



Manual for Organizing and Evaluating Sibling Support Programs

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Why are we focusing on Sibling Relationships?



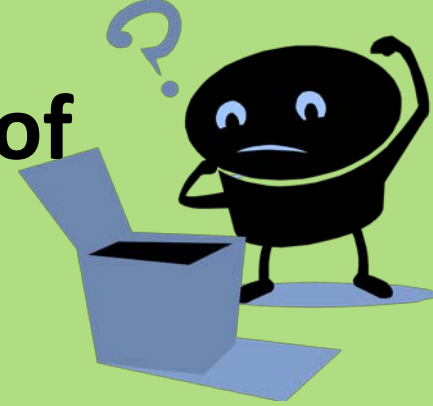
- Owing to the advanced medical technologies, individuals with disabilities now routinely outlive their parents (Sibling Leadership Network, 2008).
- Many states face fiscal deficits. Therefore, relying on center-based care-giving services can be unrealistic in the end.
- Adult siblings of individuals with developmental disabilities are assumed future caregivers for their disabled brothers or sisters (Kaiser -Arc Sibling, 2006).



Sibling Relationships in Families of Children with Special Needs

- Mixed results about the impact of disability on siblings and therefore a literature review presents inconclusive findings (Hauser-Cramm, Krauss & Kersh, 2009).
- The sibling relationships in families with children with disabilities have been reported to be “qualitatively different” from those that exist between typically developing children (Krauss & Seltzer, 2001).

Why do we have a mixed bag of studies?



- Participants that report high levels of sibling involvement are generally females rather than males (Orsmond & Seltzer, 2007).
- Siblings of individuals with Down Syndrome were more positive about their relationship than siblings of children with Autism (Orsmond & Seltzer, 2007).
- The small sample size.
- Different instruments and tools
- It is possible that the only participants who perceived their sibling relationship to be positive or are more involved consent to be a part of the study (Heller & Arnold, 2010).



What do we Conclude?

- Sibling relationships are not monolithic and are in fact ever changing.
- Examination of actual rates of siblings co-residing, rather than expectations of future care giving, found that only 10% of siblings ended up co-residing with their brother or sister with an intellectual disability (Freedman et al., 1997).
- Understanding all the moderating and mediating factors is necessary to predict sibling life trajectory.



Sibling Support Programs

“An intervention program that addresses the **psychosocial needs** of the non-disabled siblings of children with special needs.

Participants are provided an opportunity to **share their experiences** and concerns about other children in similar circumstances, in an understanding and non-threatening environment. These programs also impart **information on specific disabilities** and **assist children in coping** with certain behaviors of their siblings with disabilities.” (Meyer, 2008)



Limitations of the Sibling Support Programs in Research

- 1) Lack of control group and randomization
- 2) Small sample size and homogenous groups
- 3) None of the studies have descriptions of fidelity of implementation
- 4) No long-term follow-up assessment studies
- 5) Lack of rigorous program evaluation
- 6) No information on cultural appropriateness
- 7) Focused group interviews and open-ended questionnaire



Sibling Support Programs In Connecticut

- Sibshops are offered at eight sites in Connecticut.
- The discussions with four program coordinators who responded back revealed insufficient program evaluation, complete lack of attention being given to adolescents, lack of proper closing or exiting procedures and lack of provisions for long-term support to the participants.
- All the coordinators reported challenges of seeking grants and lack of sufficient financial resources

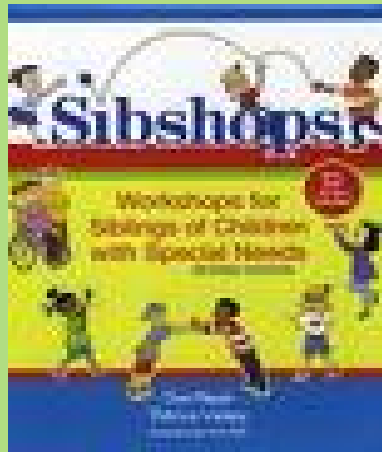
What do we need?

More programs to build on evidence-based practice

Programs that respect the siblings and not stigmatize them

Rigorous evaluation criteria

Introduction to the Meyer and Vadasy Manual



Sibshops,
Workshops for
Siblings for
Children with
Special Needs,
Donald Meyer and
Patricia Vadasy
(2008)

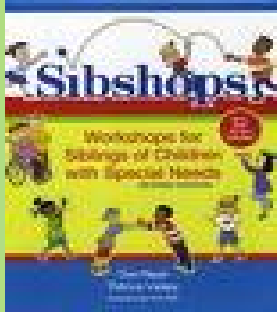
Objective of the Meyer & Vadasy's Manual:

Help the Sibshop facilitators to organize programs for the siblings of children with special needs.

The manual provides in-depth information on

- Goals of the Sibshops program
- Needs of the siblings of children with special needs
- Provides information on organizing Sibshops including recruiting participants, training facilitators, and organizing activities for the participants.

Overview of the Meyer & Vadasy's Manual



- 11 chapters, 214 page manual (excluding appendices)
- Age group 8-13 years old.
- Intended audience: Facilitators of the program

- Chapter 1 What are Sibshops?
- Chapter 2 Unusual concerns
- Chapter 3 Informational needs of siblings
- Chapter 4 Unusual opportunities
- Chapter 5 Getting Started
- Chapter 6 Putting it all together
- Chapter 7 Introductory and trickle in activities
- Chapter 8 Sibshop discussion and peer support activities
- Chapter 9 Recreational and food activities
- Chapter 10 Informational activities
- Chapter 11 Workshop on sibling issues for parents and service providers

Strengths and Limitations of the Meyer & Vadasy's Manual



- Implementation aspect of the program is thoroughly discussed.

- No chapter on program evaluation

- 1) Needs assessment

- 2) Fidelity of implementation

- 3) Collection of data before, during and after the completion of the program

- 4) Long term effects

- Literature review is outdated and not comprehensive.

- Lacks attention to adolescent siblings.

- No discussion of termination of program activities and future support to the siblings.



Proposed Revisions

Objectives: Strengthen the weak areas of the manual by Meyer and Vadasy (2008) and propose important recommendation for practice, research and program evaluation.

The revisions and proposals are based on:

- Available literature on sibling relationships and sibling support programs and their evaluation.
- Published reports -Kaiser-Arc Sibling, and Sibling Leadership Network.
- Discussions with key informants such as Don Meyer, Founder of Sibshops, four Coordinators of Sibshops in Connecticut, Edward Preneta, Director, Connecticut Council on Developmental Disabilities and Tim Marshall, DCF, CT.
- Best practices in primary prevention model and program evaluation

Salient Features of the Proposed Manual

Intended Audience: Program developers, Facilitators , Researchers, Graduate students and other professionals from multiple disciplines interested in providing support to families with special needs.

Content of the Manual: Five chapters. Approx. 60 pages excluding appendices.

Proposed Use: Use in conjunction with Chapters 5-10 of Meyer and Vadasy Manual (activities for 8-13 years old participants)

Chapter I

Introduction

- Provides information on
 - 1) Rationale for writing the present manual
 - 2) Summary of the chapters in the manual
 - 3) Objectives of the proposed sibling support program.
- Explains the Key Terms:
 - 1) Siblings
 - 2) Sibling Support Programs
 - 3) Children with Special Needs
- Significance of the Manual
 - 1) Possible Training Implications
 - 2) Policy implications
 - 3) Long-term Implications

Chapter II

Background Information

- Sibling Relationships during Childhood and Adolescent Years
- Sibling Relationship in Families of a Child with Disabilities
 - 1) Positive Aspects of the Relationship
 - 2) Negative Aspects of the Relationship
- Frameworks to Understand Family Processes
 - 1) Family Systems Theory (1970)
 - 2) Double ABCX model
 - 3) The Bioecological Model (Bronfenbrenner, 2006)
- Support Programs for Siblings
 - 1) Status of Sibshops in the US and in Connecticut
 - 2) Research Status of the Sibling Support Programs
 - 3) Program Evaluation Research on the Sibshop Model
- Recommendations for Practice and Research

Chapter III

Content of the Sibling Support Programs

- Needs Assessment of the Problem
 - 1) Pre-orienting phase of Awareness (Bloom, 1996)
 - 2) Moderating and Mediating Variables
 - 3) Allocation of Resources

- Frequency of the Program 8 Weeks, every weekend

- Location

- Potential Facilitators
 - 1) Social workers, Special education teachers , Psychologists, Nurses and Adult siblings of individuals with special needs, Graduate students and LEND fellows

- Recruitment of the Participants in Connecticut
State Agencies and Parent Networks

Chapter III Cont'd

Activities of the Program

The number of days = 8

Number of activities to be organized per day =
2-3

Total Number of activities $8 \times 3 = 16-24$

Sub categories of the Activities

1. Six- eight informational activities
2. Six- eight activities focusing on the needs and expectations of the participants.
3. Six- eight recreational activities

Chapter IV

Program Evaluation and Analysis

Research Design

Mixed- Quantitative and qualitative methods

Quasi-experimental design

Participants

Participants in the treatment group

Participants wait-list control group

Age range of participants 8-18 years



Chapter IV Cont'd

Tools of Data Collection

1) Before and at the end of the Program

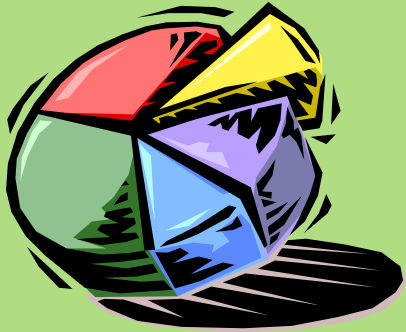
- Needs based Assessment Interview Guide
- Achenbach Child Behavior Checklist (Achenbach, 2001)
- Piers-Harris Children's Self-Concept Scale, Second Edition (Piers & Harris, 2002)
- What It is Like To Have a Brother or Sister With a Developmental Disorder (Coping/Adjustment Scale; Perry, 1989)
- The Family Adaptability and Cohesion Evaluation Scales (Olson, Gorall & Tiesal, 2004)

Chapter IV

Tools of Data Collection Cont'd

- **Data Collection During the Program**
 - 1) Formative Evaluation
 - a) Open-ended Questionnaire
 - b) Fidelity of Implementation- checklist with 2 open-ended questions
- **Data Collection After the Program**
 - 1) Interview Guide at the end of the program
 - 2) Interview Schedule after 3 months





Chapter IV Cont'd

Analysis of the Data

- Analysis of Covariance (ANCOVA) to test for significant difference between pretest and post test changes in the participants.
- Effect size
- Reporting of data about the fidelity of implementation
- Reporting of data from the in-depth interviewing, major themes

Chapter V

Next Steps



Proposed Next Steps

- 1) Formation of online sibling support group
- 2) Annual reunion
- 3) Collection of longitudinal data to assess long-term effects

Sending the manual with proposed revisions to 3-4 professionals organizing sibling support programs