

3. Consumer/Survivor Development Initiative (CSDI); Ontario Ministry of Health

Introduction

This provincial consumer initiatives project began within a significant infusion of new monies allocated on a time-limited basis. It met the challenges associated with rapid development and now has a stable resource base and a variety of well functioning programs.

Background and Purpose

The 1980s were characterized by a shift in thinking about the capacities of consumers and the potential role they could play in organizing, delivering and using community support. Increasingly governments began providing resources directly to consumer organizations to enable them to engage in advocacy, economic development and self-help, independent of professional staff or agencies. This strategy was grounded in the belief that formal services were only one paradigm for helping consumers and that non-service alternatives such as self-help and mutual aid also were valid and should be supported (Trainor et al, submitted).

In Ontario, small amounts of funding were distributed to consumer groups during the 1980s but in a haphazard manner. A number of mental health policy reports published during the decade encouraged a more explicit, substantial and systematic commitment to consumer projects. Among these were The Graham Report (1988) which identified self-help and family support as priority functions in a reformed mental health system and Putting People First (1993) which called for a reallocation of funding to help consumer/survivors and families develop alternatives to formal mental health services.

In 1991 there was a significant expansion of funding for the consumer/survivor sector in Ontario. In a major policy and funding strategy, the Ontario Ministry of Health (MOH) committed almost 3.5 million dollars from the Anti-Recession Program budget for the Consumer/Survivor Development Initiative (CSDI) which funded a large number of organizations for consumers and survivors as well as a central support and monitoring team.² The immediate goal of CDSI was to increase consumer employment. However, after one year of operation, the Ministry of Health secured continued funding

2 Consumer/survivors are defined as people who have a mental health problem and/or people who have used mental health services or programs.

from the Treasury Board and the focus broadened to include group development and member skill enhancement.

The Consumer/Survivor Development Initiative adopted the following mission:

- To support the development of a province-wide base of consumer/survivor controlled projects and organizations; and
- To support these projects in utilizing the skills and capacities of people who have used the mental health system.

A consumer/survivor organization was defined as an organization that was operated for, and controlled and staffed by people who have used the mental health system. The only restriction was that they not provide direct service.

Approach and Expected Outcomes

CSDI intended to develop a base of consumer controlled organizations that relied on the skills and talents of their members. In these independent projects consumers could meet their needs and express their views about changing and improving the mental health system. The underlying belief was that, if given the tools, consumer/survivors could play an important role in both supporting themselves and working to make the provision of mental health services and supports more effective and accountable. Consumers would have a chance to deal in a new way with the mental health issues that they faced.

Self-help and consumer advocacy have a long history as noted in the Phase I literature review (Health Canada, 1996). Most published articles about these groups have been descriptive and anecdotal. The outcomes expected from participation in consumer controlled organizations are based on this body of material and a small but growing number of controlled evaluation studies. As outlined in Chapter 5 of the Phase I review, the expected benefits of participation are as diverse as reduced hospitalization and other service use, increased knowledge, increased self esteem and confidence, stronger social networks and support, more job skills and employment, more organized advocacy.

Implementation

Initial Phase

A central team was assembled that included a coordinator (seconded from another mental health setting), administrative assistant, external consultant and three project consultants. Three team members had direct experience using the mental health system.

A proposal call was sent to over 600 contacts representing community mental health programs, addictions programs and consumer/survivor organizations across Ontario. Although the time frame in which to apply for funds was short, the response was overwhelming, with over 250 applications received. An extensive review process drew on input from the CSDI team as well as Ministry staff. The following set of considerations was used to facilitate funding decisions:

- **Authenticity:** Funded projects needed to fit into one or more of the categories specified in the proposal call: promoting long-term employment; community development of consumer/survivor groups; consumer/survivor job creation strategies.
- **Geographic distribution:** Funding distributed across the province.
- **Number and quality of jobs created:** Focus on the direct employment of consumer/survivors.
- **Viability within one year:** Funds were promised on a one-time basis for one year only. Programs needed to be able to operate within the 12-month time frame.
- **Job creation:** To maximize the proportion of funds used to increase employment, projects with costly capital and operating expenses were not included.

By June 1991, 42 programs across Ontario had been selected for funding, including two province-wide networks of self-help and advocacy groups.

During the following months the CSDI team worked with the projects to develop a set of simple operational guidelines that clarified what was expected from the initiatives and how they differed from formal mental health programs. Key elements agreed on were:

- **Non service models:** Projects were expected to follow alternative support models where control rested with consumer members who identified problems and defined unique solutions that drew on their skills, expertise, collective capacities and views about how their needs could be met. Traditional service models with providers (as the experts) and patients or clients (as the recipients) were not allowed. This restriction reflected a desire to explore the potential of new models, not an assumption that consumer/survivors should not have a role in service delivery.
- **Project independence:** Initially projects were allowed to channel funds through a sponsoring agency and to use professional consultants, but movement toward incorporation and a trained, wholly consumer/survivor staff was encouraged.
- **Democratic structures:** Projects were to have a governing structure (i.e., a board of directors or steering committee) composed of consumer/survivors and democratically elected by the membership. An active and involved membership was expected, with regular membership meetings to increase participation in planning and decision-making.

- **Inclusion:** Participation in all aspects of project operation was to be actively encouraged from Francophone communities and from Ontario's diverse cultural and racial communities.

Developmental Years (1991+)

Because projects were conceived and funded in a compressed time frame, they faced many developmental challenges. Projects needed assistance in meeting the CSDI operational guidelines and in developing the organizational, management and business skills necessary to operate. Projects needed to clarify policies - e.g., hiring practices and board responsibilities. Projects that initially had a sponsoring agency needed to develop and implement a plan to become more independent. Some projects needed to resolve ambivalence about accountability to their funder, the MOH.

The planned role of the central CSDI team was to help projects address developmental issues. Because the team also made funding recommendations, many projects were reluctant to reveal problems and weaknesses. Securing the expertise necessary to run programs presented some difficulties. Project efforts to expand their talent pools didn't always keep up with demands for skilled consumers within CSDI and in the broader mental health system. This led to multiple demands on some consumers, in some cases resulting in member burnout.

Despite these challenges most projects developed solid infrastructures and learned the skills necessary to operate their programs. Of those that ceased operations, most had reached a natural completion while a few had difficulty meeting their mandate or accountability requirements. The CSDI team composition evolved and since 1994 has been comprised solely of consumer and survivors. Thirty-six programs continue to operate.

Current Status

In 1994, the Initiative received permanent program status, with funding of about \$4 million. In 1995/96 the projects were renamed the Consumer Survivor Initiative, with the team continuing to be called CSDI. The relationship between the projects, the team and the MOH has been clarified. Each of the 36 projects and the team are accountable to a regional MOH consultant who is responsible for operational and funding issues. The team provides on-going assistance to such projects as skill development, policy clarification and member outreach. An expansion of the team mandate to provide support to consumer and family projects outside of the CSDI projects is being considered.

CSDI organizations currently work in the following areas:

- developing and maintaining self-help groups and offering peer support
- developing and operating small, community-based businesses
- providing education, sensitization and training to the public and mental health professionals

- advocating for better mental health and related social services
- providing opportunities for knowledge development and skill training

Out of 36 funded programs, six are cooperative businesses (including a courier service, commercial cleaning service and catering business). Two programs are provincially based – a business council which provides support to the six businesses and an umbrella group (the Depressive and Manic Depressive Association of Ontario) which supports over 30 local branches, is diagnostically focused and is unique in having both consumer/survivor and family members. The average membership of each of the 36 projects is 90 people. Funding ranges from \$22,000 to \$225,000, and averages \$97,222 annually per project. Salaries for approximately 80 to 85 full time equivalent positions are paid out of CSDI project funds. These positions are filled by about 170 consumers working either full- or part-time.

Initially, only about one-half of funded projects were independent organizations. Presently, the majority are incorporated and the remainder are in the midst of incorporation. All organizations are operated by a governing structure made up either exclusively or by a majority of consumer and survivors. All employed staff are consumer/survivors.

Project Examples

Waterloo Region Self-Help (WRSH): This project, started by three committed men, has developed into a thriving self-help organization with a member base of about 120 and two paid staff. WRSH has expanded its initial self-help mandate as new member interests have been identified. In addition to holding monthly member meetings the project supports a network of self-help groups and offers many social and recreational activities. An advocacy committee comprised of WRSH members and people from the community is actively involved in addressing legislative and community barriers faced by people with mental health problems. A craft collective was started recently and WRSH competed successfully for CIF funding to investigate other economic development possibilities. WRSH is well known in the community and members are involved in other community programs (e.g., WRSH members have been hired to do research by the Centre for Research and Education in Human Services in Kitchener).

Quick Bite Catering and Take-Out: This economic project began as a CMHA vocational program in Brantford that was expanded with CSDI funding. After two years it was legally incorporated with an independent board and staff. Quick Bite has a small management staff and also employs 24 servers who work approximately one day per week. All staff are also consumers. Quick Bite offers “hearty, healthy home cooked meals” during the morning and early afternoon to restaurant customers and also operates a catering business with over 60 regular clients that include City Hall, the Court and the District Health Council. Recently the membership voted to expand the project’s mandate to include peer support, public education and health promotion. In 1995, Quick Bite elected its first all-consumer board of directors.

Relationship to Best Practices

Consistent with the best practices defined for consumer initiatives in the Phase I review, the CSDI project has funded consumer-controlled projects to engage in a variety of non-service activities and to increase capacity of consumers to operate independently of service agencies and professionals. As a system-wide strategy CSDI represents a commitment by the Ontario Ministry of Health to the best practice policies of increased consumer participation and development of non-service support paradigms conceived and implemented by consumers. Providing resources to CSDI is consistent with funding goals of rebalancing system spending by directing funds to the non-formal sector and by using fiscal levers to ensure that programs comply with the non-service model that the Initiative is promoting.

Evaluation

Several sources of information are useful for examining the operation and impact of CSDI organizations. The CSDI team conducts detailed annual reviews of funded projects. In addition, two evaluation studies have been conducted. The first focused on the impact of membership in a CSDI group on the use of mental health services. Respondents from a representative sample of 14 organizations listed the various mental health services that they used for an equivalent period of time before and after becoming members. Results showed that service use dropped in all categories, with declines being most dramatic in use of inpatient services (from 48 to 4 days average per person annually) and in use of crisis and outpatient services.

A second larger study examined a range of issues including the impact of membership in a CSDI group on quality of life and the relative importance that consumer/survivors attach to various components of the mental health system. Study methods and implementation were designed and monitored by a Steering Committee comprised of 10 consumers and two consultants. Both quantitative and qualitative methods were used. Questionnaires were sent to all active members and focus groups were conducted with individuals in a sample of projects. Among study findings were that involvement in consumer/survivor organizations enhanced social skills and self-respect and led to wider involvement in the community and with other people. Involvement in CSDI positively affected self-confidence, feelings of being in control and coping. Respondents reported that other consumer/survivors were more helpful than any professional group in dealing with their mental health issues.

Success Factors and Challenges

CSDI has been successful in employing consumers, developing a pool of skilled consumers who have assumed various roles throughout the system, and creating a voice for consumers. The Ontario Ministry of Health was careful to develop an infrastructure for the Initiative that regulates form but not content. As a result projects can engage in advocacy or other activities that challenge the status quo. The Initiative is contributing to a shift in thinking about the capacities of consumers and about

the variety of supports that should be available to meet consumer needs. The success of the Initiative is affirmed by the recent, explicit commitment by the Ontario MOH to further funding (ie., a portion of the Community Investment Fund) for the consumer and family sectors.

CSDI has faced a number of challenges since its birth in 1991. The initial funding parameters (i.e., a large sum of money for a short period) meant that the start-up had to be very ambitious, with 42 new projects funded concurrently. As a result both the projects and the team faced a steep and intense learning curve. A better-paced implementation might have included funding pilot projects or providing seed money, especially for business projects where market research and preparation of business plans are important preliminary steps. Developmental issues faced by the projects were outlined in a preceding section and relate to member skill development, pace of movement toward independence, and clarification of team and MOH responsibility, particularly related to separation of funding and support roles.

The initial emphasis on project independence accelerated member skill development but created stress in the early stages. Strategies such as mixed Boards or membership Boards with external advisory committees are now being discussed to increase access to expertise, increase the talent pool and minimize risk of consumer burnout. The recent involvement of District Health Councils in managing proposal calls for CSDI projects has helped to consolidate the position of consumer initiatives in the mental health system. Improving project administration also is being addressed -for instance, through clarification of team and MOH roles. Amalgamating project Boards is being discussed for reducing burnout and streamlining administration.

Contact Person:	Marnie Shepherd - Coordinator Tel: (416) 484-8785 Fax: (416) 484-4617
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