

ASEHA Qld Inc

ALLERGY, SENSITIVITY & ENVIRONMENTAL HEALTH ASSOCIATION Qld Inc

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A volunteer community organisation providing support for people with allergy, food and chemical sensitivity

SUPPORT GROUPS: An undervalued community resource.

by Dorothy M. Bowes*

Consumer advocates

Support groups are working models of primary health care. They are an essential and important community resource as they are usually actively involved in systems advocacy and often take on individual advocacy as required. They assist people to make necessary lifestyle alterations, to manage their illnesses, provide information, emotional support and contribute to improved wellbeing. They are instrumental in keeping people out of expensive levels of care in the health system.

Special need

The existence of a support group usually indicates that there is a gap in health care services and is most likely signalling:

- an area of special need;
- poor understanding of an issue by the health care profession;
- poor service delivery;
- or no services at all.

Size not relevant

Overall numbers in support groups are not a good indicator of the need for the existence of a support group, or for service provision. Support groups are an important resource in the community and many people only see them as that, not realising that the group may be an unfunded, voluntary agency. Most enquiries are initiated by non-members who:

- only want specific information;
- only want to tap into the information base when they have a need;
- do not want to pay for the service provided;
- and do not want to join a support group.

Difficult conditions

Support groups often function under extremely difficult conditions and under unusual circumstances. Those who run support groups are usually sufferers of a specific medical condition who can assist others with the practicalities of living with their disorder. This is what they do best. They are often not professional people and do not offer professional services.

It is difficult for support groups to function because:

- they lack physical resources;
- financial resources;
- their capacity to raise funds for their group is often diminished by their personal circumstances;
- the energy in the groups is often low;
- they are usually run by sick people - by sufferers, for sufferers;
- those who are actively involved in running the groups are often bogged down responding to members in crisis - mostly medical but sometimes in other areas such as disability services, allied health care, or welfare services.
- those running support groups often do this to their own detriment financially, and at great physical and emotional expense to themselves.

Structural difficulties

Support groups often run their service out of somebody's home, which contributes to their struggle to establish a strong support group base. It is difficult for them to function efficiently, as they need financial resourcing in the form of establishment costs and administrative support to provide;

- office space;
- infrastructure;
- paid staff to ensure good energy and a better standard of efficiency;
- a greater range of services

- constant upgrading of information and reskilling

Assistance to grow necessary

Professional input into research and report writing would expedite their issues into service provision much faster, adding to knowledge of the specific disorder in the community and improved quality of life for sufferers. In effect, lack of resources, office space, structure and good energy is prohibitive to group progress, it:

- prevents groups from growing;
- limits their ability to keep adequate records;
- limits their overall output and their capacity to achieve their aims;
- prevents them from demonstrating a need for their existence;
- prevents them from demonstrating a need for health services in their area of interest;
- means that they can't measure outcomes.

This makes it difficult for groups to argue their case for funding as the current funding model is outcome focussed.

Models of Primary Health Care

However, support groups are models of primary health care that provide essential human needs for their client group. They provide:

- emotional support in the form of listening and a voice on the end of the phone to reinforce that other people have similar problems;
- understanding and experience of the problem;
- empathy;
- practical hands-on information to assist with self-care and the maintenance of wellbeing

Poor acceptance

Lack of available resources for support groups:

- disempowers them in the health care system;
- disadvantages them in the health care system;
- means that as they are not health professionals they do not have credibility and are dismissed by the stronger key players;
- they are usually not able to attend conferences or to acquire material to allow for education, upgrading of information to do research in their area of interest, and re-skilling;
- they are not on equal footing with government and the health industry;
- their issues are lost in professional interpretations of their needs;

Physical and Financial Assistance needed

Adequate resourcing in the form of recurrent funding needs to be available to groups whose illnesses are not well known or routinely diagnosed. This funding needs to include assistance from professional people to establish a firm base for support groups and to assist them to become self-funding over a period of time. Every assistance should be given to support groups to:

- allow them to establish a strong support base for their client group;
- allow them to undertake systems and individual advocacy to an effective level;
- respond to members in crisis where possible;
- acquire appropriate information, skills and expertise;
- be on an equal footing with government and the health industry;
- ensure that they have a strong voice;
- ensure that they are heard;
- ensure that their special needs are not missed in health policy making and when health services are being planned;
- allow support groups to become equal partners in the planning and development of health services.

Need for a funding model to be developed

A model needs to be developed to fund support groups to allow for their sustained growth and increased effectiveness. Support groups should be recognised for their contribution to health care and a budget for them included in health planning. They should be given a high level of assistance by government to achieve recognition and equality. Support groups should not be ignored because they do not have professional status or low numbers. Low numbers may well indicate a new or emerging disease that is not routinely diagnosed.

Not bureaucracies

Care should be taken with funding for support groups not to disrupt the main function of the support group, which is to support sufferers. They are not professional organisations and should not have to be treated as such. They should not be bogged down with the formulation of mission statements, strategic

plans and reporting requirements that take them away from their primary aim - which is hands-on support for sufferers.

Useful to planners also

Support groups are in a unique position to gather useful information for planners of health services; they are directly in contact with the public, the issues involved and should be regarded as a resource to health service planners to:

- indicate gaps in service provision;
- identify areas of special need;
- improve the range of services available;
- provide services that are truly in tune with the needs of the community.

Primary Health Care policy not working

According to Primary Health Care Policy, small groups of people with special needs should not be disadvantaged in health care. Some groups provide a free 24 hour service to the community, and for those involved in health planning to ignore the needs of support groups that flag out these areas of special need, is an affront to the huge body of (largely female) volunteers, who are compassionate enough to forego their lifestyle, their family life and sacrifice their own health for the good and wellbeing of the wider community.

Many groups work with diseases that are not recognised, included or well entrenched in health care services. In spite of the fact that many people need to be under the care of the medical profession, the health care system neglects them as it does not understand their health problems and at times rejects their illnesses and their problems. This means that people unfortunate enough to be in this position are disadvantaged by not being able to claim expenses associated with their illness from Medicare, have access to necessary medical and disability aids. Many such people are consulting private doctors or practitioners of natural therapies, and in the case of the income disadvantaged who cannot afford private doctors or natural therapists they have no treatment at all, they fall through all the safety nets and are consistently neglected in health care.

Social justice should work for all in a meaningful way and support groups are instrumental in pursuing this for the sub section of the community they represent.

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