

The Annie E. Casey Foundation

ROAD: Creating Community to Cope with Depression

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Summary

Clinical depression in mothers, which may be triggered by the stress of living in poverty or trauma like domestic violence, affects their ability to hold a job and meet other responsibilities and can jeopardize their children's social and emotional development. Mental health practice has emphasized medication and/or clinical therapy as the treatment of choice for depression, but this often is neither acceptable to many in low-income communities of color, nor effective in addressing a condition that has significant real-world contributing factors. ROAD (Reaching Out About Depression) is a grassroots, non-clinical alternative which uses peer support, education, and social activism to overcome depressed women's sense of isolation and restore their confidence and capacity to change their situation. The Annie E. Casey Foundation's interest in the program began with a recognition that maternal depression threatens many of its priorities, including school readiness, economic success, social connectedness, and civic participation. The Foundation decided to "bet" on a fledgling model that was consistent with community preferences and its own commitment to community-led endeavors, providing financial support and technical assistance to help build a sustainable organization. Simultaneously, the Foundation has supported other non-clinical models, research, and related work that together constitute an overall strategy to elevate the issue and evoke more comprehensive and culturally sensitive responses to depression among disadvantaged populations.

- Impact: Women who have participated in ROAD activities report feeling less isolated, less depressed, and better able to handle the challenges they confront. The original group who founded the program now lead the peer support and education sessions that help others.
- Influence: The National Academy of Sciences' Institute of Medicine (IOM) convened a meeting to gather information on maternal depression and family functioning, at which Annie E. Casey Foundation staff, grantees and others made presentations. Based in part on this meeting, the IOM has launched the Committee on Depression, Parenting Practices, and the Healthy Development of

Young Children to explore and make recommendations on these interrelated issues. The findings of this Committee are likely to give parental depression high visibility and prompt important and timely changes in practice. Other organizations with considerable stature and sway also are looking at the topic, including the American Academy of Pediatrics, whose members potentially could be early identifiers when mothers bring their children in for care.

- Leverage: ROAD has received grants from local foundations and has affiliated with Cambridge Health Alliance, one of the area's largest providers of mental health services. Thus far, there has not been a substantial commitment of public or philanthropic dollars to complement Casey's leadership on the issue of maternal depression. However, growing interest by the IOM, other federal entities, and a number of foundations suggest that broader engagement and support is likely to be forthcoming.

Background

In recent years, much attention has been paid to biological causes of clinical depression, with an attendant emphasis on medication as the treatment of choice. But depression also can be triggered by severe stress, such as that which arises due to domestic violence, poverty, and other circumstances common in distressed neighborhoods. It is not surprising, therefore, that there is a very high prevalence of clinical depression in low-income communities. Depression not only has serious implications for the individual, for example impeding the ability to succeed in a job, but its repercussions reach across generations; research has shown clear deleterious effects of maternal depression on children's social and emotional development. Compounding the problem are a general lack of mental health services in disadvantaged communities and a specific lack of culturally appropriate, community-sensitive programs that go beyond a narrow medical definition of mental health to address, as well, tangible issues, social isolation, and other ecological factors.

ROAD (Reaching Out About Depression)

ROAD is a grassroots self-help program for low-income women affected by depression that was created precisely to fill this service gap, providing a non-clinical alternative to traditional medical models for dealing with mental health concerns.

The program had its roots in an Annie E. Casey Foundation-supported project to explore why some mothers receiving TANF¹ were having particular difficulty making the transition from welfare to work. A key finding was that many of the women -- who were struggling to rear children in conditions of poverty and frequent crises -- reported symptoms of severe depression. The women also felt extremely isolated and expressed an eagerness to talk with others about common concerns. The City of Cambridge (MA) responded with the Kitchen Table Project, hosting weekly dinners where low-income women could come together to talk about their lives and share coping strategies.

Eventually, four women who were part of these conversations joined with three other community women who were looking for support and a recent Harvard Law School graduate, who as a student had volunteered with the Kitchen Table Project, to found an action-oriented peer support program called ROAD. At the outset, this group met weekly to build confidence through support for one another, identify and learn about aspects of depression and other relevant issues, and hone their leadership and communication skills. In time, they felt ready to reach out to other women in similar circumstances, and the program as it is constituted today took shape, with three primary components:

- Workshop series: The heart of ROAD is a series of twelve weekly meetings that combine education and peer support. A mental health professional is present as a resource, but the sessions are led by women – called “peer facilitators” – who either are one of the founding members of the group or since have qualified to be part of the facilitation team by participating in a complete workshop series. Each session focuses on a topic identified by the peer facilitators as important to share

¹The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 replaced Aid to Families with Dependent Children with Temporary Assistance for Needy Families (TANF). The legislation emphasizes employment over assistance, including a lifetime limit on receipt of benefits and a requirement that states assure that substantial portions of their recipients are engaged in work or work-related activities.

with other women who suffer from depression and poverty. Examples include "busting myths about depression," "family and relationships," "economic inequality," "motherhood and care-giving," and "treatment options and positive strategies for self-care." Information about the topic is imparted, but the session is structured primarily as discussion and exchange among the small group of participants, allowing them to express their feelings, tell their stories, and share tools, tips, and strategies for handling the issue. As the number of facilitators grows, it is anticipated that the workshop series can be offered more often and that follow-up series on new topics can be added.

- Advocacy: Graduate students in counseling from Boston College's School of Counseling and Psychology and Harvard Law School serve as volunteer advocates on ROAD's Advocacy Resource Team. Through emotional support, information and referral, joint problem-solving and coaching, advocates help the ROAD facilitators and workshop participants resolve crises such as a threatened eviction or loss of benefits and learn how to overcome barriers to secure the services and resources they need. As their own stress is reduced and their skills grow through these partnerships, the women's ability to help others in turn is strengthened. In time, to expand the availability of advocacy services, some of the seasoned facilitators will be trained as peer advocates.
- Social activism: During the workshop series, facilitators and participants identify one or more projects they want to tackle as a group. In the past, for example, they worked to keep open a local Department of Social Services office that was slated for closure and to change the operating hours of a local clinic. Another recent project involved creating presentations on the needs and experiences of low-income women that will be delivered to mental health providers on an ongoing basis. Working together to achieve a goal helps the women develop a sense of community and collective empowerment, which reduces the feelings of isolation and helplessness that contribute to their depression.

A volunteer Advisory Board of professional women provides expertise and guidance to the ROAD women and the small salaried staff². Members of the Committee

²From its inception, ROAD has had a salaried Program Manager. As the program has developed and grown, a full-time Advocacy Resource Team Coordinator, who supervises the advocates and serves as the mental health professional sitting in on workshop sessions, has been added.

also have contributed their time for critical tasks, such as designing and implementing a first-stage evaluation to understand what participants believe the impact of the program has been on their depression, relationships with others, and ability to pursue change for themselves and their community.

After about two years and two full cycles of workshop presentations which clearly were having a very positive effect on the participants, it became apparent that the ROAD idea and model had the potential to be an important addition to the field. But preserving and replicating the effort would require a much firmer organizational and operating construct than existed. The ROAD founders contemplated setting up an independent 501(c)(3) organization, but, with guidance from an Annie E. Casey Foundation-provided consultant, realized that they were not yet ready to do so. Instead, they have affiliated with the Cambridge Health Alliance (CHA) through its Department of Community Affairs. CHA is one of the area's largest providers of mental health services, and its Department of Community Affairs fosters linkages with the community to help ensure that Alliance programs respond effectively to community needs. The Department, in cooperation with the ROAD women, staff and Advisory Board, now oversees ROAD program implementation, manages the financial and administrative functions, and provides office and meeting space.

The Foundation-provided consultant also helped the ROAD women and other stakeholders address necessary organizational tasks, including defining roles and responsibilities, developing training and personnel assessment materials, and more clearly articulating key elements of workshop conduct and content. A particularly interesting aspect of this work was the specification of skills required of facilitators and establishment of different levels of facilitators. This structure, together with a series of educational opportunities, is creating a leadership development path that may eventually allow ROAD women to assume operational roles now carried out by paid professionals or to become involved in other work in the community.

Why This Was of Interest to the Annie E. Casey Foundation

Among the Foundation's system reform efforts of the 1990's was the Children's Urban Mental Health Initiative, which sought to expand mental health resources in poor urban communities. A valuable lesson of that Initiative was that the targeted communities preferred to place mental health issues in a broader context and to have

services that helped families and individuals address the range of concerns they confronted.

Annie E. Casey Foundation interest in mental health was reinvigorated when early childhood/school readiness began to emerge as a Foundation focus. Literature reviews and consultation with experts surfaced a clear link between maternal depression and problems in children's social and emotional development. On further reflection, staff recognized the likelihood that depression also affects other areas of interest to the Foundation, such as economic success, social connectedness, and civic participation.

At about this time, ROAD was taking shape. Recalling the insights gained in the Children's Urban Mental Health Initiative, the Foundation saw potential in this fledgling effort to provide a model that would be consistent with both the preferences of low-income communities and the Foundation's commitment to community-led endeavors. The decision was made, therefore, to "bet" on the idea of non-clinical peer support to address depression and on a group of grassroots innovators who were undertaking very creative work in a thoughtful and deliberative way.

Annie E. Casey Foundation Assistance to ROAD and Grantmaking to Address Parental Depression

Thus far, the Foundation has provided approximately \$200,000 in four grants to ROAD for staff salaries, stipends for peer facilitators, and operating costs, including meals and child care for the workshops. What perhaps will prove to be even more significant in the long-run is the substantial and extended technical assistance that the Foundation made available. By helping to bring organizational coherence to a promising endeavor, this consultation made a vital contribution to positioning ROAD for long-term sustainability, growth, and replication.

Support for ROAD is an integral part of an overall Annie E. Casey Foundation strategy designed to elevate the issue and evoke more comprehensive and culturally sensitive responses to depression among disadvantaged populations. Whereas previous research tended to concentrate on affluent white women, through focus groups in diverse communities and special studies such as one conducted in Washington, D.C.'s Marshall Heights neighborhood, Casey-sponsored work is documenting the

presence, impact, and implications of maternal depression in low-income communities of color. Work that is planned for the near future will deepen this knowledge and, with an eye to developing a family-focused response, explore the little-understood effects of depression among low-income fathers. Reaching across internal unit boundaries, the Foundation also is funding analyses of the policy implications of depression in the TANF population.

At the same time, Annie E. Casey Foundation-supported identification, assessment, refinement, and replication of non-clinical programs like ROAD will encourage and enable changes in practice that are indicated by the expanding knowledge base. Eventually, it is hoped that a range of options -- including approaches based on social supports/networks, counseling and other forms of therapy, and medication -- will be widely accepted and available to be used individually or in combination, as indicated by cultural context and causation.

Return on the Investment

Fully assessing the return on the Foundation's investment in ROAD calls for looking both at the immediate effects of the program itself and at the broader effects of the Foundation's work on parental depression, to which ROAD has contributed inspiration and important insights. From this perspective, the returns on a modest investment already are substantial and are likely to grow, perhaps dramatically, in the future:

- **Impact:** To date, about seventy women with depression have been part of ROAD, either as a founder/facilitator or as a participant in a workshop series. Many of these women report feeling less isolated, less depressed, and better able to address the real-world challenges they confront, with measurable progress marked by actions like getting a job, applying to school, or seeking treatment for substance abuse or other health issues. As one of the original eight ROAD women summarizes the impact: "I've become part of a community, an activist, a friend, a confidante, and a role-model. I've become a happier person, a better mom, able to take on more and take care of myself at the same time."
- **Influence:** The ROAD program is being replicated in Richmond, Virginia.

From a broader perspective, the Annie E. Casey Foundation, its consultants, and grantees such as ROAD are spearheading what promise to be significant changes in the level of attention paid to and approaches used to address depression among disadvantaged populations. With Casey support and participation, strategies to accomplish this are being formulated by the Action Network for Parental Depression, a group of leading researchers, practitioners and other interested parties.

Various organizations with the potential to have far-reaching effect on practice already are taking note. Especially important is the National Academy of Sciences' Institute of Medicine (IOM), which convened a two-day information-gathering meeting on maternal depression and family functioning. Annie E. Casey Foundation staff, consultants, and grantees were among the invited presenters. Based in part on this meeting, the IOM has launched the Committee on Depression, Parenting Practices, and the Healthy Development of Young Children to explore and make recommendations on these interrelated issues. The findings of this Committee are likely to give parental depression high visibility and prompt important and timely changes in practice.

Presentations have been made in other key forums, as well, including sessions sponsored by the Association for Public Policy and Management, the Child Welfare League, the Annual Research and Training Conference on Children's Mental Health, and the National Center for Children in Poverty. Professional journal articles and issue briefs targeted to community coalitions will further disseminate emerging knowledge and encourage action.

Finally, in a precursor of action that may be taken, pediatricians have been identified as potential early identifiers, because mothers are more likely to seek routine health care for their children than for themselves. With this in mind, the American Academy of Pediatrics (AAP) included questions in its 2004-2005 membership survey related to physicians' knowledge about depression and willingness to do screening and referral. AAP also plans to include maternal depression among the topics to be considered by its Task Force on the Psycho-Social Development of Children.

- Leverage: ROAD and other non-clinical approaches to addressing depression, though not expensive, do have some associated costs. In time, policies may change to allow reimbursement through private insurance and/or public mental health or social service systems, but for now the programs are dependent on grants, donations and, in some cases, volunteer time. ROAD still faces the challenge of financial sustainability, but it has taken positive steps in that direction by securing grants from local foundations to supplement Annie E. Casey Foundation support and by affiliating with the Cambridge Health Alliance.

In the bigger picture, as yet there has not been any substantial commitment of public or philanthropic dollars to complement Casey's leadership. However, given growing interest from the IOM, other federal entities, and grantmaker associations such as those in Baltimore and Washington, D.C., which have hosted presentations on maternal depression for their members, there is reason for optimism that broader engagement and commitments will be forthcoming.