

THIRD  
EDITION

# Sibshops

Workshops for  
Siblings of Children  
With Support Needs

Don Meyer  
Emily Holl  
Patricia Vadasy

The logo for Sibshops, featuring the word "Sibshops" in a red, serif font with a blue underline. Above the letters "i" and "o" are blue dashed lines forming a scalloped shape.

Excerpted from Sibshops: Workshops for Siblings of Children With Support Needs, Third Edition  
By Don Meyer, Patricia F. Vadasy, Ph.D., Emily Holl, MFA, LMSW





# Workshops for Siblings of Children With Support Needs

THIRD EDITION

by

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# About the Downloads

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# About the Authors

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## **Don Meyer, M.Ed., Founder, Sibling Support Project; Creator, Sibshops**

Don Meyer is the founder of the Sibling Support Project and creator of Sibshops. He created the Sibling Support Project, a Washington State–based international program dedicated to the lifelong concerns of brothers and sisters of people with health, developmental, and mental health concerns. Don was the director of the Sibling Support Project from 1990 to 2019 and has conducted workshops on sibling issues and trainings on the Sibshop model in all 50 states and in 11 countries. He is the editor of *The Sibling Slam Book: What It’s Really Like to Have a Brother or Sister With Special Needs* (Woodbine House, 2005), *Views From Our Shoes: Growing Up With a Brother or Sister With Special Needs* (Woodbine House, 1997), and *Uncommon Fathers: Reflections on Raising a Child With a Disability* (Woodbine House, 1995). With Patricia Vadasy, Don wrote *Living With a Brother or Sister With Special Needs* (University of Washington Press, 1996). With Emily Holl, he co-edited *The Sibling Survival Guide: Indispensable Information for Brothers and Sisters of Adults With Disabilities* (Woodbine House, 2014).

Don’s work has been featured on ABC News and National Public Radio and in *Newsweek*, *The New York Times*, and *The Washington Post*. He is married to Terry DeLeonardis, a special education preschool teacher and consultant. They have four children and two grandchildren.

## **Emily Holl, MFA, LMSW, Director, Sibling Support Project**

Emily Holl is the director of the Sibling Support Project at Kinderling, the first national program dedicated to the lifelong and ever-changing concerns of millions of siblings of people with developmental and health concerns. Emily is a sibling, social worker, author, and trainer who has provided workshops and groups for siblings and families, and presented extensively on sibling issues. She has conducted and published sibling research. A board member of the national Sibling Leadership Network, Emily has written about her experiences in blogs, magazines, and books such as *Thicker Than Water* (Woodbine House, 2009). She was a co-editor of *The Sibling Survival Guide: Indispensable Information for Adult Brothers and Sisters of People With Disabilities*, published by Woodbine House in 2014. Emily earned a bachelor of arts degree from the University of Massachusetts, a master of fine arts degree from Columbia University, and a master of social work degree from Hunter College at the City University of New York. Emily and her family reside near Seattle, Washington.

**Patricia Vadasy, Ph.D., Senior Research Scientist, Oregon Research Institute, Influents Innovations**

Patricia Vadasy is a senior research scientist at Oregon Research and Influents Innovations in Eugene, Oregon, where she conducts research on early reading instruction. She is most interested in research to help children at risk for reading disabilities and children who are dual language learners. Patricia and her colleagues have developed programs that paraeducator tutors can effectively use to supplement instruction for beginning readers. Patricia also works with colleagues at Influents Innovations in Eugene to translate educational research findings into technology-based interventions for underserved students and families.

# Foreword

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It was 1992. Our son was 5 months old and not hitting the typical developmental milestones. We took him for evaluation and testing. Hearing the doctor say that part of his brain was missing and that his chromosomes were abnormal was devastating. My husband and I were told that he may never walk, talk, or be able to learn. Further, only 10 other cases in the world were similar to his genetic makeup, so his future would be unclear. The doctors had no answers, no advice.

As a young mom and a family educator, I knew this news would impact our family, especially his 3-year-old sister as she grew up. I felt unprepared as a parent, yet I expected that there must be research, information, and perhaps programs to help parents and siblings as they grow up with children with disabilities. After all, there had to be other families who had faced this before. There had to be information to help me, as a parent, navigate this new world of disability and family dynamics and answer my questions about what to tell my daughter and how to anticipate her needs.

I found all kinds of books and articles, even programs and organizations, that focused on the needs of *parents* raising a child with disabilities. But I searched and searched to find anything that talked about *siblings*. There were a few mentions of siblings here and there, but I was looking for solid information, research, and practical advice to help my very young daughter immediately and as she grew. I was looking for insight into her experiences and something that would help me prepare her for challenges and enable her to find joy with her brother, regardless of how his future would play out.

One evening, my husband and I were browsing in a bookstore, something we often did on “date nights.” We’d get a babysitter and head to Barnes and Noble to spend a couple peaceful hours looking at books and reading home improvement magazines for ideas and to dream a little. Sometimes we made a purchase, but more often, we didn’t. It was 1994, our son was 2, and our daughter was 5. I remember thinking that I should look through the small “Special Needs” bookshelf again, as I had done so many times before, to see if there was anything new that could help me with my questions regarding how to support my daughter.

And this time, there it was, right in the middle of the shelf of familiar book titles about disabilities: a book cover of colorful artwork with the words *Sibshops: Workshops for Siblings of Children with Special Needs* by Don Meyer and Pat Vadasy. I’ll never forget grabbing it and immediately sitting down on the floor and reading as fast as I could. After a couple of hours, my husband said it was time to go. This time, I was making a purchase that would change not only the lives of me and my daughter, but the lives of siblings all over the state of Wisconsin and beyond.

Decades later, I enjoy a wonderful relationship with my daughter. We regularly discuss her concerns as a sibling, and I witness her loving relationship with her brother. Because of that evening in Barnes and Noble, I’ve had the privilege of introducing

Sibshops to thousands of children in Wisconsin and creating opportunities for siblings of all ages to discuss their unique joys and concerns with others who truly understand. I wish you much luck as you reach out to the young sibs in your community!

*Harriet Redman, M.S.Ed., is the founder and retired executive director of WisconSibs, a nonprofit organization dedicated to children and adults who have siblings with disabilities. She has been a classroom teacher, a family program developer, a marketing director for a Fortune 500 company, and a nonprofit organization manager. In 2021, Harriet became the first recipient of the Don Meyer Award from the Sibling Leadership Network for her outstanding contributions to sibling support throughout her career. She has an adult son with developmental disabilities whose sister is her inspiration and most honest critic.*

# Preface

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The fact that you are holding this book suggests that you already have an interest in the well-being of siblings of children with health, mental health, and developmental needs. Perhaps you are a parent of a child with support needs who wants to create peer support and educational programs for siblings in your community. Or, maybe you are an adult sib who wishes that there had been programs like Sibshops when you were younger and would like to share your experiences as a Sibshop facilitator. Or, perhaps you are a human services professional who realizes that there is much more to serving families of children with support needs than just meeting with parents. Congratulations! This book is for you.

It is our hope that this book will be different from other books you have read. Our goals for Sibshops are as follows:

1. To increase the number of programs, services, and considerations for siblings of individuals with health, mental health, and developmental needs. With this book, we hope to give you the rationale, tools, inspiration, permission, and encouragement to make community-based programs for siblings as available as Parent-to-Parent programs for parents of children with support needs. As important as these programs are, we know that they are not enough. We hope to provide you with information that will empower you to challenge current family support practices to expand to include siblings. We seek fundamental change in the way schools, disability service providers, and other community-based organizations “do business” with respect to brothers and sisters to ensure that siblings’ issues are addressed.
2. To increase the reader’s understanding of specific issues experienced by siblings of individuals with support needs. To be an effective Sibshop facilitator, and a resource for others in your community who are interested in learning about and supporting siblings, you will need to be conversant about sibs’ lifelong and ever-changing issues. The first part of the book provides an overview of the unique concerns and opportunities experienced by siblings as reported in the clinical and research literature and by siblings themselves.
3. To provide specific information for local agencies and parent groups to create programs for siblings of individuals with support needs. The second part of this book is devoted to the Sibshop model, a lively peer support, educational, and recreational program for school-age brothers and sisters. In this section, we present activities that can be adapted for siblings of children with different disabilities and illnesses, as well as for different ages.

Throughout this book, we have tried to write in a style that is accessible and even enjoyable to read. We know that most people who wish to create services and programs for brothers and sisters are not academicians. We also know that most readers, even academicians, seem to enjoy and learn more from books that do not appear to be designed to induce sleep. And we know that there is much good news to share about siblings of people with support needs.

We have also been mindful of the importance of language, especially when it comes to describing people and the spectrum of ability they experience. Throughout the following pages, you will see the term *support needs* as shorthand for a wide array of developmental, health, and mental health needs. We acknowledge that this is an imperfect term and agree with advocates with and without disabilities who say that all human beings have needs that are met in unique ways. In this book, you will also see person-first language (e.g., *person with a disability*). We recognize and respect that some people prefer identity-first language (e.g., *disabled*). We also understand that some people prefer the more gender-neutral term *sibling* to *brother* and *sister*. Whenever possible, we defer to the person to decide what terminology they prefer. Our intent is to present the information that follows with the grace, vitality, respect, and insight we frequently see in siblings of people with support needs.

We hope you will let us know if we have accomplished our goals.

# Acknowledgments

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We are fortunate to have many friends who share our commitment to providing services for siblings of people with support needs. Many of the people listed here have pioneered programs for siblings in their communities; others have provided us with support, advice, and encouragement over the years and as we prepared this volume. Although their contributions are varied, each shares the belief that brothers and sisters deserve our time, effort, and consideration. We are grateful to them all: Yasuko Arima, Katie Arnold, Bobbi Beck, Lorena Beitia, Tamara Besser, Hanna Bjornsdottir, Meghan Burke, Rosanne Carter, Raphielle Chynoweth, Tara Conley, Terry DeLeonardis, Tom Fish, Cassandra Flores, María Girado, Carolyn Graff, Anne Guthrie, Nora Fox Handler, Donna Heim, Tom Holl, Traci Hopper, Amanda Johnson, Jessica Kruger, Mo Langley, Michelle Ellison McDaniel, Hayley Menges, Nancy Micca, Beth Mix, Suzanne Muench, Jessica Nix, Michelle O'Connor-Teklinski, Debbie Parkman, Tina Prochaska, Harriet Redman, Carol Robbins, Margaret Roberts, Diana Rovetti, Suzanne Salmo, Barbara Sapharas, Greg Schell, Ursala Schwenn, Sheila Swann-Guerrero, Maryjane Westra, and Christiana Yablonowski.

We would also like to thank Mimi Siegel, Lisa Greenwald, and the staff of Kindering, the Sibling Support Project's parent organization. Having offered Sibshops and programs for fathers of children with support needs for more than 20 years, the staff of the Kindering Center have been pioneers in providing family-centered services that acknowledge the contributions of all family members.

Finally, a special acknowledgment is reserved for the George A. and Marion M. Wilson Foundation and in loving memory of Mrs. Marion "Mickey" Wilson. Without the Wilson family's commitment to our work, you would not be holding this book and there would be far, far fewer Sibshops worldwide.

*Sibshop facilitators are amazing people.*

*They invariably offer Sibshops in addition to a million other things  
they are supposed to be doing for their “day jobs.”*

*They somehow find time in their busy schedules and give up weekends and evenings  
because they care deeply about young siblings and their concerns.*

*It is with gratitude that we dedicate this book to them.*

# 1

## What Are Sibshops?

---



For the adults who plan them and the agencies that sponsor them, Sibshops<sup>SM</sup> are best described as opportunities for siblings of children with health, mental health, and developmental needs to obtain peer support and education within a recreational context. They can reflect an agency's commitment to the well-being of the family member most likely to have the longest-lasting relationship with the person who has support needs.

However, for the young people who attend them and the energetic people who run them, Sibshops are better described as *events*. Sibshops are designed to provide siblings with opportunities for peer support. Because Sibshops are intended for school-age children, peer support is provided within a recreational context that emphasizes kids' perspectives.

Sibshops are lively, pedal-to-the-metal celebrations of the many contributions made by siblings of kids with support needs. Sibshops acknowledge that being the sibling of a person with support needs is a good thing for some, a not-so-good thing for others, and, for many, something in between. Sibshops reflect a belief that siblings have much to offer one another—if they are given a chance. The Sibshop model intersperses information and discussion activities with games (designed to be unique, upbeat, and appealing to a wide ability range), cooking and craft activities, and special guests who may teach participants how to mime, how to juggle, or, in the case of one guest artist who has cerebral palsy, how to paint by holding a toothbrush in your mouth. Sibshops are as fun and rewarding for the people who host them as they are for the participants.

Sibshops are not therapy, group or otherwise, although their effect may be therapeutic for some children. Sibshops acknowledge that most siblings of people with support needs, like their parents, are doing well despite the challenges posed by a family member's illness or disability. Consequently, although Sibshop facilitators always keep an eye open for participants who may need additional services, the Sibshop model takes a wellness approach that encourages children to recognize and build on their skills, talents, and strengths.

## WHO ATTENDS SIBSHOPS?

Originally developed for 8- to 13-year-old siblings of children with developmental disabilities, the Sibshop model is easily adapted for slightly younger sibs and teens. It has been adapted for siblings of children with other disabilities and illnesses, including cancer and other health impairments, hearing loss, and mental health concerns. It has even been adapted for children of parents who have health, mental health, or developmental concerns. Children who attend Sibshops come from diverse backgrounds including suburban communities (e.g., Bellevue, Washington; Northbrook, Illinois), urban communities (e.g., New York City, St. Louis, Tokyo), rural areas (e.g., Wyoming, Wisconsin), and areas with unique cultural heritages (e.g., Alaska, Hawaii, South Central Los Angeles).

### How Sibshops Address Different Needs

At Sibshops, kids are encouraged to talk about the good and not-so-good parts of being a sibling. We recognize that no two sibling experiences are exactly alike and that some siblings struggle more than others. We know there are siblings who have concerns for their physical and/or emotional safety for a variety of reasons, including challenging or even violent behaviors of their siblings with disabilities. Not every sibling has experienced trauma, but we believe that the basic principles of trauma-informed practices, as described by the U.S. Substance Abuse and Mental Health Services Administration, reflect the values of Sibshops: safety; trustworthiness and transparency; peer support; collaboration and mutuality; empowerment, voice, and choice; and recognizing cultural, historical, and gender issues. Applying these principles can benefit all Sibshop participants and facilitators alike (see [Appendix F](#)).

### Creating Environments of Belonging

Across the United States and in countries around the world, Sibshops bring together young siblings and facilitators from a diverse array of cultural, ethnic, gender, racial, religious, and other identities. Because they bring all of these identities to Sibshops, we are committed to ensuring that Sibshops are inclusive, equitable spaces in which all participants and facilitators feel a genuine sense of belonging. We are dedicated to eradicating racial and other oppressive barriers to create a positive, safe, supportive, and comfortable Sibshop environment in which all children and adults can thrive in ways that are helpful and meaningful to them.

## WHO SPONSORS SIBSHOPS?

Any agency serving families of children with support needs can sponsor a Sibshop, provided it can offer financial support, properly staff the program, and attract sufficient numbers of participants. We strongly recommend, however, that agencies consider working together to cosponsor a local Sibshop for all the siblings in a given community. (We discuss this important topic in greater detail in [Chapter 5](#).) Among the organizations collaborating to host Sibshops in their communities are autism societies, chapters of The Arc, United Cerebral Palsy affiliates, children's hospitals, developmental disabilities councils, early intervention programs, Parent-to-Parent programs, parks and recreation programs, Ronald McDonald Houses, school districts, schools for the Deaf, and University Centers on Disabilities. We have found that Sibshops are well within the reach and abilities of most communities. They are not expensive to run and logistically are no more difficult to coordinate than other community-based programs for children, such as Scouts or Camp Fire USA.

## WHO RUNS SIBSHOPS?

We believe that Sibshops are best facilitated by a team that includes service providers (e.g., social workers; special education teachers; physical, occupational, and speech therapists; nurses; child life specialists) and adult siblings of people with support needs. At the very least, the team of facilitators will need to be knowledgeable about the disability or illness

represented, possess a sense of humor and play, enjoy the company of children, and respect the young participants' expertise on the topic of life with a sibling with support needs. We discuss qualifications for Sibshop facilitators in [Chapter 5](#).



## Planning a Sibshops Experience

Since the first Sibshop launched in 1982, organizations across the United States and around the world have adapted the model to meet the needs of siblings in their local areas. Over the years, these Sibshops have grown into a community of dedicated facilitators and best practices that may serve as helpful guidelines for new Sibshops.

### Group Size

Sibshops have been held for as few as five children and as many as 45. Smaller groups can provide fun and meaningful experiences for siblings, and larger groups can be unforgettable events for the kids who attend, as long as there is an adequate number of facilitators. We recommend a group size of about 12 children, with at least two facilitators. A group of this size is manageable for facilitators, and there are enough kids to increase chances that participants will connect with someone who laughs at the same jokes or enjoys the same sports or video games.

### Scheduling

Sibshops are often held on or near weekends; for example, Fridays from 4:30 to 7:30 p.m., or Saturdays from 10:00 a.m. until 1:00 or 2:00 p.m. For in-person Sibshops, this allows ample time for games, discussion, and information activities and for making and eating lunch. For online Sibshops, which are typically 60–90 minutes in duration, weekdays may be an easier option. Of course, there is no day and time that will work perfectly for every family. We suggest surveying the families you wish to support to find a day and time that works for most. Each community will need to determine the best day and length for its Sibshop, as discussed further in [Chapter 5](#).

When determining the frequency of Sibshops events, it is important to consider the needs and resources of the community. Sibshops may be offered as frequently as weekly (as with a 1.5-hour after-school program) or as infrequently as yearly (as with an all-day Sibshop that is a part of an annual conference for families from around a state or the nation). Generally, however, Sibshops are presented monthly or bimonthly. Set a schedule that is manageable for facilitators and that makes Sibshops feel like special occasions for participants.

Sibshops may also be offered like a class—that is, five Sibshops meeting once a month with one registration. Offering Sibshops this way can provide a stable group that can form an identity during the months the participants are together. It can be difficult, however, for some participants and families to commit to a series of dates because of conflicts with other activities. More often, Sibshops are offered in a club format with monthly or bimonthly meetings. This format offers families and participants greater flexibility, but participants may vary somewhat from Sibshop to Sibshop. We discuss these and other considerations in [Chapter 5](#).

### **Registering a Sibshop**

To ensure that when parents send their children to a Sibshop, they are sending them to a program that is true to the spirit and goals of the Sibshop model, sibling programs wishing to call themselves “Sibshops” and to use the Sibshop logo must register their program. We describe this straightforward registration process in the Sibshop Standards of Practice ([Appendix A](#)).

## **THE GOALS OF THE SIBSHOP MODEL**



### **Goal 1: Peer Support in a Recreation Context**

*Sibshops provide siblings of children with support needs an opportunity to meet other siblings in a relaxed, recreational setting.*

The chance to meet other siblings in a casual atmosphere with interactive recreational activities offers several benefits for participants. First, it can help reduce a sibling’s sense of isolation. Participants quickly learn that other siblings experience similar joys and challenges. Second, the casual atmosphere and recreational activities promote informal sharing and friendships among participants. Friendships created during Sibshops and continued outside the program offer siblings ongoing sources of validation and support. Third, the recreational aspect of Sibshops makes the events enjoyable to attend. Children who perceive Sibshops as one more thing they have to do because of their sibling may find it hard to be receptive to the information and discussion presented in the workshop. Furthermore, when a workshop does not offer anything that is personally satisfying for a participant, they are unlikely to attend in the future. Recreational activities and the importance of play during Sibshops are discussed further in [Chapter 9](#).



### **Goal 2: Healthy Discourse**

*Sibshops provide siblings with opportunities to discuss common joys and concerns with other siblings of children with support needs.*

At Sibshops, participants share stories, experiences, and knowing laughs with peers who truly understand the ups and downs of life with a sibling who has support needs. This opportunity allows participants to learn that they are not alone in their experiences and their often-ambivalent feelings.



### **Goal 3: Resilience and Problem Solving**

*Sibshops provide siblings with an opportunity to learn how others handle situations commonly experienced by siblings of children with support needs.*

Siblings of children with health and developmental needs routinely face situations that are not experienced by other children. Defending a sibling from name-calling, responding to questions from friends or strangers, and resenting the time and attention required by the sibling with support needs are only a few of the problems siblings may experience. At Sibshops, participants learn how others handle difficult situations. This experience can offer a sibling a broad array of tried-and-true solutions from which to choose. Activities that promote discussion among sibling participants are presented in [Chapter 8](#).

**Goal 4:** Knowledge

*Sibshops provide siblings with an opportunity to learn more about the implications of their siblings' support needs.*

As noted previously, brothers and sisters need information in order to answer their own questions about their siblings' support needs as well as the questions posed by friends, classmates, and strangers. Sibshops offer participants opportunities to learn about the effect that a sibling's illness or disability may have on their life, schooling, and future. We discuss informational Sibshop activities in [Chapter 10](#).

**Goal 5:** Educating Parents and Providers About Siblings' Concerns

*Sibshops provide parents and other professionals with opportunities to learn more about the concerns frequently experienced by siblings of people with support needs.*

Because parents and services providers may be unaware of the wide range of sibling concerns, some Sibshop activities attempt to help adults better understand "life as a sib." One activity allows parents and professionals to meet with a panel of young adult and adult siblings to learn about the special joys and challenges of growing up with a sibling with disabilities. Parents learn about what the panelists appreciated in their parents' treatment of the children in their family and also what they wish their parents had done differently. We discuss opportunities for parents and professionals further in [Chapter 11](#).

To advocate effectively for increased services for siblings of people with support needs, it is critical to learn more about issues affecting their lives. The chapters that follow provide an overview of the unique concerns and opportunities experienced by brothers and sisters of people with health and developmental needs.