Navigating Mental Health and Substance Use Care

An Introductory Guide for Families

SAMHSA
Substance Abuse and Mental Health Services Administration

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Office of Recovery, Substance Abuse and Mental Health Services Administration, 5600 Fishers Lane, Rockville, MD 20857.

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Introduction

Welcome to *Navigating Mental Health and Substance Use Care: An Introductory Guide for Families*. This Introductory Guide was developed through the input of family members and people with lived experience navigating supports and resources with and for a loved one who has a mental health and/or substance use conditions. In February 2025, over sixty family member representatives from a variety of perspectives gathered for a two-day meeting to help inform the content of this Introductory Guide. Based on and expanding from ideas shared in the meeting, this Introductory Guide is developed to recognize the importance of families and family relationships. The roles of family members can change throughout their lifetimes. Families who have an adult family member (or family members) with mental health, substance use, or co-occurring mental health and substance use conditions have diverse experiences yet may share common challenges when navigating resources in behavioral health prevention, treatment, and recovery support systems. Families who are navigating resources for children and youth may have different challenges and need different resources than those navigating behavioral health service systems for adults. The Introductory Guide's objectives are to:

- Understand common experiences and roles of families and family members.
- Support wellness, resilience, and recovery for all family members.
- Introduce readers to resources available to support families as they navigate behavioral health supports with a loved one experiencing mental health, substance use, or co-occurring conditions.

Readers are encouraged to reach out to the national offices and/or local affiliates of family-led and peer-led organizations in their state and local community for in-depth resources and support.

Recovery and Family-Supportive Systems of Care

Recovery

The Substance Abuse and Mental Health Services Administration (SAMHSA), along with partners from across the country, developed a working definition of recovery from mental health and/or substance use conditions:[1]

A process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential.[2]

Along with the above definition of recovery, four major life dimensions that support a person in recovery were identified:[3]

- **Health.** Overcoming or managing one's disease(s) or symptoms—for example, abstaining from using alcohol, illicit drugs, and nonprescribed medications if one has an addiction problem—and for everyone in recovery, making informed, healthy choices that support physical and emotional well-being.
- **Home.** Having a stable and safe place to live.

- **Purpose.** Having meaningful daily activities, such as a job, school, volunteerism, family caretaking, or creative endeavors, and the independence, income, and resources to participate in society.
- **Community.** Having relationships and social networks that provide support, friendship, love, and hope.

Family recovery takes the concept of recovery a step further by emphasizing that recovery is not only a personal journey, but also one that can be supported by and transformational for the full family.[4] Family recovery recognizes that families, in their many forms, experience unique challenges and healing processes to support a loved one with behavioral health conditions. This may involve the family in learning new coping strategies, navigating complex systems, and renegotiating roles and relationships within the family.

Family-Driven, Family-Supported, and Family Integrated Approaches

Families navigating behavioral health supports for children and youth will likely experience family-driven approaches that center the family in behavioral health support, while including the child in all aspects of decision making about their care. Family-driven approaches can be integrated into children and youth behavioral health services while centering care on the young person or child who is experiencing mental health and/or substance use conditions. Ensuring that families can partner with providers and systems staff honors family members as important in their loved one's care.

Families supporting adult loved ones will likely experience family-supported approaches, which recognize that family is a key part of the resilience, recovery goals, and the long-term wellness of their loved one.[5]

There are also specialized approaches that integrate support of parents and their families, such as mothers experiencing pregnancy and post-partum. Person-centered care recognizes that every person has the right to define their needs and goals for their unique journey and allows people to make informed decisions about their treatment and well-being.[6]

Elevating Well-Being

As a family member, it is always important to take care of yourself, even if your loved one is not engaging with support services for their mental health and/or substance use conditions.

Making time for personal well-being is essential to care for loved ones. Throughout this Guide you will find boxes titled “Wellness Pause” that offer practical examples and strategies for tending to your personal wellness.

Understanding the Family Resources Landscape

Understanding the language of mental health and substance use systems of care is important for families with a loved one who is experiencing mental health, substance use, or co-occurring conditions. Resources for families include both formal and informal family peer support and information about systems that families must navigate with their loved ones. The type of information that is helpful and supportive to families depends on the family’s experience and

where they live. Often, family-led organizations have various types of support to help family members.

Family support may range from resources that a person receives from a behavioral health provider to resources found through personal research online, in libraries, or through friends, neighbors, and other family members. Family-led groups and organizations often have specialized support and educational curriculums. In mental health environments, these materials and curriculums are referred to as family psychoeducation. A variety of models exist for family education and care navigation curriculums. Examples of models include:

- **Community Reinforcement and Family Training,** or **CRAFT**, is an approach for families who have a loved one with substance use conditions.[7] It provides strategies that help family members support their loved one in making positive behavior changes while also improving their own well-being.
- **The Invitation to Change** is a model focused on building communication skills, improving family relationships and self-care for families.[8] The Invitation to Change model and strategies are drawn from three evidence-based approaches—Community Reinforcement Approach and Family Training (CRAFT), Motivational Interviewing (MI), and Acceptance and Commitment Therapy (ACT).
- **National Alliance on Mental Illness (NAMI) Family-to-Family** is a free, eight-session educational program for family, significant others, and friends of people with mental health conditions. NAMI Family-to-Family is taught by NAMI-trained family members and includes presentations, discussions, and interactive exercises.[9]
- **SMART Recovery Online Meetings -** SMART Recovery is an evidence-informed approach to overcoming addictive behaviors and leading a balanced life. SMART is stigma-free and emphasizes self-empowerment.[10]

Engaging with family-led organizations and educational resources offers important opportunities for family members to counter experiences they may have with stigma and stigmatization of their loved one. Educational resources typically include ways to use respectful, supportive language when speaking of loved ones and themselves. The words family members use shape how they see their loved ones and affect how those loved ones see themselves. Negative labels can sway how family members or service providers respond to a person's needs and hope for recovery.

Family – Unique and Shared Experiences

Each family's journey with mental health, substance use, or co-occurring conditions will look different based on the severity of the conditions; the age of the person in care; or the geographic, economic, and other contexts in which the family lives. Common threads, however, connecting various experiences and core needs for support, dignity, and clear information are universal. Families often face challenges navigating complex systems, managing emotional stress, and countering stigma. No family, family member, or caregiver is on the journey alone. Sharing common experiences and differences with others enables a stronger sense of community and connection for collective wellness.

Personal Well-Being and Family Wellness

Personal Well-Being: It Matters

When supporting a loved one with mental health and/or substance use conditions, personal well-being is often difficult to prioritize. Whether your family member is experiencing mental health and/or substance use conditions or your family member is a child or an adult, prioritizing your well-being supports your loved one. Think of your wellness and energy like a car battery. If the battery is fully drained, it cannot provide the spark that the engine needs to start. Recharging emotional, mental, and physical energy is essential to prevent burnout and keep going.

Many family members report a lack of sleep, feelings of isolation or helplessness, financial stress, feeling grief or sadness when missing personal life events, and ongoing stress. These feelings are normal, and they emphasize the importance of self-compassion.

Self-compassion is:

- Accepting support, just as you might offer to a loved one.
- Letting go of unrealistic expectations.
- Understanding no one is perfect.
- Mistakes along the way do not define you, but present learning opportunities.

Family Wellness: Navigating Resources and Recovery Together

When a family member is affected by mental health and/or substance use challenges, the entire family feels the effects. Parents may feel guilt, fear, shame, or loss of control. Siblings may experience confusion, a sense of invisibility, or resentment. Children may sense that something is wrong but not express their concerns, while extended family may want to help but are unsure how. In some cases, family members take on unexpected roles, such as grandparents helping co-parent and/or raising grandchildren.

It is important to keep everyone's wellness in mind because when everyone is supported, everyone benefits. While a loved one facing a new diagnosis, crisis, or navigating their illness may need various degrees of attention, others in the family need support, too. Take time for all family members to check in with each other, share feelings without judgment, celebrate big and small wins together, and support each other's needs. This can create a strong network of communication and mutual support where all family members feel seen and heard.

Maintaining Balance and Recognizing Boundaries as Bridges

It can be challenging as a family member and as a caregiver to set boundaries. Think of boundaries not as barriers, but as *bridges* to stronger, healthier relationships. Boundaries help to protect your energy, clarify your role, and create space for both your loved one and you to heal. Your roles in relationship to your loved one may change or assume new facets at different times in your life. As you experience changes in your relationship and roles, taking time to gain new understanding of what each of you expect or hope for from each other is beneficial.

As your roles or relationship change, the following questions may be helpful:

- What support does my loved one need from me?
- What support will I seek from other people or systems of care?
- What will their responsibilities be?
- What roles do they not want me to take, and why?
- What expectations do I have for my loved one?
- How can I/we recognize and foster the strengths and gifts they provide the family?
- What do I need to stay well in this role?

Using these questions can help set clear roles and expectations can reduce tensions and prevent you from taking on more than is helpful or healthy for either of you.

MULTIGENERATIONAL EXPERIENCES

The effects of substance use and mental health conditions can be experienced over multiple generations. Recognizing this, American Indian and Alaska Native communities often incorporate cultural practices as part of community and family approaches to wellness, offering promising practices in support of community members' individual and collective sobriety and wellness. Incorporating cultural practices in native communities is central to substance use and mental health treatment and recovery. The success of these approaches may provide important models for sobriety and wellness in a variety of communities.

Wellness Pause – Tips for Finding Balance

- **Keep a Healthy Sleep Routine.** Keep a healthy sleep schedule and prioritize getting enough sleep.
- **Balance Support with Personal Care.** Set realistic expectations for yourself and what you can (and sometimes cannot) offer your loved one for support.
- **Reclaim Your "You."** Your role as a caregiver is not all of who you are. Make space for things that bring you joy.
- **Beating Burnout.** Be sure to build regular check-ins into your family and personal routine. Ask yourself questions like, "How am I feeling today? What do I need?" Ask your loved ones the same questions.
- **Little Things Matter.** Creating and finding space for balance does not have to be big. Sometimes it means taking time for little things: having a cup of coffee, taking a few deep breaths, or making a quick call to a trusted support.

Navigating Systems of Care

As you offer care and support to your loved one, you are likely to discover the complex system of care your loved one will engage with on their journey. Systems of care include care providers, insurers, and peer- and community-led support. In addition, these systems often intersect with other systems such as child welfare, justice, and school systems. Your family role is important in helping your loved one access health resources and care coordination.

Supporting a Loved One

For families navigating systems, supporting your loved one may involve coordinating with physicians, therapists, specialists, educational systems, care managers, and other service providers. Here are a few strategies that may help ease the pressure or stress that people often experience when coordinating care.

- **Keep Notes and a Documents Folder.** Keep track of communications in a notebook or communications log. Use this tool to track who you spoke with, when conversations took place, what you discussed, questions and answers during the conversation, and note any resources or tools suggested or recommended.

  As you learn new systems, consider keeping a physical or digital folder with key documents to help you stay organized and navigate systems more easily. Here are examples of documentation that can help you communicate across systems and effectively advocate for your loved one:

  - Documentation of your loved one's diagnosis,
  - Names of your loved one's providers,
  - Contacts you have made,
  - Answers to key questions that you have asked over time,
  - Medication or care lists,

    - Key contact information for providers and peer supports.

- **Confirm Your Understanding.** Do not be afraid to ask the provider to give you information in a way that you understand. Ask the provider to restate information in plain language or to explain in another way if it was too complex.
- **Request Care Coordination Support.** Ask about support available for care coordination. Organizations or providers may offer care coordination conferences, team meetings, or other forms of collaboration that can help you feel less alone in the process.
- **Request Family Peer Support.** Often, family peer support can both model and teach you coordination skills and strategies, which can help you feel more confident in navigating services.

Navigating Resources for a Minor Child or Youth

In most cases, family members who navigate behavioral health supports and resources for a child or youth are parents and/or adults in a custodial role. This can include grandparents, older siblings, aunts, uncles, adoptive parents, foster parents, and others who have kinship and guardianship roles.

When a child experiences mental health and/or substance use challenges, your role as a parent or primary caregiver shifts to include navigating new types of health care providers, advocating with schools, coordinating appointments, and more. Parents and primary caregivers of minor children will find themselves on a new journey.

Navigating the Systems Landscape

Based on the types of needs you are identifying you may encounter new systems to navigate to receive care and support that have their own language and terminology. It will take time to learn about these new systems, what they do, how they function, and how you will interact with them. Family peer support can be very helpful in learning about and navigating these systems.

There are several key systems you and your child may navigate when they have a behavioral health diagnosis:

- **School Supports.** School-based programs and systems include accommodations, in-school counseling or special education services, Individualized Education Programs (IEPs), and 504 plans for behavioral health conditions. An IEP is a formal plan that details the special education services and supports that a school will provide to meet the unique needs of a student with a disability. It includes specially designed instruction tailored to the student. A 504 plan is a formal plan for how a school will remove barriers so a student with a disability can learn alongside peers in general education. It does not include specially designed instruction specific to a student.[11]
- **Behavioral Health Systems.** Behavioral health systems include a range of services such as diagnostic and evaluation services, inpatient and outpatient therapy, recovery support, medication management, crisis services, intensive home-based and intensive day-treatment services, respite care, therapeutic foster care and residential treatment, and assistance in transitioning from child to adult services.

- **Child Welfare.** The child welfare system is a group of public and private services that are focused on ensuring that all children live in safe, permanent, and stable environments that support their well-being. Child welfare services may interact with entire families, or they may be focused on direct intervention with children.
- **Juvenile Justice.** Juvenile justice is a collection of state and local court-based systems whose purpose is to respond to young people who come into contact with law enforcement and are accused of breaking the law.

In some situations, you may find yourself navigating systems that come into play if your child's conditions include disruptive behavior or lead to involvement with law enforcement. As a parent or guardian, you have the right to request information on diverting your child from traditional juvenile justice systems and instead connecting them with support and behavioral health care options. The child welfare system may become involved if safety is a concern. As a parent or guardian, you have specific rights and responsibilities within child protective services to ensure that you remain connected to and involved in assessments, court hearings, treatment or placement options, and more.

Wellness of the Whole Family

Mental health and substance use conditions impact the whole family, not just the person experiencing them. Take time to nurture your relationship with a spouse, engage with younger family members to hear their perspectives and learn about their experiences. Explore everyone's strengths and contributions, especially the person with the conditions, and sustain typical and enjoyable activities.

Whole family wellness means keeping the young family members in mind, too. Children and youth navigating a loved one's mental health and/or substance use journey often see things differently. They are often aware of changes in their family members' health, so it is important to explain, listen, and involve them at a level appropriate to their abilities. They may begin to form their own understanding and beliefs about mental health and substance use. Sometimes adults believe that not talking with younger family members about behavioral health concerns is protective. However, the young family members' perception that they cannot discuss the topic may cause them to internalize feelings of being unseen or excluded from family discussions. Or they may internalize stigma and negative stereotypes about mental health and/or substance use conditions.

Finding Support and Resources

You are not on this journey alone. Try to engage with support groups, peers, trusted friends and family members, and professional support. Take note of resources that can help you care for your child and support the whole family.

- Join a support group with other family members who have similar or shared experiences.
- Talk to a peer supporter, counselor, or therapist who understands the stress of caring for a loved one.
- Engage in acceptance and avoid resignation; accept that you cannot control what your child is experiencing and leave room to care for them without giving up or fearing that you won't be able to support them.
- Reinforce your boundaries and honor your child's boundaries; boundaries can help you to maintain your own wellness and health.

Peer support services and community-based supports blend formal and informal supports that are rooted in similar lived experiences.

LISTENING TO YOUNGER FAMILY MEMBERS

Asking children and youth about their experiences can lead to great conversations. Young family members often have insights that may be surprising to adults. Most often, listening to children and youth about their experiences is protective and helpful. It is important to give young family members the opportunity to talk about what they are seeing and feeling. Work together to find age-appropriate language to discuss mental health and substance use topics. Remind them that they are not responsible for their loved one's mental health and/or substance use conditions. At the same time, let younger family members know that the family sees and values them, and that their experiences matter. Find ways to offer information that reduces their worry and helps them feel included in family wellness.

Peer Support Services	
Examples of peer support services: • Peer mentoring • Facilitating peer support groups • Peer respite • An approach that emphasizes mutuality in support of a person and their recovery **Categories of family peer support:** • Informational/educational support • Instructional/skills development • Emotional and affirmational support • Advocacy support	**Settings where peer services are available:** • Family-led organizations • Recovery Community Organizations (RCO) • Certified Community Behavioral Health Clinics (CCBHC) • Substance use disorder treatment facilities • Clubhouses and recovery cafés • Recovery housing programs such as sober living homes • Crisis and peer respite centers • 12-step programs • Drop-in centers • Virtual peer support networks

Supporting Young Adults

The age your child is considered to be an adult for particular services may vary state-to-state. But your role as a family member does not end when your child reaches that age. In most behavioral health service systems, the ages where a child may be considered a young adult typically span ages 18 to 26, and the landscape of providing care and support may change in significant ways.[12]

Navigating Systems

Acknowledging the shift in your role also means recognizing the challenges you may face as a family member and caregiver as your young adult family member navigates adult behavioral health resources and supports. For example, you will need to understand Health Insurance Portability and Accountability Act (HIPAA) and 42 CFR Part 2 confidentiality and privacy rules when your family member is an adult.

How you access information changes when your child becomes an adult, requiring greater collaboration with your child and their care network to stay informed. HIPAA can create challenges to accessing information about your young adult family member. Your young adult family member can sign a release of information form, which allows providers to communicate with you.

What is HIPAA?
The US Health Insurance Portability and Accountability Act (HIPAA), enacted in 1996, was established to safeguard patient privacy and secure health information. HIPAA applies to healthcare providers, insurers, and other organizations handling patient data, mandating safeguards to prevent unauthorized access or misuse of sensitive information. HIPAA regulations uphold patients' rights to confidentiality.[13]
What is 42 CFR Part 2?
Part 2 is a federal law (42 U.S.C. 290dd-2 and 42 CFR part 2) that protects the confidentiality of patient records for people receiving services for substance use disorders (SUDs). Part 2 confidentiality rules describe when and how SUD patient records may be used and disclosed. These records are called Part 2 records.[14]

Understanding Limitations

While your role as a family member and caregiver may change, it can create a healthy dynamic for you and your child as they enter adulthood.

Acknowledging your limitations means accepting that, except for situations where legal arrangements are in place, you cannot make decisions for your young adult family member. This presents an opportunity for each of you to adopt different roles and supports your young adult family member to gain greater independence.

Staying Informed

Staying informed about systems, resources, and options your child may have can help you remain a powerful ally, mentor, and guide as they assume greater autonomy and control of their own care.

Open communication is key to staying informed about your young adult family member's needs, care, and recovery journey. Checking in with them shows curiosity and care. Respect their privacy, autonomy, and try to help them feel comfortable telling you about the experiences or challenges they are facing. Be sure to offer support by asking what they need or how you can best support them.

Whether your young adult family member communicates with you about their conditions or not, you can continue to educate yourself about their specific behavioral health conditions.

If they are living outside your household, become familiar with resources in their area, such as counseling and recovery supports and crisis supports near their home.

Building Support

You can encourage them to build their own support network as they connect with peers and peer networks, education, employment or housing support, peer respite, and other programs. Encourage a healthy lifestyle, considering exercise, diet, sleep and enjoyable pastimes.

As you stay informed about your young adult family member's conditions, you also can build your own information hub in digital or physical form as described before with provider names, medical history, emergency contacts, and so forth.

Allow your young adult family member to take the lead in their care planning as you offer guidance and secondary support. You may help them develop their own crisis and action plans and what they want you to do. Offer support in answering questions, finding information, and identifying people who can be resources. Anticipate that they may be unsure about raising questions. Help with transportation or appointment scheduling, if needed. This way, you offer structure while supporting their autonomy and respecting their need to lead the way in their own recovery journey.

Navigating and Supporting Adult Family Members

Situations where an adult family member has mental health and/or substance use conditions can differ widely if the problem has been ongoing or emerging later in life. Examples include:

- Loved ones who are accessing care as a child or youth and are now navigating adult behavioral healthcare systems.
- A current or former spouse, partner, or a parent to your children who has begun to experience mental health and/or substance use conditions as an adult.
- Siblings or parents who are experiencing mental health and/or substance use concerns and who may be experiencing treatment and recovery at different times in their lives.
- Middle-aged family members who are experiencing symptoms of mental health or substance use conditions that are impacting their job or household relationships.
- Family members who are now older adult parents or relatives.

Navigating systems of care in any of these situations can raise significant challenges to everyone in your family. It can be a strain to both provide support, maintain healthy boundaries, and enlist others in supporting. Understand what you can and cannot do and communicate these limits clearly.

When the person is not geographically close, it can be difficult to gauge what is going on or maintain contact with providers or others involved in supporting them.

Showing up as a caring partner in the support they need, accepting uncertainty, and celebrating the small wins and milestones in their recovery can be a rewarding opportunity for your own personal growth.

Recognizing Change

This may be the first time you are learning the language of diagnosis, treatment, and recovery. Whether your family member acknowledges that their change in behavior is part of behavioral health conditions or not, as you name your concerns remember that *you are not diagnosing* your family member. Instead, you are trying to understand what they are experiencing and how it is affecting your relationship with them.

Understanding a Diagnosis or Changing Diagnosis

Family-led and family-designed educational curriculums (e.g., the NAMI Family-to-Family course) often address the topic of their conditions or the treatment and support options that your family member can choose.[15]

If your family member shares information with you, or if you are involved in their care, you may feel uncertain about what to say or how to respond to the situation. It can be helpful to communicate an empathetic emotion. It may be expressing gratitude, for example, that they are choosing to involve you and getting help. Many people can improve their situation, can recover, and hope is real.

Navigating Systems

Anyone navigating care for an adult family member will need a signed release of information form to avoid being denied access to information about their loved one. Without your loved one's authorization, you will encounter barriers with:

- Accessing the adult family member's medical records and personal health information.
- Navigating adult systems like Medicaid, Social Security, and housing.
- Coordinating access to resources for employment, housing, parenting, or supports such as smoking cessation.

Your loved one can limit the amount or type of information they want the providers to share, or how long the release will be valid. Releases of information usually expire within a calendar year. This will provide control over sensitive details and still allows you to help them coordinate care and resolve problems.

Roles and Relationships

Facing adjustments in your relationship with them is common. Providing support and care will look different sometimes, but maintaining normal activities and shared experiences can offer comfort to both of you. You may find help with coordinating appointments, household tasks, working through crises, or being an advocate.

Relationship dynamics affect many people, not only you and your family member. For example, if the person navigating mental health and/or substance use conditions is your spouse, you may be considering the impact on your children, other family members, friends, and others. Speak with your partner about how they want to educate friends and family about their conditions. Your partner's comfort level with sharing any information should be discussed. Set boundaries on what they can and should not expect from you in terms of providing information to others. They may expect you to guard their diagnosis as a secret, which may feel impossible. On the other hand, they may want you to explain everything to others on their behalf. Spend time talking about what the situation means for both of you. You may wish to explore formal support and counseling as a couple or just for yourself.

Grandparents and Extended Family

In various situations, a family may call upon grandparents, aunts and uncles, or other kinship caregivers to provide the stability, care, and unconditional love that a child needs. Whether for a

short or extended period, stepping into this role can be demanding, especially when layered with the complexities of mental health and/or substance use conditions. You may find yourself navigating systems you did not expect, managing multigenerational relationships, and balancing a range of emotions. As you find your way through grief, hope, fatigue, and uncertainty in your family's future, you have the right to seek and find the support you need to make this unexpected journey a little easier.

Families often call on grandparents and kinship caregivers when an adult family member experiences crisis. This crisis may include a hospitalization, a relapse, or an arrest. Circumstances may force families to make decisions quickly, perhaps without legal guidance or emotional preparation. In many cases, a grandparent or kinship caregiver takes on supporting the children of the adult family member who is experiencing a behavioral health crisis. This new role can create layers of relationships with both the adult who is in crisis and their children. You face a situation where you are concerned for your adult child who is in crisis, while co-parenting grandchildren. Or you may be caring for a grandchild or younger family member who is experiencing mental health, substance use, or co-occurring conditions. Without formal guardianship or custody, it can be hard to access school, medical, or behavioral health support for a child who may have multiple support needs. In both formal and informal kinship placements, navigating resources can be unfamiliar territory.

System Navigation

The systems you engage with may vary, depending on whether the child's parent is available to co-parent with you. If the parent is living, you may experience a change in your relationship as your role changes. You may navigate services and benefits across systems to better understand the options available for the child in your care. You may navigate legal issues to determine if you have a formal or informal guardianship role, and what visitation rights or privileges may exist. You are often in a place of having influence over decisions made for the child without necessarily having legal authority for decision-making.

The parent may be unavailable to co-parent. This can happen for a variety of reasons including hospitalization, incarceration, when the parent dies, or other reasons. In addition to navigating the child's grief and your own emotions, you may face complex system navigation as their new guardian and caregiver. This may include navigating schools, healthcare coverage, childcare, and additional financial benefits. Seek support, such as family peer support and system navigators, to help you engage various systems during your guardianship of the child.

Whether you are stepping into a formal or informal caregiver role, understand your rights and your limitations within these systems. When possible, seek legal advice to understand formal kinship care agreements or formal caregiver roles that can help you access medical care, school systems and enrollment, or public benefits for the child you're caring for. You may need to learn or find help navigating systems such as engaging with the aforementioned IEPs, behavioral health services, Medicaid, and resilience or recovery support services. Explore wraparound services available in your community, such as kinship navigator programs, school-based supports, or respite resources.

Wellness Pause – Tips for Managing Stress

- **Set Limits on Research Time.** Give yourself a time budget to research various systems, providers, and care options. It's easy to get lost as you try to read every article, law, or forum you come across. Check sources of information to ensure they are reliable, valid sources for information.
- **Know When to Ask for Help.** If you feel stuck or confused, reach out for support. Peer supporters, care coordinators, or helplines may have the answers you need. They can help you to understand topics that seem complex or determine next steps in your loved one's care.
- **Make Time for Personal Care.** Allow yourself time to step away from research and searching through systems. If your research makes you feel overwhelmed, find ways to create space to de-stress and keep well. Try journalling, texting a friend, going for a walk, other enjoyable activities and anything that helps reset your mind and relieve your stress.
- **Allow Time to Rest.** Be kind to yourself. When you start to feel overwhelmed, it's okay to rest. You need rest to be able to be at your best for your family.

Supporting Adult Family Members as They Age

Older family members with mental health, substance use, or co-occurring conditions often experience additional health concerns deserving greater or specialized integration of primary care and behavioral health care. New long-term health conditions can also emerge at ages 55 and up, such as cardiovascular illnesses. Helping an adult family member navigate multiple health providers to receive integrated care for their whole health can become a significant part of family member support.

Siblings and adults who have a parent with mental health and/or substance use conditions may have differences and similarities during their childhoods, depending on their roles and how families interacted with them as they grew up. In adulthood, siblings or adults who have a parent with mental health and/or substance use conditions often have common experiences as they navigate resources as a family member and as they age. In some cases, siblings and children who have a parent with mental health and/or substance use conditions find themselves navigating resources as co-caregivers with their parents (e.g., for a sibling) or grandparents (e.g., for a parent). As they age, siblings and people who have a parent with mental health and/or substance use conditions may feel that they need to take on a more formal caregiving role as they have increasing responsibilities. Sometimes, siblings and young adults with a parent navigating behavioral health resources (e.g., between 25 to 40 years) have challenges balancing multiple responsibilities in their lives that mirror the experiences of middle-aged adults (between 40 and 65 years) who become a "sandwich generation." Middle-aged adults often report stressors from balancing caring for aging parents while simultaneously raising their own children and maintaining a healthy relationship with their spouse. Similarly, young adult family members may experience stressors as they balance their role in support of an adult loved one (e.g., sibling,

parent with mental health and/or substance use conditions) while also being in the early stages of their career, marriage, or young family. The unique stressors of young adult family members navigating resources with an adult loved one experiencing mental health and/or substance use conditions are not always visible and are important to recognize.

Another consideration in supporting an older adult family member who has mental health and/or substance use conditions is recognizing the potential effects of social isolation and the importance of social connectedness. Ways to support your older adult family member include checking in regularly by phone or in-person, offering support and being social with your loved one. Consider whether your loved one would benefit from activities they can do with others such as starting new hobbies, participating in events at senior centers, joining clubs, or adopting a pet. Find ways your loved ones can be included in gatherings of families and friends. Helping your loved one be active with you and others in community events has positive health benefits and supports wellness for you and your loved one.

Family Peer Support and Community Connection

Just as a loved one on their personal journey isn't traveling alone, family members and caregivers are not alone either. Support comes in many forms. Whether it's a peer support group, trusted friend, or community organization, there are ways to connect with others who understand what you and your family are going through. These connections can help you avoid a sense of isolation and can validate your experiences. You also may learn practical tips from those who share similar experiences.

The process of finding support can be a bit like using a cookbook. You may need or want different types of support at different times. Possible support ingredients can include self-compassion, healthy boundaries, recognizing your feelings, feeling validated, or feeling a sense of purpose. Learning information that helps you plan, connect with others, knowing that you matter are often important ingredients. Drawing from formal and informal support is helpful as you journey with and in support of your loved ones with mental health and/or substance use conditions. To know which ingredients to use at specific times, it is helpful to know your "why." You might use supports to increase your own wellness, to model for your loved ones, to gain knowledge, or to join others with a sense of purpose.

Rather than facing these challenges alone, family members can lean on family peer supports and people who are trained in the professional family peer support workforce for a variety of supports.

What Is Family Peer Support?

Family peer support includes a range of services that focus on supporting and informing families navigating resources with loved ones who have mental health and/or substance use conditions. These services offer hope, connection, guidance, resources, and support in advocacy. The services are developed and provided by family members with shared or similar experiences in providing support for loved ones. They bring expertise of lived and living experiences to provide emotional connection and support along with informational and practical resources.

Peer Power: The Impact of Family Peer Support

Besides the value of connecting with other families who share and understand your experiences, family peer support offers numerous benefits including:[16]

- Helps family members better understand how to collaborate effectively with service providers and professionals.
- Increases family members' confidence in their abilities to successfully care for loved ones.
- Increases knowledge about treatment and recovery services and supports.
- Increases family members' knowledge of how to actively engage in the services offered to their loved ones and their family.
- Decreases internalized blame by reframing experiences and reducing internalized stigmas and myths about behavioral health conditions.
- Recognizes the significance of personal care and wellness.
- Reduces family members' sense of isolation.
- Improves family member/caregiver mental health and self-care.
- Decreases conflict and negative communication between family members and the person navigating behavioral health care.

Finding the Right Family Peer Support for *You*

Being a family member caregiver in the world of mental health and substance use systems can feel overwhelming and isolating, but remember *you are not alone*. Finding the right supports can reduce your risk of burnout, offer practical tips and strategies for caring for your family and yourself, and affirm that you, too, deserve care and support. Here are several types of family peer supports that you can turn to for information and support.

Formal Versus Informal Support

The family peer workforce includes trained volunteers and certified family peer specialists working professionally as part of behavioral health services.

Formal Certified Family Peer Specialists: Trained and certified family peer specialists offer formal family peer support. These specialists have lived experience as caregivers that allows them to offer their knowledge and lessons learned to support you in navigating systems on behalf of your own loved one. Behavioral health agencies, family-run organizations, or care navigation services often employ these specialists to offer structured supports such as education, care planning, and emotional guidance.

Trained Volunteer Family Peer Support: Several family-led non-governmental, non-profit organizations provide family peer support and resources that include family-led support groups and family-led curriculums typically facilitated by trained volunteer family members or organization staff.

Informal Family Peer Support: Informal family peer support may include less structured, but still deeply meaningful supports. These services are available through community groups, social media, mutual aid networks, and individual connections. Informal family peer support can offer a meaningful starting point for family members seeking support.[17]

Family Peer Support	
Is	**Is not**
Judgement-Free Space: Family peer support offers a judgement-free space for listening, validation, and shared living experiences.	**Clinical Care / Medical Advice:** Family peer support is not a replacement for clinical care or therapy, or place to receive or give medical advice.
Connection: Family peer support offers a way to connect with people who have walked a similar path and can offer emotional support along with practical strategies for your own journey	**Crisis Intervention:** While family peer support may guide you towards resources, it is not itself a crisis intervention service.
Confidence and Resilience: Family peer support offers an opportunity to build your own knowledge, confidence, and resilience as a family member.	**Shared Opinions and Values:** Family peer support is not a space that guarantees shared opinions, perspectives, or values. Like all communities, peer groups include a wide range of experiences and perspectives.

Family-Run Organizations

Family-run organizations are organizations established by families with lived experience supporting a family member with behavioral health needs. These organizations are family-driven, youth-guided, community-based, and responsive to the needs of individuals receiving care and support.[18] They often provide peer-led support groups, family education workshops, policy and advocacy opportunities, guidance in crisis navigation, and care coordination support. These organizations are built by families, for families. These are just a few of the numerous family-run, peer-led, or caregiver-focused organizations where you can find support:

- **Al-Anon Family Groups:** Al-Anon is a mutual support program for people whose lives have been affected by someone else's drinking. Meetings are held around the world.
- **Adult Children of Alcoholics (ACA):** ACA is a 12-step program that focuses on emotional sobriety.
- **National Alliance on Mental Illness or NAMI:** NAMI has several psychoeducation courses including NAMI Family-to-Family and NAMI Basics, along with family support groups that are structured, peer-led support groups for any adult with a loved one who has experienced symptoms of mental health conditions.
- **National Federation of Families:** Family support across the life span and certification for Family Peer Specialists.
- **Family-Run Executive Director Leadership Association** or FREDLA: Family support for children's mental health.
- **SMART Recovery Family & Friends:** SMART Recovery supports people in the United States, Canada, and all over the world to manage addictive and problematic behaviors.
- **Nar-Anon Family Groups:** A 12-step program for family & friends of people experiencing addiction.

Online and Remote Peer Support

If in-person support is not readily available, or if you are not ready to attend a group in person, online options offer flexibility, access, and anonymity. Organizations like NAMI, the National Federation of Families, and local family-run organizations or groups offer virtual support groups. Warm lines offer text- and chat-based support for family members. Family-run organizations may also offer peer match or mentorship programs to connect you virtually with a family member with similar experiences. If you are starting with an online or virtual family support option, be sure to evaluate groups or programs for privacy, data protection, content moderation, and mission. Be sure that the spaces you engage with honor the unique family roles and experiences.

Finding the Right Fit

Family peer support is a valuable lifeline, but it is not one-size-fits-all. Whether you are joining a group, meeting with a family peer specialist, connecting with a friend with similar experiences, or participating in an online community, it is helpful to ask questions before you join.

Helpful Questions when Finding Family Peer Support

As you consider which family peer support you will connect with or recommend to your other family members, consider these questions as you search:

- What do I need support with? Do I want emotional support, practical strategies, or both?
- What kind of support am I most comfortable with? One-on-one? Group settings? In person or virtual? How often do they meet or connect?
- Is the space facilitated by trained family peer specialists?
- Are there guidelines for privacy and confidentiality?

By asking yourself these questions, you can find the supports that you need, when and how you need them.

Navigating During and After a Crisis

Many families go through periods where they are navigating a crisis. Reaching out to locally based family led organizations to understand the way crisis services are structured in your local community can help to support you and your loved one before, during, and after a crisis.

The peer support workforce provides a range of supports that you, your loved one, and other family members can lean on during or after a crisis. Below are resources that may provide helpful starting points for crisis planning:

- **Peer respites:** Voluntary, short-term programs that provide community-based, non-clinical, safe and supportive environments where people can receive peer support, engage in wellness activities, and connect with resources to support their recovery.

- **Family Respite:** Short-term relief for primary caregivers that offers time to rest, travel, or spend time with other family and friends; It may be planned or on an emergency basis.

- **Warm lines:** supportive call, text, or chat lines that offer support pre-crisis and can offer additional support post-crisis to find self-determined options for wellness, resiliency and recovery.

In 2020, Congress designated the new **988** dialing code to be operated through the existing National Suicide Prevention Lifeline. The 988 Suicide & Crisis Lifeline is available 24 hours a day every day of the week. People can call or text 988 or chat 988lifeline.org for themselves or if they are worried about a loved one who may need crisis support. 988 serves as a universal entry point so that no matter where you live in the United States, you can reach a caring, trained counselor who can help. 988 offers 24/7 access to trained crisis counselors who can help people experiencing mental health-related distress. Learn more about these steps and other ways to support someone who may be in crisis by exploring the 988 and other crisis resources in your community.

Resources for Crisis Preparation and Planning

- Before a Mental Health Crisis Hits: Creating a Family Safety Plan is a helpful guide in developing a family safety plan.
- Navigating a Mental Health Crisis | National Alliance on Mental Illness (NAMI) provides helpful information for families when a family member is experiencing a mental health crisis.
- Psychiatric Advance Directives: NRC PAD | National Resource Center on Psychiatric Advance Directives - A Psychiatric Advance Directive (PAD) is a legal document where an individual outlines their treatment preferences and names a health care agent or proxy to make certain decisions during a mental health or addiction crisis.

Wellness Pause – Wellness During Crisis

- **Engage in Self-Compassion.** Remember to offer yourself the same care, patience, and understanding that you would offer a loved one. During a crisis, it's valuable to remember that both you and your loved one are doing your best.
- **Use Positive, Calming Self-Talk.** Positive self-talk can help keep you centered and calm through a crisis. Try simple phrases like, "I can get through this" and "We are not alone."
- **One Thing at a Time.** Lean on your crisis plans and focus on taking things step by step. Trying to do too many things at once as you support your loved one, yourself, and the rest of your family is a quick path to burnout. Instead, focus on what needs to come next, one thing at a time, and remember to delegate and share the load when and where you can.
- **Hydrate and Recreate.** It's easy to set aside basic needs during a crisis. Both during and after a crisis, try to create space for wellness, sleep, staying hydrated and eating healthy meals.
- **Avoid Isolation.** Utilize the support networks and contacts that are part of your crisis plan. Whether you call a friend, connect with a peer, chat with a warm line, or call on your support group, remember you aren't alone.

Family Advocacy

As a family member and/or caregiver, you know the key issues your loved one and family face, from engaging with community agencies, navigating financial hardships to challenges in finding the right resources for care, support, and respite. As an important part of your loved one's circle of care, you are in a unique position to effectively act as an advocate.

What Is Advocacy?

Family members and caregivers serve unique roles in advocacy. In short, *advocacy* is the work of identifying the community and care resources your loved one needs and helping them connect with these resources in meaningful ways.[19] Advocacy comes in many forms:

- **Family Advocacy.** Advocating for the needs, rights, and voices of the family, children, youth, or family members in care. Family advocacy helps ensure that loved ones are heard and receive needed care, while working to address barriers created by systems.

- **Personal Care Advocacy (Collaborative Advocacy).** Partnering with care providers, such as agencies, service organizations, schools, to coordinate support. Collaborative advocacy helps to bridge silos between services and build stronger networks of support.

- **Community Advocacy.** Collaborating with the community or community groups to promote awareness and education. This collaboration reduces stigma, builds local support, expands the care network, and helps everyone involved.

- **Peer Advocacy.** People with lived experiences draw from their experiences to offer mutual support with others facing shared or similar challenges. Peer advocacy builds solidarity and promotes positive social connection to mitigate experiences of isolation people may feel as family members.

- **Personal Advocacy (Self-Advocacy).** Speak about your needs, rights, and role as a family member and caregiver. Like family advocacy, personal advocacy helps your voice be heard so that your needs, including your need for personal wellness, are recognized.

- **Policy Advocacy.** Supporting laws, regulations, and other policies that affect families and behavioral health systems to create meaningful change. This form of advocacy enables change across systems so that needed services and supports more accessible and effective.

Being an advocate does not mean you have all the answers. Instead, it focuses on using your voice to support yourself, your loved one, and your full family network. The following are general tips for clear, compassionate, and strategic use of your voice as an advocate. Particularly for families on the other side of crisis, stories can offer unique, helpful, and hopeful perspectives. These stories highlight the fact that you, your loved one, and your family have walked a path another family may be about to embark upon. It is another opportunity to share that no one is on this journey alone. Your stories of crisis, and beyond crisis, highlight what helped your family, how you navigated systems, how you and your loved ones rebuilt relationships and routines, and

what kinds of support made the biggest difference. These stories can also shine a light on gaps in care and areas of need so other families can avoid the same struggles.

Advocacy Dos and Don'ts

Whether you are advocating for your loved one receiving care, your family, or yourself, remember the following key tips and tricks for advocacy:

Do

- **Stay Calm.** As with general caregiving, advocacy can be highly emotional. Do your best to stay calm and focused.
- **Write Things Down.** Write down your questions before you start conversations. Note your primary concerns and talking points. Document key conversations and their outcomes. If a resource or contact is shared with you, be sure to write it in a safe and secure place where it will not be easily lost.
- **Ask Questions.** Advocacy is a conversation. You have the right to ask questions if the feedback or guidance you are receiving is unclear or confusing. Follow up on information you receive along the way.
- **Speak Plainly.** Use simple and easy to understand language and ask those you speak with to do the same. Stay specific and on point in conversations to avoid losing track of your goals and desired outcomes.
- **Employ a Collaborative Attitude.** Approaching a conversation with "How can we work together to solve this problem?" is usually more effective than being combative. The most successful advocacy happens when people come together around a common goal.

Don't

- **Make Assumptions.** Do not assume everyone knows what you are talking about or how it relates to your experience. Prepare to answer questions or explain key things that others may not understand.
- **Make "No" as Your Final Answer.** There may be times when what you ask for is not easy or immediately possible; that does not mean you should give up. Ask for clarification, next steps, or alternatives.
- **Go It Alone.** Remember that you, your loved one, and your family are not in this alone. Help is available. Peers and supports are standing by. Do not try to take everything on by yourself—ask for help when you need it.

Finding an Advocate When You Cannot Be One

Advocacy takes energy, and sometimes it can be more than you can take on by yourself. If you cannot be the advocate, there are still things you can do to support your loved one's needs. Explore peer advocates and family support specialists within your community. If your loved one has a case worker or other care and support leaders, ask them to step in or offer direction for your

next steps. Ask trusted friends and peers who may have navigated the same or similar situations about what steps they took and where they turned to for support. Remember that asking for help is a form of advocacy.

Advocacy on the Other Side of Crisis

The best advocacy plans happens when you and your family are no longer in crisis mode. When your family has moved beyond a crisis, take time to reflect on what happened, what helped, and what did not work. Sharing what you learned or what you needed that was not readily available can make a powerful advocacy narrative. Just as you likely sought support from others, your story beyond crisis also can be a strong support for another person or family.

Conclusion: You Are Not Alone

Whether you are walking with a loved one through crisis, rebuilding relationships after a recent diagnosis, navigating loss, showing up as a steady presence in the life of a loved one, or learning how to support and offer care from a distance, your role matters. Your health, your voice, your well-being, and your resilience are important. Remember that others have walked similar roads. You are not alone and there is support for you.

Wherever you are in your journey, allow yourself space to pause, take a breath, and remember that there are networks and support systems available to lift you and help you recharge. Care for both your loved one and yourself is possible. Connection with others who walk a similar path, and with allies in your journey, is possible.

Stay Connected

One of the most powerful things you can do for your own wellness, and the care of your loved ones in recovery, is to stay connected. Engage with family peer support networks, local and national helplines, and online communities. They exist for a reason. Namely, they exist because those supports and the people behind them have recognized that caregiving is a hard journey, and family members are all better off when they reach out, connect with others who have shared experiences, and access support so that they are not navigating alone.

Find Yourself

Remember that as a family member and/or caregiver, you have an identity beyond your role as a family member to someone living with mental health and/or substance use conditions. Find time, whenever and wherever you can, to return to yourself and all that makes you who you are. Allow yourself space to breathe and space to simply be.

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