Key Worker and Parent Support

Program Standards

November, 2009



Ministry of Children and Family Development

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An Overview of the Key Worker and Parent Support Program

Program Description

The Key Worker and Parent Support program provides support to families of children and youth under age 19 with Fetal Alcohol Spectrum Disorder (FASD) and similar neurodevelopmental conditions (see Page 4 for detailed eligibility criteria).

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 are a resource to communities on FASD. They also provide emotional and practical support to families. Key Workers recognize that each family is unique and understand their role as one that builds on a family's strengths. A Key Worker works with parents, caregivers, family members and service providers in identifying ways to adapt the child's environment in response to the child's needs. The Key Worker also strives to empower the family to become their own best advocates for their child. Key Workers supplement and enhance, but do not replace, existing community resources.

Parent support offers support and FASD education opportunities for parents, grandparents and caregivers of children and youth with FASD. Approaches to parent support vary, but may include support groups, information sessions, and parent mentoring. Parent support may be delivered by Key Workers or by specialized Parent Support staff

Goals

 To maintain and enhance the stability of families with children and youth with FASD and similar neurodevelopmental conditions

Objectives

- To enhance the understanding of families, professionals and other service providers about the neurodevelopmental nature of conditions such as FASD so that the affected children and youth experience less frustration and more success
- To ensure that families of children with FASD have an ongoing network of support through various parent support mechanisms and the assignment of a Key Worker

Service Delivery

• Services are provided through contracts with community agencies

Key Worker and Parent Support Program Eligibility

The Key Worker and Parent Support Program is intended for families of children and youth under age 19 who have confirmed or suspected FASD, or who have a similar neurodevelopmental condition

Eligibility without an assessment

Parents may self-refer to the program without an assessment, or at any point during the assessment process. Key Worker services are not restricted to families of children and youth who qualify for or complete an assessment.

Eligibility following an assessment

The Key Worker Program is most likely to be of continuing benefit after assessment if the child or youth receives one of the following FASD diagnoses from the Canadian Guidelines for Diagnosis:

- Fetal Alcohol Syndrome (with confirmed maternal alcohol exposure)
- Fetal Alcohol Syndrome (without confirmed maternal alcohol exposure)
- Partial Fetal Alcohol Syndrome (with confirmed maternal alcohol exposure)
- Alcohol Related Neurodevelopmental Disorder (with confirmed maternal alcohol exposure)

Occasionally, a child or youth may have received a diagnosis following the University of Washington FASD diagnostic process (4 digit code). The following additional diagnoses indicate that a child/youth would benefit from the Key Worker program:

- Atypical Fetal Alcohol Syndrome and/or
- "Static Encephalopathy, Alcohol Exposed."

Note: Children and youth who have received a diagnosis outside of British Columbia, or from an assessment team other than CDBC, are eligible for the program.

Similar Neurodevelopmental Conditions

An assessment report may indicate that although a child does not have confirmed FASD, he or she has similar needs and challenges to those of children with FASD, and would benefit from the Key Worker Program. Neurodevelopmental conditions are most similar to FASD when they are diffuse (affecting multiple areas of brain function) and when problems with self-control and executive functioning (decision-making and planning) are prominent.

The following are examples of Similar Neurodevelopmental Conditions:

- a child who has a neurodevelopmental profile like those found among children with FASD, but for whom there is no clear documentation of alcohol exposure. This child may be referred to in reports as having "Static Encephalopathy, Alcohol Exposure Unknown"
- a child under the age of 4 who has significant functional problems and either confirmed or suspected prenatal alcohol exposure but for whom formal diagnosis has been deferred until he or she can be more accurately assessed
- a child with a genetic syndrome or structural brain abnormality who has been found by the assessment team to have multiple areas of deficit similar in impact to FASD

Introduction to Key Worker and Parent Support Program Standards

Introduction

The purpose of this document is to clarify the role, function, and framework for practice of Key Workers by presenting the standards that underpin Key Worker programs in BC. Practice standards describe the activities required for Key Workers to effectively engage individuals with FASD and similar neurodevelopmental conditions, their families, and the community, while organizational standards outline the administrative framework of the program. The program logic model is provided in the appendix.

This approach provides an opportunity for regional variation in Key Worker programs within a provincial framework.

The standards are based on the experiences of: the British Key Worker model of care coordination; the Oregon FASD research project; the Vancouver Island Health Authority/University of Victoria diagnostic clinic pilot project; and the expertise of parents and professionals who have implemented FASD services in BC. They are organized as follows:

Standard Statements

 Standard statements represent essential aspects of practice that are based on current knowledge.

Competencies

 Competencies are the skills, knowledge, and abilities needed to successfully meet the standards.

Role Descriptions

 Role descriptions provide examples of activities that demonstrate application of the standards.

CARF and COA Accreditation

The majority of agencies that are contracted to provide Key Worker and Parent Support programs have achieved accreditation from either the Commission on Accreditation of Rehabilitation Facilities (CARF) or the Council on Accreditation (COA).

The standards in this document are intended to supplement existing CARF and COA standards. They are to be applied in conjunction with the agency's operational policies and standards on matters such as confidentiality, consent, and record-keeping.

Key Worker Practice Standards

1	The Key Worker Uses a Family-Centered Approach		
	Competencies		
•	Understanding of family development and family dynamics, as well as familiarity with issues commonly experienced by families of children and youth with disabilities Understanding of the grief, loss, and guilt that can be associated with FASD Ability to support and interact with the family in a way that acknowledges their capacity, and incorporates their needs, perspectives, preferences, and expertise Ability to facilitate communication and shared decision-making between the family and service providers Ability to adapt approach to the ethnocultural, spiritual and socio-economic context of the family and community		
	Role Description		
• • • • • •	Invite families to determine the frequency of contact, select meeting times/places that are convenient for them, and which individuals are to be present at meetings Provide information in a clear, easy to understand and flexible manner by tailoring the format, timing, and content to the family's requirements Mentor families to facilitate an increase in their knowledge, skills and confidence to become their own best advocates Assist the family to select and access appropriate services by providing information on the range of available programs and services Attend multidisciplinary interagency care planning meetings when requested by the family Meet with Aboriginal elders and key community members to discuss the best approach to services for Aboriginal children and youth and their families Assist parents to identify outcomes that they wish to see in their child's program plan Assist parents to understand and implement the recommendations from the diagnostic team, other professionals, and service providers Identify and address the needs of all family members to foster a supportive environment for the child		
Definitions			
	Family: Refers to persons who play a significant role in an individual's life and act as his/her support network. Due to the diversity of family structures, it may include people who are not legally related to the individual		

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The Key Worker Uses a Cultural Safety Framework when Working with Aboriginal Families and Communities

Competencies

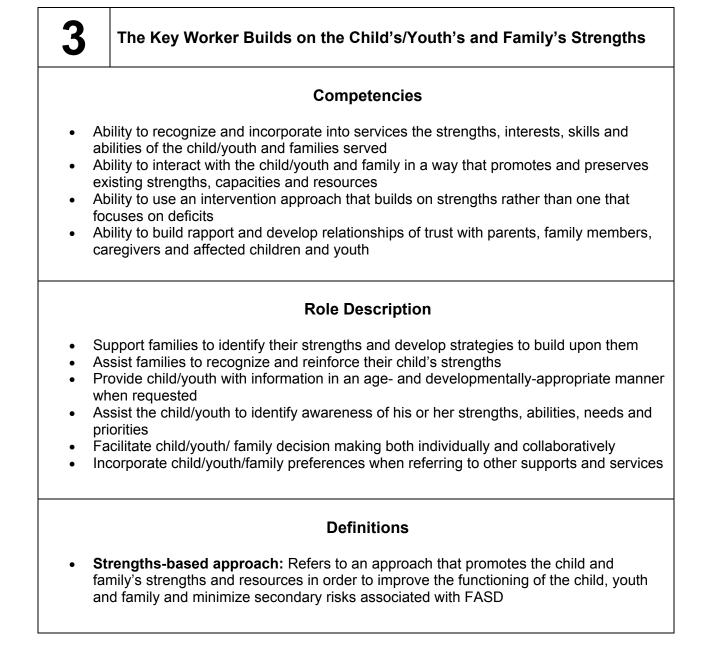
- Recognition of the social, economic, and political position of Aboriginal peoples in society, and both the historical and current relationship between Aboriginal peoples and non-indigenous service systems
- Understanding of how the colonization and cultural assimilation inflicted upon Aboriginal peoples can undermine traditional parenting skills
- Ability to adapt approach to a diversity of families, including differences in social, economic, and cultural context, educational background, family roles and family structure
- Understanding of concepts of health and well-being from an Aboriginal perspective, which may be more broadly defined to include physical, emotional, mental, and spiritual needs
- Ability to integrate traditional Aboriginal healing approaches which may involve relatives, elders, and other community members into service approach
- Recognition that each family exists within, but is not defined exclusively by, their cultural context

Role Description

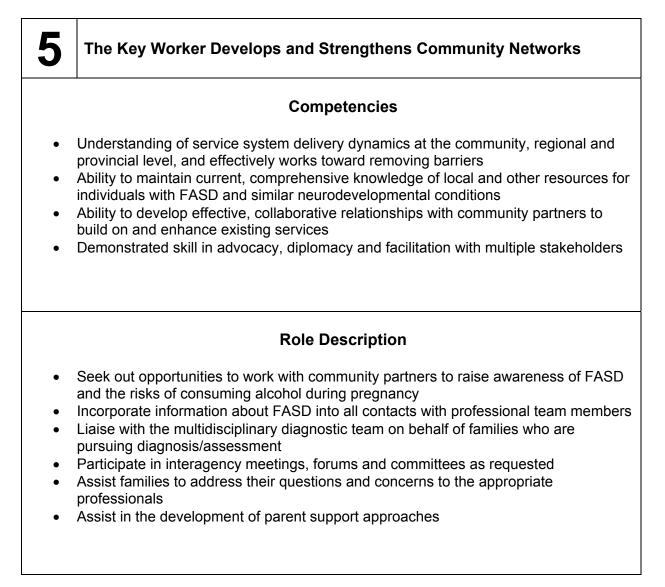
- Reflect on personal cultural perspective and biases, and how these impact the assumptions, values, and beliefs that inform one's approach to service
- Seek out opportunities to network and build relationships of trust and respect with key community members
- As determined by the family, seek input from and collaborate with parents, as well as elders and respected community members, community governing bodies, and trusted service providers when designing and implementing services
- Identify the strengths of indigenous worldviews and traditional healing practices, and seek out opportunities to incorporate indigenous perspectives in the delivery of services

Definitions

- **Cultural safety:** Refers to an approach that involves examining and understanding historical power inequities, individual and institutional discrimination and the dynamics between professionals and members of an ethnocultural group
- From: Gerlach, Alison. 2007. "Steps in the Right Direction: Connecting & Collaborating in Early Intervention Therapy with Aboriginal Families & Communities in British Columbia." B.C. Aboriginal Child Care Society, page 2



	The Key Worker is a Community Resource on FASD
	Competencies
•	Understanding of, and ability to apply, promising-practices and current research regarding FASD as a neurodevelopmental disability often characterized but not limited to challenges in executive functioning, adaptive behaviour, and
•	communication problems. Understanding of how brain functioning associated with FASD can result in
•	developmental delay in social skills and impairment in adaptive skills
•	Understanding of neurodevelopmental conditions that are similar in impact to FASE
•	Ability to maintain and enhance one's own levels of expertise regarding FASD and similar neurodevelopmental conditions
•	Understanding of the social context of women's health and addiction issues
•	Understand the social and family dynamics which can contribute to alcohol usage Ability to promote a common understanding among parents, professionals, and service providers of FASD
•	Recognition of how modifications to the environment can enhance or stabilize
•	functioning. Understanding of the distinct differences in the social and emotional dynamics
•	experienced by birth, adoptive and foster families
•	Recognition of where his or her expertise ends and when to refer on to other suppo
•	and services, access clinical consultation, or consult with professionals Knowledge of the scope and limitations of services available in the community
	Role Description
•	Help families and communities understand the process and the importance of assessment and diagnosis
•	Work with parents, family members, caregivers and service providers in identifying ways to adapt the child's environment in response to the individual child's emotiona maturity, and his or her executive and adaptive functioning.
•	Follow up on referrals to other services to ensure they are appropriate and meet
	identified needs
•	Establish and maintain effective collaborative and constructive liaisons/relationships with a variety of individuals and groups, including families, diagnostic and
	assessment teams, schools, and other agencies
•	Support local parent-to-parent organizations by referring parents to the service and acting as an information resource as requested
	Definitions
•	Similar neurodevelopmental conditions: Refers to children assessed as having
•	neurodevelopmental profile similar to those found among children with FASD, but fo
	whom there is no clear documentation of prenatal alcohol exposure.
	Neurodevelopmental conditions are most similar to FASD when they are diffuse (affecting multiple areas of brain function) and when problems with self-control and
	executive functioning (decision-making and planning) are prominent.



Organizational Standards

The Organization Recruits Qualified Individuals to work as Key Workers		
Qualifications of Key Workers		
 Undergraduate degree in health or human services (social work, nursing, psychology, child and youth care) or equivalent education and experience Extensive understanding of FASD as a brain-based physical disability Education and training in child development Demonstrated skill in applying a family-centered strength-based approach when working with families of children and youth Demonstrated ability to use a cultural safety framework when working with Aboriginal families and communities Demonstrated ability to flexibly accommodate the communication, learning styles, and ethnocultural, and socio-economic circumstances of all families Understanding of youth and women's addiction issues Good understanding of service delivery dynamics, including strengths and barriers at the community, regional and provincial level Demonstrated skill in working collaboratively with multiple community partners and service providers using diplomacy and excellent communication skills For Key Workers who also deliver Parent Support, these additional qualifications apply: Training on providing parent support for parents and caregivers of children and youth with FASD Experience in group organization and facilitation, and understanding of group dynamics 		
Definition		
• Cultural safety framework: This approach involves examining and understanding the historical power inequities, individual and institutional discrimination and the dynamics between professionals and members of an ethnocultural group.		
From: Gerlach, Alison. 2007. "Steps in the Right Direction: Connecting & Collaborating in Early Intervention Therapy with Aboriginal Families & Communities in British Columbia." B.C. Aboriginal Child Care Society, page 2.		



The Organization Provides Access to Clinical Consultation for Key Workers from a Qualified Professional

Qualifications of Clinical Consultant

- Graduate degree in health or human services with affiliation and good standing with a professional association
- Clinical experience in FASD and family support

Clinical Consultant's Responsibilities

- Accountable for competent, ethical and confidential Key Worker support services
- Provides ongoing support to Key Workers
- Reviews complex situations with Key Workers
- Authorizes only those interventions that an individual can be expected to perform competently on the basis of his or her education, training, or experience
- Engages the Key Worker in a critical analysis of his or her work
- Educates on issues such as relationship boundaries, avoiding burnout
- Provides regular feedback to the Key Worker about progress, strengths, and areas in which professional development are needed
- Awareness of the clinical issues involved in the consultation relationship
- Maintains knowledge and expertise about FASD and similar neurodevelopmental conditions

Definition

• **Clinical consultation:** Clinical consultation refers to relevant professional consultation and guidance on issues relating to the effective and appropriate provision of services, such as: maintaining confidentiality; setting boundaries, and; working with families with complex issues. In some case, clinical consultation and job supervision may be provided by the same person, but this is not a requirement.

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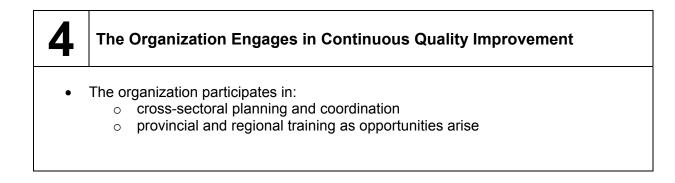
The Organization Provides Services to Families of Children and Youth with FASD and Similar Neurodevelopmental Conditions

- Services are provided to families of:
 - Children and youth under age 19 with confirmed or probable FASD; and
 - Children and youth under age 19 with neurodevelopmental conditions similar to FASD (see definition below)
- Early diagnosis is a predictor of better outcomes for children with FASD
- Key Workers assist families in locating and accessing assessment and diagnosis services through the Complex Developmental Behavioural Conditions (CDBC) Network and offer support throughout the assessment process
- Services are not restricted to families of children or youth who qualify for or complete a CDBC assessment

Note: Detailed eligibility criteria is provided on Page 4

Definitions

- **Probable FASD:** Children and youth whose challenges are likely related to prenatal alcohol exposure, including children who are too young for diagnosis, and children who do not meet the criteria for referral to the CDBC Network.
- Similar neurodevelopmental conditions: Refers to children assessed by the CDBC Network as having a neurodevelopmental profile similar to those found among children with FASD, but for whom there is no clear documentation of prenatal alcohol exposure. Neurodevelopmental conditions are most similar to FASD when they are diffuse (affecting multiple areas of brain function) and when problems with self-control, and executive functioning (decision-making and planning) are prominent.
- **Complex Developmental Behavioural Conditions (CDBC) Network:** The network of Regional and Provincial Health Authority teams which provide multidisciplinary assessments for children and youth with significant difficulties in multiple areas of function including: development and learning, mental health and adaptive and social skills.



Parent Support Approaches

Support Groups

While a great deal has been written on support approaches for parents of children with a disability, very little information is available that discusses promising practices specific to families raising a child with FASD. It is important to recognize that strategies that work well for other disabilities may not be appropriate for FASD.

Families of children and youth with FASD may be facing complex challenges not typically associated with other disabilities such as grief, loss, and guilt, difficulty identifying effective parenting techniques, and frustration with various social systems. Children and youth with FASD may experience abuse, neglect, and multiple care giving approaches. In addition, FASD can be experienced quite differently by birth, foster, and adoptive families.

Support groups are considered promising practice for families of children and youth with FASD as they provide an opportunity for individuals who share common experiences and who are facing similar challenges to come together and exchange information, provide practical strategies, and offer emotional support. Support groups can be a highly flexible means of support for participants, with their location, frequency, leadership style, and focus topics determined by group members.

Developing Support Groups

Key Workers and/or Parent Support staff can play an important role in establishing, promoting, and maintaining support groups for parents, grandparents and caregivers of children with FASD. The two most common frustrations reported by those who establish and operate support groups are difficulties with organizational tasks and lack of participation¹. Key Workers and/or Parent Support staff can alleviate these challenges through such activities as securing a location for meetings, recruiting participants and ensuring community agencies are aware of the group, assisting with transportation, and arranging for speakers or educational materials as requested by the group.

Literature shows that participants tend to be more committed to, and feel greater ownership of, parent-led groups². As well, the presence of professionals in a support group may detract from the critically important atmosphere of openness and emotional safety. Each group will vary in the desired involvement of professionals and the level of involvement will likely change over time. Depending on the strength and needs of the group, Key Workers and/or Parent Support staff may facilitate, provide informational resources, or assist with administrative tasks. The role of professionals in supporting the group should always reflect the wishes of group participants.

Research on disability support groups describes a process for group development in which a professional is highly involved in establishing and initially facilitating the group, and gradually less involved over time as peer facilitators emerge naturally from among the participants. This may not be a reasonable expectation for parents or caregivers of children with FASD, because families often face challenging transitional processes and experience recurring periods of

¹ Wituk, S. et al. 2003. "Starting Self-Help Groups: Empowering Roles for Social Workers." *Social Work with Groups* 26:1 83-92.

² Contact a Family, for Families of Disabled Children. 2007. "Professional Workers and Parent Support Groups." London, England. Retrieved March 23, 2009.

difficulty that require a great deal of time and energy. However, Key Workers and/or Parent Support staff should ensure that support is available should group members wish to assume this role. Such support can involve providing interested participants with training in group facilitation, literature and promising practice research on FASD, and information about community resources.

Generally speaking, critical aspects of effective support groups are that they provide a sense of emotional safety, so that participants feel accepted, and can share their thoughts and feelings in confidence, without fear of judgment; that they be strengths-based, meaning that they reinforce and build upon the positive, and; if preferred by group members, that they include an education component, with topics chosen by group members based on current need.

It should also be noted that support groups are not effective or appropriate for all individuals. Some will have needs that can not be addressed in the context of a support group, and some may have personal challenges, such as anger or a confrontational relationship style, that are not appropriate for a support group. To maintain the integrity of the group, it is important that such individuals are identified and provided other supports, including referrals to other professionals.

Please Note: The Key Worker program and parent support approaches may be delivered independently, by different agencies. Not all agencies are contracted to deliver both programs.

Parent Support Practice Standards

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1	Key Workers/ Parent Support Staff Support the Development and Maintenance of Parent Support Groups		
Competencies			
•	Ability to identify people for whom a support group is an appropriate means of support, based on their needs, current level of functioning, and interaction style Ability to identify people whose needs would best be met through other supports and services, and refer on as appropriate Recognition that birth, foster, and adoptive families of children and youth with FASD may have different needs, challenges, and experiences and adapt the nature and structure of the support group to effectively accommodate this diversity Understanding of the grief, loss, and guilt that families of children and youth with FASD may experience, and the impact these issues can have on functioning Ability to treat the information shared by group participants as confidential, and a complementary ability to identify situations and issues about which clinical consultation and guidance should be sought Ability to incorporate sensitivity to and knowledge of cultural diversity into service approach Ability to identify people who are able to assume the support group peer facilitator role		
	Role Description		
	Locate a venue at which support groups can be hosted on an ongoing basis Build community awareness by discussing the group with families, community agencies and other professionals who may be able to refer families Meet with prospective support group participants to describe the nature and type of support they can realistically expect from a support group, and restrict the participation of those whose presence would not be beneficial to the group Provide the group with the structure and guidance needed for group members to receive desired emotional and informational support Involve group members in determining the topics of group meetings, if a topic format is preferred Provide educational materials on FASD, information on community resources, and arrange for guest speakers on areas of interest to the group as desired Negotiate role and level of involvement in the operation and maintenance of the support group, based on the current needs and preferences of group members Provide follow-up contact to participants who raise issues or demonstrate need during group sessions that requires additional support outside the group		

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Key Workers/ Parent Support Staff Train and Support Peer Facilitators for Parent Groups

Peer Facilitator Qualifications

- Experience parenting a child or youth with FASD or similar neurodevelopmental condition
- In a stable family situation, and coping well
- Concerned about others
- Non-judgmental
- Ability to identify the needs and feelings of others
- Willing to share their experience and become personally involved with others
- Ability to cope with the problems of others without feeling hurt themselves
- Ability to handle confidential information appropriately
- Able to manage the necessary time commitment on an ongoing basis

Peer Facilitator Training

Peer facilitators should be given training and ongoing support including:

- Orientation to support group program goals, objectives, and the scope of their role
- Orientation to advocacy, confidentiality, leadership and cultural safety concepts
- Information regarding FASD as a brain-based physical disability with behavioural symptoms
- Information about community resources and the referral processes
- Assistance in developing a positive approach based on strengths and solutions
- Assistance to develop self-reflection, facilitation and communication skills

Parent Support Organizational Standards³

The Organization Recruits Qualified Individuals to Provide
Parent Support

Qualifications of Parent Support Staff

- Extensive experience and understanding of FASD
- Ability to access and apply current research and literature on FASD
- Training on providing parent support for parents and caregivers of children and youth with FASD
- Experience in group organization and facilitation, and understanding of group dynamics
- Ability to use a family centered approach, as described in Key Worker Practice Standard 1
- Ability to apply a cultural safety approach when working with Aboriginal families and communities, as described in Key Worker Practice Standard 2
- Ability to focus and build upon the strengths of families, as described in Key Worker Practice Standard 3



- The organization participates in:
 - o cross-sectoral planning and coordination
 - o provincial and regional training as opportunities arise

³ For agencies that are contracted only to deliver parent support



The Organization Provides access to Clinical Consultation Concerning Parent Support Strategies

Qualifications of Clinical Consultant

- Graduate degree in health or human services with affiliation and good standing with a professional association
- Clinical experience in FASD and family support including parent support approaches such as facilitating support groups.

Clinical Consultant's Responsibilities

- Provides ongoing support to Parent Support staff
- · Reviews complex situations with Parent Support staff
- Engages the Parent Support worker in a critical analysis of his or her work
- Educates on issues such as relationship boundaries, avoiding burnout
- Provides regular feedback to the Parent Support worker about progress, strengths, and areas in which professional development are needed
- Awareness of the clinical issues involved in the consultation relationship
- Maintains knowledge and expertise about FASD and similar neurodevelopmental conditions

Definition

• **Clinical consultation:** Clinical consultation refers to relevant professional consultation and guidance on issues relating to the effective and appropriate provision of services, such as: maintaining confidentiality; setting boundaries, and; working with families with complex issues. In some case, clinical consultation and job supervision may be provided by the same person, but this is not a requirement

If you have questions or would like to provide feedback on this document, please contact MCFD by email at: MCF.ChildrenYouthSpecialNeeds@gov.bc.ca

Appendix 1: Key Worker and Parent Support Program Logic Model

