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Fact Sheet

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Family Peer Support Services: Broadening the View

A Discussion with Family Members

Family peer support services focus on empowering and informing families caring for loved ones with a mental health and/or substance use condition. Families are assisted with understanding and accessing systems, treatment and recovery supports, and providing information about and connection to available resources. These services are important in helping to advance recovery from mental health and substance use conditions across the nation. To expand these efforts, SAMHSA's Office of Recovery convened the August 2024 Technical Expert Panel on Family Peer Support: Broadening the View. This event examined the importance of engaging various family roles (e.g., parent/caregiver, spouse, sibling, adult child) and the services that were or would have been helpful on their journey. Participants provided feedback on how to advance recovery through increased access to services and supports. Please see the appendix for stories from the Technical Expert Panel which consisted of family members representing various roles.

Background

Family members often are primary caregivers for their loved ones with a mental health and/or substance use condition. In this role, families face many challenges including navigating complex service systems and experiencing emotional and financial stress. Peer support services offer an effective way to help family members face these challenges and are most commonly offered to parents and caregivers of children (under the age of 21) experiencing a mental health and/or substance use condition. Family peer support specialists have lived experience with caring for a loved one with mental health and or substance use conditions.

They receive specialized training to support individuals and families who are navigating similar situations and offer an array of services and supports, including:[1]

- Information, referrals, and assistance to obtain access to mental health and/or substance use community services and supports;
- Individualized supports for family members to navigate and access needed services or supports;
- Peer support groups;
- Assistance with finding and navigating child and family-service systems (e.g., mental health, education, juvenile justice, child welfare, pediatrics, housing) to enable optimal outcomes;
- Intensive support during crises;
- Encouragement and advocacy for family participation in processes to develop more family-driven systems; and
- Training for co-workers and partners in various systems on how to be more family-driven while providing individualized care for individuals and families.

Formal family peer support services are primarily offered to parents and caregivers. Other family members such as significant others, siblings, adult children, and parents of adult children may also benefit from family peer support services, though this is beyond the typical scope of children's behavioral health services.

Common Experiences Across Family Roles

Although there are numerous differences between the family roles, participants identified several commonalities.

Participants love their family members who have mental health and/or substance use conditions. This love enables them to persist in the face of obstacles and constantly look for strategies to ensure their loved ones get the support they need and deserve.

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[1] National Family Support Technical Assistance Center. n.d. *Family Peer Support for Families, Parents and Caregivers in Mental Health and Substance Abuse Across the Lifespan.* Derwood, MD: National Federation of Families. https://nfs-tac.org/ResourceMaterials/Fam%20Peer%20Info.pdf

While the participants noted their love for their family members, many also shared what one described as a “complex emotional landscape.” For instance, they love their family member but may feel resentful or angry about the circumstances created by the person’s mental health and/or substance use condition. Many family participants recognized grieving their family member’s losses due to their condition and how it impacts their own mental health.

Some participants noted feelings of isolation and stigma because of their loved one’s condition. Several mentioned that they did not receive the same care or compassion from others in their community as they would anticipate if their loved one had a physical health condition. Several participants mentioned “blame and shame,” as they feel that providers, other family members, friends, and society at large may blame them in some way for their family member’s conditions.

Participants described the difficulty of navigating multiple complex and often overwhelming systems and providers. As one parent of a child under age 21 said, “It is traumatic in and of itself to have a loved one struggling, and then we encounter systems that do not understand or adequately respond to our struggles or meet our needs.”

Participants reported that they often sacrifice their own time, needs, goals, and health in the process of caring for their loved one with a behavioral health condition. Caring for a loved one can present challenges for a family member’s personal life and other relationships.

Expansion of Family Peer Support Services: Considerations and Recommendations

States and peer run organizations considering the expansion of family peer support services should consider the full range of experiences and needs of different family roles as they determine the most appropriate and effective ways to implement. Family roles can include parents of any age child, adult siblings, spouses/partners, and adult children whose loved one has a mental health and/or substance use condition. While family roles do share several similarities, they also have significant differences that must be accounted for in expansion efforts. This section outlines some of the similarities of these roles, what should be considered if and when expanding service offerings, and recommends competencies and training topics to include in family peer support programs. When undertaking such efforts, family members with diverse roles should be fully involved in the planning and implementation of expansion of family peer support services.

Considerations for Expanding Family Peer Support Services

Participants identified several important factors and potential unintended outcomes to examine when considering expanding family peer support services.

- **Matching of peer support specialist and recipient based on similar family roles.** Many of the participants have experienced multiple family roles. One participant identified as a daughter, a spouse, and a parent. While there is no way to perfectly match experiences, it is preferable to connect family peer support specialists who have similar roles and experiences as those being served (e.g., siblings with siblings, parents of young children with parents of young children, etc.). Family peer support specialists should understand common experiences for the lived experience roles they represent as well as how to navigate the various systems from which the families they support may receive services.

- **Maintaining integrity of current services.** Participants from the parent groups who receive some level of family peer support services expressed concern about those services being diluted or lost if their states expand family peer support services. It is recommended that expanding services for additional family roles be in addition to existing support, not in lieu of. The expansion of family peer support services should not diminish the current support received by parents/caregivers of children and transition-age youth under 21.

- **Role clarification and competencies.** Peer services and competencies for each family role must be clearly outlined. Currently certified or practicing family peer support specialists need to understand these new family services and why they are important. Specialized training is recommended for each family role to be served, including the role definition, scope of services, title, training, and certification. For example, the role of “parents of minor children” includes authority and responsibility for a minor and navigating child-serving systems which makes it distinct from the other family roles. Supervisors of family peer support specialists must understand the nuances and requirements for each family role.

- **Delivery of services.** Family peer support providers must have experience in the same family role as the person who will receive the services. Additionally, it is important to have a diverse workforce that mirrors the families receiving services. Based on the types of services provided in family peer support, location of peer services can be in many different environments (e.g., within family-run organizations, at hospitals, with behavioral health organizations, first responders, crisis units, etc.) and must also consider how geographic or other isolation can impact delivery of services and exacerbate challenges. There may need to be more family-run organizations (FROs) or expansion of existing FROs to accommodate the necessary workforce, as these organizations are experts on family support, specifically about hiring, training, and supporting this unique workforce and role. FROs are valuable partners in any expansion efforts.

- **Funding.** Expanding family peer support services beyond the parental/caregiver role could require additional resources to provide adequate support for individuals in the other family roles. Strategies to meet this need could include braiding and blending state and federal funds such as SAMHSA grants and Medicaid billing. Many of these roles fall outside “children’s behavioral health services” and should be identified in the “adult behavioral health system.”
- **Infrastructure.** Family members with lived experience in all roles need to be in discussions about expanding family peer support services. Changes must be intentional, organized, well-planned, and include oversight that ensures family peer support specialists have the required competencies, understand expectations, receive appropriate and sufficient training, and meet the needs of the specific family role they serve. It is also recommended that a certification board for family peer support services be created, as well as an evaluation component to measure the impact of services.
- **Education and marketing about the peer support field.** Targeted education efforts can help child and family-serving systems better understand the role and benefits of family peer support services.

Recommended Competencies for Family Peer Support Specialists

Based on SAMHSA’s Peer Worker Core Competencies, the participants identified important skills that would benefit family peer support specialists, regardless of the family role served:

- Engages peers in collaborative and caring relationships by using strengths-based approaches that focus on family members’ resilience in how they want to support their loved ones,
- Provides support and commitment to improving family members’ resilience, leading to better outcomes and/or recovery,
- Shares lived experiences of recovery in a specific role as a family member who is providing, or has provided, care to an individual with mental health and/or substance use conditions,
- Personalizes peer support by appreciating every person’s values and acceptance of how people demonstrate those values and practicing cultural humility and responsiveness,
- Provides information about skills related to health, wellness, and recovery including an understanding of trauma-informed services,
- Values strong communication skills (e.g., the ability to listen and postpone judgment for understanding),

- Promotes leadership and effective advocacy skills on behalf of, and with, the recipient of peer services
- Links to resources, services, and supports by strategically navigating relevant programs and services,
- Supports collaboration and teamwork with community resources and natural supports,
- Promotes growth and leadership development of family member receiving services through educational and networking opportunities,
- Ability to ask for assistance when needed and to practice self-care to diminish the effects of secondary trauma, and
- Encouraging easier connection to, and retention of, family peer specialists.

Looking Ahead

SAMHSA developed this guide for states and others to use when considering potential changes to the family peer support role in consultation with family peer support experts, those who provide care in some capacity for a family member with mental health and/or substance use conditions. Although parents/caregivers of children under the age of 21 who have behavioral health conditions are rightfully recognized as key to their children’s care, many people in other family roles also provide essential care for family members such as parents of adult children, siblings, partners/significant others, and adult children of parents with behavioral health conditions. For people who provide such care and support to a loved one, a peer who has lived experience in a similar family role can offer advice, understanding, encouragement, comfort, and guidance. SAMHSA seeks to expand the current family peer support specialist’s role, which focuses primarily on those caring for their minor-age children, to include family peer support services supporting other family roles.

Resources

- National Family Support Technical Assistance Center
- SAMHSA Program to Advance Recovery Knowledge (SPARK)
- Center for Addiction Recovery Support
- National Model Standards for Peer Support Certification

Family Stories

Although no single story can comprehensively represent the full range of experiences of a family role, these stories offer insight into the varied feelings, circumstances, and needs of family members who provide support and care for a loved one with mental health and/or substance use conditions. Each story is followed by descriptions about the unique aspects of various family roles, which were identified by each "family role" group during the event.

Parent/Caregiver of a Child Under 21: Linda's Story

Linda has an extensive background in children's mental health which led to her knowing about the system, but not necessarily knowing how to navigate the system. Her son had several adverse childhood experiences in his early upbringing, but she was proactive about getting him into therapy to meet his needs. She says that her first experience with her son's condition escalating to a "crisis situation" was when he was eight years old. While Linda was out of state at a conference, she received a call from her son's school sharing that her son had threatened to blow up the school. Because her son was a young Black boy, Linda says the jump to intensive therapy, counseling, and other approaches was immediate. Eventually, she realized that her son had been badly bullied and even though teachers and the school had known about it, they had not done anything to address it. She says that her son's efforts to defend himself contributed to the perception of him as an "aggressive Black boy," leading to two suicide attempts. Linda notes that because she knew the system, she had people she could call for help, but there was no support of any kind until she got to the hospital to see her son.

Linda says her experience with her son's condition has led her to feel guilt and shame, asking herself, "What did I miss? How did I not see this?" She says it would have helped her to talk to another parent who had been through similar situations, so she could have known how to support her son and avoid experiencing depression herself and feeling that she is a bad mother. She explains that even though she has a degree in this area, she still needed parent peer support to help her family through it.

Linda’s son is now in college and has learned how to manage his depression. In fact, he wants to help youth like himself. Although this is a wonderful outcome, Linda could have used support along the way. Parent peer support is “100 percent important,” she says, but it takes a village: How can we get support for all the people in the village and help them process their experiences? “We are humans who are built to be in relationship with others,” she says. Parent peer support helps parents feel less alone and have a better understanding of resources and systems as they navigate caring for their children.

Unique Aspects of the Role of a Parent/Caregiver of a Child Under 21

Parents/caregivers of children under age 21 with mental health and/or substance use conditions identified a few unique aspects of their role:

- **Feelings of guilt, shame, and grief.** A contributing factor for parents/caregivers of children under 21 is that they are often blamed for the child’s behaviors and judged for “not fixing” the behavior prior to seeking services. The blame and shame can come from providers, community members, and even extended family, which makes it difficult to identify natural supports.
- **Authority and responsibility for a minor.** Parents/caregivers of minor children often have both authority and responsibility for the child receiving treatment, unlike in most other roles. This means they are responsible across multiple systems, including mental health, education, child welfare, pediatrics, and juvenile justice.
- **Health care providers’ views of parents/caregivers.** Many parents/caregivers feel that how they are perceived really depends on each provider—some value the role of a parent/caregiver in a child’s care, while others do not. For parents/caregivers who are not valued by the child’s providers, it can be an uphill battle to get information, be included as a partner in care, or make progress in treatment plans, among other challenges.
- **Focus on resiliency and recovery.** As one parent explained, “Children are not little adults in recovery” because their minds are still in development. The focus in family peer support services is often on developing a child and family’s resilience and the building of protective factors, rather than on recovery from a behavioral health condition.

Parent/Caregiver of an Adult Child: Regina's Story

Regina noticed early on that her daughter, who was six years younger than her son, was developing differently in terms of her temperament and how she interacted with others. While her daughter met developmental milestones for her age, she did receive occupational therapy for gross and fine motor skills as well as emotional support to address her social adjustment. When Regina's daughter was in fourth grade, Regina got a call from the school saying that her daughter had tried to harm herself at school. "I couldn't understand what was happening in this little person's life that she wanted to take her life," Regina says. Her daughter had multiple hospitalizations over the years due to a combination of these challenges: attention deficit hyperactivity disorder (ADHD), a mood disorder, a developmental disability, anxiety, and asthma. Regina says her family was involved with the child welfare system because kids like her daughter tend to show up on multiple radar screens.

Regina has experienced grief about who she wanted her daughter to be, who she was and who she is. She also wondered what the family could have done better or what they might have missed in her daughter's needs. She experienced impacts on her own mental health because of the stress of caring for her daughter, managing the household, working full time, and marital challenges. She says her husband could not understand why their daughter still had so many issues even with therapy, medication, and other supports. She also felt parental guilt about not being able to give as much attention to her son whom she recently discovered was also struggling with anxiety and depression. Over the years, Regina has felt judged by different systems and people; she managed her own resentment and anger toward these systems, providers, her husband, herself, and sometimes even her daughter.

Fortunately, Regina's daughter, at age 24, is doing much better. While Regina's daughter's needs are different than they used to be, she continues to need support regarding employment and housing. Her daughter still lives at home and is considered "high functioning," which means she does not fit the typical idea of who needs help, so the family has found it difficult to access various services. Regina says, "When she was younger and I needed support navigating the mental health and school systems, peer support was very helpful. But now that she has crossed over into adulthood and adult services, I feel lost like I did when we first entered the system. My role can be limited by social norms and what's considered appropriate and acceptable when assisting your adult child."

Unique Aspects of the Role of a Parent/Caregiver of an Adult Child

Parents/caregivers of adult children with mental health and/or substance use conditions identified several unique aspects of their role:

- **Sole responsibility for caring for their children.** In contrast with some other roles, parents/caregivers have full responsibility for their children during the younger years, which can also make their child's transition to adulthood challenging. Parents/caregivers must figure out how responsible they can be, and are willing to be, for their adult child's care. Once a child becomes a legal adult, they may still need support due to their maturity and functioning level while not requiring a legal guardian. This relationship can become a power struggle between the parent/caregiver and their emerging adult child as they try to balance the needs of their adult child, themselves, and any other children in the house while also encouraging their adult child to become independent. This power struggle can lead to harsh, life-changing decisions for all involved.
- **Social norms.** Society may not understand the emerging adult child's ongoing need for support or why the parents/caregivers may continue to provide support, especially when the behaviors can be quite challenging. Being an adult of legal age does not necessarily mean someone is self-sufficient or able to handle crises on their own. For people who have not had these experiences, they might think the decision is an easy one, but may not understand how difficult a decision is in a specific situation because of their lack of understanding of the adult child's mental health and/or substance use conditions.
- **Need to consider different developmental stages.** Parents/caregivers whose children have mental health and/or substance use conditions need to be aware of how their children will develop as individuals over the years in terms of their needs and what level of support they require. Even as children get older, they may still need more assistance and advocacy from their parents/caregivers than others their age. Part of this process can include preparing and guiding an adult child to be able to manage their own life as well as learning to foster independence when possible.
- **Interactions with multiple systems.** Families in which an adult child has substance use and/or mental health conditions often have interactions with multiple systems and must navigate the transitions in and out of various age-limited systems, such as education (e.g., high school vs. postsecondary education and vocational training), adult behavioral health and children's mental health and/or substance use services, juvenile justice and adult correctional systems, independence and employment with regard to disability-related needs, pediatric and adult primary care services, and recreation and social activities. A signed release of information is now required for an adult child receiving services if they want their family's continued involvement.

- **Excluded from systems.** Despite their interactions with these systems and the efforts on behalf of, or with, their adult child, these parents/caregivers often feel excluded by the systems. These parents/caregivers also feel that providers may not view them as experts on their own children and sometimes blame the parents for "enabling" their adult children to not work toward recovery and wellness.

Sibling: Sharon's Story

Sharon is a middle child who was raised by a single mother. Shortly after her younger brother was born, Sharon's mother realized he had a serious mental health condition that would require on-going treatment. Sharon felt isolated growing up because she would not have friends over since she felt she could not explain why he "acted differently." She remembers feeling jealous of her brother because he got so much one-on-one time with her mom, not realizing until later how exhausted her mom was because she was taking her brother to doctor appointments and from one program to the next. Sharon's brother often got dismissed from services due to his challenging behaviors, and Sharon's family had to help ensure his safety and make sure he understood the dangers of the world. As he reached adulthood, there were not many supports available for him, and any supports that were available proved difficult to access.

Though she wants to be more involved in his care and understand his long-term needs, her mother does not want to talk about a plan for how Sharon's brother will be supported after her mother is no longer around. She says parents should know that siblings want to work *with* them in supporting their family members—not *instead* of them. As she says, siblings want to help and to have a sense of "passing the baton" so they do not eventually take on any responsibilities blindly. nowing about a sibling's diagnoses, care team, and relevant systems is essential. As Sharon puts it, she feels like she is one phone call away from having to "fly a plane that has not been built."

For Sharon, attending support meetings and connecting with others in similar situations has validated that she is not alone in her feelings as a sibling, in addition to giving her more empathy for her mother's experience. Many of the organizations she works with have become part of her "tribe," as she describes it, as they allow her to be transparent and vulnerable. Peer support provided the resources that enabled her family to get her brother's criminal record expunged. "Understanding the diagnosis and gaps in services to build networks of support to help my brother and mom is my mission," she says.

Unique Aspects of the Sibling Role

Siblings of individuals with mental health and/or substance use conditions identified several unique aspects of their role:

- **Peer-like relationship.** Because there is not a power dynamic in the sibling relationship in the same way as there is between a parent and their child with mental health and/or substance use conditions, siblings are more like peers who can push for the sibling with behavioral health conditions to pursue greater independence and have more “dignity of risk.” The participants said this means they often are more objective than their parents about what a sibling can do and that they might have higher expectations for their sibling as a result. The sibling perspective can often support a strengths-based approach to caring for the person with mental health and/or substance use conditions.

- **A relationship across the lifespan.** Participants noted that while many parents have life experiences before they had a child with mental health and/or substance use conditions, siblings are often born into the situation of having a sibling with mental health and/or substance use conditions. This means many siblings do not know what it feels like to not have a family member dealing with these challenges, and they often have this experience as a “baseline” from the time they are quite young. For many siblings, this results in what can feel like an obligatory long-term commitment to caring for, and about, someone with mental health and/or substance use conditions. Siblings are also most likely to be the only individuals who have a relationship across the lifespan—from childhood through adulthood—unlike the relationship between married or partnered adults or sometimes between parents and children. Although research suggests that providing siblings with support early in life results in better outcomes for the entire family,[2] siblings often perceive their needs as overlooked by busy and stressed parents and stretched service providers.

- **Resentment toward the sibling.** Siblings expressed that they sometimes felt jealousy toward their sibling who had behavioral health challenges, as that sibling often got more parental time and attention because of their condition. For children, who feel very strongly about things seeming “fair,” this imbalance can fuel resentment and frustration. In trying to earn their parents’ attention, the sibling may choose to either “act up” or be “the perfect child.”

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[2] Alexander KL, Entwisle DR, & Olson LS (2007). Lasting Consequences of the Summer Learning Gap. *American Sociological Review,* 72(2), 167–180.

- **Often excluded from treatment plans and the care team.** Individuals in the sibling group said that they are often viewed as “an afterthought” and that they are “not seen, not included” in a sibling’s care, even though most siblings will serve as caregivers when parents are no longer able to do so. Whereas a parent or a spouse would usually be viewed as a necessary part of planning for the care of someone with a mental health and/or substance use condition, siblings “usually have to fight to be on the team.” As one participant said, “We siblings are often the people who step in as caregivers for our brothers/sisters later in life, and we are more likely to elect to take on this role if we are supported early on.”

Partner/Significant Other: Sue’s Story

Sue identifies as a mother, daughter, and wife of people with mental health conditions. She also works in the mental health field for an advocacy organization, so she offers several perspectives on what individuals and families experience. It was important to Sue and her husband to have a relationship based on trust and equality which supported them in being true partners.

One day, Sue came home from a work trip and realized her husband’s arms were shaking so badly that they went to the emergency room. He was diagnosed as having an infection in his brain, could not work, and subsequently lost his job. This loss created financial and emotional pressures in their relationship. After returning to work and several years later, he developed a seizure disorder as well, causing him to lose his driver’s license and his job once again. Sue says she was viewed as “part of the team” by his providers when he had this diagnosis. Eventually his diagnosis was changed to non-epileptic seizures caused by serious depression. Once this change occurred, no one would talk to her or share information about her husband’s condition, and she was now seen as a “problem.” As Sue puts it, “I was voted off the island.” Her husband’s therapist even told him at one point to divorce Sue because she was “too controlling.”

Since Sue’s husband was unable to hold a job or assist with household chores, etc., Sue worked full time, raised their two kids, managed the household, and provided support and care for her husband. She had no support system, and money was tight since they were now a single-earner household. One day, she realized she couldn’t continue to live like this. She told her husband he needed to at least get a part-time job, which he did. Life did get better, but it was not the life she had envisioned. Sue feels what she calls “ambiguous loss” because the expectations and dreams she had for her life were lost. Her own mental health suffered due to the stress and the

lack of support. Additionally, she recognized the lack of support from friends and family members, sharing that if your spouse is physically sick, your spouse and you may receive cards, phone calls and/or meals. When a family member has depression (or other behavioral health conditions), however, people do not reach out; in fact, they often ignore you because they do not know what to say or do. Sue felt “lonely with a capital L.”

Her husband was eventually diagnosed with an autoimmune disorder which forced him to become extremely isolated during the COVID-19 pandemic. In 2021 while Sue was out of state, her husband passed away; the coroner did not rule his death a suicide, but Sue still wonders.

Unique Aspects of the Partner/Significant Other Role

Partners/significant others of people with behavioral health conditions identified a few unique aspects of their role:

- **Often blamed for their spouse’s issues.** Their children, other family members, or friends who may not understand the full picture may blame them for their partner’s condition or how they treat their partner. Many outsiders do not understand the role change, which may be temporary or long-term, between the partners/significant others. As partners, decision-making and responsibilities are shared. When one person has a debilitating condition, the other person can be forced to move in to the “take charge” position, which then might feel more like a parent-child relationship.
- **More difficult to access support.** Partners/significant others can feel other members of the family (e.g., children) have more options for support, and it can be easier for them to seek support for their children instead of themselves. If a partner shares with family and friends what they are feeling and experiencing with their significant other, the family and friends might see the partner as “less than” or judge the partner without the condition as not “committed or loyal.”
- **Frequently treated as an imposition by clinicians.** Partners/significant others often are the first to see early signs of mental health and/or substance use conditions; they often felt that many providers used confidentiality laws (HIPAA) as a shield to not allow the partner to be involved in their significant other’s treatment plan. Providers also might give priority regarding information to the family of origin for the individual in recovery. This can be especially challenging because an individual experiencing a mental health crisis might not sign off on having information shared with their partner/significant other, even if the partner is a crucial part of the recovery process. In crisis situations, if a person enters a new hospital or facility and has new clinicians and providers, it can become even more difficult for the partner to exchange relevant information with the new care team, which can hinder the recovery process and create additional stress for the partner.

- **Clinicians' lack of understanding of marital challenges.** Clinicians may not understand the challenges that mental health and substance use conditions can create in a marriage or long-term relationship. For instance, the partner can experience added financial stress if their spouse cannot work, or they work hard to shield their children from crises or day-to-day problems. Partners may balance caring for children and/or aging parents as well as their spouse, in addition to working and maintaining the household. Despite the added stressors placed on the partner of the person in working toward recovery, clinicians and providers may not acknowledge the partner's needs in that process.
- **Providers' lack of understanding of the implications of aging and multiple conditions.** Many partners/significant others feel that many providers do not fully grasp how physical health issues may intensify the symptoms related to the person's behavioral health conditions as they age.
- **The choice of staying vs. leaving.** A partner/significant other must determine how responsible they can be, and are willing to be, for their loved one's care. A relationship that is established on partnership and love may become more like a parent–adult child relationship and can create a power struggle and difficult decisions. While choosing to leave one's partner is technically an option, the reality is that this often is not a viable option, whether due to finances, the desire to fulfill their commitment to vows (e.g., "in sickness and in health"), emotions, or because of children in the family. This likely does not actually feel like a choice for most partners because they still love their significant other and want what is best for them and their family.

Children (Throughout the Lifespan) Who Care for and/or About Parents/Caregivers: Edie's Story

Edie's parents had trauma and mental health issues in their backgrounds, including abuse, parental loss, alcoholism, and depression. Her parents met when her mother was 19 and her father was 36. They married a few years later and had two sons in their first three years of marriage; Edie's mother stayed home to care for the boys. Edie's father was rigid about his "routine;" when he got home from work, he was quiet and did not like anyone talking to him, even during meals. Almost every night, he ate quickly, took a nap while the family was still eating, and went to the fire hall to drink and play poker. He spent Sundays with his siblings.

Edie was born when her mother was 34 and her father was 51. Edie remembers her father smoking cigarettes while reading the paper or watching sports without wanting to be interrupted. When Edie was seven, her mom went back to work and Edie was home alone after school. Sometimes her mom would go out after work with her friends and Edie would have babysitters. Her dad would come home early from the fire hall because he was so upset on those nights. He asked Edie if she knew where her mom was and who she was with while pacing, smoking, and drinking. Edie felt relieved that her mom seemed happier, but now worried her parents would get divorced.

Around this time, Edie began to realize that other family members had unusual behaviors. She learned that her paternal aunt was hospitalized multiple times for “nervous breakdowns.” When Edie was eight, her maternal grandmother died, so her grandfather moved in with Edie’s family. Her grandfather talked to himself, accused her mother of stealing his money, and poisoning his food. He got worse when he drank. Edie feared him, and by the time she was nine, she was often sick and had frequent doctor visits. Her family’s doctor told her, “Your grandfather has an illness in his brain called schizophrenia. That’s why he acts the way he does. He hears things and believes things nobody else does. I’m trying different medications, so he gets better, but if it’s too scary for you, tell your mom.” After this short talk, Edie did not get sick as often and she felt safer around her grandfather. The experience also made her want to learn more about the human brain.

Edie remembers being at other kids’ houses and seeing families that got along, affectionate parents, and fathers who played with their children. She felt pain as she realized her family was different and not as happy as other families. She started distancing herself from those friends and became friends with families more like her own. As a pre-teen and teenager, Edie and her best friend longed for male attention, which made them both susceptible to men who preyed on their vulnerabilities. Edie found informal peer support with these friends, especially with her best friend, because their family stories were similar. Finding this informal peer support became a major coping strategy for Edie and showed her the value of peer support, even if she did not know it as such at that time.

Unique Aspects of the Children (Throughout the Lifespan) Who Care for and/or About Parents/Caregivers

Individuals raised by and caring for and/or about parents/caregivers with behavioral health conditions identified a few unique aspects of their role:

- **Fear of asking for help.** Some participants recalled that when they were children, they felt they could not tell other adults about their experiences at home for fear of discrimination, judgment, or a lack of understanding. When they did share their reality, their families faced

difficult consequences. Children learned quickly how to disclose information in a way that would cause less harm to them and their family.

- **Parentification.** Many children who were raised by parents with mental health and/or substance use conditions take on adult roles prematurely, such as comforting their parents or caring for siblings, while not being supported themselves.
- **Lack of power.** Even though these children often have adult responsibilities, they do not have many choices about their situation and are at the mercy of other people's decisions, whether those of their parents or systems that could cause major changes in their families, such as the child welfare system.
- **Lack of access to services.** Many parents, who are experiencing their own mental health and/or substance use conditions, may choose not to seek or access services due to understanding that acceptance of services may mean separation from their family. For the child to receive services, their parent must authorize it, which can also lead to separation.
- **Transition from childhood to adulthood.** Even though many of these individuals may be providing care for a parent from a young age, at some point they must make decisions about their own future and how those decisions could affect their parent. Individuals can experience guilt if they focus on their own life rather than continuing to care for their parent. At some point during their adulthood, other expectations may arise directly around health decisions and providing continued care for their parent.
- **Fear for their own future.** People who have parents with mental health and/or substance use conditions may worry or fear they are doomed to live the same life as their parents. Additionally, they may worry they could pass these conditions on which may influence their decision about having children.
- **Balance of challenges and love for their parent.** Adults who provide support for their parents with behavioral health conditions may experience many internal struggles. They might hate some of the situations they experienced in childhood while still feeling love for their parent. Seeking help for themselves as adults might bring up feelings of being disloyal to their parent. Finding a way to balance one's own health and wellness while still acknowledging and accepting past experiences can be overwhelming and affect a person's relationship with their parent. These individuals often love and feel loyal to their parent, continuing to support them, but they can also struggle with traumas they experienced within their family of origin.