Robert Wood Johnson Foundation

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Program Results
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In Indiana Project, Economically Disadvantaged Cancer Patients Get Supportive Counseling, Medical Equipment and More

Client advocacy program for economically disadvantaged cancer patients

SUMMARY

In 2002, Cancer Services of Allen County in Ft. Wayne, Ind., a not-for-profit agency providing non-medical services to people with cancer, developed its Client Advocate Program, which provides supportive counseling, case management and wheelchairs and other medical equipment to people living with cancer.

Advocates meet with cancer patients and assist them through treatment, recovery and, if necessary, through the end stages of the disease.

The project was part of the Robert Wood Johnson Foundation (RWJF) *Local Funding Partnerships* (LFP) national program (for more information see Program Results).

Key Results

- Client advocates provided support to more than 3,000 cancer patients through nearly 24,000 contacts over the course of the grant.
- Of the clients surveyed, 96 percent reported that Cancer Services of Allen County improved their quality of life, and 95 percent reported they felt more in control of their lives.

Funding

RWJF supported the project with a $303,432 grant from August 2002 to July 2005.

THE PROBLEM

Approximately 1,400 people in Allen County, Ind., are diagnosed with cancer every year, and 635 die due to the disease or its complications, according to the Indiana Department of Health.

In late 2000, Cancer Services of Allen County commissioned a needs assessment to identify additional services the agency should offer to cancer patients in the community. The organization is a not-for-profit agency providing non-medical services to people with cancer.

The assessment included:

- Data collection and analysis on the incidence and mortality rates from cancer in Allen County.
- Input from professionals who work with cancer survivors and their families.
- Focus groups with:
  - Cancer survivors and their families.
  - Parents of children with cancer.
  - Children with cancer and their siblings.
  - Agency volunteers.
  - Those bereaved due to cancer.

According to Dianne May, project director, the assessment revealed that the community had impressive medical facilities and doctors, but a haphazard structure and sporadic assistance for meeting patients' non-medical needs.

From these findings, May says, grew the idea of the Client Advocate Program: To provide "cancer guides" for newly diagnosed patients and their families to lead them through the maze of community services available to them.

The agency pilot tested the program from October through August of 2001. The agency found that:

- Registration increased 25 percent over that period.
- Of the clients surveyed, more than 94 percent stated their needs were met and they had been referred to more services than they knew were available.

Based on this early promise, the agency sought RWJF support to expand the program.

CONTEXT

In 1987, the RWJF Board of Trustees authorized $8 million to fund a two-year trial of a matching grants program to be called *Local Funding Partnerships*. Many matching grants programs set up by national foundations seek to replicate ideas formulated by the national institution itself.

Local Funding Partnerships was to be different. The local community would identify a pressing need, design the strategy for addressing it and put together a funding package that would provide at least one dollar of outside support for every one dollar of RWJF grant money. Each project would have one lead local funder, but additional supporters would be welcomed.

To be eligible, a project would have to fall within the general scope of RWJF's interest in health and health care. But a proposal would not have to meet the kind of specific criteria common to other RWJF programs. Instead of top-down, *Local Funding Partnerships* would be bottom-up—with an emphasis on innovation. RWJF hoped this local "ownership" would ensure sufficient support to keep the project going long after the RWJF grant ended.

THE PROJECT

In 2002, Cancer Services of Allen County developed the Client Advocate Program. Advocates meet with cancer patients and assist them through treatment, recovery and, if necessary, the end stages of disease.

The goal is to provide emotional and practical services to 1,600 people each year who are diagnosed with cancer (regardless of their race, gender, age or social-economic status).

Other Funding

The English Bonter Mitchell Foundation ($150,000), St. Joseph Community Health Foundation ($79,338) and the Lincoln Financial Group Foundation ($74,094) provided matching funds to support this project.

Activities

With RWJF funds, staff from Cancer Services of Allen County:

- Hired three client advocates and one warehouse manager.
  - The warehouse manager maintains, sanitizes and delivers wheelchairs and other durable medical equipment and supplies to clients.
  - The advocates:
    - Meet with each client within five days of their contacting the agency.
    - Work to increase minority clients' use of the agency.
    - Have at least one contact per month with each client during the first year the client is registered with Cancer Services.

    - Make contact either in person (home or office), on the telephone or through a letter or note of encouragement.

- Developed a resource binder, titled "A Year of Client Contacts."
  - The binder contains educational, inspirational and humorous materials advocates can send to their clients if they have not spoken with them in any given month.
  - This allows the advocates to maintain contact with clients without being intrusive.
- Provided equipment such as hospital beds, walkers, wheelchairs, wigs and home health supplies that families can borrow, at no cost.

Clients below 200 percent of the federal poverty level are eligible to receive financial and prescription assistance. Hundreds of people each month receive nutritional supplements, help with complicated paperwork and rides to and from treatment.

Project staff conducted client satisfaction surveys to assess the quality of the Client Advocate program at three time points:

- After the intake process.
- At six months of advocate services.
- After the use of medical equipment or support groups.

Challenges

- Within weeks of receiving the grant, challenges to the project began to emerge, beginning with the resignation of the executive director of Cancer Services of Allen County, financial constraints and loss of the project director midway through the grant.
- Through all, the advocates carried on—providing supportive counseling, referrals and medical equipment to people living with cancer and their families and caregivers.

Communications

- At the start of the grant, project staff marketed the Client Advocate Program by delivering brochures to be placed in the offices of medical providers.
- Over the course of the grant, staff switched to a more direct approach of building relationships with doctors and nurses, making them aware of the Client Advocate Program and the resources provided by Cancer Services of Allen County in face-to-face meetings.
- Staff created "Celebrate Life," a Sunday newspaper supplement distributed in May 2006 to 137,900 Indiana newspaper subscribers highlighting the personal stories of Cancer Services' clients.

RESULTS

Staff from Cancer Services of Allen County documented the following results in a report to RWJF:

- Client advocates provided support to more than 3,000 cancer patients through nearly 24,000 contacts over the three-year course of the grant. In addition:
  - The number of clients served yearly increased from 1,237 to 1,518, a 22.7 percent increase.
  - The number of client contacts increased from 3,957 a year to 10,099 a year, a 155 percent increase.
  - The percentage of all newly diagnosed cancer patients in the community served by the agency increased from 40 percent to 55 percent, a 37.5 percent increase.
- Staff conducted client surveys throughout the grant period. Of the 799 clients surveyed:
  - 96 percent reported that Cancer Services of Allen County improved their quality of life.
  - 97 percent said they felt less alone because of their client advocate.
  - 95 percent reported that they felt more in control of their lives.
  - 98 percent reported that the needs of the person with cancer were met or exceeded.
  - 100 percent rated their first contact with the agency as good or very good.
  - 100 percent said their client advocate's knowledge was good or very good.
- Anecdotal evidence suggests that oncologists and other members of the medical community have recognized the value of the Cancer Advocate Program and are routinely referring their patients. The project director reported these examples:
  - When a patient experienced a crisis, dissolved into tears and refused to enter the radiation machine for treatment, her doctor called a client advocate at Cancer Services to secure supportive counseling.
  - When a medical oncologist noticed his patient stopped communicating and seemed less engaged in his treatment, he called a Cancer Services client advocate to get support group information for his patient.

LESSONS LEARNED

1. **Do not expect other people to carry your message; stand up and do it yourself.** The agency initially relied on informational brochures and support staff within

medical facilities to reach the various doctors who provide cancer care. Later, program staff learned to speak directly to doctors and nurses to make them aware of the resources offered by the Client Advocate Program and Cancer Services of Allen County. That increased the agency's credibility within the medical community, and as a result, Cancer Services has become the "go-to" source for non-medical cancer care in the community. (Project Director/May)

AFTERWARD

Staff implemented a complementary care program for its clients consisting of nutrition, exercise and massage:

- Clients receive an fitness assessment and exercise plan by staff from the Turnstone Center, and for $10 a month can use the center's exercise facility. Turnstone offers services to adults and children with disabilities.
- The agency hosts a quarterly nutrition seminar for its clients conducted by registered dieticians employed by local hospitals.
- Clients receive one free massage and three additional massages at half-price by a certified massage therapist.

The agency is developing a bereavement care program for families who have lost a loved one to cancer.

In June 2006, the agency expanded its services into 10 additional counties (see the Appendix) under its new name, Cancer Services of Northeast Indiana. Staff also launched a new website.

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APPENDIX

Counties Served by Cancer Services of North East Indiana

- Allen (original county)
- Adams
- DeKalb
- Huntington
- Kosciusko
- La Grange
- Noble
- Steuben
- Wabash
- Wells
- Whitley

BIBLIOGRAPHY

(Current as of date of the report; as provided by the grantee organization; not verified by RWJF; items not available from RWJF.)

Articles

"Celebrate Life." Newspaper Supplement, May 2006.