewise, no need to develop necessary community-based resources or responses.

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

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

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

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

Evaluation

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

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

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

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

Conclusion

In conclusion, primary strengths of the Key Worker and Parent to Parent Support Services include the province-wide implementation and capacity to increase funding over three years. As well, the provincial training has also been very well received and has raised the level of awareness and understanding with Key Workers and their agencies, of how to approach FASD in a manner that is congruent with FASD as a brain-based disability. The findings of this first formative evaluation suggest areas to build on related to developing a clear understanding of the Key Worker role, developing an agreement on common language and common understanding of the purpose of the provincial initiative, and strengthening the regional infrastructure through regional coordinators and regional inter-sectoral committees.

References

Hume, S., Hubberstey, C., & Rutman, D. (2005). *Parenting Support And Education: A Literature Review*. BC Parenting Vision Task Group, BC Council for the Family

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

Outputs		Outcomes		
Activities	Participation (Reach)	Early	Intermediate	Long Term
education services Provide information and support to families/ caregivers and to multi-disciplinary service providers and other community members		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) *Families* 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	Ongoing training and supervision/supports are available for Key Workers Key Workers have strong relationships with families/caregivers *Families* 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) Families/caregivers feel respected and are treated as partners by clinicians/service providers Families/caregivers are satisfied with the support they receive 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 Establish and maintain mutual aid support networks, including parent-to-parent support groups	Families/caregivers of children with FASD/CDBC	*Families* Parents/caregivers are engaged as support people/mentors to other parents/caregivers Information about FASD/CDBC and other related topics is available and accessible for parent to parent support people/groups	*Families* FASD/CDBC-specific parent support mechanisms (e.g., groups, buddy system, phone line, list serve) are formed Families/caregivers are connected to parent support mechanisms (e.g., groups, buddy system, phone line, list serve) FASD/CDBC-specific parent support groups meet and/or connect by phone or electronically on a regular basis	*Families* Parents/caregivers continue to be engaged as support people/mentors to other parents Parent to parent support groups are self-sustaining

Summative Outcomes

Outputs		Outcomes		
Activities	Participation (Reach)	Early	Intermediate	Long Term
Key worker activities Liaise with regional multi-disciplinary assessment team Support families/caregivers through the assessment/ diagnostic process Assist families/caregivers in following through with recommendations of the assessment Assist families to coordinate their care, both within the healthcare system, and across systems Provide advocacy and assist families in accessing existing family support, health and education services Provide information and support to families/	Families/caregivers of children with FASD/CDBC Multi-disciplinary service providers involved in FASD/CDBC assessment Multi-disciplinary service providers involved in follow-up accommodations (e.g. school, community recreation staff, social workers, legal/justice system workers, etc.)	*Communities* Professionals and/or community people working with the child can identify the child's strengths Professionals and/or community people working with children/ families are informed about the child's/family's needs Professionals and/or community people working with families with FASD feel part of a network *Families/Children* Families/caregivers are able to identify strengths of their child Families/caregivers understand their child's specific challenges and needs (e.g. primary and secondary disabilities) Families/caregivers understand the assessment/diagnostic findings and its recommendations	*Communities* Care/service/educational plans identify informed, environmental accommodations Schools and service providers make accommodations in the environment according to the individual needs of the children Multi-disciplinary service providers and/or community members learn new skills in working with children and youth with FASD/CDBC and their families/caregivers *Families/Children* Families/caregivers and service providers have a common understanding of FASD as a brain-based disability	*Communities* Use of an FASD lens when developing programs' goals, philosophies, and best practice approaches *Families/Children* 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 Families/caregivers feel less stressed	Families/caregivers are connected to community resources appropriate to their needs. Families/caregivers have confidence in their parenting Families/caregivers are socially connected and have support systems Families/caregivers feel less stressed Children's secondary disabilities are reduced Children feel less stressed	Children's secondary disabilities are reduced
Parent to parent support activities Establish and maintain mutual aid support networks, including parent-to-parent support groups	Families/caregivers of children with FASD/CDBC	*Families/Children* Families/caregivers are able to identify strengths of their child Families/caregivers are able to identify FASD/CDBC related behaviours that are problematic Families/caregivers understand FASD as a brain-based disability	*Families/Children* Families/caregivers are socially connected and have support systems Families/caregivers have confidence in their parenting Families/caregivers use parenting skills and	*Families/Children* There is (increased) family stability (i.e., fewer family breakdowns and/or breakdowns in adoption or foster placements) Children's secondary disabilities are reduced

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

APPENDIX B

SUMMARY OF DATA COLLECTION METHODS

Summary of Data Collection Methods

Province Wide Data Collection				
Information to be collected	*Intended Respondent*	*Completed by whom*	*Implementation Date*	*Time Frame*
Output data • Demographic info • Referral info • Program info	All Key Worker Agencies	Key Worker agency staff	Commencing November, 2006	Monthly, as per MCFD requirements* * quarterly information is acceptable for the evaluation as of April 1, 2007
Agency questionnaire	All Key Worker Program Managers	Key Worker Program Manager	Due January 1, 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	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: • Youth with FASD/CDBC • Parents/caregivers • Community service providers • Key Workers • 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 December 2006, this approach to be piloted in 2 MCFD regions In fall 2007, this approach to be used in all MCFD regions (10 communities)	Annually

APPENDIX C

ANNUAL AGENCY QUESTIONNAIRE

KEY WORKER AND PARENT SUPPORT SERVICES EVALUATION

The following questionnaire is designed to capture information about the agencies offering Key Worker and Parent Support Services for 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 Services.

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 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 first 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?

_____

_____

_____

_____

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 have received (will 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 <u>budget</u> for the Key Worker and/or Parent-to-Parent Support Services for the fiscal year 2006/2007

Category	Budget 2006/07	Any comments?
Key Worker Salary & Benefits		
Supervision		
Parent-to-Parent Supports costs		
Clerical Support		
Communications		
Travel		
Office Supplies		
Rent		
Activities/Resources		
Administration		
Other		

15. 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

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

From: ——————————————————— Amount $ —————————————

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

☐ Yes   ☐ No

18. If yes, 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 2006/07	Any comments?
Administration		
Supervision		
Clerical Support		
Office/meeting space		
Training		
Materials/resources		
Transportation		
Child Care		
Consultation		
Other		

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

_____

_____

_____

Staffing

20. 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.

_____

_____

21. 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 ——————————————————

22. Within your agency are the Key Workers 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

23. Please describe other duties of the Key Worker.

_____

_____

For dedicated Key Workers please answer Question 24, then skip to Question 26:

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

Key Workers with additional roles or duties:

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

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

☐ Yes ☐ No

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

28. 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

29. What are the qualifications of this person/people?

_____

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

                          _____ hours

31. Have there been any changes in the Key Worker staff since April 1, 2006?
        ☐   Yes   ☐   No

32. Reason for changes_____

33. Have there been any changes in the Parent-to-Parent Support staff since April 1, 2006?
        ☐   Yes   ☐   No

34. Reason for changes_____

35. Do you have any vacant Key Worker positions at this time?
        ☐   Yes   ☐   No

36. If so, how many positions are vacant?   ☐   positions

37. How long has the position(s) been vacant? ☐   weeks

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

_____

_____

_____

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

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

41. What are the supervisor's qualifications?

☐ BSW

☐ BSN/BN

☐ MSW

☐ MSN/MN

☐ BA

☐ MA

☐ Other_____

☐ Additional certification (e.g., AAMFT Supervisor etc.) _____

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

☐ Yes ☐ No

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

_____

_____

_____

44. Is ongoing training provided for the Key Worker?

☐ Yes ☐ No

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

_____

_____

_____

46. 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

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

_____

_____

_____

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

      ☐ Yes   ☐ No

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

_____

_____

_____

50. 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

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

_____

_____

_____

Referral Process

52. Please describe how families are referred to the Key Worker program in your agency. (Please attach

any written information about the referral process).

_____

_____

_____

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

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

☐ Yes   ☐ No

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

_____

_____

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

☐ Yes   ☐ No

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

_____

_____

_____

_____

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

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

☐ Yes   ☐ No   ☐ N/A

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

_____

_____

_____

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

☐ Yes   ☐ No

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

62. Do you have any additional comments?

_____

_____

_____

_____

_____

_____

_____

THANK YOU FOR COMPLETING THIS QUESTIONNAIRE!

APPENDIX D

AGENCIES COMPLETING TIME 1 AGENCY QUESTIONNAIRES

Agencies that Completed Time 1 Annual Agency Questionnaires.

	Agency Code	Agency /Contract
Fraser Region		
1	A01	BC Centre for Ability
2	A02	Delta Association for Child Development
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	A07	Centre for Child Development (Surrey/Langley)
7	A08	Peach Arch Community Services
8	A 09	Lower Mainland Purpose Society
9	A10	Simon Fraser Society for Community Living – *New West*
10	A11	Simon Fraser Society for Community Living – *Tri-Cities*
11	A12	Ridge Meadows Child Development Centre
Interior Region		
12	B01	ARC Program
13	B02	Cariboo Chilcotin Child Development Centre
14	B03	Cariboo Family Enrichment Centre
15	B04	Insight Support Services
16	B05	NONA Child Development Centre
17	B06	Penticton District Community Resources Society
18	B08	*Freedom Quest Regional Youth Services
North Region		
19	C01	*Axis Family Resources Ltd. – Prince Rupert
20	C02	*Axis Family Resources Ltd. – Dawson Creek
21	C03	*Axis Family Resources Ltd. – Quesnel
22	C04	College of New Caledonia
23	C05	Bulkley Valley Child Development Centre
24	C06	Child Development Centre of Fort St John
25	C08	Kermode Friendship Centre
26	C09	Northern Family Health Society
Vancouver Coastal Region		
27	D03	Powell River Association for Community Living
28	D04	Sea to Sky Community Resources
29	D05	Sunshine Coast Community Service Society
30	D07	Touchstone Family Association
31	D09	Connexus Family & Children Services
32	D14	The Children's Foundation
Vancouver Island Region		
33	E01	Campbell River and District Association for Community Living
34	E02	West Coast Resources Society
35	E03	Dist 69 Family Resources Association
36	E04	FASD Community Circle

	Agency Code	Agency /Contract
37	E05	Metis Society
38	E06	Nil/Tu,O Child and Family Services Society
39	E07	North Island Crisis and Counselling Centre
40	E08	Victoria Native Friendship Centre
41	E09	Wachiay Friendship Centre
42	E10	West Coast Resources Society
43	E11	Hiiye'yu Lelum

* These agencies submitted their Annual Questionnaires too late to be included in the data analysis.

APPENDIX E

TEMPLATE FOR OUTPUT REPORTING

APPENDIX F

KEY WORKER AND KEY WORKER SUPERVISOR INTERVIEW GUIDE

KEY WORKER AND PARENT SUPPORT SERVICES EVALUATION

INTERVIEW GUIDE - KEY WORKER

Goals and objectives

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

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

Staffing, training, supervision

How did you hear about your job?

What was your experience of the hiring process?

What kind(s) of Key Worker training or development have you taken part in?

Has the training made a difference to your understanding of the Key Worker role? Explain.

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

Has the training made a difference 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?

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 Services* 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

COMMUNITY SERVICE PROVIDER INTERVIEW GUIDE

KEY WORKER & PARENT SUPPORT SERVICES EVALUATION

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 service? If so, what was involved in the referral process?

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

How are you, or have you been involved with the family(ies) whom the Key Worker serves? What is/has been your role?

How are you or how have you been involved with the Key Worker services 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

☐ 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 service in your community?

What do you consider to be the major successes of the Key Worker service?

In your opinion, what have been some of the challenges or barriers to implementing the Key Worker service in your community project?

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 Services? 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 service?

Outcome Evaluation Interview Questions (Not used in Formative Evaluation)

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

Do you have anything else to add?

APPENDIX H

PARENT CAREGIVER INTERVIEW & FOCUS GROUP GUIDE

KEY WORKER AND PARENT SUPPORT SERVICES EVALUATION:

INTERVIEW/FOCUS GROUP GUIDE FOR PARENTS/CAREGIVERS

How would you describe your Key Worker and his/her role with you and your family?

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

Who in your family meets with the Key Worker? Has the key worker worked with your child? How does your Key Worker get on with your child?

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

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?

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? Can you give me some examples?

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

Has the Key Worker made difference in working with other professionals or accessing other services?

Have you participated in anything similar to the Key Worker program elsewhere in the community? If so what? How does this program compare to what you have experienced before?

What changes, if any would you make to the role of the Key Worker?

Do you have anything else to add?

APPENDIX I

TIME 1 FORMATIVE EVALUATION KEY INFORMANT SAMPLE

Time 1 Formative Evaluation Key Informant Sample

INDIVIDUAL INTERVIEWS & FOCUS GROUPS		
Affiliation	**# of informants**	**Comments/rationale**
Key Worker	6	Key Workers based in communities participating in community-based data collection.
Key Worker Supervisors	2	Supervisors from two of the three communities participating in community-based data collection
Service providers, including • Supported Child Care • Health Assessment Team • Child Protection SW for Aboriginal Agency • CDC staff in 2 different communities • School District Student Services Coordinator • School Principal • Paediatrician	 2 1 1 8 1 2 1	As nominated by the KWs, includes the service providers with whom the KW has worked on behalf of families in the KW's caseload. The CDC staff
MCFD CYSN Managers & Regional KW Program Coordinator	7	CYSN Managers from all 5 MCFD regions KW Program Coordinators in the 2 regions that have this designated position
Parents/caregivers	10	Includes birth, adoptive and foster families, and extended family/caregivers (grandparents).
Total Interviews	**41**	

APPENDIX J

THEMATIC SUMMARY: PROGRAM STRENGTHS AND CHALLENGES

THEMATIC SUMMARY: PROGRAM STRENGTHS AND CHALLENGES

A thematic analysis of the 39 Annual Agency questionnaires that were returned, along with in-depth community based interviews in two communities and province-wide key informant interviews, identified the following program strengths and challenges. Preliminary program milestones also emerged from the analysis and are listed as well.

Program Strengths

Employs family-centred model/philosophy of practice (n = 12)

The use of a family-centred philosophy of practice by Key Workers was viewed as a strength of the program in four out of five regions. Related sub-themes were:

- o   Use of an outreach approach
- o   KW as "someone who listens"
- o   Community-based service
- o   Strengths-based approach

"Being able to start where the client requires (flexible) open-ended, may support ½ hour via phone or attend meetings as required. Needs are client-driven." (Agency Questionnaire)

Provides advocacy, service navigation & promotes family empowerment (n = 10)

Data from four regions indicated that Key Workers helped families to communicate their needs; access services; and navigate service systems. Related sub-themes were:

- o   Help is especially useful for parents/families who themselves have FASD
- o   Support helps families who previously fell through the cracks

"Role of key worker as navigator and advocate, connecting community agencies/schools etc, with assessment process" (Agency Questionnaire*)*

Provides family & community with FASD-related expertise (n=10)

A theme in four regions, was that Key Workers provided family members and the community with FASD related expertise in the form of information, ideas for different approaches that could be used at home or in the community, suggestions, and community-based training. Related sub-themes were:

- o   provides families with information/understanding regarding FASD
- o   provides community service providers with information/understanding regarding FASD
- o   emphasis on and use of an 'environmental accommodation' approach
- o   KW as a facilitator of change

"Increase the knowledge of parents and professionals about the nature of developmental – behaviors around FASD so that the children experience less frustration and more success." (Agency Questionnaire)

Helps promote wrap-around approach with families (n=3)

A smaller number of responses from three regions indicated that providing a wrap-around approach was also an important aspect of the service Key Workers provided. Related sub-themes were:

- o KW program fits well with the KW agency's wrap-around model of service delivery
- o Integration of functions in one position

"The key worker provides guidance needed for families from pre-assessment through to the ongoing services and support. This is especially pertinent as the majority of the parents display characteristics of FASD and would be unable to access or understand this service." (Agency Questionnaire)

Promotes community development and capacity-building (n=3)

Data from two regions indicated that Key Workers' efforts to promote community development and capacity building was an important attribute and helped develop greater awareness of FASD and the needs of families within communities. Related sub-themes were:

- o Program uses a grass-roots approach – can shape the program to fit the needs of the community
- o Approach used by KW is grounded in community and (Aboriginal) culture

Opportunities for provincial networking and capacity building, through consistent provincial training (n=3)

Availability of provincially supported training for Key Workers was a hallmark of the program and helped begin to establish a common language amongst Key Workers in terms of their role and function. The training events also provided opportunities for Key Workers to network with each other and to exchange information. Regularly scheduled regional networking opportunities help continue this connection.

"Provincial wide initiative/support network. Started off with great training and role definition for all key workers and supervisors." (Agency Questionnaire*)*

"The interconnectedness of Key Workers across the province and consistent training allows for shared resources and increased capacity for creativity." (Agency Questionnaire)

Parent-to-Parent Support program

The thematic analysis revealed that it is too soon to say what the formative outcomes will be, although very early indications are that agencies hope to see the following:

- o (Will) reduce family isolation and stress
- o Peer Support is non-judgemental
- o (Will) build community capacity

Program Challenges

The following challenges were identified through the evaluation and are discussed in more detail in Sections 4 and 5.

Referral process and the intersection between Assessment teams and KW agencies (n=17; 5 regions) Related sub-themes were:

- o Lack of clarity / confusion regarding eligibility criteria for program (e.g. what is "complex" in CDBC; does the child need to have been assessed by the Assessment team); similarly, agency-specific eligibility criteria are confusing to regional referral sources, such as assessment team.

- o Lack of awareness about KW program amongst (MCFD) social workers, community professionals, and families

- o Lack of clarity / confusion regarding role of KW amongst Assessment team and community professionals

- o Scepticism about value of KWs amongst community professionals and Assessment teams, given lack of services and resources in communities

- o Difficulties accessing timely assessment

Resource issues (n=5; 3 regions)

Related sub-themes:

- o Recruiting qualified staff
- o Retaining staff and dealing with staff changes

Community-related issues (n=3; 2 regions)

Related sub-themes:

- o Lack of awareness about FASD in the community
- o Stigmatization of FASD within community
- o Lack of or limited resources for families in communities

Working with the school system (n=3; 2 regions)

This challenge was identified at the community level in one region and was also noted as a major concern during key informant interviews in another region.

> *"The biggest start up challenge was in schools: right from what (functionally) is FASD to how to write appropriate Individual Education Plans."* (Agency Questionnaire)

Other "start-up" issues, including:

- o Lack of direction from MCFD regarding program development
- o Delays in contracting process
- o Developing policies and procedures

Milestones to date:

- o Building community awareness; promoting the program within the community and region
- o Receiving referrals
- o Collaborative planning (i.e., between assessment team and KW; between KW agency and band; between KW agency and other community agencies and/or MCFD)
- o Attending trainings (KW; FASD; regional; FASCETS)

APPENDIX K

Time 1 Agency Evaluation Questionnaire Summaries for:

- **Key Worker Supervisor Qualifications**
- **Training for Key Workers and their Supervisors**
- **Changes in Key Worker and Parent to Parent Staff**
- **Choice of Key Worker and Home Visit**
- **Key Worker Vacancies as of January 2007-04-29**
- **Summary of Agencies with Waitlists for Key Worker Service**
- **Summary of Agencies with Waitlists for Parent to Parent Support Services**

Summary of Key Worker Supervisor Qualifications

(N=39 out of 53 Agency Contracts)

REGION	KEY WORKER SUPERVISOR ACADEMIC QUALIFICATIONS						
	BSW	MSW	BSN	BA	MA	Other	Additional Certification
Fraser (n=11)	3	2	-	2	3*	1 (Phd)	-
Interior (n=6)	-	1	1*	-	3	1 (Bsc & CGA)	-
North ♣ (n=5)	1 (candidate)	-	-	-	2**	1***	-
Vancouver Coastal (n=6)	2	1*	-	1	2	-	2
Vancouver Island (n=11)	1 (also MA candidate)	1	-	4	2	3 (1 MEd)	1
TOTAL	**7**	**5**	**1**	**7**	**12**	**6**	**3**

* plus 'other' unspecified   Source: Time 1 Annual Agency Questionnaire
** 1 is an MA Candidate
*** 1 MBA & Med
♣ 1 no information

Summary of Provision for Ongoing Training
Key Workers & Parent to Parent Staff

REGION	Ongoing Training Available for Key Worker (N=38 out of 53 Agency Contracts)			Ongoing Training Available for Parent to Parent Staff (N=35 out of 53 Agency Contracts)		
	Yes	No	N/A	Yes	No	N/A
Fraser (n=11) (n=10)	10	-	1	3	1	6
Interior (n=6)	6	-	-	6	-	-
North (n=4)	4	-	-		2	2
Vancouver Coastal (n=6)	6	-	-	-	-	6
Vancouver Island (n=11) (n=9)	9	2	-	1	-	8
TOTAL	35	2	1	10	3	22*

Source: Time 1 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.

Summary of Provision Training for Key Workers Supervisors
(N=36 out of 53 Agency Contracts)

REGION	Ongoing Training Available for Key Worker		
	Yes	No	N/A
Fraser (n=10)	9	1	-
Interior (n=6)	6	-	-
North (n=4)	4	-	-
Vancouver Coastal (n=6)	5	-	1
Vancouver Island (n=10)	8	2	-
TOTAL	32	3	1

Source: Time 1 Annual Agency Questionnaire

**Summary of Changes in
Key Workers & Parent to Parent Staff Since April 1, 2006
(N=37 out of 53 Agency Contracts)**

REGION	Number of Agencies in which Key Workers Have Changed			Number of Agencies in which Parent to Parent Staff Have Changed		
	Yes	No	N/A	Yes	No	N/A
Fraser (n=11)	7	3	-	4	4	2
Interior (n=6)	1	5	-	1	5	-
North (n=4)	1	3	-	-	3	1
Vancouver Coastal (n=6)	1	3	2	1	3	2
Vancouver Island (n=11)	2	9	-	2	4	5
TOTAL	**12**	**23**	**2**	**8**	**19**	**10***

Source: Time 1 Annual Agency Questionnaire

* The high number of "not applicable" 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 staff changes has already been answered in relation to Key Workers.

Summary of Key Worker Choice and Visits to Home

REGION	Number of Agencies in which Families Have a Choice of Key Workers (N=37 out of 53 Agency Contracts)			Number of Agencies in which Key Workers Visit the Home (N=37 out of 53 Agency Contracts)		
	Yes	No	N/A	Yes	No	N/A
Fraser (n=10)	-	6	4	9	-	1
Interior (n=6)(n=5)	2	2	-	5	-	-
North (n=4) (n=5)	-	3	1	2	3	-
Vancouver Coastal (n=6)	2	2	2	4	-	2
Vancouver Island (n=11)	4	5	2	10	1	-
TOTAL	**12**	**23**	**2**	**30**	**4**	**3**

Source: Time 1 Annual Agency Questionnaire

Summary of Vacant Key Worker Positions (n=38 out of 53 Agency Contracts)

- *3 agencies reported Key Worker vacancies – 2 in the Fraser Region and 1 in the North Region (Source: Time 1 Annual Agency Questionnaire)*

Summary of Agencies with a Wait List for Key Worker Services (n=38)

- 3 Agencies reported Waitlists for Key Worker Services – 1 in Fraser Region and 2 in Vancouver Island Region; 5 agencies responded "not applicable" due to recent start up of services. (Source: Time 1 Annual Agency Questionnaire)

Summary of Agencies with a Wait List for Parent to Parent Support Services Worker Services (n=38)

- No agencies reported a wait list for Parent to Parent Support Services; 7 responded "not applicable" due to recent start up of services or because they did not offer Parent to Parent Support Services. (Source: Time 1 Annual Agency Questionnaire)

Sharon Hume & Associates

APPENDIX L

Time 1 Program Output Summaries:

- **Output Item #15 – number of families receiving individual service**
- **Output Item #16 – number of parent-to-parent group sessions**
- **Output Item #17 – number of sessions of group intervention**

Sharon Hume & Associates

Output Item #15: *number of families receiving individual service* – this information cannot be provided as it appeared from the data provided by the regions/agencies that it was interpreted by some Key Workers as the number of individual sessions with families, rather than the number of families receiving individual services. The definition has been clarified on the 2007/08 output data collection tool and the information will be provided for Time 2.

Output Item #16 – number of parent-to-parent group sessions

REGION	Number of parent-to-parent group sessions
Fraser	6
Interior	28
North	0
Vancouver Coastal	No data available
Vancouver Island	42
TOTAL	**76**

Output Item #17 – number of sessions of group intervention

REGION	Number of sessions of group intervention
Fraser	2
Interior	4
North	0
Vancouver Coastal	No data available
Vancouver Island	27
TOTAL	**33**