

## SYMPOSIUM: OUR PAST, OUR FUTURE NOTRE PASSÉ, NOTRE AVENIR

As a special feature for this special issue, we invited 11 distinguished members of the Canadian mental health community to respond to the following challenge: "Identify, from your perspective, one, two, or three of the most significant developments in mental health in the last 100 years with focal implications for community mental health in Canada and identify their lessons for the future." We are pleased to provide you with their diverse reflections.

Pour donner un caractère hors ordinaire à ce numéro spécial, on a invité 11 figures de proue de la domaine de la santé mentale au Canada à répondre à la question suivante: « Identifiez, en quatre pages, le ou les enjeux les plus importants qui, au cours du siècle qui se termine, ont eu un impact déterminant au niveau du développement et du cheminement de la santé mentale communautaire au Canada ou dans votre région particulière, et indiquez les leçons à en tirer pour les prochaines décennies. » C'est notre plaisir de partager avec vous leurs pensées diverses.

### JÉRÔME GUAY

*Ayant pris depuis peu sa retraite comme professeur à l'École de Psychologie de l'Université Laval, Jérôme Guay poursuit ses activités de consultant auprès d'organismes de services publics et d'associations communautaires. En plus de ses activités comme formateur et consultant auprès d'équipes en santé mentale, il a aussi participé à la mise sur pied des projets visant une meilleure intégration des personnes psychotraitées à la communauté, en y impliquant le citoyen et la citoyenne ordinaire.*

### LES ACTEURS OUBLIÉS

Les réformes en santé mentale ont surtout porté sur l'amélioration de notre système de soins. Il y eut d'abord la désinstitutionnalisation qui s'est opérationnalisée par la fermeture des asiles, remplacés par des départements de psychiatrie dans les hôpitaux généraux, des centres de jour et des foyers de groupe. Or, ces transformations n'ont pas changé fondamentalement la situation puisque l'hospitalocentrisme s'est perpétué, c'est-à-dire un système de soins dominé par un établissement qui accapare la très grande part des ressources matérielles et humaines. Au Québec, on a bien tenté de faire jouer un rôle à d'autres acteurs. Par exemple, certains CLSC ont mis sur pied des équipes de suivi communautaire (case management). On a également subventionné, dans toutes les régions du Québec, des groupes d'entraide pour « personnes atteintes » comme on les appelle et pour

les parents et les amis et amies du malade mental. Mais, même si on peut constater les effets positifs de l'arrivée de ces nouveaux acteurs, à qui on a conféré le titre de partenaires, ils ne font pas le poids. En effet, la volonté de partenariat ne peut que demeurer un vœu pieux tant que persiste un tel déséquilibre dans la répartition des ressources humaines et matérielles. Ainsi, l'opinion du groupe d'entraide ne pèse pas lourd lorsque, en plus de disposer d'un budget qui ne représente qu'une fraction du coût d'un lit d'hôpital, il ne jouit d'aucune crédibilité professionnelle. Pourtant on a cherché à corriger ce déséquilibre, en donnant un pouvoir décisionnel à ces nouveaux acteurs qui ont maintenant voix au chapitre dans les Plans régionaux d'organisation des services (PROS). Or une conséquence du surcroit de travail, causé par cette nouvelle place que les groupes étaient pourtant très contents d'occuper, a été l'épuisement psychologique de plusieurs permanents et permanentes de ces groupes. En effet, ils ne disposaient pas du personnel suffisant pour remplir cette nouvelle tâche, tout en continuant à répondre aux besoins des usagers et usagères. Il ne sert à rien d'accroître l'influence des associations si elles ne disposent pas des ressources nécessaires pour l'assumer.

De plus, le fait d'accorder plus de place à ces nouveaux acteurs a provoqué des relations antagonistes et parfois conflictuelles à cause de la compartmentation qui caractérise notre système de soins. En effet, cette compartmentation ne peut faire autrement que de donner lieu à une compétition féroce pour l'obtention des ressources et aussi à un choc de sous-cultures. Pour pouvoir rééquilibrer les ressources, il faut en enlever à certains établissements, qui ne veulent pas s'en départir; on peut comprendre que les hôpitaux trouvent des moyens pour conserver leurs budgets en développant leur propres ressources « communautaires ». La concertation obligée entre un système hospitalier autarcique et autosuffisant et des partenaires dont il n'a pas vraiment besoin n'enlève pas les difficultés d'une cohabitation forcée entre la sous-culture médicale, la sous-culture CLSC et la sous-culture des groupes communautaires. Les expériences d'intégration des équipes de santé mentale, au moyen de Plans de services individualisés, prennent souvent la forme de tentatives pour corriger la fragmentation des services, répondant ainsi plus aux besoins du système qu'à ceux des usagers et des usagères, puisqu'elles ne servent qu'à recoller les morceaux ensemble. On se plaît à rêver à ces organisations de soins, à composantes multiples, assumées par une seule équipe, qui sont assez répandus en Europe et aux États-Unis.

On pensait aussi que l'intégration sociale de la personne vivant des difficultés sérieuses en santé mentale serait favorisée en la dépsychiatrisant, c'est-à-dire en essayant de transformer les comportements d'incompétence sociale et de manque d'initiative, qui sont souvent un effet secondaire du traitement. Or, on sait maintenant que ce n'est pas en ciblant uniquement la personne psychiatrisée, en essayant d'améliorer ses compétences sociales, hors de son milieu de vie, qu'elle va mieux s'intégrer à la société. Les interventions qui se pratiquent dans le contexte communautaire ont plus de chances de succès. En ce sens, l'agente ou l'agent de suivi communautaire (case manager) peut jouer un rôle capital car c'est lui qui accompagne la personne dans son milieu de vie. Cependant on demande trop souvent au case manager de faire le pont entre les composantes du système de soins, dans sa fonction d'agent de liaison. L'agente ou l'agent de suivi communautaire trouve sa

pertinence et son utilité lorsqu'il est centré sur les besoins de la personne, au travers d'un accompagnement personnalisé.

Par contre, le processus d'institutionnalisation peut se poursuivre même lorsque la personne psychiatrisée est sortie de l'hôpital et que l'intervenant ou l'intervenante est à ses côtés dans la communauté. La désinstitutionnalisation exige des transformations qui vont au-delà des structures et du lieu d'intervention. En effet, l'agent ou l'agente de suivi communautaire peut amener l'institution avec lui dans la rue, par ses attitudes et ses façons d'intervenir. L'institutionnalisation se définit alors comme une prise en charge, entièrement assumée par le professionnel ou la professionnelle, qui ignore les compétences de l'usager ou l'usagère et ne tient pas compte de son pouvoir décisionnel. L'intervenant ou l'intervenante ne parvient pas toujours à se défaire du réflexe de prendre sur ses épaules la responsabilité de résoudre les difficultés vécues par les personnes et les familles avant qu'elles n'y soient prêtes elles-mêmes.

Plusieurs programmes de suivi communautaire basent leurs interventions sur les capacités et les compétences des personnes psychiatrisées, dont on exige qu'elles s'impliquent très activement dans le processus de sa réinsertion. L'entraide offre une stratégie fort efficace en ce sens, car elle place les aidées et aidés, devenus aidantes et aidants, dans un rôle de compétence. Le paradigme de l'entraide, proposé par Trainor, Shepherd, Boydell, Leff et Crawford (1997) en remplacement du paradigme de service, offre une perspective qui transforme radicalement la façon de rendre nos services. Ces nouvelles lunettes perceptuelles renversent complètement notre vision des clientes et clients qui sont considérés non pas uniquement comme des personnes qui ont besoin d'aide mais comme des aidantes et des aidants. La connaissance de type expérientiel que possèdent les personnes psychiatrisées confèrent une qualité accrue à l'aide qu'elles procurent à cause de leur compréhension unique.

Enfin, on a aussi tenté d'agir directement sur la communauté, surtout par des campagnes de sensibilisation qui ont obtenu des résultats mitigés, sauf lorsqu'on les a fait suivre par des actions auprès du réseau social. Il ne suffit donc pas de transformer l'institution ou d'agir sur la personne psychiatrisée ou encore d'intervenir directement sur la communauté, car c'est sur l'interaction entre la communauté et la personne qu'il faut agir. En effet, l'adaptation sociale se définit comme la résultante d'une interaction entre le citoyen (homme ou femme) et la personne psychiatrisée.

C'est le citoyen ordinaire qui est confronté avec la personne psychiatrisée qu'on a décidé de retourner à la communauté. C'est lui qui est décontenancé, dépassé ou apeuré face aux comportements de la personne psychiatrisée. En ce sens on peut dire que le citoyen est le grand oublié de nos réformes car, sans lui, l'intégration ne peut pas se faire. Il doit donc faire l'objet de nos préoccupations autant que la personne psychiatrisée; cela signifie l'éclatement de la notion de client identifié car il devient, lui aussi, la cible de nos interventions. Le citoyen à qui on demande de participer à l'intégration sociale des personnes psychiatrisées a besoin de notre soutien, et il y a droit. Le rôle de médiation de l'agent ou l'agente de suivi communautaire s'inscrit alors dans un cadre systémique, puisque les changements de comportements et d'attitudes sont concomitants et interreliés. La

transformation des préjugés du citoyen en attitudes d'acceptation des différences est facilitée par des efforts de la part de la personne psychiatisée pour adopter des comportements moins rebutants et plus acceptables. En somme, comme j'ai pu le constater dans certaines équipes innovatrices, l'agent ou l'agente de suivi communautaire peut soutenir le citoyen et l'encourager à exiger, de la part des personnes psychiatisées, les mêmes comportements socialement acceptables qu'il s'attend des autres citoyens et citoyennes. La personne psychiatisée doit tenir compte de l'impact de ses comportements sur le citoyen. Pour acquérir le statut de citoyen et avoir droit aux mêmes droits et priviléges, il faut adhérer à un minimum de règles et normes de comportement autour duquel existe un consensus social. Agir autrement a comme conséquence de condamner la personne psychiatisée à une situation chronique de marginalité et d'exclusion. De la même façon, une attitude d'ouverture et d'accueil du citoyen, prêt à remettre en question ses préjugés, facilite l'adaptation de la personne psychiatisée qui se sent acceptée comme personne avec sa personnalité unique. C'est la non-connaissance et l'absence de contact qui contribue à maintenir les préjugés. Le professionnel ou la professionnelle doit donc offrir son soutien et sa disponibilité au citoyen lorsqu'il organise la prise de contact. Il présente la personne psychiatisée comme possédant sa personnalité et son style propres.

La transformation du rapport entre la personne psychiatisée et le citoyen implique une transformation du même ordre entre l'institution et la communauté. En effet, l'intégration sociale de la personne psychiatisée est une responsabilité collective qui ne relève pas uniquement des établissements publics et des praticiens et praticiennes qui y travaillent, mais aussi des citoyens et citoyennes et des communautés. Croyant à la participation des citoyens et citoyennes dans les efforts d'intégration sociale, les organisations doivent offrir leurs ressources matérielles et professionnelles, dont les communautés locales ont besoin, pour résoudre les difficultés qui relèvent d'une responsabilité collective.

Une conséquence qui découle de cette nouvelle conception du rapport établissement-communauté est la nécessité de rendre l'établissement véritablement imputable face aux citoyens et citoyennes et aux usagers et usagères. Or ce n'est pas face à la communauté que nos établissements publics se sentent imputables, mais face au Ministère et aux Régies régionales; les organismes de services publics gouvernementaux ne se sentent pas tenus de rendre des comptes aux milieux qu'ils desservent. Or, ils ne peuvent exiger des communautés qu'elles soient accueillantes s'ils ne sont pas prêts à accepter l'influence des citoyens et citoyennes et des communautés sur leur façons d'intervenir.

## ABSTRACT

Within the Regional Plans for the Organization of Services, Quebec's mental health reform has tried to redistribute power and influence to mutual aid groups for consumers and their families. However, it has failed to provide them with the financial resources that would allow them to exert that new power. The groups don't have enough personnel to fill the decision-making positions accorded to them under the regional plans while, at the same time, continuing to provide services to consumers. Real partnership requires equality in resources. Social integration being the product of an interaction between

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consumers and citizens, citizens are the forgotten actors of the interaction. We fail to support them when they are faced with behaviours that they find strange and disturbing. Attitudinal and behavioural changes are interrelated and concomitant; that is, the transformation of citizens' prejudice into acceptance is helped by consumers' efforts to adopt less offensive behaviours.

## RÉFÉRENCE

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## LEONARD R. DENTON

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## FROM HUMANE CARE TO PREVENTION

As I reflect on significant developments in the field of mental health over the past 100 years, I find that these can be placed into four main categories which may even be identified as revolutions: (a) humanitarian reform, (b) a psycho-dynamic/holistic approach, (c) the community mental health movement, and (d) primary prevention.

The first revolutionary development in mental health actually began over 200 years ago, following a long history of demonology and medieval theological concepts in explaining and reacting to mental disorders. In 1792, Phillippe Pinel was granted permission to remove the chains from some of the inmates of La Bicêtre in Paris to test his views that the mentally ill should be treated with kindness and consideration and not as vicious beasts or criminals. What followed was a slow but steady world-wide revolution of humane care and humanitarian reform which reached North America in the mid 1800s and early-to-mid 1900s.

In the U.S., Dorothea Dix (1802-1887), a former school teacher who had been forced from her job because of tuberculosis, vigorously advocated for hu-

mancare of the mentally ill, whom she had discovered living in deplorable conditions in jails, almshouses, and asylums. Ms. Dix also directed the opening of two large institutions for the mentally disordered in the Maritime provinces of Canada in the mid-to-late 1800s. In 1908, Clifford Beers, a Yale graduate and former inmate of three mental institutions, published his groundbreaking book, *A Mind that Found Itself*. Beers advocated educating the public about mental illness and about the inhumane treatment of the mentally ill in institutions. His efforts aroused the interest of public-spirited citizens and scientists, including the famous psychiatrist Adolph Meyer (1866-1950), who suggested the name mental hygiene (later changed to mental health) as appropriate for the Society which was founded in 1908 to educate people about mental illness and to dispel the prevalent attitude of fear and horror. Under the leadership of Beers, the movement became worldwide (Coleman, 1956).

In Canada, the process of humanitarian reform was led by Dr. Clarence M. Hincks, who founded the Canadian Mental Health Association (CMHA) in 1928. Hincks spent ten years investigating and reporting on the conditions of asylums (the predecessors of modern mental hospitals) in every Canadian province, and then pressed for reform of the deplorable conditions which he encountered. Subsequently, the focus of Canadian institutions changed from custody to treatment. By 1948, the federal government had made mental health grants available to all Canadian provinces, so that they could upgrade their institutional facilities, programs, and staff over the next ten years (Lurie, 1984). It was during this period that I was exposed to the mental health field, first through my undergraduate studies in psychology and sociology, and then through my Master's training in clinical psychology, where I benefited from the federal program through a bursary. My university years provided me the opportunity to visit both an asylum and a so-called modern mental hospital, and to observe first-hand some of the appalling and restrictive conditions of institutional care brought to light by Dr. Hincks. Although conditions of physical and psychological care have changed since that time, a stint of working in an institutional rehabilitation setting in the mid-1980s has shown me that, even today, there still is far to go in the humane and appropriate treatment of those who find themselves placed in institutions.

It was several years after I received my second graduate degree that I became aware that I had been, and was, a participant in a second major revolutionary development in the mental health field, the psycho-dynamic/holistic revolution. This revolution had been sparked by the realization that individual developmental factors play a major role in mental disorders (which previously had been believed to be purely organic in nature), and that organic processes are of significance in many functional mental disorders (which previously had been believed to be purely psychological). Freud, his students and followers, and many others contributed significantly to this psycho-dynamic/holistic concept, which was championed by the same Adolph Meyer who had involved himself in the mental hygiene movement of Cliff Beers.

Observations made in World Wars I and II about the high incidence of mental disorders of those under stress of warfare gave support to Meyer's own eclectic approach to mental disorders and led to the realization that human behaviour can be adequately approached only by taking into consideration both the organic and

social causation factors of mental disorders. This revelation has had significant implications for the diagnosis and treatment of such disorders, and has contributed significantly to both a third and fourth revolution in the past century—the community mental health and primary prevention movements.

Increased public awareness in the U.S. of the inadequacies of the current mental health system provided the impetus for the National Mental Health Act being passed in 1946. The Act provided the structure and funds to launch a broad-scale program to attack the problem throughout the nation. Community mental health services, the third revolution in mental health care, became an integral part of this program.

Canada's similar concerns about the inadequacies of its national mental health system resulted in the publication of *More for the Mind* (Tyhurst, et al., 1963). This milestone report, from a committee which began its work in 1955, made 57 significant recommendations. A recurrent theme of these recommendations was the need to develop community-based services to prevent long-term hospitalization and to provide for local accessibility rather than institutionalization at large distant mental hospitals. *More for the Mind* also made reference to the need for both tertiary and secondary preventive services, such as provisions for continuity of care, rehabilitation services, mental health services in industry and assessment and treatment of children with emotional problems (Lurie, 1984). The latter need was addressed in a subsequent report by the Commission on Emotional and Learning Disorders in Children (1970).

In the 1980s, Lurie revisited the *More for the Mind* report and conveyed his findings in "More for the Mind—Have We Got Less?" (1984). Noting that some positive changes had occurred in Canada's mental health system over the intervening 20 or so years, he made the following observation:

Yet the fundamental shift in patterns of health care delivery envisioned by the authors has not occurred. We do not yet have an integrated co-ordinated service delivery system. In 'More for the Mind' the authors explained why previous calls for change in mental health services had not occurred. We have the same problems today: the lack of an overall philosophy of care; organizational problems in government departments; tensions among services, government, lay organizations; lack of funding; as well as public attitudes which do not support an expansion of services (p.14).

From my own perspective, except for a few isolated instances, Lurie's observations are still applicable as we move into the 21st century.

As part of the second and third revolutions in the mental health field, I participated as a psychologist in one community mental health clinic and as executive director and psychologist in another. At the first clinic, I assisted in introducing a family-therapy approach (part of the psycho-dynamic focus) and directed a follow-up study of its effect, accounts of which are published elsewhere (Denton, 1965a, 1965b). By the 1980s, while I was serving at the second clinic, the tide in Nova Scotia had regressed to a hospital-based model for what became called "psychiatric mental health services." It appears that I was too strong a public advocate for developing a real community mental health thrust and preventive approach (Denton, 1981a, 1981b); my contract was terminated because of stated "philosophical differences." Only later did I realize that I also had become a par-

ticipant in a fourth mental health revolution—that of prevention—both at the secondary and primary levels, by focusing on creating a child and family development program of early detection and early intervention, and by advocating intervention into adverse social conditions which contribute to mental disorders.

The fourth revolution in the field of mental health is that of primary prevention. This movement has been, and continues to be, championed by George Albee, former president of the American Psychological Association, Chair of the Task Force on Prevention for President Carter's Commission on Mental Health, and founder of the Vermont Conference on the Primary Prevention of Psychopathology. It is a movement fraught with misunderstanding and resistance. This widespread response is the result of a public which is kept in the dark, and of the fact that prevention poses a threat of social change. Also, as Trainor, Pape, and Pomeroy (1997) note in their advocacy for a community process model, such change requires a shift from traditional ways of allocating funds and power, and this shift engenders resistance.

Despite all the mental health efforts over the past 100 years, epidemiologists report that the incidence (new cases) of mental disorders (especially depression and children's disorders) is increasing rather than decreasing. In noting this trend and its relationship to adverse socio-economic conditions, world-renowned researchers (Cassel, 1976; Kramer, 1992; the North American Regional Council of the World Federation in Mental Health, 1993; Albee, 1997; and many others) have advocated a primary prevention approach (i.e., stopping disorders before they occur). They suggest that prevention could be accomplished by removing the noxious agents (such as poverty, human exploitation, discrimination, and other social injustices) associated with wide-scale disorders. Coleman (1956), in writing about sociological prevention measures, quotes Margaret Mead's assertion, "Society is the patient" (p. 600).

In Canada, the importance of primary prevention was cited some 35 years ago at a conference held at McGill University (Prevention of mental illness and social maladjustment, 1964). The statement made in the leading article of the report—"Prevention: An Attainable Goal?"—is as apropos at the beginning of the 21st century as it was then:

Preventive programs at the primary level must promote the social, emotional and physical well being of all people. The ingredients for well being include: food, shelter and other physical necessities for health; wholesome interpersonal relationships, and the exchange of love and affection; opportunities to make satisfactory adaptation to the social values and customs of one's environment; and finally, the opportunity of feeling a worthwhile member of a worthwhile group (p.1).

At the end of this century, examples of this preventive revolution abound. The public outcry by those advocates who point out that, despite the proclamation of our government leaders that child poverty would be eliminated in Canada by the year 2000, it has increased in the last 10 years, and the current mental health promotion initiatives of the CMHA are hopeful signs. There are, however, battles to be fought in response to what Albee (1996, 1997) calls a counterrevolution to prevention. The primarily ideological aspects of this counterrevolution include: (a) the lack of real recognition—if not denial—of social causation of disorders; (b) the

attractiveness of simple explanations of chemical causation and treatment; (c) the profit-oriented interests of pharmaceutical companies; and (d) the resistance exerted by powerful, persuasive, and wealthy groups which want to keep things as they are. All serve as barriers to taking social responsibility for change (Albee, 1997; Denton, 1999).

All four of these developments—humanitarian reform, a psycho-dynamic/holistic approach, the community mental health movement, and primary prevention—have focal implications for community mental health in Canada. All have lessons for the future. As was emphasized at the first meeting of the World Health Organization's Expert Committee on Mental Health in 1949, we must turn to preventive measures for the ultimate solution to the problem of mental illness, and we must take on the responsibility for promoting both the mental and physical health of the community (Coleman, 1956). Though writing 44 years ago, Coleman's observations are even more applicable in the year 2000:

Gone is the relative self-sufficiency of a hundred years ago, and the old idea that each individual should be able single handedly to make a successful adjustment to life. With greater interdependency has come greater responsibility for each other's welfare and greater need for careful joint planning in the best interests of all. Society is expected to provide the individual with the opportunity to acquire certain essential skills and with sufficient security to enable him[her] to make successful occupational, marital, social, and philosophical adjustments. An intelligent society will take all possible steps to set up a general socio-cultural climate which not only permits healthy personality function and growth but is actively conducive to it (p. 603).

My perspective of having worked for 50 years in the professional fields of education, social work, mental health, and research leaves me hopeful. I foresee scientific knowledge (that which is currently available and that which will be gained in the future) being transmitted into credible public knowledge which can be used to establish both psychological and sociological conditions for human welfare. Such conditions are required to enable all of our citizens—of whatever age or status—to realize their potentials for enhancing their interests and those of Canadian society. I also see the recognition of social causation in mental disorders and the implementation of preventive measures which are based on scientific findings offering the most effective long-term approaches both to group and individual mental health problems and to overall community mental health. I believe that the challenge for the new century in community mental health will be:

With what we have learned, what we are learning, and with what we have yet to learn, can we bring into being those conditions that foster healthy development by which each individual, of whatever ability or disability, can become an accepted and integrated member of our communities, where all feel one belongs and has a meaningful part to play, where each person has not only the resources for meeting basic needs, but also the opportunities to acquire the attitudes to oneself and others, and the knowledge and the skills by which one can realize that one's contribution is vital to the community's endeavours and to his/her physical and mental well being (National Institute of Child Health and Human Development, 1968, p. iv, adapted by author).

The four major developments which I have identified provide several lessons for the future in meeting the above challenge. These are as follows:

1. A change in ideology (our way of thinking about or perceiving a person, group, or human phenomena) leads to changes in actions and programs. The 18th-century revolutionary idea that the mentally disordered had human needs and would respond positively to humane care, though strongly resisted at the time, subsequently led to significant changes in institutional practices. As the public became informed, the humanitarian reform movement gathered strength and impacted on both the U.S. and Canada. Although the stigma of mental disorder has lessened, it still remains; clearly, educating the public must be a continuing process if past myths are to be corrected.

Further, it is clear that, in the mental health field, studies, reports, and the best recommendations will have little impact if they are not followed by concerted, focused, and persistent efforts and leadership. Someone has to carry the ball, with active thought and thoughtful action. A public which is informed and educated about the issues is the most effective tool for enlisting the support of elected government representatives of that public, for attaining social change, and for overcoming the inadequacies in mental health treatments and services.

2. The recognition of psycho-dynamic factors in the understanding and treatment of mental disorders, and of the need to take a broad holistic approach in understanding causation and relevant interventions, teaches us that simple explanations of mental disorder are insufficient. The emphasis on genetic and chemical causal explanations in the past quarter century distracts us from assuming a holistic approach. Obvious causal explanations keep us from pursuing the real reasons that the physiological changes which respond to chemical intervention have occurred in the first place. There is need to look more vigorously into environmental and stress factors which can produce physiological changes that adversely affect behaviour.

3. The development of the community mental health movement teaches us that efforts to provide appropriate and adequate services at the community level still have to compete with traditional institutional services for adequate funding. There is considerable public education yet needed and vigorous advocacy supported by credible research yet to be done if we are to develop truly comprehensive community mental health programs. We also have learned that actual, as well as potential, users of mental health services must be involved in policy formation and program implementation in order to meet *their* needs, rather than those of mental health professionals or others with vested interests.

4. The mental health field needs to incorporate the revolutionary idea of primary prevention of mental disorders. This idea has encountered resistance similar to that originally found in the field of physical health. In the past, there were many dissenting voices, and even ridicule of those who first championed the idea that poor sanitation produced disease. Today, society itself has made an adjustment to include this knowledge in its very structure—in health departments, public health services, meat and water inspection processes, and so on (Coleman, 1956). Although status-quo comfort produces resistance to change, society needs to make a similar adjustment in its ideas about mental health. When we see research facts of social causation factors by credible scientists being ignored, we learn that all the facts in the world won't distort the tunnel vision of those whose power is threatened by social change.

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5. Mental health professionals, at both the administrative and field levels, need to be trained and re-trained so that they: (a) acquire the attitudes, knowledge, and skills required for relating to community processes and to socially causative factors in mental disorders; and (b) become experts in applying such knowledge and skills. This education is needed to facilitate the development and implementation of appropriate and effective interventions for effecting positive social change, and for preventing disorders at tertiary, secondary, and primary levels. Mental health professionals also must acquire the knowledge and skills needed to overcome the barriers to the implementation of such interventions.

## RÉSUMÉ

On identifie quatre développements majeurs dans le domaine de la santé mentale qui ont fait une forte impression au Canada et aux États-Unis. Ces développements, perçus comme révolutionnaires, sont: (a) la réforme humanitaire, (b) l'approche psychodynamique-holistique, (c) le mouvement de la santé mentale communautaire et (d) la prévention primaire. Dès la perspective d'un demi-siècle de travail dans les domaines de l'éducation, la santé mentale et la recherche, l'auteur lance un défi pour la santé mentale communautaire dans le nouveau siècle et il présente des leçons du passé qu'on peut appliquer à ce défi.

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## YVES LECOMTE

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### LA RECONNAISSANCE: CONSTRUCTION THÉORIQUE D'UN ENJEU SOCIAL

En guise de réponse à la question qui nous a été posée, nous élaborons une construction théorique sur un enjeu commun à tous les réseaux de la santé mentale, laissant aux lecteurs et lectrices le soin de mettre les nuances qui s'imposent et de relativiser cette construction en fonction de leur contexte et position dans le réseau. Au souvenir des événements survenus depuis les années 60, années de coupure radicale avec les modes antérieurs de dispensation de services, deux réactions peuvent être présentes: un sentiment de toute-puissance si l'on croit satisfaire cette demande en si peu d'espace, ou d'impuissance tellement les enjeux du champ de la santé mentale sont multiples, complexes et en continue mouvance d'une décennie à l'autre, d'un groupe social à l'autre, d'une institution à l'autre ou d'une région du Canada à l'autre. Ces deux réactions inverses laissent entrevoir l'enjeu qui sort de ces événements.

Mais de quels événements parle-t-on? Les rapports officiels québécois surgissent spontanément car ils cristallisent les enjeux de leur époque: le *Rapport Bédard* en 1962 (la perte du contrôle des religieux et des religieuses sur les soins

au profit de la profession médicale); la *Commission d'enquête Castonguay-Nepveu* à la fin des années 60 (instauration d'un système de santé et de services sociaux, et réintégration de la psychiatrie dans le giron technocratique); la *Commission Rochon* en 1988 (modernisation du système de soins); le *Rapport Harnois* en 1987 suivi par la *Politique de santé mentale* en 1989 (reconnaissance des particularités de la santé mentale et des groupes communautaires). Ces commissions d'enquête et ces rapports, au nom de leur président, s'appuient sur de nombreuses études faites par les usagers et usagères, les praticiens et praticiennes, les administrateurs et administratrices, les chercheurs et chercheuses et les universitaires. Deux méritent une mention spéciale à cause de leur influence sur la pratique ou la compréhension des enjeux du système: le livre *Les fous crient au secours* (1961) de Jean-Charles Pagé, ex-patient psychiatrique, qui a servi de levier pour séparer la psychiatrie de l'ordre religieux; et le livre *De l'asile à la santé mentale* (1984) de la sociologue Françoise Boudreau qui a révélé les enjeux et les luttes du système psychiatrique des années 70 et 80.

Dans le champ de la pratique, les nouveaux enjeux sont mis à jour par la création d'associations: le Regroupement des ressources alternatives en santé mentale du Québec en 1982 (la revendication des initiatives de la communauté); l'Association québécoise de réadaptation psychosociale en 1992 (l'instauration d'une nouvelle philosophie et de nouvelles approches); l'Association des groupes d'intervention en défense des droits en santé mentale du Québec (le respect des droits et du choix du traitement), l'Association des parents et amis des malades mentaux (la revendication d'une écoute de la part des parents), l'Association québécoise de suicide (la revendication d'une réponse à la souffrance des Québécois et des Québécoises). Les véhicules de réflexion et de diffusion des connaissances, à l'importance souvent négligée, sont un autre exemple. Deux retiennent l'attention: la revue *Santé mentale au Québec* (fondée en 1976) et ses colloques comme « Les femmes et la folie » (1980), et le Comité de la santé mentale du Québec (fondé en 1970) avec ses *Avis*. Enfin, un dernier événement qui risque de passer inaperçu revêt une grande importance de notre point de vue: la création des certificats universitaires en santé mentale (l'enjeu de la formation et du travail multidisciplinaire).

Pour se sortir de l'impasse créée par la possibilité des deux réactions de toute-puissance ou d'impuissance, il faut trouver la réponse à partir de sa position. Celle de l'auteur dans le réseau est double: (a) institutionnelle, étant clinicien psychologue dans une clinique externe de psychiatrie dont la philosophie initiale s'inspirait de la psychiatrie communautaire américaine et, 25 ans plus tard, d'une psychiatrie bio-psychosociale, et (b) communautaire comme initiateur de projets, administrateur, clinicien et chercheur dans le milieu communautaire.

Cette position, parfois inconfortable, a l'avantage de sensibiliser aux critiques et aux récriminations des uns par rapport à l'autre, l'autre étant le réseau dans lequel on n'œuvre pas et qui apparaît parfois comme un véritable étranger. Cette position permet de percevoir qu'un aspect latent du discours des deux milieux est semblable: la croyance dans la possession de la solution aux problèmes du champ de la santé mentale, solution dont l'autre est exclu. Autrement dit, les deux réseaux sont à risque de s'emprisonner dans un sentiment de toute-puissance, avec pour corollaire l'enfermement de l'autre dans l'impuissance.

Parfois, des voix s'élèvent et clament que la toute-puissance affichée est un piège, une façade, et que s'y enfermer mène à une impasse. Georges Aird, psychiatre et pionnier de la psychiatrie communautaire, l'énonce en 1985: « Le réseau public a peut-être lui-même créé ce débordement en s'imaginant qu'il était seul capable de s'occuper des problèmes psychiatriques de la société. » Ce sentiment de toute-puissance a exclu les groupes communautaires, les parents et les usagères et usagers qui se plaignaient au moment de cette déclaration de ne pas être entendus, écoutés et acceptés par le même réseau institutionnel, sinon comme objet de son intervention. Bref ces gens se plaignaient de l'impuissance dans laquelle le réseau institutionnel les confinait, tout en disant dans leur discours pouvoir régler les problèmes de la santé mentale si les moyens d'agir leur étaient donnés.

Deux réactions semblables à celles ressenties suite à la question initiale de cette réflexion. Deux réactions qui se retrouvent en miroir dans le réseau institutionnel et dans le réseau communautaire, réactions qui permettent de constater la présence d'une constante dans le réseau de la santé mentale qui transcende les réseaux et les époques, et qui synthétise les enjeux qui le traversent.

Cette constante est la quête de la reconnaissance, c'est-à-dire la reconnaissance du discours, des raisons d'être et des valeurs sous-jacentes de l'identité sociale d'un groupe. Cette quête semble suivre un modèle. Chaque groupe affirme la possession d'un savoir composé de nouvelles connaissances qui lui confèrent la capacité d'améliorer le traitement des patients et patientes, et d'infléchir leur devenir négatif. De facto, cette capacité suppose que le groupe socialement reconnu et déjà au pouvoir est devenu impuissant à améliorer le sort des patients et patientes (l'on sait comment faire; l'autre ne sait plus comment).

Également, cette quête de reconnaissance se fonde sur un fantasme, d'autant plus puissant que d'autres groupes s'y identifient. Mais une fois la reconnaissance acquise, le fantasme se transforme en une illusion, c'est-à-dire en la conviction qu'il correspond à la réalité. Un sentiment de toute-puissance (le seul ou le mieux placé pour savoir faire) s'en suit, sentiment qui provoque progressivement l'exclusion d'un autrui en émergence de reconnaissance. Et le cycle recommence.

Cette hypothèse peut en partie expliquer la dynamique de l'enjeu de la reconnaissance depuis la fin des années 50 au Québec. En effet, durant les années 1960-1962, s'opère une transformation majeure du système psychiatrique. Boudreau (1984) a bien analysé la dynamique des stratégies utilisées par les acteurs en présence: les traditionalistes (corporations religieuses et neuropsychiatres) et les modernistes (psychiatres formés à de nouvelles approches). L'analyse de ce mouvement de transformation en fonction de l'hypothèse formulée permet de constater que les modernistes affirment avoir la capacité de transformer le système au bénéfice des patients et des patientes. Ils ont acquis un nouveau savoir, contrairement aux traditionalistes qui n'ont pas renouvelé leur discours. Les modernistes revendiquent la reconnaissance de leur groupe social en l'appuyant sur un fantasme: « La maladie mentale est une maladie comme les autres. » Ce fantasme justifie la réintégration de la maladie mentale dans le giron psychiatrique et hospitalier. Ce fantasme est puissant car il rejoint les attentes des patients et des forces progressistes de l'époque qui s'y identifient.

Le résultat de cette quête de reconnaissance est le rapport Bédard, Lazure et Roberts (trois psychiatres) qui propose en 1962 une réforme progressiste avec une intégration dans les hôpitaux psychiatriques et généraux. La création de 9 600 lits est proposée et les hôpitaux généraux doivent consacrer 10% de leurs lits à la psychiatrie. Donc, le traitement de la maladie mentale est intégré dans le réseau hospitalier psychiatrique, sous l'autorité exclusive des psychiatres modernistes, dans une structure distincte du système de santé. Progressivement, ceux-ci développent un sentiment de toute-puissance, étant ceux qui savent. C'est l'âge d'or de la psychiatrie.

Durant les années suivantes émerge un nouveau groupe de professionnelles et professionnels des sciences humaines, les technocrates, qui véhiculent de nouvelles valeurs, un nouveau savoir qui, selon eux, leur confère la capacité de transformer le système, non seulement psychiatrique, mais de santé et de services sociaux en butte à des difficultés. Ils revendentiquent la reconnaissance de leur groupe en s'appuyant sur le fantasme « La rationalisation étatique peut tout régler ». Habiles, ils utilisent le fantasme « La maladie mentale est une maladie comme les autres » pour justifier leur objectif: l'intégration complète du système de santé. En effet, si la maladie mentale est une maladie comme les autres, elle doit être intégrée dans le réseau de la santé sans particularité. Cette reconnaissance est consacrée à la fin des années 60 par la commission Castonguay-Nepveu (deux technocrates) qui implante leurs valeurs et leur savoir. Progressivement, ces technocrates imposent leur pouvoir et deviennent eux aussi victimes de l'illusion que leur fantasme est la réalité: tout peut être prévu et la planification règle tous les problèmes. Mais cette toute-puissance finit par exclure des groupes en émergence que sont les usagers et usagères, les citoyens et citoyennes et les jeunes professionnels et professionnelles qui ne trouvent pas de débouchés dans le réseau. Georges Aird a dénoncé cette illusion en dévoilant l'impuissance dans laquelle le réseau institutionnel s'était lui-même plongé.

Entre temps, au début des années 80, un autre groupe (les professionnelles et professionnels paramédicaux) tente de se faire reconnaître (Syndicat des professionnels des affaires sociales du Québec, 1981), mais contrairement aux autres groupes, il ne développe pas un discours cohérent sur son savoir et ses connaissances. De plus, il ne fonde pas sa quête de reconnaissance sur un fantasme mobilisateur. Cette quête de reconnaissance apparaît une lutte de pouvoir corporatiste, et demeure sans lendemain.

Durant les années 80, les nouveaux groupes en émergence (usagers et usagères, ressources communautaires, groupe de défense des droits, parents et amis et amies des malades mentaux) tentent de se faire reconnaître. Ils développent un discours pour publiciser leur savoir et faire part de leurs connaissances et valeurs (Comité de santé mentale du Québec, 1985; Guertin & Lecomte, 1983) censées pouvoir donner lieu à un nouveau système psychiatrique. Ils fondent leur quête sur le fantasme « Ailleurs et autrement » qui est adopté par d'autres groupes sociaux. En 1989, la *Politique de santé mentale* les reconnaît socialement. Mais ces groupes n'accèdent pas au pouvoir. Ils sont laissés à la marge du réseau étatique. La dynamique de renouvellement des pratiques et du discours est bloquée. Comment expliquer cette impasse?

Une hypothèse est que le système public est encore aux prises avec l'illusion de son fantasme. Il a phagocyté le réseau communautaire qui n'avait pas, en rétrospective, le savoir pour transformer radicalement le réseau public. Le réseau communautaire a accédé au statut de réseau complémentaire, et est confiné à un rôle de garde-fou du réseau public.

Dans ce rôle, le réseau communautaire peut faire évoluer divers enjeux du réseau public dont deux peuvent être cités. Le premier concerne le libre choix du traitement. Dans le réseau public, le traitement des patients et patientes s'est beaucoup diversifié, mais le traitement médicamenteux est la plupart du temps le premier choix offert au patient (homme ou femme), et parfois le seul choix. Certes, la médication est importante sinon essentielle, et le développement de nouveaux médicaments encore plus performants est une priorité. Mais une telle pratique favorise-t-elle un véritable libre choix du patient? Si des traitements psychologiques sont aussi efficaces que la médication, le réseau public ne devrait-il pas les offrir afin que le patient puisse choisir un traitement conforme à ses valeurs? Il s'avère important de s'interroger sur la philosophie de traitement en cours car un cercle vicieux risque de se produire: le développement unique des traitements médicamenteux au détriment de nouvelles modalités de traitement plus conformes aux valeurs et aux modes de vie du patient.

Un deuxième enjeu, très complexe éthiquement, est l'ordonnance de traitement obligatoire. La valorisation des droits individuels a pour effet de changer les règles régissant les modalités de traitement, avec une augmentation du recours à cette ordonnance. Où est la limite à ce recours? Peut-il y avoir tendance à l'utiliser pour obliger la compliance au traitement de patientes et patients non dangereux, avec pour motif caché d'économiser? A-t-on suffisamment élaboré les règles de son recours et évité aux intervenants et intervenantes qui doivent la recommander de tomber malgré eux dans le piège de la subjectivité?

Une autre hypothèse explicative de l'impasse actuelle est que celle-ci est un blocage temporaire qui sera résolu par l'apparition d'un groupe suffisamment organisé pour être socialement reconnu, et en mesure de modifier le système actuel. Les entreprises privées sont un de ces groupes. Elles ont développé un discours qui fait part d'un savoir et de la capacité de corriger le système actuel. Elles s'appuient sur le fantasme « L'économie régit tous les processus humains, et les lois du marché équilibrivent constamment le système ».

Mais les entreprises privées ne sont pas le seul groupe. Il est encore possible que le réseau communautaire puisse devenir un véritable réseau alternatif. Il devra toutefois se transformer radicalement pour être un véritable réseau autonome en santé mentale. La condition de cette transformation est l'ouverture à d'autres partenaires et le développement d'un savoir sur le traitement qui n'est pas encore suffisamment élaboré pour recueillir le consensus collectif nécessaire à l'obtention de la reconnaissance et du pouvoir.

Un enjeu est commun à ces deux derniers groupes: le financement. Quelle que soit l'orientation des deux groupes, une partie de la clientèle ou des usagers et usagères ne sera pas en mesure de défrayer les coûts de leur traitement à cause de leur situation économique.

Cette situation oblige les deux groupes à recourir à une aide financière. D'où proviendra-t-elle? Ne devrait-elle pas l'être par les entreprises qui ont actuellement les moyens d'influencer les pratiques du réseau, de par leur richesse et les politiques gouvernementales qui les favorisent, c'est-à-dire les compagnies pharmaceutiques? Ces entreprises pourraient allouer une partie de leurs profits à un institut national de santé mentale dévoué à l'innovation des pratiques sociopsychologiques et à leur diffusion. Elles contribueraient à la création de véritables alternatives pour les patients et patientes, et à l'actualisation du principe du choix du traitement.

Assisterons-nous à une nouvelle reconnaissance et à la relance de la dynamique de renouvellement du réseau de santé mentale?

## ABSTRACT

*Analysing individual reactions—omnipotence or helplessness—to the question put forward in this symposium, the author observes that the same reactions are present in the mental health field. Investigation of these reactions shows that they alternate in time and are based on a quest for recognition. This quest follows a pattern: First, a group proclaims new knowledge which is based on a fantasy. Then, when this group obtains recognition with its corresponding power, making the transition from a position of impotence to one of power, the fantasy becomes an illusion of omnipotence which excludes others, triggering the cycle again in the excluded groups. This pattern could explain the evolution of the mental health field over the last four decades. Over the last few years, however, there have been some failures in this process, and the author suggests possible solutions to move beyond the impasse.*

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## CYRIL GREENLAND

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### REMINISCENCES AND REFLECTIONS ON MENTAL HEALTH SERVICES IN ONTARIO

I was charmed by Françoise Boudreau and John Benjafield's generous invitation to present a personal perspective on significant developments in community mental health in the past 100 years. At the same time, I am alarmed by the responsibility for identifying lessons for the future.

In my view, one of the most significant developments in the past 100 years has been the incorporation of psychiatric units into general hospitals. This being so, the early history of psychiatric units in Ontario is worth recalling. In 1906, Dr. Donald Campbell Meyers, neurologist-in-chief at the Toronto General Hospital (TGH), opened its Nervous Ward. Its purpose was to provide early treatment for patients with nervous and mental disorders with the minimum of formality. Dr. C.K. Clarke, Professor of Psychiatry and Dean of Medicine at the University of Toronto and Medical Superintendent at TGH, was displeased with Meyers and his negative attitude towards psychiatry. Clarke, who was largely responsible for building the profession of psychiatry in Canada (Greenland, 1966), believed that neurologists were not qualified to treat mentally ill patients. He also was concerned about the poor physical conditions at the TGH Nervous Ward. Accordingly, Clarke closed the Nervous Ward and in 1909 opened his own out-patient clinic at TGH. Dr. Ernest Jones, a prominent psychoanalyst and Freud's first biographer, was the first Medical Director of the Ward Clinic (Greenland, 1961b).

Travelling mental health clinics attached to Ontario hospitals were pioneered in the 1930s by Dr. B.T. McGhie, Director of Ontario Hospitals (see Simmons, 1990). An innovative administrator, McGhie also inaugurated Approved Homes and a probation system which allowed patients to be cared for by their relatives in the community. McGhie's proposal for the establishment of community mental health programs were ignored in 1944, but they have much in common with *Putting People First: The Reform of Mental Health Services in Ontario* (Ontario, 1993).

My modest involvement in the development of mental health programs and policies in Ontario began in the early 1960s. Having been recruited in October of 1958 from the Crichton Royal, in Dumfries, Scotland, where I was Director of Psychiatric Social Work, I was appointed Director of Social Work at the Ontario Hospital in Whitby. Two years later, toughened by my stint at Whitby, I was kicked upstairs to become the Social Work Advisor, under Dr. Burdett McNeil, Chief of the Mental Health Branch at the Department of Health. Being a member of a small energetic team and working at the cutting-edge of change with virtually unlimited funds at our disposal was an exhilarating and memorable experience.

## SYMPOSIUM

At the Queen's Park-based Mental Health Branch, our blueprint for change was the *Dymond Report* (see Greenland, 1961a). This report had been presented to the Ontario Legislature in February of 1959 by Hon. Matthew Dymond, then Minister of Health. Inspired by the work of the Tyhurst Committee on Psychiatric Services, the Dymond plan incorporated McNeel's ideals:

- (1) The life of (mentally-ill) patients should be disrupted by psychiatric treatment as little as possible.
- (2) Psychiatric services should be located where they may care for the patient (a) without loss of his job; but if that is necessary, (b) without leaving home; but if that is necessary, (c) without leaving the community; but if that is necessary, (d) without loss of his community ties and relationships (Tyhurst et al., 1963).

This theme, spelled out in *More for the Mind* (Tyhurst et al., 1963) included five major propositions and 57 detailed recommendations. The five propositions incorporated in the Dymond Plan were: (a) that psychiatric services be integrated with the physical and personnel services of the rest of medicine; (b) that a wide range of psychiatric services be established in centres of population on a regional basis; (c) that the management and administration of psychiatric services be decentralized; (d) that patients should receive appropriate professional help in their community through all phases of their illness without interruption; (e) that local psychiatric services in hospitals, clinics, and other services and agencies be co-ordinated to promote maximum effectiveness.

Promoting change was easy. Coping with hostile colleagues who resisted change was difficult, time-consuming, and exhausting. For instance, although the psychiatric profession welcomed the close relationship between psychiatry and medicine, opposition to the Dymond Plan came from some of the senior staff members of the original 12 Ontario Hospitals (Brockville, Hamilton, Kingston, London, New Toronto, North Bay, Penetanguishene, St. Thomas, Thunder Bay, Toronto, Whitby, and Woodstock). Since these hospitals were desperately overcrowded, understaffed, and run-down, the staff were outraged by the decision to invest large sums of money into psychiatric units of general hospitals. These new units, it was claimed, would attract the best staff and the most desirable patients away from the Ontario Hospitals.

A few members of the Ontario Legislature and some municipal politicians also were unhappy about the proposed move to community-based mental health services. It seemed that the Premier of Ontario already had promised to build new mental hospitals in their constituencies. Eventually, compromises were made and four small mental hospitals were built at Goderich, Owen Sound, Penetanguishene, and South Porcupine. This development taught me that the decision to build mental hospitals and prisons had more to do with political expediency than with effective social planning. An alternative explanation is that the Ministry of Health and the Ministry of Government Services (formerly Public Works) had different political agendas.

Developments at 999 Queen Street in the late 1960s provide a similar example of this dilemma. When the future of the Ontario Hospital in Toronto was being planned (Greenland, 1996), Dr. Paul Christie, its last Medical Superintendent, proposed building a Community Mental Health Centre without beds. Appreciating that the politicians would be offended by this "harebrained" scheme, the Mental

Health Branch supported Christie's innovative idea, but recommended building a residential unit with a maximum of 100 beds. However, much to our chagrin and Paul Christie's dismay, the Ministry of Government Services decided to build four separate residential towers. These concrete block-like buildings were designed to look like the University residences which were typical of the period.

Although it was unplanned at the time, the surplus of beds at Queen Street enabled the government to close the Lakeshore Psychiatric Hospital in 1979. And in 1998, by order of the Hospital Restructuring Commission, the Queen Street Mental Health Centre was divested from the Ministry of Health and merged with the Clarke Institute of Psychiatry, the Addiction Research Foundation, and the Donwood Institute to form the new Centre for Addiction and Mental Health.

These quixotic developments would have surprised Dr. W.H. (Bill) Henderson, who died in 1996 (see Sussman, 1989). As Director of Community Mental Health Services from 1957 to 1966, Bill was primarily responsible for establishing the comprehensive network of psychiatric units in general hospitals. The fact that the large majority of people in Ontario with mental health problems are these days treated in psychiatric units rather than in provincial psychiatric hospitals (PPH) is due largely to his vision and tenacity. Bill, who was passionately committed to medicalizing mental health services, succeeded Dr. Burdett McNeil as the Executive Director of the Mental Health Division. In this role, he was instrumental in replacing the medical superintendents with lay hospital administrators. This move was an attempt to make the PPHs function more like general hospitals. Whether the psychiatric hospitals were better managed in this way remains a matter for debate.

By adopting the *Putting People First* recommendations, the government committed itself to reducing the expenditure on PPHs from 80% in 1992/3 to 40% by the year 2003, and increasing the expenditure on community mental health programs to 60% in the same period (Goering & Lin, 1996). In preparation for this Draconian measure, six longstanding psychiatric hospitals (Brockville, Kingston, Hamilton, London, St. Thomas, and Lakehead) have been scheduled for closure. The remaining PPHs (Whitby, North Bay, and Penetanguishene) will, in the near future, be divested and managed by independent boards.

Reducing the number of psychiatric beds for people with severe mental illnesses, and depending instead on largely untested and underfunded community mental health agencies—as was proposed by the Metropolitan Toronto District Health Council (1997) but not approved by the Ministry of Health—is fraught with danger. The public is rightly concerned about the presence of homeless mentally ill people in the community. At the same time, large numbers of people with psychosis and/or problems of addiction, who would be better cared for in mental hospitals, are languishing in jails and penitentiaries.

The wheels of change have turned full circle in less than 150 years. In the 1850s, alienists (now called psychiatrists) and prison reformers fought to remove mentally-ill people from prison dungeons into the light, safety, and security of the newly built asylums. In the 1990s, having decanted the mentally-ill into largely uncaring communities or prisons, the authorities expect compliant mental health workers to resolve social problems which are exacerbated by the lack of affordable

## SYMPOSIUM

housing, cuts in social-welfare benefits, and sadly depleted community-service agencies. These problems will be compounded by Compulsory Community Treatment orders (CTOs, also called Community Commitment or Out-patient Commitment), which require psychiatrists to medicate refractory patients into a state of compliance (Boudreau & Lambert, 1993a). In some jurisdictions, not yet in Ontario, armed with police-state powers of Orwellian proportions, assertive Community Treatment teams may also represent a major assault on civil liberties (Boudreau & Lambert, 1993b).

Defeating this imminent threat to democratic values demands the creation of alternative visions and priorities for community mental health. For example, a recent publication by MIND in the U.K. shows that people with mental illness are among the most socially excluded members of society: "Only 13 percent are working and the mortality rate for those diagnosed with schizophrenia are two-and-a-half times greater than the national average" (MIND, 1999). In addition to describing the problems, *Creating Accepting Communities* (MIND, 1999) offers a range of social strategies for improving the lives of people with serious mental illnesses. I hope that this timely report will encourage Canadian community mental health practitioners to adopt new and more challenging visions for the year 2000 and beyond.

## RÉSUMÉ

L'intégration des services psychiatriques aux hôpitaux généraux marque le développement le plus important du dernier siècle dans le domaine de la santé mentale communautaire. L'auteur nous rend compte de l'origine de ce développement et il jette un regard dans l'avenir en nous prévenant que la législation du traitement non volontaire dans la communauté est une grave erreur tant au niveau politique que pratique.

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## ABRAM HOFFER

*Abram Hoffer was born on a farm in Southern Saskatchewan in 1917 and has maintained an interest in food from the farm gate to the dinner plate. After obtaining a Ph.D. from the University of Minnesota and an M.D. from the University of Toronto, he became Director of Psychiatric Research for the Province of Saskatchewan in 1950 and Professor of Psychiatry in 1955. In 1967, he went into private practice in Saskatoon and moved to Victoria in 1976, where he continues to practice. Dr. Hoffer has published some 20 books and over 600 papers. He is Editor of the Journal of Orthomolecular Medicine and President of the Canadian Schizophrenia Foundation. His main interest is to see effective treatment provided for all schizophrenics—something which is not yet offered by modern psychiatry.*

## THE CURRENT MENTAL HEALTH SYSTEM FOR SCHIZOPHRENIC PATIENTS

The humanity, decency, and respect for human rights of any society can be measured by the way it treats its most afflicted and unfortunate patients, the schizophrenics. A humane society treats these patients in hospitals, or asylums, or good shelters with decent food, proper care, respect, dignity, and privacy—and it does so until they are well enough to look after themselves in the community. A less humane society houses them in prisons, rundown hostels, decrepit hotels, nursing homes, and on the streets—in doorways, cardboard boxes, parks, and city sidewalk grates. In my opinion, developments in the treatment of schizophrenics, particularly over the past 40 years, provide the most telling account of the history of community mental health practices.

A plan was developed in Saskatchewan 40 years ago to regionalize mental hospitals and to provide better care for patients. The plan was to construct small hospitals in seven regions of the province so that no patient was more than one

hour's drive from the hospital. But—and this is important—these buildings were hospitals, and they were designed to provide all of the necessary conditions for recovery and to treat patients until they recovered.

However, with the advent of tranquilizers—and specifically the discovery of chlorpromazine—this plan became corrupted into a second plan, which became known as deinstitutionalization. Today, as a result of deinstitutionalization, city streets have replaced hospitals for the treatment of schizophrenics. The community at large has become our new treatment centres, and prisons have taken on much of the burden. Indeed, one of the largest mental hospitals in North America is run by the prison system in California.

The objective of the original Saskatchewan plan was very clear. It was designed to treat the mentally ill close to home. By contrast, deinstitutionalization—which was developed by the combined efforts of psychiatrists, other mental health workers, and civil libertarians—was based upon the following hypotheses: (a) that governments would save money by closing the large mental hospitals, (b) that patients would recover faster in the *healing* community, (c) that patients would heal faster in the bosom of their families, and (d) that deinstitutionalization would enable patients to avoid the stigma associated with mental hospitals. Unfortunately, however, these hypotheses have proven to be false.

Governments were supposed to—and frequently pledged that they would—prepare better facilities in the community for deinstitutionalized patients. They did not. There is no saving of money if one takes into account the community and policing costs of streets filled with the sick and homeless, of multiple homicides and suicides, and of destroyed urban areas. Earlier this year, the British Columbia government admitted its policy of deinstitutionalization was a failure and promised to create more beds. I have not seen them.

The idea that patients would heal faster within their communities is bizarre. These same patients originally came from the communities whose healing qualities clearly were not sufficient to prevent them from becoming sick in the first place.

The notion that patients would heal faster in the bosom of their families is equally problematic. Many families are too sick, or too tired, or simply do not have the resources or the energy to cope with very sick patients.

And, certainly, the stigma associated with mental hospitals is no worse—and perhaps is better—than that associated with homelessness, poverty, and erratic public behaviour.

We still have psychiatric wards and smaller mental hospitals, but their main objective is to discharge their patients as quickly as possible. This objective can be realized, in large part, because of the development of tranquilizers, most notably the discovery of chlorpromazine. Because these drugs are very powerful and are rapidly effective in suppressing schizophrenic symptoms, they were greeted with widespread enthusiasm by psychiatrists and drug companies alike, who believed that a cure for schizophrenia had been found. Certainly, with the use of these drugs, hallucinations are reduced in intensity and frequency, thought disorder is no longer as prominent, and agitation is calmed. Tranquilizers cool what I call the hot symptoms of schizophrenia—those symptoms which force patients into hospital be-

cause their behaviour is intolerable to families and to the community—and make it appear as though the patients are on the road to recovery.

The drugs do little, however, for the cool symptoms (such as milder hallucinations and thought disorder which is not grossly paranoid). As a result, the same patients are re-admitted to hospitals, often dozens of times. They are, in effect, recycled. On their way through the hospitals, they are filled with tranquilizers—usually whichever drug is most fashionable in any given year. These drugs become increasingly expensive, and generally are no better than the previous ones. Usually, though, they have slightly different side effects. Patients in this cycle seldom achieve my criteria for recovery: (a) freedom from signs and symptoms, (b) an ability to get along well with family and with the community, and (c) an ability to be economically independent.

I do not consider the exclusive use of drugs as optimum treatment for schizophrenic patients. Even though these patients are better with the drugs, they do not recover fully. The tranquilizers convert a natural psychosis (schizophrenia) into an iatrogenic psychosis (tranquillizer psychosis). Theoretically, it is simple to predict that this conversion will happen: Tranquillizers do make many patients better (they decrease the intensity and frequency of the signs and symptoms of schizophrenia); however, the same drugs will make normal people sick (as was vividly demonstrated in communist Russia when dissidents were declared schizophrenic and medicated). The drugs do initiate the process of recovery; but, as patients begin to improve, they begin to react to the drug as if they were well (i.e., they become sick).

Tranquillizer psychosis is characterized by a decrease in symptoms and by an increase in apathy. Patients with tranquilizer psychosis also exhibit both a decrease in their ability to reason and major physical side effects (such as tardive dyskinesia, obesity, and impotence). These reactions explain why so many patients are desperate to quit taking these drugs, and why so many schizophrenics have to be forced by legal sanctions and injunctions to remain on medication. The only treatment for tranquilizer psychosis is to discontinue the drug. Unfortunately, though, if no other treatment is made available to the patient, the original psychosis will reappear. There seems to be nothing in between for these patients; they oscillate between two psychotic states, their place on the continuum being dependent upon the amount of drug they are taking.

In my opinion, orthomolecular psychiatry provides a way out of this dilemma, a way toward recovery for over 90% of non-chronic patients. Regardless of venue, effective treatment must include the following elements: (a) shelter, (b) optimum nutrition, (c) good nursing care, and (d) optimum psychiatric treatment. Of these, the psychiatric treatment is the most important—although all are crucial. With optimum treatment, the use of drugs is combined with improved nutrition and with the proper use of vitamins and minerals, especially vitamin B-3. However, as the patients begin to recover, the drug is slowly withdrawn in order to prevent the tranquilizer psychosis. Over time, the patients remain well either on no drug at all or on such tiny amounts of these drugs that the side effects either do not exist or are minimal.

The potential for orthomolecular psychiatry is great. In a study I completed which compared over 100 chronic patients who had been treated in a simple nursing home with similar patients who had been treated in the university hospital, the outcome of treatment was the same. The significant difference, though, was one of cost; costs at the university hospital were four times as great as they were at the nursing home. By attending to all four elements (shelter, optimum nutrition, good nursing care, and optimum psychiatric treatment), orthomolecular psychiatry will, I believe, save governments money, redress the social problems created by deinstitutionalization, and—most importantly of all—improve the quality of care for schizophrenic patients. And that, I think, must be the direction for community mental health work in the 21st century.

### RÉSUMÉ

Insistant sur les développements dans le domaine du traitement de la schizophrénie, l'auteur explique qu'en Saskatchewan, il y a 40 ans, un projet de régionaliser des hôpitaux mentaux a été conçu dans l'espoir d'améliorer le soin des patients et des patientes. Pourtant, à cause de l'avènement des tranquillisants et, en conséquence, l'augmentation d'opinion en faveur de la désinstitutionnalisation, ce projet a été déformé. L'auteur fait le bilan des résultats de la désinstitutionnalisation: aucune économie des fonds gouvernementaux, aucune amélioration du niveau de soins pour les patientes et les patients atteints de la schizophrénie, transformation de la communauté entière en hôpital mental. De plus, il souligne que la psychiatrie orthomoléculaire offre le meilleur traitement possible.

### CÉLINE MERCIER

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### ESPOIR ET DÉFIS: SANTÉ MENTALE COMMUNAUTAIRE ET TROUBLES MENTAUX GRAVES

#### Introduction

La seconde moitié du 20<sup>e</sup> siècle aura été le témoin de la « désinstitutionnalisation » des personnes souffrant de troubles mentaux graves. Entre 1960 et 1976, le nombre de lits en psychiatrie au Canada est passé de 47 633 à 15 011. Au

Québec, il a diminué de 17 730 en 1960 à 4 774 en 1998. Relativement à la population, on est ainsi passé d'un ratio de 3,75 lits par 1 000 habitants à 0,58. La norme de 0,40 lits par 1 000 habitants devrait être atteinte en 2002. Les autres provinces canadiennes ont connu un mouvement semblable et projettent pour le début du nouveau millénaire des ratios du même ordre. En 1995, la Colombie-Britannique disposait de 0,46 lits par 1 000 personnes et l'Ontario de 0,48.

Au cours de la seconde moitié du 20<sup>e</sup> siècle, la société canadienne a donc vécu un changement radical dans sa façon de traiter les personnes avec des troubles mentaux, depuis l'exclusion et la prise en charge dans des asiles jusqu'à la réintégration et le maintien dans le milieu. Dans ce mouvement de transformation, la santé mentale communautaire a d'abord joué un rôle de soutien aux personnes et aux communautés dans le contexte du retour en milieu naturel des personnes ayant séjourné en institution. Maintenant que les personnes atteintes de troubles mentaux graves demeurent dans leur milieu de vie, l'action communautaire auprès de ces personnes est appelée à prendre des formes inédites.

### L'accueil des ex-patients et des ex-patientes psychiatriques

Les communautés locales et la société en général ont été au premier chef concernées par la désinstitutionnalisation. Au départ, et au plus fort du mouvement, les milieux de vie ont été brutalement confrontés au défi de l'accueil des personnes qui avaient vécu de longues années en institution et se trouvaient fort démunies pour reprendre la vie en société (absence de réseau, perte des habiletés de base, symptômes résiduels). Les écueils ont été nombreux et les effets non désirés parfois très lourds: attitudes négatives et mouvements d'opposition à l'implantation de services dans la communauté; abandon ou absence de soutien aux personnes désinstitutionnalisées; difficultés d'accès aux services avec comme conséquences les readmissions multiples, l'itinérance ou la diversion vers le système judiciaire; far-deau des familles et des proches appelés à suppléer aux lacunes des services.

Quarante ans plus tard, ces problèmes demeurent, en même temps que l'on peut faire état de certains acquis. Les droits des personnes avec des troubles mentaux sont maintenant mieux reconnus dans les textes de loi et des ressources sont consacrées à la défense de ces droits. Les services offerts près des milieux de vie des personnes sont plus nombreux, plus diversifiés et mieux intégrés. Les communautés elles-mêmes semblent plus ouvertes. En général, les personnes considèrent qu'elles jouissent d'une meilleure qualité de vie en demeurant dans leur milieu qu'en étant prises en charge dans des structures encadrées spécialisées. Elles désirent vivre dans la communauté.

Socialement, il est reconnu que les asiles sont choses du passé. Les politiques gouvernementales, les plans d'action et les meilleures pratiques mettent tous de l'avant les principes de la participation de la personne atteinte de troubles mentaux graves à la vie collective et de la réappropriation du pouvoir sur sa propre vie. Cependant, la mise en œuvre de ces orientations nouvelles et des pratiques qui les accompagnent pose de nouveaux défis et confronte les communautés et les acteurs sociaux à des enjeux d'un ordre différent de ceux que l'on a jusqu'ici expérimentés.

### Le soutien à l'exercice de la citoyenneté

Depuis une dizaine d'années, on observe un « changement de paradigme » dans la conception des services, changement relié à l'émergence d'une situation nouvelle. La grande majorité des personnes avec des troubles mentaux graves ne sont plus « désinstitutionnalisées », mais plutôt « non institutionnalisées ». La désinstitutionnalisation étant pratiquement complétée, l'objectif n'est plus de réinsérer dans son milieu une personne avec des troubles mentaux graves, mais bien de la maintenir dans ses droits et de lui donner les moyens d'assumer ses responsabilités et ses rôles en tant que citoyenne ou citoyen. Le changement de perspective est radical. À titre d'exemple, le logement n'est plus considéré comme un lieu de traitement ou de réadaptation, mais sous l'angle de l'accès à un logement abordable, sécuritaire et de qualité, correspondant aux préférences de la personne. Les programmes de soutien au logement autonome visent à ce que la personne puisse conserver ce logement et se comporter comme locataire responsable et comme un voisin ou une voisine d'agréable compagnie. Il en est de même pour le travail ou toute activité productive. Ils ne sont plus envisagés comme des soutiens à la réadaptation ou des interventions occupationnelles, mais comme des activités qui doivent permettre à la personne de subvenir à ses besoins et d'accéder à des rôles socialement valorisés. Avec l'aide d'un soutien en emploi, d'un mentorat ou d'aménagements sur les lieux de travail, la personne peut contribuer, dans la mesure de ses moyens, au développement économique et social.

Dans ce changement de vision, la santé mentale communautaire se trouve interpellée d'une façon complètement différente. Dans le processus de désinstitutionnalisation, le travail de soutien à la personne en vue de sa réinsertion et de soutien aux communautés pour l'accueil des « ex-patients » demeure dans l'ordre du service spécialisé. Il s'adresse à une population cible identifiée à titre de personnes avec des troubles mentaux. Or, dans la mesure où la personne atteinte demeure dans son milieu de vie, la rencontre entre l'intervenant ou l'intervenante communautaire et la personne avec des troubles mentaux graves ne se fait plus nécessairement dans le cadre des services spécialisés. Elle peut intervenir dans le contexte d'une autre problématique ou tout simplement d'une activité orientée vers la population générale. Ainsi, du fait même qu'elles sont mieux intégrées, des femmes avec des problèmes graves de santé mentale peuvent se trouver victimes de violence conjugale, avoir besoin de soutien à la naissance d'un enfant, ou bénéficier des campagnes de prévention de l'abus de médicaments prescrits. De jeunes adultes peuvent avoir besoin d'aménagements pour poursuivre leurs études collégiales et universitaires, participer à des programmes de gestion du stress ou croiser des intervenants et intervenantes sociaux et des travailleurs et travailleuses de rue, suite à leur participation à des activités illégales ou leur fréquentation de milieux à risques élevés. Des hommes et des femmes doivent avoir accès aux programmes conçus pour la population générale, programmes de prévention aussi bien que programmes d'accès au logement subventionné, de développement de l'employabilité, ou de loisirs communautaires.

Ainsi, le travail avec les personnes qui connaissent des problèmes de santé mentale relève de moins en moins exclusivement d'un domaine spécialisé. Quel que soit son champ d'activité, tout intervenant ou intervenante en santé mentale communautaire va de plus en plus fréquemment rencontrer des personnes qui ont

« aussi » des troubles mentaux graves. Cette rencontre aura pour contexte des situations critiques ou de crises aussi bien que les activités courantes à l'intention de la population générale. Étant donné les préjugés entourant la maladie mentale, l'intervenante ou l'intervenant est appelé à un travail de sensibilisation et de soutien auprès des proches, des voisines et voisins, des professionnelles et professionnels et des aidantes et aidants naturels, des organisations locales, des services publics. La capacité des intervenantes et des intervenants de jouer un rôle médiateur et facilitateur s'avère déterminante pour le succès du rétablissement et de la réappropriation du pouvoir des personnes avec des troubles mentaux graves.

### L'espoir et les défis

Est-ce réaliste de promouvoir cette vision d'une participation entière des personnes avec des troubles mentaux graves à la vie collective, sans tenir compte d'un contexte général peu favorable? Les conditions structurelles actuelles entraînent une polarisation de plus en plus marquée entre les groupes sociaux et l'exclusion de segments de plus en plus larges de la société. Face à un rétrécissement du marché du logement subventionné ou de l'emploi, assorti d'un accroissement de la demande, les programmes d'accès au logement et d'insertion à l'emploi deviennent de plus en plus ciblés et tendent à prioriser les clientèles les plus aptes à bénéficier rapidement des mesures. Les orientations et les pratiques progressistes se butent ainsi à des impératifs d'efficience à court terme aussi bien qu'à des hiérarchies implicites ou explicites entre les clientèles, suite à l'application de critères de priorité.

Dans ces conditions, les groupes déjà marginalisés risquent de le devenir encore plus. Alors, prôner l'accès des personnes avec des troubles mentaux graves aux programmes réguliers, plutôt que de les maintenir dans des circuits spécialisés parallèles, n'est-ce pas courir à la catastrophe? Ne vaut-il pas mieux préserver des programmes subventionnés au titre de la santé mentale, même s'ils maintiennent les personnes dans un statut de « patients » ou de « bénéficiaires »? Le changement de paradigme évoqué plus haut ne va pas sans risque. L'espoir suscité par des réalisations telles que les entreprises sociales dirigées par des consommateurs et consommatriices ou les coopératives de logement s'accompagne aussi de doutes. Ces histoires à succès peuvent-elles vraiment devenir la norme? Certaines des personnes atteintes ne risquent-elles pas de devenir les victimes de nos visions généreuses, parce que de moins en moins protégées par un système de soins et d'assistance qui leur est spécialement dédié? Comment prévenir que l'exclusion à titre de malades mentaux ne se transforme pour certains à une exclusion à titre de citoyennes et citoyens déclassés en raison de problèmes multiples? Comment ne pas ajouter aux ratés de la désinstitutionnalisation, les erreurs potentielles de la non institutionnalisation?

Ces doutes sont le fruit de l'expérience acquise au cours du processus de désinstitutionnalisation. Expérience qui nous a rendus plus réalistes, mais qui permet aussi de s'appuyer aujourd'hui sur certains acquis. Ainsi, on peut maintenant se référer à des types d'interventions bien documentées et dont on a pu démontrer qu'elles sont mieux adaptées aux objectifs d'insertion. Ces « meilleures pratiques » ont pour point commun de mettre l'accent sur les personnes plutôt que sur les structures, tant au niveau des ressources que des objectifs. En termes de

ressources, on sait qu'il vaut mieux privilégier des équipes et des intervenantes et intervenants mobiles, flexibles, généralistes, formés à être présents dans des situations et des lieux les plus diversifiés, plutôt que dans des services fixes, avec des missions spécifiques. On reconnaît aussi que les interventions qui ont le plus de chances de réussir sont celles qui prennent en compte les projets et les aspirations des personnes en cause, de même que la diversité de leurs modes d'insertion et de participation à la vie civile. Enfin, il va de soi que ces changements de pratique ne peuvent s'implanter et se généraliser que si l'on investit dans des activités de formation (de base et continue).

### Conclusion

Dans les années 50, jamais on n'aurait cru possible de fermer autant de lits dans les hôpitaux psychiatriques. Aujourd'hui, on a du mal à croire qu'il y a moins de 40 ans, ces asiles constituaient des municipalités autonomes pouvant accueillir jusqu'à 5 000 personnes. La transformation est loin d'être achevée et les réponses aux besoins des personnes avec des troubles mentaux graves restent déficientes. En termes d'intégration et de participation, les frontières du possible n'ont cessé de reculer, mais en même temps, certaines situations s'aggravent, parce que des personnes vulnérables sont davantage exposées aux problèmes de santé publique, aux problèmes sociaux et économiques.

Le défi reste donc le même qu'au début de la désinstitutionnalisation: comment multiplier les réussites et favoriser une amélioration constante de la qualité de vie pour tous? Cependant, aujourd'hui, face à ce défi, certaines histoires à succès témoignent du fait que ces objectifs peuvent être atteints. Pensons, à titre d'exemple, à cette entreprise sociale qui prépare des plats individuels congelés et les vend à des prix modiques aux personnes majoritairement isolées et à très faible revenu du quartier. De tels projets parviennent à transformer des rapports traditionnels d'assistance des personnes avec des troubles mentaux en une contribution réelle à leur milieu. Ils permettent la participation de tous au bien-être de la collectivité et apparaissent comme des réalisations exemplaires dans l'ordre de la santé mentale communautaire. De quoi entretenir l'espoir, stimuler la créativité et encourager l'audace éclairée, dans les moments de doute.

### ABSTRACT

Over the second half of the twentieth century, the way in which Canadian society treats people with mental challenges has changed radically, from exclusion and containment in asylums to reintegration and maintenance in the community. Now that deinstitutionalization is practically complete, the objective has increasingly shifted from reintegrating people with severe mental challenges in their communities to upholding their rights and ensuring that they have access to resources allowing them to assume their responsibilities and roles as citizens. This change of vision results in a completely different set of issues for community mental health. Given the prejudices surrounding mental illness, the capacity of community mental health professionals to play a mediating and facilitating role becomes a determining factor in successfully re-establishing and re-empowering people with severe mental challenges. The advances that have clearly been made give cause for hope, but in the context

of the unwanted effects of deinstitutionalization and unfavourable socio-economic conditions, significant obstacles still need to be overcome before people with severe mental challenges can participate fully in the life of the collectivity.

## JILL STAINSBY

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### EXTENDED LEAVE

A chronic tension exists in mental health between treating individuals with mental illness against their will, for their own good or the good of the public, and allowing people the autonomy to make their own choices regarding treatment. Extended leave allows patients who are involuntarily committed to hospital because they require mental health treatment to be released to the community while remaining certified. The leave typically contains conditions which must be met by the patient under threat of rehospitalization or mandatory treatment in the community. Extended leave, which is also known as community treatment orders or outpatient committal, exists in Canada in Saskatchewan and has recently been expanded into Manitoba and British Columbia.

The debate, which previously was centred on whether or not to hospitalize the mentally ill, has now moved on to the issue of control in the community. On the face of it, extended leave appears to provide the least restrictive environment for mental health consumers, in the sense that they are not necessarily kept in hospital as they continue to meet the criteria for involuntary committal. In fact, however, those patients who can be released on extended leave would, in the past, have been discharged from hospitals, at least until they decompensated.

The reality is that extended leave is an attempt to enforce compliance with medication regimes and treatment plans. In effect, it increases the element of control over mental health clients. Those who favour the practice of extended leave argue that the practice reduces the "revolving door" treatment cycle for individuals who typically would decompensate in the community in a brief period of time after discharge. They argue that those individuals who do not accept medications are those who have little insight into their illness (Boudreau & Lambert, 1993).

It would seem likely that, as outcomes for patients improve, particularly as a result of the newer medications, the need to exercise control over the patients who

remain also would be reduced. However, such does not appear to be the case. Instead, the combination of reduced hospitalization and increased control over individuals with mental health diagnoses indicates that efficiency—both in terms of money and resources—is the primary motivator.

The mental health system is being required to do more with fewer resources. Psychiatrists are in great demand in the public mental health system, and many of them prefer to work in private practice. Other resources in the community are stretched as well. Acute-care hospitals find that there is a great demand for psychiatric beds, both in their emergency departments and in their in-patient units. Tertiary care facilities, such as Ontario's psychiatric hospitals, are being downsized or amalgamated, thereby putting new strains on the health care and mental health care systems.

The cost argument regarding extended leave is one that is not publicly popular, but it is clear that in-patient days cost more than access to community supports and community services. The concern, of course, is that the capacity of the community to support and service patients on extended leave is not being increased at a rate commensurate with the rate of increase in the number of patients. In fact, members of the British Columbia Schizophrenia Society have spoken of involving non-profit agencies and volunteer groups in efforts to expand the community capacity, rather than relying on government-funded social service agencies. Clearly, there is a trend towards less government involvement and the further dismantling of our social safety net, to the detriment of mental health consumers/survivors who may need services. We are releasing into the community individuals who typically deteriorate, and are relying on a legal requirement to abide by the conditions of their leave (much like parole) to keep them appropriately treated and medicated—instead of providing either hospital or community supports to these individuals. Extended leave is a cheap solution, but its efficacy remains in question.

The literature is mixed regarding the outcomes for individuals placed on extended leave. Some researchers find that extended leave reduces rehospitalization (Van Putten, Santiago, & Berren, 1988). Others find that it is the increased supports and assertive case management, which ideally is provided for individuals placed on extended leave, that makes the difference in their ability to cope with life in the community (Boudreau & Lambert, 1993). Extended leave exists in many American states (Miller, 1999) and in Australia (McIvor, 1998), though its conditions vary. Its use is under discussion in England and Wales (Sensky, Hughes, & Hirsch, 1991; BBC, 1998). The long-term effects of this kind of treatment have not been studied as yet.

Extended leave exists in Canada in Saskatchewan (Matthews, 1995) and was proclaimed in Manitoba and British Columbia in October and November 1999 as part of amended Mental Health Acts in those provinces. The Ontario government has been discussing extended leave (McCluskey, 1999), but there is a strong lobby against it in that province as a result, at least in part, of the existence of a strong consumer/survivor political community.

Extended leave in British Columbia existed under the previous Mental Health Act (British Columbia, 1979/1996), but it was infrequently used. Riverview Hospi-

tal, the provincial mental health facility, for example, did not place adult patients on extended leave between the years of 1992 and 1999. The hospital's justification for not using extended leave was that doctors within the hospital felt that if people were ill enough to be involuntarily committed, they were ill enough to be hospitalized. Riverview Hospital did, however, allow patients to leave for up to three days while involuntarily committed and, in fact, allowed patients to leave the hospital but remain certified for a maximum of two weeks under a pre-discharge policy.

There are significant differences between the old and the new Mental Health Acts in British Columbia concerning the implementation of extended leave. In the new Act (British Columbia, 1998/1999), the ability to place a patient on extended leave is indicated by the language around committal which indicates "the patient . . . requires care, treatment or control in or through a designated facility" (Section 22 (3.c.ii), emphasis mine), which permits extended leave and is consistent throughout the act. In Section 25 (1.1) of the new Act, there is a requirement that a patient on leave for 12 months or more must have his/her treatment record reviewed by a Review Panel chair, and, "if there is a reasonable likelihood that the patient would be discharged following a hearing under this section, [the chair] must order that a hearing under this section be held." The grounds under which a person can be placed on extended leave are, of course, the same as for an involuntary committal to hospital. In both cases, in B.C., involuntary committal includes compulsory treatment under the deemed consent provisions (Section 31 (1)).

There are pragmatic concerns with regard to extended leave as well:

1. If a person has to meet the criteria for committal in order to be placed on extended leave, for example, then what determines the distinction between those who are hospitalized and those who are placed in the community? Is it their ability to manage their own illness? Is it (hopefully) the ability of the community to provide adequate supports? If it is the second, few individuals will be placed on extended leave in British Columbia.

2. If there are conditions placed upon the release of a hospital patient, as extended leave suggests, then there must be consequences for his or her non-compliance with those conditions. Without such consequences, the legal requirements are unenforceable—which, I would argue, currently is the case. Patients are convinced they must abide by the conditions of leave; however, very little will happen as long as they do not deteriorate in the community. If they deteriorate—which they well may do, on leave or not, without adequate supports—they then may be rehospitalized. This threat of rehospitalization has always existed; the difference is that physicians and psychiatrists can now rehospitalize without completing an Involuntary Committal form. This difference illustrates the new Act's thrust towards efficiency.

3. How will overcrowded acute care hospitals accommodate these returning patients?

Several cases of individuals with mental health diagnoses acting violently towards themselves or others which recently have been reported in the media make the expansion of extended leave in B.C. politically possible. There is not, however,

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widespread agreement on its use. The B.C. Schizophrenia Society, for example, has supported the increased use of extended leave (1998), while the Canadian Mental Health Association (CMHA)—in B.C., Ontario, and nationally—has spoken against its use (CMHA-BC, 1998; CMHA-ON, 1998; CMHA, 1998). Unfortunately, there is no provincial consumer/survivor organization in British Columbia to present a unified viewpoint.

My sense is that extended leave will come into play in British Columbia and Manitoba slowly. At Riverview Hospital, in exceptional cases, physicians are now placing geriatric individuals onto extended leave in community facilities, so that staff there have the legal power to keep the patient within the facility. In all likelihood, there will be an increased use of conditional release or community treatment orders over time. Their effectiveness, however, remains to be proven.

I believe that the therapeutic alliance which may be achieved between a patient and a physician or treatment team, which already has been eroded by involuntary committal in the first place, will be further weakened by the practice of extended leave. People will avoid the mental health system because of its focus on control over individuals with mental health diagnoses. A lack of resources will mean that increased services will not be made available for those individuals who require them in order to maintain themselves in the community. Extended leave will expand the locus of control over these individuals to include the community setting. Individuals with mental health diagnoses increasingly will be required to manage their own care while attending community facilities to receive medications.

I believe that this approach to care not a positive step for mental health: It is antagonistic, and it involves the use of threats—mandatory treatment, rehospitalization—in order to maintain individuals in the least expensive treatment regimen.

### RÉSUMÉ

Actuellement en Saskatchewan, au Manitoba et en Colombie-Britannique, le traitement non volontaire dans la communauté est ordonné par la loi. La force de cette législation a récemment été étendue au Manitoba ainsi qu'en Colombie-Britannique. Le traitement non volontaire dans la communauté exemplifie la tension chronique qui existe dans le domaine de la santé mentale entre le traitement obligatoire et le traitement volontaire et autonome. En Colombie-Britannique en particulier, on a justifié l'existence du traitement non volontaire par un besoin perçu d'augmenter le contrôle sur les patients et les patientes psychiatriques et par le besoin accru d'efficacité. Dans la pratique, la législation a le potentiel de détruire tout lien thérapeutique atteint entre patient ou patiente et médecin ou équipe de traitement. Le traitement non volontaire dans la communauté entrera en vigueur progressivement et aura l'effet d'obliger les individus certifiés de gérer leur propre traitement. Cela ne constitue pas un pas en avant pour la santé mentale.

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## KEN ROSS

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## THE EMERGENCE OF STAKEHOLDER CONTRIBUTIONS

In my experience with community non-governmental organizations and with the public service sector, and as I look back over the last one hundred years in the field of mental health, I believe the most significant development which has occurred has been the emergence of stakeholder contributions in the planning, delivery, and evaluation of mental health services. In this discussion, I include

consumers/survivors, family members, community organizations and agencies, and mental health workers as stakeholders. The conceptual model which best captures this important resource base was developed by the Canadian Mental Health Association in the mid-eighties and is called *A Framework for Support for People with Severe Mental Disabilities* (Trainor & Church, 1984). This model places the person at the centre, supported by the stakeholders, who work in partnership with one another. The model was revised in 1993 to include the dimensions of education, work, housing, and income—the key determinants of healthy people and a healthy society.

Goss (1998) describes community activities for the mentally ill in New Brunswick at the beginning of the 20th century, as "allowing convalescing patients to leave the grounds [of the provincial asylum] to walk to churches . . . with attendants . . . and there had been no disagreeable incidents during these outings" (p. 55). Today, as we enter the 21st century, 22 consumer-run activity centres throughout the province of New Brunswick provide social support and community activism to assist vulnerable people. This approach is radically different; it represents a dramatic shift in how we view and treat people who experience mental health problems.

By the mid-20th century in New Brunswick, Centracare, the oldest psychiatric hospital in Canada, reached a resident population of 1,697. At that time, the first community mental health clinics were created. A provincial Division of the Canadian Mental Health Association was established, and branches in a number of New Brunswick communities soon followed. The 1960s and 1970s saw an expansion of the mental health clinic system in the province, and new medications fostered the first attempts at community-based treatments.

In the 1980s and 1990s, New Brunswick, like many other jurisdictions, initiated mental health reforms which were based on best practice evidence, and built upon the experience of other jurisdictions. With a shift in care from in-patient to community and with a 10-year plan to reallocate resources from the institution to the community sector, the resident population of the psychiatric hospitals decreased. Centracare now has a patient population of 50.

Now, at the end of the 20th century, we can look at the various experiences we have had and the changes we have undergone, and identify some of the advances which have had a major impact on mental health and mental illness. These include developments in assertive community treatment, new mental health legislation, the placement of psychiatric units in regional hospitals which provide in-patient care closer to an individual's home community, first-break treatment programs, and a new generation of medications. As well, the inclusion of consumer and family initiatives and the expansion of mental health care beyond the formal mental health system to include housing/accommodation, vocational, income-issues, social, and community networks have resulted in a more community-driven approach to services for this at-risk population.

Of all of these developments, the collective resource base reflecting stakeholder contributions has the most powerful implications for the future, two dimensions of which have particular importance for community mental health: (a) making mental health a possible job, and (b) developing social capital.

In *Impossible Jobs in Public Management*, Hargrove and Glidewell (1990) identify four dimensions of public-sector jobs which make it impossible to ensure good outcomes for people: (a) client legitimacy, (b) conflict among constituencies, (c) public confidence in the profession, and (d) the strength of the kinds of myths surrounding the issue.

The implied message is that if we, the stakeholders in the field of mental health, do not work together to positively affect these dimensions, it will be impossible to engage public support to our cause, to influence the political agenda, and to get the sustained collective will to make the right changes. Our challenge is to make mental health a possible job.

The *Framework for Support* model of stakeholder contributions provides a forum to positively affect these four dimensions through the promotion of knowledge and experience transfer among consumers/survivors, families, community organizations, and mental health professionals. We have learned from our experience with this model that consumers/survivors and family members will no longer accept being passive partners in the provision of care, and will insist on more involvement in, and control over, treatment and other issues which affect them.

We have learned from practice that, when experiential and scientific knowledge are brought to a forum to address what works or doesn't work in mental health—or what's missing and needs to be addressed collectively—ideas, plans, and suggestions which are put on the table always get improved upon, because not one of us is as smart as all of us. We have also learned that, while perfect solutions are hard to come by in this world, participants generally come away from such a process with a better sense of, or at least a better appreciation of, other points of view. As partners participating around the table, collective wisdom is one of the great advantages that we will gain.

In the past, policy-makers looked to professional groups almost exclusively for advice on policy and program direction. Today we have witnessed a shift in this pattern. Stories, observations, and descriptions of life situations from people who receive public services now elicit equal or greater response from policy- and decision-makers. David Rochefort (1998), in a discussion on the role of anecdotes in regulating managed care, describes how anecdotes can make valuable contributions. He describes how "their relative brevity, the qualitative information they provide, and their illustrative poignancy invoke special interest or emotion" (p. 142), and how successful politicians understand the human interest value of anecdotes.

The involvement of consumers/survivors, families, communities, and mental health workers as equal partners in the field of mental health represents, I believe, one of the real opportunities for making mental health everyone's business in the years to come. However, we have not worked hard enough to establish the trust and reciprocity that are necessary among the stakeholders of the *Framework for Support* model. When we achieve this trust and reciprocity, mental health will become a possible job.

A second dimension of stakeholder contributions, the development of social capital, has significant implications for the new millennium. If we use strategies

such as the *Framework for Support* model to generate and build social capital, we will create some of the best opportunities available to us today to promote a healthy (including mentally healthy) society.

Judith Maxwell (1996), in her address to the Eric John Hansen Memorial Lecture Series, talks about the importance of social capital and developing a resilient society. She defines social capital to include "institutions, patterns of behaviour, and the trust and reciprocity that enable citizens to solve problems, adapt, and grow" (p. 13). She further suggests that social capital is eroded when people are marginalized by unemployment and poverty and are displaced from family and neighborhood connections.

In *Making Democracy Work*, a study of democracy in Italy over many years, Robert Putnam (1990) concludes that the regions of the country where social capital was present fared far better in terms of health, economic prosperity, lawabidingness, and satisfaction with government than did the regions of Italy where social capital was not present. He describes the elements of social capital as a process where mutual trust is established, resulting in reciprocity developing among people. Buy-ins are created and people help one another because, as the relationship develops, there is a growing commitment to the "if you help me, I'll help you" philosophy.

Social capital is not easy to develop because it is value-driven. It takes time and works through many stages, and immediate results are not evident. Over the longer term, social capital provides a sound basis for investing in human potential. Social capital provides forums for stakeholders to collaborate and co-operate for mutual benefit, which makes good business sense. People get supports and services in a desired manner, and government gets good outcomes for people at reasonable costs. Over time, the establishment of trust leads to actions of reciprocity between people and government. Duplication and inefficiencies in mental health services are reduced because people are focused on mutual success. Coercive enforcement, which is expensive and less efficient, is not required.

An example of developing social capital is the support of consumer/survivor-run initiatives. Investment directly in enabling people to do things for themselves leads to less dependence on the mental health system, and provides opportunities for a formerly disenfranchised group of citizens to contribute to the overall mental health of the community. Empowered people feel more in control of their lives, are confident about what does and doesn't work for them, and tend to have greater insight into the challenges of their illness.

An abundance of social capital breaks down the element of clientelism. Putnam (1990) describes clientelism as "the product of a disorganized society and tends to preserve social fragmentation and disorganization" (p. 144). Clientelism has the state doing things for people and creates products of dependency.

Social capital looks at open systems, open boundaries, contributions of experiential and scientific knowledge, and issues of power, control, and capacity. If we could look more at how we do our business and ask the question, "Is what I am doing today helping develop a little bit of social capital?" we would go a long way towards addressing the issues which will confront community mental health in the next century.

All this is really about our challenge to reconnect to one another. It's also about our commitment to break down social and constituent isolation. With the opportunities which stakeholder contributions offer in terms of trying to help people, we need to change our behaviour so that it is based not upon an adversarial approach but rather upon a sense of mutual obligation, where our focus is on the needs of the individual. Whether the person is being served by hospital, public health, community mental health, housing, or social services, professional territory or the boundaries of the organization do not matter as much as people getting what they need in the right place at the right time. It would be more productive if the energies which are put in to competing or offloading problems were directed towards helping individuals. I suggest that today there is far too much non-value-added work, where bureaucrats and professionals use tremendous human capital in negotiating and trying to explain why (or why not) we will (or will not) do certain things.

Change is the only constant we have in our environment today. Our capacity to thrive and survive in the 21st century will depend upon our ability as individuals, organizations, and communities to be flexible and adaptable in a seemingly chaotic environment. Margaret Wheatley (1992) suggests that we stop focusing on building organizational structures and instead focus on core competencies, values, information, and the internal and external connections which we make in our environments. In today's context, her suggestion is indeed timely. We need to position ourselves to take whatever opportunities present themselves to move our agenda forward, however incrementally. A vision shared among the stakeholder constituents identified in the *Framework for Support* model is, I believe, the best starting point for moving forward in today's dynamic environment.

## RÉSUMÉ

Cet article décrit la contribution des intervenants et intervenantes (clients/survivants et clientes/survivantes, membres de la famille, organismes communautaires, professionnels et professionnelles en santé mentale) comme étant la percée la plus importante du dernier siècle dans le domaine de la santé mentale. Le modèle qui réussit le mieux à mettre à profit cette ressource importante, soit le modèle *Framework for Support*, a été conçu par l'Association canadienne de la santé mentale en 1984. Cette base de ressources collectives agit sur deux aspects de la santé mentale communautaire. D'une part, on vise d'abord à obtenir l'appui du public en matière de santé mentale, et ensuite à changer le programme politique pour faire de la santé mentale une priorité chez les Canadiens et les Canadiennes. D'autre part, on vise à constituer un capital social pour établir un esprit de confiance et de reciprocité entre les citoyennes et citoyens et le gouvernement. Une vision commune chez les intervenantes et intervenants du modèle *Framework for Support*, un engagement plus solide envers les valeurs, la mise en commun des renseignements, ainsi que les rapports internes et externes que nous entretenons avec notre milieu, voilà les éléments qui nous aideront à faire progresser le dossier de la santé mentale.

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### PAUL E. GARFINKEL and DAVID S. GOLDBLOOM

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### SIGNIFICANT DEVELOPMENTS IN PSYCHIATRY: IMPLICATIONS FOR COMMUNITY MENTAL HEALTH

We have been asked to comment on developments in the mental health field which have had a major impact on community mental health, and we are pleased to do so from the perspective of practising psychiatrists dealing with people facing severe and persistent mental illness. While we could have selected many possible topics, we have confined our discussion to three issues: (a) the changing theoretical

frameworks for understanding psychiatric disorder, (b) the role of clinical research, and (c) the consumer movement.

### Theoretical Frameworks

Psychiatry is the branch of medicine which deals with the emotional and nervous system disorders of thinking, feeling, and behaving. It properly addresses the interface of mind, brain, and body while evaluating and integrating knowledge at various levels—molecular, neurochemical, intrapsychic, interpersonal, systemic, and sociocultural. The practice of psychiatry is informed by the broad sciences of human behaviour—including psychology, anthropology, and sociology—and by the basic sciences which study the complex activities of the central nervous system.

As both practitioners and investigators within the field of psychiatry, we have a need to order the potential chaos of observation and information into conceptual frameworks which give meaning to the nature of the work and provide the models by which we care for our patients. Debates about the essence of our field have been waged throughout the history of humanity. In the latter part of the 19th century, an extreme biological reductionism was in evidence, only to be replaced by an equally extreme over-reliance on the explanatory nature of psychological mechanisms in the first half of the 20th century. This approach was typified by such hurtful and destructive concepts as the schizophrenogenic mother as a cause of schizophrenia and refrigerator parents as the genesis of autism. The primacy of psychoanalytic psychiatry was subsequently drawn into question by the social perspectives of the 1960s, which themselves faded as community psychiatry failed to eradicate mental illness. At the present time and with our current levels of knowledge, we most usefully understand psychiatric disorders as multi-determined illnesses with complex etiologies demanding multiple approaches to treatment which encompass the biological, psychological, and social realms.

Without the breadth of a conceptual model which incorporates the multi-determined nature of illness and thereby leads to individualized care, compassion in care, and advances in treatment, the essence of the psychiatric care of the patient is diminished. Such broad models best capture the essential emphasis on the individual patient as a unique human being and permit the integration of various perspectives and schools of thought depending on the patient's particular needs. A full understanding of psychiatric disorders and the individuals who suffer from them requires the integration of several models and theoretical frameworks to be coalesced into an explanatory whole, rather than the supremacy of one or another based on the scientific fashion of the day. The maintenance of this comprehensive and integrative stance embodies psychiatry's intellectual and ethical obligation to the broad determinants of health and of illness and thereby incorporates housing, employment, social, and financial supports as part of treatment, rehabilitation, and relapse prevention.

### Clinical Research

Clinical research is a new discipline. Following the first randomized controlled trials evaluating the efficacy of antibiotics in tuberculosis and pneumococcal pneumonia, comparative studies of psychotropic agents were reported in the early

1950s. Scientists then realized that entering a large number of patients into a clinical trial enhanced the validity of the findings and allowed conclusions to be drawn more quickly than when treating individual patients in an unsystemized fashion. Furthermore, these early investigators soon appreciated the power of statistical analyses to determine, with some degree of certainty, the presence of small but significant differences between treatments when they were applied to large groups.

Fifty years ago, when these studies were first being reported, physicians treated severely mentally ill people by wrapping them in ice-cold sheets; the wrapping immobilized the patients, while the cold supposedly calmed them. Repeated electroconvulsive therapy was one of the only other instruments against severe mental illness of the time and, as a result, physicians often overused this still highly-effective treatment, sometimes with catastrophic results. Fifty years ago, there were no drug therapies specifically designed to combat mental illness, while treatments such as insulin therapy, which were borrowed from other fields and used to treat schizophrenia, were spectacularly unsuccessful and carried significant risk. The value of specific and tailored psychotherapeutic techniques for different groups of patients had not yet been determined and there was widespread misapplication of treatments even within the psychotherapies, in the absence of any scientific evidence for their benefit.

Today, psychiatrists using lithium and other mood stabilizers are able to successfully treat 60-70% of the patients who suffer from bipolar disorder; as a result of these treatments and supportive psychotherapies, most of these individuals lead gratifying and independent lives. Patients with even the most severe forms of schizophrenia may now be greatly helped by advances in pharmacotherapy, social skills training, family education, and outreach. Major depression and anxiety disorders, including obsessive-compulsive disorders, may all respond to a combination of pharmacotherapy and specific, tailored psychotherapeutic interventions with enormous benefit to the sufferers. The reduction of stigma and the shifting conceptual frameworks regarding mental illness have contributed to these changes. On the whole, though, it is clinical research which has dramatically altered the course of illness and of clinical care by taking us from ice wraps to lithium, from insulin shock to olanzepine, and from psychoanalytic regression to cognitive-behavioural therapy. This research has been meaningful at basic, clinical, and health-systems levels.

Currently, within the broader field of medicine, there is an increasing recognition of the need to demonstrate empirically the effectiveness of treatments. At the end of the 20th century, it can be said that psychiatric treatments fare very well against this standard and that the empirical support for the efficacy of psychiatric treatments has significantly enhanced the respectability of the discipline. This success applies as fully to psychotherapies and rehabilitation techniques as it does to pharmacotherapies.

### Consumer Movement

An active consumer movement was beginning to form in Canada shortly after the turn of the last century. Recently, there has been a dramatic shift in this move-

ment. No longer are we witnessing the delivery of service to passive consumers; patients and their families now are demanding to be part of the planning, governance, and evaluation of treatments. Similarly, clients are beginning to question the research agenda and to want a role in determining which studies are being funded and how they are being conducted. The earlier discouragement of patients seeking employment in the setting of their treatment is now being questioned, and vocal groups are requesting employment opportunities as a requisite part of clinical care and rehabilitation. Similarly, as the asylums have been emptied, patients are identifying adequate housing as essential for improved outcomes. As we enter the 21st century, pressure will be maintained for continued restructuring of the health care system with enhanced home care and community care and the further development of innovative models for service delivery both within and outside institutions.

Closely related to this movement is the stigma towards the mentally ill, which dates back to antiquity and has its origins in fear, lack of knowledge, and ingrained moralistic views. While erroneous, these views remain pervasive. The idea of losing one's mind is very frightening to all of us; mental illness produces behaviour we might be ashamed of and it represents a loss, a loss of a core aspect of who we are as people. The fact that the causes and effects of mental illness have, in the past, not been well understood has added to these fears and misperceptions. At times, the unusual, and even unfounded, nature of psychiatric theories and practitioners has compounded the problem. Families often have hidden the mentally ill out of concern for their own safety and reputation, while communities have shunned them. Terror of the unknown is embodied by mental illness and, as a result, society does not treat the mentally ill as it does other forms of human pain and suffering.

But things are changing. The new assertiveness of patients has forced a re-evaluation of the stigma of mental illness. This movement has been greatly facilitated by the more biological and less moralistic views of pathogenesis. The fact that visible role models have been prepared to come forward with personal descriptions of illness has had immense impact. The public better understands conditions such as depression, stress, and anxiety disorder as relating more to everyday experience, and is less likely to construct them as moral weakness.

Advocacy for schizophrenia, however, remains more problematic. While there is, in general, a more tolerant and less judgemental view of the illness and an understanding that it has a genetic/biological base, there still is a widespread fear of psychosis. Deinstitutionalization, poverty, decreased income support, and homelessness have resulted in mentally ill people with behavioural disturbance being more visible in the community. The media have responded with lurid attention to fortunately rare episodes of violence due to psychosis, thereby tragically increasing the public's fear of psychosis.

Further understanding of the connections linking the social determinants of illness, such as poverty and violence, with complex symptom patterns, supported by extraordinary developments in brain functional imaging, may advance broad awareness of conceptual frameworks linking mind, brain and body. Such advances in understanding will further erode the damaging myths and stereotypes surrounding mental disorders. Progressive destigmatization of mental illness may be

reflected by public funding for care, research, and education which is proportionate to the prevalence and the morbidity engendered by mental illnesses—a day we are nowhere near. This change will require a concerted partnership between the profession and the public—to reduce fear and ignorance, and to promote hope, compassion, and understanding.

A potent force for change lies in the developing alliance between the profession and an aware and knowledgeable community. This partnership of profession and community is actively combating stigmatization and is arguing for a fair share of the health care resource and for improved funding for research, with the result that the future for our field looks brighter than it has in decades.

### RÉSUMÉ

Trois développements en psychiatrie ont été retenus pour des études plus poussées: le cadre théorique, l'homologation scientifique et la participation accrue des clients et des clientes. À certains moments, le cadre théorique de la psychiatrie a été basé sur un réductionnisme, parfois biologique et parfois psychologique, minimisant la complexité et l'authenticité de la maladie mentale. Un grand besoin de modèles multidimensionnels et d'intégration se fait sentir. D'ailleurs, mesurées selon la norme d'homologation scientifique, diverses interventions psychologiques, biologiques et sociales en psychiatrie se sont révélées efficaces. Enfin, la participation accrue des clients et des clientes dans le domaine de la santé mentale est en train de transformer la manière de laquelle les services sont offerts et évalués, ce qui contribuera à enrayer les préjugés envers la maladie mentale.

### JOHN LORD

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### "IS THAT ALL THERE IS?" SEARCHING FOR CITIZENSHIP IN THE MIDST OF SERVICES

It is very difficult to "stand in the future" as King Arthur did. In 1950, who could have predicted economic globalization, the demise of the Soviet Union, or the fact that institutions for citizens with disabilities would be closing in all parts of the world by the end of the century? As we enter a new millennium, I think it is valuable to reflect back upon the events which have shaped our practice of commu-

nity mental health, but it is important to recognize that any implications we come up with for the future can only be best guesses.

Deinstitutionalization generally is regarded as the pivotal development in mental health in the 20th century. Certainly, the policies and practices which have created community-based services challenged 150 years of institutionalization. Prior to their development, people with serious mental health problems were confined to jails, poorhouses, and almshouses and were often put on display as part of freak shows (Foucault, 1965; Scull, 1977). However, Davidson (1999) has argued that deinstitutionalization has failed to let people into full citizenship. Rather, he suggests, most individuals with severe mental illness continue to live out their lives within the institutional and contrived world of community-based programs.

Some years ago I was involved in a series of qualitative studies which involved listening to the stories and experiences of consumers/survivors. Robert, an articulate young man who had been through a very difficult time, was sharing his life narrative with me. Having been deinstitutionalized, he was considered a success because he was able to stay out of the hospital and was living in a group home. Robert attended a segregated day program, took extensive medication, and had no friends or relationships outside of one family member and other residents of the group home. He had no connections with community groups or associations. Referring to his life amidst services, Robert wondered aloud, "Is that all there is?" This question sums up for me the significance and disappointment of the deinstitutionalization movement.

I believe the legacy of the 20th century will be more sustaining than deinstitutionalization. There are three other significant developments which reflect an emerging empowerment-community integration paradigm in community mental health and give hope that people may experience more than a life of services (Nelson, Lord, & Ochocka, 2001). These developments are: (a) the recognition of power in mental health, (b) the importance of self-help and consumer/survivor initiatives, and (c) the re-discovery of community. Several implications and impacts emerge from these three areas for the new century.

Beginning in the 1980s, a growing consumer/survivor literature described people's experience with the mental health system as difficult, alienating, and a major contributor to oppression (Burstow & Weitz, 1988; Capponi, 1992; Chamberlin, 1990). The introduction of power into mental health discourse makes current and future mental health reform different than earlier reform efforts. We have learned that power exists on many levels. At the individual level, we have learned that recovery is partly about regaining personal power. Recent research shows that having personal control is a key determinant of health (Lord & Hutchison, 1997). In my experience in helping mental health organizations to change, power imbalances are so dominant that it is often hard for people to imagine organizational alternatives. One study showed that many mental health staff were defensive when they heard consumer criticisms of their organization, but at the same time felt they could not speak about their own lack of power (Wadsworth & Epstein, 1998). I now believe that the issues of power relations (including gender, class, and race) must infuse our thinking and acting in community mental health.

Consciously shifting power has now become a critical systemic and organizational issue in mental health. In reviewing several mental health reform initiatives, McCubbin and Cohen (1999) point out that the good intentions of paternalistic governments and caregivers have never been able to ensure progressive reform. They further emphasize that "the objectives of reform will best be met in the long run by placing control of the shaping of the reform in the hands of those whose interests are most consistent with the reform objectives" (McCubbin & Cohen, 1999, p.11). While I agree that participation of consumers/survivors in reform is essential, this shifting power must be accompanied by a shift in valued resources. To date in Canada, there has not been a significant reallocation of funding from the institutional sector to those community alternatives which are based on the values of the empowerment-community integration paradigm (Nelson, Lord, & Ochocka, 2001). Shifting power and the re-allocation of valued resources—such as housing, jobs, and support services—in many ways are prerequisites to the development of full citizenship.

In the last third of the 20th century, the western world witnessed a phenomenal growth in self-help initiatives. The development of autonomous consumer/survivor self-help organizations has been an important reflection of the empowerment/community-integration paradigm. These organizations emphasize mutual aid, peer support, consumer/survivor businesses, and advocacy. They are becoming significant sites of resistance for consumers/survivors (Nelson, Lord, & Ochocka, 2001). In working closely with two consumer/survivor organizations over several years, I have found that the self-help group creates a context for people's gifts and strengths to be honoured. In an effective group, there is sustained mentoring, mutual learning, heartfelt communication, and equal relationships. Peer support relationships enable people to talk freely and test out ideas about their recovery and about their selves in community (Lord, 1997). The self-help process also has the potential to nurture hope and self-respect.

Autonomous consumer/survivor organizations do not exist in isolation. In many communities, they have formed alliances with other players around particular local or provincial issues, such as economic development and work. These groups also serve as a springboard and vehicle for consumers/survivors to have a voice in mental health decision-making. Furthermore, recent research has shown that consumer/survivor self-help initiatives are important mediating structures on the path to community and citizenship (Nelson, Lord, & Ochocka, 2001).

Governments and formal agencies often fail to understand the importance of consumer/survivor initiatives which give voice to new stories and new awareness. Ruth Behar, in her book *The Vulnerable Observer: Anthropology that Breaks Your Heart*, argues that "there are new stories . . . rushing to be told in languages we've never used before, stories that tell truths we once hid, truths we didn't dare acknowledge, truths that shamed us" (Behar, 1996, p.33). Many of the stories we hear from consumers/survivors are filled with emotional pain and woundedness, but they are people's reality. The stories also reflect people's struggle for identity, meaning, and community participation. When we really listen, we learn volumes about how communities and services could respond differently to people who are vulnerable.

The re-discovery of community in the late 20th century reflects both the limitations of the modernist era and the desire of the human spirit for social activity and sense of community. It is well known that citizens with significant mental health problems often have few friends and relationships and have very limited community involvement. Unfortunately, both the structure of modern suburban communities and the professionalization of services have kept people with mental health challenges separate from the fabric of community life—whether it be neighbourhoods, personal networks, or associations of common interest (McKnight, 1995; Putman, 1993). Our understanding of community has been complicated by the fact that, in the traditional mental health paradigm, community has come to mean community-based services—which simply reflects the location of the services, not the capacity of organizations to foster genuine community participation.

I have found, however, that genuine community is everywhere in our own towns and cities; we simply are not used to looking for it! One basis for community is people coming together in associations of common interest, ranging from art galleries to fitness clubs. As part of the Welcome Home Initiative in Kitchener-Waterloo, for example, people with significant mental health problems have been able to participate in settings of common interest. When hospitality is central to such communities, people are welcomed and included. In the last 20 years, a growing number of groups (such as the Healthy Communities movement) have become concerned with building the capacity of communities. In addition, the commitment to community and inclusion has become a central tenet of all disability movements throughout the world (Carling, 1995; Condiluci, 1991; Schwartz, 1997). There is great promise here for the 21st century, as citizens hunger for more sense of community in their lives.

I have suggested that the three significant legacies from the 20th century (power, self-help, and community) have the possibility of framing a new paradigm of community mental health in the new century. This empowerment/community-integration paradigm has many implications for the principles we use, the policies we implement, and the practice we support (Nelson, Lord, & Ochocka, 2001). It is clear that values will be a central guide to the emerging vision—values which are grounded in dialogue with people, and values which reflect strengths, relationships, capacity, and community. It would be hopeful to think that the deficit-oriented approaches that dominated the 20th century will vanish, and that social justice will emerge as a key value in the new paradigm.

Let me conclude by re-visiting Robert's story. If his story of being surrounded by community services represents the best of the 20th century, can we dare to hope that citizenship and meaningful relationships will be at the centre of his story in the new century? Can we build welcoming communities which respect citizenship and inclusion? With work, commitment, and collaboration, can we build on the legacies of the 20th century to create such a world in the future?

## RÉSUMÉ

Il y a trois héritages du 20<sup>e</sup> siècle qui durent et qui engendrent un nouveau paradigme pour la santé mentale communautaire. Le premier est la reconnaissance du pouvoir dans le domaine de la santé mentale. Le deuxième reconnaît

## SYMPOSIUM

L'importance des efforts personnels et des initiatives des consommatrices/survivantes et des consommateurs/survivants. Le troisième est la redécouverte de la communauté. On discute en bref ces trois héritages dans le contexte du besoin d'établir des histoires, des valeurs et des pratiques pour assurer que la citoyenneté et des communautés accueillantes font partie de l'avenir des individus qui vivent avec des maladies mentales.

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