

ASSESSING THE NEEDS OF A STATEWIDE
SELF-HELP ORGANIZATION*

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ABSTRACT

The needs of twenty-three affiliate groups comprising a statewide self-help organization were assessed. Loosely coupled systems theory, as proposed by Weick (1976), provided concepts which were useful in understanding the needs of local affiliate groups. Most important needs of local groups, which could be addressed by the state organization, included continuation of advocacy activities, greater contact with the state organization, and ideas for enhancing public awareness and reducing stigma. Loosely coupled systems theory supports concepts by which a statewide self-help organization can be of assistance to local groups: leadership by example and conversation, preservation of local autonomy, and organizational change within rather than between groups.

Self-help groups, which have been described as a "full fledged American institution" (Jacobs & Goodman, 1989, p. 536), are generally categorized by the types of problems they address, including those which assist members in adjusting to an unchanging status, those in which members strive to change an intra-individual problem, and those in which members confront problems caused by larger political forces (Levine & Perkins, 1996).

Across the major categories of self-help groups, there is a continuum of organizational complexity along which most self-help groups fall (Schubert & Borkman, 1991). The unaffiliated self-help group has the most simple organi-

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zational structure, involving a self-help group which is specific to one site and is not affiliated with other groups or a professional organization. Other self-help organizations, known as federated self-help groups, have developed state or national networks which engage in chapter development and advocacy activities. The National Alliance for the Mentally Ill (NAMI) is an example of a federated self-help organization, made up of local self-help groups. NAMI's goal is to help members adjust to the status of their friends and family members who have severe and persistent mental illness.

NAMI was founded, in part, as a response to the deinstitutionalization of people with chronic mental illness. In many instances, planned community care and localized services, which were to have been in place for formerly hospitalized patients when they returned to their hometowns, were inadequate or nonexistent. Most often the families of adults with severe mental disturbances were faced with the overwhelming burden of caring for their relatives with mental illness in their homes. Drawn together by both the subjective burden and the objective burden of living with their relatives with mental illness (Solomon & Draine, 1995) and providing for their needs, parents, spouses, siblings, and friends of adults with mental illness banded together to form small groups, which use a self-help format for supporting the emotional needs of members.

NAMI, as a national organization, was established in 1979 (Hatfield, 1987). Over the following years, various state alliances were created. Currently, NAMI has more than 850 local affiliate groups located in all fifty states and headquarters in a majority of states (Hatfield, 1987).

In regard to the effects of participating in NAMI self-help groups, Medvene and Krauss (1989) found that rather than blaming themselves for their relative's mental illness, NAMI members accepted the illness as a biological disorder. Such attributions resulted in lower feelings of personal responsibility for the illness and better relationships with their relatives with mental illness, thereby reducing stigma and alleviating family burden for NAMI members.

NAMI is somewhat unique among self-help organizations in that it offers opportunities for members' participation in three areas of activity: advocacy, sharing-and-caring self-help meetings and/or informational meetings, and education for the public (Williams, Williams, Sommer, & Sommer, 1986). Participating in advocacy activities on the local, state, or national level may be a natural step for those NAMI members who have accepted their relative's illness. Additionally, NAMI groups have developed an influential lobbying force at the legislative level.

Other NAMI members may never follow an advocacy path, feeling more satisfaction in attending the sharing-and-caring meetings and/or meetings focused on education. Still other members of NAMI affiliate groups may engage in pub-

lic education activities, designed to reduce the stigma of mental illness for both victims and their families.

Members of local groups may serve the organization in numerous positions on both the state and national levels. Anyone wishing to join an organization which addresses the problems of those with mental illness may be a member of NAMI. However, those serving on the national board of directors must have a relative with mental illness or be a mental health consumer themselves (Hatfield, 1987).

LOOSELY COUPLED SYSTEMS THEORY

Weick proposes an approach to defining organizations which is based in loosely coupled systems theory (1976). In the context of a needs assessment, loosely coupled systems theory provides useful concepts for understanding the organizational needs of a statewide network of self-help groups. From the group perspective, it provides a way to understand the needs of local affiliates, including chapter maintenance and new chapter development. Additionally, from the statewide organization perspective, loosely coupled systems theory results in understanding the resources of local chapters, which may complement the advocacy activities and the organizational mission of the state organization.

Weick (1976, p. 3) defines loosely coupled systems as those in which elements are "responsible among themselves but each also preserves its own identity and sense of physical and logical separateness." Such elements influence each other "suddenly rather than continuously, occasionally rather than constantly, negligibly rather than significantly, indirectly rather than directly and eventually rather than immediately" (Orton & Weick, 1990, pp. 203-204). The flexibility of the elements is necessary for the successful functioning of a loosely coupled system.

Weick (1986) notes that while loose ties exist between individual elements in a loosely coupled system, there are also tighter ties, based on shared core values, within those elements. He contends that loose coupling and tight coupling can exist within the same system. For example, within a statewide NAMI organization, there may be tight coupling within a staffed state NAMI office. However, the structure between the self-help groups within the state organization is much looser, to the point that contact between groups only occurs once or twice yearly.

Loose coupling also indicates a responsiveness between the elements which fosters stability within the system and buffers it to outside influences (Orton & Weick, 1990). Therefore, the problems of one element in the system may not spread to other elements; and the failure of an individual element may not preclude the success of other elements. In regard to NAMI, the growth

and success of a particular affiliate group may provide examples which a more recently organized group may follow. However, if another group disbands, its dissolution should not threaten the stability or longevity of other groups in the organization.

NEEDS OF A STATEWIDE SELF-HELP ORGANIZATION

A statewide NAMI organization appears to fulfill the theoretical criteria of a loosely coupled system. Local self-help groups, also known as NAMI affiliates, maintain their individual identities based on the diversity of each affiliate's individual members; the group's location in the state; the history of each group; and the various challenges regarding leadership, advocacy, and public awareness at the local group level.

Theoretically, responsiveness between affiliate groups, however intermittent, is facilitated by the more formal structure of a statewide NAMI organization. Many states have a staffed "state office" to engage in statewide group development and support, to advocate at the legislative and service-provider level, and to serve as an organizational and communication hub for the network of NAMI self-help groups across the state.

In their work with loosely coupled systems, Orton and Weick (1990) list various descriptors from which loose coupling can be understood. The most definitive characteristics of loose coupling, which may apply to a statewide NAMI organization, include 1) autonomy of each affiliate group which allows for flexibility in dealing with diverse, external demands in the local environment; 2) state leadership by modeling and through personal contact with the state board, which is primarily made up of other parents; 3) various approaches to initiating change within the statewide organization; and 4) an unpredictable internal environment within the statewide organization. Needs of NAMI, a statewide self-help organization, will be considered and interpreted through these four constructs of loosely coupled systems theory.

Autonomy of a Response to Challenging External Environments

Turbulent community environments, in which self-help organizations exist, are characterized by multiple and changing interest groups with different goals and possibly incompatible expectations (Hasenfeld, 1983). Within a statewide NAMI organization, external environmental challenges and ways to successfully address them may differ across communities. Depending on the size of the com-

munity, its place in the rural or urban population, levels of stigma attached to mental illness, and many other factors, ways for addressing these and other issues may vary from local group to local group. Autonomy allows each group to determine the most effective means for dealing with diverse and unexpected challenges within its own community.

Leadership by Example

Weick (1986) suggests that leadership within a loosely coupled system is most effective when leaders get out of the office and spend one-on-one time with local members, reminding them of the shared vision within the organization, and assisting them in operationalizing that vision in their affiliate groups. He mentions a need for leaders to influence by personal interaction rather than by setting rules. In a loosely coupled system, strong leadership is modeled by those in leadership roles (Weick, 1986).

Change Within a Loosely Coupled System

Weick (1982) says that change in a loosely coupled system is most effective when it occurs on the lowest level of analysis. With elements being more tightly coupled within than between, change is more easily accomplished within each element rather than between elements, and/or across elements. On the state organization level, attention should be paid to changes within individual groups with the goal of promoting change across the organization, rather than introducing statewide policies.

Small step or “small win” strategies (Weick, 1984), such as reducing the means for change to a basic format and allowing each element to adapt the format to its specific needs, are other means for successful change. Change is also determined by resources and availability of leaders.

Loosely coupled systems theory would predict the need for state guidance in instigating change within the local group. Guidance would be based on communication between the local groups and the state office and in response to needs within the local group and the surrounding community. For example, the state leadership might suggest that the local group develop stronger advocacy efforts in response to group members’ concerns about local mental health services. With the local group’s permission, the state office would then assist the group in developing a strategy to accomplish that task.

Unpredictable Internal Environment

An unpredictable internal environment within a statewide organization is characteristic of loose coupling in the sense that “few participants are constantly involved or care about every dimension of the organization’s operations” (Pfeffer, 1978, p. 37). This is the case with an NAMI organization, in that few members from local groups are consistent in donating their time to the statewide organization.

In addition, because the internal environments of various local communities are different, the state office cannot offer direction to two self-help groups in the same way. Loose coupling allows the state office the freedom to provide different services to local groups, based on the individual group’s specific needs. A needs assessment survey was considered helpful by the state organization in determining interests of local members within the state organization and understanding perceived problems within their groups and within the statewide organization.

In summary, a needs assessment of a statewide NAMI organization was conducted to determine the local self-help groups’ perceived needs and how the state organization might be helpful in addressing those needs. In response, concepts from loosely coupled systems theory, guided by ideas about autonomy within external environments, leadership style, change within the system, and unpredictable internal environments, suggested ways that those needs might be most effectively addressed.

Needs of local affiliate groups were conceptualized on two levels: 1) needs of the groups on a local level and how they may be addressed and 2) needs of the groups in regard to support provided by the organization’s state office. Local groups also indicated the particular resources of their group which might complement the organization’s advocacy activities and enhance the mission statewide. Concepts from loosely coupled systems theory were used to understand the needs of local NAMI self-help groups and to maximize the advantages of loosely coupled systems in responding to those needs.

METHOD

Procedure

The needs assessment survey was conducted by the Self-Help Network of Kansas, a self-help clearinghouse and action research unit of the psychology department at Wichita State University.

Prior to the telephone interview, a letter describing the study was sent from the NAMI state office to the affiliate contact person in each of the state’s twenty-three local groups. In addition to participating in the survey, each contact

person was asked to provide names of other experienced group members within his or her affiliate group to complete the survey. Contact persons were asked to list those who currently held offices or were especially active in the group, had recently held office, or had been especially active but were no longer so.

Interviewers were graduate students in psychology. They were trained in telephone interviewing techniques and were presented with an in-depth review of the statewide NAMI organization and the purpose of the survey. They were sensitized to the delicate nature of the issues about which questions were to be asked. A mock interview was conducted. Interviewers were instructed to tell participants that their answers were confidential and their participation was voluntary. They also informed participants that they could terminate the interview at any time. An average of thirty minutes was required to complete each survey.

Table 1. Activities of the State Organization which Relate to Successful Functioning of Local Groups

State Organization's Most Important Activities	Responses	Percentages
1. Legislative activity, on both state and local levels, and communication regarding legislation	27	29
2. Providing information regarding MI, meds, research, national issues	20	21
3. Supporting affiliates with visits, technical assistance, education	15	16
4. Newsletter, acting as liaison with NAMI	14	15
5. The statewide convention	10	11
6. Ideas for public awareness/education to reduce stigma	6	6
7. Other	2	2

Instrument

A telephone interview was developed specifically for this study. The instrument included some items from past research (Meissen, Gleason, & Embree, 1991) and other questions, written for this project. There were both open-ended questions and Likert-scaled questions.

Needs Assessment Scale

Participants were asked, in an open-ended format, to name the most important activity of the state organization which related directly to the successful functioning of their local groups (see Table 1). Additionally, they were asked their level of agreement regarding the importance of eighteen activities and services which were being provided by the state office at that time (see Table 2). Responses were on a 4-point scale: 1) strongly agree, b) agree, c) disagree, and d) strongly disagree.

Table 2. Perceived Importance of State Organization Activities

Activity	Mean	Rank
Advocacy Activities		
Lobbying/State	1.09	1
Lobbying/Local	1.40	4
National MH Issues	1.47	6
Link with NAMI	1.57	8
Support for Affiliates		
Newsletter	1.21	2
Annual Convention	1.45	5
800 Phone #	1.52	7
Resource Directory	1.58	9
Leadership Material	1.59	10
Regional Workshops	1.67	12
Fund Raising	1.75	15
Telephone Support	1.79	16
Educational Activities		
Public Awareness	1.23	3
Program Grants	1.66	11
Clergy Network	1.99	17
Self-Evaluation Tool	2.18	18

Note: Responses were on a 4-point scale: 1 = strongly agree, 2 = agree, 3 = disagree, and 4 = strongly disagree.

Table 3. Problems Within Self-Help Groups as They Apply to NAMI Affiliates

Problem	Mean	Rank
Regarding Members		
Getting new members	1.73	1
Getting members involved in group work	2.12	3
Overworked leaders	2.16	4
Getting members to attend meetings	2.26	5
Keeping members in the group	2.49	6
Members' inappropriate behavior	3.50	9
Reducing Stigma		
Lack of public awareness	2.03	2
Lack of professional awareness	2.63	8
Other Problems		
Lack of funds	2.55	7
Making meeting arrangements	3.50	10

Note: Responses were on a 4-point scale: 1 = strongly agree, 2 = agree, 3 = disagree, and 4 = strongly disagree.

Also, participants were asked to agree or disagree concerning a list of ten problems common to self-help groups, which their own self-help group might be facing (see Table 3). The list was developed by reviewing problems common to self-help groups in past literature. They responded on the same 4-point scale.

Participants

In 1994, the state NAMI organization had approximately 400 names on its membership roll. Of that number, at least seventy-five were mental health professionals or representatives of professional organizations and did not qualify for the survey. Of the remaining members, 114 were contacted by phone and asked to participate in the survey. Twelve did not wish to answer the questions for various reasons (e.g., ill health, lack of time, family member was deceased, etc.). Eight were not able to complete the survey for various reasons (e.g., did not understand the questions, did not feel qualified to answer the questions, etc.).

A total of ninety-four NAMI members, including each of the twenty-three NAMI group leaders, completed the survey. A majority (73%) of those surveyed were female. They included parents (87%), spouses (7%), siblings (3%), and children of people with mental illness (1%). Ages of responders ranged from

thirty-three to eighty-two years, with the median being sixty-four years. A majority (76%) had attended college. Fifty-five percent were working full-time or part-time. Annual incomes ranged from under \$10,000 (4%) to over \$100,000 (3%), with the median income being between \$30,000 and \$40,000 (32%).

Sixty-six percent of the relatives with mental illness were male. Ages at which relatives first experienced mental illness ranged from one year to forty-five years, with a median of nineteen years. Age at diagnosis ranged from seven years to forty-seven years, with a median of twenty-one years. Diagnoses included schizophrenia (48%), bipolar disorder (13%), schizoaffective disorder (13%), and others (13%).

RESULTS

Responses to the survey clarified the needs of individual groups in local communities in relation to the state organization. The general theme of responses related to the local groups' desire for a greater connection with the state organization, especially concerning advocacy. Also, the needs assessment provided insight into the importance of state office support for local activities, which affiliates consider necessary for ensuring the longevity of their local NAMI groups. Finally, the results determined a need for greater public awareness at the local group level, which could be enhanced by strong state leadership, as guided by the loosely coupled systems theory.

Advocacy/Lobbying Activities

Realizing the importance of keeping the NAMI perspective on various legislative issues in full view of policy makers throughout the state, the membership saw a need for the state organization's continued advocacy in the state capitol and assistance with similar endeavors in local communities. Table 1, which lists responses to the open-ended question regarding perceptions of the most important activity of the state office which relates directly to the successful functioning of local groups, shows that 29 percent of the ninety-four responses agreed that lobbying and communication about legislative activities were important.

Table 2, which contains responses to eighteen specific Likert questions, reflects similar findings: lobbying at the state level was considered the most important activity of the state organization and local lobbying was listed as the fourth most important activity. Information which the state office provides about national mental health issues was sixth. Also, the state organization's link with NAMI regarding pending legislation and research about mental illness was the eighth most important activity of the state office.

Need for Greater Contact with the State Organization

The desire for more frequent contact between local NAMI groups and the state organization was a second area of need identified by the survey results. Specifically, 16 percent of the responses to the open-ended question saw a need for the state organization to visit local affiliate groups more often and to provide technical assistance and education, when requested (see Table 1).

Similar insights were found in responses to the specific need items regarding activities which enhance contact between the membership and the state organization and provide support for local groups (see Table 2). They include a newsletter, ranked second among eighteen items; the annual convention ranked fifth; the 800 phone number ranked seventh (see Table 2).

Needs of Local Chapter for Support

Another set of questions was focused on common problems within self-help groups as they apply to NAMI affiliates (see Table 3). The most often mentioned was the problem of attracting new people. In addition, local NAMI members were concerned about getting members involved in group work, ranked third of ten specific items; overworked leaders, ranked fourth; getting members to attend meetings, ranked fifth; and keeping members in the group, ranked sixth. These issues could be addressed, in part, by technical assistance and information provided by the state organization and through local visits by the state organization to local affiliates.

Need for Public Awareness and Reduction of Stigma

Stigma related to having a friend or family member with mental illness remains a pervasive and longstanding concern. Members indicated that they benefit from the state organization's expertise in providing information about mental illness and devising workable plans and specific awareness activities to enhance local public educational endeavors. Of responses to open-ended questions, 6 percent noted the importance of public education and outreach activities provided by the state organization in addressing stigma (see Table 1). In response to specific Likert questions, public awareness activities ranked second among eighteen items, which were perceived to be important state organization activities (see Table 2). Additionally, in noting the importance of problems within self-help groups as they apply to NAMI affiliates, NAMI members ranked lack of public awareness as second of ten specific items and lack of professional awareness as eighth (see Table 3).

DISCUSSION

Loosely coupled systems theory provides a unique perspective from which the needs of a statewide self-help organization can be addressed. The four specific descriptors of loosely coupled systems are reflected in the needs of local NAMI groups, as reported by survey participants. By linking NAMI needs with loosely coupled system descriptors, leaders of the statewide self-help organization may develop a new understanding of the importance of services which they provide to local groups.

Understanding NAMI Needs Using Concepts from Loosely Coupled Systems Theory

Advocacy/Lobbying Activities and a Fragmented External Environment

One of the reasons for which NAMI was originally founded was to support parents and friends of people with mental illness to assist their relatives in living outside an institutional setting. With training and guidance from their NAMI group, parents became effective advocates for their children's needs in the community (e.g., housing, jobs and job training, education). By approaching social service agencies as representatives of NAMI, they were able to create awareness of the specific needs of their relatives with mental illness. Advocacy remains an important task of local affiliate groups because of the constantly changing external environment in local communities. With an unpredictable financial milieu and changes in social services and personnel, it is vital that NAMI members stay in close touch with local authorities and agencies.

While local NAMI groups can be effective advocates within their own communities, it is less practical for them to represent their cause at the state and national levels. However, it is necessary for the organization to be represented during the legislative session when issues related to mental illness are being presented. It is also important for the membership to be represented throughout the year to the state agencies, associations, and policy makers who are generally located near the seat of the state government.

The affiliate groups expressed their appreciation through the needs assessment for the important role the state organization has played in keeping NAMI's perspective in full view of state level policy makers. Not only is the organization keyed into the legislative issues regarding mental illness, but they also keep the affiliates informed through the newsletter and often solicit their assistance in calling their local representatives and writing letters regarding a particular issue. The local affiliates acknowledged the importance of the state and national of-

office's work in the legislative and policy-making arena and requested that they maintain the activity with the highest priority. NAMI members are convinced that advocacy and lobbying are the means for positive change in the lives of people with mental illness. From the loosely coupled systems perspective, advocacy and lobbying provide a way to manage the pressures of a fragmented external environment.

Public Awareness Activities to Reduce Stigma and a Turbulent External Environment

Outside their local groups, NAMI affiliates continue to wage the battle within their individual communities against stigma related to mental illness. Based on the core value of mental illness being a disease of the brain that strikes as haphazardly as cancer or heart disease, local affiliate groups have mounted public education campaigns to teach their communities about mental illness and what they can or cannot expect from those who have the disease.

Because it is acknowledged that education about mental illness is the answer to stigma, affiliate groups wanted help from the state organization in devising workable plans and specific activities to enhance their local public educational endeavors. They wanted more information about programs which have been successful in other cities or states; they requested advice in choosing a plan for their own communities; and they asked for assistance in overseeing such projects. With the theme, "Mental Illness is a Disease not a Disgrace," local affiliates indicated readiness to renew their educational battle against stigma with the support and expertise of the state leadership backing them.

From the loosely coupled systems perspective, reducing stigma through awareness and creating understanding and acceptance of mental illness would result in quelling the turbulence people with mental illness and their friends and family members experience in the external environment.

Greater Contact with the State Office and Leadership by Example

Of the various needs expressed in the survey, the most encompassing called for more personalized communication and contact with the state organization specifically through visits by the state organization to the local groups. Weick suggests that leaders of a loosely coupled system be subtle in their leadership style and guide the system through example and conversation rather than by rules and regulations. This concept was actualized in the NAMI members' desire for leaders of the state organization to visit their local communities frequently. While NAMI members apparently feel connected with members in their

local groups, as is the nature of relationships in self-help groups, the results of the needs assessment survey indicate the individual group's desire to feel the same sort of connection with other affiliate groups and with the larger organization. Affiliate groups perceive that a sense of connectedness within the organization would be augmented by having personal communication and relationships with the state organization more like those which exist at the local level.

The enhanced communication and relationships would likely benefit both parties. It would allow the state leadership to become acquainted with individual group members and learn about challenges they face which may be unique within their groups of communities. Local members would be able to ask questions and get to know those at the helm of the state organization in a more personal way. Likewise, the leadership may be able to recruit those who are interested in advocacy for activities at the state level for both local and state leadership development. A meeting of state leaders with local government officials, helping professionals, and media representatives during the yearly visit would create public awareness in the community and lend credence to the local organization. Having the state representative visit the local group would likely result in an infusion of energy and excitement within the local group. In-person visits would be reinforced by communication through the newsletter published by the state office and attendance at the annual state convention.

Needs of Local Groups for Support and Fragmented Internal Environment

Weick said that a fragmented internal environment is characteristic of a loosely coupled system in that most people in the organization are not involved at the same level all of the time. In this regard, NAMI members indicated that one of their greatest concerns in maintaining the viability of their local groups was attracting new members, keeping current members active, and enlisting members to be leaders. These concerns would indicate that a few people are doing most of the work in local groups and that levels of interest and activity vary greatly. Such a variety of responses indicate fragmented internal environments within individual affiliates.

Change Within NAMI and Change at the Lowest Level of Analysis

Change within a self-help organization is a complex process and was assessed indirectly by the needs assessment survey. Weick said that change within a loosely coupled system must begin at the lowest level of analysis, which in NAMI affiliate groups would be with individual members. Change that is needed

within local groups is dictated by the unique characteristics of each group. Overall, the survey indicated that local affiliates would like to encourage current members to stay active in the group and remain enthusiastic about activities and develop leaders within the membership.

Encouraging a member to participate in the group or to take on a leadership role is making a change in that member's position within the group and also in the status of the group. Addressing a member's concern about his or her relative with mental illness may enable that person to move from grief to action, by participating in advocacy activities or in offering emotional support to other group members. Changes within individual members alter the dynamics of the affiliate groups and ultimately the structure and characteristics of the group itself. They also result in a strong call for action outside the immediate group, resulting in people becoming advocates on the local, state, or even the national level. Change on the lowest local of analysis, that is with an individual NAMI member, will change the local group and perhaps affect the structure of the organization on other levels.

In summary, responses gathered through the needs assessment survey reflect not only the grassroots history of the NAMI organization but also Weick's general descriptors of loosely coupled systems. While affiliate groups want to maintain their local operational autonomy, they also want more organizational and emotional connectedness statewide, much like they feel within their local group. Additionally, local groups requested help from the state organization in planning and monitoring local awareness activities rather than in actually carrying out those plans. The interpretation of the needs assessment responses, using Weick's descriptors of a loosely coupled system, provides an understanding of the issues that allow appropriate activities by the state organization and is a starting point for future research.

CONCLUSION

By framing the needs assessment survey of a statewide network of NAMI self-help groups with loosely coupled systems theory, it is possible to clarify and to understand the needs of local groups in a more accurate way. In the specific areas where loosely coupled systems theory and the perceived needs of NAMI groups are complementary, Weick offers some constructive solutions to the successful management of a loosely coupled system. It is such suggestions that the statewide network of NAMI self-help groups find useful in assuring the viability and longevity of local groups and the statewide organization.

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