Ministry of Children and Family Development

KEY WORKER AND PARENT SUPPORT PROGRAM

Time 1 Summative Evaluation Report

April 2008

Prepared by:

Sharon Hume and Associates
Sharon Hume, MSW; Deborah Rutman, PhD
Carol Hubberstey, MA; Tanya Lentz, MA
Nancy Sandy, LLB & Marilyn Van Bibber, RN

Table of Contents

APPENDICES

TABLES

What is the Key Worker and Parent Support program?

The BC Key Worker and Parent Support program, funded by the Ministry of Children and Family Development (MCFD), was initially based on research and practice evidence from four areas: research in Fetal Alcohol Spectrum Disorder (FASD) such as that conducted by Dr. Anne Streissguth and her colleagues (1996, 2004); Diane Malbin's Oregon-based FASD project (www.fascets.org); research in the disabilities field; and community-based, FASD-related parent support projects that were operating in BC at the time of the program's inception.

The purpose of the Key Worker and Parent Support program is to provide early intervention and support for families dealing with long term behavioural challenges associated with their children's developmental-behavioural conditions. The program evolved during the early stages of implementation to incorporate the following characteristics:

Regional service delivery model that allows for regional variation and modifications to meet unique local needs and family circumstances

Availability of an expert in FASD to provide consultation to regional MCFD offices and contracted agencies, in order to help facilitate learning and strategies related to use of appropriate environmental accommodations

The Key Worker as a 'facilitator" who assists parents, family members, caregivers and service providers in the child's environment to come to a common understanding of the child's/youth's needs and to develop supportive environmental accommodations accordingly

Key Worker supervision by a qualified professional

Training

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

An independent and ongoing formative and summative evaluation was included as part of the program's implementation. The summative evaluation is examining whether the program's intended outcomes have been achieved. The overarching research questions for the Key Worker and Parent Support summative evaluation are:

What difference have the Key Worker and Parent Support services made to *parents/families and/or caregivers*?

What difference has the Key Worker and Parent Support services made to *children and youth* with FASD/CDBC?

What difference have the Key Worker and Parent Support services made to *community service providers and community partners*?

To answer these questions, the summative evaluation has involved a time series design, and qualitative and quantitative methods of data collection. Data were collected provincially from all Key Worker agencies; in addition, data were gathered face to face in 10 BC communities - two communities per each of the five MCFD regions. For the Time 1 summative evaluation, multiple methods of data collection were employed, including:

    Intake Evaluation Questionnaires with parents/caregivers
    Qualitative, semi-standardized interviews or focus groups with samples of program participants, (e.g., parents/caregivers)
    Qualitative, semi-standardized interviews or focus groups with samples of community service providers and/or community partners
    Monthly output data, collected electronically

What are the key findings of the Time 1 Summative Evaluation?

The Time 1 Summative Evaluation Report provides descriptive findings regarding the characteristics of the families and children being served by the Key Worker and Parent Support program. Based on
Intake Questionnaire data from parents/caregivers (n = 198 respondents):

    32% were foster parents
    23% were birth parents
    20% were adoptive parents
    16% were grandparents

Based on the cumulative output data, nearly two-thirds (64%) of the children/youth served by the Key Worker program were male. In all regions except the Fraser, at least half of the children/youth served by the program were of Aboriginal heritage and 34% were Caucasian.

About 75% of the parent/caregiver evaluation questionnaire respondents in all regions reported that stress was the most frequent challenge they faced. In addition, a high percentage of parents/caregivers reported facing the following challenges:

    Finances
    Parenting concerns
    Accessing community support services, and
    Isolation.

All questionnaire respondents identified one or more 'significant strength' for each child in their care who was the focus of the Key Worker program. The following qualities were rated most frequently by parents/caregivers as being a 'moderate' or 'significant' strengths for their child(ren):

Experiential learner	Visual learner
Relational	Determined
Desire to please	

In terms of secondary behaviours, parents/caregivers perceived that their child experienced a variety of secondary behaviours that were both school-related and of a more social/emotional nature. The most frequently reported secondary behaviour was **being frustrated in school;** school frustration was reported to exist for 73% of the children seeking Key Worker services.

The social/emotional secondary behaviours most frequently identified by parents/caregivers to occur on a (very) frequent basis were: **anger**; **blaming others**; **disruptive behaviours**; **anxiousness;** and **aggression**.

Findings regarding selected secondary behaviours based on the child's age revealed that a notably higher percentage of adolescents (12+ years of age) were experiencing certain social/emotional secondary behaviours, including: blaming others; suspension from school; depression; trouble with the law; and alcohol/drug use. Such age-related findings may not be surprising given that these high-risk behaviours are generally associated with teenagers rather than with younger children.

In relation to <u>what difference the program is making for parents/caregivers</u>, a strong theme in the community-based interviews with parents and caregivers concerned parents'/caregivers' understanding of FASD as a brain-based disability. The new information received about FASD helped parents and caregivers realize their child's behaviour was not as a result of wilfulness on the child's part, but as a result of their neuro-developmental disability. This understanding in turn led to different expectations for the child, and to a reframing of and response to their child's behaviours. Most importantly for parents/caregivers was the importance of thinking in terms of their child's developmental age rather than chronological age.

Learning about FASD also helped parents and caregivers gain a better understanding of their child's strengths and needs.

Dealing with the education system was a major issue for parents and caregivers, about which Key Workers often provided support and advocacy assistance. Successful meetings with schools contributed to reduced stress and frustration for caregivers and parents.

In relation to <u>what difference the program is making for children</u>, the community-based interviews revealed that, when parents/caregivers had the support of the Key Worker, and when the schools were receptive to learning how best to work with the children, parents reported that their children began to learn, stayed in school (instead of getting "kicked out"), liked going to school, and in some cases, received vital help in making the transition from elementary school to high school.

In relation to <u>what difference the program is making for communities</u>, the community-based interviews revealed that community-based practitioners of various disciplines were increasingly viewing Key Workers as a resource and a source of information and support regarding FASD.

The enhanced understanding by community practitioners of FASD as a neuro-behavioural disability increased practitioners' understanding of a child's behaviour and thus their response to it, including making environmental accommodations. By turn, this led to changes in practice, approaches and skills.

At the same time, community practitioners involved in working with people with FASD wanted more professional and/or personal support in order to work more effectively with children/youth who have FASD and other neuro-behavioural disabilities. Less clear was whether community service providers felt that they were part of a broader network, or whether they primarily regarded the Key Worker as their sole source of information and support.

What were the implications of the findings?

There was great diversity in the types of families with whom the Key Workers are working – the differing family structures potentially presented unique sets of needs and challenges. Along these lines, parents/caregivers faced a number of challenges including stress and financial concerns. Furthermore, birth parents seemed to experience a greater number of stressors relative to other parents and caregivers. The information regarding the constellation of demographic information, the challenges parents face, and the relationship between the challenges and parents'/caregivers' sense of their own competence has implications for Key Workers' practice in relation to meeting the needs that parents/caregivers may experience as a result of their circumstances. Along these lines, Greco and Sloper (2007) found that when Key Workers were sensitive to the needs and circumstances of the family as a whole, families experienced better outcomes overall.

Early outcomes for families and for children/youth

Qualitative findings from this evaluation show that the Key Worker program has been highly successful in providing families and caregivers with practical and/or emotional and advocacy-related support. Similar to the findings from Greco and Sloper (2007), parents/caregivers identified the following as characteristics of the service that made a difference for them and their children:

Assistance in accessing services;

Assistance in helping parents and caregivers strengthen their voice with other service providers in the community, in particular with the education system;

flexibility - being able to work across a variety of mandates to attend to the needs of the whole family.

Further, the provision of relevant, up to date information and education for parents about their child's abilities, along with information about appropriate environmental accommodations, was profound and contributed to changes in parents' and caregivers' behaviours and feelings of stress. In contrast, and not dissimilar to the findings from Greco and Sloper (2007), when parents and caregivers expressed frustration in this evaluation, it was in relation to:

The lack of understanding, on the part of other service providers, of FASD as a brain based disability and of its impact on children's behaviour

The difficulties and stress in accessing programs and services for their children.

Intermediate outcomes for families and for children/youth

Findings in this report indicated that there has been progress toward achieving some of the intermediate outcomes associated with social support, connections with community resources and parent/caregiver confidence. According to many parents and caregivers, the Key Workers have been instrumental in helping them strengthen social supports amongst their family and friends and in connecting them and their children with community programs and services. At the same time, while there is some suggestion that the program is helping to improve parents'/caregivers' confidence, it is also clear that those parents/caregivers who are experiencing stress, anxiety, and financial challenges, feel less confident in their parenting.

While it is very early in the program implementation, there was early evidence that for some families, the overall program goal of maintaining and enhancing the stability of families with children and youth with FASD/CDBC was being achieved. Given that a stable living situation is a strong protective factor for children with FASD/CDBC (Streissguth et al, 1997), this is potentially very powerful.

Early outcomes for communities

In relation to outcomes for communities, what emerged was the importance of the broad nature of the Key Workers' position, as well as the relational nature of the role in creating positive relationships between the Key Worker and community service providers, and between parents/caregivers and community service providers. As described by Sloper and Greco (2006), "key working crosses the boundaries of different agencies and disciplines" (p. 452). This means that Key Workers need to be knowledgeable about a variety of community resources, services, professionals and organizations, and at

the same time to be knowledgeable about FASD and families' circumstances. To the extent that Key Workers were able to successfully navigate their dual roles (i.e. with communities and with families), their success was based in part upon their ability to establish positive working relationships and to act as a bridge between community service providers and families. When Key Workers were successful in maintaining that delicate balance between being an advocate for families and developing trusting relationship with service professionals, all parties reported benefiting through increased knowledge, more effective strategies for the children, and reduction in stress for the adults.

Another important outcome was that the Key Worker program was having a positive impact on the agencies in which the Key Workers were situated. The Key Workers were instrumental in broadening their host agencies' understanding of FASD as a brain-based disability, thereby further enhancing both the agencies' and communities' capacity to understand and work with those living with FASD. The addition of the Key Worker program also increased the ability of multi-service agencies to offer integrated and coordinated services by providing a unified conceptual framework for working with children and families with FASD/CDBC.

SECTION 1   INTRODUCTION

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

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 (Ministry of Children and Family Development, 2005).

In response to the FASD Strategic Plan, and taking into consideration research that "indicated that family supports produce better outcomes for children with disabilities and their families as a whole" (Rutman, Hume, Hubberstey & Luettgen, 2007), MCFD decided to implement a Family Support Program that was inclusive of children with FASD and complex developmental-behavioural conditions[1] (CDBC) similar in impact to FASD. The **Key Worker** and **Parent Support Program** were chosen as the models of service delivery.

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

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

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

---

[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

assess whether the activities were implemented as planned, and whether the expected outputs were produced.

The summative evaluation looks at whether the program's intended outcomes have been achieved and asks the question, what difference has the Key Worker and Parent Support program made to parents/ families and/or caregivers as well as to children and youth with FASD/CDBC?

The evaluation has the following deliverables*:*

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

Two Formative Evaluation Reports have been completed, the first in March 2007 and the second in March 2008 and can be viewed on the Ministry of Children and Family Development (MCFD) web site: http://www.mcf.gov.bc.ca/fasd/partnership.htm

The current Summative Evaluation Report is the first such report and covers the timeframe from June 2006 to December 2007. The report is divided into several sections:

> **Section 2:** Why a Key Worker/Parent Support Program?
>
> **Section 3**: Evaluation Research Questions and Process
>
> **Section 4**: Characteristics of parent/caregivers and their children
>
> **Section 5:** What difference has the program made for parents/caregivers
>
> **Section 6**: What difference has the program made for children
>
> **Section 7:** What difference has the program made for communities
>
> **Section 8**: Discussion and recommendations

Sharon Hume & Associates

The Key Worker and Parent Support program was initially based on research and practice evidence from four areas: FASD research such as that conducted by Dr. Anne Streissguth and her colleagues (1996, 2004); Diane Malbin's (nd) Oregon-based FASD project; research in the disabilities field; and community-based, FASD-related parent support projects that were operating in BC at the time of the program's inception. These origins are discussed in more detail in the *Time 1 Formative Evaluation Report* and are summarized briefly below.

Literature

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

As well, research from the disabilities field also contributed to the development of the Key Worker and Parent Support program, especially studies demonstrating that families caring for a disabled child benefited from having a multi-agency 'key' worker, along the lines of the model in place in the United Kingdom (Greco & 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). Greco and Sloper (2005) reported that family outcomes varied between and within areas, but overall there was improved access to resources in the community, including school, and that families felt supported by the Key Worker, especially those who took a holistic, family-centered approach. Moreover, the best outcomes for families were achieved when the role of the Key Worker included:

> *"providing information to families about services and support available;*
> *providing information about the child's condition where needed;*
> *identifying and addressing the needs of all family members;*
> *coordinating care and supporting families with care planning and review;*
> *improving access to services;*
> *speaking on behalf of the family when dealing with services; providing emotional support; and*
> *providing help and support in a crisis" (p. viii, emphasis added).*

Further, parents receiving key worker services reported reduced stress in part because the key workers either helped them obtain services or helped them spend less time looking for information, writing letters, and making telephone calls (Greco et al, 2007, p. 167).

When parents reported no reduction in stress it was often attributed to the Key Worker not being proactive enough: only giving advice rather than following up with other services and professionals; just giving out phone numbers but not facilitating a connection between parent and professional/service provider; and not taking any action other than that suggested by a parent (p. 170). Ultimately, parents who did not experience a reduction in stress felt that they were coping on their own and that the Key Worker had not materially improved their lives.

One area in which parents/caregivers continued to experience unmet needs, however, was respite. This is consistent with a Canadian report on parenting guidelines for families of children with FASD, which similarly heard from parents/families that the provision of respite was a critical area of need that was not adequately addressed (Victoria Order of Nurses, nd).

Findings from a recently completed small-scale study of families successfully caring for children with FASD, found that these families faced a number of barriers and challenges, mostly to do with a lack of substantial knowledge and understanding of FASD amongst health, social services, and education professionals (Frankel, Frankel & Opie, 2007**)**. This suggests that providing education and information regarding FASD to other service delivery agents is critically important to families in helping to reduce the stress they experience when dealing with these systems and organizations.

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

According to Seligman and Darling (1989), support groups for parents have four positive functions:
> alleviating loneliness and isolation;
> providing information;
> providing role models; and
> providing a basis for comparison (p. 44).

Support programs exist in many forms and differ in terms of their eligibility requirements, types of services offered, and administration, but generally, are either structured or unstructured. Characteristically,

Sharon Hume & Associates

structured support groups are facilitated by a professional such as a nurse, social worker, or counsellor, whereas non-structured support groups are more often facilitated by a parent or someone with personal knowledge and experience of the particular topic (Livingston, 2005).

Regardless of how programs are structured, there are a variety of ways in which parents are connected to each other, either face to face such as in a group, or one to one for the purpose of individual support. Programs designed to match parents with each other for the purposes of offering one to one support for example, have the additional option of matching parents/families on the basis of personal characteristics and needs, regardless of where they live. Along these lines, a survey (Santellii, 2000) of parent support programs in 21 states in the US, reported that three fourths of matches between parents were made at the state level, two-thirds were made at the regional level and slightly less than half of matches were made at the local level. In this respect the Internet has been used to good effect as a venue for parent support and as a way of offsetting differing geographic locations of participants, as well as a way of accommodating busy lives. For example, a study of internet support groups for caregivers of children with special health care needs conducted by Baum (2004) noted that parents' level of stress was reduced and they reported 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).

In contrast to the wealth of literature related to outcomes for parents/caregivers with children with disabilities, there is a relative dearth of research regarding interventions that have demonstrated outcomes for children/youth with FASD, particularly with respect to secondary behaviours such as helping them achieve social and academic success. Several studies, funded by the Centre for Disease Control and Prevention, are underway in the US (http://www.cdc.gov/ncbddd/fas/intervening.htm). These offer insight into strategies that work with children and their families. It is noteworthy, however, that all of these programs involve some type of training/education for parents/caregivers along with a specific intervention – also involving training of some type – directed at children/youth. For example, one program provided social skills training (Child Friendship Training) to high functioning children with FASD (O'Connor et al, 2006). The training intervention resulted in improved social skills as well as fewer behavioural problems at school. The high degree of participation from parents/caregivers in the youths' lives and in the training was seen as a contributing factor in the students' success, particularly as there was little in the way of broader community support for the students. A Canadian study – not part of the CDC funded research - looked specifically at adolescents with FASD who had achieved a measure of success in school by virtue of the fact that they were attending regularly, and concluded that a major contributing factor in the students' success was the presence of a parent or adult who could advocate on their behalf "in order to guarantee appropriate accommodations and programs" (Duquette et al, 2006, p. 230). This is consistent with the literature on FASD, which has shown that a stable home life and/or the presence of an adult who can act as an advocate can protect against secondary disabilities (Streissguth et al, 1997). It also suggests that in order to achieve positive outcomes for children and youth with FASD, either

parents/caregivers or an adult in a position of authority and responsibility, such as a teacher or social worker, needs to be included as part of the intervention strategy.

BC Key Worker and Parent Support Program

The BC Key Worker and Parent Support Program evolved during the early stages of implementation to incorporate the following characteristics:

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

Draft Key Worker and Parent Support Program 'Practice Standards' developed by MCFD in 2007 describes the function of Key Workers in part as follows (p.3):

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

Relationship to literature

In addition to key workers, the BC program also offers parent support services through facilitation of education workshops and support groups. In keeping with the literature noted previously, MCFD anticipated that parents/caregivers of children with FASD/CDBC would come together through parent support groups, or other mechanisms, such as the Internet or a 'warm' phone line, to actively support each other and exchange ideas and information. However, provision of FASD-specific parent support groups presents some distinctive challenges both in relation to geography and group membership.

Birth families and grandparents raising grandchildren, for example, present a unique set of issues and support needs. Due to the 'preventable' nature of FASD, birth parents may not feel welcomed in support groups comprised primarily of adoptive and foster parents; it has been noted in the literature that a

significant barrier to participation in programs by women who have addictions issues, or who are birth parents, is the fear of being judged and shamed about their behaviour (Legge, Roberts & Butler, 2000; Canadian Centre on Substance Abuse, 2001). A mixed group can further exacerbate feelings of guilt and remorse (Ontario Federation of Indian Friendship Centres, 2002). Along these lines, being associated with an FASD program may be yet another barrier for birth families, particularly in small, rural, or isolated communities, a situation that prompted one service in Ontario to change the name of its FASD program in order to promote a more holistic approach and reduce the stigma connected with FASD (Canadian Centre on Substance Abuse, 2001).

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

Geography, particularly in rural areas where inclement weather and distances between communities and between families can be a deterrent, is another barrier to face-to-face support groups. As described above, these can be overcome through use of the Internet and one to one matching that involves telephone or Internet support.

SECTION 3   EVALUATION RESEARCH QUESTIONS, FRAMEWORK & PROCESS

Research Questions

The overarching research questions for the Time 1 Key Worker and Parent Support summative evaluation were:

> What difference have the Key Worker and Parent Support services made to parents/families and/or caregivers?
> What difference has the Key Worker and Parent Support services made to children and youth with FASD/CDBC?
> What difference have the Key Worker and Parent Support services made to community service providers and community partners?

Additional summative evaluation questions included:

> How have the support services affected parents'/families' and/or caregivers' expectations of their child with FASD/CDBC?
> What difference have the support services made to parents'/families' or caregivers' knowledge, beliefs, and attitudes regarding FASD/CDBC?
> What difference have the support services made in terms of parents'/caregivers' sense of confidence and competence in caring for their child?
> What difference have the support services made in terms of parents'/caregivers' feelings of being stressed?
> What difference have the support services made in terms of parents'/families' or caregivers' ongoing support network?
> What difference have the support services made in relation to the secondary disabilities of children/youth with FASD/CDBC?
> How have the support services made a difference with respect to the community partners' knowledge of FASD/CDBC and skills in addressing issues and challenges related to FASD/CDBC?
> How have the support services made a difference in community partners' use of common approaches in working with children with FASD/CDBC and their families?

Evaluation Framework

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

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

populations. Feedback on the Evaluation Framework and data collection plan was received from all MCFD regions.

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

Overview of Evaluation Process

The Time 1 summative evaluation employed a Time Series design, and involved qualitative and quantitative methods of data collection. As well, the summative evaluation involved both province-wide data collection and more intensive data collection in two communities in each of the five MCFD regions.

Data collection methods for both the formative and the summative components of the Key Worker and Parent Support evaluation are summarized in **Appendix B**. In the Time 1 summative evaluation, multiple methods were used, including:

> Intake Evaluation Questionnaires with parents/caregivers
>
> Qualitative, semi-standardized interviews or focus groups with samples of program participants, (e.g., parents/caregivers)
>
> Qualitative, semi-standardized interviews or focus groups with samples of community service providers and/or community partners
>
> Monthly output data, collected electronically

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

Province-wide data collection process

Province-wide evaluation data for the Time 1 Summative Evaluation Report were comprised of the Intake Questionnaires for Parents/Caregivers and the Key Worker Program Output data.

Intake Questionnaires for Parents/Caregivers were to be administered by program staff in the agencies delivering the Key Worker and Parent Support Services and returned to the evaluation team upon completion. This questionnaire was to be administered at intake, or as soon as possible after initial contact with the program. In the Time 1 summative evaluation, the data from these questionnaires were used to provide information regarding the families and the children/youth accessing the programs, including:

> Parent/caregiver and child demographics
> Child's strengths
> Child's Secondary Disabilities
> Parents' Sense of Competence and Confidence
> Stress
> Social Support

Additional information follows regarding the source of the questionnaire items derived from existing scales.

Child's strengths and *Secondary Disabilities*:
These items came from the FASCETS questionnaire, which was developed by Diane Malbin and her colleagues in order to evaluate a three-year intervention/demonstration project for children with FASD and their families (Malbin, 2004).

The FASCETS tool assesses the child's/youth's functioning, using a Likert scale format; participants identify their child's strengths, as well as the frequency that the child/youth exhibits both primary and secondary characteristics of FASD/CDBC. Using a Likert scale format as well as open-ended items, participants also rate their own shifts in knowledge, expectations, attitudes, practice/behaviour, including environmental accommodations and stress levels.

Parents' Confidence and Attitudes
Parents'/caregivers' confidence and attitudes was measured using an adapted version of the *Parents' Sense of Competence Scale* and an item from the FASCETS questionnaire. The seven-item *Parenting Sense of Competence Scale* (PSOC) that was used in this evaluation was derived from the 12-item PSOC Scale developed by Ohan, Johnston and Leung (2000), who adapted it from the 16-item version of the scale originally created by Gibaud-Wallston and Wandersman (1978).

Based on feedback the FASD Consultant and members of the Evaluation Advisory Committee and in order to ensure that our data collection instruments were congruent with the philosophy of the FASD/CDBC support services, we reduced the number of PSOC Scale items from 12 to seven. The seven-item scale includes items relating to both dimensions of the PSOC Scale (parental efficacy and parental satisfaction).

Finally, a question taken from the FASCETS questionnaire that relates to parents'/caregivers' sense of confidence was used ("Overall, my confidence level in my current ability to parent or work effectively with the child with FASD/CDBC is...").

Families' Stress
The Parent/Caregiver Intake Questionnaire includes an item assessing parents'/caregivers' feelings of stress in relation to working with/parenting their child with FASD; this question comes from the FASCETS Questionnaire.

Social Support

To measure parents'/caregivers' social support, the Intake Questionnaire includes Kahn and Antonucci's (1980) concentric circle measure of social networks. In this measure, three concentric circles are used to represent emotional closeness.

Appendix C contains a copy of the Intake Questionnaire for Parents/Caregivers.

As of January 31, 2008, the evaluators had received 198 Parent/Caregiver Intake Questionnaires from 33 agencies in the five MCFD regions.

Further examination of the breakdown of the Intake Questionnaires, by region, revealed that there was variability across regions in the number of agencies per region that submitted Intake Questionnaires to the evaluation. There also was variability in the percentage of questionnaire respondents relative to the total number of family intakes in each region, based on output data. Table1 presents these findings.

**Table 1: Number of Key Worker Agencies and
Number of Intake Questionnaires Received, by region**

	Fraser	Interior	North	Vancouver Coastal	Vancouver Island
# KW agencies submitting Q'naire/# of KW agencies per region	10/13	6/9	4/9	5/15	8/12
# Intake Questionnaires	52	46	41	24	31
# new family intakes Feb – Oct 2007 (based on output data)	104	66	129	82	133

Key Worker Program Output data – Since summer 2006, all Key Worker and Parent Support agencies had been 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 D** contains the 2007/2008 template for the output data reported by the agencies.

As of December 15, 2007, the evaluators had received at least partial program output data for 54 out of 57 communities/contracts in the five MCFD regions; this represents a 95% response rate. At the same time, there were many agencies that had not submitted output data on a consistent basis and a handful that had not submitted any output data.

Community-based data collection process

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

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

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

To create the sample of community-based interview participants, the evaluators requested that the Key Worker(s) in these communities informed parents/caregivers and community partners about the evaluation, and sought their assent to take part in face to face or telephone interviews. The sampling process was guided by purposeful sampling (Patton, 1990, p. 171), an approach to sampling that is particularly suited to program evaluation because it involves the selection of "information-rich" informants who are knowledgeable about the program and/or about their own experience of the program and can voice or articulate their experiences and observations[2]. After parents/caregivers and community partners had provided their assent to the Key Worker to share their contact information with the evaluators, the evaluators scheduled interviews with participants. An informed consent process was followed prior to commencing the interviews.

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

---

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

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

In nine of the 10 communities, qualitative interviews/focus groups were conducted with parents/caregivers. Across the 10 communities, the sample of parents/caregivers included birth, foster and adoptive parents, and grandfathers and grandmothers. Interviews with parents/caregivers focussed on aspects of satisfaction with the program as well as perceived outcomes for parents/caregivers and for their child(ren). See **Appendix F** for a copy of this interview guide.

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

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

Limitations to the evaluation

Parent/caregiver intake questionnaires were not completed by all families. While the response rate was reasonably good in relation to typical 'uptake' rates in survey research, there were a number of agencies that to date have not submitted intake questionnaires to the evaluation. We do not know whether the parents/caregivers comprising the sample that has completed the intake questionnaire is representative of the total population of program participants. We are also aware that we have not received intake questionnaires from Aboriginal agencies, so it is likely that the intake questionnaire data may not reflect the experiences and perspectives of these families.

FASCETS as a research tool is still very new and has not been formally assessed in terms of its psychometric properties (i.e., its reliability and validity).

Intake Evaluation Questionnaires are intended to provide baseline data when families first begin to receive the Key Worker services. Nevertheless, often the Intake Questionnaires are not administered by the Key Workers until several weeks or months after initial contact. Thus, the data cannot be considered truly baseline in all situations.

SECTION 4   CHARACTERISTICS OF PARENTS/CAREGIVERS AND THEIR CHILDREN

Introduction

This section provides descriptive information regarding the characteristics of the children, youth and families served by the Key Worker and Parent Support program. Findings presented include: socio-demographic data about the parents/caregivers, children and youth served, and the issues and challenges that parents/caregivers themselves face and their perceptions of their needs.

Data reported in this section have come primarily from the 198 Parent/Caregiver Intake Questionnaires submitted as of January 31, 2008, augmented by the monthly output data submitted by Key Worker agencies.

Socio-demographic information regarding the parents/caregivers served by the program

Family type

Table 2 provides information regarding the types of families (e.g. birth, adoptive, and foster families, as well as grandparents raising their grandchildren) that have been receiving service through the Key Worker program, based on data from the Parent/Caregiver Intake Questionnaire[3].

In all regions, there were birth, foster, adoptive and extended families who were receiving Key Worker and/or Parent Support services. Overall, foster parents comprised a higher percentage of the families who had accessed the program (32%), followed by birth parents (23%), adoptive parents (20%), and grandparents (16%).

At the same time, the relative percentage of each type of family varied by region. For example, in the North, birth parents comprised 41% of the sample of families completing the Intake Questionnaires, while in Vancouver Coastal and Vancouver Island, birth parents comprised about 25% of the sample, and in the Interior, birth parents comprised only 7% of the sample. Another striking finding was that on Vancouver Island, 34% of the sample that completed the Intake Questionnaire were grandparents raising their grandchild(ren). Indeed, on Vancouver Island, grandparents were the most frequent category or type of

---

[3] Please note that not all of the families involved in the Key Worker or Parent Support program have completed the Parent/Caregiver Intake Questionnaire. As stated in the Methodology section, this Time 1 Summative Evaluation report was based on the 198 Intake Questionnaires submitted to the evaluation team as of January 31, 2007; by contrast, as stated in the Time 2 Formative Evaluation Report, there were a total of 514 new family intakes in the Key Worker and Parent Support program.

family, although there were grandparents who were the questionnaire respondents (and presumably the child's primary caregivers) in all regions.

It is also important to note that since a parent/caregiver may have had more than one child who was the focus of the Key Worker service, and also may have had different relationships with different children for whom s/he was caring (e.g. may be a foster parent to one child and an adoptive parent to another), there were more responses to this questionnaire item than respondents. For example, in the analysis of this questionnaire item, the sample of 196 questionnaire respondents reported on 284 parent/caregiver relationships.

Table 2: Parent/Caregiver Relationship to Child(ren)
Served by Key Worker Program, by Region

Caregiver Family Demographics							
		Fraser (n=67)	Interior (n=61)	North (n=76)	Vancouver Coastal (n=33)	Vancouver Island (n=47)	Total (N=284 parent/caregiver relationships)
Caregiver Type (N=196 questionnaire respondents)	**Birth**	18%	7%	41%	24%	23%	**23%**
	Adoptive	27%	25%	21%	3%	13%	**20%**
	Foster	24%	44%	24%	61%	23%	**32%**
	Grandparent	18%	10%	12%	6%	34%	**16%**
	Other	13%	15%	3%	6%	6%	**9%**

Source: Parent/Caregiver Intake Questionnaire

Parent/Caregiver age

As shown in Table 3, the majority of parents/caregivers were in the 35-49 year old age group; as well, there were no respondents who were under age 20 in any of the regions.

At the same time, there were some regional differences in parents'/caregivers' age: the Interior had the highest percentage of parents/caregivers (53%) who were over age 50, while the North had the lowest percentage (23%) who were over age 50.

Table 3: Parent/Caregiver Age, by Region

Caregiver Family Demographics						
Age of Parent/Caregiver (N=185)	Fraser (n=50)	Interior (n=42)	North (n=43)	Vancouver Coastal (n=22)	Vancouver Island (n=28)	Total # and (%)
< 20 years	0	0	0	0	0	0 (0%)
20-34 years	16%	10%	21%	9%	11%	26 (14%)
35-49 years	56%	38%	56%	45%	43%	90 (49%)
50-64 years	18%	48%	21%	36%	36%	56 (30%)
65 or over	10%	5%	2%	9%	11%	13 (7%)

Source: Parent/Caregiver Intake Questionnaire

Ethnic Origin of Parent/Caregiver

In all regions, the majority of parents/caregivers who completed the Intake Questionnaire were of European/Caucasian origin. The region with the highest percentage of Aboriginal families was the North (31%), followed by Vancouver Coastal (22%). See Table I (1) in **Appendix I** for further details.

Number of parents in household

Approximately one-third of the parents/caregivers who completed the Intake Questionnaires were living in one-parent households. Again, there were striking regional differences: the percentage of single parent households amongst families in Vancouver Coastal was much higher than in other regions. See Table I (2) in **Appendix I** for additional details.

Education Level of Parent/Caregiver and Spouse

Across all regions, at least 40% of parents/caregivers and their spouses completing the Intake Questionnaire had some college or university education. The education level of parents/caregivers and their spouses was fairly consistent between regions, although Vancouver Island had the highest percentage of parents/caregivers who did not complete high school. See Table I (3) in **Appendix I** for additional details.

Parent/Caregiver Income

Income disparities of families were evident between regions: Vancouver Island had the highest percentage of families earning less than $20,000 a year while Vancouver Coastal and Vancouver Island had the lowest percentage of families earning higher incomes (e.g. $60,000 or more).

Table 4: Parent/Caregiver Household Income Level, by Region;

Parent/Caregiver Demographics						
Parent/caregiver Income (N=163 respondents)	Fraser (n=46)	Interior (n=40)	North (n=39)	Vancouver Coastal (n=12)	Vancouver Island (n=26)	Total # and (%)
Less than $19,999	15%	17%	31%	25%	46%	**41 (25%)**
$20,000 to $39,999	33%	20%	18%	33%	15%	**38 (23%)**
$40,000 to $59,999	15%	25%	15%	33%	27%	**34 (21%)**
$60,000 to $79,999	20%	13%	8%	0%	4%	**18 (11%)**
≥$80,000	17%	25%	28%	8%	8%	**32 (20%)**

Source: Parent/Caregiver Intake Questionnaire

Issues and Challenges for Parents/Caregivers

In order to gain an understanding of the context under which parents and caregivers were caring for their child(ren), the Intake Questionnaire asked respondents to check whether they faced any of a variety of challenges (listed below); respondents were asked to check off all challenges that applied to their circumstances. Table 5 shows the percentage of respondents, by region, indicating that they faced these various issues or challenges.

As shown, the most frequently reported challenge that parents/caregivers faced, across all regions, was **stress**; indeed, in all regions, nearly three quarters of respondents indicated that this was an issue for them. Although regional differences existed, other challenges that a high percentage of parents/caregivers in most or all regions reported facing were:

Finances;

Parenting concerns

Accessing community support services; and

Isolation.

A striking finding was that a substantial number/percentage of parents/caregivers reported having health and/or mental health concerns, in particular anxiety and depression. Approximately 40% of respondents in all regions indicated that they had (physical) health challenges; mental health issues varied by region, but were reported by over one third of the parent/caregiver respondents in three of the five MCFD regions.

Preliminary analysis was also suggestive that there may be differences between family types in relation to these stressors. For example, a higher percentage of birth parents appear to report experiencing a range of stressors relative to other family types. In addition, the questionnaire data suggested that many

parents/caregiver were experiencing multiple challenges, and that challenges were often inter-related. For example, respondents' housing challenges often occurred in tandem with challenges with transportation, finances, health, physical disability, and family violence. Similarly, parents' and caregivers' financial challenges were linked with depression, anxiety, stress, family violence, and difficulties with housing and transportation. These findings will explored in greater detail at Time 2.

Table 5: Parent's/Caregiver's Self-Reported Challenges, by Region

Parent's/caregiver's self-reported challenges	Fraser (n=48) %	Interior (n=34) %	North (n=32) %	Vancouver Coastal (n=16) %	Vancouver Island (n=26) %	TOTAL (N=156) %
Stress	74%	70%	69%	75%	75%	**72%**
Finances	65%	59%	47%	63%	62%	**59%**
Parenting concerns	64%	55%	37%	67%	54%	**55%**
Accessing community support services	42%	47%	53%	44%	62%	**52%**
Isolation	41%	38%	46%	40%	61%	**44%**
Health	40%	42%	39%	47%	41%	**41%**
Child care	58%	37%	41%	38%	21%	**41%**
Anxiety	40%	36%	26%	25%	50%	**37%**
Transportation	23%	36%	38%	44%	46%	**35%**
Depression	33%	24%	37%	19%	50%	**33%**
Drug/alcohol use in family	20%	7%	26%	27%	32%	**21%**
Housing	12%	7%	19%	40%	33%	**19%**
Mental health	13%	12%	26%	19%	29%	**19%**
Physical disability	15%	19%	19%	7%	23%	**17%**
Family violence	14%	3%	15%	13%	17%	**12%**
Having FASD myself	2%	0%	2%	4%	9%	**4%**
Family conflict	0%	0%	0%	0%	0%	**0%**

Source: Parent/Caregiver Intake Questionnaire

Child/Youth demographics

Number of children/youth within the family served by the Key Worker program

For the majority of families in all regions, the Key Worker or Parent Support service was sought to address the issues or needs of 1-2 child(ren) in the family. In the North, however, 20% of the parents/caregivers who completed the Intake Questionnaire had three or more children who were the focus of the Key Worker/Parent Support program activities, and in the Interior, 15% of families had 3 or more children for whom the Key Worker/Parent Support service was being sought.

**Table 6: Number Of Children/Youth Within The Family Served
by Key Worker Program, by Region**

Caregiver Family Demographics							
		Fraser (n=51)	Interior (n=41)	North (n=44)	Vancouver Coastal (n=24)	Vancouver Island (n=31)	Total (N=191)
# children/ youth in family served by program	1-2	48	35	35	22	28	**168**
	3-4	3	4	9	1	3	**20**
	5-6	0	2	0	1	0	**3**

Source: Parent/Caregiver Intake Questionnaire

Age of children/youth served by the Key Worker / Parent Support program

Based on the cumulative output data provided to the evaluators by the Key Worker agencies[4], the age breakdowns of the children/youth being served by the Key Worker and Parent Support program were calculated for each region. As shown in Table 7, the breakdown of child/youth intakes by age groups varied substantially by region, especially the percentage of intakes that were young children (age 0-6) and older youth (16-19). For example, Vancouver Coastal and the Fraser had a relatively large number/percentage of intakes involving young children, while on Vancouver Island, a relatively high number of intakes involved older youth.

---

[4] Output data were used for these analyses rather than Intake Questionnaire data because the output data were more comprehensive.

Sharon Hume & Associates

Table 7: Age Of Child(ren) and Youth Intakes to Key Worker Program, by Region

Region	June 2006 – October 2007			
	# and % of total for region, age 0-6	# and % of total for region, age 7-10	# and % of total for region, age 11-15	# and % of total for region, age 16-19
Fraser (n=152)	65 (43%)	38 (25%)	37 (24%)	12 (8%)
Interior (n=178)	43 (24%)	51 (29%)	63 (35%)	21 (18%)
North (n=221)	80 (36%)	76 (34%)	56 (25%)	9 (4%)
Vanc. Coastal (n=240)	100 (42%)	41 (17%)	69 (29%)	20 (8%)
Vanc. Island (n=281)	51 (18%)	78 (28%)	85 (30%)	67 (24%)
TOTAL	**272 (34%)**	**210 (26%)**	**214 (27%)**	**98 (12%)**

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

Gender of child/youth intake

Based on the cumulative output data, just under two thirds (64%) of the children/youth served by the Key Worker program were male. The gender breakdown was fairly consistent across the five MCDF regions. See **Appendix J** for details.

Cultural heritage / ethnicity

The ethnic origin of the children and youth served by the program was analyzed based on data from the Parent/Caregiver Intake Questionnaire. Although these data were not as comprehensive as the output data, they provided greater detail than the output data, which only indicated whether children identified as being of Aboriginal descent or not. Nevertheless, as reflected in the Time 1 and Time 2 Formative Evaluation reports, there was good congruency between the questionnaire data and the output data.

As shown in Table 8, Vancouver Island was the region with the highest percentage of children and youth who were Aboriginal, relative to other cultural backgrounds. At the same time, in all regions except the Fraser, at least half of the children/youth served by the program were of Aboriginal heritage. As also shown in Table 8, there were very few child/youth intakes that identified as being from a visible minority.

Table 8: Ethnic Origin Of Children and Youth Served by Key Worker Program, by Region

Child/Youth Demographics						
Child's/Youth's Ethnic Origin (N=283)	**Fraser (n=66)**	**Interior (n=62)**	**North (n=67)**	**Vancouver Coastal (n=41)**	**Vancouver Island (n=47)**	**Total # and %**
European/ Caucasian	44%	27%	30%	39%	28%	**95 (34%)**
Aboriginal	29%	52%	55%	59%	64%	**142 (50%)**
East Asian	0%	0%	0%	0%	0%	**0 (0%)**
South Asian	5%	0%	3%	0%	0%	**5 (2%)**
Middle Eastern	2%	0%	0%	0%	0%	**1 (0%)**
African	0%	2%	0%	0%	0%	**1 (0%)**
Central/ South American	2%	3%	0%	0%	0%	**3 (1%)**
American	0%	2%	0%	0%	2%	**2 (1%)**
Other *	18%	11%	7%	2%	6%	**28 (10%)**
Not sure	2%	3%	4%	0%	0%	**6 (2%)**

Source: Parent/Caregiver Intake Questionnaire

* Frequent response was "Canadian"

SECTION 5 WHAT DIFFERENCE HAS THE PROGRAM MADE FOR PARENTS/CAREGIVERS

Early and intermediate outcomes for parents and caregivers are the focus of this section of the report. Quantitative and qualitative data reported in this section have come primarily from the 198 Parent/Caregiver Intake Questionnaires submitted as of January 31, 2008, augmented by the monthly output data submitted by Key Worker agencies, and by community-based interviews with parents/caregivers.

Based on the qualitative data collected during the community based interviews with parents and caregivers, the *Time 2 Formative Evaluation* report (January 2008) explored parents' and caregivers' perceptions of the Key Workers' role and found that the Key Workers were instrumental in:

- ✓ Providing parents and caregivers with emotional support to manage the parenting/caregiving role
- ✓ Providing parents and caregivers with very useful educational resources, and information
- ✓ Providing advocacy on behalf and interfacing of parents and caregivers with various 'systems' (e.g. schools or pre-schools) and/or accessing various services and resources
- ✓ Helping parents and caregivers to access the CBDC assessment and then supporting them through the assessment process.

Utilizing the same qualitative data, the findings in this section explore parents' and caregivers' views about how these various aspects of the Key Workers' role have made a difference in their lives. Further, findings emerging from the quantitative data include: baseline information regarding parents'/caregivers' feelings of confidence and attitudes about parenting, stress level, and social support.

Together, these findings reflect that considerable progress has been made toward achieving many of the early summative outcomes for parents and caregivers. In addition, the data show that progress has been made toward accomplishing some of the intermediate summative outcomes.

Early Summative Outcomes
- √ Families/caregivers understand FASD as a brain-based disability
- √ 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
- √ Families/caregivers feel less stressed

One of the most important early outcomes that parents and caregivers identified is how their **understanding FASD as a brain based disability** has helped them to respond differently to their child(ren**)**. In parents'/caregivers' words:

> *I realized I had to change my expectations because consequences weren't working. Both of us were getting frustrated. He (the son) presents so normally that it is difficult to appreciate that he doesn't absorb information/directions in order to change his behaviour.*

Parents and caregivers reported that the Key Workers brought new information to the families – information that has helped them reframe their children's negative behaviour and helped them adapt their own responses to their children.

> *"Don't try harder – try differently". In terms of how I'm working with my son at home. Now I'm learning how to distinguish between when he doesn't understand and is acting out because of his disability.*
>
> *[The Key Worker] has helped me to understand how immature she is. Think younger. She might be 10 in years, but not developmentally. It's been a learning thing. Without [the Key Worker] I wouldn't be this far along. Don't say "act your age".*
>
> *We do things differently, e.g. remind kids with cues – word association – what he needs to bring home – his school planner. Also I've learned that some kids with FASD don't get cold. I've learned about kids' sensory issues. Also, I've learned that we matter, as parents we matter [to our children]!.*

For parents/caregivers this new information about FASD was profound; it was as if a light went on and they suddenly realize their child's misbehaviour is not wilful on the child's part but is the result of their neuro-developmental disability*.* With this new understanding regarding FASD, parents and caregivers experienced a certain amount of relief, and a letting go of their sense of blame and/or guilt.

> *Having the knowledge and support [from the Key Worker] has made a difference. My kids are brained damaged. Their behaviour is not intentional. That takes it away from the intentionality.*
>
> *[The Key Worker] helped me accept the fact that the adult has to change – because the child can't. This is counter to the way you normally parent. This has been profound.*
>
> *The idea of brain-based disability has helped. The Key Worker has given me books to read. This has been good and very informative. It has lifted the problem from being bad parenting.*

Some parents and caregivers reported that this shift in perspective freed them up to be more inquisitive about their child(ren)'s behaviour and encouraged them to play "the detective", "to find out why the children behave the way they do." In the process, these parents reported that they were more proactive in their parenting, that they learned how to talk to their children to help change behaviour and developed "strategies to help prevent (mis)behaviour before it occurs".

An unanticipated outcome of this increased understanding of FASD as a brain-based disability was parents' and caregivers' desire to share what they learned with others in their social networks. Several

reported that they shared this new information with family and friends in order to build a consistent and supportive network for their children.

> *I am taking what I am learning and passing it along to our oldest son who lives in the same community as our son with ADHD. He supports our son but can be very impatient with him. I pass along what I am learning to him so that he is better able to support his brother. This information has also had a big impact on my husband who has tended in the past to be quite behavioural.*

> *This information has had a ripple effect in our family. The information has changed behaviour and attitude of other members of the [foster] family towards child with FASD. They could finally understand his behaviour. Now other members of the family are taking in foster children with FASD.*

Learning about FASD through information provided by the Key Worker also **helped parents and caregivers gain a better understanding of their own child(ren)'s specific challenges and needs**. Similar to the discussion above, with a better understanding of their child(ren)'s specific needs parents and caregivers reported changing their own behaviours and responses which, in turn, contributed to less stress.

> *I have learned how my daughter can understand things one day and not the next. I have more patience – I don't lose it as much. I don't raise my voice. My daughter says noises bother her.*

> *A little compartment in my brain opened up and now I want more information. This has really opened my eyes to my son's behaviours and the reasons for them.*

Other parents/caregivers found that "routine and structure are important" to their children and looked for ways to provide it, while others learned that changing expectations, specific to their child with FASD, can make a difference.

> *My son kept running away – ALL the time. It is hard to say what would trigger him running away but since I backed off in terms of my expectations (related to chronological age and expressive language strength), he has stopped running away.*

In addition to providing information about FASD, the Key Workers provided information and support that helped parents/caregivers **understand and implement the assessment/diagnostic findings and recommendations**.

> *I am really appreciative of the Key Worker service. The Key Worker is a sounding board for me. She helps me to make sense of all the reports and recommendations, and takes the perspective of what is best for me and the girls - from the broad picture - not narrow interests (like other professionals).*

> *The Key Worker explained things to me. She also helped explain to the school that even if my son had ADHD, the FASD does not go away.*

> *Now we`re putting into practice some of the ideas from the FASD assessment recommendations. For example: How to set up my son`s room so it works for him. Also, we are making other changes in the house, e.g., there are sources of over-stimulation – too bright, too many toys - in order to minimize the sensory simulation.*

Another parent, who herself had FASD, felt the diagnosis and recommendations made "a huge difference" for her and her daughter.

> *Finally she is getting the help she has needed all along. She is no longer mad at me and we are not bumping heads over schoolwork. I now know from the diagnosis that she has intellectual limitations. Before, she would not finish tasks around the house, so we have to simplify things for her and do only one thing at a time, like taking a shower, changing clothes. We were also told to involve her in things like horseback riding and pottery, so the Key Worker is helping with this.*

For the most part, parents and caregivers were appreciative of the support and guidance they received from the Key Workers in relation to understanding and implementing the assessment recommendations. However, other parents and caregivers felt more could be done.

> *I'm not sure what to do with all the recommendations from the assessment. We could use some guidance in helping us interpret them and get them implemented.*

Another parent, who was very frustrated with his son's CDBC assessment report, said that he spent considerable time synthesizing the findings and recommendations so that they were understandable and useful for others (such as teachers) who were working with his son. He said he would have liked help from the Key Worker in his community with this task, but she was not available to help with this task.

Parent and Caregiver stress

Parents and caregivers reported on stress both in the Intake Questionnaire and in the community based interviews.

An item from the FASCETS Questionnaire focusing on parenting stress was included in the Intake Questionnaire in order to gather baseline data about this aspect of caring for children with FASD/CDBC. As shown in Table 9, over one-third of respondents reported having a 'high' or 'maxed out' stress level. Further, more than 75% of respondents reported having at least 'moderate stress' in relation to parenting/caregiving their child(ren).

Table 9: Parents'/Caregivers' Stress Level in Relation to Living With a Child With FASD/CDBC

	No Stress	Mild Stress	Moderate Stress	High Stress	Maxed Out Stress
Stress Level Around Caregiving (N=176)	9 5%	31 18%	73 42%	45 26%	18 10%

Source: Parent Intake Questionnaire

While parents were not asked directly in the community-based interviews about stress, they did talk about the many ways in which the Key Worker program affected their stress levels. Interview data that spoke to both the early and intermediate summative outcome that **families and caregivers feel less stressed** revealed that several facets of the Key Worker program, as reported in the Formative Evaluation Reports, were contributing to the achievement of this outcome. These process-related components included: the family-centred and flexible nature of the program; the individual support for the parents and caregivers; the empathy and understanding; help with accessing services; and advocacy. Many parents summed up these facets of the program, and related outcomes, by saying: "Someone is there for me."

Findings highlighting how these dimensions of the Key Worker program are contributing to reducing parents' and caregivers' stress follows.

√ *Family-centred and flexible nature of the program*

> *I am a member of huge team. The Key Worker is the only one who comes into my home. The only other one is the Social Worker on occasions.*

> *The Key Worker has been supportive, resourceful, helpful. It is huge for me to have someone like her available - knowing that she is there for support. She is so available through phone or email, and is flexible.*

√ *Support*

> *The biggest thing is just to talk with her (the Key Worker).*

> *Instead of floundering alone in this world, I feel like I am moving forward with support.*

> *The support. Someone to talk to with who does not start by suggesting that it is my parenting skills. The Key Worker gets it. Others say we are too strict, too lax, etc.*

For some parents, the emotional support from the Key Worker meant the difference between parents carrying on with their child's assessment or not.

The Key Worker provided lots of emotional support for us as a family, more than I thought I was going to need. The emotional support was much needed. The bad experience with the psychologist was such that, without the Key Worker, we would have withdrawn from the whole assessment process.

Through support and education from the Key Worker, parents and caregivers were changing how they cared for their children. In turn, this change in parenting contributed to a reduction in stress as parents felt more congruency between their values, knowledge and experiences.

I have been less stressed in relation to dealing with my son's behaviour. Parenting skills have changed. I grew up in culture where spanking was okay, where discipline was authoritarian. Parents didn't care about children's feelings. For me, respect towards parents is important but it's two way. I respect children as human beings. The program has helped me see how to do that. So, parenting skills changed to reflect this.

√ ***Empathy and understanding***

[The Key Worker's] willingness to lend a helping hand. No matter what a parent asks of the Key Worker, he is willing to do it. He understands what parents go through emotionally and the physical demands.

The Key Workers know exactly what it is like. They have been around. I am comfortable with them. My daughter is comfortable with them

√ ***Help with accessing services***

The Key Worker helps take up some of the load/stress. I wouldn't have had time to do the research for new resources, so having the Key Worker to do that is such a help.

The Key Worker has helped me access things I couldn't on my own. This helps my foster child, which makes me happier.

One family that expressed frustration with the support they were receiving from the Key Worker highlighted the importance of having a helping hand to take up some of the burden of accessing services, making appointments and researching what might be available for their son.

We want someone to help organize appointments – a proactive approach. We need someone to take us and help us with appointments and talk to people. We're exhausted – burnt out! Our needs are immediate and not necessarily expensive.

√ **Advocacy**

The Key Worker has relieved the stress when doing advocacy for my children. When you have a person with a title behind their name it makes so much difference. I am no longer going to meetings stressed out because he's there (with me). The Key Worker makes suggestions and [the school] is more accepting and receptive to the Key Worker's suggestions for my child's behaviour.

Sharon Hume & Associates

> *The Key Worker really helped me through the school situation last year. They weren't listening to me until the Key Worker came along. It felt like I was ganged up on. I was thankful to have her there to advocate for me.*

Findings related to education system

Dealing with the education system was a topic of discussion that arose, unprompted, in almost every community-based interview with parents and caregivers. This is not surprising given that over two thirds of the children and youth involved with the Key worker program were of school age. For some parents/caregivers, the experience with the school system was good, or had recently improved. For others there was considerable frustration and tension. Regardless of their experiences, involvement with the school system affected outcomes for both children and parents involved in the Key Worker program.

Many families had received support and advocacy assistance from the Key Workers in working with their children's schools, and they met with success, which, in turn, contributed to a reduction in stress or frustration levels for the parents and caregivers.

> *The Key Worker was a big help. I wouldn't have made it through last year and all the meetings at the school without her. She really helped me through school situation last year. They weren't listening to me until she came along.*
>
> *School is very frustrating – the Key Worker helps me deal with it –we brainstorm plans, ways to deal with the situations. I'm not sure how receptive the school is to the Key Worker's input but I asked her to come to meetings to help me advocate for my daughter.*
>
> *The Key Worker legitimizes our issue when she attends meetings with us. The school seems to listen more when the Key Worker comes (to meetings at the school).*

Others were not as successful and found that even the Key Workers were not welcomed by the school.

> *We can't provide strategies to school because of process that has been set in place by the school board. Someone filters all the information for schools. We aren't allowed to meet directly with the teacher. I don't find this helpful.*
>
> *The schools pick and choose who they will listen to. They are not so willing yet to listen to or accept the Key Worker's input.*

Surprisingly, some parents and caregivers found that the school had little knowledge of their child's disability and/or had very little knowledge about FASD more generally. In some of these situations the Key Workers were able to support the parent/caregiver and to supply information and education about FASD generally, and the child's needs specifically, so that the schools could begin to respond more appropriately to the child's behaviour.

> *I was shocked that my daughter's teachers did not know she was affected by FASD, especially since she has been at school since kindergarten. Also, she still doesn't have an IEP. The school has a copy of CDBC assessment, but I'm not sure that they have acted on any of the recommendations. But the Key Worker and I have meetings planned to address them.*
>
> *The Key Worker came down to school. The school had no idea of his disability. The Key Worker was a big help – she helped me to understand his disability. What was happening for him – secondary disabilities – he was violent offender at age seven. We informed the principal of his disability. We set up things in the school to help him focus. We were having major issues with the principal. She didn't believe he had FAS – thought he was spoiled brat.*

Other parents/caregivers reported that their ongoing frustration with the lack of understanding about FASD and the perception that teachers and school personnel were not willing or able to make accommodations that would help their children succeed in school had led them to opt out of the public school system. These parents/caregivers had enrolled their children in private schools that were willing to work with them and their children to meet the needs of the children and create a successful educational experience. Several parents/caregivers who felt the public school system could be more responsive, suggested that children with FASD should have the option to attend "their own school" where the teaching staff would be more knowledgeable about FASD and the environment would be more suitable for children with FASD.

Intermediate Summative Outcomes

Parents' and caregivers' responses in community-based interviews suggested that progress has been made toward achieving some of the intermediate summative outcomes. These intermediate outcomes included:

- √ Families/caregivers are socially connected and have support systems
- √ Families/caregivers have confidence in their parenting
- √ Families/caregivers and service providers have a common understanding of FASD as a brain-based disability
- √ Families/caregivers are connected to community resources appropriate to their needs.

Findings relating to these intermediate outcomes are primarily based on the qualitative data collected during the community based interviews with parents and caregivers.

As an additional measure of social support, the Parent/Caregiver Intake Evaluation Questionnaire included the "Circles of Support" diagram, in which three concentric circles are used to represent emotional closeness (Kahn & Antonucci, 1980). In this evaluation, the Circles of Support measure is being used to examine how parents' and caregivers' social support networks change over time and with the support of the Key Worker.

For the Time 1 Summative Evaluation Report, however, a descriptive snapshot of questionnaire respondents' social support is provided.

Circles of Support

Quantitative and qualitative data analyses were undertaken on the Circles of Support data to explore both the number of support people named in the three concentric circles, and the nature of the relationships between the respondent and the support people (e.g. family members, friends, unpaid community people such as church members, and paid or professional service providers).

Examination of the Circles of Support diagrams revealed that the vast majority of respondents indicated the presence of support people in one or more of their Circles. However, there were a small number of respondents (n=10) in all regions who named <u>no one</u> as a support person in their entire Circles of Support diagram[5].

In the Interior and Vancouver Coastal, there were higher percentages of respondents who named more than three people as Inner Circle supports, while in the North and on Vancouver Island, there was a greater percentage of people who had 0 or 1 people as Inner Circle supports, relative to the other regions. Parents/caregivers in these same two regions also reported higher levels of feelings of isolation than other regions (for example, see Table 5: Parent/caregiver self reported challenges by region). See **Appendix K** for a summary of the additional Circles of Support findings.

Who do you turn to for support?

A thematic analysis of parents'/caregivers' responses to the open-ended question "Who do **YOU** turn to for support?" revealed a number of themes and responses. Themes in relation to this question included:

> Many respondents reported receiving support from their spouse (even if the spouse was not listed in the Circles of Support)
>
> Many respondents reported receiving support from their own parents
>
> Many respondents reported receiving support from their (adult) children
>
> Many respondents reported the Key Worker as a personal support
>
> Other (foster) parents or their child's former foster parents were named as supports
>
> Faith institutions and/or God were named as supports
>
> Parent/caregiver support groups were named as supports
>
> Internet-based support group and/or resources were named as supports.

---

[5] The diagrams which were categorized as having no one named in any Circle were distinguished from "no response" if the respondent reported in the open-ended question that followed ("Who do you turn to for support?") that s/he had no support.

Parents' and caregivers' responses during the community-based interviews revealed similar themes to those above. As one parent stated:

> *My son has a whole army behind him and he doesn't know it. He has his church, and others.*

Others noted the importance of having the Key Worker work with other members of the family so that they were all working in the same direction and were able to provide support to each other as well as to the child with FASD.

> *The Key Worker met with my husband and girls (age 14). Although the girls were very involved with their brother, they benefited from the work that the Key Worker did with me. Older kids had to follow the same strategies that I used. Eventually my son learned to accept some direction from his sisters. Sometimes the girls would just come to get me to help sort out problems. It was good to have the Key Worker to talk things through with. A real accomplishment as a family was for girls to walk their brother to school.*

Parenting Sense of Competence

Given that intermediate summative outcomes in the Evaluation Framework pertain to parents' and caregivers' perceptions of confidence in their parenting *(Families/caregivers have confidence in their parenting)*, as well as parents'/caregivers' feeling less stress living or working with their child with FASD/CDBC, the Intake Questionnaire included items on parenting sense of confidence and competence.

As noted in the Methodology section, the questions relating to parenting sense of confidence were adapted from the Parenting Sense of Competence Scale developed by Ohan and colleagues (2000). Consequently, in this report we have not calculated a total score for the Scale, but instead present findings based on the 7 scale items included in the Intake Questionnaire.

As shown in Table 10, the three scale items about which parents and caregivers reported most positive feelings of confidence or competence were items relating to parenting self-efficacy (e.g. parents'/caregivers' belief that they were doing a good job, and that they knew what to do to be a good caregiver or parent). Relative to this, respondents had more varied views in terms of their feelings of satisfaction and tension as parents/caregivers.

Table 10: Parents'/Caregivers' Parenting Sense of Competence

Parenting Sense of Competence Scale items	No Answer	Strongly Disagree	Disagree	Agree	Strongly Agree	% Agree or strongly agree
Doing Good Job as a Caregiver (N=179)	4	1	8	94	72	93%
Know What to Do to Be Good Caregiver (N=178)	2	1	10	88	77	93%
Able to Figure Out Trouble with Child (N=178)	2	3	18	101	54	87%
Satisfaction as a Caregiver (N=175)	8	7	32	71	57	73%
Difficulty Parenting Child (N=177)	5	41	63	57	11	38%
Have Necessary Information to be a Good Caregiver (N=176)	4	13	72	60	27	49%
Anxiety/Tension Around Being a Caregiver (N=177)	8	30	54	66	19	48%

Source: Parent Intake Questionnaire

In addition to the adapted Parenting Sense of Competence scale, we also included a question taken from the FASCETS questionnaire that relates to **parents'/caregivers' sense of confidence**: "Overall, my confidence level in my current ability to parent or work effectively with the child with FASD/CDBC is..."

As shown in Table 11, nearly 50% of respondents expressed having either a 'Moderate/Great' or 'Great' degree of confidence. At the same time, about half of respondents reported having 'Moderate' to 'Low' sense of confidence.

Table 11: Parents'/Caregivers' Confidence in their Caregiving Ability

	Low	Low/Moderate	Moderate	Moderate/Great	Great
Confidence in Caregiving Ability (N=176)	7 4%	7 4%	77 44%	61 35%	24 14%

Source: Parent Intake Questionnaire

In addition to the findings regarding the intermediate outcomes associated with parent competence and social support, parent/caregiver responses from the community-based interviews suggested that initial progress is being made in relation to the development of a **common understanding of FASD as a brain based disability** and that **families are connected to community resources**.

All the comments related to families and service providers having a common understanding of FASD as a brain-based disability involved the education system. When parents and the school personnel have a better understanding of the child's behaviour, they are in a better position to communicate strategies to mitigate behaviours associated with the disability[6]. It seems that everyone benefits, the child is happier in school, the parents experience a sense of relief, and the teacher (at least in the latter example) receives additional support in the classroom.

> *For the first time, [the child] wanted to go to school. In the previous school, they did everything wrong. At this school, when he misbehaves, the teaching assistant takes him on a walk to chill out. The difference in his life – he stands a chance now. Before, his destiny was jail for sure. Last year – going to school on Halloween would have been horrific. This year, he went. I came too. What they did differently was not to force him to go to the parade. They could see his needs. When they saw he was uncomfortable they stopped. They looked at things in terms of his needs.*

> *In kindergarten there were a lot of students. The teacher was very frustrated because [the child] was going under tables, or to the bathroom to get away from being overwhelmed by noise of the class. With the assessment information, the teacher understood [the child's] behaviour. Then it became permissible for her to take a walk or to go to the bathroom, etc., to remove herself from being overwhelmed. So her school experience turned around right away. We were better able to problem solve with teacher when we all had the information. Also, with the diagnosis, we got a TA in the class, which the teacher really likes. The TA works with a lot of other students. [Having a TA] frees up the teacher to pay more attention to [the child].*

In many cases the Key Workers were working with families to connect them and their children to community resources, both as a way to increase the levels of social support and to provide needed resources or supports for the family. Many Key Workers were helping families increase children's participation in community sports, such as soccer, swimming, horseback riding and so on. Others found

---

[6] Secondary disabilities are discussed further in Section 6.

social skills development programs or social groups (e.g. girls groups) that the children and their siblings could join. In some cases, helping parents and caregivers access financial support through such organizations as KidSport was necessary in order for the child to be able to participate in community activities.

In other situations, the Key Workers advocated for and helped parents and caregivers access professional services such as occupational therapy, therapy with a psychologist or day care programs. As well, many parents/caregivers mentioned that the Key Workers provided them with information, books, pamphlets, and tools such as computer programs and films they used to support their children's learning and development.

Lastly, there is some very early evidence that for some families, the overall **program goal of maintaining and enhancing the stability of families with children and youth with FASD/CDBC** was being achieved. The support, advocacy, patience, and understanding of the Key Worker, coupled with the increased knowledge about how to work with the child's disability that parents/caregiver had gained both through the Key Worker program and the assessment process resulted in some families feeling stronger and more stable.

> *The Key Worker is a really good support – to know Key Worker is there, and the family won't be dropped from the caseload, this service has kept our family in the community. My husband was offered a transfer but we decided to stay here because of the Key Worker program. He empowers parents to be better parents.*
>
> *These (foster) children wouldn't still be here if it weren't for the Key Worker. They are two of the most difficult kids in the region but they are staying with us because of his help.*

SECTION 6   WHAT DIFFERENCE HAS THE PROGRAM MADE FOR CHILDREN

This section provides descriptive information regarding the characteristics of the children and youth served by the Key Worker and Parent Support program. Findings presented focus on parents'/caregivers' perceptions of their child(ren)'s and youths' strengths and challenges, including secondary behaviours associated with FASD. This section also reports findings related to early and intermediate summative outcomes relating to children and youth, in particular:

Early Summative Outcomes

✓   Families/caregivers are able to identify strengths of their children
✓   Families/caregivers understand their child's specific challenges and needs

Intermediate Outcomes

✓   Children secondary disabilities are reduced
✓   Children feel less stressed

Findings related to children/youth are drawn from two sources: Parent/Caregiver Intake Questionnaires, including results from the FASCETS questions, and community-based interviews with parents and caregivers. With the caveat noted in the Methodology section in relation to the timing of administration of the Intake Questionnaire, the information is considered baseline.

Child/youth strengths

Parent/Caregiver Intake Questionnaire items based on the FASCETS questionnaire asked parents/caregivers the degree to which a number of strengths/abilities commonly found in people with FASD were in evidence in their child(ren).

All respondents identified one or more 'significant strength' for each child in their care who was the focus of the Key Worker program. As well, there were noteworthy commonalties in the strengths/abilities amongst the children being served by the program. Parents/caregivers rated the following qualities most frequently as being 'moderate' or 'significant' strengths for their child(ren):

    Experiential learner
    Relational
    Visual learner
    Determined
    Desire to please

At the same time, the strength that was most frequently said to be 'not in evidence' or was only present to 'some' degree was being an auditory learner.

All other strengths/abilities were reported to be present to a 'moderate' or 'significant' degree for about half – or more - of the children/youth. Findings regarding parents'/caregivers' ratings of their child(ren)'s strengths are shown in Table 12.

Table 12: Parents'/Caregivers' Ratings of Their Child(ren)'s Strengths

Child's Strengths (N=198 respondents) (N= 277 responses)	Not in Evidence	Some	Moderate	Significant Strength	Don't Know	% Moderate or signif strength
Experiential Learner (n=276)	11	32	110	116	7	82%
Relational (n=272)	7	43	88	134	-	82%
Visual Learner (n=271)	6	33	92	126	14	80%
Determined (n=270)	16	38	75	139	2	79%
Desire to Please (n=270)	12	52	91	115	1	76%
Athletic (n=271)	39	50	77	101	4	66%
Creative (n=272)	27	55	89	89	12	65%
Computer Skills (n=272)	24	57	95	70	26	61%
Artistic (n=271)	54	62	63	74	18	51%
Musical (n=271)	42	77	74	61	17	50%
Expressive Language Skills (n=249)	46	80	67	52	4	48%
Auditory Learner (n=256)	45	124	43	22	22	25%
Other	5	3	3	52	11	

Source: Parent Intake Questionnaire

*Note: responses # combines ratings for first, second and third child in family with FASD/CDBC.

Although questions regarding the identification of children's strengths were not a focus of the community-based interviews with parents and caregivers, a number of respondents reiterated how important it was that the Key Worker encouraged them to focus on the positives and the strengths of their child(ren).

Sharon Hume & Associates

> *The Key Worker helps me get the positive things about my daughter and her strengths.*

> *The Key Worker works to make things better for our foster child and easier for me. She looks for strengths and tries to acknowledge those as a way to work on self-esteem.*

Secondary Behaviours of FASD

As noted above, an early summative outcome of the Key Worker and Parent Support program was that: *Families/caregivers understand their child's specific challenges and needs*. As a measure of parents'/caregivers' appreciation of the child(ren)'s needs, questionnaire items based on the FASCETS questionnaire asked parents/caregivers to rate the frequency with which a number of secondary behaviours associated with FASD were present for their child(ren). These findings are presented in Table 13.

At the same time, these FASCETS questionnaire items were included in order to provide a measure of the intermediate summative outcomes relating to decreases in children's/youths' secondary disabilities. In this regard, the data presented below can be viewed as baseline information providing a descriptive snapshot of respondents' perceptions of secondary behaviours experienced by their child(ren).

As can be seen, parents/caregivers perceived that their child experienced a variety of secondary behaviours that were both school-related and of a more social / emotional nature. The secondary behaviour that was most frequently reported to occur either "frequently" or "always or almost always" was **being frustrated in school;** school frustration was believed to exist for 73% of the children seeking Key Worker services.

Of the social/emotional secondary behaviours, the ones that were most frequently identified by parents/caregivers to occur on a (very) frequent basis were: **anger**; **blaming others**; **disruptive behaviours**; **anxiousness;** and **aggression**.

Table 13: Parents'/Caregivers' Ratings of Their Child(ren)'s Secondary Behaviours Associated with FASD/CDBC

Child's Secondary Behaviours (N=198 respondents) (N=277 responses)	Not in Evidence	Rarely	Frequently	Almost Always/ Always	Don't Know	% Frequently or almost always/ always
Academic: School-related behaviours						
Frustrated in school (n=259)	15	40	107	83	14	73%
Disruptive in class (n=257)	46	54	90	44	23	52%
Does not turn in work at school (n=254)	40	49	71	45	49	46%
Tantrums in school (n=259)	54	81	67	43	14	42%
Other	11	7	13	29	17	
Social / Emotional Secondary Behaviours						
Anger (n=269)	22	68	105	69	5	65%
Blames Others (n=267)	37	47	75	96	12	64%
Disruptive Behaviours (n=243)	47	39	81	62	14	59%
Anxious (n=267)	35	72	91	60	9	57%
Aggression (n=270)	44	72	95	56	3	56%
Low Self Esteem (n=269)	65	64	66	50	24	44%
Shut Down (n=269)	65	82	67	45	10	42%
Destructive (n=267)	64	91	62	46	4	40%
Fearful (n=269)	67	85	63	40	14	38%
Isolated (n=270)	77	77	68	34	14	38%
Calls Self Names (n=250)	73	74	55	31	17	34%
Bullied by Others (n=267)	86	61	59	33	25	34%
Bullying (n=269)	85	87	55	31	11	32%

Child's Secondary Behaviours (N=198 respondents) (N=277 responses)	Not in Evidence	Rarely	Frequently	Almost Always/ Always	Don't Know	% Frequently or almost always/ always
Class Clown (n=268)	99	65	53	20	31	27%
Runs Away (n=266)	166	45	28	19	8	18%
School Suspension (n=264)	172	37	24	15	16	15%
Depressed (n=267)	130	73	28	9	27	14%
Trouble with Law (n=265)	219	11	14	4	17	7%
Alcohol/Drug Use (n=264)	218	14	6	5	21	4%
Other Social/Emotional Difficulties	13	4	9	19	10	

Source: Parent Intake Questionnaire

*Note: response # combines ratings for first, second and third child in family with FASD/CDBC.

Given that a number of the secondary behaviours included in the FASCETS questionnaire were potentially linked to chronological age, additional analyses of these frequencies were carried out. For example, it could be hypothesized that the secondary behaviours categorized as being school-based would be less likely to be in evidence amongst children who were pre-school age.

As shown in Table 14, children age six and older most frequently demonstrated two of the school related secondary behaviours relative to the pre-school age children (being disruptive in class and not turning in school work). Nevertheless, in contrast with the above hypothesis, there were more pre-school age children than children age 6+ who were frequently/always frustrated in school. Parents/caregivers likely were identifying secondary behaviours taking place in pre-school or daycare settings in their ratings of the young children's frustration in "school".

Table 14: Parents'/Caregivers' Ratings of Their Child(ren)'s School-Related Secondary Behaviours, by Age of Child (Age 0-5 And 6+)

Child's Secondary Behaviours	% Not in Evidence or rarely (age 0-5)	% Frequently or almost always/ always (age 0-5)	% Don't Know (age 0-5)	% Not in Evidence or rarely (age 6+)	% Frequently or almost always/ always (age 6+)	% Don't Know (age 6+)
Academic: School-related behaviours						
Frustrated in school	16%	81%	4%	24%	59%	17%
Disruptive in class	40%	40%	20%	34%	61%	5%
Does not turn in work at school	28%	14%	59%	35%	53%	12%
Tantrums in school	43%	43%	14%	53%	37%	10%

Source: Parent Intake Questionnaire   *Note: responses are for first child in family with FASD/CDBC.

Table 15 similarly shows findings regarding selected secondary behaviours based on age breakdowns. Here, the data revealed that when separate analyses were run for children age 0-11 and for adolescents (12+), a notably higher percentage of adolescents were experiencing certain social/emotional secondary behaviours, including: blaming others; suspension from school; depression; trouble with the law; and alcohol/drug use. While these age-related findings may not be surprising given that these high-risk behaviours are generally associated with teenagers rather than with younger children, they enrich the findings presented in Table14, above.

Table 15: Parents'/Caregivers' Ratings of Their Child(ren)'s Selected Secondary Behaviours by Age of Child (Age 0-11 And 12+)

Child's Secondary Behaviours	% Not in Evidence or rarely (age 0-11)	% Frequently or almost always/ always (age 0-11)	% Don't Know (age 0-11)	% Not in Evidence or rarely (age 12+)	% Frequently or almost always/ always (age 12+)	% Don't Know (age 12+)
Social / Emotional Secondary Behaviours						
Blames others	36%	56%	8%	16%	84%	0%
School Suspension	81%	12%	8%	70%	29%	1%
Depressed	73%	12%	16%	74%	23%	3%

Child's Secondary Behaviours	% Not in Evidence or rarely (age 0-11)	% Frequently or almost always/ always (age 0-11)	% Don't Know (age 0-11)	% Not in Evidence or rarely (age 12+)	% Frequently or almost always/ always (age 12+)	% Don't Know (age 12+)
Trouble with Law	87%	2%	11%	81%	19%	0%
Alcohol/Drug Use	86%	2%	13%	87%	9%	4%

Analysis of qualitative data rounded out the picture, particularly in relation to how support and advocacy provided by the Key Worker could make a difference to secondary behaviours. For example, when the parents/caregivers had the support of the Key Worker, who often provided information and education about FASD and environmental accommodations to education personnel, changes occurred in programming, school attitudes, and practices that better supported the children's learning[7]. When the schools were receptive to learning how best to work with the children, parents reported that their children began to learn, they stayed in school (instead of getting "kicked out"), they liked going to school, and some received vital help in making the transition from elementary school to high school. As indicated in the bolded portions of the quotes below, these differences potentially had a positive impact in relation to reducing secondary disabilities.

> *The Key Worker was at the IEP meeting at the new school. It was the best school and meeting. They are awesome. They accept his disabilities. When they wrote the IEP report, they weren't condemning him. They accept his disabilities. I now work closely with them. **He's starting to change. He used to hate school. Now he doesn't. They're working with him to have his own curriculum. He's got services – SLP, reassessment. He's starting to learn**. The first year of school was a waste of time. Now he's getting something. It's because of the Key Workers.*

> *The Key Worker met with the Teacher's Assistant and the teacher and explained the need for changes in their teaching approach. **Now my foster son has been in school all year and only has been sent home one time, whereas before he was being kicked out constantly**.*

---

[7] This was also noted in the findings related to parents' sense of competence in Section 5. Once parents and service providers achieved a common understanding of FASD as a brain-based disability and agreed on relevant and appropriate strategies for accommodating this reality, everyone benefited. It could be further extrapolated that some of the benefits included reduced secondary behaviours.

SECTION 7   WHAT DIFFERENCE HAS THE PROGRAM MADE FOR COMMUNITIES

Outcomes for communities

This section provides findings in relation to early summative outcomes relating to communities. The early summative outcomes identified in the Evaluation Framework were:

- ✓ 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/families' needs
- ✓ Professionals and/or community people working with families feel part of a network

Relevant evaluation research questions were: *How have the support services made a difference with respect to:*

- o Community partners' knowledge of FASD/CDBC?
- o Community partners' use of common approaches in working with children with FASD/CDBC and their families? and
- o Community partners' skills in addressing issues and challenges related to FASD/CDBC?

Findings related to community professionals and partners are drawn from two sources: community-based interviews with community partners and agency managers. In addition, embedded in the interview with community members was a brief questionnaire relating to perceived outcomes of the Key Worker and Parent Support program.

Early summative outcomes for communities

Analysis of the qualitative community-based interviews revealed that the majority of interview participants did not have direct and ongoing involvement with individual children/families. In large part this was because many of the participants were agency managers or school principals. Consequently, many interview participants could not speak to the anticipated outcomes that related to individual children and/or their strengths and needs. Moreover, the evaluators did not direct their interview questions in relation to a given family's particular circumstances, as this would have required an additional consent process and/or have raised issues regarding confidentiality.

Nevertheless, interview participants were able to speak about other ways in which the Key Worker and Parent Support program had made a difference to their knowledge and practice, including outcomes in keeping with the evaluation research questions above. In light of the data, findings regarding outcomes for communities will be organized by the evaluation research questions rather than the anticipated early summative outcomes for communities.

Increased awareness and understanding of FASD

An important outcome for the Key Worker and Parent Support Services program is increased awareness and understanding of FASD as a neuro-behavioural disability such that community service providers and others adapt their professional practice with children/youth with FASD accordingly. Qualitative interviews indicated that this was beginning to occur and that, through a combination of training, as well as hands on support and input from Key Workers, the program had become a valuable source of information regarding strategies, resources, and approaches relevant to FASD.

Several community practitioners who were interviewed described how they had learned about FASD through community-based training events and interactions or consultations with the local Key Worker. Further, practitioners noted that these connections and events had been influential in helping change their understanding and conceptualization of FASD. In the words of participants:

> *I attended FASD training in Ft St John with Diane Malbin. It changed the way I view FASD and the interventions I use. I was really drawn to get more information from Diane. Her whole modeling – "don't try harder, try different" had an impact.*

> *The Key Workers' presence has had a huge influence. It has brought the recognition of what behaviours to look for and what questions to ask. Therefore, other agency clinicians are much better informed. Having the Key Worker within CDC agency has also informed our own practice.*

Key Worker as a community resource – a source of information and support regarding FASD for community-based practitioners

Community-based practitioners (including MCFD staff) commented that they benefited from the availability of Key Workers as a resource in a variety of situations. Some described seeking help from the local Key Worker to answer questions or address confusion arising from training related to FASD, while others described asking the Key Worker to help them deal with difficult situations or to confirm a direction or approach being taken.

> *We run some group homes where people have FASD. I am heavily pressured by social workers in terms of consequences (for children). I ask the Key Worker what appropriate consequences are and she reinforces that we are doing things appropriately.*

> *The Key Workers are a useful resource for me and help educate me. For example, with one youth we are trying to develop a structure that will help him go back to school because he is currently only doing 1-2 hours a day at school. The Key Worker talked with the foster parents and looked over the program and made some recommendations that helped.*

> *At our organization, people are treated as adult learners who benefit from making decisions for themselves. Recently I have learned that for people with FASD, support in making decisions is needed because of the brain-based nature of their disability. Now I call the Key Worker for consultation regarding teaching strategies. And also to find out about what is available for people with FASD.*

Others were appreciative of the Key Workers' input because of their availability and ability to mediate difficult situations on short notice; for busy professionals this was an important contribution of the program. The Key Worker's knowledge and expertise was also invaluable in helping to diffuse difficult situations and/or helping to bridge between family members and community professionals, thereby increasing the possibilities for positive outcomes.

> *The family sees everyone – i.e. the professionals – working together. They see people listening and responding to what the family says. It builds communication at the school; the child sees me as someone who is working to support him.*

> *I was working with a foster family with a 14 year old who had FASD. Because of dysmaturity the youth needed a lot more supervision than the foster parent anticipated or wanted to provide. I was in contact with the foster home regularly - sometimes daily. It was a constant struggle to remind the foster home that the environment needed to change. The Key Worker provided education, support, assistance with boundaries, rules for the youth for visits to a previous foster home and support to the youth and to the family. I learned a lot about FASD and impacts on behaviour from discussions with the Key Worker.*

Along the lines of previous comments, respondents to the Time 2 Agency Questionnaire noted several ways in which the presence of Key Worker and/or parent support services staff had had a mostly positive impact. In multi-service agencies for example, having the Key Worker and parent support services program rounded out the range of services offered, thereby expanding what could be offered to families:

> *The programs fit together much like a puzzle, determining what is needed in terms of wrap-around.*

> *Finally, we can tell parents there are assessment and diagnosis services. This has been truly amazing! We offer services from pre-conception to adulthood. This is the final piece of the puzzle.*

In terms of knowledge and practice, having a Key Worker the program made a difference in that it was seen as a resource to the staff of existing agency programs as well as a source of information and knowledge about FASD. In the words of several respondents:

> *The knowledge gathered by our Key Workers and their growing expertise is being shared across our agency.*

> *It is fabulous to be part of a new program where cutting edge training is being accessed and shared.*

> *The Key Worker has had a positive impact on staff awareness, learning and ability to address the needs of children and youth.*

One aspect that seemed to make a difference for community service providers, no matter which region or community they resided in, was having a relationship with the Key Worker. Several people noted that they knew the Key Worker from other settings or through other venues or that the Key Worker had gotten to know them apart from a specific family or child. Their relationship with the Key Worker became the basis for them trusting the Key Worker's expertise, knowledge, support, and guidance and indeed in being willing to seek out their input.

Enhanced understanding of FASD leads to changes in practice, approaches and skills

Participants described how having enhanced knowledge regarding FASD had changed their understanding of a child's behaviour and therefore their response to it, including making environmental accommodations. As a result, community practitioners/educators gained valuable insight that helped them to see beyond behavioural problems and to consider a more strengths-based approach and/or to find environmental accommodations that helped shift the focus to achieving positive outcomes for the child and family. They also used the information to seek out other community resources that could benefit families. The comments from service providers below may be linked to early summative outcomes regarding enhanced understanding of children's/youths' strengths and needs and/or to reducing secondary behaviours although they were not made with reference to individual children or families.

> *I learned about FASD from the Key Worker, like what to expect from the child's behaviour; emotional state in relation to hypersensitivity so that we focus on strengths, positive reinforcement. I have a quiet corner that the child can use when she is feeling overwhelmed. As a result I have noticed that her defiance is related to hypersensitivity (emotional), so I try to remove her from those stressful situations.*

> *I have tried some strategies recommended by the Key Worker in relation to a specific child. Also, I meet with the Key Worker to problem solve in relation child with FASD/CDBC and/or their family/caregivers. I get help from the Key Worker in finding and accessing other resources in the community that can help with the child.*

> *The Key Worker taught me about exercise being a good stimulus for children with FASD – like swimming, mountain biking, and connection to the environment. As a result I went with the children to an adventure camp that was strong on team building, self esteem building and so forth.*

Some community professionals sought hands-on support and guidance by inviting the Key Worker to be directly involved in their work. This type of direct involvement from Key Workers helped service providers to formulate realistic and well-informed interventions and offered them an opportunity to solidify gains made with respect to their understanding of FASD and appropriate strategies, an area with which participants suggested they wanted more help. The comments below also illustrate ways in which Key Workers were facilitating community partners coming together to develop common approaches in working with families with a child/youth with FASD/CDBC a summative outcome embedded in the evaluation questions above.

Sharon Hume & Associates

We work together. The Key Worker goes along on house calls/community calls to observe children and to educate me about how to do a service plan with appropriate goals and strategies.

The Key Worker did a plan of care with me (MCFD Social Worker). The Key Worker helped in the writing of the plan; the foster placement had broken down, as had the adoptive home. I asked the Key Worker to be part of writing the plan. The Key Worker's recommendations focused on what needed to be in place in the foster home such as a suggestion to get adaptive functioning assessed and for me to be in touch with the school and teachers. The Key Worker also suggested getting the youth involved in an art program as an extra curricular activity. The Key Worker suggested using the youth's artistic ability to have the youth research his cultural identity.

I have had two or three meetings with the Key Worker – all have been meetings about [the child]. The Key Worker was very helpful in giving us information about how to work with this child and what worked well in the past. She attended three meetings at the school. The first meeting was oriented to ease what could have been very difficult transition. The Key Worker's information was very helpful, for example, background information on the boy. The Key Worker also gave us background information on FASD, as well as a booklet regarding FASD. The information emphasized that developmental age does not equal chronological age. The Key Worker also attended IEP meetings. The boy now has daily plan that we're following. The Key Worker was also supportive of the parent – and accommodated his needs – given that he had difficulties in advocating on his own.

Moreover, in terms of families, some Agency Directors indicated that the addition of the Key Worker had helped to expand the base of families they were able to serve and, had led to improved linkages with other service delivery organizations:

This program has allowed for families to access our services that maybe would not have previously. It has opened doors to continue our eager desire to work with First Nations families and children. We have established great relationships with clinicians and other partners. We are also beginning to demystify FASD and work towards removing labels and blame. By providing a valuable program to our agency we have been fortunate to recruit a very committed and professional staff member who has been a wonderful asset to the team. This program has also been very well linked with the Family Service program and the therapists.

Relationships with the school district have been strengthened.

Link between Key Workers and Community Service Providers in the North region

Finally, in the North region the connection between intake, assessment, and Key Workers meant that there was a different relationship between community service providers/professionals and the program. Those who had been involved in the assessment process were varied in their responses about how the Key Worker and Parent Support program had made a difference to them. Some community practitioners for example said they were unsure of the Key Workers' role, and wanted to have all roles within the assessment team spelled out. Others wanted the Key Workers to take more of a lead in providing training on FASD.

However, most community service providers in the North stated that the Key Workers' role in relation to facilitating everyone's involvement in the assessment was appreciated and made a positive difference. As described by one participant:

> *The Key Worker facilitates the (assessment) process and helps me get on with fulfilling the service needs for the kids and families. The Key Worker makes sure that I know when discharge meetings are set. I feel like we are part of a team, sharing resources and ideas.*

Further, the Key Worker was seen as a valuable conduit of information from the community back to the assessment team as well as a bridge between the team and families.

> *The Key Worker listens well and is supportive and trusts other professionals; it makes me feel like I am understood and that my perspective is valued. It gives me comfort that she will be the same with parents and will convey our perspectives to the team.*

> *The Key Worker was a constant throughout the assessment process and it was great to have her. I always knew what was going on; she maintained communication with the foster parents so they know what was going on too. The assessment will be very helpful for future planning; I will incorporate the assessment in the plan of care and in placement planning.*

> *The Key Worker provides additional information and input to the assessments regarding the worker's knowledge of the family. The Key Worker is able to gather and collect information in a package that I can make sense of. Also, the relationship with families helps as well.*

In summary, interview findings suggested that an increasing number of community service providers understood FASD as a neuro-behavioural disability and felt supported and encouraged to try out relevant and appropriate strategies and interventions that were in keeping with a strength-based approach. Findings also indicated that community service providers were beginning to change their practice and skills in keeping with their understanding of FASD as a neuro-behavioural disability, although at the same time they wanted more professional and/or personal support in order to work effectively with children/youth who have FASD. Nevertheless, the findings were more equivocal regarding whether community service providers felt that they were part of a broader network or if they primarily regarded the Key Worker as their sole source of information and support.

Sharon Hume & Associates

This is the first opportunity to report findings and reflect on outcomes associated with the Key Worker and Parent Support program. In this section, we will discuss the findings reported in previous sections related to:

        The characteristics of the families served by the program

        Early outcomes for families and for children/youth

        Early outcomes for communities.

Where applicable, our discussion of findings will be linked to relevant literature.

Family characteristics

There is great diversity in the types of families with whom the Key Workers are working. That Key Workers are seeing many birth parents is not insignificant, given the challenges reported by Key Workers in engaging with birth families noted in the Time 1 Formative Evaluation Report. In addition, it is worth mentioning that a substantial number/percentage of respondents were grandparents: 16% of those completing the Intake Questionnaire were grandparents. By contrast, less than 1% of children in BC overall lived with grandparents (http://www.bcstats.gov.bc.ca/data/cen06/facts/cff0603.pdf.[8] Moreover, as noted in the literature, grandparents present a unique set of needs such as legal issues (e.g. custody and guardianship issues), financial and health concerns, and isolation as a result of being out of sync with their peer group (Whittington, Brown, MacKenzie, Pearson, Burns, & Gracey 2007; Fuller-Thompson, 2005).

The Intake Questionnaire provided further information about the kinds of challenges that parents faced. Across all regions, financial concerns were the second most frequently mentioned challenge, after stress. Furthermore, as noted in Section 4, birth parents seem to experience a greater number of stressors relative to other parents and caregivers. The information regarding the constellation of demographic information, the challenges parents face, and the relationship between the challenges and parents'/caregivers' sense of their own competence have implications for Key Workers in terms of the needs that parents/caregivers may experience as a result of their circumstances. What we know from Greco and Sloper's (2007) research is that when Key Workers were sensitive to the needs and circumstances of the family as a whole, families experienced better outcomes overall.

---

[8] What is missing from the literature, however, is demographic information regarding the living arrangements of children/youth in BC who have FASD, and the percentage of children/youth who live with their grandparents versus the percentage living with their birth parents, or with a foster or adoptive family.

Early outcomes for families and for children/youth

Overall findings of this evaluation indicate that the Key Worker program has been highly successful to date. Similar to the findings from Greco and Sloper (2007), parents/caregivers identified the following as characteristics of the service that made a difference for them and their children:

emotional and practical support, especially around accessing services;

advocacy - helping strengthen their voice with other service providers in the community, in particular with the education system;

flexibility - being able to work across a variety of mandates to attend to the needs of the whole family.

Further, the provision of relevant, up to date information and education for parents about their child's abilities, along with information about appropriate environmental accommodations, was profound and contributed to changes in parents' and caregivers' behaviours. This in turn led to positive changes in their children's behaviour and a reported reduction in parent/caregiver stress. In contrast, and not dissimilar to the findings from Greco and Sloper (2007), when parents and caregivers expressed frustration in this evaluation, it was in relation to:

The lack of understanding, on the part of other service providers, of FASD as a brain based disability and of its impact on children's behaviour

The difficulties and stress in accessing programs and services for their children.

This report has been silent in relation to parent support, primarily because this aspect of the program has taken longer to develop and there were relatively few parents/caregivers directly involved in activities associated with parent support. We expect that there will be more to report in the Time 2 Summative Evaluation Report.

Intermediate outcomes for families and for children/youth

Findings in this report also indicated that there has been progress toward achieving some of the intermediate outcomes associated with social support, connections with community resources and parent/caregiver confidence. According to many parents and caregivers, the Key Workers have been instrumental in helping them strengthen social supports amongst their family and friends and in connecting them and their children with community programs and services. While there is some suggestion that the program is helping to improve parents'/caregivers' confidence, it is also clear that those parents/caregivers who are experiencing stress, anxiety and financial challenges feel less confident.

While it is very early in the program implementation, there was early evidence that for some families, the overall program goal of maintaining and enhancing the stability of families with children and youth with

FASD/CDBC was being achieved. Given that a stable living situation is a strong protective factor for children with FASD/CDBC (Streissguth et al, 1997), these are potentially very powerful findings.

The Time 2 Summative Evaluation Report will comment further on achievement of intermediate outcomes and the interplay of family circumstances.

Early outcomes for communities

In relation to outcomes for communities, what emerged was the importance of the broad nature of the Key Workers' position, as well as the relational nature of the role in creating positive relationships between the Key Worker and community service providers, and between parents/caregivers and community service providers. As described by Sloper and Greco (2006), "key working crosses the boundaries of different agencies and disciplines" (p. 452). This means that Key Workers need to be knowledgeable about a variety of community resources, services, professionals and organizations, and at the same time to be knowledgeable about FASD and families' circumstances. To the extent that Key Workers were able to successfully navigate their dual roles (i.e. with communities and with families), their success was based in part upon their ability to establish positive working relationships and to act as a bridge between community service providers and families. When Key Workers were successful in maintaining that 'tricky' balance between being an advocate for families and developing trusting relationship with service professionals, all parties reported benefiting through increased knowledge, more effective strategies for the children and reduction in stress for the adults.

Another important outcome was that the Key Worker program was having a positive impact on the agencies in which they were situated. The Key Workers were instrumental in broadening their host agencies understanding of FASD as a brain based disability, thereby further enhancing both the agency's and communities capacity to understand and work with those affected by FASD. The addition of the Key Worker program also increased the ability of multi-service agencies to offer integrated and coordinated services by providing a unified conceptual framework for working with children and families with FASD/CDBC.

Limitations of the evaluation

The data collected to date were intended to provide baseline information. As noted in the Methodology section, this may not be the case as Key Workers are completing the questionnaire with families at varying times, depending on a number of factors including parent/caregiver readiness. The timing of completion of intake questionnaires will be examined more closely at Time 2 by comparing the start date for service in relation to the date on which the questionnaire was completed.

The data from the Parent/Caregiver Intake Questionnaires allow us to describe the characteristics of families and children receiving Key Worker services. However, due to the wording on the questionnaire the evaluation is unable to differentiate characteristics and outcomes on the basis of a diagnosis/assessment of FASD versus that of a CDBC.

The FASCETS portion of the Intake Questionnaire provided parents/caregivers with the opportunity to identify children's strengths and secondary disabilities. The types of strengths identified by parents and caregivers were generally in keeping with existing literature (e.g. Malbin, nd) and may ultimately extend this literature, given that discussion of the strengths of children and youth with FASD is often overlooked.

Nevertheless, upon additional reflection on the FASCETS as a research tool, the evaluation team observed that while the FASCETS questionnaire asks parents/caregiver to rate the frequency of various negative secondary behaviours/symptoms, parents/caregivers are not asked to list the frequency with which their child engages in various positive or pro-social behaviours. In other words, while secondary characteristics are described in behavioural terms ("destructive", and "disruptive in class"), strengths are described as personal attributes, for example, "artistic" and "musical". This potentially represents a limitation of the FASCETS as a research tool in that, while we would not expect to see changes in a child's strengths as attributes over time, we would hope to see a reduction in secondary behaviours because of a better "fit" between the child and the various environmental accommodations made in keeping with that child's needs. As it is, a reduction in negative behaviours may be demonstrated via the FASCETS questionnaire, but not an increase in positive behaviours. These observations point to the potential value of including a checklist of positive or pro-social behaviours in the FASCETS tool, along with the child's strengths and the existing negative behaviours conceptualized as being primary and secondary effects of FASD.

The Key Worker and Parent Support Services program has made great strides in achieving early and some intermediate outcomes with a diverse range of parents/caregivers and families. Also, notably, there are some indications that the program is being successful with some families in achieving the long-term goal of increased stability. In conclusion, the Time 1 findings have provided a snapshot of characteristics of families and children and parents'/caregivers' perceptions of early outcomes of the program. These data will be used for comparative purposes in subsequent analyses.

Sharon Hume & Associates

REFERENCES

Armstrong, H., Wilks, C., & Melville, C. (2003) Evaluation of the parent group experience. What helps and what hinders. *International Journal of Adolescent Medical Health. 15 (1)* 31-37.

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.

BC Stats. (2006) Census Fast Facts: Children in BC Families. Ministry of Labour and Citizens' Services, Victoria, BC. http://www.bcstats.gov.bc.ca/data/cen06/facts/cff0603.pdf

Brown, M. (no date) *Recommended Practices in Parent Education and Support – A Literature Review*. University of Delaware Cooperative Extension. www.fasdconnections.ca/id111.htm

Canadian Centre on Substance Abuse. (2001). *Helping communities respond to alcohol use and pregnancy issues: A conversation with Judy Kay.* http://www.ccsa.ca/CCSA/EN/Topics/Populations/FASDIntervention.htm

Centers for Disease Control and Prevention. (date retrieved: January 2008). *Developing Intervention Strategies for Children: Intervening with Children and/or Adolescents with Fetal Alcohol Syndrome or Alcohol-Related Neurodevelopmental Disorders*. http://www.cdc.gov/ncbddd/fas/intervening.htm

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.

Duquette, C., Stodel, E., Fullarton, S., & Hagglund, K. (2006). Persistence in high school: Experiences of adolescents and young adults with Fetal Alcohol spectrum Disorder. *Journal of Intellectual & Developmental Disability*. 31(4). 219-231.

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

Frankel, H, Frankel, S., Opie, S. (2007). *Service Needs, Environmental Facilitating Factors and Barriers: The experience of Families Successfully Caring for Children Affected by FASD*. Webcast: 8th Annual FACE Research Roundtable. http://www.knowledgenetwork.ca/fas/webcast/index.html

Fuller-Thompson, E. (2005). *Grandparents Raising Grandchildren in Canada: A Profile of Skipped Generation Families.* Social and Economic Dimensions of an Aging Population. SEDAP Research Paper 132. Hamilton, Ontario: McMaster University.

Gibaud-Wallston, J. & Wandersman, L.P. (1978). Development and Utility of the Parenting Sense of Competence Scale. Paper presented at the meeting of the American Psychological Association, Toronto.

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: Social Policy Research Unit, University of York. Research Report No. 656

Greco, V., Slper, P., Webb, R., & Beecham, J. (2006) *Key worker services for disabled children: the views of staff*. Health and Social Care in the Community 14(6), 445-452.

Greco, V., Sloper, P., Webb, R., & Beecham, J. (2007) Key Worker Services for Disabled Children: the Views of Parents. *Children & Society*. 21. 162-174.

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

Kahn & Antonucci (1980). Convoys over the life course. Attachment, roles, and social support. In P. B. Baltes & O. G. Brim (Eds.), *Life-span development and behavior* (pp. 254 –283). New York: Academic Press.

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.

Legge, C., Roberts, G., & Butler, M. (2000). *Situational Analysis of Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of Other Substance Use During Pregnancy*. Health Canada. Ottawa, Ontario. http://www.cds-sca.com

Leslie, M. & Roberts, G. (2001). *Enhancing Fetal Alcohol Syndrome (FAS)-related Interventions at the Prenatal and Early Childhood Stages in Canada*. Canadian Centre on Substance Abuse. Ottawa, Ontario. http://www.ccsa.ca

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

Livingstone, S. (2005). *A Glimpse at Support Groups*. Renfrew Educational Services. Calgary, Alberta. www.renfreweducation.org

Malbin, D. (nd) FASCETS *Conceptual Foundation: A Neurobehavioral Construct for Interventions For Children and Adults with Fetal Alcohol Spectrum Disorders (FASD).* www.fascets.org/conceptualfoundation.html

Malbin, D. (2004). Fetal Alcohol Spectrum Disorder (FASD) and the Role of Family Court Judges in Improving Outcomes for Children and Families, *Juvenile and Family Court Journal, 55,* 53-63.

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 http://www.mcf.gov.bc.ca/fasd/pdf/fasd_strategic_plan-final.pdf).

Ministry for Children and Family Development (2007). Draft Key Worker and Parent Support Program: Program Standards. Victoria, BC. Ministry of Children and Family Development.

O'Connor, M.J., Frankel, F., Paley, B., Schonfeld, A.M., Carpenter, E. & Laugeson, E.A. (2006) A controlled social skills training for children with fetal alcohol spectrum disorders. *Journal of Consulting and Clinical Psychology*. 74(4), 639-648. Postprint available at: http://repositories.cdlib.org/postprints/1769

Ohan, J.L., Leung, D.W. & Johnson, C. (2000). The Parenting Sense of Competence Scale: Evidence of a stable factor structure and validity. *Canadian Journal of Behavioural Science, 32,* 251-261.

Ontario Federation of Indian Friendship Centres (2002). *Aboriginal Approaches to Fetal Alcohol Syndrome/Effects.* A Special Report by the Ontario Federation of Indian Friendship Centres. Toronto, Ontario. http://www.ofifc.org/page/FAS_MAG_ED1.pdf

Patton, M. (1990). *Qualitative Evaluation and Research Methods* (2nd ed.). Newbury Park, CA: Sage Publications, Inc.

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.

Rutman, D., Hume, S., Hubberstey, C. & Luettgen, J. (2007). *Supporting Families with Children and Youth with FASD: An Overview of British Columbia's Family Support Initiatives and Evaluation.* Workshop presentation made at FASD conference, Victoria, BC March 2007.

Santelli, B., Turnbull, A., Marquis, J., & Lerner, E. (2000). Statewide parent to parent programs: Partners in early intervention. *Infants & Young Children, 13*(1), 74-88.

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. (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.

Streissguth, A., Barr, H., Kogan, J. & Bookstein, F, (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.

Streissguth, A., Barr, H., Kogan, J., & Bookstein, F. (1997). Primary and secondary disabilities in Fetal Alcohol Syndrome. In A. Streissguth & J. Kanter (Eds.), *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities* (pp. 25–39). Seattle, WA: University of Washington Press.

Streissguth A., Bookstein F., Barr H., Sampson P., O'Malley K. & Young J. (2004). Risk factors for adverse life outcomes in fetal alcohol syndrome and fetal alcohol effec*ts. J Dev Behav Pediatrics, 25(4),* 228-38.

Victoria Order of Nurses. (nd). *Parenting Guidelines for Families of Children with Fetal Alcohol Syndrome/Fetal Alcohol Effects.* http://www.von.ca/FASD/index.html

Whittington, B., Brown, L., MacKenzie, P., Pearson, T., Burns, D., Gracey, M. (2007). *Supporting Grandparents Raising Grandchildren Resource Booklet: A Work in Progress* (2nd edition). University of Victoria

Sharon Hume & Associates

APPENDIX A

KEY WORKER & 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		*Community*	*Community*	
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	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 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*	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 for Time 2

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

APPENDIX C
INTAKE EVALUATION QUESTIONNAIRE FOR PARENTS AND CAREGIVERS

Intake Evaluation Questionnaire
for Parents/Caregivers

To be completed by Key Worker/Office

Participant ID #: _____

Written Informed Consent completed and on file in Key Worker's office
☐ Yes
☐ No

Today's date (day/month/year) _____ _____ _____

Has the parent/caregiver accessed Key Worker and/or Parent to Parent Support Services in another community or agency?
☐ Yes
☐ No
If so where? _____

When did parent/caregiver start receiving services from the Key Worker? (day/month/year).

_____ _____ _____

Who referred parent/caregiver to the Key Worker or Parent to Parent Support services?
☐   Self-referred
☐   Referred through FASD/CDBC assessment process
☐   Referred by another MCFD program
☐   Referred by another agency or government program
☐   Other _____ (describe)

Is parent/caregiver (also) participating in Parent to Parent Support activities?
☐   Yes
☐   No

If so, when did parent/caregiver start participating in Parent to Parent activities?

_____

Section 1: Background

We would like you to complete the following background questions about your family and your child(ren) who may have FASD or a Complex Developmental Behavioural Condition (CDBC). This information will be used only to describe the group of families participating in this study. Your individual responses will not be identified in any way.

1. How many children are in the family? _____

2. How many children in the family are currently living at home? _____

3. How many of the children have or are suspected of having FASD or a Complex Developmental Behavioral Condition (CDBC)? _____

4. Birth date of the (first) child with FASD or CDBC. (day/month/year) _____ _____ _____

5. What is this child's gender?
   ☐ Male
   ☐ Female

6. Has this child been assessed as having FASD or CDBC? **Check one only**.
   ☐ Yes
   ☐ No
   ☐ Self-identifies as having FASD or CDBC
   ☐ Not sure

7. How old was this child when he/she was first assessed as having FASD or CDBC? **Check one only**.
   ☐ Not yet assessed
   ☐ 35 months or younger
   ☐ 3 to 6 years old
   ☐ 7 years to 11 years old
   ☐ 12 years or older
   ☐ Don't know/not sure

8. What type of school setting does this child currently attend? **Check one only**.
   ☐ No school
   ☐ Special pre-school
   ☐ Pre-school
   ☐ Regular school

☐ Regular school, special program
☐ Special school
☐ Other _____
☐ Not applicable

---

9. What is your relationship to this child? **Check one only**.
☐ Birth mother
☐ Birth father
☐ Stepmother
☐ Stepfather
☐ Adoptive mother
☐ Adoptive father
☐ Foster mother
☐ Foster father
☐ Grandmother
☐ Grandfather
☐ Other primary caregiver, please specify: _____

---

10. How many different caregivers/homes has this child had since birth (apart from birth or adoptive parents)? **Check one only**.
☐ 1–2
☐ 3–5
☐ 6–10
☐ 10+
☐ Don't know/not sure

---

11. Which best describes this child's ethnic origin? **Check one only**.
☐ European (Caucasian)
☐ Aboriginal
☐ East Asian
☐ South Asian
☐ Middle Eastern
☐ African
☐ Central/ South American
☐ American (US)
☐ Other _____
☐ Don't know/not sure

If there is only one child/youth with FASD or other CDBCs in the family, please skip to Question 28. If more than 3 children, copy and use this form again

12. Birth date of the (second) child with FASD or CDBC. (day/month/year) _____ _____ _____

13. What is this child's gender?
    ☐ Male
    ☐ Female

14. Has this child been assessed as having FASD or CDBC? **Check one only**.
    ☐ Yes
    ☐ No
    ☐ Not sure
    ☐ Self-identifies as having FASD or CDBC

15. How old was this child when he/she was first assessed as having FASD or CDBC?
    Check one only.
    ☐ Not yet assessed
    ☐ 35 months or younger
    ☐ 3 to 6 years old
    ☐ 7 years to 11 years old
    ☐ 12 years or older
    ☐ Don't know/not sure

16. What type of school setting does this child currently attend? **Check one only**.
    ☐ No school
    ☐ Special pre-school
    ☐ Pre-school
    ☐ Regular school
    ☐ Regular school, special program
    ☐ Special school
    ☐ Other _____

17. What is your relationship to this child? **Check one only**.
    ☐ Birth mother
    ☐ Birth father
    ☐ Stepmother
    ☐ Stepfather
    ☐ Adoptive mother
    ☐ Adoptive father
    ☐ Foster mother
    ☐ Foster father
    ☐ Grandmother
    ☐ Grandfather
    ☐ Other primary caregiver, please specify: _____

18. How many different caregivers/homes has this child had since birth (apart from birth or adoptive parents)? **Check one only**.
   ☐ 1–2
   ☐ 3–5
   ☐ 6–10
   ☐ 10+
   ☐ Don't know/not sure

19. Which best describes this child's ethnic origin? **Check one only**.
   ☐ European (Caucasian)
   ☐ Aboriginal
   ☐ East Asian
   ☐ South Asian
   ☐ Middle Eastern
   ☐ African
   ☐ Central/South American
   ☐ American (US)
   ☐ Other _____
   ☐ Don't know/not sure

If there are only two children/youths with FASD or other CDBCs in the family, please skip to Question 28

20. Birth date of the (third) child with FASD or CDBC. (day/month/year) _____ _____ _____

21. What is this child's gender?
   ☐ Male
   ☐ Female

22. Has this child been assessed as having FASD or CDBC? **Check one only**.
   ☐ Yes
   ☐ No
   ☐ Not sure
   ☐ Self-identifies as having FASD or CDBC

23. How old was this child when he/she was first assessed as having FASD or CDBC? **Check one only**.
   ☐ Not yet assessed
   ☐ 35 months or younger
   ☐ 3 to 6 years old
   ☐ 7 years to 11 years old
   ☐ 12 years or older
   ☐ Don't know/not sure

24. What type of school setting does this child currently attend? **Check one only**.
   ☐ No school
   ☐ Special pre-school
   ☐ Pre-school
   ☐ Regular school
   ☐ Regular school, special program
   ☐ Special school
   ☐ Other _____

25. What is your relationship to this child? **Check one only**.
   ☐ Birth mother
   ☐ Birth father
   ☐ Stepmother
   ☐ Stepfather
   ☐ Adoptive mother
   ☐ Adoptive father
   ☐ Foster mother
   ☐ Foster father
   ☐ Grandmother
   ☐ Grandfather
   ☐ Other primary caregiver, please specify: _____

26. How many different caregivers/homes has this child had since birth (apart from birth or adoptive parents)? **Check one only**.
   ☐ 1–2
   ☐ 3–5
   ☐ 6–10
   ☐ 10+
   ☐ Don't know/not sure

27. Which best describes this child's ethnic origin? **Check one only**.
   ☐ European (Caucasian)
   ☐ Aboriginal
   ☐ East Asian
   ☐ South Asian
   ☐ Middle Eastern
   ☐ African
   ☐ Central/South American
   ☐ American (US)
   ☐ Other _____
   ☐ Don't know/not sure

28. Please indicate if you are a two parent/caregiver (parents/caregivers living together in the same house) or a single parent/caregiver family. **Check one only**.

☐ Two parent/caregiver family
☐ Single parent/caregiver family

29. Please check the category that includes your age.

☐ Under 20 years
☐ 20–34 years
☐ 35–49 years
☐ 50–64 years
☐ 65 or over

30. Which best describes your ethnic origin? **Check one only**.

☐ European (Caucasian)
☐ Aboriginal
☐ East Asian
☐ South Asian
☐ Middle Eastern
☐ African
☐ Central/South American
☐ American (US)
☐ Other _____

31. What is the highest level of education that you (and your spouse/partner) completed? **Check one level for each parent**. Answer only for yourself if you are a single parent/caregiver.

	Yourself	Your spouse or partner
Grade 8 or less		
High school completion		
Attended trade or technical school		
Attended college or university		

32. Which category listed below represents your total family income before taxes? Please include income from sources such as wages, salaries, commissions, pensions, family allowance, rental income, and so forth. **Check one only**.
   ☐ Less than $19,999
   ☐ $20,000 to $39,999
   ☐ $40,000 to $59,999
   ☐ $60,000 to $79,999
   ☐ More than $80,000

33. What community do you live in? _____

34. How long have you lived in this community? _____ years, _____ months

35. How many times have you moved since the child(ren) with FASD or CDBC was/were born or began living with you? _____

Section 2: The Child(ren)'s Strengths and Secondary Disabilities

When people with FASD do not receive the proper assessment or supports, they often experience chronic frustration. Over time, patterns of defensive behaviours commonly develop. These behaviours are called secondary characteristics because they are believed to be preventable with appropriate supports. Typical secondary characteristics in children, adolescents, and adults include: fatigue and/or tantrums; anxiety, withdrawal; mental health problems, e.g. depression, self-injury, anger or aggression; running away; drug/alcohol abuse; troubles with the law. (Source: Malbin, www.fascets.org)

Please circle the number that best reflects the (first) child's strengths.

D/K = Don't know/can't judge
0 = Not in evidence
1 =Some
2 = Moderate
3 = Significant strength

36. Artistic	0	1	2	3	D/K
37. Musical	0	1	2	3	D/K
38. Athletic	0	1	2	3	D/K
39. Good at using computers	0	1	2	3	D/K
40. Strong expressive language skills, storytelling	0	1	2	3	D/K
41. Learns by doing: experiential, kinesthetic (movement)	0	1	2	3	D/K
42. Relational: friendly, outgoing	0	1	2	3	D/K
43. Determined, persistent	0	1	2	3	D/K
44. Wants to please	0	1	2	3	D/K
45. Creative	0	1	2	3	D/K
46. Visual learner	0	1	2	3	D/K
47. Auditory learner	0	1	2	3	D/K
48. Others: _____	0	1	2	3	D/K

Please circle the number that best reflects the (first) child's secondary disabilities.

D/K = Don't know/can't judge
0 = Not in evidence
1 = Rarely
2 = Frequently
3 = Always or almost always

ACADEMIC: SCHOOL-RELATED BEHAVIORS

49. Does not turn in work	0	1	2	3	D/K
50. Disruptive in class	0	1	2	3	D/K
51. Frustrated	0	1	2	3	D/K
52. Tantrums	0	1	2	3	D/K
53. Others: _____	0	1	2	3	D/K

SOCIAL/EMOTIONAL CHARACTERISTICS

54. Calls self names (i.e. "I'm stupid", "no-brainer", etc.)	0	1	2	3	D/K
55. Isolated	0	1	2	3	D/K
56. Class clown	0	1	2	3	D/K
57. Anger	0	1	2	3	D/K
58. Aggression	0	1	2	3	D/K
59. Bullying, meanness to others	0	1	2	3	D/K
60. Fearful	0	1	2	3	D/K
61. Anxious	0	1	2	3	D/K
62. Destructive	0	1	2	3	D/K
63. Blames others	0	1	2	3	D/K
64. Shut down	0	1	2	3	D/K
65. Low self esteem	0	1	2	3	D/K
66. Runs away	0	1	2	3	D/K
67. Alcohol/drug use	0	1	2	3	D/K
68. Depressed	0	1	2	3	D/K
69. Trouble with the law	0	1	2	3	D/K

70. Leaving school (suspensions)	0	1	2	3	D/K
71. Victimized, bullied by others	0	1	2	3	D/K
72. Disruptive behaviours _____	0	1	2	3	D/K
73. Others: _____	0	1	2	3	D/K

74. Are any secondary behaviours seen in one setting and not another? For example, are the behaviours different at home than at school or elsewhere?

Please comment: _____

_____

_____

If there is only one child/youth with FASD or other CDBCs in the family, please skip to Section 3.

Please circle the number that best reflects the (second) child's strengths.

D/K = Don't know/can't judge
0 = Not in evidence
1 = Some
2 = Moderate
3 = Significant strength

75. Artistic	0	1	2	3	D/K
76. Musical	0	1	2	3	D/K
77. Athletic	0	1	2	3	D/K
78. Good at using computers	0	1	2	3	D/K
79. Strong expressive language skills, storytelling	0	1	2	3	D/K
80. Learns by doing: experiential, kinesthetic (movement)	0	1	2	3	D/K
81. Relational: friendly, outgoing	0	1	2	3	D/K
82. Determined, persistent	0	1	2	3	D/K
83. Wants to please	0	1	2	3	D/K
84. Creative	0	1	2	3	D/K
85. Visual learner	0	1	2	3	D/K
86. Auditory learner	0	1	2	3	D/K
87. Others: _____	0	1	2	3	D/K

Please circle the number that best reflects the (second) child's secondary disabilities.

D/K = Don't know/can't judge
0 = Not in evidence
1 = Rarely
2 = Frequently
3 = Always or almost always

ACADEMIC: SCHOOL-RELATED BEHAVIORS

88. Does not turn in work	0	1	2	3	D/K
89. Disruptive in class	0	1	2	3	D/K
90. Frustrated	0	1	2	3	D/K
91. Tantrums	0	1	2	3	D/K
92. Others: _____	0	1	2	3	D/K

SOCIAL/EMOTIONAL CHARACTERISTICS

93. Calls self names (i.e. "I'm stupid", "no-brainer", etc.)	0	1	2	3	D/K
94. Isolated	0	1	2	3	D/K
95. Class clown	0	1	2	3	D/K
96. Anger	0	1	2	3	D/K
97. Aggression	0	1	2	3	D/K
98. Bullying, meanness to others	0	1	2	3	D/K
99. Fearful	0	1	2	3	D/K
100. Anxious	0	1	2	3	D/K
101. Destructive	0	1	2	3	D/K
102. Blames others	0	1	2	3	D/K
103. Shut down	0	1	2	3	D/K
104. Low self esteem	0	1	2	3	D/K
105. Runs away	0	1	2	3	D/K
106. Alcohol/drug use	0	1	2	3	D/K
107. Depressed	0	1	2	3	D/K
108. Trouble with the law	0	1	2	3	D/K

109. Leaving school (suspensions)	0	1	2	3	D/K
110. Victimized, bullied by others	0	1	2	3	D/K
111. Disruptive behaviours _____	0	1	2	3	D/K
112. Others: _____	0	1	2	3	D/K

113. Are any secondary behaviours seen in one setting and not another? For example, are the behaviours different at home than at school or elsewhere? Please comment:

_____

_____

_____

If there are only two children/youths with FASD or other CDBCs in the family, please skip to Section 3.

Please circle the number that best reflects the (third) child's strengths.

D/K = Don't know/can't judge
0 = Not in evidence
1 = Some
2 = Moderate
3 = Significant strength

114. Artistic	0	1	2	3	D/K
115. Musical	0	1	2	3	D/K
116. Athletic	0	1	2	3	D/K
117. Good at using computers	0	1	2	3	D/K
118. Strong expressive language skills, storytelling	0	1	2	3	D/K
119. Learns by doing: experiential, kinesthetic (movement)	0	1	2	3	D/K
120. Relational: friendly, outgoing	0	1	2	3	D/K
121. Determined, persistent	0	1	2	3	D/K
122. Wants to please	0	1	2	3	D/K
123. Creative	0	1	2	3	D/K
124. Visual learner	0	1	2	3	D/K
125. Auditory learner	0	1	2	3	D/K
126. Others: _____	0	1	2	3	D/K

Please circle the number that best reflects the (third) child's secondary disabilities.

D/K = Don't know/can't judge
0 = Not in evidence
1 = Rarely
2 = Frequently
3 = Always or almost always

ACADEMIC: SCHOOL-RELATED BEHAVIORS

127. Does not turn in work	0	1	2	3	D/K
128. Disruptive in class	0	1	2	3	D/K
129. Frustrated	0	1	2	3	D/K
130. Tantrums	0	1	2	3	D/K
131. Others: _____	0	1	2	3	D/K

SOCIAL/EMOTIONAL CHARACTERISTICS

132. Calls self names (i.e. "I'm stupid", "no-brainer", etc.)	0	1	2	3	D/K
133. Isolated	0	1	2	3	D/K
134. Class clown	0	1	2	3	D/K
135. Anger	0	1	2	3	D/K
136. Aggression	0	1	2	3	D/K
137. Bullying, meanness to others	0	1	2	3	D/K
138. Fearful	0	1	2	3	D/K
139. Anxious	0	1	2	3	D/K
140. Destructive	0	1	2	3	D/K
141. Blames others	0	1	2	3	D/K
142. Shut down	0	1	2	3	D/K
143. Low self esteem	0	1	2	3	D/K
144. Runs away	0	1	2	3	D/K
145. Alcohol/drug use	0	1	2	3	D/K
146. Depressed	0	1	2	3	D/K

147. Trouble with the law	0	1	2	3	D/K
148. Leaving school (suspensions)	0	1	2	3	D/K
149. Victimized, bullied by others	0	1	2	3	D/K
150. Disruptive behaviours _____	0	1	2	3	D/K
151. Others: _____	0	1	2	3	D/K

152. Are any secondary behaviours seen in one setting and not another? For example, are the behaviours different at home than at school or elsewhere? Please comment:

_____
_____
_____

Section 3: Parent's/Caregiver's Experience Of Parenting/Caregiving

The following statements deal with being a parent/caregiver, and are not specific to each child. For each statement please indicate the extent that you agree or disagree, and check your response.

	Strongly Disagree	Disagree	Agree	Strongly Agree	No answer
153. I feel like I am doing a good job as a parent/caregiver.					
154. If something is troubling my child, I can usually figure out what it is.					
155. I know what I need to do to be a good parent/caregiver.					
156. Being a parent/caregiver is as satisfying as I expected.					
157. I believe I have all the information necessary to be a good parent/caregiver to my child.					
158. Being a parent/caregiver makes me tense and anxious.					
159. It's really difficult to decide how to parent or provide care for my child.					

160. Overall, my confidence level in my current ability to effectively parent or provide care for the child(ren) with FASD or a CDBC is:

Low		Moderate		Great
1	2	3	4	5

161. On a scale of 1 to 5, please circle the number that most closely reflects your current stress level related to living or working with the child(ren) or adolescent(s) with FASD or a CDBC.

No stress		Moderate stress		Maxed out
1	2	3	4	5

162. As a parent/caregiver, do you face any of the following challenges?
    Please check all that apply:

☐ Finances
☐ Transportation
☐ Isolation
☐ Drug/alcohol use in family
☐ Health
☐ Physical disability
☐ Parenting concerns
☐ Family violence
☐ Housing
☐ Family conflict
☐ Child care
☐ Mental health
☐ Anxiety
☐ Depression
☐ Stress
☐ Accessing community support services
☐ Having FASD myself
☐ Other (please identify)

Section 4: Circles Of Support

We are interested in knowing who you feel provides support to you and your child(ren). The circles represent how close and important your support people are to you and your child(ren). In your inner circle, the circle closest to CHILD, write the initials and relationships of people that are closest to you and your child(ren). For example, you could write Ms B – teacher, JM – sister, MK – best friend and so on. These would be people who you consider most important in your and your child(ren)'s life. In the next circle, write the names and relationships of people not as close, but still very important to you and your child(ren). And in the outer circle, write the names and relationships of people who are even less close. People in the outside circle would be adults, who are in your and your child(ren)'s life who may provide support in less direct ways (e.g., employers, or work colleagues, service providers who work with you or your family and so forth).

Other
Supports

Supportive
People

Closest
Support
People

Child
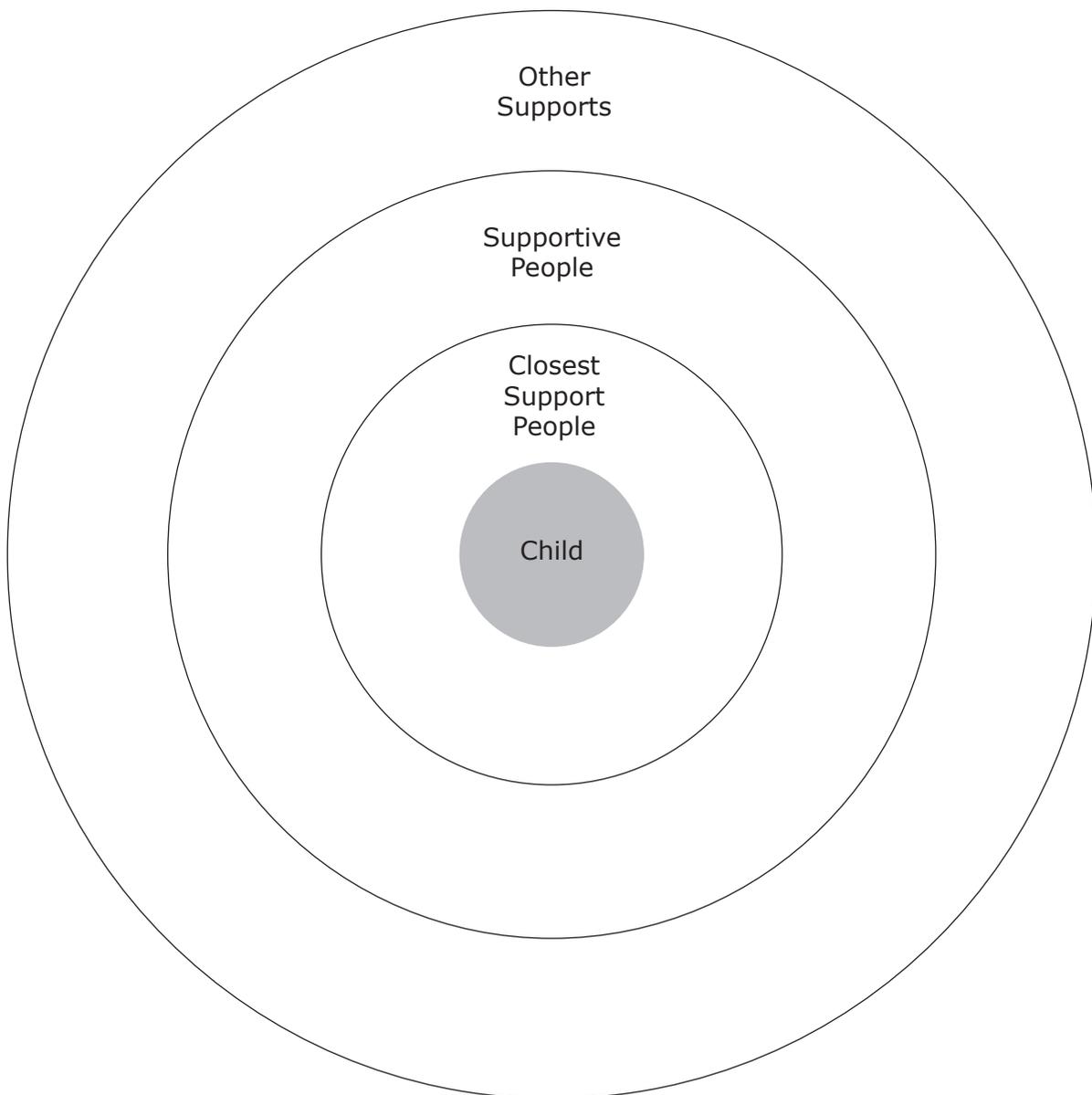
163. Who do you turn to for support?

_____
_____
_____

164. Do you have anything else you would like to add or comment on?

_____
_____
_____
_____
_____
_____

Thank you!

APPENDIX D

2007/2008 TEMPLATE FOR OUTPUT DATA

KEYWORKER EVALUATION OUTPUT DATA TEMPLATE

<table>
<tr><td>Agency:</td><td colspan="2">For the Evaluation please provide data for items 1 to 18.</td></tr>
<tr><td>Contract Number:</td><td colspan="2">The additional data fields, items 19 to 28, are for your own records.</td></tr>
<tr><td>Community:</td><td></td></tr>
<tr><td>Contact person:</td><td></td></tr>
</table>

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

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

Sharon Hume & Associates

DEFINITIONS OF INDICATORS FOR EVALUATION OUTPUT DATA

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

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

Intakes - all referrals accepted for and receiving service

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

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

Sharon Hume & Associates

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

APPENDIX E

SUMMARY OF COMMUNITY BASED INTERVIEW PARTICIPANTS

Appendix E: Summary of Community-Based Interview Participants 2007/2008

# of interview participants	Fraser		Interior		North		VC		VI		Total
	Com. #1	Com. #2	Com. #1*	Com. #2	Com. #1	Com. #2**	Com. #1***	Com. #2	Com. #1	Com. #2****	
Parent/Caregiver	6	8	4	6	6	3	0	9	6	1	**49**
Community Service Partner	2	3	3	7	7	11	0	5	4	8	**50**
School-based	0	1	0	1	1	2	0	1	0	1	
MCFD or SW	0	1	0	1	2	2	0	1	4	1	
Other	2	1	3	5	4	7	0	3	0	6	
Total	**8**	**11**	**7**	**13**	**13**	**14**	**0**	**14**	**10**	**9**	**99**

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

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

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

APPENDIX F

PARENTS/CAREGIVERS INTERVIEW GUIDE

INTERVIEW GUIDE FOR PARENTS/CAREGIVERS

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

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

Probe: If so, how was this role described? and what was your feeling at the time?

Does the Key Worker look at the needs of the whole family? If so, in what ways?

Who in your family meets with the Key Worker?

What do you like best about the Key Worker program?

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

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

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

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

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

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

Probe: For example, as a result of the Key Worker, do you understand your child differently? Has this made a difference in how you handle things with your child?

Is your Key Worker able to meet the needs of you and your family?

If so, what needs have been met? Tell me more…

If not, what needs are not met?

Do you have anything else to add?

APPENDIX G

COMMUNITY PARTNERS AND SERVICE PROVIDERS

INTERVIEW GUIDE

INTERVIEW GUIDE FOR COMMUNITY PARTNERS AND SERVICE PROVIDERS

Referrals, Roles and Relationships

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

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

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

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

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

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

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

Strengths, Challenges and Milestones

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

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

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

How were these barriers addressed?

Training

Have you participated in any training about FASD/CDBC since the launching of the Key Worker and Parent Support 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 and Parent to Parent service(s)?

Outcome Evaluation Interview Questions

In the past year, what kind of support have <u>you</u> 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 |

Sharon Hume & Associates

APPENDIX H

COMMUNITY PARTNERS PARTICIPATING IN THE EVALUATION

Sharon Hume & Associates

Time 2 Community-based Interview Participants - Community Partners

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

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

APPENDIX I

PARENT DEMOGRAPHIC INFORMATION:
ETHNIC ORIGIN, ONE AND TWO PARENT FAMILIES, EDUCATION

APPENDIX I

Table I (1): Parent/caregiver ethnic origin, by region

Parent/Caregiver Demographics						
Parent/caregiver Ethnic Origin (N=185 respondents)	Fraser (n=50)	Interior (n=42)	North (n=42)	Vancouver Coastal (n=22)	Vancouver Island (n=29)	Total # and (%)
European/ Caucasian	70%	76%	55%	68%	72%	126 (68%)
Aboriginal	14%	12%	31%	23%	17%	35 (19%)
East Asian	0%	0%	0%	0%	0%	0 (0%)
South Asian	2%	0%	2%	0%	3%	3 (2%)
Middle Eastern	2%	0%	0%	0%	0%	1 (1%)
African	2%	0%	0%	0%	0%	1 (1%)
Central/ South American	0%	0%	0%	5%	0%	1 (1%)
American	2%	0%	5%	0%	3%	4 (2%)
Other *	8%	12%	7%	5%	3%	14 (8%)

Source: Parent/Caregiver Intake Questionnaire

* Frequent response was "Canadian"

Table I (2): Percentage of parents/caregivers living in one-parent and two-parent household, by region

Parent/Caregiver Demographics						
# of parents in household (N=186 respondents)	Fraser (n=50)	Interior (n=42)	North (n=43)	Vancouver Coastal (n=22)	Vancouver Island (n=29)	Total # and (%)
Single Parent	40%	31%	23%	59%	41%	68 (37%)
Two Parent	60%	69%	77%	41%	59%	118 (67%)

Source: Parent/Caregiver Intake Questionnaire

Table I (3): Education level of parent/caregiver and spouse, by region;

Parent/Caregiver Demographics						
Education level of parent and spouse (N=299 responses, based on 189 respondents)	**Fraser (n=81)**	**Interior (n=71)**	**North (n=73)**	**Vancouver Coastal (n=32)**	**Vancouver Island (n=42)**	**Total # and (%)**
≤ Grade 8	4%	4%	4%	3%	5%	**12 (4%)**
Grade 9-11	6%	6%	12%	6%	14%	**26 (9%)**
High School Completion	26%	21%	32%	31%	26%	**80 (27%)**
Trade/ Technical School	20%	8%	11%	16%	2%	**36 (12%)**
College or University	44%	61%	41%	44%	52%	**145 (48%)**

Source: Parent/Caregiver Intake Questionnaire

APPENDIX J

GENDER OF CHILDREN AND YOUTH

Appendix J: Gender of children and youth, by region

Region	June 2006 – October 2007	
	Total # and % of male child/youth	**Total # and % of female child/youth**
Fraser (n=152)	101 (66%)	51 (34%)
Interior (n=178)	107 (60%)	71 (40%)
North (n=221)	151 (68%)	70 (32%)
Vancouver Coastal (n=240)	153 (64%)	87 (36%)
Vancouver Island (n=281)	170 (60%)	111 (40%)
TOTAL	**682 (64%)**	**390 (36%)**

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

APPENDIX K

SUMMARY OF CIRCLES OF SUPPORT

Analysis of the Circles of Support focussed on the number of people named in the *Inner Circle* and the nature of these relationships. As shown in the Table below, the majority of respondents in all regions named at least three people in their Inner Circle. At the same time, there was some regional variability.

Appendix K
Parent/caregiver Inner Circles of Support, by region

Parent/Caregiver Inner Circles of Support						
Parent/caregiver Circles of Support (N=179 respondents)	**Fraser (n=49) # and %**	**Interior (n=41) # and %**	**North (n=36) # and %**	**Vancouver Coastal (n=24) # and %**	**Vancouver Island (n=29) # and %**	**Total # and (%)**
0 people named in Inner Circle	3 6%	3 7%	3 8%	2 8%	5 17%	**16 (9%)**
1 person named in Inner Circle	4 8%	0 0%	8 22%	0 0%	2 7%	**14 (8%)**
2 people named in Inner Circle	10 20%	4 10%	3 8%	3 13%	4 14%	**24 (13%)**
3+ people named in Inner Circle	32 65%	34 78%	22 61%	19 79%	18 62%	**125 (70%)**

Source: Parent/Caregiver Intake Questionnaire

Qualitative analyses of the diagrams revealed that of the respondents who named only one person in their Inner Circle, the person named was nearly always the respondent's husband.

Nearly all respondents named family and/or friends, and/or unpaid community members in their Inner, Middle and Outer Circles. Indeed, there were only three respondents who did not name family, friends, or unpaid community members/groups, but who did name a paid/professional service provider. Organizations named as supports by these respondents included MCFD and the Key Worker's agency.

Finally, a total of 47 respondents (26% of the n=179 who completed Circles of Support diagrams) named their Key Worker in their diagram. Of these, 7 respondents placed the Key Worker in the Inner Circle, 27 respondents named the Key Worker in the Middle/Second Circle, and 13 respondents named the Key Worker as the Outer/Third Circle support.