



THE WORLDWIDE PALLIATIVE CARE ALLIANCE
Advancing hospice and palliative care

An Advocacy Tool Kit

for Hospices and Palliative Care Organisations

UK forum for hospice and palliative care worldwide



help the
hospices

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Forward

In March 2003 many national hospice palliative care associations came together for the 1st Global Summit of National Hospice and Palliative Care Association in The Hague, Netherlands. We listened and learned from one another and this led to the 2nd Global Summit in Seoul, Korea. This subsequently led to the Korea declaration (see www.hpc-associations.net). To prepare for this summit Help the Hospices facilitated an advocacy committee to assist in preparing the content and agenda.

Not surprisingly, one of the key issues we heard repeatedly is access – access to both hospice and palliative care programs and services and access to essential medicines including morphine. We heard that access is an issue for both developed and developing countries. Advocacy becomes a key response to the access issue.

Help the Hospices took the lead to help prepare this advocacy document using resources and references from around the world. We hope it is a good summary and that it assists you in your own countries with this much-needed advocacy.

Together we can make a difference

Sharon Baxter
Chair, Advocacy Committee
Executive Director
Canadian Hospice Palliative Care Association

“One of the core steps to service development is advocacy (national policies and guidelines) integration of palliative care into the continuum of care, education and training, drug access and data systems, and the need for opioids is fundamental to palliation.”

Palliative Care in Sub-Saharan Africa: An Appraisal 2004.
Dr Richard Harding & Prof. Irene Higginson, Dept for Palliative Care and Policy, Kings College, London.

Introduction

There are many useful documents and guides available on how to approach advocacy work (see annex 1). This document is not attempting to replicate or improve on what is already available. What this document is attempting to do is to highlight the key advocacy tools that are specifically of relevance to hospices and palliative care organisations, which wish to develop their advocacy work, and to provide examples of how these tools have been used and have worked in practice.

This document is in three parts. Part one provides a general summary of what advocacy is and suggests a basic framework to follow when approaching an advocacy issue. Part two lists the main advocacy tools identified as useful to hospices and palliative care organisations and includes examples of how these have been used in practice. Part three lists the key documents and guidelines that guide hospices and palliative care organisations. Annexes have been included to provide a more detailed step-by-step guide to some of the most commonly used tools.

PART 1 Introduction to Advocacy

1.1 Definition

Advocacy can be defined as “seeking to influence policy makers to design, adopt, implement or change policies and practices”. Policy makers may be within the state or private sector and can be on any level e.g. within a small NGO, a council of elders, a ministry of health, a national parliament, an multilateral agency or indeed any other type of organisations.

Advocacy:

- Is a process which can lead to change through influence
- Is a way of influencing public policy through information and communication
- Can act as a voice of the voiceless
- Is a way of directing decision-makers towards a solution
- Can be used to inform influential groups and raise their awareness of specific issues.

Advocacy can achieve:

- Increased resources for hospice and palliative care and build the case for palliative care where it is not yet recognised or in existence
- Changes in restrictive policies and practices within countries e.g. for morphine use
- An increase in palliative care organisation’s profile amongst the public, the donor community and influential groups

- Increased awareness of the reality of the grassroots situation and the specific problems faced by the people and communities they serve.

Source: workshop report “Advocating Palliative Care Worldwide” March 2004, UK forum for hospice and palliative care worldwide, Help the Hospices, UK

Broadly there are 3 aspects to advocacy:

- Lobbying – influencing through direct, private communications with decision makers
- Campaigning – speaking publicly on an issue with a view to generating a response from the wider public.
- Educating –building understanding of issues to provide a more receptive context for change.

Context for Advocacy

This document inevitably focuses on how to approach advocacy on palliative care issues in democratic countries. Most, if not all, of the advocacy tools detailed are effective because either:

- Policy makers are influenced by public opinion.
- Governments are primarily concerned with the rights of their citizens.
- People have an influence on the media.

All of the examples of advocacy work included in this paper have come from democratic countries because these are the countries in which advocacy can be

effective. Where the above conditions do not exist it is likely that the most effective way of changing policy is through pressure from outside from international agencies and from actual and potential economic partners.

1.2 Models of Advocacy

In approaching their advocacy work organisations can take one of two basic approaches. They can take a condemnatory approach or a collaborative, encouraging approach. In practice advocacy work can combine the two to a greater or lesser extent, for example, highlighting the inadequacies of specific policies and practices, and also suggesting alternatives that would have more desirable effects. On the whole taking a condemnatory approach is advised against when addressing issues related to palliative care. Taking a collaborative and supportive approach has in general proved to be the most effective.

The way in which an advocacy message is delivered can also take one of two basic approaches. The first being through lobbying, talking quietly to the policy makers and practitioners, and the second being through campaigning, using the mass media to attract public attention to the issue. Again in practice much advocacy work uses a combination of both approaches. Content, style and method of delivery will vary between and within organisations according to the advocacy targets and circumstances of the specific issue being

addressed. However, most organisations will in general find a model within this range that best suits the nature of the organisation. For all organisations professionalism and respect are crucial.

Whichever approach is taken the key to successful advocacy is knowledge and the effective use of evidence to back up your position. Uniformed and unsupportable opinion will not bear up to cross-examination by policy makers and possible opponents to your position. Effective advocacy should be evidence based.

An issue, which inevitably influences the model of advocacy adopted by an organisation, is that of funding. Those organisations with a heavy dependence on government funding will be less likely to take a confrontational approach using the mass media and more likely to take an encouraging, inspirational approach. Condemnation of government policy is likely to be restricted to face-to-face lobbying.

The advocacy objectives when advocating for a change within an institution, such as a government department or a hospital, fall into two main types:

- Policy change objectives
- Practice change objectives

In most cases, an institution will need to adopt a new policy before it changes its practice. Therefore policy change objectives may be seen as an intermediate goal, with change in practice being the end point that can lead to change in the situation of the beneficiaries.

Effective advocacy requires a systematic, well-planned approach. One-shot attempts to address issues are unlikely to be effective.

1.3 Potential barriers to change when advocating on palliative care issues

Achieving policy change is rarely quick or easy. There are a large number of potential barriers to achieving change in palliative care practice. The type of state you are operating in has wide reaching consequences to the type of barriers you will face.

For example, representatives from Hospice Africa Uganda who have worked extensively throughout Africa to achieve policy change on the availability of low cost oral morphine. They have found a wide variety of starting points. Visits to Governments in Ethiopia, Nigeria, Ghana, and Zambia revealed different conditions in different countries are sometimes barriers. In Ethiopia, the Government restricts the use of “step 1” analgesics (according to the WHO “pain ladder”) and it is difficult to bring in step 3 analgesics under these circumstances. Zambia already has a limited supply of morphine being used for cancer only and with prescribers limited to the cancer service. They are not using the step methods but old formulas. (Source: Anne Merriman, Hospice Africa Uganda, email 3rd Feb 2005)

Barriers to the Availability and Access to Palliative Care

Individual level
Ignorance and illiteracy
Privatisation of medicine
Lack of information for patients
Fear of contagion
Poor communication (both in teaching skills and imparting information to patients)
Denial of incurable condition and irreversible prognosis of death (that modern medicine will cure all)

Socio Economic Conditions

Poverty
Lack of confidence in local institutions
Corruption
Difficulty to achieve change e.g. because of rigid hierarchy and bureaucratic approaches
Superstition and ignorance
Lack of knowledge about palliative care
“Enormity of challenge”
High cost of Opioid Analgesics

Organisational

Lack of appropriate infrastructure to provide care
Lack of adequate and safe storing and distribution systems for opioid analgesics
Lack of adequately trained staffing
The status of doctors in society and the low status of nurses
Doctors not working in a team

Finding a committed person to make change
Priority of other areas of health care in seeking funding
Conflict with private practice interests

Regulatory and Policy Issues

Palliative Care is not included in the Health Policies

Bureaucratic Barriers

Overly restrictive laws and regulations on the use of analgesic opioids

Palliative Care services are not reimbursed or covered by health insurance or government programs

Source: adapted from a workshop report "Advocating Palliative Care Worldwide" March 2004, UK forum for hospice and palliative care worldwide, Help the Hospices, UK

1.4 Why and when to advocate

Wherever change in policy and /or practice needs to occur, advocacy has a role to play. Advocacy is the act of identifying a problem, speaking up, drawing attention to an issue and directing decision-makers towards a more appropriate alternative policy.

Government policies at a national and/or local level can restrict good palliative care practice. It may be that inappropriate policies are implemented through lack of awareness of their negative impact or that policies are too restrictive due to unfounded fears such

as abuse of drugs. Advocacy has a vital role to play in demonstrating the effects of policies and ensuring appropriate policies exist to enable good palliative care to take place and be available to all who need it. Advocacy is needed to create a policy environment, which will make practical work as effective as possible.

Advocacy can most appropriately take place:

- Before an election / just after an election
- When something happens to bring the issue to public attention
- Before the issue goes public
- Before the issue gets to parliament
- When legislation is being changed
- On quiet news days
- When you have information and expertise relevant to the issue
- When the target audience are potentially interested in the issue

1.5 Targets for Advocacy

Both lobbying and campaigning should target the decision-makers involved in the issue identified. It is important to remember these are actual people. It is vitally important, though not always straightforward, to identify which specific individuals have the power / responsibility for ensuring policies are implemented appropriately and the individuals who have the power / responsibility to change policies / legislation.

It will assist in developing an advocacy

message that will appeal to your target audience if you learn as much as possible about these individuals for example, what are their political interests and what group of people do they represent. Do they know anything about your issue already, have they already taken a public position on the issue, can you link your issue to something you know they support.

"The key lesson is to closely cooperate with policy makers! And sharing/demonstrating needs for and experiences in hospice/Palliative care."
Jacek Luczak, Polish Association of Palliative Care

1.6 Who should do advocacy

Legitimacy to represent the issues on which you wish to advocate is vital. To do this you must involve the people directly affected by the advocacy issue or problem. The people affected by an issue or problem, other people representing them, or by both groups together can carry out advocacy. Advocacy is often more powerful if those affected by the problem or issue are involved with or lead the process.

If you advocate on behalf of others you need to ensure that you represent their opinions and interests fairly. This means having a very close relationship with those affected by the problem or issue, a deep understanding of the issue, and permission from those affected by the problem or issue to advocate on their behalf

It is also important to ensure that your advocacy work is supported by the mission or aims of your organisation, by your organisations senior managers, and by any external funders.

Why it is important to involve those directly affected by the advocacy issue, from early in the planning process

- They will have expert knowledge of the issue or problem
- They can suggest workable solutions based on direct experience of the problem
- They can view a problem from a different perspective
- They are often highly motivated, because they are directly affected by the issue
- People living with or affected by HIV/AIDS have been centrally involved in most major improvements in the field of HIV/AIDS
- Affected individuals and groups will gain more skills and confidence. It is a good opportunity to reduce stigma against people affected by HIV/AIDS.

Problems caused by lack of legitimacy

Involving those affected by the problem or issue late, superficially ('tokenism') or not at all can result in:

- identifying irrelevant issues
- suggesting solutions which do not solve the problem, or make the problem worse

- public disagreement
- loss of credibility for the organisations and individuals involved in advocacy
- increased stigma and legitimised exclusion and non-involvement of those affected by the problem or issue
- disempowerment of those affected, so they are less in control of their own situations.

Source: Advocacy in Action: a toolkit to support NGOs and CBOs responding to HIV/AIDS

"This is a very important issue in our part of the world. Given the vast gulfs in our society between the haves and have nots it is usually the former who become advocates on behalf of the latter. However, they do not necessarily represent the interests of all" Harmala Gupta, President, CanSupport, India.

It is equally important to ensure that the most appropriate individuals represent your organisation in communicating your advocacy message. The best person to communicate your advocacy message is:

- Someone who understands the issues very well and can talk with credibility
- Someone who understands the advocacy targets very well and can talk their language.

Often the ideal lobbying team will be a combination of these. See annex 2 Effective representation

1.7 Alliances and networks

Alliances are groups of organisations working together in a coordinated fashion towards a common goal. Networks are individuals and organisations that have come together more loosely and are willing to assist and collaborate. Both are important in advocacy work as they are in a stronger position to bring about change than individual organisations. Where diverse ranges of different interest groups agree and work together on a given issue the message is more compelling. Alliances and collaborations that cut across power differences can be especially important. For organisations that join a network or alliance it can prove a more time and cost-effective method of reaching their target audience. However for those seeking to establish a new alliance and network this can be time consuming and will take considerable resources to develop and maintain, but will result in the ability to target many more decision makers or influencers at the same time. Networks and alliances maintain contact through a wide variety of means; exchange visits, seminars, conferences, internet groups, joint media initiatives.

Reasons for alliances and linkages

- Policy changes that are driven from below - that have a strong grassroots power base and are supported by civil society - are likely to be more lasting.

- Not all agencies have the capacity for policy dialogue at the national level. However, agencies that operate only at the community or district level can also make an invaluable contribution to advocating for policy change. It may be a possibility to increase their influence on policy by establishing partnerships with other agencies that has greater capacity at the national level.

For Hospices and Palliative Care organisations being represented by an effective, professional and determined national association which is able to advocate for appropriate policies with health institutions at the national level and maintain international links is vital.

Within alliances and networks, particularly international ones cultural differences need to be taken into account

- The different cultural power levels and attitudes towards gender and family
- Attitudes towards truth-telling – some cultures discourage this especially if it might lead to anxiety
- Social acceptability – in some countries diseases such as cancer are seen as contagious, which means that confidentiality becomes a big issue
- Acceptance of higher levels of pain by some groups
- Religious attitudes to certain conditions
- Religious / non- religious rites around death

Palliative Care Australia has advocated, in conjunction with its member associations (the state and territory palliative care associations) for improved resources and recognition. This has been undertaken in different ways:

Collating or generating the evidence of the value of palliative care

Meeting with and influencing key decision makers in government and politics

Increasing community awareness of the worth of palliative care

Forming alliances with other key stakeholder groups who are prepared to take up the fight for us.

Source: Will Hallahan, Acting Executive Director, Palliative Care Australia

1.8 An Advocacy Framework

(adapted from Advocacy In Action : A Toolkit to Support NGO's and CBO's Responding to HIV/AIDS International HIV/Aids Alliance 2002)

There are a number of steps to take once you have decided to undertake advocacy work.

1. Issue identification.

Deciding which problem or aspect of a problem to address. Your advocacy efforts will be more effective if the problem is very clearly defined.

2. Analysis

This is essential for making informed decisions when choosing which issue or aspect of an issue to work on, identifying solutions to the problem and setting a realistic goal and objectives. Good, credible data is essential to put together a persuasive argument. It is important to select the data that can be used to best support your argument and to plan how this data will be gathered. See annex 3 Information gathering and learning

3. Developing the advocacy message

Different audiences respond to different messages, e.g. a politician may become motivated when they know many people in their district care about an issue. The Ministry of Health may take action when presented with data on the prevalence of a problem. A local council may take action when they see a local group drawing the community's attention to an issue. It is important to decide what type of message will best encourage your target audience to act as desired. Opportunities to influence decision makers are often limited. Careful and thorough preparation of convincing arguments and a clear presentation style is required. It is useful to ask if you have one chance to reach the decision-maker, what do you want to say and how will you say it?

Developing a clear and compelling message is vital to the success of your advocacy work. Your message should

explain what you want to change, why, and the benefits of doing this. Messages will need to be reviewed regularly and revised as you learn new things about your issue or your target audience. In just a few sentences your message should say why your issue is important and what you want others to do in support of the issue. It should give the audience a clear choice of actions and explain the consequences of these. Your message should take into account the interest and knowledge of your target audience and should be short and simple.

4. Goal and Objectives.

The goal is what it is hoped to achieve in say a 10-20 year period. The goal is the vision for the future. The goal needs to be clear and to encompass what you are trying to be achieved.

Problems can be complex and the goal often long term. The advocacy objectives are what the organisation wants to change in the shorter term, who will make the change, by how much and by when. The objectives must be narrowed down into things that are achievable within the project timeframe; they should be specific and measurable and clearly address the problem identified. A number of solutions may present themselves the advocacy will be most effective if the solutions which are most politically, economically and socially feasible are identified.

Your organisation may also have legitimate, short-term goals, for example, making a complete list of all the hospice

and palliative care programmes in a country and finding out if they have adequate morphine.

What an advocacy objective should look like

An advocacy objective: Start a national government programme to build 12 schools in each district in the next 2 years

Not an advocacy objective: Increase girl's attendance at district level primary schools

An advocacy objective: In the next year, increase funding for family planning education programmes for married couples through the Family Planning Council

Not an advocacy objective: Increase the use of family planning among married couples.

See annex 4 for more details on Monitoring and Evaluation.

5. Identifying targets

Advocacy efforts need to be addressed to the people who have the decision making power, and ideally, also the people who influence the decision makers e.g. staff, advisors, influential elders, the media or the public. Named individuals need to be identified who can make the objective a reality. You also need to identify who and what influences the key decision makers. Appropriate methods need to be chosen to reach the audiences identified.

6. Identifying allies

Building political support to act on the problem is a key stage. Actions should include coalition building, meeting with decision-makers, awareness building and delivering effective messages. The power of advocacy is increased in the numbers of people who support the objective. Where democracy and advocacy are relatively new phenomena involving large numbers of people from diverse interest groups can provide safety as well as build political support for the issue. Even within an organisation internal coalition building can help build a consensus for action. Suitable allies need to be identified, such as other groups who may share a desire to achieve the advocacy objectives.

7. Identifying resources

Advocacy requires resources. Sustaining an effective advocacy effort over the long-term means careful planning of cost implications. It is important to think through all the costs and resources, which will be required. These need to be budgeted for and potential funding sources identified.

8. Create an action plan and timeframe

The timeframe needs to take into account important points in for example the parliamentary calendar.

9. Implementation

10. Monitoring and Evaluation

It is important to know if and when the advocacy objective has been achieved and to continually assess how the advocacy strategy can be improved. A system should be put in place to ensure feedback and evaluations of the effectiveness of the strategy employed. You need to be clear how it will be known when the objectives have been achieved.

Annex 4 Methods of monitoring and evaluating advocacy work.

"In my experience factors for success are;

- *A clear and attainable objective*
- *Genuine deep seated/widespread support for change/improvement from within and around your core constituency*
- *Irrefutable empirical evidence of the worth of a new initiative/s*
- *Compelling personal stories excellent presentation/representation of the key messages*
- *Committed and well-prepared allies and collaborators.*

Getting all these ducks in a row requires careful planning, some material resources (cash, time and people), a bit of nerve and a lot of persistence. No tricks or shortcuts ever seem to work.

Looking at the success of an advocacy campaign: The essential tool is, I think, strategic planning: from objective thru to day-to-day operations - creative and imaginative people can identify the everyday things which need to happen in order to steadily progress towards a greater goal without wasting energy on irrelevant things." Will Hallahan, Acting Executive Director, Palliative Care Australia.

1.9 Four factors are crucial to effective advocacy

- Effective identification of advocacy target audiences. The primary audience are the decision makers with the authority to affect the outcome of the goal and objectives directly. Their decision-making processes must be understood and you need to work within this process. The secondary audience are the individuals and groups that can influence the primary audience. There may be opposition forces, i.e. groups opposed to the objective, it is important these groups are included, understood and their arguments addressed as part of the strategy.
- An effective advocacy message. A concise and persuasive statement about the advocacy goal that captures what it is wanted to achieve and why. The message should be tailored to each audience, in an appropriate delivery format and should include a specific action for that particular audience.
- Demonstrating the credibility of your organisation(s) in advocating on an issue. You should be able to demonstrate a clear platform for addressing the issues you are supporting. This can be from experience of working in the area affected by the issues and/or partnership with other organisations working in the area. You need to clearly explain and demonstrate who you represent.
- Effective use of data and research. This should be from a source that your target audience perceive as credible. It should focus on a few questions that can be answered and address the information needs of the policy makers. Ideally it should be presented in a way that emphasises the lessons learned.

PART 2

Advocacy Tools

Your methods and approaches to advocacy work will vary depending on the type of organisation you are, the advocacy plan you have developed, and the type of state you operate in. The role of the state varies greatly from country to country. States assume the role of service provider and commission others to provide services to a lesser or greater extent depending on their ideology and wealth. In advocacy it is important to be clear about who is responsible for what and to ask for what is appropriate and possible.

Below we will look at a range of practical advocacy tools that can be used by hospices and palliative care organisations. Case studies of actual advocacy work have been included to illustrate how some of these tools can work in practice.

Annex 5 How to choose appropriate advocacy methods

Here the tools have been divided into 5 main groups, in practice an advocacy strategy would involve a variety of tools from some or all of the groups below.

1. Directly Influencing Policy
2. Monitoring State Performance
3. Providing Information and Training
4. Demonstrating Good Practice
5. Public Education and Awareness Raising

2.1 Directly Influencing Policy.

The tools included in this section are those which can be used to directly talk to the policy makers, ideally, at times when they are receptive to ideas or in a position to make the policy changes desired. Many countries have systems that are in transition and this can provide good opportunities for policy change or creation. The key to using these tools is

- Understand your parliamentary process.
- Know which individuals are responsible for making the decisions required and who influences them.
- Identify the most appropriate people you have to influence and develop contacts these individuals.
- Involve the WHO-WR as their office influences health policy makers.

2.1.1 Analysing Legislation or Policies

It is important to understand the effects of an existing policy or law and its implementation. It is also important to understand the likely effects of proposed new policies or laws.

Policies and legislation may not be written down. Practice may be based on traditional laws and customs or decisions communicated without being written down. These kind of policies are harder to analyse as there may be disagreement on what the policy is.

Advocates should try to:

- a. Agree what the policy or law is, or how it is implemented
- b. Analyse the policy and / or its implementation
- c. Suggest how it can be improved
- d. Suggest how it can be implemented better
- e. Try and get it written down

(Adapted from: Advocacy in Action, International HIV/AIDS Alliance 2002)

Always remember to give the historical responsibility of a member state of the UN as stipulated in the 1961 convention on the Use of Narcotics as amended by the 1972 Protocol that the state has the following responsibilities:

1. To ensure opioid analgesics are available for medical use
2. Opioids are available for research and at the same time the state has to ensure that Narcotics are not abused or diverted.

Refer to the 16 guidelines in the WHO publication "Achieving Balance in National Opioids Control Policy" WHO/EDM/QSM/2000.4

Annex 6 How to Analyse Legislation or Policy

*In **Romania** Palliative and hospice care is still at an early stage. There are few palliative care services that would comply with the national standards issued in 1999 by the National Palliative Care Association. These services are mainly run by NGO's with funding from outside*

Romania and most offer home care services as this is a less expensive service with a broader coverage of patients. Romania is a country ascending the EU. As a result international recommendations are a powerful tool in bringing about changes. Recommendation 24 of the EU regarding Palliative care together with sustained lobbying from ANIP, Hospice Casa Sperantei and it's international supporter made it possible to bring palliative care onto the agenda of the Ministry of Health. A commission within the Ministry of Health is now responsible for developing a plan for palliative care services at the national level. Legislative changes in the areas of patient rights and partial state financing of palliative care have been achieved through advocacy work.

Source: Dr Daniela Mosoiu, President, Romanian National Association for Palliative Care

2.1.2. Position Papers

A position paper is a formal, written record of the opinion of an organisation or coalition. It is written to be read by the advocacy targets. Position papers can be:

- Left with an individual decision-maker at the end of a face-to-face meeting to summarise the main points of your message.
- Be sent to local or national governments during consultation exercises.
- Be sent to people in influence, in response to a policy or action, to explain an alternative or supporting a position.

- Summarise the resolutions of a conference or workshop
- Show that a coalition of many different allies support the same advocacy objectives.
- Be given to delegates or committee members at a meeting or conference – whether or not you are allowed to speak at the meeting

(Adapted from: Advocacy in Action, International HIV/AIDS Alliance 2002)

See Annex 7 How to produce a briefing note / position paper.

2.1.3. Working from Inside the System

Participating in decision-making bodies can be one of the most effective ways of influencing policy change. Decisions affecting your advocacy issue are made in many different situations, for example, sub-committees and working groups, district health committees, social welfare committees, advisory committees to government ministries. It is important to find out when and how decisions are made, and then to find out how people can take a seat at the key meetings and to influence their decisions. Take full advantage of official positions already enjoyed by members of your organisation or coalition. It may also be possible to invite receptive members of decision-making bodies to become involved in your organisation or coalition.

(Adapted from: Advocacy in Action, International HIV/AIDS Alliance 2002)

In **Croatia** the President of the Commission for Palliative Care (Dr Anica

Jusic) is a member of the National Bioethical Board of the Ministry of Health and Social Welfare. The Boards responsibility is to develop ethical legislation on issues such as informed consent and resuscitation orders.

Source: Dr Anica Jusic, Hrvatska Udruga Prijatelja Hospicija, email 24 January 2005

In **Poland** the Ministry of Health set up an advisory body in 1993, The National Council for Hospice & Palliative Care Services consisted of leaders of the Polish Palliative Care Association and the Voluntary Hospice Movement Forum (12 persons met for 5 years usually monthly with a very supportive representative of the Ministry of Health. Together they developed the Ministry of Health Program of Developing Hospice and Palliative Care and made huge progress in developing policies including organization and funding of public and non-public palliative care services, improved opioids availability, undergraduate and post-graduate education and practical training in palliative care for professionals. They also established a specialization in palliative medicine for physicians and palliative care specialization for nurses. There are now over 500 palliative care and Hospice services in Poland.

Source: Jacek Luczak, Polish Association of Palliative Care

In **Australia** there is a National Palliative Care Strategy and a National Palliative Care Program to underpin the Strategy. Palliative Care Australia was an influential player in bringing about both the Strategy and the Program, and has played a large

role in helping the government to decide how to spend Program funds.
(www.palliativecare.gov.au)

Source: Will Hallahan, Acting Executive Director, Palliative Care Australia

2.1.4 Lobbying

Making direct contact, and building a professional relationship, with key individuals who are responsible for taking the decisions you wish to influence is another very effective way of achieving policy change. There are 2 main ways of doing this;

- Write a letter
- Face to Face Meeting

Anne Merriman and Dr Jagwe, of Hospice Africa based in Uganda have together lobbied in a number of African countries to achieve policy changes on the use of morphine. They are seeking to encourage more governments to allow the use of oral morphine, which is relatively low cost form of the drug but which many countries do not currently allow.

They work as a team. Dr Jagwe was employed in 1998 by Hospice Africa as the Advocacy Representative. He was selected because he was very well qualified on the issues being addressed and would therefore be a person who policy makers could respect and listen to. He is a qualified doctor, has worked in government, he was the Director of Medical Services and Head of the National Drug Authority

Their approach is to meet directly with the key policy makers within government who

have the ability to make decisions and set policies on morphine use, for examples in January 2005 they undertook visits to Cameroon and Nigeria.

Anne Merriman provides the background information on hospices and palliative care, and describes the positive changes already achieved in Uganda. Dr Jagwe provides information on the more technical aspects of morphine use, the levels of prescribing in different countries, how morphine can be made affordably available in Africa. They leave a number of pieces of information with the policy makers.

- Photocopied recommendation pages from the WHO booklet "Achieving a balance in narcotic control"
- A graph showing by country the level of morphine use per person
- Information on where to buy morphine
- The formula for making oral morphine in a pharmacy

As a direct result of this lobbying both Malawi and Tanzania now allow oral morphine to be used in their country. The issue of training for those prescribing and administering the drug is now being addressed.

Source: Anne Merriman, Hospice Africa, Uganda, Telephone conversation 3rd Feb 05

"Our experience is that having a key person in government who supports palliative care is very important." Joan Marston, Advocacy Officer, Hospice Palliative Care Association of South Africa.

"In India, advocacy depends on your personal contacts in the government, this includes politicians and bureaucrats. We have found that an experience with cancer, especially if the bureaucrat or politician concerned has lost a loved one to cancer, makes it easier to make headway through the system. This can, however, work both in your favour and against you for it depends on an individual's goodwill and should he/she get transferred one has to begin all over again. Therefore, it is very important to keep the pressure on while the sympathetic person is still there. I would also add that you need to have oodles of patience. Everything takes its time. Some times rushing things can go against you. You must be prepared for the long haul." Harmala Gupta, President, CanSupport, India, email 14 January 2005.

"The Vice Minister of Health and the Government Secretary were helpful for us, but after political changes in Mongolia, after July elections the Vice Minister changed and I have now to activate new Vice Minister using all my skills and attitude" Dr Odontuya Davaasuren, President of Mongolian Palliative Care Society

See Annex 8 How to lobby / hold a face-to-face meeting

2.2 Monitoring State Performance

Even when adequate policies are in place or appropriate guidelines are accepted actual practice may not match up to these. Highlighting these

differences can be an important method for encouraging policy implementation to improve. The keys to using these tools are;

- Understand very well what international and / or national guidelines have been accepted.
- Know which policies are intended to guide implementation
- Have clear and credible means of gathering information on actual implementation of policies.

2.2.1 Improving Government Transparency

It can be effective to increase the availability of information about the making and implementation of government policy. Activities can include the discovery, publication and dissemination of information about items of legislation, legal provisions, public expenditure allocations, the implementation of policy and programs, and special enquiries. Enhanced transparency in government may contribute to more effective implementation of health policies by helping citizens monitor the delivery of development resources and staunch the appropriation of resources by bureaucrats and local elites.

2.2.2 Monitoring guidelines and policies that govern how authorities meet their obligations under national or international statutes or guidelines.

The policy environment can be measured and comparisons made with other parts of a country or with other countries. This tool can serve to see if an authority has adequately addressed its obligation to adopt national policies and international guidelines.

*In the **USA** the Pain and Policy Study Group, University of Wisconsin, produces a progress report on the states within the USA's Pain Policies. The centre grades each state on the quality of their current statutes, regulations and guidelines that govern the medical use of the medications needed for pain relief.*

www.medsch.wisc.edu/painpolicy/

2.2.3 Citizenship through accountability and democratic governance

Increasingly ideas of governance and accountability focus on forms of broader interaction of public and private social actors, especially at the local level. Citizen participation in this sense

involves direct ways in which citizen's influence and exercise control in governance. This means creating possibilities for dialogue between citizens. This approach acknowledges the importance of the state and supports citizens entitled to the services to demand and negotiate directly with government for greater performance and accountability.

The WHO Expert Committee on Cancer Pain Relief and Active Support Care 1990 stated "Freedom from cancer pain should be seen as a right of every cancer patient and access to pain therapy as a measure of respect for this right" This is a human right.

"Accent on human rights is very important because we begin to establish new democratic processes" Dr Odontuya Davaasuren, President of Mongolian Palliative Care Society

*In **South Africa** HIV/AIDS has been the reason palliative care is now seen as essential care. The best advocacy has been the work of hospices in their communities and the advocacy by patient's families, and a great deal of support from the National Directorate of HIV and AIDS.*

The Hospice Palliative Care Association of South Africa has succeeded in getting palliative care into the government health plan for 2005-2010. The National Department of Health has included palliative care in the guidelines for chronic care and community home-based care and a national palliative care task team

has been set up with three sub-committees- for policy, education and clinical care.

Source: Joan Marston, Hospice Palliative Care Association of South Africa. Email 20 Jan 2005

2.2.4 Citizens monitoring and evaluating the state

In some countries groups have used monitoring and evaluation techniques and developed indicators of good performance and then used them to monitor policies and programmes.

In **Colombia**, the Association of Indigenous Councils of Southern Cauca (ACIN) a community-based organisation spanning 13 municipalities has developed a monitoring and evaluation system as part of the local and regional planning and development process, in which member communities define indicators based on their indigenous worldview and cultural practices. In the process the communities assess the work of their own institutions that are held liable in terms of fulfilling their commitments and responsibilities.

(Source: Cornwall, A. and Gaventa, J. 2001 "From Users and Choosers to Makers and Shapers: repositioning participation in Social Policy" IDS working paper 127)

2.3 Providing Information and Training

Much of the advocacy work undertaken by Palliative Care organisations is about informing and educating decision makers on issues such as what palliative care is and what policies are needed to support organisations to provide appropriate palliative care. Often policy change can be brought about when officials better understand the issues involved and the reasons why particular policies present difficulties for providers of palliative care. The keys to using these tools are;

- Target the decision makers and those who influence them.
- Ensure the facts you use are correct and up to date.
- Provide information from sources your decision makers will trust.

In **Italy** treatment of pain caused by cancer had been reported as inadequate for more than a decade. Low morphine consumption reflected concern that pain medication was not adequately available to suffering cancer patients. The reasons for under treatment included lack of physician education, low public awareness about pain management and overly restrictive regulations that inhibited the prescription of opioid analgesics. In 1999 a workgroup appointed by the Ministry of Health began to address this. In 2000 the workgroup issued a proposal to reform national policy.

The changes, when fully implemented, will be an important step towards relieving cancer pain.

The methods used to change policy involved leadership and cooperation from government and non-government organisations and experts who used available data to define the problems and then devise measures to address them. In 1998 the Italian Society of General Practice devoted 2 issues of its journal, which presented statistics about medical use of opioids and reviewed the regulatory and healthcare system barriers to adequate cancer pain management.

Source: Blengini C., Joranson D.E., Ryan K.M., (2003) *European Journal of Cancer Care* 12, 28-34 "Italy reforms national policy for cancer pain relief and opioids"

2.3.1 Production of reports

Reports that draw together research and highlight situations can be an effective tool to highlight key issues to interested individuals. They can be an effective means to illustrate differences between countries that may be a useful tool in lobbying government officials.

In the UK to mark World Hospice and Palliative Care Day on 8th October 2005, Help the Hospices are producing a report "Suffering at the End of Life: The State of the World"

Source: Nick Pahl, Development Director, Help the Hospices

2.3.2 Websites and Maintaining Databases of Information

Many organisations, particularly those concerned with campaigning and advocacy use their websites to make information available to others, and to gather and collate information.

*In the **UK** the International Observatory on End of Life Care website provides accessible research-based information about hospice and palliative care provision in the international context. It presents public health and policy data relating to hospice and palliative care services. This is complemented by material drawn from the social and cultural analysis of end of life issues, including ethnographic, historical and ethical perspectives. Data is currently available on 28 countries in Eastern Europe and Central Asia, in ways that facilitate cross-national and regional comparison and analysis.*
info@eolc-observatory.net
www.eolc-observatory.net/global_analysis/about_us.htm

*In the **USA** Americans for Better Care of the Dying (ABCD) an organisation that aims to improve end-of-life care by learning which social and political changes will lead to enduring, efficient and effective programmes. Their organisational goals are to build momentum for reform, explore new methods and systems for delivering care and shape public policy through*

evidence-based understanding. They maintain a page on their website which collates suggestions from advocates, policy makers, providers and consumers for legislative reform in the USA.

www.abcd-caring.org/tools/action1.htm

*Also in the **USA** the Pain and Policy Study Group maintains a database of statutes, regulations and other policies in relation to palliative care in the USA. This is updated regularly and is publicly available. It provides a valuable source of information for professionals.*

www.medsch.wisc.edu/painpolicy/

Source: David Joranson, Pain and Policy Studies Group, University of Wisconsin, USA

2.3.3 Inviting and Funding Key decision makers to attend International Conferences / meetings.

Providing the means for decision makers to access information at an international level and to network with decision makers from other countries can enable them to make comparisons with other countries and see what can be achieved. This tool is particularly important in resource poor countries where lack of finance can be a real obstacle to gaining access to up to date information and ideas.

*In **Romania** in 2002 March after returning from the WHO-OSI workshop in Budapest*

the Health Minister appointed a group of specialist for pain therapy and palliative care responsible for evaluating the needs in relation to palliative care. In February 2004 this group was changed into a proper Ministerial Commission responsible for developing a strategy for a national network of Palliative Care services. In 2004 the commission's 2 major objectives were

- Draft the order of Minister that will define the palliative care services for Romania
- Present the strategy for the development of services at a national level and the new opioid law.

Source: Dr Daniela Mosoiu, President, Romanian National Association for Palliative Care

*In **Poland** the Eastern and Central Europe Palliative Care Task Force (ECEPT) try to assist with policy change in other countries in Central & Eastern Europe. Their main ways of doing this are;*

- Discussing/advising colleagues.
- Visits and training at their centre to share experiences.
- Workshops-eg. How to develop services and policies in palliative care.
- Organizing meeting with Polish Ministry of Health and National Health Fund representatives.
- Taking part in the meetings with officials and palliative care leaders and Polish Embassy delegates abroad.

Source: Jacek Luczak, Polish Association of Palliative Care

2.3.4 Organising Conferences for Educating Decision-makers and practitioners

Organising conferences and workshops within your own country for decision makers and practitioners can be a successful way of bringing the 2 groups together to learn from one another. It also provides a forum for sharing knowledge, ideas and guidelines.

*In **Mongolia** the Mongolian Palliative Care Society organized a 2 days Leadership Conference on Palliative Care for Health decision makers in 2002. In 2003 they organised a 1 day Conference “Essential drug for palliative care” in the Ministry of Health and in 2004 they organized two 2 day “Palliative Care Policy Development Conferences” in Ulaanbaatar for health Decision makers.*

They wanted to educate decision makers on the needs for improving palliative care in Mongolia and to stimulate Ministers to change the rules on drug prescription right, on budgeting palliative care services in Mongolia, and developing palliative care education as a medical specialty. The Vice Minister of Health and Government Secretary of the Ministry of Health participated in one of the conferences as an expert. After this Conference the Vice Minister of Health and Government Secretary prepared Ministers Order about establishing working groups on palliative care. MPCS dictated what these working groups have

to do for developing palliative care in Mongolia.

As a result of this many improvements have been made in terms of palliative care in Mongolia. These include: all medical schools now have palliative care teaching programmes, palliative care is officially recognised as a medical discipline and a budget for 20 palliative care beds in the National Cancer Centre was approved by the Ministry of Health in January 2005

Source: Dr Odontuya Davaasuren, President of Mongolian Palliative Care Society

2.3.5 Providing training and Guidelines

Training and awareness raising of elected officials and government staff in the issues related to the advocacy issue can be an effective tool. To take an example outside of palliative care, in some countries such as India, where quotas were allocated to women and representatives of lower castes in local government, newly elected representatives who had no previous experience of leadership in formal politics have been trained. In Karnataka, leadership development programmes were offered to thousands of newly elected women representative. These women went on to hold their own convention, formed their own network and are using village-to-village peer education and support methods to strengthen their capacity.

*In **Australia** Palliative Care Australia has published Standards - the current edition is from 1999 but a new, substantially redesigned document will be launched mid 2005. (Service providers, to argue for more resources from government, have sometimes used these Standards). They have also published a Planning Guide which gives the per 100,000 of population staffing levels for palliative care in Australia, and very soon will publish a policy document which outlines a model of service provision and planning framework for palliative care services which will help state/territory system planners ensure the needs of dying people are met. There is strong demand for these policy documents in Australia amongst service providers, educators, health system planners/funders, service managers etc. (www.pallcare.org.au)*

Source: Will Hallahan, Acting Executive Director, Palliative Care Australia

2.3.6 Providing professionals with access to information

Often an authority may be supportive of a policy or of palliative care as a practice but lacks the resources to provide the information and the support health care professionals require. By providing access to the appropriate information and training materials, in the correct language, palliative care practice may be improved.

In **Mongolia**, MPSC translated, published and distributed the main WHO guidelines ("Symptom relief in end of life", "Cancer pain relief and palliative care in children", "Prevention and control of common cancer", "Principles of end of life care") in the Mongolian language. They also prepared and published national palliative care, palliative treatment handbooks and palliative nursing handbook for education of palliative care in 2002-2003.

The translation and distribution the WHO palliative care guides was very helpful because officers in the Ministry of Health believed the WHO recommendations more than the recommendations of an NGO such as the MPCs. For example, all participants of the Conferences understand very well the WHO triangle, and palliative care in Mongolia has been developed according this triangle with integration education, drug availability and policy.

Source: Dr Odontuya Davaasuren, President of Mongolian Palliative Care Society

In **Mongolia** the Mongolian Palliative Care Society produced and distributed a calendar "Life begins with love and should finish with love" to all Mongolian Health Centres and participants of their Leadership Conferences. After receiving the calendars several health centres invited them to give lectures on palliative care and as a result of this last year they organized 4 days palliative care trainings in 4 health centres and hospitals.

Source: Dr Odontuya Davaasuren, President of Mongolian Palliative Care Society

In **Eastern Europe** EAPC East is translating and distributing the EU Recommendation 24 as a tool for organisations to use for information and lobbying. Media campaigns will be used as a means to spread the contents of the recommendations.

Source: EAPCEast website www.eapceast.org

2.3.7 Providing Training to Medical Students

In **Italy** there is now a national curriculum for palliative care and a network of schools for teaching palliative care to professionals has been established.

Source: Franco Toscani, Direttore Scientifico Istituto di Ricerca in Medicina Palliativa "L. Maestroni", Italy

In **Uganda** law change was achieved by Hospice Africa Uganda through lobbying to increase the number of prescribers for oral morphine. Nurses and Clinical Officers, following a 9 month training programme at Hospice Africa Uganda, may now prescribe, as well as doctors. Uganda is the first country in the world to take on this type of initiative.

Source: Dr Anne Merriman, Hospice Africa Uganda, telephone conversation 3rd Feb 2005

2.3.8 Release of statements and declarations

The outcomes of conferences and workshops can include a declaration.

Declarations are statement of intent or summaries of the desirable situation to which participants intend to work and to which they would like to encourage others to work.

In May 1998, the 9th Annual Palliative Medicine Advanced Course in Puszczkowo, **Poland**, was organized by the Palliative Care Department of the University of Medical Sciences in Poznan, Poland and the Sir Michael Sobell House in Oxford, UK. An outcome of this meeting was the Poznan Declaration which gave the countries represented an opportunity to outline their goals in palliative care and outline steps to achieve them. (www.medsch.wisc.edu/painpolicy/publicat/00ppsgar/section_ice.html)

This declaration has had wide-ranging effects on the development of palliative care services in Eastern Europe:

The Eastern European Palliative Care Task Force (ECEPT) based in Poznan focuses on **issues brought forward by the Poznan Declaration** of 1998 which sought to improve and widen access to the region's palliative care services. The European Association of Palliative Care, (EAPC) has established an office in Stockholm, the EAPC Centre for Support to Palliative Care in Eastern Europe (www2.soros.org/death/newsletter9/easteurope.html)

In **Latvia** from at least 1995 there was evidence of some external interest in the development of palliative care. In 1998 palliative care was included as a topic in the 2nd Baltic Congress of Oncology and Radiology and in the same year, an **Albert Schweitzer Foundation** seminar on

palliative care and pain control was held in Latvia. These together with sickness fund recognition and the widening of educational opportunities in palliative care have been **attributed to the direct influence of the Poznan Declaration**, which has provided leverage for palliative care innovation in Latvia. In 2002 palliative care sessions were included in the 3rd Baltic Congress on Oncology and in the same year, in response to growing public debates about euthanasia, a short pamphlet on the history of palliative care was published.

(www.eolc-observatory.net/global_analysis/latvia_pc_history.htm)

Other key declarations in the development of palliative care internationally have been:

The **Barcelona Declaration** 1995. Ministry of Health, Government of Catalonia, WHO Cancer and Palliative Care Program, 4th Congress of the European Association of Palliative Care and 1st Congress of the Spanish Society of Palliative Care.
(www.eapcnet.org/download/forPublications/Declaration_Barcelona_GB.pdf)

The Palliative Care Trainers Declaration of Cape Town 2002. This declaration came out of a meeting of palliative care trainers in Cape Town in November 2002. The meeting also resulted in the establishment of the African Palliative Care Association (APCA). The declaration is detailed in the *Journal of Palliative Medicine*, June 2003, Vol. 6, No. 3, Pages 341-343. Posted online on July 7, 2004

<http://www.liebertonline.com/doi/abs/10.1089/109662103322144646>

The Korea Declaration – see www.hpc-associations.net

2.4 Demonstrating Good Practice

Excellence in providing clinical care and in palliative care professionals own work is crucial as a platform from which to advocate for policy change. Showing how good palliative care can be cost effective can also be an important catalyst for policy change. The key to using these tools are;

- Having impeccable palliative care policy and practice of your own or of the organisations you represent.
- Communicating effectively how practice could be incorporated into national policies.

2.4.1 Enhancing State Performance

The quality and effectiveness of public services and expenditures can be contributed to by working directly with government in shaping, financing and delivering public services in a variety of ways. These can take the form of public-private partnerships in which civil society organizations work closely with state institutions in designing and providing health and educational services, by mobilizing funds from among client groups and other sources, by providing services directly

2.4.2 Self-provisioning and Piloting Practice to Demonstrate it Works

A method of advocacy that has proved effective is to use what space is available to develop solutions to problems, rather than to engage directly against state policy. In other words, to start a service independently to demonstrate how it can work in practice. Once the service is running effectively to ask the authorities to start funding it or to take it into the state health service.

In India, CanSupport runs a palliative care home-based service for people with terminal cancer. Over the last 3 years they have been lobbying their government to recognise the right of a not-for-profit organisations such as CanSupport to hold and dispense oral morphine to patients who need it for their pain relief. They have also been asking the Government to simplify the procedures for acquiring a license for oral morphine.

With the help of the Indian Association of Palliative Care and the WHO Collaborating Centre for Policy & Communications in Cancer Care, USA, this is about to become a reality. While the regulations were simplified more than a year ago, CanSupport is about to receive its own license for acquiring oral morphine which will be a first in the national capital region of Delhi for any organisation other than a recognised medical institution. They hope this will open the path for other organisations

working in the field and augur well for the growth of palliative care services in the region.

Source: Harmala Gupta, President, CanSupport, India

In **Malawi**, Lighthouse, began at the Lilongwe Central Hospital (LCH) in 1997. There was severe congestion in the medical wards due to increasing numbers of HIV/AIDS patients being admitted. Patients shared beds and there were many more admissions than discharges. Two nurses, volunteered to follow up those patients living nearby who were discharged from the wards. Any health problems were then handled straight away at home instead of returning to the hospital.

Traditionally in Malawian communities, neighbours and friends would care for the ill and dying, so these nurses used the existing system by working with those neighbours. The nurses gave basic nursing care training to those volunteers. Gradually the numbers grew as people became more interested in caring for the increasing numbers of ill and dying.

At this time the hospital was conducting an HIV testing research project with patients who had TB but were smear negative. About 80% were HIV positive. All received TB prophylaxis at the clinic, but when the project ended it was difficult for the patients to manage without the support they had received within the project. By that time the neighbourhood support system and the clinic were working closely together, and the effects were already being felt in decongestion in the wards.

An old building in the hospital grounds was refurbished to become the joint facility for the home based care and the clinic and was opened in 2002. It was named Lighthouse as a symbol of hope. At that time the term hospice was unknown in Malawi, and the use of opioids and narcotics was looked upon with suspicion.

In 2002, Dr. Anne Merriman from Hospice Africa, Uganda came to sensitize the Malawi government to the use of opioids and morphine, in particular for severe pain in terminally ill patients. She recommended that Lighthouse become known as a hospice and took the palliative care lead in Malawi.

Source: The International Observatory on the End of Life website
www.eolc-observatory.net/global_analysis/about_us.htm

In **Croatia** an important concern for the Croatian Society for Hospice and Palliative Care is to establish the first, independent Institution for Palliative Care, which has full time staff paid by the Croatian Institution for Health Insurance. This has been under negotiation for several months. The Society has been demonstrating how a centre can effectively operate but now feel that enthusiastic volunteering must change into official recognition and full time jobs.

Source: Dr Anica Jusic, Hrvatska Udruga Prijatelja Hospicija, email 24 January 2005

2.5 Public Education and Awareness Raising

Raising awareness among the public of the issues surrounding palliative care can cause the public to start asking for services. This can be a very effective tool in democratic societies. "When people ask for a service, and when people show disappointment for a lack of assistance, politicians become nervous and must do something" Franco Toscani, Direttore Scientifico Istituto di Ricerca in Medicina Italy Palliativa "L. Maestroni" email communication 22 January 2005.

"If you succeed in changing people's attitude to death and dying, transforming it from resignation to the awareness that a good, dignified and human death is not only a possibility but also a right, you create the true premises of the change." Franco Toscani, Direttore Scientifico Istituto di Ricerca in Medicina, Palliativa "L. Maestroni", Italy The Hague Conference 2007

If influencing public opinion is an important part of your advocacy strategy then you will need to use the media. Policy makers often pay close attention to the media so using the media may assist you to reach several target audiences at once. Using the media will enable you to reach large numbers of people and should enable you to gain the public's attention for an issue. It may also assist you to gain credibility with your primary target audiences. Using the media also brings risks as there is always the possibility that your organisation or cause will be inaccurately or unfavourably represented.

2.5.1 Media Strategy

There are several ways in which you can use the media and the methods you chose will depend on the audience you want to reach, the media that is accessible to you and the nature of your message. You need to consider all of these factors and develop a media strategy. This can include actions such as;

- Interest a reporter in your story
- Pitch a story to the media
- News Advisories
- Press releases
- Be available for interviews
- Press Conferences
- Write a commentary / position statement

It is important that you;

- Target the right media and journalists
 - Give them information in the format they want
 - Provide good spokespeople
 - Timing is crucial
 - Know their deadlines
 - Monitor your media coverage
 - Link your media campaign with other relevant events
 - Make pictures that tell your story available
- Annex 9 How to write and use a press release,
- Annex 10 How to carry out a media interview

2.5.2 Profile Raising and Fundraising Events

These can be on a local, national or international level. Organising an event provides a focus around which to direct public and media attention to a cause.

Voices for Hospices *The world's largest simultaneous singing event in aid of hospice care. In 2003 in just 24 hours over 500 performances took place world-wide. Voices for Hospices is a charity which has enabled more than \$8 million to be raised for hospice and palliative care since it started in 1991. Voices for Hospices will next take place on 8th October 2005.*

For more information see www.voicesforhospices.org

2.5.3 A day around which to focus attention

A day designated to a particular cause to provide a focus for organisations, often globally, to raise awareness of the key issues related to that cause. Often this type of awareness raising event is held annually, for example, World Aids Day.

World Hospice and Palliative Care Day *is a new unified day of action to celebrate and support hospice and palliative care around the world, it will take place on 8th October 2005. The day has three key aims:*

- To share a vision to increase the availability of hospice and palliative care throughout the world. To create opportunities to speak out about the issues which affect provision of hospice and palliative care around the world, to influence opinion formers including health care funders and policy makers
- To raise awareness and understanding of the needs – medical, social, practical, spiritual - of people living with a terminal diagnosis and their families. To explain how hospice and palliative care can transform people's lives and to show how it can help to meet those needs
- To raise funds to support and develop hospice and palliative care services around the world – particularly through Voices for Hospices events.

For more information see www.worldday.org

2.5.4 Public Education through the arts.

Highlighting the issues around death, dying and palliative care to the general public can be effectively achieved through the arts. By using plays, television programmes, films and other art forms to illustrate issues the mass media can effectively be used to reach large portions of a population with key messages

In **Mongolia** the Mongolian Palliative Care Society commissioned a song about palliative care and prepared video clip. The song was sung by a famous singer in 2002 to raise the profile among the public of palliative care.

Source: Dr Odontuya Davaasuren, President of Mongolian Palliative Care Society

In the **USA** the Open Society Institutes Project on Death in America (www.soros.org/initiatives/pdia/focus_areas/arts_humanities) provided funding for Arts and Humanities activities which illustrated through language and image the experiences surrounding death, dying and bereavement in the United States with the aim to evoke and deepen peoples understanding of the experiences of suffering, dying and bereavement. For example A grant was made to Ed Kashi and Julie Winokur to produce a compilation of photographs and essays exploring the strains that have resulted from people living longer. The book examines solutions being pioneered to deal with the end stages of life.
<http://www.msnbc.msn.com/id/3677346/>

In the **USA** the Robert Wood Johnson Foundation worked to develop a close relationship with producers in Hollywood to encourage them to describe advance care planning and palliative care accurately and give people positive models of how to talk about these issues

They worked to take advantage of a number of TV productions and plays that have focused on these issues. For

example, a four-part television series, Bill Moyers's "On Our Own Terms," included a broad dissemination plan and community engagement initiative as part of the project. For details see www.pbs.org/wnet/onourown/terms/tools/index.html.

The Pulitzer-prize-winning play "WIT" (for details see <http://bookcomplex.us/0571198775.html>) and TV dramatisation of the best-selling book, "Tuesdays with Morrie," (for details see www.albom.com/morrie.htm) both provided opportunities to talk about dying in community groups around the country. Scenes from WIT were dramatised in medical and nursing schools to engage students in the dialogue on the appropriate care of the terminally ill person.

Source: Victoria Weisfeld, Robert Wood Johnson Foundation, USA

2.6 Involving the public

Providing the public with clear information about your advocacy issue, what they should be able to expect in terms of end of life care and letting them know how they can get involved in campaigns are essential tools to raising public awareness.

In **Poland** the Polish Association for Palliative Care seek to educate and mobilize the general public using various strategies, these include; on-going cooperation with media (press conferences, meetings with the legislators and media, web site,

publications, posters, leaflets, newsletters, workshops, special events, letter writing campaigns, fax or E-mail, petitions). Also Hospice Open Doors Days for citizens, TV interviews, charitable concerts (Voices for Hospices), and a campaign against cancer pain called

"Life without Pain". The support of the Church, especially Caritas is important. One of the ways used to popularise the hospice philosophy and explain its needs is fundraising.

Source: Jacek Luczak, Polish Association of Palliative Care

In **Mongolia** the Mongolian Palliative Care Society prepared TV programmes about:

1. Palliative care 10 minute (2002)
2. About essential drugs for terminally ill patients 5 minutes (2004)
3. Needs for developing palliative care as a part of Health Program in Mongolia 20 minutes (2004)
4. About rights of terminally ill patients 35 minutes (2004).

These TV programmes have been shown many times on TV and many Mongolian people have watched them. The MPCS prepared 32 copies of the Palliative care song and the TV programmes and distributed them to all 21 aimags (Regions) of Mongolia, 6 districts of Ulaanbaatar and all 8 medical schools of Mongolia (together with 2 video tapes with 3 hours palliative care video educations).

After watching the TV programmes, and reading information about palliative care in the newspapers many people called the MPCS for information. As a result the MPCS opened a telephone advice line in the Palliative Care Department and Home Hospices. Now most of the population in Mongolia is informed about the rights of terminally ill patients and about existing palliative care services in Ulaanbaatar. As a result the demand for services is extremely high.

Source: Dr Odontuya Davaasuren, President of Mongolian Palliative Care Society

In **Uganda**, Hospice Africa have used FM radio phone-ins to reach out to large audiences.

Source: Dr Jack Jagwe, Hospice Africa Uganda, email 3rd Feb 2005

2.7 Providing Funding / persuading donors to fund palliative care initiative

For all countries, particularly for resource-poor countries, advocating for the increased provision of funding for palliative care is crucial. Without the resources to implement changes appropriate palliative care policies and practice can be of only limited use.

*In **Malaysia** policy changes were made making palliative care mandatory, but there were no resources and no health care workers adequately trained to provide the care. So there are many hospices staffed with the wrong people who do not have the skills or commitment or motivation, but were sent there to fill in these positions.*

Source: Liliانا de Lima, IAHP

“How to get success in advocacy – financial support of international organisations. Without financial support of the OSI (Open Society Institute – www.soros.org/initiatives/) we can do nothing and will stay on zero point” Dr Odontuya Davaasuren, President of Mongolian Palliative Care Society

PART 3

Key Guidelines on Palliative Care

The Solid Facts- Palliative Care. Ed. E Davis and I Higginson 2004 WHO

This booklet is part of the WHO Regional Office for Europe's work to present evidence for health policy- and decision-makers in a clear and understandable form. It explains why health services should provide good quality palliative care for all people facing serious chronic illness. It provides evidence for the effectiveness of palliative care, shows how it can be improved, and explains the need to ensure full access. The booklet also explores the varied cultural and health care contexts in different countries, and reveals how to educate professionals and the public about these issues. A companion booklet entitled Better palliative care for older people considers this vulnerable group in more detail.

www.ilcusa.org/_lib/pdf/facts.pdf
publicationrequests@euro.who.int

Better Palliative Care for Older People. Ed. E Davis and I Higginson 2004 WHO

This booklet is part of the WHO Regional Office for Europe's work to present evidence for health policy- and decision-makers in a clear and understandable form. It presents the needs of older people, the different trajectories of illness they suffer, evidence of underassessment of pain and other symptoms, their need to be involved in

decision-making, evidence for effective palliative care solutions, and issues for the future. A companion booklet entitled Palliative Care - The Solid Facts considers how to improve services and educate professionals and the public.

www.euro.who.int/document/e82933.pdf
publicationsrequests@euro.who.int

Cancer Pain Relief and Palliative Care: Report of a WHO Expert Committee. (Technical Report Series No. 804), Geneva: WHO, 1990. Available in 13 languages.

www.who.int
bookorders@who.int

Cancer Pain Relief and Palliative Care in Children, WHO, 1998

www.who.int
bookorders@who.int

Cancer Pain Relief with a guide to Opioid Availability, 2nd Ed, WHO, 1996

www.who.int
bookorders@who.int

Council of Europe Recommendation Rec(2003) 24 of the Committee of Ministers to member states on the organisation of palliative care and explanatory memorandum.
[www.coe.int/T/E/Social_Cohesion/Health/Recommendations/Rec\(2003\)24.asp](http://www.coe.int/T/E/Social_Cohesion/Health/Recommendations/Rec(2003)24.asp)

Pain and Palliative Care in the Developing World and Marginalized Populations: a Global Challenge 2003. Ed D. Mazza, MR Rajagopal, A Lipman
www.hospicecare.com/bookstore/Reviews/bt108.htm

National cancer control programmes: policies and managerial guidelines 2002. www.who.int/cancer "National Cancer Control Programmes" advocates for Prevention, Early Detection, Active Care and Palliative Care

Availability of Opiates for Medical Needs. Special Report prepared pursuant to Economic and Social Council Resolutions 1990/31 and 1991/43. Vienna: INCB. 1996

International Narcotics Control Board. Calls on governments to improve the availability of potent analgesics for the relief of cancer pain.

Achieving Balance in National Opioid Control Policy: Guidelines for assessment, 2000.
www.medsch.wisc.edu/painpolicy/publicat/00whoabi/00whoabi.htm

Palliative Care in Resource-constrained settings: for people living with HIV/AIDS and other life-threatening illnesses 2003 Ed J Holloway and R Seaton HIV/AIDS Bureau Health Resources and Services Administration, US Dept of Health and human Services
<http://hab.hrsa.gov/publications>

Standards in palliative Care – a list of national palliative care associations that have published national standards/guidelines is available from Hospice Information
email: avril@hospiceinformation.info or
fax: + 44 (0)20 8776 9345

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Nick Pahl, Development Director, Help the Hospices, UK

Annex 1

Useful contacts, websites and documents

Hospice and Palliative Care Organisations and services

Hospice Information, worldwide resource and network for hospices and palliative care services. Enquiry service, website, publications includes electronic bulletin and statistical information. Aim to help organisations develop professional links within the worldwide hospice community. International skills database www.hospiceinformation.info email: info@hospiceinformation.info

Hospice and Palliative Care Worldwide. A directory of Hospice and Palliative Care Services, Contacts and Useful Resources. Separate directories published for Africa, Asia, Australia and New Zealand, Caribbean, North and Latin America, Central and Eastern Europe, Western Europe, UK and Ireland. Available from Hospice Information contact details as above.

The Hospice and Palliative Care Worldwide: Useful Resources. Introduction to the different types of

support that may be helpful to hospice and palliative care services under development. Available from Hospice Information, contact details as above.

International Association for Hospice and Palliative Care (IAHPC)

Manual of Palliative Care, Guidelines on Getting Started, Newsletters, International Directory, Ethics, Research and Educational tools. Available in www.hospicecare.com

Advocating Palliative Care Worldwide, a report of a workshop held on 4th March 2003 UK Forum for hospice and palliative care worldwide, Help the Hospices, UK international@helpthehospices.org.uk

International Observatory on End of Life Care
Institute for Health Research, University of Lancaster, UK
info@eolc-observatory.net
www.eolc-observatory.net/global_analysis/about_us.htm

Palliative Care campaigning / advocacy / networks

Pain and Policy Studies Group, University of Wisconsin. A World Health Organisation collaborating Centre for Policy and Communications in Cancer Care. Their aim is to promote pain relief by improving public policy and communications.
www.medsch.wisc.edu/painpolicy/

Advocacy - general

Advocacy In Action: A Toolkit to Support NGO's and CBO's responding to HIV/AIDs. International HIV/AIDS Alliance 2002

<http://www.aidsmap.com/en/docs/4782D096-C740-41A5-AF06-D67C14B46DB8.asp>
www.aidsalliance.org
publications@aidsalliance.org
 fax: +44 1273 718 900

CARE USA manual "Advocacy Tools and Guidelines: Promoting Policy Change, 2001" Downloadable as a series of .pdf files. A step by step guide to planning an advocacy initiative.

www.careusa.org/getinvolved/advocacy/tools.asp#english

Advocacy, Communication and Coalition Building. Community Empowerment and Social Inclusion (CESI), The World Bank 2003

The aim of this workbook is to share the basic elements of a methodology of participatory planning for advocacy for development effectiveness. It is designed as a practical guide for individuals and organisations interested in becoming agents of change and strengthening their influence towards local, municipal and national governments and institutions.
www.worldbank.org/wbi/communityempowerment/Modules/Advocacy.html

Research and Advocacy for Policy Change: measuring progress. Kelly, L. The Foundation for Development Cooperation 2002

Research and advocacy work designed to influence policy is a growing area for the non-profit sector. Assessment of the effectiveness of such work has received little attention. This paper draws on discussions about evaluation of advocacy programmes and the broader literature about organisational performance measurement.

www.fdc.org.au/publications/20020521_43.html

Annex 2

Effective representation (legitimacy)

Involving people directly affected by the advocacy issue or problem

Advocacy can be carried out by the people affected by an issue or problem, by other people representing them, or by both groups together. Advocacy is often more powerful if those affected by the problem or issue are involved with or lead the process.

If we advocate by representing others, we need to ensure that we represent their opinions and interests fairly. This means having a very close relationship with these affected by the problem or issue, a deep understanding of the issue, and permission from those affected by the problem or issue to advocate on their behalf. Having permission or the 'right' to advocate for other people is known as 'legitimacy'.

It is also important to ensure that advocacy work is supported by the

mission or aims of our organisation, by senior managers, and by any external funders.

Why it is important to involve those directly affected by the advocacy issue, from early in the planning process

- They will have expert knowledge of the issue or problem
- They can suggest workable solutions based on direct experience of the problem
- They can view a problem from a different perspective
- They are often highly motivated, because they are directly affected by the issue
- People living with or affected by HIV/AIDS have been centrally involved in most major improvements in the field of HIV/AIDS
- Affected individuals and groups will gain more skills and confidence. It is a good opportunity to reduce stigma against people affected by HIV/AIDS.

Problems caused by lack of legitimacy

Involving those affected by the problem or issue late, superficially ('tokenism') or not at all can result in:

- identifying irrelevant issues
- suggesting solutions which do not solve the problem, or make the problem worse
- public disagreement
- loss of credibility for the organisations

- and individuals involved in advocacy
- increased stigma and legitimised exclusion and non-involvement of those affected by the problem or issue
- disempowerment of those affected, so they are less in control of their own situations.

Methods of involving those directly affected by the advocacy issue

Finding a way of genuinely involving those directly affected by the advocacy issue will greatly strengthen the advocacy work in the long term. But it may take more time in the short term, especially if they are very busy, frequently ill, do not trust you, are hard to identify and reach, or challenge your ways of working.

People affected by the problem or issue can be involved at all stages of advocacy: defining the problem or issue, planning, implementation and evaluation – as advisers, implementers or managers.

“It is important for any organisation working in the field of HIV/AIDS to include people living with the virus because it is we who have first hand experiences of the problems that we face.”

Emily Chigidwe, Chairperson, Zimbabwe National Network of People Living with HIV/AIDS (ZNP+).

Source: Advocacy in Action
This is an extract from **Advocacy in Action: a toolkit to support NGOs and CBOs responding to HIV/AIDS**,

developed in collaboration with the International Council of AIDS Service Organizations (ICASO) and published by the International HIV/AIDS

Alliance in June 2002.

Annex 3

Information gathering and learning

It is the lessons learned and analysis made from NGO's actions and experience at the grassroots level that is the key to effective advocacy at higher levels as it gives organisations the confidence and credibility that they can relate theory to real-life experiences. Learning from the field is also a foundation for improved accountability amongst INGO's to their intended beneficiaries. Increasingly in recent years there has been greater emphasis on monitoring, evaluation and impact assessment of health programmes that is leading to improved learning from the field this provides useful information for advocacy work.

The balance between participatory, field-based learning and learning which feeds into wider policy and advocacy-related work is difficult to maintain. Direct learning among field workers is the foundation for other forms of learning linked to good practice, policy and advocacy work, yet this learning is some of the most difficult to capture and policy departments can so often be completely detached from lessons learned in the field. Professional distinctions between programme and research staff can

cause problems.

- Documentation and information-gathering skills

Documentation and information-gathering (research) are vital for nearly all kinds of advocacy work. Documentation and information-gathering are needed to help us develop our ideas and as well as then support our opinions so that they will be taken seriously by those in influence.

There are two basic kinds of information that can be used for advocacy work: primary and secondary information.

Primary documentation and research includes information and data collected by yourself. It may include narrative documentation, data that has been collected (both numerical and narrative), interview notes and quotes, focus group discussions, notes, surveys, participatory research (rapid appraisal), photographs, etc.

Secondary documentation and research includes information which has been sourced from elsewhere and which was gathered by others for reasons unrelated to your work. This includes surveys such as national demographic and health surveys, national censuses, HIV/AIDS facts and statistics, behaviour studies (for example, condom use), reproductive health reforms, sociological studies such as decision-making in the household, information from Internet research, websites, e-mail discussion lists, etc.

Secondary research can also include academic research and action/operations research and conference abstracts.

There are many advantages to using secondary information from a source you trust:

- inexpensive to obtain
- readily available
- valid and reliable
- current
- comprehensive
- credible to those you need to influence.

However, primary research also has its advantages:

- more trustworthy because you know how the information was collected
- more directly relevant and tailored
- demonstrates your experience of any issue directly.

Documenting primary information as you go along is vital and requires NGOs/CBOs to develop simple documentation systems within their organisations to collect and keep information. When the need and opportunity arises, this information can then be used to support ideas and arguments for advocacy work as well as a broad range of other uses within an organisation.

(For more information on developing documentation systems for organisations see **Documenting and Communicating HIV/AIDS Work – A**

Toolkit to Support NGOs/CBOs, International HIV/AIDS Alliance)

Source: Advocacy in Action

This is an extract from **Advocacy in Action: a toolkit to support NGOs and CBOs responding to HIV/AIDS**, developed in collaboration with the International Council of AIDS Service Organizations (ICASO) and published by the International HIV/AIDS Alliance in June 2002.

Annex 4

How to choose appropriate advocacy methods

There are no simple rules for choosing the best advocacy methods.

Your choice will depend on many factors:

- a) the target person/group/institution;
- b) the advocacy issue;
- c) your advocacy objective;
- d) the evidence to support your objective;
- e) the skills and resources of your coalition; and
- f) timing – for example, external political events, when a law is still in draft form, immediately before a budgeting process, time of year, stage of advocacy process.

Below is an example of the strengths and weaknesses of some methods for a particular advocacy objective and targets. Remember that every case is different.

Advocacy objective: To persuade managers of the 10 largest companies in the Andhra Pradesh state to end compulsory testing of workers and dismissal of HIV+ workers.

Direct targets: General managers of companies.

Indirect targets: Labour unions, boards of directors, personnel managers.

Method // Strengths // Weaknesses

Analysing and influencing legislation and policies or their implementation

// If analysis shows that a company's current practices are costing them money, this can be powerful evidence
Beneficiaries can provide expertise // Criticism of policies could anger managers Not useful for managers who dislike formal policies

Position paper or briefing note //

Suitable for presenting to senior directors and managers Useful background briefing for journalists Ensures that public statements by allies always agree // Can easily be lost among other paperwork Some managers do not like reading papers Difficult to involve beneficiaries

Working from inside //

Some managers will listen more closely to people they know Many opportunities within labour unions // Limited opportunities in companies – all policy is made by managers and directors

Lobbying or face-to-face meetings //

Opportunity to present 'human face' of the issue and to build a personal relationship Beneficiaries can explain

their case directly // Managers often too busy to attend Board members not interested in the issue, and afraid of HIV+ people

Presentation // Opportunity to present the issue in a controlled way, direct to decision-makers Beneficiaries can speak directly // Managers often too busy Difficult to gain permission for presentation to board of directors

Drama // Emotional appeal works with some managers Suitable for mass meetings of labour unions Beneficiaries can advise on story, or perform // Some decision-makers will feel that drama is only for the illiterate Difficult to find opportunity to perform to managers or directors

Press release // Useful for organisations needing public support Useful to launch a campaign or for quick reaction to opposition or new developments Inexpensive // No use for companies who do not need/want public support Difficult to involve beneficiaries

Media interview // Same as for press release Useful at times when advocacy issue needs 'a human face' Inexpensive // Can have negative impact if the interviewee is not prepared or does not deliver message well Can be manipulated by journalists

Press conference // Same as for press release Good for presenting evidence, esp. case studies/examples Useful to launch a major campaign or for reaction to serious opposition or major new

developments Easy to involve beneficiaries and allies, and give them public recognition // As for press release Requires high level of organisation Expensive

Source: Advocacy in Action

This is an extract from Advocacy in Action: a toolkit to support NGOs and CBOs responding to HIV/AIDS, developed in collaboration with the International Council of AIDS Service Organizations (ICASO) and published by the International HIV/AIDS Alliance in June 2002.

Annex 5

Methods of monitoring and evaluating advocacy work

Monitoring is the measurement of progress towards achievement of objectives, and noting which activities are going well and which are not.

Evaluation is about making judgements about quality and impact. Evaluation asks why some activities went well and others did not. It also looks at the impact of activities, on the people affected by the problem or issue, on the organisation and anyone else.

There are numerous ways of monitoring and evaluating our advocacy work. The same methods can be used in advocacy as in monitoring and evaluating other activities. Methods can be:

- **qualitative** (for example, case studies, stories, opinions, feelings)
- **quantitative** (for example, statistics, numbers).

When monitoring and evaluating, we need to agree on our definitions of success, i.e., agree on the signs that will show us whether the situation is improving or not – these signs are impact indicators. Well-written aims and SMART objectives often make it obvious what kinds of evidence (indicators) are needed. For example:

Advocacy objective: To stop police harassment of sex workers (SWs) in Ulaan Baator by November 2003

Quantitative indicators: Reduction in violence, extortion and arrests

Qualitative indicators: SWs do not fear police, police attitudes more positive.

People affected by the problem or issue are often the best people to choose indicators of success and monitoring and evaluation methods, and undertake the monitoring and evaluation.

Monitoring methods can be simple or complex, depending on indicators and resources. For example, they may include:

- keeping records of anecdotes and conversations with target audiences
- tracking when others have used your arguments or wording in their literature or presentations
- keeping significant letters and e-mails that have been received

- documenting and filing the messages that you have put out, number of meetings held, and invitations to contribute to the issue from key external parties
- carrying out surveys and interviews to determine the impact that your actions have made
- monitoring the media for mentions of your work.

Whatever methods you choose, try to only collect information that will be useful in relation to your indicators.

Evaluating your work does not need to be a complex process. It can be simply analysing, discussing and making judgements from your monitoring information. Here are some examples of questions that may be useful:

- Have you achieved your aim and objectives?
- Is the situation better than before? By how much? If not, do you need to change your aim and objectives?
- If you did not achieve what you set out to do, why not? What will you do differently next time?
- Are the people involved in the advocacy work happy with the results? With the process?

Source: Advocacy in Action

This is an extract from **Advocacy in Action: a toolkit to support NGOs and CBOs responding to HIV/AIDS**, developed in collaboration with the International Council of AIDS Service Organizations (ICASO) and published by the International HIV/AIDS Alliance in June 2002.

It is helpful to have a list of criteria for developing the advocacy objectives.

- Do qualitative and/or quantities data exist to show that achieving the objective will improve the situation?
- Is the objective achievable, even with opposition?
- Will the objective gain the support of many people; do people care enough to take action?
- Will the resources be available to support the work required?
- Can the target decision makers be clearly identified, what are their names and positions?
- Is the objective easy to understand?
- Is there a clear, realistic timeframe?
- Are there the necessary alliances with key individuals or organisations, how will the objectives help to build new alliances with other NGO's, leaders and stakeholders?
- Will work on the objective provide people with opportunities to learn about and become involved with the decision-making process?

Indicators

Indicators are signs or evidence that the changes you seek to achieve through your advocacy work are happening. The use of indicators is crucial to assess the effectiveness of planned advocacy strategies. Advocacy indicators can be difficult to establish, particularly if the goal and objectives are not clear. It is helpful to break down the indicators into 3 types process, outcome and impact.

Process: monitoring the implementation of activities and how effectively this is done, i.e. the project strategy, work styles and management arrangements.

Outcome: measuring the effect of the activities that have been undertaken, and their progress towards achieving the project purpose.

Impact: ascertaining the longer term and more widespread, intended and unintended, consequences of an intervention, and monitoring progress towards broader livelihoods goals.

(Adapted from An Introduction to Advocacy by Ritu Sharma (SARA Project)).

Annex 6

How to analyse legislation or policy

The first step in analysing and influencing a piece of legislation or policy is to understand what it is actually saying and consider whether it can be improved.

Questions to ask when reading public policy or legislation

The following list of questions may help you analyse a policy or legislation:

- 1 Who benefits from this legislation or policy (if anyone)?
- 2 Who loses (if anyone)?
- 3 What will be the consequences five years from now of enforcing this?
- 4 How does the legislation or policy affect marginalised groups?

- 5 Is this something ordinary people can understand?
- 6 Who supports this law/policy, and why?
- 7 How did this issue first come to the notice of decision-makers?
- 8 What is the financial cost?
- 9 Can it be enforced? If so, by whom, and how?
- 10 What is the penalty if you don't obey this law/policy?
- 11 Does the law/policy violate the UN Declaration of Human Rights or any other convention signed by your country?
- 12 Is the law/policy consistent with your own country's Bill of Rights and/or Constitution?

Reference: Adapted from **Training for Transformation, Book 4**, by Anne Hope and Sally Timmel, Mango Press, Zimbabwe, 2000.

NOTE: When using these questions to analyse unwritten laws or policies, begin with this question:

- What does the unwritten law/policy/tradition say?

How to use your analysis to influence legislation and policy

Once the answers to these questions have been agreed you need to act by writing a position paper to the policy-makers, sending a press release to the media, organising a meeting or giving a presentation, etc.

Source: Advocacy in Action

This is an extract from **Advocacy in Action: a toolkit to support NGOs and CBOs responding to HIV/AIDS**, developed in collaboration with the International Council of AIDS Service Organizations (ICASO) and published by the International HIV/AIDS Alliance in June 2002.

Annex 7

How to produce a briefing note/position paper

Position paper

Ideally a position paper should be written in full sentences and typed neatly. Follow the format for policy documents used in the target organisation, if you know it. Otherwise, use the format below. It should include:

- 1 **Statement of main recommendation:** One to two sentences.
- 2 **Background:** Explanation of why the position paper has been written. List of laws, international treaties, decrees, policies, etc., which support the recommendation.

- 3 **Evidence supporting the recommendation:** (see Step 2 of planning framework.)
- 4 Quantitative evidence: Facts and figures.
- 5 Qualitative evidence: Case studies, personal testimonies, anecdotes or examples supporting the recommendation. Ask for permission from individuals quoted, to protect confidentiality.
- 6 **Our position:** Logical explanation of how the evidence leads to the recommendations. Answers to possible questions or objections.
- 7 **Recommendations:** Specific, realistic actions that the decision-maker can take.
- 8 **Organisations and individuals supporting this position paper.**
- 9 **The name of your organisation or coalition**, and logo if appropriate.
- 10 The date.
- 11 A contact name, address, telephone and fax number, and e-mail address, where available.
- 12 The mission/goals of your organisation or coalition.

Briefing note

This document will only be seen by individuals within your organisation, or within your advocacy alliance, to assist them in delivering advocacy messages. Therefore it is acceptable to write notes instead of full sentences, and to use bullet points. Follow the same format as above, but also:

- Emphasise the most important points – for example, using bold type/underline or a coloured pen.
- Suggest possible strategies, tactics, minimum demands that cannot be compromised.
- Include possible questions that might be asked, and suggested answers.
- Include problematic issues that might arise, and suggest how to deal with them.

General advice

- Briefing notes and position papers should be as short as possible. People are less likely to read them if they are too long.
- Do not assume that the reader knows the subject well – make sure that sufficient background information is included for the reader to understand the issue without needing to carry out additional research. Try to keep this information concise.
- Separate fact from opinion. Provide supporting evidence to back up facts, and write opinions as quotes where appropriate.

Source: Advocacy in Action

This is an extract from **Advocacy in Action: a toolkit to support NGOs and CBOs responding to HIV/AIDS**, developed in collaboration with the International Council of AIDS Service Organizations (ICASO) and published by the International HIV/AIDS Alliance in June 2002.

Annex 8

How to lobby/hold a face-to-face meeting

Establish 'points of entry'

Think creatively about how you can get a meeting with the target person. Is there something you have in common? For example, if a friend of yours attends the same mosque as the decision-maker, ask your friend to introduce you to them so that you can negotiate a time to meet, or alternatively use the opportunity as a face-to-face meeting in itself.

Ask for a meeting

Send a letter explaining what your advocacy goal is and why you would like a meeting. Follow up with a phone call. Often you will not get a meeting with the 'direct target' but with one of their staff (an 'indirect target'). Always meet with the staff, and treat them in the same way you would treat the decision-maker.

Invite them to see the issue or problem themselves

Invite them out of their office to see the issue or problem first-hand and to show them why you need their support. If the decision-maker cannot leave their office, try taking your issue to them – bring people directly affected by the issue to your meeting, show a short video addressing the issue or take a few photographs with you. If you have a friend who knows the decision-maker or someone on their staff, ask your friend to

send the letter or make the phone call to support your views.

Preparing for meetings

Step 1: Know your target

Analyse your target, using the questions/table headings in Step 4 of the advocacy framework (Section 2).

Step 2: Focus on your message

Choose your main objective and develop a simple message from it:

- **What** you want to achieve
- **Why** you want to achieve it (the benefits of taking action, and/or the negative effects of doing nothing; evidence for the problem – statistics and anecdotes)
- **How** you propose to achieve it
- **What** action you want the target person to take.

Write a short position paper to give to the decision-maker, to remind them of your points.

Step 3: Choose the right messenger

Often the messenger is as important as the message. If a friend arranged the meeting, ask them to come to the meeting with you. Or someone directly affected by the issue or problem may be able to 'personalise' the issue and get the decision-maker's attention. Make sure the messenger has appropriate negotiation skills and appropriate attitude to result in a positive outcome.

Step 4 : Practise!

Rehearse your message with colleagues or friends. Ask someone to role-play the meeting, pretending to be the decision-maker, asking difficult questions.

After the meeting

Write to the person who you met, thanking them for the meeting (even if the person was not helpful), briefly repeating your key points and any supporting comments made by the target person, especially any promises to take action. Tell the target person what you plan to do next, promise to keep them informed, and express the hope that you will be able to work together on the issue in future.

Reference: Adapted from An Introduction to Advocacy by Ritu Sharma (SARA Project).

Source: Advocacy in Action

This is an extract from **Advocacy in Action: a toolkit to support NGOs and CBOs responding to HIV/AIDS**, developed in collaboration with the International Council of AIDS Service Organizations (ICASO) and published by the International HIV/AIDS Alliance in June 2002.

Writing a Letter

This is a good way to deliver a message especially if you do not yet have a personal relationship with your target audience. It can be the first step to

building a relationship. There are a few key points to bear in mind

- Find out if a letter, email or fax would be best received
- Be clear in the letter if you would like a response
- Decide if it would be appropriate for others to also sign the letter
- Include attachments with further information if appropriate
- Decide if it would be helpful to send copies of your letter to other individuals or groups.

Face to Face Meeting

This is a good way to build a professional relationship with your key advocacy targets.

Preparation

- Be familiar with the issues you wish to discuss and what you have outlined in your request for a meeting.
- Arrive early and use this time to make contact with key bureaucrats in the officials office.
- Take written copies of your advocacy message and supporting documents and leave extra copies with officials.
- If possible go as a team of 2 but no more than 3, agree in advance who will present what.
- Send a briefing to the official you are going to be meeting explaining what your organisation does, your concerns and what you want to

address at the meeting.

During the meeting

- You will only have approximately 15 minutes to present your case, make sure you have lots of supporting documents to leave behind.
- Be prepared to give background information, don't assume the official knows this already.
- Be clear and concise about asking the official for specific actions eg raising the issue in parliament, making a public statement, talking to other official on your behalf).
- Take charge of the meeting and stay on the topic
- Encourage questions, try to engage them as much as possible.
- Try and find a personal connection.
- Don't try and go beyond your allotted time unless the official indicates they wish to
- End the meeting by asking for a response by a certain date.

After the meeting

- Debrief your colleagues, discuss what went well, what could have been done better and what the next steps are
- Send a thank you letter the official, highlight the issues discussed and remind them what you would like to achieve next.
- Keep the official informed of what is happening as appropriate, keep the link open.

(Adapted from the Canada Hospice Palliative Care Organisation, 2005 Advocacy Strategy.)

Annex 9

How to write and use a press release

Content of the press release

Write a simple and interesting headline – this helps the journalist understand the story immediately. The first sentence should summarise the most important facts of the story

- **Who** is involved?
- **What** is happening?
- **Where** is it happening?
- **When** is it happening?
- **Why** is this happening?

The main part of the press release should then explain these points in further detail. This information helps to persuade the journalist of the facts and importance of the subject, and why it is of interest.

Quotes can often make a press release more interesting and appealing to the journalist, because they may not have access to the relevant people or perhaps because the event has passed. Direct speech quotations from people involved in the issue or activity:

- should express an opinion, fact, or be able to support the view you have expressed in your press release
 - allow you to give strong opinions that would look wrong in ordinary text
 - give a human dimension to the story
 - are better than indirect quotations.
- Gain permission from a person affected by the issue, if you are quoting them.

Style

- Short sentences, maximum 20 words.
- Short paragraphs, maximum two to three sentences.
- Copy the format and story structure from a newspaper article.
- Use a good case study or anecdote as evidence to support your point of view.

Presentation

- Use headed paper so that it looks official and professional.
- Make sure that it is well laid out and easy to read.
- Type it, using double spacing, on one side of the paper only.
- Include the date and the name of the organisation.
- Provide a contact name, telephone and fax number, and e-mail address as available.
- Give an embargo time (the day/time when the journalists are allowed to use the information). This should include the day, date and time.

Photographs

- Include photographs of key people, places or action mentioned in the press release if you have them.

NOTE: Once a press release has been written it should be distributed to selected journalists and press associations by fax or e-mail – you can telephone them to ask for these numbers/addresses. Once the journalists receive the press release they will consider whether to include the story in their media work. They may also contact you for further information.

Source: Advocacy in Action

This is an extract from **Advocacy in Action: a toolkit to support NGOs and CBOs responding to HIV/AIDS**, developed in collaboration with the International Council of AIDS Service Organizations (ICASO) and published by the International HIV/AIDS Alliance

Annex 10

How to carry out a media interview

Preparing for the interview

Find out the answers to the following kinds of questions before any interview:

- Where and when will the interview take place?
- How long will the interview be?
- Who else, if anyone, is being interviewed?
- Will the discussion or interview follow a film or be linked to another story?
- Why have they chosen the subject to address and selected you for the interview?
- Will the interview be broadcast live?

Find out about the journalist who will be interviewing you and:

- Investigate their audience – who are the targets amongst their audience and what kind of information do you need to get across?
- Contact them and agree the subject to be discussed. Remember that the interview starts as soon as you begin talking to a journalist. There is no such thing as 'off the record'. Define the issues clearly. Ask the journalist what kind of questions they will ask and whether they will be supportive or argumentative. Prepare appropriate information beforehand – for example, statistics, facts, a personal story, etc.

- Make a list of key messages you want to get across with three or four key points for each.
- Prepare catchy sentences ('sound-bites') that summarise your message.
- Check that you have up-to-date information on your issue.
- Work closely with your colleagues to develop a draft list of possible questions. Prepare answers to these and practise developing responses to them.

What to do during the interview

- Try and keep calm and composed.
- Remember that the journalist is not your advocacy target – the target will either be influential people listening or watching or the general public as indirect targets.
- Remember that you have the facts you need and that you know more than the journalist does about your area. Keep your answers concise and short, using simple language, without jargon or acronyms. Do not get side-tracked – keep to your key points. If a question strays from your topic, try to move back to the area you want to talk about – for example, "I think what you are asking about is important but the main issue is..."
- If you need time to think about a response, repeat the question before responding.
- Always bring the journalist back to your key messages/points, repetition is a way of getting your message across.

Differences between media

Press interviews tend to be more relaxed than radio or TV interviews. If you make a mistake, say so and answer again.

Radio interviews: In a studio, the studio manager will give you specific instructions about where to sit, how to use the microphone, etc. Sometimes this is done with little time to spare. However, take your time and be sure you understand the instructions. Ask what the first question will be to help you concentrate. You can take notes with you – but try not to rustle the pages. (Brief notes on postcards are often more helpful.) If you make a mistake during a recorded interview, you can ask to try the answer again. If it is live you can say, "Perhaps I might explain that answer", and continue.

TV interviews: The same rules apply as for the radio interview but you can be seen! TV interviews are usually shorter than radio interviews. The interview may be pre-recorded or live.

Source: Advocacy in Action

This is an extract from **Advocacy in Action: a toolkit to support NGOs and CBOs responding to HIV/AIDS**, developed in collaboration with the International Council of AIDS Service Organizations (ICASO) and published by the International HIV/AIDS Alliance in June 2002.

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