

Government and Non-Government Organizations

Chapter 8 is a two-part chapter in which we explore what governments and non-government carer organizations can do in order to promote best-practice care for the mentally ill. In Part 1, Antony Sheehan describes how policy issues can influence the course of family involvement in mental health care, and in Part 2, Margaret Springgay outlines how a non-profit charity can succeed in influencing government and societal thinking about mental health.

Part 1

POLICY ISSUES AND GOVERNMENT

Antony Sheehan

A clear national policy is necessary for the development of Human Resources for mental health. An HR policy should define the values and goals for developing a mental health workforce, and provide a coherent framework within which countries can plan, train and develop human resources for mental health. It should also provide a means of accountability and encourage continuous improvement in the quality of care. (WHO, 2005.)

In most societies, families are at the heart of sustainable communities. From so-called “developing” to “developed” countries, society at all levels, is reliant on family units to bare much of the burden of supporting a loved one who is unwell. Whilst the door in the office can close at the end of a span of duty, family opening hours are 24/7. Although staff *should not* give up on service users, families *cannot*; so are left unsupported when services do. The arguments for politicians and policy makers to create policy and strategy conditions that support families are unassailable and yet all too often ignored. Were the burden that families carry each day to fall upon the state, the effects upon the economy would be profound. Put another way, families and carers provide a service to those with an illness or long-term condition, which has enormous value. The 2001 census in England and Wales showed that there were 5.2 million carers, of whom 13,000 provide care for 50 hours per week or more.

Given the economic and care contribution families and carers make, what role can policy play in supporting those who care? What can be written into national strategy that sustains family support?

This chapter will examine some of the ways in which national policy can centralise the needs of families and carers with particular reference to families caring for people with psychiatric conditions. English health policy is used as a case example to describe markers of good practice in terms of developing family-focused health and social care

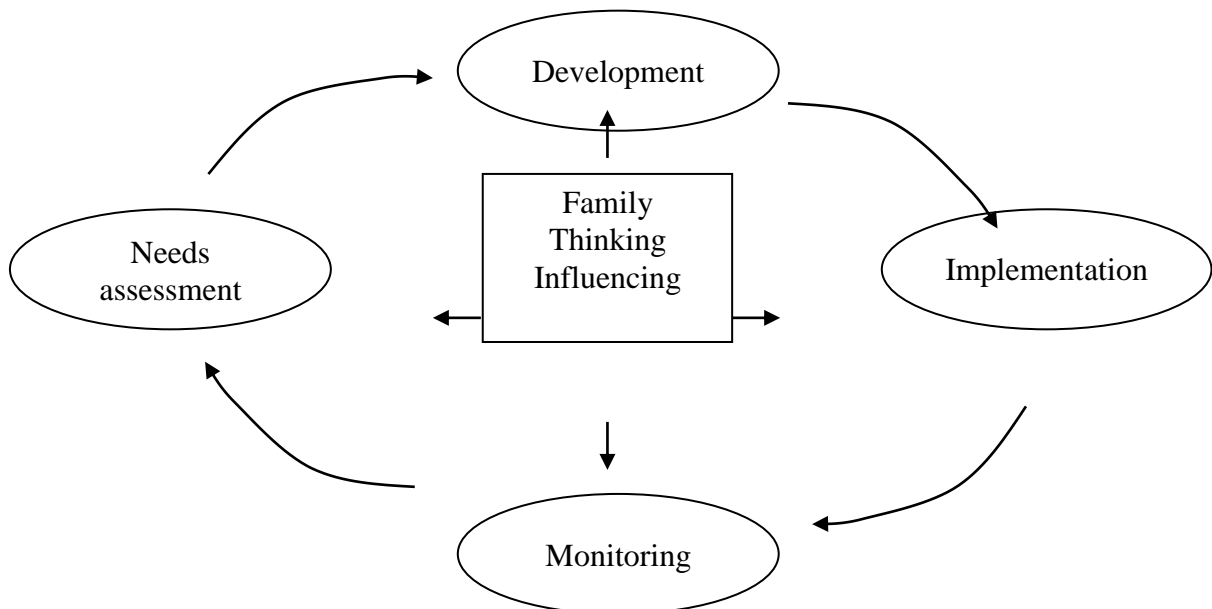
policy. Although English material is used, many of the principles are relevant to countries worldwide.

Introduction

Policy makers are used to focusing their efforts on the needs of individuals. The key role that families and carers play is too often neglected. This informal support must be central to the contribution of national policy and to the delivery if that policy has a chance of successful implementation.

In most countries, government (whether national, provincial or internal state) takes responsibility for aspects of public service such as education, policing and health. Each government department (including the finance department through its fiscal policy) should try to sustain families. Health departments have a specific responsibility given the burden of care support that families provide for those in their family with a physical or emotional need. Figure 1 highlights the need for engagement of families at every stage in the policy evolution process.

Figure 1



Negative consequences of lack of policy engagement include:

- Families lose energy and momentum as they struggle to cope alone.
- Long-term disorders mean that many children are caring for a parent or a sibling, often over a long period of time.
- Mental health problems for other family members commonly develop.
- Exclusion of those with significant needs from mainstream services creates 'ghettos' of disabled people and reduces life opportunities.
- Dealing with public services puts even greater strain on families.
- Hours, days or weeks of employment are lost by families attending to the disabled person's needs.

Markers of good policy for families

Given that positive services for families and carers can help sustain individuals with health needs, policy set at a national level needs to create a framework which challenges local services to offer an integrated and high quality support system for families.

Why focus on families? Because doing so extends to the well-being for the individual as well as their family. Certain countries, including Scandinavia, plan on a family rather than on individual basis and have better outcomes. This seems to be a positive approach given that we know of the negative consequences of plans that are too narrow on the diagnosis of the individual.

National policy should look to create services which:

- Inform families of their entitlements.
- Structure provisions around the needs of the family.
- Provide families with solutions that maintain and develop all of family life.
- Respond to the fluidity of the real lives of families.
- Recognise family carers as potential experts.
- Understand that the needs of families change and that family's culture and background should be respected.

The importance of health literacy in families

Understanding what individuals and families can do to improve and maintain their own health and well-being is fundamental to the effective and efficient use of health and social care resources. Studies have shown that once people know what to do to care for themselves and their families they can use services in a far more meaningful and less intensive way.

The Director of Patient and Public Involvement in England described health literacy as:

“The ability to make sound health decision in the context of everyday life”

(Health literacy is the strongest predictor of an individual's health status).

The National Expert Patient Programme, a policy initiative in England aimed at improving effectiveness and efficiency in use of health services through developing health literacy, has shown that use of services in the following areas was reduced:

- GP consultations	7%
- Outpatient visits	10%
- Accident & Emergency attendance	16%
- Physiotherapy use	9%

Developing the model of “expert” service users to families and carers

A new national Expert Carer Programme (ECP) will provide a framework of support for families/ carers. This expert care model has the following key characteristics:

Training support for families/carers in relation to their loved one's condition

- Having access to specific organisations such as national mental health charities to use their existing knowledge and networks to provide this training and harnessing their resources as partners in the mental health system to integrate families into treatment
- Information on how to access services and entitlements
- Evaluation of the programme

The ECP has been developed in close co-operation with national carer organisations. It will be a “generic” programme offering support to a range of families and carers with members living with different disabilities and long-term conditions. In developing the program, it has been essential to work co-operatively with carer representation whose expertise has been invaluable in formulating content. Programmes such as the Carer Educational Support Programme (CESP) developed by Rethink Mental Illness, a national mental health charity, has been really important to national policy development in the Expert Carer Programme. It is likely that the following content will be delivered to carers through the Expert Carer Programme:

<p>Training for their caring role</p> <ul style="list-style-type: none"> • Knowledge about the cared for person’s condition/illness and its development, and about medication and its effects. • Knowledge and skills in dealing with psychological aspects of caring • Fostering independence skills for the cared for person
<p>Knowledge and skills to deal effectively with the care system including:</p> <ul style="list-style-type: none"> • knowledge of local services • where to go for help • how “the system” works • understanding the terminology used by professionals • person-centred planning • advice on putting together a care package • how the cared for person can be heard • negotiating skills especially with service providers • knowledge of carers’ rights and legislation • direct payments – how they work and how to gain access to them
<p>Training for outside the caring role</p> <p>Personal development including:</p> <ul style="list-style-type: none"> • returning to work and education • employment advice, including managing work and caring
<p>Training to sustain themselves and their health</p> <ul style="list-style-type: none"> • financial matters

Health literacy is only one of the things that is important to families of the mentally ill. They sometimes have to be the eyes and ears or even lips of their relatives so they have a particular role in treatment and care. This role is insufficiently understood, even by mental health professionals.

Policy makers and politicians have a key role in providing effective services for families/ carers. They also have an important part to play in ensuring that services are used as efficiently as possible. The Expert Patient and Expert Carer Programmes are

excellent examples of national, policy-based initiatives, which are proving to be useful in raising levels of health literacy.

As one policy leader has said:

“The question isn’t can we afford to inform patients and families but rather can we afford the ill-informed patient?”

The position of families and carers in English national health policy

Supporting informal care has been an important issue for the English government over the last decade. Recently, impetus has been given to a family/ carer focus in national strategy through a new national white paper called *Our Health, Our Care, Our Say* (2006). This white paper focuses on preventive and community services and recognizes the role of carers by committing the English government to create a new deal for carers which delivers:

- More respite care (a break from caring responsibilities):
“We will ensure that, in each council there is short-term home-based respite care to cover crisis or emergency situations.”
- Establishes a national help and advice service (improving access to information and entitlements):
“We will establish an information service/help-line for carers.”
- Revises the Prime Minister's strategy on carers (leadership from the top). This political level leadership is critical in influencing local services. Without this leadership, policy will not be taken as seriously.
- Creates an expert carers programme (builds health literacy and expertise as discussed above):
“We will allocate specific funding for the creation of an expert carers’ programme.”

Over recent years, the government in England has tried to develop supportive approaches to families affected by ill health. Government’s role includes:

- Providing financial resources
- Delivering a national strategy (to give direction to local services)
- Ensuring that the policy is implemented (a monitoring and evaluation role)
- Creating new legislation where necessary in support of policy goals.

Proposals for progressing individual components of the Policy Initiatives

Key elements in the project to develop provision for emergency respite care include:

- Defining good practice in respite care and support (not in terms of prescriptive detail but the key features of the service to be delivered). In straightforward terms, this is about pre-planned cover for emergency

situations. It should not focus exclusively on having a system in place that can quickly put together service provision at the time of an emergency.

- Develop the Prime Minister’s strategy on carers and families to ensure that every effort is made by government departments to co-ordinate their support for families and carers effectively.

Table 1

THE LEGISLATIVE FRAMEWORK FOR FAMILY/ CARER SUPPORT IN ENGLAND		
1995	Carers (Recognition and Services) Act.	Gave carers the right to request an assessment of their needs on the condition that the person they are caring for has been assessed as well.
1999	Government’s first national strategy for carers, Caring about Carers	Created a grant for carers in England and focused on providing breaks for cares and services to support them.
2000	Carers and Disabled Children Act	Fixed the loophole in the Carers (Recognition and Services Act 1995), entitling carers to an assessment in their own right upon request, regardless of whether the person they were caring for had been assessed.
2004	Carers (Equal Opportunities) Act	Obligated councils to inform carers of their rights to an assessment; and extended assessments to cover carers’ opportunities for education, leisure, training, and employment.

Supporting the position of families of people who experience mental health problems through national policy

The inclusion of Standard Six in the National Service Frameworks (NSF) for Mental Health was a key moment for carers in English national mental health policy (see [Chapter 6 and later in this chapter](#)). It established for the first time, carer and family support as an explicit national priority for local mental health providers.

The NSF for Mental Health recognized that there was a compelling argument for enshrining carers’ needs in a national strategy document. It offered a confident statement on behalf of government that an evidence base and related interventions were available.

Interventions and Evidence Base

About half of those with severe mental illness live with family or friends, and many others receive considerable support from them. Carers of service users, including young carers, should be involved in their own assessment and care planning process, which takes account of the state of their own mental and physical health needs, and ability to continue to care.

Women are more likely to be carers than men - 58% of carers in Britain are women - and are also more likely to carry the main responsibility for caring, where there is more than one person with some responsibility.

The families of individuals with severe mental illness may have to contend with demanding behaviour, extra financial burdens, restrictions upon their social and family

life, and occasionally a risk to their own safety. The needs of those caring for people with severe mental illness are especially high.

Assessing Carers' Needs

The Carers (Recognition and Services) Act 1995 (see table 1 above) gives people who provide “substantial care on a regular basis” the right to request an assessment from social services. The loophole refers to patchy implementation across England of this important piece of legislation. Assessments are not always carried out. Some carers are offered very sensitive, practical and emotional support, but others receive little or no help. Solutions may not be more enforcement. There is a real issue about getting information to families and carers. Another route to achieving a more consistent approach would be to find ways of sharing the best of practice that does exist.

The Prime Minister’s strategy on carers is attempting to deal with some of these problems – in health terms “Our Health, Our Care, Our Say” described health and social services responsibilities in terms of making good practice common practice. It also reinforces responsibilities under the 1995 Act.

The Carer’s Plan Should Include:

- information about the mental health needs of the person for whom they are caring, including information about medication and any side-effects which can be predicted, and services available to support them
- action to meet defined contingencies, e.g. inability to care
- information on what to do and who to contact in a crisis
- what will be provided to meet their own mental and physical health needs, and how it will be provided
- action needed to secure advice on income, housing, educational and employment matters
- arrangements for short-term breaks or respite care
- arrangements for social support, including access to carers’ support groups
- information about appeals or complaints procedures.

It is an insufficient condition simply to set standards and markers of good practice. A key aspect of the implementation strategy includes a clear view on how progress will be measured. (See table 2.)

Table 2. Measurement of Progress

In addition, progress will be monitored through local milestones, for example:	
<p>Milestones</p> <ul style="list-style-type: none"> • Carers of people with severe mental illness who provide substantial care on a regular basis should: <ul style="list-style-type: none"> - be identified by health and social services - have an assessment of their caring, physical and mental health needs 	<p>Data</p> <p>CPA review returns, data will be integrated into Mental Health Minimum Data Set</p>

- have a care plan agreed and implemented to meet their own needs	
<ul style="list-style-type: none"> • Carers of people with severe mental illness who provide substantial care on a regular basis: - have seen and had explained to them the care plan of the person for whom they provide care - understand the nature of their loved-one's illness - know how to contact services if they need to 	CPA review returns, data will be integrated into Mental Health Minimum Data Set
<ul style="list-style-type: none"> • Carers express increasing satisfaction with services: - for those they care for - for themselves 	CPA review returns, data will be integrated into Mental Health Minimum Data Set Local survey
• Carers involved in service review and development	Strategic Health Authorities' monitoring of health improvement programmes

There are certainly significant challenges in improving care and family supports. However, there has been progress since the NSF (supported by the Carer's Implementation Guide) was published.

Progress on Carers' National Standards Framework

Based on the NSF councils now have a duty to inform carers of their right to an assessment of their needs and to consider carers' needs and wishes in respect to work, training or leisure opportunities.

The Department of Health published a good practice guidance document entitled *Developing Services for Carers and Families of People with Mental Illness* in 2002. A specific target to recruit 700 more staff to provide a range of supports including arranging respite care for carers by 2004 has been surpassed. As of December 2006, there were 796 carer support workers in post, therefore exceeding a national set target.

The Role of National Representative Organisations in Developing Government Policy for Families/ Carers

National "carer" representative organisations can be very effective in developing national strategy to support the needs of families/ carers. These organisations often have the following characteristics:

- They are membership led – involving families with either specific caring responsibilities (e.g. mental health) or generic responsibilities; (e.g. caring for children).
- They lobby government on behalf of the their membership.
- They provide high quality information to their membership.
- They collect information and build a case for change, which they often use in their lobbying of government.

Therefore, these organisations can provide the following supports to national government in developing national policy:

- Bringing a grassroots perspective.
- Offering a conduit for consultation with people who have day to day experience of caring.
- Intelligence data on needs and service use.
- Ideas for innovation in policy, strategy and service development.
- Views on progress towards delivery of national policy objectives.

Good examples of national care organisations in England include:

- Carers UK – www.carersuk.org
- Princess Royal Trust for Carers – www.carers.org
- Rethink – www.rethink.org
- Partners in Policy Making – www.partnersinpolicymaking.com

Conclusion

We are aware of the extent to which families and carers provide the majority of support for a member with disabilities or long-term illness, particularly those with mental health problems. We also know that providing proper support and services to families can be one of the best ways of helping people with mental illness. The position that the English Government has taken is that support for carers is fundamental to their support of those with mental illness and other long-term conditions. This will be ensured by the inclusion of family and carer policy in the program of inspection and monitoring led by government regulation bodies in health and social care. Support must be mainstreamed into the activities of all mental health and social care services.

It is hoped that the growing recognition of carers and families will increase services and resources aimed at sustaining their informal care. Without such support, the burden on the state would no doubt increase.

Part 2

Advocacy and the Family Organization

Margaret Springgay

Nongovernmental organizations (NGOs) often play an important role in mental health promotion, prevention and treatment. For the HR planner in mental health, NGOs can provide useful resources in terms of competencies and expertise for training and supervision of public sector staff, advice in service planning, and liaison over specific aspects of service provision (WHO 2005).

Introduction

Family self-help and advocacy organizations for mental health have grown over the past two decades as a formidable force internationally. They are accepted in most countries as a legitimate source of advice about the needs, concerns and practical problems faced by families/ carers and consumers. Family organizations have also emerged in many countries as an essential sector to work with government and build solutions to mental health issues. This section will explore the opportunities that exist for family organizations to advocate for improved mental health services. Through examining what family organizations are able to accomplish in the voluntary sector, mental health professionals can consider how forming alliances for shared initiatives with them can help in achieving common goals.

NGOs have been called the ‘unelected strata of influence and patronage that lies between voters and their government’ (Hywood, 2004). Hywood goes on to say that the proliferation of NGOs is a world-wide phenomenon which involves a range of countries including the United States, Canada and the U.K. and global institutions including the United Nations and the Organisation for Economic Cooperation and Development. A British study described the growing influence of NGOs as ‘involving efforts to change institutions’ policies in ways that are expected to favour the poor and marginalized’ (Hudson, 2002). People affected by mental illness have been marginalized in almost all societies and NGOs in many countries are becoming powerful players to redress that marginalization.

These organizations in the mental health sector generally have as the majority of their membership either people who have experienced illness (consumers) or family/ carers. With membership drawn from the grassroots in mental health, these organizations are in an excellent position to promote the needs of their members and to work in a collaborative partnership with mental health services and government to get their support. That said, it takes time to build and establish a legitimate voice as an NGO. Planning, integrity and strategic thinking will need to drive progress in order to establish a partnership role. Family and patient mental health organisations often have diverse demands and carry out multiple roles as:

- service providers to people affected by mental illness;
- a provider of education programs to families and carers;
- a provider of education to mental health services and the community;
- an information source for government departments, politicians, etc.

To maximise their effectiveness these NGOs need to work as change agents. The multiple roles that they perform help ensure their acceptance as a legitimate voice speaking on behalf of, and in partnership with, consumers and families/ carers.

To become an effective advocacy voice there are a range of activities for NGOs to carry out which form critical elements. Such elements include becoming informed, awareness raising, education, networking, capacity building, lobbying and campaigning. NGOs can provide the means for their members to raise issues and influence public policy. The involvement of families in advocacy can give a sense of achievement and real empowerment (The Kit, 1999).The following table gives examples of the activities involved to achieve each of the critical elements.

Becoming an Effective Advocate

Table 1

Critical Elements	Examples of activities
<p>Become informed</p> <p><u>Defined as:</u> Knowing your subject: Gather information from local, national and international sources</p>	<ul style="list-style-type: none"> • Recruit people to your Board who have experience with government or dealing with government departments. • Ensure you are well informed about the impact of mental illness/es your organisation represents. • Know your organization’s key issues. • Use the mental health statistics within your country and compare them with other countries. • Identify whether local, regional or national government is responsible for the issue. • Identify “champions” or sympathizers in government and mental health services and court them. • Introduce your organisation and what it does to relevant government departments as well as politicians. Contact and arrange to meet them on important issues. • Use tertiary students to assist in sourcing information. Educational institutions often welcome such requests and it gives students issues to investigate as part of their studies while contributing to the education of the public about mental illness.
<p>Awareness raising</p> <p><u>Defined as:</u> The process of informing others about the effects of mental illness</p>	<ul style="list-style-type: none"> • Keep your membership informed and ready to lobby. • Produce and disseminate newsletter that covers your key issues and circulate copies to government– use real stories – remember members of government respond to individual stories sometimes better than statistics. • Arrange for members who have a story to talk direct to members of government if possible. • Respond in a timely manner to requests for submission/information – this ensures you will be seen as a reliable source of grassroots information.

<p>Education</p> <p><u>Defined as:</u></p> <p>Ensuring that accurate information is provided. This is an important way to address stigma</p>	<ul style="list-style-type: none"> • Don't assume government members know about mental health. Develop postcards with short facts about mental illness—a useful quick check for busy people. Use stories from carers and consumers. • Become known to the media and appoint a spokesperson from within the NGO—informed media stories contribute to educating the public. • Educate your communities through a speakers' bureaus and include families as speakers. • Establish links with research institutions. NGOs are well placed to contribute to the design, process and dissemination of findings of research because of their close relationship within communities.
<p>Networking</p> <p><u>Defined as:</u></p> <p>Establishing relationships with significant individuals and organisations to further common issues</p>	<ul style="list-style-type: none"> • Identify important organisations and people that would support your NGO to achieve it aims and approach them to work together. • Identify people within your organisation who have people skills and support them to establish and maintain relationships with mental health and other organizations.. • Acknowledge assistance you get with a thank you. More formal acknowledgement, such as certificates, is appreciated in some situations.
<p>Capacity building</p> <p><u>Defined as:</u></p> <p>Increasing your organisation's ability to fulfil its role by increasing skills, knowledge and resources</p>	<ul style="list-style-type: none"> • Build your organisations' resources: use your networks to recruit new members, encourage members to volunteer to assist the NGO carry out its role. • Build your financial base: approach corporations, seek grants from philanthropic societies and make submissions to government for project funds. • Provide staff and volunteers with opportunities for continued learning, support and resources to carry out their roles. • Participate in research. Research is a critical input to human and socioeconomic development (Delisle H et al, 2005).
<p>Lobbying</p> <p><u>Defined as:</u></p> <p>Raising issues with legislators/government to influence formulation of policy</p>	<ul style="list-style-type: none"> • Identify and prioritise important issues on which you wish to raise awareness. Prepare key messages in short and digestible formats. • Keep government informed • Use local and national media to highlight issues – prepare press releases ready to be used—one issue only. • describe both the problem and what needs to be done to improve the situation. Establish your NGO as a reliable commentator on mental illness. • Use multiple methods to disseminate information e.g. press releases to capture media attention for print, radio and TV.
<p>Campaigning</p> <p><u>Defined as:</u></p> <p>Undertaking a planned, structured approach to achieve your NGO's goals through representation to the public and government</p>	<ul style="list-style-type: none"> • Campaigning is similar to lobbying but is directed at a wider audience than government. It is based on well-developed and well researched issues. • Develop a campaign plan for the organisation which lists: 1) the purpose, 2) the tasks and timelines and 3) the outcome you are seeking. This enables a full evaluation of how well you met your targets. • Form a core group or committee. Harness the members of your

	<p>organisation to participate in your campaign. This is important to give a real ‘voice’ and personalize the issues.</p> <ul style="list-style-type: none"> • Have clear goals and make quite explicit the actions you want taken. • If you are able, obtain professional assistance in the development of material to ensure it is presented in a professional way. • Evaluate and use results to identify successes and faults for future planning.
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Examples of successful campaigns from Australia

The following describes some effective activities in Australia in recent years that have raised the awareness of mental illness on the individual and families and contributed to increased government action. While national organisations such as the Mental Health Council of Australia and SANE Australia have been working for many years to change attitudes and influence decision-makers, the examples draw specifically from more recent actions by family associations.

The examples draw specifically from actions by family associations.

While Australia developed its first National Mental Health Strategy in 1993 following a number of significant reports describing the inadequacy of services for people affected by mental illness, it took a great deal of time for the magnitude of neglect, disadvantage and stigma facing those affected by mental illness to be understood. Now, over a decade after the initial strategy, and through the work of many NGOs, researchers, health professionals and people affected by mental illness who have spoken out about their situation, there is a greater level of awareness by the public, politicians, government and the media about mental illness and its impact.

1. Formation of the Federal Parliamentary Friends of Schizophrenia

This group of bi-partisan politicians was formed in June 2004 following 12 months of strategic lobbying. All members of federal parliament were visited on several occasions and provided with information about schizophrenia and its effect in the community. Information on a post-card sized card containing pertinent facts about schizophrenia from research was circulated. For example:

- the incidence in the community
- the age of onset and gender distribution
- the level of disability (obtained from international statistics (WHO 2000))
- the impact on families and carers (e.g. national statistics on number of hours spent caring)
- the cost of treatment & economic impact of schizophrenia (from international studies)

People with schizophrenia and carers from the Mental Illness Fellowships of Australia (MIFA) arranged appointments and visited Members of Parliament to tell their story and describe the impact of schizophrenia. The process of education occurred over a 12 month period with approximately three visits for each Member of Parliament. Members of Parliament were encouraged to join the bi-partisan group, to ‘meet regularly to consult with a variety of experts, sufferers, and carers to learn more about schizophrenia

and to consider new policy approaches and opportunities to minimise the impact of the disease.’ Establishment of the PFS group was supported by funds from industry and in association with MIFA and SANE Australia.

The Parliamentary Friends of Schizophrenia (PFS) was formed and is co-chaired by two members of different political parties. The joint co-chairing emphasizes that it is bipartisan and the fact that schizophrenia affects the population indiscriminately. Forty-five members of parliament joined in 2004 with the co-chairs inviting ‘all Parliamentarians to participate in Parliamentary Friends of Schizophrenia to identify opportunities in helping Australians better cope with this significant illness’. This represented 20% membership by Members of Parliament.

The PFS has continued to meet a minimum of four times a year, during sitting times in Australia’s Parliament House in Canberra. Each meeting is run as an information session highlighting such issues as: what it is like to have schizophrenia, current research opportunities, and ways in which the situation could be improved. Speakers have included researchers, people with schizophrenia, carers of people with schizophrenia and international visitors to present specific programs e.g. Major Sam Cochran from Memphis Police talked about the Memphis Police Crisis Intervention Training program for police when dealing with people with a mental illness. Other presentations in 2006 included the launch of an Australian Psychosis Research Network, the launch of a Guide to Mental Illness for Electorate Offices produced by SANE Australia especially to improve mental illness knowledge and confidence of staffers. MIFA also provided a response to the international survey of carers conducted by the World Federation of Mental Health.

Attendance by PFS members varies at their meetings according to the time of day (e.g. demands if parliament is in session) and other priorities of the PFS member. By 2007, membership had increased by an additional 30 bringing the total members of the PFS to 75. This means 33% are Members of Parliament – a growth of 13% in three years. The idea of such a group has now spread to some Australian states with State Parliaments in New South Wales and Victoria developing their own Parliamentary Friends’ groups.

There is no doubt that the awareness of the impact of schizophrenia and mental illness has increased in all political parties and among members of parliament since its introduction.

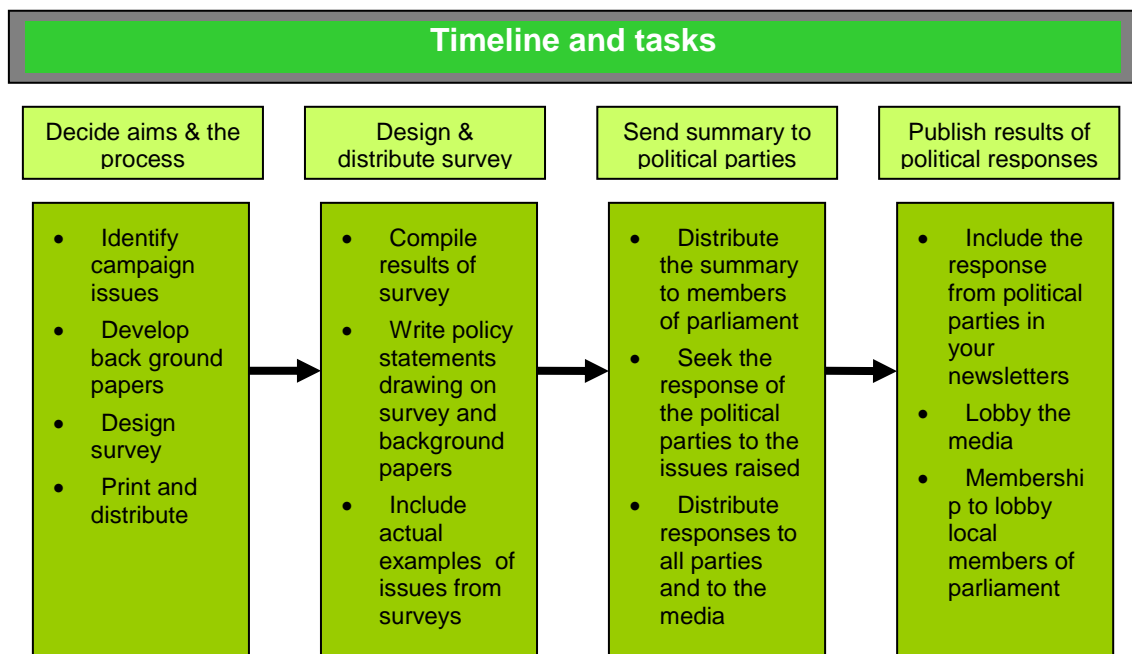
2. National election campaign – incorporating a survey of members

With a federal election announced for 2007, the Board of MIFA decided to embark on a national election campaign highlighting the needs of those affected by mental illness. A campaign plan was developed which set out the aims and objectives, method, tasks, timelines and responsible person(s). A membership survey was conducted to provide a legitimate voice about the issues affecting people. Areas of responsibility pertinent to the federal government formed the basis of the survey design. Background papers on each of the pertinent areas were written. The survey form was designed, printed and distributed through the MIFA State and Territory member organisations and made available on the MIFA website for electronic entry. It was also widely advertised to service providers inviting them to complete the survey. Respondents were asked to identify whether they were prepared to have their story used and whether they wanted to speak publicly about the issues they raise. This provided MIFA with people who could best provide ‘the legitimate voice’.

The response was over 2,000 survey and electronic forms completed. The survey results provided a rich source of information about priority needs, the impact on families/carers, and what they wanted done. A four page summary of the issues was compiled using actual quotes from the respondents. At the time of writing there remains a further five months before the predicted date of the election. The survey summary will form the basis of questions raised with political parties and ask for their response, outlining specifically what actions they intend to take. The response from political parties will be used as a tool by both the member organisations and individual members to lobby federal members of parliament.

Table2

An example of an NGO’s National Election Campaign



It is important that not only the executive of the NGO approach and lobby government but also the grass roots membership at the local level. This ensures that local politicians understand that the issues are relevant to their own constituents.

A final task in any campaign is to evaluate its success. The evaluation considers whether the aims have been achieved as well as considering additional benefits that may not have been predicted. The evaluation should also identify what could have been done differently and/or better so that it informs future campaigns.

3. Consumer Consultants

In the past six months in the state of South Australia, mental health services have appointed consumer and carer consultants in all the mental health hospital units and forensic services. All appointed carer consultants have been sent to the South Australia Fellowship to undertake the Well Ways program as part of their induction (See Chapter 2). Well Ways is a 12 month program: an initial eight weeks with follow-up sessions every three months for 12 months. This is typical of what is occurring in all states.

4. Public Awareness

Another result of successful campaigning is the initiation by police departments of mental health training for police officers that involves consumers and carers. One impetus for this was MIFA's programme that brought Major Sam Cochran from the Memphis Police Department to Australia.

MIFA has just hosted a national speaker tour by Australian researchers in schizophrenia who visited and spoke in right cities – the speakers were drawn from the newly formed Australian Psychosis Research Network (APRN) – a consortium of research institutions in four states. The President of MIFA is the co-chair of the Steering Committee of the APRN.

Conclusion

Involvement by consumers, families and carers in the formulation of mental health policy is occurring increasingly throughout the world. In many countries the inclusion of consumers, families and carers into all levels of consultation has been written in to national strategies. Despite national policy supporting partnership and family inclusive approaches, changing the practice of mental health professionals takes time. There are mental health professionals who are champions of a partnership approach and family inclusive practice and find themselves as frustrated as many families with a mental health system working from old paradigms. Alliances are therefore welcome. The growing strength of the family/consumer voice provides the opportunity to redress the marginalized sector of mental health and improve future alignment of services, policy and practice.

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