

Family Support Specialist Role & Activities

(for teams with clinical + family peer support)

Introduction:

Family peer support activities can resemble the activities of other types of providers, and for this reason, Family Support Specialists (FSS) are often viewed in roles that are *not quite accurate*. This document describes some of the activities that FSS do and may help to clarify the role to create better cohesion among those involved in multidisciplinary teams.

It is important to note that Family Support Specialists are not substitutes for the important roles of care coordinators, social workers, skills trainers, legal advisors, case managers, personal friends, or therapists.

While activities across many of these roles can look similar, the Family Support Specialist performs them in a unique way that is rooted in the competencies of the peer workforce, uses perspectives of lived experiences, and meets a range of needs that arise for the family across many life domains.

Family Support Specialists (FSS) are individuals who have direct experiences in a parenting role of a child with complex health needs combined with specialized training in the unique process of “walking beside” families experiencing complex needs.

They provide **specialized support to parents, caregivers and other adult family members** who are raising children with behavioral and/or other complex health challenges.

FSS designation is a sub-specialty of Oregon’s peer workforce, described in the Traditional Health Workers rules.

Focus is on the parent/primary caregiver of the child

Based on strategic self-disclosure related to family experiences

Encourages and supports parents to achieve their own identified outcomes

Communicates active acceptance in all interactions

“Partners with” rather than “delivers to” parents and family members

Suspends bias and blame

Holds a relational stance of respect in all interactions with parents and family

Connects with others in collaborative problem solving

(SAMHSA Webinar, Benefits of Family Peer Support Services)

Role Description & Activities

Through personal experiences, FSS have gained knowledge about: how healthcare, education, and other child-serving systems work; how insurance can be both a barrier and a benefit; and how meeting the needs of children with complex health and social needs can be challenging on many levels.

The FSS assists families in identifying areas of their lives that may be impacting their ability to maintain stability and wellness in their day-to-day living. Identified obstacles (or barriers) may fall outside the scope of what might be more typically addressed through a clinical lens. Using an approach grounded in shared “lived experiences” can be a powerful and validating support for families.

Through this support, families can grow their knowledge, capacity, skills, and overall resilience.

Family Support Specialists partner with parents, caregivers, guardians and other adult members of the family to pursue outcomes determined by the families themselves. They help to de-stigmatize mental and behavioral health challenges, normalize help-seeking, increase the family’s capacity for self-advocacy and self-efficacy, and increase supports across systems and life domains.

Personal Disclosure

The practice of family peer support includes having discussions of shared experiences raising a child with complex health challenges and navigating complex health, education and social systems.

Personal experiences are shared with the explicit intention to assist the family in their process.

Activities that may resemble: care coordination or case management

- Helps the family with strategies to coordinate care activities for their child and to identify who their Case Managers are (with their insurance, with their Coordinated Care Organization, with their health plan, etc.).
- Consults with the team therapist on family needs, barriers, and progress.
- Assists the family in learning how to obtain services in all facets of the family's life (ie. helping them develop capacity to navigate systems).
- Supports the family during crisis periods with collaborative communication among individuals involved with the family and youth (may include: therapists, school personnel, insurance, and others).
- Communicates regularly with the family about barriers and strategies for accessing services and supports.
- Assists the family with understanding the value of therapeutic support for all members of the family; assists them in accessing services.
- If the family is uninsured, helps connect them with Oregon Health Plan or other insurance options and provides application support.

or may look like: social work

- >> Helps family identify resources to meet their needs.
- >> Helps family locate resources in their community, such as support groups, food pantries, and other community-based family supports.
- >> Helps family understand the importance of their natural support network and helps them with ideas to build (or repair) those relationships.
- >> Helps family identify their needs and find useful information and resources to meet them.

The Family Support Specialist models hopefulness and mindfulness.

FSS activities that may look similar to: **therapy and crisis safety planning**

Important note: FSS does not provide any form of clinical services and does not create the crisis safety plan.

FSS talks about safety and explores family-centered safety planning for all family members.

- >> Discusses with family their safety concerns and supports them to express concerns and ask for what they need
- >> Asks family about safety, including lethal means, drug and alcohol use, interpersonal violence, and self-injury
- >> Discusses the plan with the family and the clinical partners
- >> Communicates with expertise about how to meet the family's needs regarding safety planning
- >> Assists family in understanding clinical language
- >> Practices collaborative communication with clinicians and other health care providers

Some Family Support Specialists are trained in CALM (Counseling on Lethal Means), QPR (Question, Persuade, Refer), ASIST (Applied Suicide Intervention Skills Training) and will use knowledge in these areas to support families.

***Important note:** *Interpretation and translation are formal services that involve specialized training. FSS does not act as an interpreter between the therapist and the family or their child, even if FSS is fluent in the family's primary language.*

The FSS may communicate in family's first language if they are fluent in that language.

FSS may access language interpretation or translation services, if needed by the family, and will advocate for all service providers to do the same. They may help to explain the safety plan in family's primary language (*only if FSS is fluent in that language or their role is as a bilingual/bicultural FSS*). All FSS will assist with family understanding by re-stating clinical information into everyday language and assist community partners in understanding questions or concerns the family may be hesitant to express.

Significant gaps exist in this area across all programs and needs to be addressed at a systemic level.

While the FSS helps the family learn about advocacy, they do not serve as:
the family's advocate or legal advisors

The FSS helps the family to learn skills for self-advocacy and assists them to advocate for their needs.

Describes situations in which FSS had to advocate and “push back” on systems barriers, even providers.

Assists the family in accessing information about complaint or grievance processes and helps them file using their own words.

Helps family prepare for and attend school and other education or vocation-related meetings, such as IEP meetings.

The FSS may also assist families with reviewing and discussing paperwork or processes related to the following:

- Employment topics (FMLA, how and what to share with employer)
- Insurance (OHP, commercial insurance)
- Social system supports (TANF, food stamps, childcare)
- Education system (401 plans, IEPs, school meetings)
- Intellectual and Developmental Disabilities
- Social Security Disability Insurance (SSDI)
- Child Welfare, Juvenile Justice
- Confidentiality, Release of Information, Consent to Care
- And more

Some Family Support Specialists are permitted by their employers to go to court meetings with families, however not all employers consider this the responsibility of their FSS.

FSS activities involve a lot of skill development, however they are not: skills trainers

- Helps the family develop skills to get through crises, including de-escalation, emotion regulation, communication and asking for help.
- Supports family's skill development in areas they need or want to further develop and to help them manage day-to-day life demands.
- Does tasks with the family, such as filling out paperwork for insurance and making phone calls to systems providers (ie. school, insurance, therapists, child welfare or foster system).

* Some Family Support Specialists also teach classes designed for families and caregivers, such as NAMI Basics for Parents and Caregivers, Collaborative Problem Solving, Family-Centered Safety Planning, QPR, and Emotional First Aid.

FSS activities involve learning, but they are not: teachers* or educators

The FSS shares psycho-education information, as well as knowledge they acquired through personal experiences, including how they overcame barriers and obstacles. They also share what they've learned in their work-related trainings.

- Provides the Crisis Family Guide and other materials, using the content for discussion, exploration, and learning.
- Models skills related to parenting, positive communication, and self-care.
- Informs family on where to get information if FSS knows about a resource that might help them fill a need.
- Describes and role models "Collaborative Problem Solving" and other positive parenting techniques and helps the family get connected with classes and parent groups.
- Assists family in how to evaluate new information from the Internet, friends, and other sources.

FSS services should never be confused with: **personal friendships**

Important note: A Family Support Specialist's work can appear very personal and friendly; FSS are trained in how to maintain appropriate boundaries and to support the family in ways that honor those boundaries.

The FSS will share personal stories and experiences for a specific purpose and to benefit the family's process.

They will also help the family understand the importance of their natural support network and helps them with ideas to build (or repair) their natural supports, rather than rely solely on paid services.

Other activities include:

- Helping the family connect or reconnect with their cultural and/or spiritual supports.
- Communicating regularly with the family by phone, email, and/or text, sometimes during "off hours." Supportively listens through the family's grieving process, about their anger and frustrations, and about aspirations and hopes for their family's future.
- Locating and connecting with support groups and other community social events, and may attend with them.
- Meeting with the family when and where it is convenient to the family (community spaces, home, office/clinic).

Where Family Support Specialists do their work:

Family Peer Support generally takes place in locations that are family-friendly. Ideally, these settings do not look like “systems” environments (ie. doctor’s offices, government buildings) unless this is the family’s preference.

The FSS joins the family at locations where it is convenient and preferred by the family, in the home or in community locations (coffee shops, schools, libraries, or family resource centers).

FSS may travel across county lines if family moves or resides in more than one county.

About driving and transportation:

Employers have varied policies when it comes to transporting families or youth. Some staff, including FSS, may not be permitted to transport families or youth in their business or personal vehicles.

About communication:

FSS communicates with the family using methods that the family prefers and chooses (ie. phone, text, email, in person), unless the FSS employer places restrictions.

Keep in mind that some Family Support Specialists are not permitted by their employer to use text for any communication.

Some final notes on the work of Family Support Specialists

In the role as Family Peer Support Specialist, the FSS should never be expected to:

- X Work directly with youth
- X Babysit or supervise youth
- X Supervise DHS visits
- X Teach families how to parent or discipline their child(ren)
- X Fix or change the behavior of the parent or tell the family what to do
- X Take *instructions* from clinicians or other providers involved with the youth/family
- X Give the family legal advice
- X Become personally involved with the family

This document was originally prepared in a collaborative process with Family Peer Support Specialists and program staff from the OHSU DAETA Team, NAMI Multnomah, Oregon Family Support Network, Lifeworks Northwest, and Oregon Health Authority (2019)

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