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**Abstract:** Deinstitutionalisation has changed both the setting and delivery of mental health care. Mental health nurses are now providing complex and diverse services in contexts that are often far removed from the traditional realms of health care provision. If they are to meet the challenge of contemporary and future mental health care needs, it is essential that mental health nurses be aware of, and understand, the changing mental health environment. One specific change that has received limited attention in the literature is the increase in socio-political awareness of family carers of people with mental illness, and the concomitant increase in their collective voice and influence through self-help groups.

**Key words:** Deinstitutionalisation, family carers, mental health, self-help groups.

**INTRODUCTION**

The provision of health care services has changed significantly over the latter part of this century. Health care has increased in complexity as well as diversity and has expanded beyond acute care settings into the community for the purpose of health restoration, health maintenance, and health promotion. The changes in both the setting and delivery of physical and mental health care embody the changes in the values, beliefs and philosophies evident within society, and as Kickbusch (1987) claims, there is currently a growing ‗individual, social and political concern for what constitutes health, extending far beyond the traditional realms of health care‘ (p. 437). In order to meet the challenge of contemporary and future health care needs, mental health nurses need to be aware of, and understand, the social and structural changes that affect the social context and thus health care services. One such change within the mental health context is the increase in socio-political awareness of family carers of people with mental illness, and the concomitant increase in their collective voice and influence through self-help groups. This article undertakes to raise awareness and understanding about this change by briefly overviewing the mental health context with specific reference to family care; illuminating the nature of self-help groups in general through a review of the literature; and then discussing the development and functioning of a specific family self-help group.

**THE CONTEXT**

Following reforms in the nineteenth century, incarceration in closed and organised communities behind high walls became the fate of those who were classified as lunatics, inebriates, or vagrants. However, as a result of the process known as ‗deinstitutionalisation‘, such institutions no longer constitute the centre of the mental health system. Increasingly, people experiencing mental illness continue to live and receive treatment in the community. It is ironic, as Scull (1989) and Warner (1994) argue that both the institutionalisation and the deinstitutionalisation movements have been underscored by campaigns for reform on the basis of both therapeutic and humanitarian grounds. Scull (1989, p. 304) maintains that the nineteenth-century reformers argued that the family and the community were unsuitable arenas for the care of the insane who needed to be insulated, in a forgiving and nourishing environment, from the pressures of the world. Conversely, modern reform, according to Scull (1989), has rested on the argument that ‗the worst home is better than the best mental hospital‘ (p. 310) and that ‗community care would restore independence and initiative‘ (p. 314).
The process of emptying institutions has, according to O'Connor, Wilson and Thomas (1991), been justified in the professional discourse in terms of 'normalisation' (p. 44). Warner (1989) terms this 'the rhetoric of community care - increased individual freedom and anticipated higher patient functioning' (p. 22). This rhetoric corresponds to the tenets, the ideology, that Minkoff (1987) maintains has been and still is, the moral basis for deinstitutionalisation policy:

* Institutions . . . are bad for chronic mental patients and should be eliminated.

* Deinstitutionalisation . . . is good . . . and, if done properly, will make their lives better and easier.

* Community care and freedom of choice are better . . . than the paternalism and restrictiveness . . . and should be encouraged (p.945).

Such simplistic and reductionist promotion of community care as inherently good, and institutional care as inherently bad, serves to deny or hide the economic and political pressures that some authors (e.g., Scull, 1976, 1984, 1989; Turner, 1987; Warner 1989, 1994) claim were the driving force behind the process of deinstitutionalisation. Warner (1989) argues that 'economic and political circumstances, more than professional philosophy or technical innovation have shaped our mental health system' (p. 27). Regardless of why the movement came about, deinstitutionalisation has dramatically changed both the setting and delivery of mental health care. However, the issue of whether or not there has been any improvement in the general condition of people with mental illness remains problematic, and consumers and their families are becoming increasingly cynical about the motives and adequacy of the 'experts' in determining their health needs. They are demanding as a right, participation in decisions about the organisation and provision of health care (Bates & Linder-Pelz, 1987).

The increase in family socio-political awareness is not surprising considering the changes that have occurred in the setting and delivery of mental health care. O'Connor et al. (1991) argue that these changes have transferred back to the private arena public responsibility for social care, specifically in terms of family care. Skelton (1994) argues that 'the present policy of treating mentally ill people in the community could not exist without family carers who bear the main burden of care in most cases. Carers are the glue that holds the system together' (p. 2).

It is implicit within deinstitutionalisation discourse and doctrine that family life is best. However, as the Australian Health Ministers' Advisory Council (1989, p. 38) has recognised, the recommendation of home-based care as 'best and cheapest' fails to take into account the cost, financial or otherwise, to all concerned. Indeed, this lends support to the claim by many authors (e.g., Baldock, 1990; Mowbray & Bryson, 1984; Thurer, 1983) that deinstitutionalisation has been premised on the use of the unpaid labour of volunteers, who are mainly women, in the home or in private organisations.

**FAMILY NEEDS**

The needs of families caring for a mentally ill person have received much attention in the literature (e.g., Bernheim, 1987; Doll, 1976; Hatfield, 1981, 1983; Lefley, 1989; Potasznik & Nelson, 1984; Torrey, 1988; Walsh, 1987), and findings strongly indicate that the strains of living with a mentally ill person has the same devastating effect on the family's ability to cope as does any other severe and chronic illness. Lefley (1989, p. 556) professes that there are two descriptive categories of burden for the family: the actual objective problems or objective burdens, such as those associated with financial hardship,
or disruptions to household and social functioning; and the subjective burdens, such as the anguish of feelings associated with guilt, embarrassment, or loss.

There is general agreement in the literature that many carers have difficulty in coming to terms with their family member's illness; they experience ongoing grief and loss; they may experience feelings of shame and guilt and blame themselves; the needs of the ill family member are often so great that they can only be met at the expense of those of the other family members; meeting personal needs beyond those that are basic to life are almost impossible for the primary carer; social life, or a balanced life of any description, is almost beyond expectation. Many of the costs are hidden costs. For example, as Lefley (1989) contends, frequently the burden is such that it necessitates role and occupational changes for the primary caregiver. This change may not only result in financial loss but also in loss of opportunity and potential.

Over the last few decades there have been many articles and books directed at different strategies for coping as a primary care, and at psychoeducative measures (see Torrey, 1988; or Woesner, 1983, for a list of some of this literature). Much of the literature is written for the lay person, often offering personal accounts of experiences, and as such is not only a valuable source of information, but tends to lessen the carer's sense of isolation and alienation through the message that 'you are not alone'. This message was further enhanced as the carers, often at the instigation of concerned health care professionals, began to form mutual support or self-help groups.

**SELF-HELP GROUPS: HISTORICAL ORIGINS**

Mutual support has been practised by human kind since time immemorial. The early tribal or clan societies grouped together largely for physical survival, but as civilisation developed so did the repertoire of ways of helping that were offered through group support (Katz & Bender, 1976). Self-help forms of organisation are especially salient during periods of 'social fragmentation and unrest, characterised by loss of relatedness and alienation' (Katz and Bender, 1976, p. 266). This is evidenced, for example, in the formation of organised collectives such as the guilds of the Middle Ages and Renaissance, and the subsequent Unions and Friendly Societies, which came to the fore along with the social effects of the Industrial revolution. By the 18th and 19th centuries these two particular mutual-aid organisations, Katz and Bender (1976) claim, 'served not only to deal with the immediate needs of their members but served also to politicize them . . . raise their consciousness" (p. 270). This lends support to the suggestion by Tracy and Gussow (1976) that to some extent self-help groups follow a pattern of movement over time. Katz (1961; cited in Katz & Bender, 1976, p. 281) conceptualised a model of five stages which he claims self-help groups typically experience: 1) Origin, 2) Informal organizational phase, 3) Emergence of leadership, 4) Beginnings of formal organization, 5) Paid staff workers and professionals. Tracy and Gussow (1976) suggest that while providing support for their members is the original concern for many groups, as they grow this may change and expand to include social advocacy or similar concerns.

For various reasons the phenomenon of self-help and the increasing visibility of self-help groups were the subject of renewed interest in the 1970s. The reasons behind the upsurge of visibility and interest, although complex and manifold, were, according to Katz and Bender (1976), closely linked to two developments. Firstly, a burgeoning consumer movement was arising in part from exclusions and discrimination in the larger society. Secondly, professional developments in theory, research, and practice in many fields were producing clear evidence of the importance and value of involving consumers in decision making about their own lives. These reasons are supported and expanded by
Jacobs and Goodman (1989, p. 538) who claim that preconditions for the contemporary upsurge of self-help groups have been created by social changes.

Jacobs and Goodman (1989) appraised social changes such as the erosion of the traditional family format, which in turn has reduced the available supply of social support; the increased sense of personal entitlement and empowerment that has been stimulated by various civil and consumer rights movements; the failure of mental health services to adequately address or meet needs; and the greater acceptance of experientially gained knowledge and social support as useful assets in health maintenance. Jacobs and Goodman consider these to be the most influential social changes affecting the development of self-help groups. What in a sense was a rediscovery of self-help groups in the 1970s as 'ameliorative of psychological distress' (Lieberman & Borman, 1976a, p. 261), gave recognition to what has been described as a social force that had long been neglected by the policy elite in many countries (Katz & Bender, 1976).

**SELF-HELP GROUPS: DIFFERING VIEWS**

Various theoretical models have been conceptualised for looking at the diversity of groups that exemplify the self-help movement. These models, Lieberman and Borman (1976b) claim, centre around unmet needs in one form or another. From one perspective, Lieberman and Borman (1976b) argue, self-help groups have emerged to fill the unmet needs that apparently 'fall between the cracks' of available services. It is the unresponsiveness or incapacity of professionals and their institutions to meet needs that give rise to an alternative social movement - the joining with other people in a common cause (Back and Taylor, 1976). Lieberman (1986) claims that the most frequently cited reason for the proliferation of self-help groups is the unavailability of needed mental health services. From this view, self-help groups are seen as stigmatised or fighting against the mainstream (Borkman, 1991).

From another perspective, self-help groups have been conceptualised as developing in order to provide alternative pathways to obtaining services. Hence, it is the incorrectly or inadequately met need - the form in which the service is offered - that is emphasised (Lieberman & Borman, 1976b). Explanations for the development of self-help groups from this perspective usually reflect broad social shifts in values. For example, Steinman and Traunstein (1976) claim that there is a strong tendency for self-help organisations to 'reject professionalization and bureaucratization (the primary characteristics of service organisations) in favour of autonomy and solidarity (the primary features of mutual-benefit associations)' (p. 359). Such rejection suggests an emphasis on the value of democratic and egalitarian principles. Indeed, Dumont (1974) claims that the self-help movement 'articulates and reifies the aspirations . . . of democratic idealism' (p. 632). The notion that self-help groups are in some essential ways like a miniature democracy is supported by the many democratic characteristics that Jacobs and Goodman (1989, p. 537) claim are embedded within the beliefs of implicit constitutions of a typical self-help group. Jacobs and Goodman point to democratic characteristics such as member governance, equal rights within group processes, leadership at the pleasure of the group, free expression of thought and feeling, independence from external rule, internal system of checks and balances, and deemphasis of rank and privilege.

Rappaport (1993) argues that although it is not unreasonable to view self-help groups as 'alternative treatments for people with problems in living' (p. 241), this view is largely the result of professional service providers' application of an implicit medical or human services model. A model that has a style of delivery which regards people as passive recipients of services, and is defined more by the purposes of the professional community than by the contexts in which people live their lives. In order to better understand the
various issues under study, Rappaport (1993) advocates the use of theories and methods that are more consistent with the experiences of the members, and with the nature of self-help groups.

The self-help ethos, as outlined above, centres around the rejection of professionalization and bureaucratization in favour of autonomy and solidarity. Borkman (1990) claims that the ethos, or constellation of norms, sentiments and themes, underlies practices within the groups and highlights 'empowerment, self-determination, mutuality, noncommodity character of help, prosumerism, antibig, antibureaucratic, and experiential wisdom' (p. 328). Such values indicate a rejection of themselves as passive recipients of services, together with rejection of professional hegemony.

Individual needs for affiliation and community with others in a similar condition provides another perspective for the growth and development of self-help groups. It is not the service provided that is important and valued so much as the fulfilment of identity, intimacy, and affiliation needs (Lieberman & Borman, 1976b). Members of a group share a common experience; each has had personal experience with the same or similar happenings (Killilea, 1976). According to Borkman (1976), when it has been integrated the personal experience or knowledge can be applied to a problem. Borkman (1976) claims that the degree of competence or skill developed in resolving a problem through the use of one's experience varies and develops over time, and that this attribute may serve as a basis for leadership in self-help groups. Those who have 'made it' become a role model and a source of hope to the newcomer.

ARAFMI: AN EXAMPLE OF A FAMILY SELF-HELP GROUP

Numerous self-help groups, varying in size, purpose and character, have emerged since the 1970s. In Australia, the group that has been the most germane to the needs of families with a mentally ill person has arguably been the Association of Relatives and Friends of the Mentally Ill (ARAFMI), which was founded in Sydney, NSW, in 1975, with the primary aim of fostering mutual support among its members (Lukes, 1985). This aim has remained the ongoing basis for activities and involvements within the various ARAFMI groups that have been established throughout most Australian states. All ARAFMI groups conduct regular share-and-care meetings where 'carers are emotionally supported, encouraged and shown ways of coping' (ARAFMI document - 'What's It All About?'). As the groups grow from immature, informally structured groups to well developed, formal groups they often expand their activities to include psychoeducation and social advocacy.

There has certainly been change and expansion for the group officially called 'ARAFMI Brisbane Inc.'. This group developed from a nucleus of five people called a 'Relatives Discussion Group' (ARAFMI Brisbane Inc., 1987). It was convened in late 1976 by a social work student, and the group met in a room at the Psychiatric Clinic, Stones Corner, an inner city suburb of Brisbane. The group affiliated with ARAFMI Sydney in 1977, and became incorporated in 1986 (ARAFMI Brisbane Inc., 1987). The group has matured and developed; changed and extended. It now has its own headquarters in New Farm, Brisbane, from which it not only provides care and support for carers in the Brisbane area, but has reached out to offer care and support for other fledgling groups throughout Queensland. As well as providing within group and between group support, ARAFMI Brisbane Inc. (hereafter referred to as ARAFMI) is also concerned with social advocacy and psychoeducation. Although inextricably linked, these three central concerns of ARAFMI can be seen as three arms: a support arm; an advocacy arm; and an education arm.
The support arm is evident in the form of share-and-care meetings; a 24 hour telephone support line; and Young ARAFMI, a support group for the young relatives and friends of a person with mental illness. The advocacy arm is evident in 'the increasing involvement of ARAFMI representatives in state, regional and local mental health advisory groups' (ARAFMI document - 'What's It All About?'). The education arm provides many different information, referral and advisory services, such as the quarterly newsletter; the lending library, which is available by mail to country members; and the 24 hour telephone support line. The education arm also conducts community awareness and education programs: 'ARAFMI frequently speaks with the media, church, community, professional and educational groups, and students in the helping professions' (ARAFMI document - 'What's It All About?'). The awareness and education programs are aimed primarily at 'demystifying' or 'normalising' mental illness, and have a carer's perspective.

The education arm is arguably most evident in the many 'How to' workshops ARAFMI offers, not just to carers in the Brisbane area, but to those in rural and regional areas through the Outreach program. These workshops aim to build skills and develop self-confidence, and address issues such as suicide intervention, loss and grief, self-esteem, and coping skills. Other workshops conducted by ARAFMI can be seen as 'staff development' or 'train the trainer' programs. Interested ARAFMI members are encouraged to attend various 'How To' workshops in order to learn about, for example, facilitating workshops or groups, or providing support over the telephone, or addressing a group of students or police. Although the workshops are primarily intended for carers, all the workshops are available to in-home service providers, such as Home and Community Care (HACC) workers, who participate in the workshops as part of their ongoing training and education.

Notwithstanding its growth and expansion, ARAFMI still largely relies on volunteers. Most of the volunteers are primary carers although there has always been a number of 'friends', including health care professionals, who volunteer their help. Indeed, as Wintersteen and Young (1988) argue, many self-help groups receive their initial impetus for formation from professionals who remain with the group in an advisory or facilitative role until the group develops enough to function autonomously. As a group, ARAFMI greatly values its independence, and guards it closely. However, possibly in accordance with the claim by McTaggart, Caulley, and Kemmis (1991) that there is a strong traditional view that knowledge about practice is the domain of experts, ARAFMI does consult with mental health professionals about its various practices, such as curriculum making. Formal consultancies are commissioned with caution and monitored closely to ensure the grass-roots orientation and way of doing things is maintained. This valuing by ARAFMI of notions related to independence and self-determination is reflected in the makeup of ARAFMI committees. A precedent was established at the first meeting in 1975 of the committees comprising at least 51 per cent of relatives of mentally ill persons (Lukes, 1985). This strategy ensures that control of ARAFMI is kept firmly within the hands of lay carers in the belief that as the primary care-givers they are the ones who 'are most aware of the needs and problems which ARAFMI aims to ameliorate' (Lukes, 1985, p. 6).

Many of the carer volunteers have been with ARAFMI for years, and over time have become the linchpins of the association. Some of these long-time members work quietly behind the scenes offering their time and energies where, and when, they can (for example, in the making of crafts for market stalls or in the folding and mailing of the newsletters). A few others are deeply involved in the organisation and management, especially in the support and education arms of ARAFMI. The nature and strength of these two arms has largely developed from the visions of a few charismatic leaders. Until
recently, the education programs have been based on those experienced elsewhere and modified according to trial and error methods with very little written record of 'how we go about it' (ARAFMI - personal communication). These visionary leaders, although very few in number, are dedicated to ARAFMI and to the continuance of the education programs that they have developed for other carers. However, the leaders are getting older, and as the need to slow down and take on less activity and responsibility has grown, so has their concern for the future leadership of ARAFMI and the future of the support and psychoeducative programs (ARAFMI - personal communication). Essentially, ARAFMI has developed and expanded its role beyond the resources of the volunteers who are largely primary carers.

The situation has recently been alleviated to some extent through means of government funding. Government grants have funded the employment of three full time staff members for ARAFMI: a manager, a community services worker, and an office worker. The manager and the community services worker now provide support and assistance for carers in Brisbane and throughout Queensland within ARAFMI's outreach program. Although always accompanied by an experienced primary carer (in keeping with the basic tenets of the organisation), the paid workers are slowly taking over many of the activities and responsibilities of the education arm of ARAFMI. The funding and the employment of paid workers has relieved some of the burden on the voluntary workers and lowered concerns about the continuance of the education programs. However, such forms of relief will no doubt be accompanied by their own problems as members of ARAFMI Brisbane Inc. endeavour to maintain the grass-roots orientation of the association in the face of ongoing development and change.

CONCLUSION

Self-help groups each have their own culture and customs, and have unique needs, concerns, and problems with regard to their practices. However, they all share many characteristics, especially those associated with democratic and egalitarian principles. Self-help groups, such as ARAFMI, function within a self-help ethos that highlights and values notions associated with empowerment, self-determination, mutuality, and experiential wisdom. Such values indicate a rejection of themselves as passive recipients of services, together with rejection of professional hegemony. For mental health nurses endeavouring to provide services or assistance within self-help groups, it is essential that they not only recognise and understand the nature and ethos of self-help groups, but that they also approach health service provision in ways that are sensitive to, and congruent with, those characteristics, beliefs and customs. To neglect to do so is to risk rendering the service or assistance inappropriate and unacceptable, and thus ineffectual in bringing about any true difference or improvement.

Acknowledgements: The helpful comments contributed by Mrs Ailsa Whitehead AM (Foundation member, past President, and incumbent Secretary of ARAFMI Brisbane Inc.) on relevant aspects of an earlier draft of this paper, are gratefully acknowledged.

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