

# The Hand-to-Hand Family Education Program: A Means of Reducing Parental Stress and Increasing Support in Families of Children with Brain Disorders

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The prevalence of emotional and behavioral disorders in children and adolescents underscores the need for programs to educate and provide support for parents and caregivers. To foster learning, healing, and empowerment among parents and caregivers, the National Alliance for the Mentally Ill (NAMI) created the Hand-to-Hand Family Education Program. Goals of this eight-week class, taught by family members who are part of NAMI, are to provide members with information about the etiology and symptoms of childhood emotional, behavioral, and neurobiological disorders and their treatment, guide parents on being advocates in their children's school and mental health services, and help parents increase levels of support and coping skills. To examine the effectiveness of Hand-to-Hand in reducing parental stress levels and increasing support for families of children with brain disorders, we collected data from members of four Hand-to-Hand groups. The following is a summary of our research findings.

## Participants and Procedure

Data were collected from 46 parents of children with brain disorders enrolled in the Hand-to-Hand program in a Midwestern metropolitan area. Written informed consent was received from participants prior to their enrollment in the study. Data collection occurred at two time points. Time 1 (T1) occurred at the

first meeting and Time 2 (T2) occurred eight weeks later, at the final group meeting. Because a number of participants did not complete the program or were absent from the final meeting, pre-post data were only available for 18 participants. Also, though we attempted to contact families on the Hand-to-Hand waiting list to use as a control group, we were unable to collect sufficient data from wait-listed participants.

## Parental Perceptions of Treatment Needs

First, we examined parents' thoughts about their child's treatment needs by asking them to respond "Yes" "Maybe" or "No" to whether their child needed medication, psychotherapy, family therapy/parent guidance, and/or school services to help them cope with their problems. Responses were

scored along a three-point continuum (1 = No; 2 = Maybe; 3 = Yes). Parental responses demonstrate that almost all Hand-to-Hand participants believed their child's illness required all forms of treatment (see Table 1). The high scores at T1 left little room for an increase in scores from T1 to T2. Therefore, it is not surprising there were no significant differences between parent beliefs before and after group participation. Overall, parental opinion about their child's need for services remained stable over the course of this program.

## The Role of Hand-to-Hand on Caregiver Stress

We also assessed the level of parental stress associated with raising a child with a brain disorder. According to scores on the Stress Checklist, a 25-item scale that assesses pa-

TABLE 1. Mean parental responses regarding their child's need for services on the Caregiver Concordance Questionnaire

Service	Mean Response <sup>a</sup>	
	Time 1 <sup>b</sup> n = 18	Time 2 <sup>c</sup> n = 18
Medication	2.94	2.83
Psychotherapy	2.89	2.94
Family Therapy/Parent Guidance	2.71	2.88
School Services	2.78	2.72

<sup>a</sup>(1 = no; 2 = maybe; 3 = yes). <sup>b</sup>Time 1 = Initial Hand-to-Hand meeting. <sup>c</sup>Time 2 = Final Hand-to-Hand meeting (8 weeks after T1).

TABLE 2. Parental Stress Levels Prior to Enrollment in NAMI Hand-to-Hand Family Education Program

Event	Ma
Accusations of implications from family that you are a bad parent or you are at fault.	1.7
Accusations or implications from your friends that you are a bad parent or that you are at fault.	1.3
Accusations or implications from school personnel that you are a bad parent or you are at fault.	1.4
Accusations or implications from your child's treatment provider that you are a bad parent or that you are at fault.	1.3
Finding a clinician who believed that there was something medically wrong with your child.	1.9
Dealing with your insurance company or having no insurance coverage.	2.4
Pressure from work because of absences due to your child's illness.	1.9
Having less time to devote to your marriage or significant relationship.	2.7
Having less time to devote to your adult friendships.	2.4
Divorce or separation as a result of the stress of raising a child with a brain disorder.	1.0
Having less time for taking care of yourself.	2.5
Dealing with your own multiple bouts of physical illness.	2.1
Dealing with your own headaches.	2.4
Dealing with your own depression.	2.6
Accusations from your child that you are a 'mean' parent.	2.8
Walking on eggshells around your child to avoid rages.	3.2
Trying to get your child to do homework.	3.1
Trying to get your child to do chores or self-care.	3.4
Witnessing self-harming or suicidal acts or hearing suicidal statements from your child.	3.3
Not having enough time or energy to address you other children's needs.	2.3
Feeling embarrassed by your child's public rages.	3.2
Dealing with the stigma of having a child with a brain disorder.	1.9
Not knowing how to disclose your child's disorder to family, school, etc.	2.1
Paying for costly medical bills not covered by your insurance company.	2.4
Dealing with lost wages in your family due to taking off work or quitting your job.	2.0

\*Scored on a continuum where 0 = Not at all stressful and 4 = Very stressful.

rental stress levels in areas related to their child's disorder (Sisson & Fristad, 2001), Hand-to-Hand participants experienced stress in a number of domains. The most stressful experiences reported included: dealing with insurance companies; less time to devote to a marriage or significant relationship; less time to take care of themselves; walking on eggshells around their child to avoid rages; trying to get their child to do homework; witnessing self-harming or suicidal acts or hearing suicidal statements from their child; and not having enough

time or energy to address needs of other children (see Table 2).

The level of stress endorsed by Hand-to-Hand participants suggests this group would benefit from learning more about their child's disorder and interacting with other parents with similar experiences. Using paired *t*-tests to compare stress survey data from T1 with data from T2, we examined whether parents reported less stress following Hand-to-Hand participation. While parents' overall level of reported stress did decrease from T1 (57.3) to T2 (51.0), this dif-

ference was not statistically significant [ $t(17) = 1.70, p = .11$ ], likely due to the small sample size included in the analyses. A power analysis indicated a sample size of 64 would be needed for adequate power to detect significant differences between stress levels at T1 and T2.

Next, we examined whether participation in Hand-to-Hand led to decreased stress in specific areas as determined by parental responses to individual items on the Stress Checklist. Paired *t*-tests indicated parents reported significantly lower amounts of

TABLE 3. Changes in Mean Parental Report of Stress between T1<sup>a</sup> and T2<sup>b</sup>

Event	Mean Response				
	T1	T2	t	df	p
Having less time for marriage/ significant relationship.	2.7	2.0	2.49	17	.024
Dealing with your own depression.	2.6	2.2	2.20	17	.042
Trying to get your child to do chores or self-care.	3.4	2.8	2.15	17	.046
Witnessing your child's self-harming or suicidal acts.	3.3	2.2	3.08	17	.007
Feeling embarrassed by your child's public rages.	3.2	2.2	2.72	17	.015

<sup>a</sup>T1 = Time 1 = Initial Hand-to-Hand meeting. <sup>b</sup>T2 = Time 2 = Final Hand-to-Hand meeting (8 weeks after T1).

stress in the following areas: relationship with their spouse; dealing with their own depression; child compliance with chores; witnessing their child's self-harming acts; and embarrassment about their child's public rages. Overall, results suggest the education and support provided by the Hand-to-Hand program may lead to reduced levels of stress in parents of children with brain disorders (see Table 3).

#### Parent Comments

As a qualitative analysis of the Hand-to-Hand program, we examined parental comments regarding their satisfaction with the course, their teaching-support team, and proposed areas of improvement. One parent responded: "I liked this program. It was the

most informative program I have attended so far." Another parent indicated, "This was the single most important thing I have done to help me understand and meet other parents." Comments were also positive regarding the Hand-to-Hand teaching-support team. One participant indicated that the teachers "seemed very experienced, knowledgeable, and so calm about how to approach mental health issues." Another stated: "it helps having someone help you who has been through it himself."

Participants also proposed changes for the program, including: brainstorming about strategies to cope with personal situations; more open discussion; and more meeting times.

#### Discussion and Limitations

The lack of a control group means we cannot unequivocally conclude a causal relationship between Hand-to-Hand participation and decreased stress in parents of children with brain disorders. However, the data provide us with important information regarding the beliefs and experiences of these families. Further, the decreases in specific experiences of stress combined with parental comments regarding the importance of group participation demonstrate the importance of the Hand-to-Hand education program for the families who participate. Perhaps the words of one parent best describe the benefits of Hand-to-Hand: "This

course is great. I'm sad to see it end."

To locate a NAMI chapter in your area, visit [www.nami.org](http://www.nami.org) or call 1(800) 950-NAMI (6264).

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#### Suggested Reading

Sisson, D. P., & Fristad, M. A., (2001). A survey of stress and support for parents of children with early-onset bipolar disorder. *Bipolar Disorders*, 3(2), 58.

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