

# Closing the gap: building the capacity of non-government organizations as advocates for health equity

**SALLY NATHAN, ARIE ROTEM and JAN RITCHIE**

*School of Medical Education, The University of New South Wales, Sydney, Australia*

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## SUMMARY

*Seeking achievement of health equity has underpinned national government and global health policies for decades. However, major difficulties and challenges faced in the practice of achieving 'Health for All' has led to a recognition of the need to broaden the focus of efforts to improve health equity. Civil society groups have been identified as key stakeholders in attempts to achieve health equity, and the importance of strengthening their capacity to influence relevant government policy and practice has been highlighted. This paper presents the results of a qualitative study which examined the role of organizations outside government in advocating for health equity, and the capacities and conditions that were related to their success. In-depth, unstructured interviews were conducted with 26 non-government organizations (NGOs) who were active in three important health policy debates in Australia. The*

*grounded theory method was used to direct data collection and analysis, and member checking was employed to ensure soundness and build ownership of the findings. Effective advocacy was found to be a dynamic process characterized by flexibility and opportunism within a framework of longer term goals. Two key ways of working were identified—in partnership and in conflict with government, with shifts in emphasis in response to organizational strengths and a changing environment. A number of domains of capacity, which together are termed 'capacity for advocacy', were also identified. It is clear that NGOs can learn a great deal from each other, but there needs to be investment by governments, international agencies and NGOs themselves if advocacy for health equity is to be strengthened.*

*Key words:* advocacy; capacity building; health equity; non-government organizations

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## INTRODUCTION

Seeking the achievement of health equity has underpinned national government and global health policies for decades (WHO, 1978; WHO, 1981; McClelland, 1991). Health equity is defined as providing all people with the same opportunity and enabling factors to have the same level of health and access to health care services according to their need, not their ability to pay (McClelland, 1991; WHO, 1998a).

Over the past decade significant barriers have become apparent and new challenges have arisen around the concept of equity in health. Recently,

the role of the WHO and its member countries in equity issues has been the subject of discussion papers and consultations (WHO, 1998a; WHO, 1998b); the renewed interest is timely. While there have been some marked improvements in health around the world in terms of gross average indicators, there are significant and growing inequalities in health between and within countries (Freeman and Rotem, 1997).

Recently, the focus on the role of governments in addressing health equity has been re-assessed (WHO, 1997; WHO, 1998a). It has been noted

that some governments may not view health equity as a priority and that other organizations outside government have an important role in keeping health equity on the agenda (WHO, 1998a). The WHO has recognized the need to support and empower civil society groups to take on this role (WHO, 1997; WHO, 1998a; WHO, 1998b).

This study examined the views of organizations or individuals outside government regarding effective advocacy tactics and the necessary organizational capacities to focus public attention and stimulate government action to address health equity.

## **METHODS**

The study involved in-depth, unstructured interviews with non-government organizations (NGOs) who were active in recent policy debates in Australia.

### **Sampling**

Case examples were chosen to provide an opportunity to observe a rich diversity of organizations engaging in debates and exerting influence (Stake, 1994). The term 'case example' refers to the debates studied, each of which involved a number of actors who were attempting to influence government policy and practice. Case example selection together with the selection of actors within each case example were guided by the principle of theoretical sampling (Strauss and Corbin, 1990).

The three Australian case examples selected for study were:

1. a debate in 1999 about the provision of needle exchange services and safe injecting rooms for injecting drug users in the state of NSW, Australia;
2. an attempt by the Australian Federal government in 1997 to introduce user-pays arrangements in nursing homes; and
3. a state government's efforts in 1996 to move hospital services from the higher socio-economic suburbs to the lower socioeconomic suburbs.

Print media articles that appeared in major state and national newspapers over at least a 3-month period around the height of each of the debates were used to identify the key stakeholders in each case example and to begin forming a

picture of their position and influence in the debate. Individuals within organizations were identified by name in media reports and these individuals were then contacted and interviewed. These interviews were also used to identify additional stakeholders for interview. Individuals in these organizations were named specifically by interviewees and this facilitated follow-up. Interviews continued until no new information was emerging and a point of data saturation had been reached (NHMRC, 1995).

### **Interview technique**

Unstructured in-depth telephone, and where possible, face to face interviews were conducted to seek out commonalities and differences, and to discover how each individual or organization operated in a specific context (Stake, 1994). This latter aim was one of the key reasons case examples were chosen as windows through which to view the role and capacities of advocates. The interviews were informal and conversational to allow flexibility to pursue relevant information as it emerged (Patton, 1990).

Interviews were conducted by the principal researcher who has a background in consumer advocacy in the Australian context. Interviewees were given a brief background to the study and it was clearly explained that interviewees would not be identified in the final report. All but one of the interviews was taped. A computer with telephone facilities and speakers was used for the 'phone interviews.

### **Data analysis**

Data analysis occurred almost immediately upon entering the field. After three or four interviews were conducted and transcribed they were analysed using the grounded theory method. Categories that began to emerge were coded with reflections of the researcher on the meanings and relationships between these conceptual categories. It was both an inductive process, with ideas and theories emerging from the data, and a deductive process, with emerging theories tested back in the field (Guba and Lincoln, 1989; Strauss and Corbin, 1990).

Findings and key themes that emerged from the study data were related to other findings, models and theories in the areas of advocacy, public policy development and capacity building. The literature review was guided by the findings

in the data and in turn the literature helped sensitize the researcher to emerging theory (Strauss and Corbin, 1990). The literature forms an integral part of the findings.

### **Data triangulation and rigour**

Data source triangulation (Mays and Pope, 2000) was used in this study and involved comparison of the interviewee comments with media reporting of the debate. This method of data triangulation could only be used to check the importance of public tactics. Therefore, interviewees were also asked to respond directly to views expressed by other respondents and differences in opinion or confirmation of earlier findings noted. This study focussed on the perspective of organizations or individuals outside government regarding effective advocacy tactics and necessary organizational capacities to focus attention and stimulate government action to address health equity. However, it is difficult to trace cause and effect in policy debates and the opinions of the NGOs interviewed may have been biased towards viewing their own actions as successful. Therefore, views expressed about successful tactics and key capacities were cross-checked with different interviewees to enhance the credibility of the findings. The range of different groups interviewed in this study was itself an important check of the soundness of the findings (Mays and Pope, 2000).

A check of understanding and interpretation was undertaken with some respondents, not only to ensure soundness of the observations and recordings, but to build a shared understanding of the constructs that emerged (Guba and Lincoln, 1989; Mays and Pope, 2000).

## **RESULTS**

In total, 26 groups across the three case examples were interviewed. The collective findings from the three case examples identified a diversity of organizations outside government who were advocates for health equity. The approaches and tactics they used were explored and the capacities and conditions that were related to success identified.

### **Case 1: access to services for injecting drug users**

In January 1999, the NSW media began to widely cover the issues surrounding illicit drug use in

NSW, particularly access for injecting drug users to needle exchange services. Historically, this debate has been quite polarized, with harm minimization proponents on the one hand and those advocating an increased law enforcement approach on the other. The debate culminated in a Drug Summit held in NSW (17–21 May 1999), which led to a number of recommendations supporting increased efforts to expand prevention efforts, needle exchange, treatment services and harm minimization. Some of these recommendations are now being implemented.

The key health inequities perceived by the advocates for health equity in this debate included prejudice experienced by injecting drug users (IDUs) in the community, the perception of drug use as a legal, rather than a health issue, the over-representation of disadvantaged population groups among IDUs and lack of access to appropriate services. A diverse range of groups were represented in this debate including those directly representing users, their families, providers of services to users and researchers. This case example involved interviews with groups working at the local, state and national level, and provided a valuable opportunity to understand the interactions between groups working at different levels in the community and with all levels of government.

### **Case 2: user-pays for nursing homes**

Access to a nursing home in Australia has historically been based on need, not ability to pay, where residents have been charged a fee per day, capped at a fixed percentage of the pension, regardless of income. A Commission of Audit Report in mid 1996 raised the prospect of reforms to the nursing home sector. The newly elected government then proposed such reforms in its first budget in August 1996, which included an uncapped 'Accommodation Bond' for people with a certain level of assets (which in some cases included the family home) and an increase in the daily fees. These reforms were due to come into effect on 1 July 1997. Advocacy groups saw health inequities being created by the reforms, which introduced further user-pays arrangements. Media attention became intense in early 1997 when key groups outside government raised the prospect of elderly Australians having to sell 'the family home' to pay the Accommodation Bond. In October 1997, the government made major concessions in line with the concerns of key interest groups, including

a scrapping of the one-off Accommodation Bond which was to be replaced by a smaller annual charge based on an asset test. This case example was selected to document and analyse the activities of groups representing older Australians, churches and aged care service providers. This case example provided a national focus as groups involved in the debate were mainly national peak groups interacting with the Federal Government.

### **Case 3: re-location of hospital services**

This case involved efforts by a state government in 1996 to redistribute hospital resources from the higher socioeconomic eastern suburbs of Sydney to the lower socioeconomic western suburbs. This debate was very polarized, with only some organizations and individuals arguing for a re-distribution of resources based on issues of equity in access to services, and with others arguing for a maintenance of the status quo based on other issues, such as maintaining centres of expertise. The attempt to move services was not successful and lack of consultation was identified by a number of the groups interviewed as a key failure of the proposal. The tactics of 'both sides' of the debate were explored as the advocates for health equity were ultimately unsuccessful in their attempts to influence it. This case example was selected as it represented an opportunity to document and analyse the activities of health provider associations. This case example provided a state focus as groups involved were state based and interacted with state government to influence policy.

### **Who are the advocates for health equity?**

Advocacy is defined as involving 'the use of tools and activities that can draw attention to an issue, gain support for it, build consensus about it, and provide arguments that will sway decision makers and public opinion to back it' (Rice, 1999). A range of NGOs were found to take on the role of being advocates for health equity, including those representing consumers and providers, researchers and professional associations interacting at all levels of government. The common factor among the groups studied was their not-for-profit status. Groups who represented providers were found to be important allies on some issues, although in some debates conflicts of interest arose. The study also found that peak groups, who represented a number of organizations and those working at the state and national level,

were better placed to take on a direct advocacy role than local level groups, who were often constrained by resources and limited networks.

In all three case examples, the successful advocacy activities were found to be similar both in range and type, and therefore the case examples are presented together. This combined presentation is also important to ensure confidentiality for respondents. However, it was found that some types of organization favoured certain approaches related primarily to differences in membership base and funding sources. Identification of the type of organization is therefore included in the presentation of findings, and differences in approach related to the type of organization or to a particular case study are discussed where relevant.

### **Advocacy action**

Flexibility and opportunism in the choice of tactics was found to be central to effective advocacy, as was the existence of a clear long-term vision and goals to direct advocacy efforts. Some groups were clearly more sophisticated in their choice of tactics and gained substantial influence as a result of being able to switch between approaches: 'We have taken a different tack in other debates and got the result we wanted. You've got to learn to change tactics as the thing goes and not be too consistent' (national peak provider association).

By contrast, some consumer groups, particularly those in the nursing homes debate, were more limited in their choice of tactics, as they had little power in direct negotiations. Public conflict approaches were therefore their most effective means of initial influence, which could then be followed by direct negotiations once public credibility in the debate had been attained. These findings highlight the importance of NGOs understanding their organizational capacities in making tactical choices.

The continuum and variety of tactical choices open to groups and the need for opportunism and responsiveness has been reported in the literature (Chapman and Lupton, 1994; Dalton *et al.*, 1996), as has the importance of advocacy being linked to a long-term strategic vision (IPPF, 1995; Jernigan and Wright, 1996; Disability Action, 1997; Marsh, 1997).

### *Partnership and conflict*

The ability to work in partnership with government while simultaneously generating public

debate and conflict was central to many groups' perceived effectiveness: 'So although we had a media presence which was petulant, privately we were giving constructive ways through the problem' (national peak provider association).

One of the main reasons given for partnership approaches, by all types of organizations in all three case studies, was that the group could provide valuable input to government policy and practice, and was a short-cut for government to receive input from the sector they represented. Others in the literature have raised the value of knowledge, representativeness and authority, which arises from community closeness and provides a short-cut to community and sectoral views for governments (PIAC, 1996; Gilsonan, 1997; Marsh, 1997; Long, 1998). '[Government] have created a rod for their own back by funding us, but they need us. We provide representation of issues across the sector' (state peak provider organization). These partnership approaches were also seen as valuable in protecting both provider and consumer groups (in particular their funding base and access to government) in times when they took on activities that brought them into conflict with government.

Consumer groups across all three case examples were less enthusiastic about partnership approaches and raised negative aspects about working closely with government: 'Involvement in the policy process by making comment can be seen as being party to it ... your ability to speak out might then be compromised' (state consumer group). Diminishing freedom to be critical in public as influence behind the scenes increases has been reported by others (Dalton *et al.*, 1996; Gilsonan, 1997).

Some consumer groups in the nursing home debate, who felt they had little power with government, used public media approaches almost exclusively despite risks to funding: 'We don't often have many bargaining positions, but talking in the media is one of these strengths' (national peak consumer organization). In contrast, other consumer groups in this debate and provider groups in the harm minimization debate reported that they only used public methods if other partnership approaches were not effective in getting a response from government. These groups first tried partnership approaches to demonstrate their willingness to negotiate directly: 'Because we were excluded from being at the table, we switched into a watchdog role and started monitoring what was going on and put questions out to the media

and government' (national peak consumer organization).

Despite being seen by some as a last resort, many groups stressed the importance of the media and being public on health equity issues in terms of having an impact on government policy and practice: 'Media attention raised the stakes on the reforms ... I think there was only one campaign that worked ... and that was the media campaign' (national peak provider organization). A few groups commented that not going public compromised their influence significantly and this further supports the critical importance of public visibility in influencing health equity. 'We don't go very public with some of these real big issues. I think they're [government] aware that we don't do that ... so we're rarely a check on government' (national provider organization). In the hospital relocation debate, use of the media was a central tactic for all the groups interviewed. However, in the final analysis the power and media savvy of vocal provider groups in the more affluent suburbs, coupled with threats of industrial action, succeeded in defeating the proposal. This case study clearly illustrated the power of provider groups in health policy debates and the importance of capturing media attention.

The importance of the media in influencing public policy has also been highlighted in the literature on advocacy (Chapman and Lupton, 1994; Jernigan and Wright, 1996; PIAC, 1996).

While the media were seen as useful in influencing government decision-making by raising relevant issues, media comment was used cautiously by many of the groups interviewed: 'We are selective about the media we do, while useful as it can be, it can be equally damaging and not useful' (state consumer organization). Groups used a range of tactics to minimize adverse impacts (for example, on their funding and future access to government) when making public comment. In this study, a number of groups reported working through higher level state networks to be heard on issues or talking to government about their findings and comments before going public.

#### *Monitoring the external environment*

Monitoring and scanning the external environment was found to be essential in alerting groups to key issues and providing evidence for their case for change. Informal networks both within and outside government, and information from clients and members were found to be the most

common source of information for time-poor NGOs: 'We have extensive networks in the community, among practitioner and consumer organizations as well as receiving grass-roots feedback. It is very informal—we get calls ... when we get calls we know we're on the right track' (national consumer organization).

#### *Traditional lobbying techniques*

The impact of traditional lobbying techniques as a sole strategy is questionable (PIAC, 1996; Long, 1998), but they were reported to be important as a first step for groups facing a new issue and to help clarify and sharpen arguments. Writing letters, doing submissions, sending delegations to meet with politicians and government officials were examples discussed by interviewees: 'When we heard this was a possibility we did all the typical lobbyist things, like petitions, letters to the Minister and requested meetings' (state consumer organization).

#### *Building community support*

Building community support was reported to be helpful in influencing government. Some groups used the media to provide a fast track to achieving this end. Working directly with communities was also seen by some groups as an important opportunity for community members to participate in issues which affect them, while simultaneously allowing NGOs to build their understanding of community views.

Local level groups also generated community support for their programmes and issues by involving community members as volunteers, having key community leaders on management boards, and additionally by providing leadership that enabled community members to take their own action. This was seen as an important activity, but one that was time-consuming and often not well resourced: 'Need support from the community, but it is time consuming—you've got to be patient' (local provider organization).

Advocacy has been reported in the literature as being important in catalysing public opinion and support (Baum, 1998) and in turn this public support becomes central in effective advocacy (IPPF, 1995; Disability Action, 1997; Warhurst, 1997).

#### *Alliances and coalitions*

Forming alliances or coalitions with other groups was often seen as critical to effectiveness through the sharing of expertise and drawing on each

other's credibility base: 'Coalitions of organizations together can be more powerful—the more people lobbying together the better' (local provider organization). The body of literature and publications on advocacy confirms the importance of coalitions and alliances to successful advocacy (Jernigan and Wright, 1996; Disability Action, 1997; Warhurst, 1997). The formality of the relationships between organizations was found to vary according to purpose and this is supported by the literature (Harris *et al.*, 1995; IPPF, 1995).

In summary, NGOs shifted between a partnership approach and one that brought them into conflict with government. Use of the media, monitoring the external environment, traditional lobbying, building community support and forming alliances and coalitions were key activities underpinning their action.

#### **Capacity for advocacy**

To take action successfully a number of capacities for advocacy were also identified. A capacity is defined as the combined force of individual competencies and organizational capabilities that work synergistically to advance an organization to achieve its major goals (Paul, 1995). In this study, the domains of capacity for effective advocacy were identified based on the views of the interviewees about what enabled them to influence debate.

#### *Planning and consultation*

The ability to identify key issues and desired outcomes through consultation and planning processes was reported as important by a number of the groups interviewed. This finding was consistent with the literature, with clarity about long-term goals and priorities highlighted (Jernigan and Wright, 1996; Disability Action, 1997; Gilsonan, 1997). This is due not only to the need to focus efforts and be strategic, but also to build credibility through internal consensus (IPPF, 1995).

#### *Credibility*

Credibility was drawn from a number of sources, including grass-root connections/membership base, a strong track-record, bi-partisanship, an open and independent approach, being fair and representative, supporting claims and having expertise, and having no vested interest in the debate: 'What is central is your ability to present

yourselves as a credible organization' (state peak provider association).

In the literature on advocacy, policy and NGO action, credibility and legitimacy is often mentioned (IPPF, 1995; Jernigan and Wright, 1996; Gilsenan, 1997) and as found in this study, conflicts of interest or vested interests are highlighted as important to avoid if NGOs are to remain credible in the eyes of the public and decision-makers (Hogan, 1995; Disability Action, 1997; Warhurst, 1997).

### *Leadership*

The presence of individual leadership qualities and organizational support for taking the lead were viewed as important for effective advocacy by a number of the groups interviewed: 'We are a forward thinking organization with good leadership' (state provider organization).

### *Networking and relationship-building*

Creating productive relationships and contacts both within and outside government, and developing and maintaining a diverse network of like-minded groups was reported by many groups as a key capacity: 'We develop contacts and we undertake proactive relationship building—get out and meet people' (state peak provider association). The literature on advocacy and public policy often refers to the importance of networks and access to government through formal and informal means, which can be a source of intelligence for groups and an opportunity to represent their views and mobilize support (Dalton *et al.*, 1996; Marsh, 1997; Warhurst, 1997; Long, 1998). Networking, i.e. initiating and maintaining contact with other individuals or organizations who share or support your goals, is constantly referred to as a key skill in guides published on advocacy (IPPF, 1995; PIAC, 1996).

### *Information management*

NGOs reported needing skills in identifying and obtaining relevant information and in analysing and synthesizing the information obtained: 'It's about how you manage information' (national peak consumer organization). The literature highlights that research data is necessary to make news and influence policy makers (Dalton *et al.*, 1996; Jernigan and Wright, 1996; Disability Action, 1997; Gilsenan, 1997). Others have referred to political intelligence as well as more general information about an issue as being important to effectiveness (Democracy Center, 2000).

### *Communication*

The groups interviewed emphasized the importance of understanding and using the media effectively. Understanding and harnessing community sentiment as well as clear internal communication processes were seen as central to successful media management: 'We paint a picture of what is happening and how it could be addressed' (state provider organization). This is supported by the literature, which stresses the importance of building relationships with the media and using emotive material and personal stories (Chapman and Lupton, 1994; IPPF, 1995; Jernigan and Wright, 1996).

### *Demand management*

Many groups reported the need for responsiveness to the fast pace of reform and having the ability to manage multiple roles. Hogan picks up on this issue of demand, observing that many community organizations are overwhelmed by requests for individual assistance such that they cannot devote any time to changing the system that causes the problems (Hogan, 1995). As one respondent in this study commented: 'It exhausts us trying to stay on top of the debate ... it can be really disempowering as we can't be effective because things are moving at such a rate' (state consumer organization). A recent study in Australia also found the fast pace of reform was a problem for some groups who were under-resourced (Gilsenan, 1997).

### *Resources*

Funding sources that do not overly limit influence and independence, and the availability of human and physical resources were viewed as important capacities for effective advocacy: 'Barriers to our influence are human, financial and physical' (national peak consumer organization). The literature raises the issue of resources, and particularly funding, which is seen as crucial, but often scarce or unequally distributed (Jernigan and Wright, 1996; Disability Action, 1997; Gilsenan, 1997; Warhurst, 1997). Independence from decision-makers, funders or politics is also cited in the literature as a tension which NGOs often face, with agencies funded by government being threatened for 'rocking the boat' or risking being co-opted to the government's agenda because they hold the purse strings (Hogan, 1995; Warhurst, 1997). This was clearly an issue for many groups in this study: 'I think there is no



seen as influential even if this was not the case. However, the use of media coverage as a major element of the sampling frame meant that most of the groups interviewed were likely to be influential in shaping public opinion through being quoted in the media. Seeking the views of interviewees on the role of other groups also helped build a more complete and accurate picture of influence.

A key limit to capacity for advocacy identified in this study was the ability to secure funding independent of government. It is imperative that NGOs identify and try to obtain a wide range of possible income streams and material supports for their work. Public donations, grants from philanthropic or international agencies and membership fees are examples of this. Where this is not possible, NGOs need to be able to make a separation between the activities government fund and advocacy, which may need to be funded by member groups or the community. However, others in the published literature saw funding as less important to capacity than other resources. Jernigan and Wright saw the main resource as people, whether they be volunteers or paid staff (Jernigan and Wright, 1996). Marsh also views money as only one of the necessary resources and not necessarily the most important one in politics (Marsh, 1997), especially given examples of political action by local groups defeating well-financed producer interests. Other resources may include membership numbers, skilful publicity and ingenuity (Davis *et al.*, 1993). However, Warhurst has observed that cuts to group funding has had a negative impact on their participation in policy making (Warhurst, 1997).

In general, capacity building for advocacy with NGOs should include both training and institutional strengthening in line with identified advocacy actions and domains of capacity (Rotem, 1988; Ritchie *et al.*, 2000). The potential for groups to learn from each other should also not be overlooked, nor should the importance of trial and error in building sustainable capacity for effective advocacy among NGOs, as indicated by the two-way arrow between capacities and advocacy action in Figure 1.

The major constraints on capacity building for NGOs are likely to be the time required and costs associated with training and development, which highlights the need for investment by governments, international agencies and NGOs themselves if advocacy for health equity is to be strengthened. External agencies seeking to build

the capacity of NGOs should also not limit the breadth of groups identified to consumer and community groups, since those that represent providers can also be important allies.

This study also highlights the importance of NGOs understanding the dynamic context in which they work and how this may influence choice of tactics. In applying these findings in other contexts, careful attention must be paid to the similarities and differences in organizations, and also context, which may impact on the kinds of actions groups can take and the capacities that may be important. The similarity of the findings in this study with other Australian studies (Gilsenan, 1997; Long, 1998), as well as to advocacy and related capacity building guides from New Zealand (NZ Ministry of Foreign Affairs and Trade, 1999) and America (The Democracy Center, 2000), provides some support for the transferability of the findings in this study to other groups in similar country contexts.

A limited comparison with overseas studies (Miller, 1994; Sibanda, 1996) and feedback from two NGOs working in different country contexts also provides some support for the broader applicability of the findings of this study, even in vastly different political and economic contexts. However, there were key differences identified that could limit the choice of advocacy tactics and the scope and direction of capacity building efforts in different environments. These included the resistance of government to NGO input to policy development and the historical role of NGOs as sub-contractors to government rather than as advocates for change. Despite these differences, it is clear that capacity building for effective advocacy is needed in these countries, but would require a commitment of funds, provision of training and other resources from international agencies before it was able to occur.

The findings from this study represent a first step in an important research and action agenda, which has the potential to impact greatly and sustainably on health equity. Future research efforts should focus on:

1. exploring the role of NGOs as advocates for equity in other countries to test further the transferability of the findings described in this paper;
2. uncovering in greater detail the internal organizational constraints and enablers for effective advocacy, including observational studies of effective NGO advocates in action; and

- identifying appropriate models of training and capacity building for NGOs.

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*Address for correspondence:*

S. A. Nathan  
School of Medical Education  
Centre for Public Health, University of New South  
Wales  
Sydney NSW 2052  
Australia  
E-mail: S.Nathan@unsw.edu.au

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