Introduction

I developed the Sibling Support Program: A Family-Centered Mental Health Initiative (SSP) at UMass Chan Medical School in 2011. The program was piloted later that year on the inpatient psychiatry units at The Cambridge Hospital, a teaching hospital affiliated with Harvard Medical School in Cambridge, Massachusetts. The SSP goals are to:

- Increase resiliency and decrease trauma among siblings of youth with mental and/or behavioral health needs
- Increase parental competency and confidence
- Strengthen the family unit
- Build capacity among providers who practice a family-centered approach

To reach those goals, I began offering weekly groups for caregivers and siblings of children and adolescents who were psychiatrically hospitalized. The sibling groups—led by social workers, psychiatry residents, and other trainees—engaged the siblings in activities aimed at facilitating open discussion about their experiences growing up with an emotionally dysregulated family member. This helped them process their stories, which were frequently traumatic, and recognize that they were not alone. Coping skills, embedded within each activity, were designed to teach siblings tools to manage the difficult situations they encountered at home.

Recognizing that parents and adult caregivers have an enormous impact on siblings, I knew it was important to provide education and support to them as well. So, I developed two distinct adult caregiver groups, each led by trained parent mentors and offered at the same time as the sibling groups. The first caregiver group was psychoeducational in nature. It provided parents and caregivers insight into the specific challenges faced by siblings, described patterns that might indicate a sibling was having a rough time, taught methods and strategies for building sibling resiliency, and provided resources to help strengthen the family unit.

Initially, this psychoeducational session was the only caregiver group I offered. Over time, I began to see parents and caregivers repeatedly because their children were being readmitted to the psychiatric unit. These caregivers appeared even more exhausted and disheartened than during the child's first hospitalization. It was clear they needed an immediate boost as well as ongoing support.

To meet the needs of these returning parents, who had already participated in the psychoeducational group and therefore had a foundational understanding of the sibling experience, I began offering a returning caregiver group, which consisted of

a facilitated discussion that allowed parents to present problematic scenarios in their families and engage with peers who generated ideas and practical solutions. With this parent-to-parent support, returning caregivers felt more empowered and better equipped to handle conflicts among their children, which, in turn, increased parents' ability to provide siblings with the support they needed.

Some parents have asked, "Why is the child with behavioral challenges not included in the sibling group?" To answer this question, I ask parents to think of a series of concentric circles with the challenging child listed in the innermost circle, the parents in the middle ring, and siblings and other family members in the outermost circle (see Figure I.1). The challenging child, sometimes known as the patient, is the one who receives the bulk of services. Then the needs of the parents are addressed if resources are available for them.

The outermost circle with siblings and other family members is rarely considered by medical professionals, and resources to support them are scant at best. Therefore, the first reason the child with behavioral challenges is not included is because that child

CIRCLES OF CARE

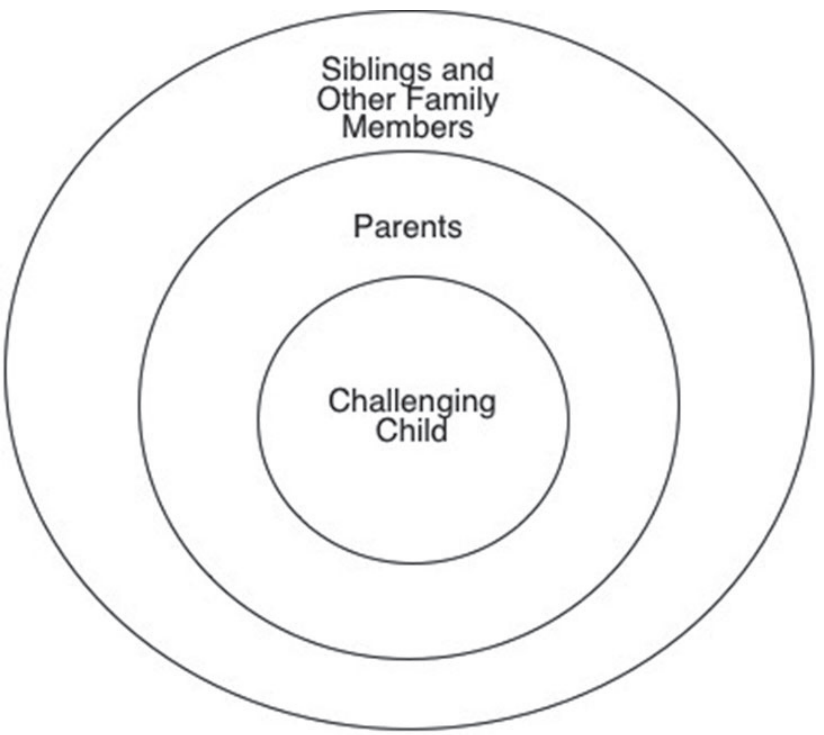

FIGURE I.1

is usually already receiving services, followed by the parents. The needs of other family members, notably the siblings, historically have not received any services. The second reason the challenging child is not included in the sibling group is to avoid inhibiting the siblings from sharing their experiences; many siblings are afraid to speak openly in front of the challenging child for fear of retaliation. Third, siblings require a safe and calm setting in which to process their trauma.

The SSP model focuses on teaching coping strategies to family members so they can learn to respond more effectively to the challenging child. Often, the skills and strategies that siblings and caregivers learn can be modeled for the challenging child at home. Additionally, one of the reasons clinician training is included in the SSP model is to effect systems change. The more clinicians learn to practice family-centered mental healthcare—to routinely inquire about the well-being of siblings and other family members—the better supported the entire family will be.

HOW WAS THE NEED FOR THE SSP DETERMINED?

I created the SSP based on compelling research that indicated that siblings of children with mental health needs are at risk of developing maladaptive behaviors themselves (Ma et al., 2015), repeated exposure to traumatic events leads to anxiety and depression (Angulo et al., 2024), and siblings—particularly female-identified siblings (sisters)—tend to become caregivers for brothers and sisters with disabilities in adulthood (Burke et al., 2012). Further, the SSP is also based on the knowledge that healthy family functioning, along with family involvement in treatment, has been positively correlated with improved outcomes for children with behavioral health needs (Haine-Schlagel & Walsh, 2015). Anecdotally, I had observed in psychiatric settings how the affected child's quality of life and opportunities for growth were directly related to the resiliency of family members. It can be difficult for the challenging child to improve at home when other family members are in crisis themselves.

When creating this program, I consulted with an advisory board comprising parents with lived experience. One of the recurring themes that surfaced among the advising parents was that most providers treating their child never inquired about the impact of the child's behavior on family members. Given this input, I wanted to educate clinicians about the importance of providing family-centered mental healthcare. That is why I created opportunities for mental health trainees to have hands-on experience facilitating groups for siblings. The sibling group described in this book has been integrated into the psychiatry residency training programs at both Harvard Medical School and UMass Chan Medical School.

Fast forward to today: The SSP has expanded well beyond inpatient psychiatric units. The program has been successfully implemented in the community environment, the residential environment, the outpatient clinic environment, and the hospital environment. One of the strengths of the SSP is its inherent adaptability; this book describes features of the SSP that are easily customizable for different settings. For example, some providers might choose to include groups for caregivers and siblings, and others might opt to focus exclusively on siblings. To date, SSP providers have worked

with thousands of school-age siblings and caregivers with high rates of satisfaction and knowledge gained.

The SSP currently serves families of youth with autism spectrum disorder (ASD), developmental disabilities, and mental health diagnoses. The program also serves families whose child has not been diagnosed but demonstrates unsafe behaviors that are unpredictable and sometimes beyond the ability of the parent to manage. Sound familiar? Read on.

SUPPORTING SIBLINGS: WHAT GETS IN THE WAY?

The idea of offering support in a group setting to siblings of children with behavioral or mental health needs is not new. Many agencies and hospitals have implemented such programs, but they often face difficulty in sustaining them over time. Their sibling initiatives tend to run into several common problems.

One problem is that these programs usually follow a *drop-off model* in which the sibling is dropped off at the program site and picked up when the group is over. Although the intention may be to provide a bit of respite for already struggling parents, it also means that the parent is not engaged in any aspect of the intervention and does not actively receive coaching or guidance for supporting the sibling.

A second stumbling block is that many sibling groups include siblings of children with all kinds of disabilities. This one-size-fits-all approach tends to use playful, fun activities to launch conversations about dealing with differences and managing sibling conflict. Even though this approach is immensely helpful for many families, siblings of children with significant behavioral or mental health needs can feel out of sync in that playful setting. These siblings face a very particular set of challenges at home that revolve around aggression, safety, secrecy, and/or shame, and these siblings benefit from a different curricular approach.

Funding obstacles can create additional barriers. Getting insurance to cover sibling support services typically involves clinicians assigning a mental health diagnosis to the sibling, and many parents are not comfortable with that. Providing sibling support without insurance often involves billing the family, and not all families can afford to pay.

Another pitfall is scheduling. Involving caregivers as well as siblings means scheduling the program outside of school and work hours. Sometimes agencies and schools are unable to provide staff for this type of schedule.

The biggest problem, however, has less to do with the program delivery model than with getting family members—caregivers and siblings—to agree to participate at all. When parents are emotionally and physically exhausted from managing a child's mental health needs at home or are overwhelmed by the events leading up to a child's psychiatric hospitalization, a trip with siblings to attend group sessions can feel like too much.

The SSP tackles these hurdles head on and has had a remarkable success rate with getting siblings and caregivers to participate. Many parents are desperate to get siblings the help they need, and given the right environment, siblings are highly responsive to connecting with peers that understand their experiences. Given the demand, the key is

delivering the program in a way that is not only convenient, but the value of participation is abundantly clear.

WHY PARENT MENTORS?

Here's a quick story about why I included parent mentors in this intervention. When I piloted the SSP at The Cambridge Hospital, I relied on clinicians and staff to recruit families of patients on the inpatient psychiatric units by distributing flyers to parents and promoting the benefits of the program. Despite careful planning (including ordering dozens of pizzas!), no families showed up. So, I shifted the recruitment strategy. With approval from the hospital, the program's trained parent mentor began to call parents of hospitalized children, introduced themselves as a parent of a child with mental health needs, and personally invited family members to join the groups. This made an immediate difference: Caregivers were much more responsive when the person inviting them to participate was an empathetic parent mentor who had stood in their shoes. The SSP's numbers rose rapidly.

The efficacy of parent mentors is well documented, with several explanations for why they are so effective. First, when a child struggles with significant behavioral or mental health issues, parents can feel as though the child's behavior reflects poor parenting, and they can feel ashamed. That can quickly lead to feelings of isolation. Parent mentors approach these caregivers as peers—not as representatives of a clinic or agency. The common ground of a shared experience quickly establishes a connection. This type of rapport can be tough for traditional clinicians to create despite the important work they do. Second, hearing about the program from another parent reinforces the value of the program. Parents with a child in acute distress—whether the child is explosive or withdrawn—already have a lot on their hands. They don't have time to waste on something that might not help. The involvement of parent mentors reassures parents that they are talking to someone who "gets it" and who knows exactly the kind of guidance parents need.

IN-PERSON OR VIRTUAL DELIVERY?

I delivered this program in person during the first 10 years of its existence. I believed that in-person delivery was the most appropriate and effective method for implementing the program. Then came the COVID-19 pandemic.

I'm happy to say that, although in-person groups have their own advantages, virtual delivery via videoconferencing technology has its advantages as well. First and foremost, this option can make it easier for multiple family members to attend. Second, it reduces the stress and cost of commuting and parking. Third, many family members, especially siblings, prefer to participate from the comfort of their homes. Fourth, it allows the program to provide support to families wherever they live. Indeed, during the pandemic, the geographic reach of this program quickly went from local to national.

Each of the sibling activities in this book was developed during the COVID-19 pandemic and piloted on the videoconferencing platforms Zoom or Google Meet. This book provides options for in-person program delivery, virtual delivery, or a combination of both.

IMPORTANCE OF CULTURAL COMPETENCY

Mental health issues impact families of all cultures, ethnic groups, and religions, and it is imperative that the SSP team is skilled in cultural humility and cultural competency. *Cultural competency* in the field of mental health refers not only to the ability of practitioners to have awareness of and respect for different cultures but to have the capacity to integrate cultural understanding into the way they provide care. Different cultures may have values and belief systems around disability issues that are in stark contrast with your own belief system (National Association of Social Workers, 2015). Some traditions may uphold that a child's disability is a gift, and other traditions may believe that a disability is a form of punishment bestowed on a family. To ensure that SSP team members explore both their own beliefs around disabilities and the beliefs of people from other cultures, developing cultural humility and cultural competency skills is part of SSP training.

In addition to ethnicity, race, and religion, every family has its own style and approach related to mental health. Occasionally, there are clashes within a family when parents approach mental health issues from opposing perspectives. Sometimes one parent wants to keep mental health issues private, and the other parent wants to share publicly. Family culture can include expectations around caregiving, communication, and internalized stigma. This topic is one that surfaces quite often in SSP caregiver groups and is included in the cultural competency training.

STRUCTURE OF THIS BOOK

The structure of this book is quite simple. In chapter 1, I describe the principles and theories that guided the development of the SSP, and I present the group framework that is the core offering of the program.

In chapter 2, I review the essential elements for implementing the SSP. It all starts with assembling your SSP team. This chapter opens with a story of how the SSP began with a crew of one person who assumed multiple roles.

In chapter 3, I present one of the innovative aspects of the SSP: utilizing parent mentors. For providers who choose to include a parent mentor as a member of the SSP team, I provide a profile of the ideal candidate for this role, how to recruit the right person, and how to train and support them. This chapter also includes the curricula for the caregiver groups.

In chapter 4, I focus on the sibling group. I describe the process of recruiting and training clinicians, mental health trainees, or educators to lead the sibling group. This chapter reviews the sibling group curriculum too.

In chapter 5, I describe the logistics and resources needed to launch and sustain the SSP, including launching the program in different settings—from schools to community centers to mental health clinics.

In chapter 6, I focus on what you need to know about protecting the privacy of participants and complying with security protocols.

This book's robust companion website (see https://naswpress.org/rubin) includes the group activities (in PowerPoint) and the handouts and printouts (in PDF) needed to launch the program successfully. I have made 17 sibling support groups available as

PowerPoint slides. Each PowerPoint presentation comprises a complete sibling group session, starting with Introductions and ending at Wrap-Up, including speaker notes for each slide. Discussion questions are color coded, and each question is linked with a theme that emerged in my sibling research, including sibling guilt, sibling anxiety, building self-esteem, safety concerns, sibling aggression, love–hate relationship, fair is not equal, family rules, and shame/embarrassment. Every activity emphasizes coping skills. In addition, two appendixes at the end of the book contain surveys and sample documents that can be used in the program.

NOTES ON LANGUAGE

To identify the sibling with behavioral challenges, I use the terms **affected child** or **challenging child**. The sibling without behavioral challenges is referred to as the **sibling**.

I use the terms **behavioral challenges** or **mental health needs** to describe the affected child's issues.

You will notice that I rarely mention a child's **diagnosis**. Instead, I focus on the behaviors of the challenging child that are common to a wide range of diagnoses.

I avoid the term **typical sibling** because many "typically developing" or "neurotypical" siblings develop mental health issues of their own, such as anxiety and depression.

The term **caregiver** refers to all adults in a caregiving role, including parents, stepparents, grandparents, aunts, uncles, and foster parents.

When possible, I use the word **sibling** instead of *brother* or *sister* because sibling is a gender-neutral term. Occasionally, to avoid confusion, I use the terms *brother* and *sister*.

I use the pronouns **they** and **them** instead of *he* and *she* to maintain gender neutrality.

I look forward to starting this journey of supporting siblings with you!