SERVICE USER INPUT: FACT OR FICTION? THE EVALUATION OF   THE TRAUMA PROGRAM, DEPARTMENT OF REHABILITATION, SAULT STE. MARIE, ONTARIO

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Abstract: This study explores the current trend of incorporating service user data into program evaluations. Using a case study approach and citing three years of evaluation data of the Trauma Program at Sault Ste. Marie General Hospital, northern Ontario, the author challenges the traditional assumptions that promote service user data in program evaluations. The main conclusion is that although service user data is touted as being important, its political importance far outweighs its evaluation value and utility, in particular with hard-to-access samples. Implications are directed toward evaluators, administrators, and policy makers.

Résumé: Cet étude sonde la tendence actuelle d'incorporer les données provenant de l'usager dans les evaluations de programmes. En se servant d'une méthode d'étude de cas et en citant en exemple trois ans de données issues des évaluations du programme de traumatologie à l'hôpital général de Sault Ste. Marie, l'auteur conteste l'hypothése traditionelle qui veut promouvoir l'inclusion des données provenant de l'usager dans l'évaluation des programmes. L'auteur conclut que de telles données sont d'une utilité marginale dans le sens pratique et que l'importance politique de cet information dépasse de loin son importance pratique, surtout en ce qui concerne les échantillons qui sont d'un accés difficile. Les implications de sa conclusion sont dirigées vers les responsables de l'évaluation, l'administration et la politique des programmes.

A cursory review of the empirical literature pertaining to evaluation of social and health care programs may leave some with the impression that such evaluations are devoid of methodological problems (Pelletier, 1991, 1993; Phillips, Palfrey, & Thomas, 1994). This is certainly not the case. Program evaluation studies are

appearing in core professional North American journals with greater frequency than ever before (Makris, 1987); for the sake of the programs being evaluated, it is important that evaluators better understand their field's methodologic issues and concerns (Holosko, 1996).

It is an indisputable fact in today's "climate of consumerism" that any evaluation that does not incorporate service user (formerly called "patients," "clients," or "consumers") opinions is likely to be deemed seriously remiss (Shadish, Cook, & Leviton, 1991). Ironically, despite the fact that a national agenda has radically cut health care and social programs across Canada, in many instances stripping citizens of their basic rights to such programs and services, service user opinions are still of central concern to federal and provincial policy makers (O'Brecht, 1992). For example, in 1995 the Canadian Council on Health Services Accreditation (CCHSA) specified three main foci for accrediting health care institutions, with the first being the patient and family as the facility's primary customers. The council goes on to state: "the emphasis is not only on the scientific basis for care or the clinical judgement of the provider, but also on the patient's perceived needs and expectations and the patient's participation in the decision-making process" (p. 2). Thus, the question of how evaluators can incorporate service user data into their evaluations requires attention.

Two assumptions that underpin this article are: (1) although service user opinions are solicited for program evaluation purposes, often we do not incorporate their input into the programs that serve them; and (2) for some service users and programs, it is difficult for evaluators to either access such samples or readily assess their opinions. Although there have been some reports of meaningful consumer input into program evaluations (Hedrick, 1988; O'Brecht, 1992; Peach & Hirst, 1989), my experience with evaluating small to medium-sized health and social care programs has proved otherwise. That is, it appears that in a number of instances the process of inclusion seems to have greater political than evaluation significance, with the latter understood as discovering new data and using such input to plan for better services or to enhance decision-making, or simply seeking the "real truth" or the real "facts" about various programs or services.

BACKGROUND AND PURPOSE

For the past three years (1992–93, 1993–94, 1994–95) I have conducted program evaluations for the Trauma Program (TTP), Depart-

ment of Rehabilitation at Sault Ste. Marie General Hospital in Sault Ste. Marie, Ontario. TTP was originally designed to provide case management and life skills for trauma victims and their families in Sault Ste. Marie and the surrounding Algoma district (Grand, 1992). This initiative was funded by the Ministry of Health (MoH), Institutional Programs Branch, Province of Ontario, and was cost-shared by the General Hospital. Owing to provincial cost cutting in 1995, TTP's budget was phased out by the MoH. Since then, it has been supported by the hospital and its own fee-for-service arrangements (primarily through insurance carriers). From all accounts, TTP was a success, as was indicated in the three years of formative and summative outcome evaluative data (Holosko, 1993, 1994; Holosko & Dutta, 1995).

The budget dollars earmarked for evaluation activities varied annually, and evaluation activities varied accordingly. As one might assume, monies allocated to TTP by the MoH and the hospital were mostly targeted for services (usually staff positions), which in turn influenced the potentially available evaluation dollars. However, both the MoH (primarily) and the hospital expected a comprehensive annual evaluation without ever allocating a set or fixed amount for this "essential activity." (Unfortunately, this coincides with my experience over the years in evaluating small to medium-sized health or social programs: evaluation rhetoric and importance prevails over actual evaluation dollars, and more often than not such an "essential activity" remains a budget afterthought.) Despite this, each year a comprehensive evaluation took place and resulted in funding for the subsequent three years; a main element of these evaluations was service user input.

This article will focus on the service user input of these evaluations (e.g., how users were canvassed and how their opinions were utilized). Its purpose is to provide evaluators with some candid insights into the nuances, challenges, and difficulties involved in incorporating service user input into program evaluations with difficult-to-access populations. Hopefully, such an account will stimulate discussion and debate, contribute data to a distinct void about this subject matter in the literature, and challenge some of the more traditional assumptions put forward in this regard—namely, that service use input is valued, is easy to incorporate, and can be readily generalized.
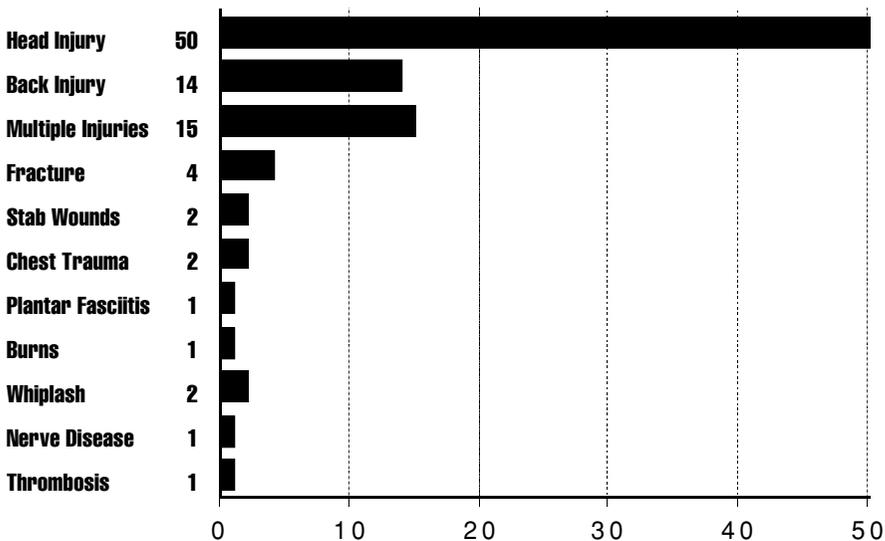
THE TRAUMA PROGRAM

The main goal of TTP, consistent with the current provincial goals and reforms of the MoH (in providing more community-based services

to clients) is to provide individual case management and life skills intervention to trauma victims and their families within the context of a community reintegration approach (Holosko & Dutta, 1995). TTP was designed to serve as a link between various hospital-based services and the community and to provide specialized preventative, acute, and community-based care. Normally, individuals who are beset by a trauma episode move along a continuum of care from acute onset to in-patient status at a hospital to out-patient status to community reintegration. TTP fills a distinct service gap in its community by providing a highly specialized service to trauma victims and their families, where no similar service exists in the community. Main services include education, referral, specialized multidisciplinary assessments, life skills/occupational therapy, individual and group counselling, discharge planning, in-home care, case management, and community liaison.

Client Characteristics

In a typical year (January 1–December 31, 1993) there were 93 referrals accepted to TTP, demographically broken down as follows:

Figure 1
Trauma Referrals by Diagnosis, January 1–December 31, 1993, to the Trauma Program

Diagnosis	Count
Head Injury	50
Back Injury	14
Multiple Injuries	15
Fracture	4
Stab Wounds	2
Chest Trauma	2
Plantar Fasciitis	1
Burns	1
Whiplash	2
Nerve Disease	1
Thrombosis	1

Accepted Referrals = 93

residence—73% from Sault Ste. Marie, 27% from Algoma district; *gender*—62% male, 38% female; *marital status*—39% married, 37% single, 14% divorced, 4% common law, 3% widowed; and age—38% were 30–39 years old, 24% were 24–29, 21% were 20–24, 17% were 40–49 (Holosko, 1993). Although situated in a relatively small northern Ontario community, demographically speaking, the clients treated in this year were similar to those in other trauma programs in Ontario (personal communication, Ministry of Health, January 1994). In this same year, the 93 referrals to TTP were diagnosed as indicated in Figure 1.

In regard to the cause of injury for these 93 referrals: 59% were motor vehicle accidents (MVAs), 20% work-related accidents, 9% from falls, 3% from assaults, 3% from snowmobile accidents, 3% were suicide attempts, 1% was due to gunshot, and 1% from physical abuse. From 1992 to 1995 one trend worth noting was that head-injured individuals accounted for between 40% and 70% of the client mix. Finally, over all three years about 40% of the clients were deemed "short term" (0–3 months, both in- and out-patient); 25% were "moderate term" (3–6 months, out-patient only); and 35% were "long term" (7 months or more, out-patient only).

METHOD

The evaluation design used each year was based on a qualitative-naturalistic approach (Guba & Lincoln, 1981) using multiple data sources with both formative and summative components (cf. Holosko, 1987; Holosko & Dunlop, 1992). Table 1 indicates a typical design strategy used for 1993–94, as an illustration of this approach. As indicated in Table 1 and the corresponding Table 2, service user input from both clients and community stakeholders was an essential feature of this evaluation design.

Generally, the client and community surveys reported in Table 2 were brief (three to four pages) with both open- and closed-ended questions. Both forms (client and community) annually included (1) demographic information; (2) satisfaction with services, including asking individuals to rate their satisfaction with various services offered by the program on a four-point Likert-type scale; (3) service use, including an assessment of various services used and their perceived degree of helpfulness and importance, also rated on a four-point Likert-type scale; and (4) future suggestions. Each year, both forms were modified slightly, pretested, and administered by a

Table 1
The Overall Evaluation Design and Data Sources for the Trauma Program, 1993–94

Design Components	Data Sources	Main Study Variables
I. Formative (process)		
1. Goal determination assessment	Original proposal, policy & procedure manual, progress report submitted to MoH Nov. 1993	Goal assessment, objectives assessment
2. Administrative development of the program	All correspondence and related materials; monthly & annual budget, the administrative chronology	Personnel, budget, demographic shifts; reviewing trends in administrative development of the program, policies and procedures; service shifts
3. Treatment data	Clinical records, policy and procedural manuals; pathways to treatment charts	Treatment processes, pathways of treatment, treatment protocols, continuum of care, services offered
II. Summative (outcome)		
1. Client survey ($n_1 = 24$)	Survey questionnaire developed to determine effectiveness of the program	Background information, satisfaction with services by social work and life skills counsellor/occupational therapist
2. Community survey ($n_2 = 20$)	Survey questionnaire developed to determine impact of program in community	Service utilization, helpfulness of services offered, relationship to the program
3. Service needs	Examining demographic and population data on services and program needs, gaps, and unserved populations	Program needs, gaps, service-based data

Table 2
Consumer Input for Program Evaluations of the Trauma Program (1992–93, 1993–94, 1994–95)

Evaluation Year	Service User Group	Sample Sizes	Strategy/Comments
1992–93	Clients	$n_1=7$	Consumers who could write support letters were asked to do so
	Community stake-holders	$n_2=5$	Agencies who worked directly with TTP were asked for support letters
1993–94	Clients	$n_3=24$	Survey questionnaire: random, administered face to face
	Community stake-holders	$n_4=20$	Mailed survey questionnaire random sample, agencies familiar with TTP
1994–95	Clients	$n_5=17$	Survey questionnaire, random, administered face to face
	Community stake-holders	$n_6=25$	Mailed survey questionnaire, random, random sample of agencies familiar with TTP

staff person from TTP. Also, an attempt was made annually to se-
lect a random sample of clients and community agencies. This was
done using a systematic random sampling procedure carried out by
the researcher and targeted at a 50% (potential) sample of both cli-
ent and stakeholder populations.

RESULTS

The results highlighted herein pertain only to the service user in-
put of the evaluations. (Readers interested in the overall evaluation
reports may obtain a copy through the MoH, Institutional Programs
Branch, Toronto, Ontario.) The main findings for the three years,
broken down from Table 2, are outlined below.

Service User Input Findings

1992–93

Clients. The testimonials written by clients (n_1 = 7) in this year were
universally positive. They were personal and very emotional sce-
narios about the impact TTP made in individuals' lives, and all cli-
ents stressed the need for more services in the community.

Community Stakeholders. The agencies (n_2 = 5) who worked directly
with TTP this year all offered their support to the program. The
majority (four of five) applauded this provincial initiative and spoke
about the gaps in service in this community for such clients.

1993–94

Clients. The main presenting problems for clients (n_3 = 24) *entering*
TTP were memory loss (44%), followed by emotional difficulties (17%)
and the need for home support to attend to the tasks of daily living
(13%). The main presenting problems for clients *completing* TTP were
still memory loss (25%), followed by lifestyle adjustment (12%), emo-
tional problems (12%), social skills (12%), and depression (12%). In
terms of changes perceived by TTP clients, 27% reported "improved
coping skills," 17% were "happier," 15% reported "increased confi-
dence," and 13% said they had gained "a better understanding of
my injury."

All of the clients reported that their "concerns were addressed" by
participating in TTP. Clients were asked to rate the "degree of

helpfulness" on a four-point Likert-type scale (from 1–4) of the case manager and life skills/occupational therapist (the two main staff persons), and the mean scores were 4.0 and 3.9, respectively. When asked, on an open-ended question, what would have happened to them had there been no trauma program in this community, 70.8% of clients said that *they would have considered suicide/death if they had not received the services provided by TTP.* Specific suggestions offered to improve TTP included more staff (26.0%), increased financial support (15%), more education on head injuries (15.0%), and increased accessibility (11.0%). The concluding open-ended suggestions all endorsed the importance of this program in this community and the region.

Community Stakeholders. Of the 20 community agencies, 40% provided complementary services, 20% were recipients and consumers, 5% were competing organizations, and 35% were providers of clients according to a typology developed by Hasenfeld (1983) (which has been used successfully in other community evaluation studies [Holosko and Dunlop, 1992]). The main service activities of the agencies included: direct treatment (21%), residential services (10%), psychological services (10%), social work (8%), psychotherapy (8%), and referral services (8%). When asked which additional services TTP should provide, 21% said community education, 21% said client feedback, 17% said more services generally, 9% said more vocational training, and 9% said more counselling. When asked about the perceived degree of helpfulness of services offered by TTP, 100% reported consultation, 87% said assessment, 36% said individual counselling, 100% said life skills, 100% said cognitive retraining, and 100% said discharge and transfer. When asked whether it would make a difference to their agency if TTP did not receive funding in the future, 85% reported it would directly affect their services in the following ways: increased strain on their resources, harm to client care, creation of a community gap, and reduction of service integration in the community. Suggestions the agencies offered to TTP included more staff, more feedback reports on clients, more needs assessments, more client assessments, expanded caseloads, more community education, more service evaluation, and closer liaising and community networking. In general, all of the agencies surveyed indicated that TTP was a much-needed community program.

1994–95

Clients. When clients (n_5 = 17) were asked what would be helpful to them in a discharge plan, 77% said "a list of community profession-

als whom I could talk to about my concerns," 65% said "a cassette or videotape I could play at home to help me," and 53% reported "an individual written plan I could take home." Further, 59% reported "feeling better about themselves personally" after being discharged from TTP. When asked what specific areas of their lives had changed significantly after their injury, 94% reported leisure activities, 88% said social activities, 88% said their outlook on life, 88% said personal goals, 82% said their jobs, 76% said friends, 70% said family, and 70% said their income. When asked about their current problems, 88% reported getting back to work, living a life of pain, social outlets, meeting persons of the opposite sex, daily coping, memory loss, and problems with comprehension and communication. When asked what services they currently needed, 76% reported financial assistance, 76% reported general medical/therapeutic assistance (e.g., wheelchair, walker, assistive devices, intercom, home modifications), 70% reported activities of daily living (homecare, shopping, housekeeping, transportation), and 68% said specialized therapeutic assistance (e.g., physiotherapy, chiropractic, MD, psychologist, occupational therapy, family counselling, speech therapy). All the respondents (100%) wanted additional services from TTP, including written treatment plans, professionals to talk to, after-hours telephone services, regular telephone follow-up, in-home counselling, and in-home specialized therapies. Further, 65% self-reported that they did not feel they would have a relapse if such services were provided to them. Final comments included testimonials about the overall differences in their lives that TTP had made, which were all in profound ways positive.

Community Stakeholders. The 25 agencies who responded to the 1994–1995 survey were from a variety of health and social services, namely, counselling services, psychiatric assessments and care, housing, welfare and employment, vocational rehabilitation, mental health, homecare, crisis intervention, and medical. In terms of services offered to post-discharged trauma clients, 40% provided referrals to community services, 30% offered periodic reviews and check-ups, and 70% offered referrals to self-help/support groups. When asked about gaps and needs in service provision for trauma clients in this community, the majority reported rehabilitation facility/services, specialized health care (e.g., radiology, neurology, neurosurgery, speech pathology), assessment and diagnosis, crisis response, follow-up services, and after-hours services. The majority of these agencies were very satisfied with the services provided by TTP but wished they could do more, as the client group is underserved. Additional suggestions included a hotline, better

coordinated services, better quality services, and more rural outreach to remote and underserved areas.

DISCUSSION

An inspection of the demographics of the clients served by TTP revealed that they were more similar than dissimilar to other individuals in trauma programs across Ontario (personal communication, Ontario Hospital Association and the Ontario Head Injury Association, January 1995). In January 1994, when it appeared that the MoH would not fund TTP for the forthcoming year, 1995, the program redefined its mandate and services, shifting them to incorporate more head-injured clients in their population mix, as this group could provide fee-for-service dollars directly to the program. Thus, the three years of data previously presented reflected this disproportion and its respective input.

According to data (not reported here), the program could be administratively characterized as: (1) filling a service need in the community; (2) stretched to the limits in terms of its resources and service demands; (3) always lagging behind the community service demands; (4) constantly redefining its overall implementation strategy toward more efficiency (doing more with less); (5) reeducating clients, families, and community agencies about how to best utilize its resources; and (6) always overshadowed by financial uncertainty about its future (Holosko, 1993, 1994; Holosko & Dutta, 1995). The challenges involved in providing a quality service under such auspices are indeed formidable. However, one may speculate that an inspection of other small to medium-sized health care programs currently in the province of Ontario would probably yield similar administrative conclusions.

Historically, provincial governments across Canada have been much slower than their federal counterparts in allocating resources to and providing technical assistance and policy direction for evaluation. As Hudson, Mayne, and Thomlinson (1992) indicate, Canadian provincial governments generally have not taken as active a role in establishing evaluation units in their departments or carrying out evaluation work on a systematic and sustained basis (p. 16). This MoH-sponsored initiative was indeed a case in point. Thus, the issue of the "politics" of such evaluations requires some discussion.

Foremost, given my experiences with evaluating programs of this nature, I agree that it is important to include service user input

into such activities. However, as evaluations continue to include such input (this being the current trend), one may ask, Is the political imperative more important than either the purpose of the evaluation itself or the purpose for including such input? The data in this article seem to indicate so. That is, a researcher would have been remiss not to seek such input, but that input, when obtained, was not used to fulfil the ideal purpose of any evaluation, which is to better manage its programs; to improve the delivery of programs; to challenge the direction of programs; to improve future programs; or to better account for its performance (Hudson, Mayne, & Thomlinson, 1992). Only a tepid case could be offered for the latter when one carefully examines the three years of data collected.

For example, for three years both clients and community stakeholders made very specific requests and suggestions for additional services—for example, more diagnosis, more in-home care planning, prevention/education materials, an after-hours telephone support program, and more counselling services, *none of which* could be provided under the existing and funded mandate of the TTP. Thus, the extent to which evaluation processes perpetuate political motives and in turn give the appearance of legitimacy to such programs needs to be addressed. In this context, the field of program evaluation has evolved considerably in North America, now being recognized as a bona fide method of assessing the efficacy of a wide variety of health and human service programs. As well, it is inherently political and distinct from social science research (Holosko, 1996). As Cronbach (1982, pp. 1–2) indicated, "the central purpose of evaluation differs from that of basic research and evaluations fit into a different institutional and political context." Thus, as previously indicated, it seems incumbent upon evaluators to attempt to ascertain the political context of their evaluation activities and, if possible, incorporate such issues directly into their evaluations.

From a methodological standpoint, the Sault Ste. Marie and district was by any measure a "difficult to access and assess" population. In regard to the client sample, many were cognitively impaired; had comprehension problems; were medicated; were depressed (by self-report), alienated, or anxious; and had documented short-term memory problems. As the majority of the clients sampled were head injured, such findings are not surprising (Holosko & Huege, 1989). Further, although random client samples were drawn each year, they were derived from a list that staff had provided—and the criteria for client inclusion was simply that the individual *could* participate in a face-to-face survey. Thus, the population domain from which

samples were selected was likely to have been biased from the standpoint of their ability to participate effectively in this undertaking.

The community samples were also randomly selected annually. Although the returned surveys represented 21–28% of the overall population rates annually, deemed acceptable by most mailed survey standards (Grinnell Jr., 1993), the issue of nonreturns (despite at least two follow-up calls) was perennially troubling and provoked a number of questions. For instance, were the returned surveys from those stakeholders who had established relationships with TTP and were themselves part of the limited service network serving this population in this community? The data provided certainly pointed in this direction when both the closed-ended and open-ended responses were tallied. Thus, consistent with the literature on nonrespondent concerns (Gliksman, Smythe, & Engs, 1992), such overwhelming support for TTP from community stakeholders needs to be tempered with research realism.

Concerning instrumentation, a number of methodologic issues were apparent. Most significant was the reliability and validity of the survey itself, and subject expectancy contaminants that threatened the validity of findings (Campbell & Stanley, 1963). In regard to the former, outside of staff input, an annual pretest, and the author's personal experience in researching this population, the psychometric properties of the instrument were not and realistically could not be empirically scrutinized. For example, the way in which questions needed to be formatted and asked, the small sample sizes, and the lack of standardization of administration times (i.e., some clients were discharged for two months and others for a year, which in a rehabilitation mode makes an enormous difference for such clients) rendered the instrument suspect in its overall measurement integrity.

As regards subject expectancy, the majority of clients interviewed openly expressed fears about losing the program, as there was no other service available to serve this population in the community in this way. Further, the fact that 20% said they would seriously have thought of suicide in 1994 if they hadn't entered TTP is in of itself a frightening reflection of both their own clinical needs and the program's perceived impact. As a result, the generally overwhelming positive findings presented probably had much to do with the program's impact, but so did the client's expectations—which were revealed verbatim in these data.

CONCLUSION

The lessons learned about service user input from this experience were many and varied. In short, for this and many other similar programs, service users are difficult both to access and to assess for evaluation purposes. In regard to the latter, the nature of how we determine samples of service users for evaluation purposes, and how we collect information from them *in which we have some confidence*, needs to be addressed by future evaluation research. Indeed, the more we continue to avoid this reality, the more our credibility as evaluators is called into question. Certainly, the field of program evaluation does not need any other attacks on its professional credibility, given its evolution in Canada to date (Hudson, Mayne, & Thomlinson, 1992).

Despite the methodologic problems noted earlier, service user data in this study above all else clearly revealed two things: (1) consumers *did have something to say* when they were asked about programs/services, and (2) realistically, *no one incorporated their input.* On the first, the brief findings presented here gave only a glimpse of the overall data. Indeed, excellent suggestions, ideas, and opinions were offered by both client and community stakeholders every year they were canvassed. In turn, each year the evaluation results were discussed by staff and hospital personnel and sent off to the MoH, and no feedback from the MoH was offered to act on such data. In regard to the second point, at one level the staff of TTP "listened" to their input, but they were constrained by their own mandates and organizational realities, and realistically couldn't do any more than they were doing to serve these clients in the community.

In sum, Canadian policy makers both federally and provincially are currently touting the importance of service user data in evaluations of their health and social programs. However, as this study has revealed, it appears that the political importance of including service user input and their ability to lend the appearance of legitimacy to these evaluations outweighs the utility of that input. The extent to which giving the appearance of legitimacy generates an "appearance of empowerment" to such consumer groups should be examined in the future. For example, evaluation feedback loops (such as service user data) are integral elements linking group identification, group consciousness, and self and collective efficacy to individual or group empowerment (Gutiérrez, 1995). It would be a terrible irony if evaluation activities achieved the opposite—further

disenfranchising the very groups of individuals whom they are attempting to empower through their efforts.

ACKNOWLEDGEMENTS

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