

Key Worker and Parent Support

Program Standards

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Ministry of
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Table of Contents

Program Overview	3
Introduction to Program Standards	4
Practice Standards	5
Organizational Standards	10
Parent Support Approaches	14
Parent Support Standards	16
Appendix 1: Program Logic Model	18

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 with Fetal Alcohol Spectrum Disorder (FASD) and similar neurodevelopmental conditions.

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. 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, family members, adoptive parents, caregivers 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 approaches vary, but may include local parent and grandparent FASD training, parent mentoring and parent support groups.

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

Eligibility Criteria

- Families of children and youth with FASD, with probable FASD, and with similar neurodevelopmental conditions

Service Delivery

- Services are provided through contracts with community agencies

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 Description

- 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). Where possible, links are provided to relevant CARF and COA organizational standards.

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

Practice Standards

1	The Key Worker Uses a Family-Centered Approach
<p style="text-align: center;">Competencies</p> <ul style="list-style-type: none">• Understanding of family development and family dynamics• Ability to support and interact with the family in a way that 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 cultural, ethnic, and socio-economic context of the family and community	
<p style="text-align: center;">Role Description</p> <ul style="list-style-type: none">• Invite families to determine the frequency of contact, select meeting times/places that are convenient for them, and decide which individuals are to be present at meetings• Provide information that is easy to understand and in a 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 diagnostic team's recommendations• Identify and address the needs of all family members to foster a supportive environment for the child	
<p style="text-align: center;">Definitions</p> <ul style="list-style-type: none">• 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	

2

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
- 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 a cultural/ethnic 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

3

The Key Worker Builds on the Child, Youth and Family Strengths

Competencies

- Ability to recognize and incorporate into services the strengths, interests, skills and abilities of the child/youth and families served
- Ability to interact with the child/youth and family in a way that promotes and preserves existing strengths, capacities and resources
- Ability to use an intervention approach that builds on strengths rather than one that focuses on deficits
- Ability to build rapport and develop relationships of trust with parents, family members, caregivers and affected children and youth

Role Description

- Support families to identify their strengths and develop strategies to build upon them
- Assist families to recognize and reinforce their child's strengths
- Provide child/youth with information in an age- and developmentally-appropriate manner
- Encourage the child/youth to identify his or her strengths, abilities, needs and priorities
- Facilitate child/youth/ family decision making both individually and collaboratively
- Incorporate child/youth/family preferences when referring to other supports and services

Definitions

- **Strengths-based approach:** Refers to an approach that promotes the child and family's strengths and resources in order to improve the functioning of the child, youth and family and minimize secondary risks associated with FASD

4

The Key Worker is a Community Resource on FASD

Competencies

- Understanding of, and ability to apply, best-practices and current research regarding FASD as a brain-based physical disability with behavioural symptoms
- 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 FASD
- 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
- Ability to promote a common understanding among parents, professionals, and service providers of FASD as a brain-based, physical condition
- Recognition of how the "goodness of fit" between an individual with FASD and his/her environment can improve functioning and reduce challenging behaviours
- Understanding of 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 supports and services, access clinical consultation, or consult with professionals

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 emotional 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 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.

5

The Key Worker Develops and Strengthens Community Networks

Competencies

- Understanding of service system delivery dynamics at the community, regional and provincial level, and effectively works toward removing barriers
- Ability to maintain current, comprehensive knowledge of local and other resources for individuals with FASD and similar neurodevelopmental conditions
- Ability to develop effective, collaborative relationships with community partners to build on and enhance existing services
- Demonstrated skill at advocacy, diplomacy and facilitation with multiple stakeholders

Role Description

- Seek out opportunities to work with community partners to raise awareness of FASD and the risks of consuming alcohol during pregnancy
- Incorporate information about FASD into all contacts with professional team members
- Liaise with the multidisciplinary diagnostic team on behalf of families
- Participate in interagency meetings, forums and committees as requested
- Assist families to address their questions and concerns to the appropriate professionals
- Assist in the development of parent support approaches

Organizational Standards

1	The Organization Recruits Qualified Individuals to work as Key Workers
<p style="text-align: center;">Qualifications of Key Workers</p> <ul style="list-style-type: none">• 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• 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 cultural, ethnic, 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	
<p style="text-align: center;">Definition</p> <ul style="list-style-type: none">• 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 a cultural/ethnic group. <p>From: Gerlach, Alison. 2007. “<i>Steps in the Right Direction: Connecting & Collaborating in Early Intervention Therapy with Aboriginal Families & Communities in British Columbia.</i>” B.C. Aboriginal Child Care Society, page 2.</p>	
<p style="text-align: center;">Links</p> <ul style="list-style-type: none">• CARF Child and Youth Services, Section 2B Standards 6, 7• COA CA-CFD 15.01	

2	The Organization Provides Access to Clinical Consultation for Key Workers from a Qualified Professional
<p style="text-align: center;">Qualifications of Clinical Consultant</p> <ul style="list-style-type: none">• Graduate degree in health or human services (eg. MSW social work, MN nursing, MA psychology) with affiliation and good standing with a professional association• Clinical experience in FASD and family support	
<p style="text-align: center;">Clinical Consultant's Responsibilities</p> <ul style="list-style-type: none">• 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	
<p style="text-align: center;">Links</p> <ul style="list-style-type: none">• CARF Child and Youth Services, Section 2B Standard 16• COA CA-CFD 15.05	
<p style="text-align: center;">Definition</p> <ul style="list-style-type: none">• 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.	

3

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 with confirmed or probable FASD; and
 - Children and youth 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
- Services are not restricted to families of children or youth who qualify for or complete a CDBC assessment

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.

4

The Organization Engages in Continuous Quality Improvement

- The organization participates in:
 - cross-sectoral planning and coordination
 - provincial and regional training as opportunities arise
 - external Key Worker and Parent Support Program evaluations

Links

- **CARF** Child and Youth Services, Section 1C Standard 5, 6
- **COA** CA-PQI 1.03

Parent Support Approaches

Developing Parent Support Programs

The most important step in developing effective parent support programs is to seek input from local parents regarding the types of support they feel would be most beneficial and would best meet their needs. Collaborating with parents to develop support opportunities increases parent engagement and participation, and ensures that supports reflect the best-practice principle of parent driven family-centered care. Described below are two parent support approaches that participants have rated as helpful in meeting their needs.

Group Support

To foster the development of parent support groups, parents of children with FASD and similar neurodevelopmental conditions should be provided with opportunities to come together for group education and information sharing sessions. Such sessions not only increase knowledge, but also create an important opportunity for parents to build supportive relationships with peers who can understand and relate to the challenges they face.

Key workers can assist parents to build on and expand the benefits of this informal networking by encouraging and acting as a resource to parents who wish to organize support groups. Interested parents should be supported through the provision of training in group facilitation; literature on FASD and similar neurodevelopmental conditions and best-practice research; information about community resources and through provision of administrative assistance.

It is important that the groups be led by a resource parent, someone who has experience raising a child with FASD or a similar neurodevelopmental condition and who has the ability to create a safe space in which participants feel comfortable sharing and discussing their experiences.

The two most common frustrations reported by support group founders are difficulties with organizational tasks and lack of participation¹. By assisting with administrative responsibilities - such as securing a meeting place - and referring support-seekers to the group, organizations can offset these challenges and contribute to the group's success.

There will be variation between groups as a result of differences in the number of involved parents, the group members' preferred organizational style, and the needs of participants. However, each group should be encouraged to include an educational component and focus on solutions and strengths.

Parent Mentoring

One-on-one parent mentoring is a highly valued peer-support approach that has been shown to meet parents' desire for information, and emotional and practical support. Parents can connect with each other either in person or over the phone, making this a

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

Key Worker and Parent Support
Program Standards

particularly innovative way to bring the benefits of peer-support to parents in small or remote communities where support opportunities are limited.

Parent mentoring matches support-seeking parents with resource parents who have experience raising a child with FASD or similar neurodevelopmental condition. Shared experience and life circumstances allow parents to exchange information and practical coping strategies and receive emotional validation.

Research has consistently demonstrated that participation in a 'parent to parent' or parent mentoring program leads to significant increases in parents' ability to cope, accept the situation, and deal with day-to-day challenges². In addition to being helpful for participants³, the program is highly sustainable. Many parents who join as support-seekers experience such success in overcoming challenges in their own lives that they are able to assist others by becoming resource parents themselves⁴.

The following standards represent best-practices in the development and implementation of parent support approaches.

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.

² Santelli, B. "Developing and Expanding a Statewide Parent to Parent Program." Retrieved Mar 22, 2007 (http://www.beachcenter.org/resource_library/beach_resource_detail_page.aspx?intResourceID=767&Type=Manual)

³ Singer, G., et al. 1999. "A Multi-Site Evaluation of Parent to Parent Program for Parents of Children With Disabilities." *Journal of Early Intervention* 22:3 217-229.

⁴ S M Kerr, 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.

Parent Support Standards

1	The Organization Recruits, Trains and Supports Resource Parents for Parent Groups and Parent Mentoring
<p style="text-align: center;">Resource Parent Qualifications</p> <ul style="list-style-type: none">• 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• Able to identify the needs and feelings of others• Willing to share their experience and become personally involved with others• Able to cope with the problems of others without feeling hurt themselves• Able to handle confidential information appropriately• Able to facilitate groups or provide one to one support• Able to identify the limits of their expertise, and know when to refer the support-seeking parent to others	
<p style="text-align: center;">Resource Parent Training</p> <p>Resource parents should be given training and ongoing support including:</p> <ul style="list-style-type: none">• Orientation to group support or parent mentoring 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 similar neurodevelopmental conditions• Information about community resources and the referral processes• Assistance in developing a positive approach based on strengths and solutions• Assistance to developing self-reflection, facilitation and communication skills	
<p style="text-align: center;">Definition</p> <ul style="list-style-type: none">• Resource parents: Parents whose experience raising a child with FASD or similar neurodevelopmental condition, has given them the knowledge and expertise to be a supportive resource to another parent. These individuals are able to offer emotional and practical support, and serve as valuable role models	

2

The Organization Matches Resource Parents with Parents Seeking Support

- In general, the more that support-seeking parents and resource parents have in common the more successful the match. Examples of criteria:
 1. Families face or have faced similar problems (Families of children with FASD are best matched with families of children with FASD)
 2. Families live near each other
 3. Families have similar family structures (birth, foster, or adoptive parents)
 4. Families have similar cultural/ethnic/socio-economic backgrounds
 5. Families have similar parenting philosophies and attitudes towards disability

Definitions

- **Resource parents:** Refers to parents whose experience raising a child with FASD or similar neurodevelopmental condition, has given them the knowledge and expertise to be a supportive resource to another parent. These individuals are able to offer emotional and practical support, and serve as valuable role models
- **Parent matching:** Refers to the process of connecting a support-seeking parent with a resource parent.

Appendix 1: Key Worker and Parent Support Program Logic Model

