

**Explaining Outcomes: Developing Instruments to
Assess the Critical Characteristics of
Community Support Programs for People
With Severe Mental Illness**

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INTRODUCTION AND BACKGROUND

In the last two decades, the focus on community integration for people with severe mental illness has been a dominant force in the mental health field. The growing advocacy of people with psychiatric disabilities, and research evidence indicating that persons with psychiatric disabilities value independence and productivity more than other treatment outcomes (Anthony & Blanch, 1989, Cohen & Anthony, 1988), have challenged many fundamental assumptions. The field has moved away from the perspective that these people are hopeless, or helpless, and in need of institutional care; through a "transitional" period in which people were seen as service recipients and in need of professional support (Turner & Ten Hoor, 1979); to a new perspective which now views people as partners, as "citizens with a potential for, and a right to, full community participation and integration" (Carling, 1992, p21).

As a result of new thinking about community integration, and specific policy initiatives that have supported the paradigm shift, a wide array of community support programs has emerged. The goals of these programs are broadly stated as helping persons with severe mental illness become reintegrated into the community, and improving their quality of life and that of their families (Burns & Santos, 1995). Central to the philosophy and practices of these programs are such core values as the benefits of remaining outside hospital, the importance of being productive, and the need to be happy (Cumming, 1968).

Models of Community Support: The proliferation of community support programs over the past several years has resulted in the development of a number of different models, each one having its own traditions and practices. Case management, widely seen to be a critical service in achieving continuity of care in community-based services, is understood and delivered in a variety of ways (Bachrach, 1993). There is general consensus that case management functions must include assessment, planning, linking, monitoring and evaluation in order to meet client goals (Intagliata, 1982; Thornicroft, 1991; Goering and Wasylenki, 1996). However, other services are often included to varying degrees, including outreach, direct service provision, meeting special needs, and advocacy (Intagliata, 1982; Levine and Fleming, 1985). As pointed out by Goering and Wasylenki (1996), considerable difference exists between case management programs with regard to the emphasis placed on various activities and functions, as well as methods of carrying them out.

The Training in Community Living (TCL) model, also known as Program for Assertive Community Treatment (PACT), or Assertive Community Treatment Team (ACTT), is characterized by comprehensive care provided by a single treatment team; provision of care in community settings in order to minimize difficulties with generalization of learning; assertive community service to lessen drop-out and increase involvement in care; and a focus on teaching clients community living skills and providing necessary emotional, cognitive and instrumental supports (Stein & Test, 1980). Since its development in the early 1960's, extensive evaluation and replication of the model have resulted in its use in a variety of clinical settings. Variations of the model have occurred due to reasons of both inadequate implementation, as well as deliberate adaptation to meet particular needs. The model has been adapted to such a degree that Test, Knoedler and Allness (1985) examine two distinctly different forms of the original model which are now competing with one another in clinical research trials. As noted by Thompson, Griffith and Leaf (1990), the question of how the model will (or should) continue to change without diluting its essence, is a critical one.

In summary, several models of delivering community support to people with severe mental illness have emerged in response to the broader paradigm shift toward de-institutionalization and community integration. In practice, there is tremendous variability in the delivery of these models. This variability must be taken into account in the evaluation of the efficacy and cost-effectiveness of community support programs.

Efficacy and Cost-Effectiveness: Reviews of evaluation research on clinical case management suggest that it results in increased satisfaction and engagement with services, improved social functioning and social networks, and decreased use of hospital services (Thornicroft, 1991; Holloway, Oliver, Collins & Carson, 1995). Nelson, Sadeler and Cragg (1995) compared changes in rates of hospitalization for psychiatric consumers participating in a case management program and found that the number of days hospitalized was reduced during participation in the program compared with a 6-year baseline period. A study comparing outcomes of rehabilitation-oriented case management with matched controls who did not receive this service produced mixed results. Case management clients had significantly better occupational functioning, lived in more independent living settings and were less isolated. However, the groups did not differ in the number of hospitalizations (Goering, Wasylenki, Farkas, Lancee & Ballantyne, 1988). As pointed out by White (1992), the differing outcomes of case management are likely due to the many existing versions of it and "the compromises made in implementing this labour-intensive strategy" (p91). The different findings yielded in these studies underscore the need to carefully measure program characteristics and processes in the context of program evaluation.

There have been many randomized controlled trials on the efficacy of Assertive Community Treatment Teams. Many of these studies suggest that such programs are effective along a number of dimensions including reduced hospitalization, improved symptomatology, increased compliance and residential stability (Hoult & Reynolds, 1984; Muijen, Marks, Connolly, Audini & McNamee, 1992; Stein & Test, 1980, Burns & Santos, 1995; Scott & Dixon, 1995). In particular, the impact of such programs on reducing hospital bed-days is clear (Test, 1992; Marks, Connolly, & Muijen, 1994; Merson, Tyrer & Onyett, 1992). However, ambiguity remains regarding its impact on different areas of functioning. A review of assertive community treatment programs by Test (1992) pointed to less favourable psychosocial outcomes in programs in which the original model had been modified, for example in programs using additional mental health services. Other reviews (Olfson, 1990; Taube, Morlock, Burns, & Santos, 1990) have also produced mixed findings and concluded that further research is needed to specify those conditions within the ACTT model which contribute to desirable outcomes.

Studies comparing ACTT models with traditional case management models have favoured ACTT programs. A study by Wolf, Helminiak, Morse and Calsyn (1997) compared ACTT treatment conditions to case management and found ACTT clients had more contact with their treatment programs, reduced symptomatology, and greater satisfaction with their treatment. In their controlled study, Quinlivan, Hough, Crowell, et al. (1995) also found participants in intensive programs had fewer inpatient days than traditional case management recipients. Teague, Drake and Ackerson (1995) concluded that continuous treatment teams were also more effective in implementing substance abuse treatment than standard case management programs. In their review of ACTT and case management programs for schizophrenia, Scott and Dixon (1995) point out that greater fidelity to the ACTT model produced better outcomes. Apparently, some component of assertive case

management minimizes hospital use more effectively than other case management approaches. However, there is lack of clarity on components which may be responsible for this finding. As stated by Burns and Santos (1995) "it is unclear whether this decrease in hospital use is attributable to improved medication compliance, intensity of services, site of services, continuity of caregivers, assertive outreach, 24-hour coverage, the program philosophy, the therapeutic alliance, or a combination of the preceding factors" (p673).

In summary, the research evidence on case management, assertive community teams and other models of individualized community support offers little advice to program funders, administrators, staff, consumers or family members as to the most important attributes of individualized community support programs. While results of research on the efficacy of these community support programs has been positive, the results are inconclusive in many respects. The mixed results reflect the tremendous variation across the models being evaluated, the different organizational and community contexts in which services are delivered, and the methodological challenges of outcome evaluation research. Given such wide variation in program characteristics and their community context, it is clear that controlled trials which compare a small number of program alternatives will contribute very limited information about which program characteristics and activities contribute to client outcomes.

New Research Paradigm: Researchers are increasingly seeing randomized controlled trials as only one part of a broader health services research strategy that is required to not only assess program outcomes, but also to link the outcomes achieved with resources expended and the services actually received by the consumer and/or family member. Controlled trials help establish the "efficacy" of a mental health-related intervention as it operates in ideal circumstances. The results, however, are often limited by low statistical power; unrepresentative samples and failure to measure or control for variability in the consumer population or services received. Furthermore, variability of conditions within communities with respect to such issues as existing services or available housing pose major challenges in the evaluation process. A complementary approach to controlled trials and quasi-experimental evaluations involving two or three programs, is the monitoring of outcomes across a large network of community mental health programs as they operate within a given jurisdiction. Such system-level monitoring systems are in place, or under development, in several jurisdictions (see for example, Centre for Mental Health Services, 1996; Roth, Doklovic, Burns, & Lauber et al., 1997).

Jurisdictions such as Ohio, Kansas, and Utah have outcome monitoring systems. Researchers in many other jurisdictions are focusing on the development of outcome measures appropriate for such systems (e.g., Srebnik, Hendryx, Stevenson, Caverly et al., 1997).

One critical goal of outcome monitoring systems is to optimize a core set of outcomes by changing the services provided to the consumer by programs (Dennis, Godley, Godley et al., 1996).

Analysis of data to achieve this goal requires a conceptual shift whereby the program rather than the consumer becomes the unit of analysis. It also requires reliable and valid measurement of the program characteristics and assessment of the relationship of these characteristics and outcomes achieved. Unfortunately, there has been little attention given to measuring the actual program characteristics that contribute to positive outcomes of community support programs in the mental health field. This echoes the concern noted above in the major reviews of the outcome evaluations of these programs; namely, there is as yet no way to characterize the essential ingredients of community support programs and assess quantitatively their relationship to consumer outcomes. Reliable, valid and practical measures of program characteristics are needed to play this important

role in outcome monitoring across a network of community support programs. Without such measures to help explain outcomes (positive or negative), those individuals who plan, fund and manage these programs have little to guide their attempts to make program improvements that will achieve the best possible outcomes with the resources available to them.

Internal Program Evaluation: Just as there is increased emphasis on system-level monitoring and evaluation there is also a trend toward increasing the capacity for evaluation within individual community programs. In early models of program evaluation, evaluators were typically external agents, valued for the expertise, independence and objectivity they brought to the evaluation of a program. Their role was to help judge the program as “good” or “bad,” and assess its accountability to the funder and the general public. In the past decade, there has been a dramatic shift away from this accountability paradigm to view evaluation as an essential component of good program management and ongoing quality review. There is new widespread agreement that, in many instances, the evaluation activities should be driven by the program itself, relying on experts as the need for their expertise and objectivity arises.

Evaluation tools are needed to examine program characteristics and internal processes of community support programs for the people with severe mental illness. Instruments that help show the relationship between program characteristics and outcomes across a network of programs can also be used in several ways within an individual program. First, the program characteristics shown to be associated with outcomes can be used in the need assessment phase and help guide the planning and design of a new program. Second, longitudinal assessments of program characteristics, when combined with parallel assessments of outcomes, can help programs identify the comparative benefits and costs of changes in their methods of operation, within their specific community context. Third, the instruments can be used to monitor changes within the program over time to guard against inappropriate drift from the original design specifications. Lastly, the instruments can be used as part of ongoing quality reviews, either with a simple checklist of important program characteristics, as a complement to a more formal accreditation process, or as a component of a peer evaluation model.

Ontario Context: In Ontario, the priority for community integration for people with severe mental illness has been supported by the development of provincial policy and related policy documents. Examples include the *Report of the Provincial Community Mental Health Committee* (1988) (the Graham Report), *Putting People First* (Ministry of Health, 1993) and the Canadian Mental Health Association’s *Framework for Support* (Trainor & Church, 1984; Trainer, Pomeroy & Pape, 1993).

In *Putting People First*, case management, including housing support, was identified as one of four priority areas for development in the Ontario community mental health system. In response to recommendations coming from these, and other policy and funding initiatives, community mental health services in Ontario have grown significantly. In 1992, a snapshot of community mental health services in Ontario (Lurie, 1992) revealed 309 community programs and 34,724 active clients. Case management programs were providing services to 3,865, or 11% of these clients overall, with higher percentages in particular parts of the province (e.g., 18.8% in North Eastern Ontario). Case management programs frequently reported waiting lists of three months or more.

In Ontario, there is a broad spectrum of community support services ranging from brokerage case management to more intensive models of care. Over the years, there has been increasing attention to the more intensive models. Some community mental health programs follow a psychiatric

rehabilitation model, others are providing services based on the strengths-based model (Saleebey, 1996), and still other programs, such as the Hamilton Program for Schizophrenia, have developed hybrid models. In the area of supportive housing, there has been a shift away from facility-based group home programs to “delinked” community supportive housing programs that are very similar to case management programs. In rural areas, mental health service providers have developed models of service that allow them to respond to a variety of community mental health needs, including the need to focus interventions on the people with severe mental illness. Different models of service are also beginning to emerge as ethnoracial and francophone communities obtain funding for more culture-sensitive, community mental health services.

With respect to program evaluation, there are several examples of process and outcome evaluation within specific agencies in Ontario (Lurie, 1992). A number of groups have developed formal approaches, but there is no consistent approach being followed that would allow for comparison across programs. For example, CMHA Ontario has developed a process tool that is used by nine of its 36 branches. CMHA Metro Toronto has developed an accreditation-based, program logic model approach which uses an application of United Way of Canada’s Onsite Analysis (Myers & Ufford, 1989; McGuire & Lurie, 1993) to assess program strengths and weaknesses. Waterloo Regional Homes for Mental Health has used both external and internal evaluation processes (Lord, Ochacka, Czarny & MacGillivray, in press; Nelson & Smith-Fowler, 1987). Alternatives, a community mental health program in East York, is involved in a major values-based, self-assessment project which will be published shortly.

In addition to these evaluation activities within specific programs, there is a variety of initiatives that reflect the need to monitor and evaluate the broader regional or provincial network of mental health services. At the regional level, the need for monitoring service outcomes and program characteristics is highlighted, for example, in the final report of the Central East Region Mental Health Planning Table (1997). Some of the provincial initiatives include: new requirements for transfer payment agencies for *organizational, program, and financial* data; work underway by the Joint Policy and Planning Committee to recommend and implement a common *assessment* tool for purpose of classifying consumers for cost and outcome comparisons; a “Minimal Data Set” currently being piloted across the province by the MOH to capture basic *demographic and other characteristics* of consumers; the MOH Information Technology Strategy which includes *health records* and *registered person’s database* and a *practitioners database*; implementation of the “PSR Toolkit” by the Ontario Federation of Community Mental Health and Addictions Programs for assessing *consumer outcomes*; and finally the work of the Mental Health Policy Research Group, including this very competition, to engage community mental health agencies in the evaluation of outcomes and build a common database for outcome evaluation. The plan for the latter initiative calls for the eventual integration of information across several domains including, for example, demographic characteristics, severity of illness, quality of life, type and amount of services used and cost of these services.

All of the above evaluative work notwithstanding, very little attention is being given to measuring program and service delivery characteristics that will help explain outcomes. This is a significant gap in current regional and provincial planning for system-level monitoring and evaluation. For example, traditional indicators of service delivery such as “hours of case management” provide no information about the actual characteristics of case management services that are associated with outcomes, and which could be modified by a program to optimize outcomes.

Measuring Program Characteristics and Implementation: Brekke (1988) points to a lack of empirical knowledge about the actual implementation of community support programs, including the methods employed, how they can be replicated, or components which account for their success. He advises that understanding and replicating effective social programs can only be achieved if we answer the questions "what do the programs consist of?" and "are we delivering the services we think we are delivering?" (p946). Durbin, Goering, Wasylenki and Roth (1997) further emphasize the need to describe and assess program components in order to compare a program's implementation to its conceptualized model, gain important information for program management, and test hypotheses about the program. Accordingly, process evaluations "are a logical precursor to outcome evaluations, allowing program delivery as it exists, not as it is conceptualized, to be linked with program impacts" (p49).

There is a small body of literature in the evaluation field that assists in the measurement of program characteristics and program implementation at both the conceptual level, and actual development of measurement strategies. At the conceptual level, Brekke (1987) advocates an hypothesis-driven approach to measuring program implementation whereby specific hypotheses are developed that guide the assessment of actual versus intended practice. Rush and Ogborne (1991) recommend the use of program logic models to explicate the presumed causal relationship between program implementation objectives (i.e., activities and services to be delivered) and program outcome objectives (i.e., the changes to result from delivering these activities and services). The implementation objectives highlight the program characteristics and processes which should be measured. Recently, logic model analysis has been extended to relate program processes and outcomes quantitatively through path analytic models (Wong-Rieger & Lindee, 1996). Yates (1996) has recently formulated a more comprehensive conceptual model to guide the measurement of program information on resources expended (i.e., costs), procedures, processes and interim and long-term outcomes. Yates' distinction between procedures and processes is especially helpful; the former being actual program activities (e.g., 24-hour crisis telephone line; individual counselling) and the latter being psychosocial processes that result from these activities (e.g., problem solving skills; self-efficacy). Yates' model, known as Cost, Procedures, Processes and Outcomes Analysis (CPPOA), also goes so far as to delineate spreadsheet analyses on how these different domains of data can be integrated quantitatively. In CPPOA analyses, and with less complex program logic models, the data can be analysed at either the individual-level (i.e., looking for relationships among costs, procedures, processes and outcomes across individuals within a program) or the program-level (i.e., looking for relationships among costs, procedures, processes and outcomes across programs).

In terms of specific measurement strategies, it has been suggested that there are at least seven potential techniques for measuring program attributes (Scheirer & Rezmovic, 1983). There are: technical measures, unobtrusive indicators, behavioural observations, institutional records, interviews, questionnaires and ethnographic observations. While technical measures such as measures of equipment functioning may be applicable to some types of programs, they are of little relevance to community mental health. Feasible and relevant unobtrusive measures (Webb, Campbell, Schwartz & Sechrest, 1966) for such programs are also difficult to discern. Ethnographic observations are very helpful but difficult to use on a large scale because they require individuals with very specialized training and skills. This leaves the primary techniques for assessment of program characteristics as gathering information from program records, interviews and questionnaires. Such methods appear to be appropriate options for developing feasible, meaningful and reliable measures.

McGrew, Bond, Dietzen and Salyers (1994) report the most detailed attempt to measure important characteristics of community support programs for people with severe mental illness. Their approach focussed on the ACTT model and involved the measurement of the characteristics of community support programs as they relate to this model specifically. McGrew et al. developed their instrument on the basis of expert opinion about which elements are most critical to the ACTT model and then developed measures of these elements which could be readily obtained from program records. While the basic approach to instrument development is sound, the underlying assumption that the ACTT model is the normative model to use as a template for assessing the critical characteristics of community support programs is questionable. Indeed the need for the current competition reflects the fact that there is not sufficient justification for considering a particular model of individual support program as ideal for all clients (Bachrach, 1980; 1993).

In summary, conceptual and measurement models are available to measure program characteristics and integrate data on program characteristics with consumer outcomes. What is needed are data collection instruments that are appropriate for use across a wide range of community support models and practices as they exist in the community mental health system in Ontario.

PROJECT OBJECTIVES

The objectives of the project are:

- (1) Development of an instrument package to measure critical characteristics of community mental health programs in Ontario which provide support to individuals suffering from severe mental illness;
- (2) Assess the reliability of such an instrument package and its feasibility as a method for ongoing monitoring of program characteristics;
- (3) Carry out an initial pilot assessment of the relationship between the characteristics assessed by the assessment package and program outcomes; and
- (4) Develop and field test alternative strategies for application of the instrument package in the Ontario community mental health system.

RELEVANCE: Promoting a Culture of Evaluation in Community Mental Health

The central focus of this Community Mental Health Initiative competition is evaluation of the effectiveness of community mental health services and supports. The underlying premise of this proposal is that we need to learn more about characteristics of programs delivering individual support services, and the relationship of these characteristics to consumer outcomes within the context of various communities in Ontario. Research in this area is extremely important, but challenging. Three of the greatest challenges are: (1) outcomes of programs need to be evaluated along a number of dimensions which are largely independent of one another (e.g., Corrigan, 1989; Dickerson, 1997; Lebow, 1984; Rosenblatt & Attkinson, 1993; Srebnik, Hendryx, Stevenson et al., 1997); (2) meaningful controlled trial comparisons are very difficult because of the manifold ways in which specific programs and their community context actually differ (Brekke, Long, Nesbitt & Sobel, 1997; Tessler, Willis & Gubman, 1996); and (3) the proper unit of analysis for assessing outcome as a function of program characteristics are programs rather than individuals within programs (Cornfield,

1978; Donner, Birkett & Buck, 1987; McKinlay, Stone & Zucker, 1989), and this makes the recruitment of adequate sample sizes (of programs) for meaningful and powerful analyses very difficult and expensive. Such problems are not unique to the community mental health field, but rather characterize research on any community health initiatives (see McKinlay, 1996). How can these challenges be met?

With reference to the first challenge, the Competition prospectus suggests that the Coordinating Centre (C.C.) will be taking an initiative in ensuring that common and comprehensive outcome measures will be included in all projects funded. This should insure that common (and hopefully standardized) instruments are used to assess major dimensions of outcome for consumers (symptoms, level of functioning, quality of life, satisfaction with services, use of health care resources, subjective well being, empowerment etc.). In addition, the current initiative of the Ontario Federation of Community Mental Health and Addictions Programs in disseminating the PSR Toolkit for measuring consumer outcomes (International Association of Psychosocial Rehabilitation Services, 1995) will contribute to the development of a core set of outcome measures across community support programs. For purposes of this proposal we will assume that two outcome goals shared by all community mental health programs offering individual support are reduced hospitalization for psychiatric reasons and improved quality of life.

While the use of comprehensive and shared outcome measures is essential in drawing conclusions about the relative effectiveness of community programs, it is not sufficient. The attribution of the causes for differences in program outcomes is also a major challenge. Simple comparisons between a few programs on shared outcome measures may yield statistically significant differences, but the conceptual and practical significance of such comparisons are doubtful given the multiple ways in which such programs are likely to differ. Furthermore, given that aggregated program data rather than individual client data are most appropriate for analyses investigating the relationship between program characteristics and outcome, data concerning large numbers of programs are needed in order to draw meaningful conclusions. The collection of data describing programs requires the use of an instrument, or package of instruments, designed to assess program attributes that are likely to be most important for explaining differences in outcome.

Although the need for better information on program content and process is generally recognized in the mental health and other fields (e.g., Fairweather, Sanders, Tornatzky & Harris, 1974; Brugha & Lindsay, 1996), no appropriate instrument for this purpose currently exists. It should also be recognized that characteristics of effective community mental health programs will vary as a function of the broader community environment in which they operate (e.g., availability of housing, vocational placements, universal health care, social services). Thus, instruments for use in different jurisdictions (for instance the United States versus Canada) may have to assess different characteristics.

This proposal will result in the development of such an instrument, or package of instruments, for use in Ontario, and perhaps eventually other parts of Canada. Its development and application will contribute significantly to the monitoring and evaluation of community support programs across a provincial or regional network of such programs. Specifically, it will contribute to multivariate investigations of cross-sectional relationships between program characteristics and outcomes, as well changes over time in the characteristics and outcomes of the provincial or regional system over time. If such an instrument could be developed for general application to community mental health programs in Ontario, then multivariate techniques such as regression analysis could be used to relate

characteristics to outcomes on a program level, thereby providing a much stronger basis for policy development and implementation and program design.

The development of an instrument, or package of instruments, that assesses the critical characteristics of community support programs will also contribute significantly to evaluation and quality improvement activities within individual programs. It will provide program managers, staff, consumers and family members with a template to examine services with a view toward maximizing the potential for achieving positive outcomes through ongoing improvements to program design. While there are examples of independent evaluations underway in community support services in Ontario, the field will benefit significantly from a common language and measures by which to discuss and assess critical program characteristics. Alternatives for eventual application of the instrument(s) include simple monitoring checklists as part of ongoing quality improvement initiatives, and comprehensive program assessments in the context of a peer-evaluation model. These alternatives will be developed and field tested in the latter stage of the proposed project.

Finally, the proposed project will involve a significant number of Ontario's community mental health programs in the development of the instrument(s) to measure critical program characteristics. Experience in other health care sectors in Ontario (e.g., addictions services) indicates that this will increase buy-in for potential application of the measures in a provincial information system, as well as lead to more, and improved, evaluations conducted by individual programs. The active involvement of the system in developing this proposal; advising the project team through a formal Advisory Committee (see below); and in developing and field testing the instruments and application strategies, will be a positive learning experience for those involved, and will reduce anxieties that often arise in evaluations driven largely by an external research agenda. Thus, the overall project and the specific instruments to be developed will contribute significantly to a positive culture for evaluation within Ontario's community mental health system.

COMPLEMENTARITY OF PROJECT WITH CMHEI

Our project, by design, takes a very different approach to addressing questions about program effectiveness. Other projects approved in the competition are each comparing one or more models of delivering community mental health services to people with severe mental illness. An important objective of the overall initiative is to pool the results from each of the projects in order to identify those types of programs that are most effective (and cost-effective) in achieving a common set of consumer outcomes. Thus, the underlying assumption of the overall initiative is that more (Canadian) evaluation information is needed before one could recommend one particular program model over another. The recognition of this need is also central to our proposal.

While we agree that the pooled results from other projects that have been funded will be of value in addressing these issues, our proposal takes a different approach to informing any such recommendations. Our project is grounded on the belief that there are likely to be some program characteristics that make a stronger contribution to consumer outcomes than others, and that these characteristics are not necessarily uniquely identified with different program "models". Some important characteristics can be shared across program models that may differ on overall effectiveness. Research also tells us that program "models" are rarely implemented in their entirety, and that programs can drift significantly over time in their design and implementation. Thus, we believe it is critical to go beyond discussions of program "models" and provide program funders and

managers with more detailed information about important program characteristics that should be incorporated into community support programs, and monitored on a regular basis.

We are also very conscious of the difficulties inherent in making comparisons between very small numbers of programs. Such comparisons often involve comparing programs which vary not only in the “model” on which they are based, but also on other potentially important factors such as the type of consumers they serve, qualifications/skills of staff, characteristics of the community in which they are located, availability of other services to consumers, etc. Comparisons of small numbers of programs do not allow researchers to adequately assess or control the possible role of such factors in explaining any differences in outcomes. This can compromise the robustness and generalizability of any finding and these are important considerations in using research findings for policy formulation. These issues could be better addressed by the development of an instrument that could be used across large numbers of programs and provide data using the programs as the unit of analysis in assessing the relative importance of various program and community characteristics.

Our project seeks to develop appropriate measurement tools and processes to tease out the important ingredients of community support programs for people with severe mental illness. A five-year development process is proposed, with *20 months* dedicated to initial instrument development; the remainder of *year two through year four* dedicated to testing, instrument refinement and assessing relationships between selected program characteristics and consumer outcomes; and *year five* concerned with the development and field testing of various strategies for application of the instrument package in the community.

In the broader context of recognizing that we are different from the other funded projects, complementarity to the initiative as a whole can be maximized in three ways.

Firstly, during Phase I of our proposed project we will offer to involve the other funded sites in the interviews (service providers, consumers, and/or family members), from which we will be developing our initial item pool for instrument development. There was preliminary interest in this type of collaboration from some of the investigators attending the Sept. 18 meeting of the Coordinating Centre (eg. Ottawa; Metro Toronto). Since the interviews are concerned with the respondents’ perspective on factors associated with achieving positive outcomes (quality of life and reduced or more appropriate hospitalizations) this will provide useful contextual information for interpreting the results of the outcome information they will be collecting. Having our qualitative data drawn from at least some of the research sites will also aid in the interpretation of the aggregated Coordinating Centre data.

Secondly, we believe that, by the third-quarter of year three of our project (see attached time line), our instrument package will be in sufficient form to be used by each of the research sites evaluating a community support\ case management program, as a supplement to the Index of Fidelity of Assertive Community Treatment (IFACT), and other measures of service structure and program characteristics be used in the Coordinating Centre package¹. While the IFACT is the best the literature currently has to offer with respect to the ACT model per se, it will not completely capture the important characteristics of other types of community support programs such as housing or case management. Further, since the IFACT is based on the ACT model as implemented in the US, our

¹ We would also be pleased to offer our assistance to the Coordinating Centre in the development of their items that will supplement the IFACT in the early stage of data collection in each site.

instrument will be helpful in keeping the interpretation of the IFACT data grounded in an Ontario context. We are aware that the Coordinating Centre is planning one or more site visits to each of the programs in the multi-site study, during which time some data on program characteristics will be collected. We are unsure of the timing of the site visit but assume that it will be in 1999 -2000 to coincide with the collection of most of the baseline consumer data and the nine month outcomes. We would recommend, if resources allow, that the Centre conduct a second site visit to reassess program characteristics and monitor the stability of each program being evaluated. We believe our instrument could be a useful part of the Centre's second site visit², if it can be accommodated in (our) Year Three (i.e., Sept. 2001). If this were possible then data from our measures of program characteristics could be included in the full Coordinating centre database. This is an exciting possibility which we feel would add considerable value to the initiative.

Thirdly, we will be involving a very large number of community mental health programs from across the province. Thus, it will be of significant value to the Coordinating Centre in assessing the external validity of the results from their pooled analyses. Comparisons will be possible on selected consumer characteristics (e.g gender, age, diagnosis, duration in program) and on selected outcomes from both the PSR Evaluation Tool-kit and the CMHEI package. Thus, while we do not anticipate providing outcome data directly to the common data pool (see point five below on the outcome measures), our results will be of significant value in interpreting the results of the overall evaluation initiative.

METHODOLOGY

Overview

The project will focus on community mental health programs which provide comprehensive individual support for clients with severe mental illness, including housing support. The methodology for the development of the instrument for measuring critical characteristics of such programs represents a melding of two areas: program evaluation (particularly the assessment of program characteristics), and instrument development. It also represents a melding of quantitative and qualitative approaches.

The literature cited above on measuring program characteristics and implementation (e.g., McGrew et al., 1994; Brekke & Test, 1992), including conceptual models (Yates, 1996), provides guidance for the current project both in terms of aspects of programs that may be important to assess (see description of Phase One following), and advantages and disadvantages of differing levels of measurement (see description of Phases Two and Three following). Standard procedures for instrument development also provide us with methodological signposts for moving from general conceptual suggestions of what might constitute important program attributes, to the development of parsimonious, comprehensive, and reliable indices of those characteristics (e.g., Ghiselli, Campbell & Zedeck, 1981; Michell, 1990; Rost, 1989). Our approach will utilize qualitative and multivariate methodologies in this process of instrument development.

² We recognize that our instrument package will not be appropriate for the crisis intervention services and the consumer/family services that are being evaluated.

There are essentially four phases to the proposed methodology: (1) casting a broad net to capture many different perspectives on the most important characteristics of community-based individual support programs for individuals with severe mental illness. Qualitative analyses will be used in the identification of broad domains, and themes within these domains, which in turn will form the basis for developing items to be included in a draft instrument package; (2) developing a draft instrument package, based on the characteristics identified in Phase One; (3) assessing the reliability and feasibility of items in the preliminary instrument(s) through iterative field testing on independent samples of programs; and initial investigation of the relationship of the characteristics measured by the instrument package to program outcomes. The results of Phase Three will provide the basis for selection of items to be included in the final instrument; and (4) developing and pilot testing alternative strategies for application of the instrument(s).

The above phases of instrument development and testing must be carried out in order, and details of most aspects of the process are sequentially dependent. We cannot, therefore, provide a description of an inflexible protocol that will be used in instrument development. We can, however, provide the rationale, principles and an outline of the strategies that will be used.

Procedures

Phase One:

The first phase of instrument development typically revolves around the identification of the domains that should be included in the instrument, and specific exemplars or items that may be useful for the assessment of these domains. We could take a normative approach in which we begin with a particular program model (for example the PACT model, (Stein & Test, 1980; Brekke & Test, 1992), or the clubhouse model, (Propst, 1992). Such an approach to describing community mental health programs would appear premature given that (a) there is still insufficient evidence of any one model having general superiority as a template for such services (Bachrach, 1980; 1993); (b) the most crucial program characteristics in determining outcome may not be those emphasized by a particular model; and/or (c) the characteristics which are most important in determining outcome may vary as a function of broader aspects of the social and political environment, client characteristics and/or the outcomes of interest. For these reasons, we are electing to use a broader, non-normative (“bottom-up”) approach to the identification of crucial program attributes.

It is important that multiple perspectives be used in the selection of program characteristics to be assessed. We have elected to proceed on the assumption that it is important to consult a broad constituency, including the “expert” opinion represented by published articles as well as consumers, family members and direct service providers. There will be done in two stages. The first stage will consist of a review of the published literature on community mental health services for those with severe mental illness. Content analysis methods will be used to abstract a set of crucial program characteristics. In the second stage, representatives of three groups will be interviewed for the purpose of soliciting opinions concerning additional important characteristics. The groups to be consulted are: (1) consumers or potential consumers as represented by clients receiving services at community-based, individual support programs for those with severe mental illness and members of community-based consumer/survivor groups; (2) service providers (including administrators) of such community support programs; and (3) family members and other individuals providing support to those with severe mental illness who are living in the community. The combined list of program characteristics will then be analysed through qualitative, grounded-theory analyses, (Glaser & Strauss,

1967) and complimentary methods drawn from numerical phenomenology (Kuiken, Schopflocher, & Wild, 1989).

Literature Review and Content Analysis: Articles published in journals and books concerning critical components and characteristics of community-based individual support programs for those with severe mental illness will be identified using standard data bases such as Medline and Psychinfo. The identification procedure will ensure that we include commentary articles, reviews, and reports of specific evaluation studies. It is at this point that we will also be able to integrate suggestions from any and all implementation studies of specific program models referred to earlier. Initial searches that we have carried out suggest a minimum of 175 articles over the past 10 years. Standard content analysis procedures will then be used for purposes of developing a list of crucial characteristics suggested by this literature (Berg, 1995, Weber, 1990). The content analysis will be carried out by two or more individuals trained and supervised by an experienced qualitative researcher (B.K.). Appropriate qualitative software (NUDIST) will be used in the content analysis and steps will be taken to insure that there is convergent validity in the characteristics identified by those carrying out the analysis. A template will be employed to summarize the content of articles for purposes of subsequent content analysis. This includes: author/title/year; description of program(s) and participants; measurement procedure/follow-up period; comparison groups/programs; program and outcome measures used; results; key characteristics inferred by authors. These procedures will result in a set of program characteristics to be used in subsequent interviews.

Stakeholder Interviews and Content Analysis: As indicated earlier, the three groups of stakeholders to be included in this phase are: (1) consumers, or potential consumers, as represented by people receiving services at community-based individual support programs; (2) service providers and administrators of such community support programs; and (3) family members and others providing interpersonal support within the social network of individuals with severe mental illness living in the community. Although it would be ideal to use random or stratified random sampling within each of these populations, such a procedure will not be feasible given funding limits for this competition. We will, therefore, use purposeful samples which are represented by the membership of organized consumer/survivor groups; clients of several selected community support programs; attendees at meetings of the Ontario Federation of Community Mental Health and Addictions Programs, meetings of Schizophrenia Society of Ontario. Given the possibility of major differences between urban and comparatively rural areas in needs and circumstances of programs and clients (e.g., Blank, Jodl, & McCall, 1996, LaChance & Santos, 1995), every effort will be made to ensure that individuals from urban and rural areas will be represented in approximate proportion to the general population. For purposes of the qualitative methodology to be used in abstracting themes from these interviews, we will wish to interview approximately 10 individuals from each of the three populations of stakeholders (Sandelowski, 1995). Family members and consumers will be reimbursed \$20.00 for their participation in the semi-structured interview.

Data will be collected from consumers, families and service providers through semi-structured interviews guided by interview protocols specifically designed to reflect the objectives of the project. Semi-structured interviews will allow participants to reflect their individual perspectives and at the same time will provide a consistent framework for gathering data. Participants will be asked to share their views on characteristics of community support through reflection on their own lived experience.

In suggesting characteristics they will be asked to focus on those which they see as being critical in “allowing clients to remain out of hospital and improving clients' quality of life.” They will be asked to suggest characteristics, and they will be asked to identify specific and objective indicators of each of the characteristics which they consider to be important. This will be done in the context of reflection on their own experiences with community support programs. This latter aspect of the interview will be designed to allow us to identify the most specific and important attributes of programs to be assessed. As a hypothetical example, the concept of “adequate access to personal support” might be considered as best specified as 24-hour availability of personnel and/or small client: staff ratio. The concept of “adequate access to psychiatric care” might best be specified as having a psychiatrist on the treatment team, or arrangements being in place for rapid assessment at a psychiatric facility. Interviewees will also be asked to review the list of characteristics gleaned from the literature review and suggest additional characteristics that they consider important which are not included in the list.

It is possible that some participants will think of “program characteristics” in terms of broader determinants of health (e.g., help me find a friend have a job). We will then look for ways in which the program specifically addresses these issues. Interviews with consumers and family members will be conducted in person, while interviews with service providers will be conducted either by telephone or in person.

The interviews and focus groups will be audiotaped and the tapes will be transcribed verbatim.

The interview protocols and consent forms have been reviewed and approved by the University of Toronto Ethics Committee (Appendix B).

Focus Groups: Compared to semi-structured interviews, focus groups have the *potential* to provide a rich experiential description from a larger number of people as ideas develop and snowball in the group. We have been somewhat hesitant, however, to go in this direction since we anticipate having to probe respondents on the actual operationalization of program characteristics that they feel contribute to positive outcomes. Such probing is better suited to semi-structured interviews. This will be less of an issue for the collection of data from service providers since we will more easily be able to follow-up with individuals in person or by telephone. Thus, we will anticipate some use of focus groups for service providers and, in order to be efficient with travel funds, we will capitalize on situations where service providers have been brought together for other purposes. With respect to consumers and family members we will explore this option within the other funded research sites interested in participating in Phase I of our project. Follow-up contact for clarification will be facilitated in these instances and we see the value of using a small number of focus groups to help us finalize the content, and probing strategies, required in the semi-structured interviews.

Content Analysis of Stakeholder Interviews: Using similar procedures as in the content analysis of the relevant literature, project staff will use qualitative software (NUDIST) to prepare a list of the key program characteristics that emerge from the interviews. The goal at this stage is to identify the characteristics that emerge from the interviews which can be combined with those identified in the earlier literature review. We will be looking for a broad range of possibly important program characteristics reflecting multiple perspectives. Characteristics should include not just the formal structure of the program (for instance staff/client ratio, whether vocational counselling services are

provided, demographic and clinical characteristics of clients, training and professional background of staff), but characteristics of how such services will be provided (staff optimism, perceived empathy, etc). Program characteristics will not be limited to services that are provided directly by the program, but also services from other agencies that can be accessed by the program and other attributes of the community setting in which they operate.

Grounded Theory Analysis: Grounded theory, as described by Glaser and Strauss (1967), will be drawn upon for analysis of the characteristics emerging from the literature review and interviews.

This approach links or *grounds* inductively developed categories to the data from which they are derived. The grounded theory approach will enable conceptualization of domains and themes identified in the program characteristics emerging from the content analysis of the literature and the interviews. These domains and themes will be converted into questionnaire items and a draft instrument in Phase II of the study. This approach, often referred to as "the constant comparative method of analysis" (Glaser & Strauss, 1967), links or *grounds* inductively developed categories to the data from which they are derived. It includes a systematic set of procedures for analysis including unitizing, categorizing and forming themes (Lincoln & Guba, 1985; Stern, 1980). The grounded theory approach will enable conceptualization of domains and themes identified in the program characteristics emerging from the content analysis of the literature and the interviews. Two broad strategies will be used to maximize the trustworthiness of the grounded theory analyses: triangulation and numerically aided phenomenology.

Triangulation of findings has been identified as a means of ensuring trustworthiness of interpretations. Brannan (1995) draws on the work of Denzin (1970) to describe three types of triangulation, all of which will be employed in this study. They are: multiple investigators, multiple data sets and multiple theories. In the proposed study, at least two separate research personnel will be engaged in assessing the research literature, the transcribed interviews and the resulting list of program characteristics to ensure that emerging themes are grounded in data, and that interpretations are sound. We will be conducting interviews with three separate stakeholder groups (consumers, families and providers) in order to capture different perspectives concerning program characteristics. It is anticipated that the experiences and perspectives which emerge will not be consistent with one another, and will even include conflicting points of view. The role of qualitative research is to capture the core of these meanings and contradictions (Denzin, 1988). Finally, with respect to triangulation methods, the data collection process includes both the research literature and semi-structured interviews with stakeholder groups. This will provide an opportunity to contrast competing perspectives about theoretical and operational issues in community support for people with severe mental illness.

In addition to these processes for triangulation, the inductive, grounded-theory analysis will be supplemented by a numerically aided, phenomenological method of analysis (Kuiken, Schopflocher & Wild, 1989; Wild & Kuiken, 1992). Several basic principles underlie this methodology: (1) numerical phenomenology provides descriptions of the experience of participants by systematically determining regularities in verbal and written accounts of these experiences; (2) properties of experience are empirically identified and classes of similarly reported experiences are formed; (3) classes are formed such that members share a large number of expressed meanings, although no single meaning (set thereof) is necessary or sufficient for class membership and (4) multivariate procedures such as cluster analysis systematically identify classes of reported experience. In this last step,

meanings expressed by at least two participants or two research articles will be scored as present (1) or absent (0) in all other program participants or research articles. Clustering algorithms (Everitt, 1974) will determine the extent to which classes of program characteristics with similar profiles of expressed meaning are represented in the classes of program characteristics under study. These classes are then examined to determine expressed meanings that are more-or-less invariant for members of the class. These procedures provide a rigorous qualitative analysis that remains faithful to the point of view of the participant (Kuiken & Wild, 1988) and will identify the themes that will be transformed into the questionnaire items in Phase Two.

Overall, the analysis process in Phase One moves through the conceptual stages identified in the following diagram.

Phase Two:

The objective of the second phase will be to take the universe of domains and themes identified in the first phase and convert them into items and a draft instrument which will be further refined on the basis of information obtained in Phase Three. We anticipate that the universe of domains and themes which emerge from Phase One will relate to some program characteristics that are comparatively “objective,” such as client/staff ratio or central location of program facilities. Such “objective” characteristics will be best identified through an observation of the program and program records. Other characteristics, such as the empathy of staff, will by nature be more “subjective,” and may be best identified through administration of existing standardized instruments to consumers and/or providers (e.g., Bennett, 1995; Williams, 1990). Still other characteristics such as 24-hour availability of service may require both “objective” and “subjective” methods of assessment. The assessment tool will, therefore, likely consist of a package of instruments including standard data to be retrieved and recorded by an objective third party (e.g., peers from similar community mental

health programs), and instruments to be completed by consumers, service providers, family members or other members of social support networks of consumers.

The assessment instrument(s) will be designed to include multiple sources of information about specific program characteristics. The development of items for the instrument(s) will follow generally accepted guidelines regarding simplicity of structure, reading level, use of specific and concrete referents etc. and will be drafted in a fashion which allows them to be administered to service providers, clients and members of client social support networks. Although every effort will be made to simplify and standardize response formats, some variation in format will be inevitable - some issues will require simple numerical responses (e.g., “How long in minutes is your average contact with staff personnel”); others require analogue scales (e.g., “Rate on the following seven point scale the extent that you feel you are treated with respect by program staff”), and others may require simple checkmarks (e.g., “With reference to which of the following areas do you receive services from this program? a. Medication ___; b. Housing ___; c. Life skills training ___, etc.).

The draft instrument will then be structured so as to allow its easy administration in Phase Three.

Phase Three:

The objective of the third phase will be the refinement of the instrument through an iterative process of field testing and revision. Each field test will be carried out on multiple programs, with generally increasing numbers of programs used in each consecutive field test as the issues being addressed become more subtle. An independent sample of programs will be used for each iteration. Such a process is important in assuring the final development of a feasible, reliable and valid instrument.

Assessing the Feasibility of the Instruments: Feasibility of the instrument will be addressed in several ways. First, we will have to determine for which of the universe of characteristics it is possible to develop appropriate measures (having face validity) that can actually be assessed. For instance, if one of the characteristics to be assessed was to be joint decision-making on service goals between consumers and providers then we might wish to use measures derived from program records regarding joint goal-setting, reports of service providers regarding joint goal-setting, and similar reports from consumers. Feasibility issues to be assessed would include the availability of records, client and provider confidence in their recollection, and agreement between the various sources of information. It may well be that early field trials will lead to discarding of some measures accompanied by suggestions for other measures to replace them. Other aspects of assessing feasibility will include having respondents rate items in the instruments for ease of comprehension and completion, and confidence in the information provided. Another critical aspect of feasibility is the total length of time required to complete the program assessment. Within each domain, only those items empirically showing the strongest correlation with the total domain index (comparable to an item-total correlation) will be retained in the final instrument in order to keep length of time required for assessment feasible. As indicated earlier, multiple sources of information will be used in the program assessment package. If it should turn out that there is high convergent validity between different data sources (e.g., records, providers and consumers agree that there is participatory goal-setting then not all sources need be included in the final instrument. If there is frequently discrepancy

between sources, then information from each source will be retained - indeed such discrepancies in themselves may prove to be of interest and importance.

In addition, we will ask respondents assisting in field trials to rate (on a seven-point analogue scale) each of the items included in the assessment package for their perceived importance. Importance is, of course, a relative concept. In order to ensure some comparability of these ratings, respondents will be asked to rate the importance of these characteristics for “allowing clients to remain out of hospital and improving clients' quality of life”. These criteria have been selected as best representing the shared goals of most, if not all, community-based individual support programs.

Field-Testing and Assessing the Reliability of the Instruments: Test-retest reliability will be assessed by re-administering the instrument package within the same programs one month after the initial assessment. This period of time should prove adequate for assessing test/retest reliability, and should not be sufficient for major changes to have actually occurred in programs' characteristics. The re-administration will allow the calculation of test-retest reliability for each item.

We expect that the first several field trials will be primarily concerned with issues related to feasibility and perceived importance of items, and latter trials with assessment of reliability (and, therefore, requiring larger sample sizes). The first of the field trials will be carried out on a sample of 5 programs, a subsequent trial on 10 programs and final trial on 30 programs, for a likely total requirement of 45 programs for field trial purposes. We will ensure that the programs included in field trials reflect a wide range of sizes, models, and settings, including urban and rural.

Data on Client Characteristics and Outcomes: In addition to collection of data by means of the draft tool, data will be collected from each of the programs involved in the last field trial using the common assessment protocol discussed in the Request for Proposals of the Community Mental Health Evaluation Initiative. It appears likely that this protocol would include measures that would be interesting to relate to program characteristics assessed by the draft instrument. Of particular interest would be information on client characteristics and outcomes such as rehospitalization rates and quality of life. It would be particularly propitious if the quality of life measure was to be the Wisconsin Quality of Life Scale as it provides an assessment of several domains of likely importance in mediating program effectiveness such as social support, goal attainment and aspects of empowerment. In addition, the Wisconsin Scale's three forms (client, provider and family member) parallel the three groups of stakeholders being sampled in this protocol, thereby providing the opportunity for several interesting secondary analyses of interrelations between program characteristics and outcomes within each group and degree of consensus between groups about program characteristics or outcomes.

Data collection and outcome measures related to PSR Toolkit : The relationship between program characteristics and outcomes will also be examined through the use of outcome data gathered by programs using the Toolkit for Measuring Psychosocial Outcomes that is being adopted by members of Ontario Federation of Community Mental Health and Addictions Programs. The Toolkit provides for the assessment of several important outcomes including empowerment, life satisfaction and perceived relevance of program services to personal goals.

Our reliance on the PSR Toolkit data is due to the fact that we require so many programs in the latter part of Phase III for collection of outcome data. Minimally, we require 30 programs for

data analysis where we will combine the consumer outcome data with the data on program characteristics (see below). With the annual cap on funding available through this research competition, it will not be feasible to engage this many programs in a totally new data collection process using the comprehensive core package of the Coordinating Centre. Thus, we must capitalize on the provincial dissemination of the PSR Toolkit for assessing the relationship between consumer outcomes and program characteristics.

Feedback from Ms. Corinne Eckhardt, the Project Manager of the Federation's PSR Toolkit project, indicates that the Canadian version of the Toolkit has now been distributed to 327 Ontario programs with 50 currently trained on the use of the package. Materials are being distributed at the rate of about 10 packages per month. Attendance at the training workshops for the Toolkit has been outstanding with all sessions booked to capacity or more. For example, a training event at the Federation's annual general meeting was booked for 35 and 77 people attended. A training event sponsored by the Hamilton District Health Council had 28 anticipated and over 40 attended. While it is not feasible at this time to provide letters of agreement from each agency, the dissemination of the Toolkit is widespread and likely to continue and we have the strong support of the Federation in securing participation (letter in original proposal). Furthermore, Ms. Eckhardt has agreed to participate on our Project Advisory Committee and this will ensure close communication and collaboration with the Federation's Toolkit initiative. Thus, we remain confident that we can secure the participation of at least 30 community support programs using the Toolkit in Phase III of our project.

For those sites using the Toolkit, we will liaise directly with a key staff member identified by Ms. Corinne Eckhardt, and who is verified through the agency's Executive Director as our primary agency contact. Our objective will be to have the staff representative maintain a separate, consumer-level, database of selected results from the administration of the Toolkit and to monitor quality and completeness of data. These results will come at different points in time, beginning with the baseline, and then coinciding with the beginning and conclusion of our reporting period for program characteristics (see timeline). A variety of methods will be required to accommodate the level of information technology in the program site. Options for collating and submitting our "minimal data set" will include downloading from the Toolkit data collection software currently under development; data collection and submission with a runtime version of Access2 provided to each site; regular teleform submissions by fax to the central project site; and paper with data entry by our project staff.

Table 1 shows the descriptive and outcome measures to be drawn from the Toolkit:

Table 1: Descriptive and outcome measures to be abstracted from the PSR Toolkit and collected through the CMHEI Core Package

	PSR Toolkit	CMHEI Core
Descriptive Measures	<ul style="list-style-type: none"> ▪ member status/time in program* ▪ age* ▪ gender* ▪ racial background* ▪ education* ▪ marital status* ▪ primary diagnosis* ▪ age at first hospitalization* ▪ current DSM-IV Axis I Diagnosis ▪ current DSM-IV Axis II diagnosis 	
Outcome Measures	<ul style="list-style-type: none"> ▪ number of days in inpatient psychiatric care in past year (and past 9 months)* ▪ community tenure in past year (and past 9 months)* ▪ current residential status and setting* ▪ current job status* ▪ total monthly income* ▪ program satisfaction (from member survey) ▪ quality of life (from member survey) ▪ mastery (from member survey) 	<ul style="list-style-type: none"> ▪ social support ▪ empowerment ▪ symptom distress ▪ quality of life (Lehman) ▪ frequency of contact in past nine months

**Toolkit measure corresponds exactly to CMHEI outcome measure or can be recoded to make appropriate match (see Appendix C for details).*

Our reliance on the PSR Toolkit notwithstanding, we anticipate collecting several data elements in common with the core set of measures to be used by the Coordinating Centre. This commonality results from the Toolkit being used in the selection of several of the outcome measures in the core set. While several of the Toolkit measures have been adapted (e.g., the reporting period for some items has changed to accommodate the 9- month follow-up schedule) other items remain as is or can be constructed from the original data. Demographic and outcome measures in the Toolkit which parallel those in the CMHEI packages are asterisked in Table 1.

Addition of Some CMHEI Instruments: We also propose to ask our participating programs to add a number of instruments from the Coordinating Centre package to their data collection with the Toolkit. This extra complement of measures must be kept to a minimum to prevent the agency staff and consumers from being burdened with excessive and unnecessary information gathering. However,

we are balancing this need for caution with the desire to maximize the overlap between our outcome measures in the Toolkit and those in the Coordinating Centre package. We also note that the Toolkit contains items to be completed by the program staff as well as a “member survey” to be completed by the consumer, the latter being a 20- item questionnaire. We recommend adding a small number of *self-report* measures for the consumer and a data element to be abstracted from the agency records concerning frequency of contact with the program. Pending further advice from our Advisory Committee we anticipate using the measures from the Coordinating Centre protocol that are identified in Table 1.

Selection of Participating Programs: With respect to our selection procedures within each participating agency we estimate average program size to be 50-75 consumers, based on the results of the “mental health snapshot” - a descriptive study of all community mental health services in Ontario conducted by a member of our project team (S. Lurie). Based on the current dissemination strategy and training with respect to the PSR Evaluation Toolkit, we aim to collect the descriptive and outcome measures identified in Table 1 on all consumers enrolled in the program. This is intended to maximize the likelihood of achieving at least 30 consumers per program (see discussion of sample size in the next section) providing both baseline and outcome data with attrition from the original sample expected to be between 20-30%.

Statistical Analysis of Program Characteristics and Outcomes: Multi-level designs such as the one in this project are especially relevant in situations where there is an inherent hierarchical structure in the research design, as in our design with a group of programs and a group of consumers in each program. In this situation, it is common in traditional approaches to either aggregate the data to the group level or disaggregate the data to the individual levels. If one aggregates the clustered data, this increases the possibility of Type II error (i.e., a real association between outcome and an exposure variable is deemed to be insignificant) mainly through the reduction in sample size and statistical power. On the other hand, disaggregating the data, that is assigning group-level data to each individual, increases the likelihood of Type I error (i.e., a chance association between outcome and an exposure variable is deemed to be significant) because the nature of the clustered data results in unexpectedly small variance estimates due to high interclass correlations within clusters. Multi-level models keep the hierarchical nature of the data intact thus avoiding the unit of analysis problem. Multi-level analyses also allow one to test for cross-level interactions, an important feature since a group (program) characteristic will not necessarily have the same effect on all types of individuals (consumers).

In Phase III, hierarchical linear modelling will be used as an analysis strategy and will be performed with the statistical package HLM/3L³ (Bryk, Raudenbush and Congdon, (1996)). As is appropriate for this type of modelling both the measures of program characteristics and consumer outcomes will be assessed over the same time period (see attached Timeline). HLM/3L can produce both full information maximum likelihood solutions (FIML) as well as a residual maximum likelihood solution (REML), the latter being the most appropriate for data sets with a small number of groups. The HML/3L program also has the advantage of being user-friendly with a Windows interface. The

³We anticipate a new version of this software to be available in September 1999.

specific plan for the multi-level analysis will follow that recommended by Kraft and De Leeuw (1998) and as outlined in the HLM/3L manual.

With respect to assessment of statistical power, formal a priori calculations will be possible with the new software recently developed by the developers of HLM/3L. For proposal development we relied on existing simulation studies which have determined optimal sample sizes for two-level data. Bassiri (1988) and Van der Leeden et al (1994) found that in order to obtain sufficient power (.90) for cross-level interactions, 30 groups and 30 observations per group were required, the critical factor being the number of groups. Thus, our target of 30 community support programs and 30 consumers per program for Phase III is appropriate.

Refinement and selection of items for the final instrument will be based on the following considerations: (1) feasibility; (2) reliability; (3) perceived importance of characteristics as reflected in the ratings made by respondents during the field trials; and some initial data that would be available from the measures described in the preceding paragraph on the extent to which specific items show strong relations to outcomes as assessed by the common assessment protocol prescribed by the Coordinating Centre and the Evaluation Toolkit.

Phase Four:

This final phase of the project (Year 5) will involve the development and field testing and various strategies for application of the instrument package.

The Project Description Manual: A detailed manual will be developed which describes the objectives, rationale, target population and recommended methods of administration for each instrument in the package. Information will also be provided on instrument development, reliability assessment (test-retest and inter-rater) and scoring procedures. A prototype of the manual will be pretested in three to five new programs to get feedback on language used, overall ease of comprehensive, layout etc. prior to publication.

Use of the Information System to Implement the Evaluation Tools Province Wide: Another aspect of this phase early in year five will involve consultation with information system specialists (e.g., the Coordinating Committee; those involved in developing Ontario's SMART system; and the Joint Planning and Policy Committee) on the potential application of the evaluation tools in provincial/regional monitoring systems for community mental health programs. We will also consult with the membership of the Ontario Federation of Community Mental Health and Addictions Programs; other non-member service providers; consumers and family members (e.g., Friends of Schizophrenics) to explore their ideas for potential application across the system and within individual programs.

Two specific types of internal program application are currently planned. The first is a user-friendly checklist or template that encourages program managers, staff, consumers and family members to: (1) raise key questions about the most critical program characteristics emerging from Phases 1-3; (2) identify needs for enhancing these characteristics in their program (or local network of programs); and (3) suggest strategies for program improvement. A guidebook will be prepared which describes how this process might fit with other quality management practices within the program or local network. The guidebook will emphasize the need for ongoing, rather than a one-time, review of critical program characteristics, and the parallel examination of outcomes being achieved (e.g., with the PSR Toolkit and/or the core outcome measures recommended by the Coordinating Committee). Such procedures would allow programs themselves to readily examine

the consequences of program changes for various dimensions of outcome for their clients. Such information could be extremely valuable in program planning and management.

The second, more comprehensive, application of the instrument package will involve the development of a peer evaluation model that will include the one-time assessment of critical program characteristics, and potentially, the longitudinal application of the instrument(s) to parallel ongoing outcome monitoring. Peer evaluation brings outside objectivity to a program's evaluation activities in a non-threatening, supportive manner conducive to service enhancement. The literature on "peer review" will be reviewed early in the project to guide our model development, and a special sub-committee of the Project Advisory Committee will be struck in Year 2 to focus on this component.

The group will be able to build from a peer evaluation model developed by one of the principal investigators (B. Rush) for Supported Employment Programs which assist people with developmental disabilities in community living (Community Involvement Council, 1996). An important condition for a program wishing to involve peer evaluators is to agree to have one or two people in their program trained in the model to subsequently support other programs in a similar process. This approach has been successfully employed with Supported Employment Programs. With the support of the current project team in preparing guidelines, training peer assessors and supporting on-site application, it is anticipated that a similar "snowball" effect will occur in the Ontario community mental health system.

Final Field Test and Cost Benefit Assessment: In Year 5, we will field test the basic application for ongoing quality management (3-5 programs) and the more comprehensive peer evaluation model (2 programs). Qualitative feedback will be obtained through telephone interviews with the key personnel involved in these sites (estimated five interviews per site), review of documentation about the recommendations emerging from the application of these two strategies, and documentation about actual changes to program characteristics. We will also carefully assess the costs associated with these two strategies in the field sites and prepare a report outlining the costs and benefits.

This proposal for development of an instrument package for measuring program characteristics has focused on characterizing each program as an aggregate. Such an approach is central to developing and monitoring program policies at a system level. On the other hand, it could also be beneficial to use those characteristics which emerge as important on an aggregated program level, and examine the extent to which they characterize the procedures and processes provided to, and related to, outcomes for individual clients within programs. As noted earlier, the CPPOA model (Yates, 1996) provides the conceptual model for such a potential transition of assessment data to be used to characterize variation across individuals within programs, in addition to variation across programs. Such an undertaking will also be initiated in Phase Four and could allow programs to analyse relations between program costs, procedures, processes and outcomes at the individual as well as program level.

Informing the Community of Project Results: The final component of Phase Four will involve a formal debriefing about the project with Ontario's community mental health agencies and critical stakeholders. This will involve presentations and workshops at meetings of particular organizations (e.g., Federation Annual General Meeting and annual conference), and organized presentations and feedback sessions at the Centre for Addiction and Mental Health. The regional structure of both the

Federation and CAMH will facilitate regional debriefing to ensure the opportunity for relevant, local feedback.

SUPPORT FROM THE FIELD:

As can be seen from the enclosed letter of endorsement, this project has the enthusiastic support of the Ontario Federation of Community Mental Health and Addictions Programs (see Appendix A). Also various presentations about the proposal (e.g. the Annual General Meeting of the Federation (Oct.24/94); Executive Directors of the Ontario Division of the CMHA) have been well-received and resulted in several program managers coming forward after the presentations to discuss the project and their participation. With the active support of the Federation, its Research Committee, and the Project Advisory Committee, recruitment into the project will occur through additional presentations, mail-outs and telephone calls. Feedback to date suggests that we will not have difficulty recruiting the required number of programs to participate, since the target audience has been impressed by the collaborative work between program representatives and the research team on the development of the proposal; the clear intention to incorporate multiple perspectives into the identification of program characteristics; our desire to produce an instrument, or package of instruments, useful for both system-level monitoring and individual agency-level evaluation; current efforts across the province to engage in outcome monitoring with the PSR Toolkit; and finally our intention to engage the participating agencies (and our Project Advisory Committee), in a meaningful learning experience about the evaluation of community mental health programs.

PROJECT MANAGEMENT:

The project is very large in scope and we recognize that the successive phases of implementation are dependent on the achievement of milestones in the preceding phases. In order to be very clear on task definition and roles of the various members of the project team, and to monitor progress carefully, we plan to use project management software (Microsoft Project) to develop a detailed Project Plan and conduct a bi-weekly review of progress against specific objectives and milestones. The Project Plan will be updated on a regular basis and submitted to OMHF as a supplement to the routine reporting protocol to be established for all the projects funded in the initiative. All hired project staff will be located at the CAMH - Addiction Research Foundation site in Toronto and supervised in this location on a daily basis by the P.I. (B. Rush).

WORKPLAN AND TIMEFRAME

The four phases of the project described in the methodology section will be implemented over a five-year period: Phase One (one-year); Phase Two (eight months); Phase Three (two years, four months); and Phase Four (one year). Prior to Phase One attention will be devoted to project organization and management. Important milestones include the hiring of staff and development of the Project Advisory Committee. Figure 1 shows a detailed timeline for the major task areas within each phase and the preliminary work on project management.

Within Phase One (one year), time must be allocated for recruitment of staff and training . While we will be recruiting staff with experience with qualitative analysis, we also anticipate some training will be required to ensure an appropriate level of skill in this area and in the use of NUDIST software specifically. Training will be coordinated and conducted by Bonnie Kirsh and Cam Wild. We anticipate the following steps: assessment of training needs; assignment and discussion of

selected readings; practice with identification of themes using qualitative information available from other projects; participation in NUDIST training sessions as indicated by the learning needs assessment; follow-up consultation by NUDIST trainers as appropriate; and close monitoring through the Project Plan. Much of this activity will occur simultaneously with other tasks in the early stages of Phase I. The other critical milestones in Phase I will include completion of the literature review; preparation of a list program characteristics from the initial content analysis; completion of stakeholder interviews and focus groups; transcription of the interviews; preparation of an integrated list of characteristics from the literature review and interviews; completion of the numerical phenomenological analysis and grounded theory analysis; preparation of an interim report for the Project Advisory Committee, a briefer report for participating service providers, consumers and family members and a report on the results of the overall qualitative analysis for publication and presentation at a scientific meeting. The research team, in particular Cam Wild, Brian Rush, and Bonnie Kirsh, has considerable experience in the conduct and analysis of focus groups.

Within Phase Two (eight months), critical milestones include the development of items, compilation of these items into instruments for particular target populations and identification of existing instruments that address particular domains and themes that emerge from the qualitative analysis.

Phases I and II represent a very critical period for the project since they build the foundation for the instrument development, and therefore the success of the overall endeavour. While we remain committed in principle to the time frame established in the proposal, we will seek every opportunity to shorten Phases I and II when we can do so without threatening the achievement of the overall project objective. We are sensitive to the value of completing Phases I and II in a timely fashion so the instrument can be used by the Coordinating Centre to complement the use of the IFACT. Assuming prompt final release of funding, we should achieve this milestone in the fall of the year 2001. However, it is possible that we will get to this stage earlier in that year, if recruitment and training of staff can be accelerated based on the qualifications and experience of the successful applicants.

Within Phase Three (2 years, four months), critical milestones include completion of data collection with draft instruments in five field sites; revision of the instruments; completion of data collection in 10 field sites; revision of the instruments; completion of data collection with final instruments in the 30 field sites; collection of cross-sectional outcome data in the same 30 field sites; analysis of aggregated program-level outcomes and the measures of program characteristics; final revisions to the instruments; completion of interim reports for Project Advisory Committee, briefer reports for participating programs and reports for publication and presentation.

Within Phase Four (one year), critical milestones include the development of a manual; development of a brief checklist and guidebook for use in internal quality review processes; a report on development and application of a peer evaluation model using the program assessment instruments; a report on application of the instrument(s) in provincial or regional monitoring systems (including models for statistical analysis); final reports and presentations.

ETHICAL ISSUES

Participants involved in the interviews in Phase One of the study will include consumers, family members and service providers (including administrators) of community support programs. Representatives of the Ontario Federation of Community Mental Health and Addictions Programs

will contact its membership and other selected community support programs, consumer/survivor and family groups (e.g., Consumer/survivor Information Resource Centre, Ontario Friends of Schizophrenics) will be contacted regarding participation in the study as well. Appropriate materials describing the study, and Phase One in particular (including Letters of Information for Potential Participants), will be distributed to program staff, consumer and/or family members. Potential participants will be invited to express their interest by calling the specified project phone number and an interview time and location which is convenient for the participant may then be arranged. The goals and procedures of Phase One will be reviewed with each potential participant and a consent form will be given to each participant for signature. Participants will be informed, verbally and within the Consent Form, that they can withdraw from the study at any time. For consumers and family members, the letter will make it clear that participation in the interviews will in no way influence the course of services they will receive from any community mental health program. Assurances of confidentiality among the qualitative analysts on the project team will be clearly given. Interviews will be tape recorded and verbatim transcriptions will be made. All written data will have names of participants deleted and replaced by codes known only to the investigators conducting the analysis. All data, including audiotapes, will be stored in locked cabinets in the research office. No names or identifying data, other than the name of the overall program (which is in the public domain) will be included in any of the papers or reports which will result from the study.

A draft of the interview protocol and the consent forms for Phase One have been approved by the University of Toronto Ethics Committee. In Phase Three, consumers will be invited to participate in the outcome component of the project through an explanatory letter which outlines the purpose of the project and the request for a one-hour appointment for completion of the outcome measures. Participants will also sign a Consent Form specific to this phase of the project. The full protocol for Phase Three, including the measures, data collection procedures, letters to participants and consent forms will be submitted to the University of Toronto Ethics Committee at the appropriate time for approval prior to data collection.

PROJECT STAFFING PLAN

Co-Principal Investigator: Dr. Brian Rush (20%)

Dr. Rush is a Senior Scientist with the Centre for Addiction and Mental Health (CAMH) and currently Program Leader for the Priority Program on Monitoring, Evaluation and Information Systems in the Addiction Research Foundation Division of CAMH. He will be responsible for overall project management, scientific and financial, and accountability, supervision of the Project Coordinator and Research Associate and will assume primary responsibility for the achievement of all project milestones in a timely and quality manner. He will take the lead role in liaison with the Coordinating Centre, the Project Advisory Committee and key stakeholders.

Co-Principal Investigator: Dr. Ross Norman (20%)

Dr. Norman is an experienced clinician and mental health services researcher currently playing an active role in the delivery and evaluation of a community mental health rehabilitation program in London, Ontario. He will play a significant role in the identification of the relevant research literature and supervision of the content analysis; item and instrument construction (with Dr. Wild) and integrated analysis of program characteristics and aggregated outcomes at the program level.

Co-Investigator: Dr. Bonnie Kirsh (15%)

Bonnie Kirsh is a mental health services researcher with considerable expertise in qualitative methods. She will play a significant role in supervision of the content analysis of the stakeholder interviews and grounded theory analysis to identify key domains and themes for subsequent item development. She will also play a major role in the integrated analysis of program characteristics and outcome and the application of the instruments in a peer-evaluation model.

Co-Investigator: Dr. T. Cameron Wild (10%)

Dr. Cam Wild is a health services researcher with considerable expertise in instrument development and qualitative methods. He will play a major role in the grounded theory analysis, in particular the numerically-aided phenomenological analysis. His psychometric expertise will be drawn upon extensively during instrument construction testing and revision.

Project Coordinator: Ellen Tate (100%)

Ms. Tate will be responsible for coordinating the day-to-day aspects of the project including the literature review, content analysis, stakeholder interviews, grounded theory analysis and all data collection in the project sites. Under supervision, she will also conduct the analyses required for instrument revision and assessing the relationship between program characteristics and outcomes. she will also prepare draft reports for presentation and publication.

Research Associate: Stasey Tobin (50%)

Ms. Tobin will assist the Project Coordinator and Investigators in all aspects of the project, in particular serving as a second (independent) assessor in the content analysis and grounded theory analysis, and supporting data collection and analysis in Phases 3, 4, and 5.

INVOLVEMENT OF KEY STAKEHOLDERS

A Project Advisory Committee was established immediately upon approval of the research grant. Over the course of the project, it is anticipated that composition and required input from the committee will evolve. The committee will play a very significant role in guiding the research team through difficult conceptual and philosophical issues; securing support for the project in the field; interpreting results and developing strategies for application of the instrument(s). The role of the Advisory Committee as essential, not only to the successful execution of the project, but to the eventual dissemination and application of the results on a wide scale.

The Committee has been designed to reflect the collaborative partnership between the researchers on the project team and the Ontario Federation of Community Mental Health and Addictions Programs. The Committee consists of 12 members, plus the research team, and includes individuals with experience of individual support programs targeted at people with severe mental illness (e.g. supportive housing and case management programs). The Committee includes: consumers, family members and staff associated with a wide variety of program types and geographic areas. Board members will be desirable but not necessary.

Specific spots on the Advisory Committee are designated for: (1) ex officio membership of Federation staff, with Corinne Eckhardt suggested to ensure a strong link to the PSR Tool-kit project; (2) a psychiatrist familiar with community mental health programs (Dr. Peter Prendergast has agreed to participate; and (3) a representative from the Canadian Mental Health Association.

The basic function of the Advisory Committee is to facilitate the execution of the research proposal. This will involve:

- input and advice including conceptual and methodological feedback to the research team, including the user friendliness of instrumentation
- identification of limitations and potential problems
- facilitating the piloting of questionnaires and interviews
- review and approval of the overall plan for each phase; review of results and suggestions for next steps/ modifications

The Advisory Committee will meet 4-6 times per year in order to ensure continuity and meaningful participation of the group, with some meetings timed to occur at the beginning and completion of each phase. The group will interact primarily by teleconference. As the project progresses, workgroups will be established with potential involvement of other programs and stakeholders.

The Advisory Committee provides information to and obtain feedback and suggestions from the Mental Health Council of the Board of the Federation of Addiction and Community Mental Health Programs. Reporting will be for the purposes of information and obtaining suggestions, not approval, since the investigators will be formally accountable to the Ontario Mental Health Foundation through the Centre for Addiction and Mental Health which is the project sponsor.

BUDGET

The total budget for the project is \$397,697, over the five-year granting period. Annual breakdown is as follows Year 1: \$79,838; Year 2: \$78,945; Year 3: \$79,724; Year 4: \$79,829; and Year 5: \$79,361.

The budget details were included in the grant application form and the Budget Justification which accompanied the budget. In developing the budget we were very attentive to the annual cap on the budget for each project to be funded in the competition (\$80,000). We were as detailed as possible in preparing our budget estimates especially given the uncertainty in Years Three, Four, and Five on the actual location and travel costs related to the sample of programs which will participate in the project (e.g., Northern and Eastern Ontario with resulting costs of airfare for essential on-site work and consultation). No grant administration fees were included for space, human resources, payroll, computing facilities etc. In addition, the CAMH will provide a variety of resources in-kind including word-processing, and statistical consultation, human resources and payroll, and office supplies. The Research Committee of the Federation will provide some administrative support for the Project Advisory Committee and will contribute their time as advisors to the project.

Figure 1. Estimated Time Line and Main Task Groups by Project Phase
(Currently being finalized)

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Appendix A

Letter of Support

Appendix B

Phase One: Consumer Interview Guide for Semistructured Interview

The following are the questions and probes developed for the Phase One interviews with consumers. Any additional questions and probes developed by the researchers and the Advisory Group will be similar in nature and related closely to those listed below.

1. What type of community support programs have you been involved in, and for how long?
1. Probe: What type of support did you get in this (these) program (s)?
2. What type of time limits, if any, exist in this (these) program(s)?
2. How did you become connected with this (these) programs?
1. Probe: How accessible is (are) the program(s)?
3. Do you feel involvement in this (these) program(s) benefitted you? In what way(s)?
4. Please describe specific components (parts) of the program(s) that helped you most.
1. Probe: What activities, interventions or services were helpful?
5. Were there people in the program that were helpful to you? In what way(s) were they helpful?
1. Probe: What human qualities were helpful? What components of the relationships were helpful?
6. What specific aspects of the program(s) would you say were most valuable to you?
1. Probe: What was good about the program? How was the climate of the program experienced?
7. Were there things missing from the program(s) that you think would have helped you improve your life in the community?
8. I'd like to show you a list of program characteristics which was developed from an examination of the research on community support. Please tell me how important you think each item is to staying out of hospital and improving life in the community.

9. Can you offer advice on how you think programs should put each characteristic into practice (for example, what should a program do to best address the characteristic "adequate access to psychiatric care")?
10. What other characteristics do you think are important in helping people with mental illnesses stay out of hospital and improve their lives in the community?
11. Is there anything else you'd like to ask me or tell me?

Phase One: Interview with Family Member
Guide for Semistructured Interview

The following are the questions and probes developed for the Phase One interviews with family members. Any additional questions and probes developed by the researchers and the Advisory Group will be similar in nature and related closely to those listed below.

1. What type of community support programs has your (family member) been involved in, and for how long?
 1. Probes: What type of support did he/she get in this (these) program (s)?
 2. What type of time limits, if any, exist in this (these) program(s)?
2. How did your (family member) become connected with this (these) programs?
 1. Probe: How accessible is (are) the program(s)?
3. Do you feel involvement in this (these) program(s) benefitted your (family member)? In what ways(s)?
4. Please describe specific components (parts) of the program(s) that helped your (family member) most.
 1. Probe: What activities, interventions or services were helpful?
5. Were there people in the program that were helpful to you and your (family member)? In what way(s) were they helpful?
 1. Probe: What human qualities were helpful? What components of the relationships were helpful?
6. What specific aspects of the program(s) would you say were most valuable to (your family member)?

1. Probe: What was good about the program? How did you perceive the climate of the program?
7. Were there things missing from the program(s) that you think would have helped your (family member) improve his/her life in the community?
8. I'd like to show you a list of program characteristics which was developed from an examination of the research on community support. Please tell me how important you think each item is to staying out of hospital and improving life in the community.
9. Can you offer advice on how you think programs should put each characteristic into practice (for example, what should a program do to best address the characteristic "adequate access to psychiatric care")?
10. What other characteristics do you think are important in helping people with mental illnesses stay out of hospital and improve their lives in the community?
11. Is there anything else you'd like to ask me or tell me?

Phase One: Interview with Service Provider
Guide for Semistructured Interview

The following are the questions and probes developed for the Phase One interviews with service providers (including administrators). Any additional questions and probes developed by the researchers and the Advisory Group will be similar in nature and related closely to those listed below.

1. What type of community support does your program provide?
1. Probes: Is there a philosophy that guides your program?
2. How do consumers become involved in your program?
1. Probes: How accessible is the program?
3. In what way(s) you feel involvement in this program benefits mental health consumers?
4. Please describe specific components of the program that you feel are most helpful to consumers.
1. Probes: What activities, interventions or services are helpful?
5. How are staff of the program helpful to mental health consumers?
1. Probes: What human qualities are helpful? What components of the relationships are helpful?
6. What specific aspects of the program would you say are most valuable to consumers?
1. Probes: What is good about the program? How would you describe the climate of the program?
7. Are there things missing from the program that you think would help consumers stay out of hospital and improve their quality of life?

viii I'd like to show you a list of program characteristics which was developed from an examination of the research on community support. Please tell me how important you think each item is to staying out of hospital and improving quality of life.

ix How should programs best operationalize each characteristic? (for example, what should a program do to best address the characteristic "adequate access to psychiatric care")?

- x What other characteristics do you think are important in helping people with mental illnesses stay out of hospital and improve their lives in the community?
- xi Is there anything else you'd like to ask me or tell me?

Explaining Outcomes: Developing Instruments to Assess the
Critical Characteristics of Community Support Programs for
People With Severe Mental Illness.

Investigators: Brian Rush, PhD.; Ross Norman, PhD.; Cameron Wild, PhD.;

Bonnie Kirsh, M.Ed., PhD candidate.

Advisory Group: Steve Lurie (Chair); Lynn Raskin; Wendy Czarny; others to be determined.

This group will consist of consumers, family members, and service providers (including administrators).

Letter of Information for Potential Participants

Dear Consumer/Parent /Service Provider:

We are a group of researchers, service providers, consumers and family members working on a research project dealing with community support for people with serious mental illness in Ontario. We would like to invite you to participate in the first phase of our study.

The purpose of this research is to develop a new method of assessing important characteristics of community support programs in the province of Ontario. In this first phase of the study, we are interested in finding out what the essential ingredients of community support programs are, so that we may ultimately determine how these ingredients affect the consumers of these programs. Our goal is to ask consumers, families and service providers what they consider to be the most important characteristics of community support programs, based on their own experiences with such programs. This information will be used in the development of an assessment which will reflect issues identified by people who have had experience with community support programs. The assessment that will result from this study will be an important tool for evaluating community mental health programs so that they may provide the highest quality of service.

If you decide to take part in this research, you will participate in an interview for approximately one hour. You will be asked to reflect on your experience with community support programs and discuss important characteristics of them. You will also be asked to review a list of program characteristics and give your opinions about their importance in improving community life for mental health consumers. The information that you and others provide will be used to develop specific questions that can be used to find out whether these critical characteristics exist within programs.

The interviews will be held at a time and place that are convenient to you. The interviews will be tape recorded so that important information is not lost. Only members of the research team will have access to the tapes and the tapes will be erased when the project is completed. No names will be used in any written material or reports that result from this research. If you choose not to answer any particular questions in the interview, you will not be pressured to do so. You are also free to withdraw from this research at any time without any negative effects for you.

There are no known risks in this research. Although you may not directly benefit from participating in this study, your involvement will contribute to the development of a way of identifying important characteristics of community support programs for people with severe mental illness.

If you would like to participate in the study, or if you have questions about the study, please contact Dr. Brian Rush at . Thank you for taking the time to read this letter.

Sincerely,

Appendix C

Cross-walk of Selected Variables Derived From PSR-Toolkit and Coordinating Centre Core Package

PSR - Toolkit	CMHEI
I. DEMOGRAPHICS (completed by agency staff based on information from consumer and files)	some of the demographic information is self-report by consumer, other is complete by agency staff
<i>Time in program</i> - difference between Date of Program Enrolment and Baseline Date (in days, months or years). Also records status in program as: new, renewed, ongoing, semi-active and inactive.	- length of Program Participation is recorded on agency form
<i>Gender</i> · female · male	same
<i>Age</i> - baseline age in years	same
<i>Racial background</i> - self-description of “race or colour” <ul style="list-style-type: none"> • aboriginal / first nations • black / African origin • hispanic • South Asian • East Asian • West Asian • white (European origin) • mixed race • other (specify) 	Self-description of “racial background” <ul style="list-style-type: none"> · aboriginal · asian · black · white · mixed · other (specify)
<i>Country of Origin</i> <ul style="list-style-type: none"> • Canada or other plus year of permanent residency 	· open-ended (to be coded) · if not Canada, year of immigration
<i>Preferred Language</i> <ul style="list-style-type: none"> • English • French • other (specify) 	same
<i>Education</i> <ul style="list-style-type: none"> - years of education completed (0-20) - also recorded into categories 	- same
<i>Marital Status</i> 1 = single/never married	- same

PSR - Toolkit	CMHEI
2 = married 3 = cohabiting with significant other 4 = separated 5 = divorced 6 = widowed	
<i>Age at first hospitalization</i> - refers to psychiatric hospitalization and is recorded in years. - can compute length of time since first hospitalization	- same
<i>Primary Psychiatric Diagnosis</i> ·mood disorder ·anxiety disorder ·schizophrenic disorder ·personality disorder ·developmental handicap ·substance-related disorder ·mental disorders due to a medical condition ·delirium, dementia, amnesic other cognitive disorders ·specific disorder of childhood/adolescence ·other ·unknown Also records current DSM-IV numerical codes within both Axis I and Axis II and whether each is primary or secondary diagnosis	- same categories for primary diagnosis
<i>Employment</i> (re: most responsible job) agency staff report - descriptive not outcome variable - no equivalent for “ever employed” - no equivalent to description of “most responsible job” - employment outcomes are recorded (see below)	- ever employed yes no - for job with highest level of responsibility · status - FT or PT · hourly wage or annual salary · paid or volunteer · job support · number of months job held · year job held · type of job · human service worker · employed in CSI · self employed
II. OUTCOMES	
<i>Hospitalization</i>	

PSR - Toolkit	CMHEI
<p>(1) # episodes during any given period (based on admit and discharge date) coded as <u>psychiatric</u>, <u>substance abuse</u> or <u>medical</u> based on type of facility. Each episode also coded as voluntary/involuntary.</p> <p>(2) length of stay in days based on admit and discharge dates</p> <p>(3) community tenure: number of days spent in community outside inpatient facility (# of days in period minus sum of LOS)</p>	<p>(1) focus is on # of days <u>in the past 9 months</u></p> <ul style="list-style-type: none"> - psychiatric, substance abuse and medical reason (can check all that apply) - hospitals also coded (PPH, GHI, SP, GH, other) - voluntary/involuntary coded - can compute community tenure <u>in past 9 months</u>
<p><i>Residential status</i></p> <ul style="list-style-type: none"> · <u>current</u> residential status coded with separate variable for: <ul style="list-style-type: none"> (a) who consumer lives with (5 categories) (b) level (reflecting type of accommodation / housing as well as <u>level of responsibility</u> for maintaining their dwelling and living status <ul style="list-style-type: none"> • independent • assisted/supported • supervised non-facility • supervised facility • treatment institutions • homeless • correctional facility (c) setting (17 categories) <ul style="list-style-type: none"> · current situation is coded as “stable” (0) or “temporary/transitional (1) with 30 days guideline for coding · if transitional, then <u>prior</u> and <u>planned</u> status is coded 	<p>(still under revision)</p> <ul style="list-style-type: none"> · <u>current</u> residential status is coded with separate variables for <ul style="list-style-type: none"> (a) who consumer lives with (6 categories - extra category is “Alone”)) (b) level <ul style="list-style-type: none"> · independent · assisted/supported · supervised non-facility · supervised facility (c) setting (same 17 categories as Toolkit) · expectation re: setting over next 60 days · residential status <u>over past nine months</u> also recorded using both level and setting codes · # of different settings coded
<p><i>Employment</i></p> <ul style="list-style-type: none"> - total paid jobs since (beginning of current assessment period) - currently working (yes/no) - current hours per week in remunerative activity - hourly wage (volunteer = \$0) - start date of current job (if more than one job code start date of highest level job) - benefits - health insurance (yes/no) - current job status: <ul style="list-style-type: none"> • independent competitive emp. • assisted competitive model • job coach model • transitional employment model 	<ul style="list-style-type: none"> - focus is on employment status in past 9-months - currently working (including volunteer) (yes/no) - total number of different jobs - for <u>each</u> job held in 9 month period the following are recorded <ul style="list-style-type: none"> · status FT, PT casual, PT reg. · volunteer/paid and if paid, hourly wage · support <ul style="list-style-type: none"> * sheltered workshop * other supported * independent · self-employed (yes/no) · employed by CSI (yes/no) · human service worker (yes/no)

PSR - Toolkit	CMHEI
<ul style="list-style-type: none"> • agency paid transitional model • in-house transitional model • work-crew model • sporadic or casual emp. • sheltered workshop • non-paid work experience • no employment of any kind <p>(manual contains recommendations for collapsing categories for better ordinal scale)</p>	<ul style="list-style-type: none"> • duration of job
<p><i>Education</i></p> <ul style="list-style-type: none"> - has consumer engaged in any formal program of education since (beginning of current assessment period) (yes/no) - currently a student (i.e., in past week (yes/no)) - if yes, what type of educational institution <ul style="list-style-type: none"> • secondary / high school (9-12) • adult education • community college • vocational/technical centre • trade school • university • other <ul style="list-style-type: none"> · credit/classroom hours per week · current start date (if multiple, the earliest is coded) 	<ul style="list-style-type: none"> - focus is on educational status in the past 9 months - engaged in past 9 months (yes/no) - currently a student (i.e., in past week (yes/no)) - for most <u>recent</u>, what type? Same categories as Toolkit <ul style="list-style-type: none"> · full-time/part-time · how regular was attendance <ul style="list-style-type: none"> · most of the time · about half the time · less than half the time · unknown
<p><i>Financial</i></p> <ul style="list-style-type: none"> - amount of money received in the past <u>month</u> is recorded within 10 categories - various sub-totals then calculated (e.g., total earnings; total welfare; total all income and benefits) - if no income, a zero is entered in each category 	<ul style="list-style-type: none"> - amount of money received in a <u>typical</u> month during the past 9 months, reported within 11 categories - various sub-totals possible - place to record “no income”
<p>Categories:</p> <ul style="list-style-type: none"> · General Welfare Assistance · Ontario Disability Support Program (FBA) · GAINS - D · CPP Disability · Earnings (self and spouse/partner) · Employment Insurance · Workman’s Compensation · Old Age Supplement · Allowance/Income from family · Other (e.g., alimony; trust fund) 	<ul style="list-style-type: none"> - same categories as PSR - Toolkit

PSR - Toolkit	CMHEI
<p><i>Legal</i></p> <ul style="list-style-type: none"> - Total number of different types of incidents since (beginning of assessment period or other date of interest) <ul style="list-style-type: none"> ·arrest (yes/no and #) ·prison/jail nights (yes/no and #) ·prison/jail episodes (#) ·on parole/probation (yes/no and #) ·violent victimization (yes/no and #) ·other victimization (yes/no and #) 	<ul style="list-style-type: none"> - focus is on legal status past 9 months <p>Same categories and variables</p> <ul style="list-style-type: none"> · also for prison/jail and parole/probation the # of episodes for offences committed in the last nine months is recorded
<p><i>Other Outcomes</i></p> <p>Self-report</p> <p>member survey - 20 item scale with three sub scales</p> <ul style="list-style-type: none"> ·program satisfaction (9-items) ·quality of life (7-items) ·mastery (4-items)⁴ 	<p>separate self-report questionnaires</p> <ul style="list-style-type: none"> · program satisfaction (8-item CSQ-8) · quality of life (11-item) - Lehman subscale · satisfaction with life (5-item) - SWLS · empowerment (23-item) - Self-Esteem Scale and Making Decisions Scale

Outcomes in CMHEI Core Set that are not in the PSR - Toolkit

- consumer health status (agency report)
- social support (self-report with Social Provision Scale)
- symptom distress (self-report with Symptom Distress Scale)
- service use and cost (agency report based on worker logs)
- symptoms and functioning (provider ratings on the Brief Psychiatric Rating Scale (BPRS) and the Multnomoh Community Ability Scale (MCAS))
- alcohol and drug use (provider ratings using the Alcohol Use Scale and Drug Abuse Scale)
- substance abuse treatment (provider ratings using the Substance Abuse Treatment Scale)

Unique to Self-help Data Set

- organizational empowerment
- involvement

⁴Toolkit manual recommends supplementing this measure with other available measures due to its low retest reliability and internal consistency