Who We Are
The Multiple Sclerosis International Federation (MSIF) is a charity which links and supports the work of MS societies around the world.

Our mission is to lead the global MS movement to improve the quality of life of people affected by MS and to support better understanding and treatment of MS by facilitating international cooperation in research.

What we do
Development
We support national MS societies in their work to improve the quality of life of people affected by MS.

Research
We stimulate and facilitate international cooperation in research to better understand the nature of MS and to develop better treatment and rehabilitation of people with MS.

Communication
We work with MS societies to increase awareness, knowledge and understanding of MS and of the needs of people with MS.

Advocacy
We support MS societies and people affected by MS to influence laws, policies and decisions in order to improve the quality of life of people affected by MS.

More than 2,000,000 people in the world have MS.
You may feel that challenging policy is beyond the scope of your organisation, or that as an individual you have limited opportunity or know-how to impact on the decision making process. However, as somebody who is responsible for the needs and rights of people with MS, it is appropriate and necessary to target decision makers, and take steps to positively affect their decisions.

Don’t be afraid to make clear suggestions or to ask for specific changes. Decision makers are people too, and should be keen to hear your opinions as representatives of people with MS. Often they are open to suggestions from those who are directly affected by the decisions that they make.

Not only can advocacy be simple and effective, it is also one of the most cost-effective ways to make real change in your community. It costs very little to undertake many of the advocacy activities suggested in this guide. One of your main resources will be your own time. Don’t forget to invest time in planning your strategy; this is arguably the most important part of any advocacy programme.

Remember that whether you are a small or large organisation, or an individual, everyone is capable of advocating for change. Think about which changes will have the furthest reaching impact and prioritise what you will advocate for on this basis.

Take it one step at a time and you will find that you are able to achieve lasting and sustainable positive change for people with MS in your country.
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**How to use this guide**

MSIF put this guide together to help you plan and implement your own advocacy campaign. The guide is designed to be easy to use, with helpful examples and case studies along the way.

Whether you’re just starting out or are already running an initiative, there is something in here for everyone. Planning your campaign will ensure that you are responding to the most pressing issues in the most appropriate way. Make sure that you leave plenty of time to consider your options and to involve your colleagues and other stakeholders.

Look out for the bus symbol throughout the guide – this illustrates a worked example of an advocacy campaign on access to transport.

Tables are made to be filled in! Use them to help you think through ideas and plan your initiative.
Chapter 1
What is advocacy?

What is advocacy?
Using a rights-based approach
Understanding the big picture
Chapter 1 What is advocacy?

What is advocacy?

Advocacy is an approach used to influence policies, legislation and the activities of governments, businesses, institutions and other organisations. Non-governmental organisations (NGO), activists and individuals use advocacy to make a difference in their countries and communities. Policy makers exist in all sectors: government, private and charity. Policy makers are human beings, not institutions.

Advocacy is:
- about influencing people who make policy decisions
- about building relationships with individuals
- often a long-term commitment

Advocacy is not:
- simply providing information, education or communication
- focused on raising awareness about your organisation
- a means to raise funds

Advocacy

n. Verbal support or argument for a cause, policy, etc.
Using a rights-based approach

By establishing and agreeing that all human beings are entitled to certain rights, the decision maker has already agreed that in theory he/she has certain responsibilities to ensure that these rights are protected and promoted at a governmental, economic and societal level.

When policy makers are not fulfilling their responsibilities to others, advocacy is a great approach to use to hold them accountable. When policies foster discrimination, advocacy can be used to suggest concrete solutions to policy makers.

The United Nations Convention on the Rights of Persons with Disabilities

The Convention on the Rights of Persons with Disabilities and its Optional Protocol were adopted on 13 December 2006 at the United Nations Headquarters in New York, and were opened for signature on 30 March 2007.

The Convention lays out the rights of disabled persons from the right to equal recognition before the law to the right to education. The Protocol is a mechanism by which a specialist UN committee can hold signatories of the Convention to account.

By early 2011, 147 countries had signed the Convention and 99 had ratified it. The Protocol had been signed by 99 countries and ratified by 61. Only those who have ratified the Convention are legally bound to it.

To read more about the Convention and to find out whether your country has signed and ratified it visit www.un.org/disabilities/
Understanding the big picture

Gathering policy and political information
Before you begin an advocacy initiative, it is important to understand how key institutions and organisations in your community or country work. You will also need to identify who has the power to make the changes you want to see.

Identifying other organisations that may have the same advocacy objectives as you is a good idea. Examples are fellow MSIF member organisations, disability organisations, health organisations, and organisations concerned with Human Rights. Working together often brings strength and credibility to your advocacy agenda.

Gather information informally by speaking to friends, family, people in your community and people within your organisation. Look online for information about large companies or government structures and departments. Information about specific policies may also be available online. You will also be able to find out what kinds of international declarations and agreements your country has committed to by looking on the various United Nations websites.

Even if you decide that it is not the best time to start advocating due to political, environmental or economic conditions in your country. By analysing the problems that people with MS face, and understanding the causes, you will be in a better position to engage with the policy process as part of an organisation or as an individual.

Building strategic relationships
Many MS societies and organisations spend time building relationships with government officials and policy makers through their everyday work. This is especially true when working at a regional or local level. These relationships are often related to service delivery and working together in a more coordinated manner, but it is easy to add an advocacy dimension to established relationships.
Persistence pays off in Russia

The Samara branch of the Russian MS Society needed a meeting space where they could hold sports and social activities for groups of people with MS. They identified the empty basement floor of a residential building as a potential meeting place for their social groups, but the building was not accessible and the cost of purchasing and converting the space would have been prohibitively expensive.

The first step was to identify local, regional and national authorities who were responsible for property management, health and disability in the area. From here, the Society worked to identify the key decision makers in each of these departments. Approaches were made, and target audiences were asked for their support in acquiring the space and making it accessible to people with disabilities like MS. Staff and volunteers approached their audiences using a variety of techniques including letter-writing, gaining public support through the production of printed and online campaigning resources and television interviews.

The campaign paid off and despite legal, bureaucratic and financial problems, eventually a compromise was reached. The Samara branch was granted the use of the space and given three million roubles (US$100,000) to make it accessible to disabled users.

Pavel Zlobin, a staff member at the Russian MS Society, was thrilled with the result.

“We held meetings in nine city centres, and with several government departments, right up to the State Governor level. At the meetings we gave a presentation about the types of activities that the Russian MS Society runs, and why it was so important for us to have a space where we could deliver these services to our beneficiaries.”

“Of all of the advocacy techniques that we used, face-to-face meetings proved the most successful. People connect with the issues when they are confronted with them directly.”

Pavel Zlobin, Russian MS Society
Chapter 2
Planning an advocacy initiative

- Analysing policies
- Finalising an advocacy strategy
- Outlining an advocacy strategy
- Making a plan
Chapter 2 Planning an advocacy initiative

Analysing policies

Policy analysis examines plans and regulations set by government, business or other institutions, and how these policies (or lack of policies) affect specific groups. It analyses the dynamics within civil society.

Sometimes opportunities to advocate arise quickly and there is limited time for preparation. You may need to react to something a government minister or local business leader says, or you may be invited to speak about an issue that people with MS face in your community.

Understanding the local, national and regional context in which you work and live will help you to react to these events. You will have time to focus on the three most important elements of policy analysis: 1) the policy causes, 2) key actors that influence policies and their interests, and 3) the policy environment. The more thoroughly you are able to analyse these elements in advance, the more likely you are to succeed in advocacy.

By setting problems in a policy context you will be able to uncover why problems exist, which policies are related to these problems and who is responsible for them. Identify problems that people with MS face in your country and use the table on page 12 to analyse which type of policies are related to these problems.

Identify key actors and institutions

Once you have identified a policy issue it is necessary to research the ‘actors’ that make decisions about these policies. Actors can be individuals (like government ministers), groups (like trade organisations), businesses or organisations (like NGOs). Your analysis should identify the individual who is responsible for policy decisions, and who is best placed to influence this decision maker. The more information you have about the actor, the better. If you understand what his/her interests and previous support for the issue has been you will be better placed to begin dialogue.

Use the table on page 13 to help you think about who is responsible for the policies related to the problems that you identified in table 12.

Civil society is the range of institutions and organisations that connect people to government and the private sector. Creating a strong civil society means ensuring a dynamic and beneficial relationship between government, business and the non-profit sectors that contributes to the well-being of individual citizens.
### Table (1)
#### Analysing policies

<table>
<thead>
<tr>
<th>What is the problem?</th>
<th>Who does it affect</th>
<th>Supportive policies</th>
<th>Restrictive policies</th>
<th>Policy enforcement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example</td>
<td>Example</td>
<td>Example</td>
<td>Example</td>
<td>Example</td>
</tr>
<tr>
<td>People with limited mobility cannot access public trains or buses.</td>
<td>People with physical disabilities across the country. People who live in more rural settings are particularly affected as their access to basic services such as shops, health services etc. may be affected.</td>
<td>There are no national policies that specifically support access to transport. Ratification of the Universal Declaration on the Rights of the Disabled Person. Articles 5 and 9.</td>
<td>No specific policies restricting access to transport, however since public transport is privately run, the lack of policy or guidance on accessibility leaves the companies providing services little incentive to modify their vehicles.</td>
<td>There are no national programmes that support accessibility however there are many NGOs working with disabled people. Further research is needed to understand how they are currently working with the private sector.</td>
</tr>
</tbody>
</table>
### Table (2)
Identifying key actors and institutions

<table>
<thead>
<tr>
<th>Actor</th>
<th>Relevant policy decisions formally controlled</th>
<th>Activities that affect policies</th>
<th>Degree of influence on policies</th>
<th>Degree of support for regulating private companies</th>
<th>Motivating interests</th>
<th>Resources</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Example 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Minister of Transport</strong>&lt;br&gt;Ms. Laxmi Shah</td>
<td>Currently no policies with regards to accessibility are in place</td>
<td>Financial cost, economic cost, public opinion, party political position</td>
<td>All policy decisions must be signed off by her</td>
<td>Very supportive of regulations for private companies; has been instrumental in reducing carbon emissions from commercial vehicles in the capital city</td>
<td>She has a disabled son</td>
<td>Responsible for the budget</td>
</tr>
<tr>
<td><strong>Example 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Owner of Smithson travel company</strong>&lt;br&gt;Mr. Alan Smithson</td>
<td>Which type of buses to buy</td>
<td>Financial resources</td>
<td>Final decision rests with him</td>
<td>Likely to be opposed to regulations that will restrict or change the way that the company works.</td>
<td>Profit motive: accessible buses mean more potential customers</td>
<td>All company profits ($3bn in last fiscal year)</td>
</tr>
</tbody>
</table>
Analyse the policy environment

Focus on answering the questions in the bubbles below. Your answers will suggest whether the policy environment could potentially change. This analysis will help you determine whether policy change is likely or not.

Potential sources of policy information are government ministries, corporations, donors, UN agencies, the World Bank, universities and other NGOs. Newspapers and other media can be a good source of information too, however it is important to think about the reliability of the sources that you use and whether there may be any political bias. Reading the recorded speeches of actors can also give you vital information about policies and the interest of the actor him/herself.

Sometimes the information that you need will be easy to find, but where you are dealing with an unfamiliar or complex issue, you may need help from someone who is more familiar with the issue in question. Below are some ideas for getting the information that you need:

- Read the local newspaper regularly to learn what different stakeholders think about a high profile policy or issue.
- Contact the office of public information or the relevant ministry to get the names of those responsible for the relevant policies to your issue.
- Search online for names of organisations that work on the issues that you are interested in.
- Obtain a copy of any relevant laws or relevant clauses in your constitution.

1. Can people participate in policy decisions about the issue in question?

2. Where are key decisions on this issue made and who controls these decisions?

3. Are these issues discussed widely? Is the topic of interest to the general public? Has news regarding policies related to these issues been featured in the media?

4. Is this issue a priority for the current government? Does the government plan to make any changes to the existing regulations? What related policies were approved or rejected in recent years?
Summarise policy findings
To summarise your findings arrange them under the following headings.

Remember that identifying the problem is only the tip of the iceberg!

- **Problem identification**
  Specify who is affected by the problem and what the problem is.
  For example, people with MS cannot use public buses.

- **Direct causes**
  The cause directly leading to the problem. For example, buses are not accessible to people with disabilities.

- **Behavioural causes**
  The culture of a person, company, institution or organisation that leads to the direct causes of a problem. For example, bus companies are profit motivated and replacing old buses with accessible ones could cost a lot of money.

- **Causes that lead to behaviours**
  Why do households, policy makers, NGOs, and businesses behave in a certain way? Here you will need to assess knowledge, attitudes, beliefs, preferences, interests and other behavioural causes. By addressing these underlying causes you can affect the problem that you identified through awareness raising or education. For example, bus companies don’t know how many people have disabilities and how many additional passengers they could accommodate with accessible vehicles.
### Identify options for policy change
At this stage you need to assess which changes would lead to your desired result. To identify your options clearly it is useful to list all of the policy issues and describe what changes would need to take place in order to have an impact on the problem. A change on any of the identified policy issues should have a positive impact on the problem you want to solve.

Rank your ideas in order of preference, which policy solutions are more achievable? Which will have the most impact on the problem? Which solutions are more likely to be supported and which are likely to face opposition?

<table>
<thead>
<tr>
<th>Policy contributing to problem</th>
<th>What would need to change?</th>
<th>What is the likelihood of this change taking place?</th>
<th>Who would support this change?</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Example 1</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No specific policy on access to transport for persons with disabilities.</td>
<td>Introduction of a policy on access to transport.</td>
<td>Minister X has shown support for this issue in the past. Introduction of new laws or policies at national level takes a long time.</td>
<td>Minister X People with disabilities Other disability organisations (research which org).</td>
</tr>
<tr>
<td><strong>Example 2</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Private companies run public transport with a profit motive.</td>
<td>Private companies need to see disabled people as customers who will add to their profits.</td>
<td>Can influence company shareholders through advocacy. Replacing vehicles is expensive so they are unlikely to replace unless they are at the end of their life.</td>
<td>Minister X People with disabilities Other disability organisations (research which ones).</td>
</tr>
</tbody>
</table>

Table (3) Options for policy change
Outlining an advocacy strategy

Select a policy issue
You need to select which policy issues to advocate on. Use the table on page 19 to think about which policy changes will have the greatest impact on your identified problem. You may wish to come up with your own criteria for selecting which issues to advocate on. Make sure that you include your colleagues. By including them at this early stage you will ensure that you and your team have a shared purpose and direction.

Select target audiences
The target audience is the person, or group of people who can bring about the policy change that you hope to achieve. There are two kinds of audiences; primary and secondary. Primary audiences are those who have direct authority to make policy changes (e.g. Minister of Transport), secondary audiences are those who may be able to persuade or influence the primary audience (e.g. interest groups, business leaders, local organisations).
**Set a policy goal**
Setting clear and specific goals will help you measure your success.

Policy change is not the final goal of your initiative. The changes should translate into positive change in the lives of people with MS. Define both 'effect-level' goals (related to the policy) and 'impact' goals (should refer to the problem you want to address, and clearly state what changes in people’s lives as a result of your efforts.)

<table>
<thead>
<tr>
<th><strong>Policy issue</strong></th>
<th>Lack of policy with regards to accessible public transport</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Primary audience</strong></td>
<td>Minister of Transport</td>
</tr>
</tbody>
</table>
| **Secondary audience** | – Private companies involved in the provision of public transport  
– National Disabled persons groups. |
| **Effect-level policy goal** | – By September 2012 the Minister of Transport will commit to approve and enforce policy that will ensure that all buses will be made accessible by 2020.  
– By October 2012 the bus company will agree to replace old buses with accessible buses as replacements need to be made. |
| **Impact goal** | By 2020 all disabled people living in this country will be able to access all buses. |
### Criteria

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Relative contribution to the problem</th>
<th>Scale of potential impact</th>
<th>Likelihood of success</th>
<th>Potential for working in coalitions</th>
<th>Potential risk</th>
<th>Potential for your organisation to advocate effectively</th>
</tr>
</thead>
</table>

**Example**

- **Private companies run public transport with a profit motive**
  - Significant contribution to the problem, however can be solved with legislation from the government or by convincing company that they can make profit from widening their customer base.
  - Could have an impact on all disabled persons who want to use public transport.
  - Likely to have some long term success - not a quick fix.
  - Great potential, will need to work with other disability groups.
  - No real risk - not taboo or politically sensitive.
  - Our organisation is not considered an expert in this area. It may be better to create a coalition or to allow a different organisation to lead.

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**Table (5)**

Selecting policy issues
### Table 6: Determining target audiences

<table>
<thead>
<tr>
<th>Policy issue</th>
<th>Primary audience</th>
<th>Secondary audience</th>
<th>Effect-level policy goal</th>
<th>Impact goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lack of policy with regards to accessible public transport</td>
<td>Minister of Transport</td>
<td>Private companies involved in the provision of public transport National disabled person groups</td>
<td>By Sept 2012 the Minister of Transport will commit to approve and enforce policy that will ensure that all buses will be made accessible by 2010.</td>
<td>By 2020 all disabled people living in this country will be able to access all buses.</td>
</tr>
</tbody>
</table>
Working with others
In many cases you will find that your 'effect level' policy goals are similar to those of other organisations and interested groups. You are more likely to be successful in advocating for change when you collaborate with other organisations to achieve your goals. Not only are your voices stronger together, the cost of implementing your advocacy initiative will be split between you.

Think about which organisations may be interested to work with you on your advocacy initiative. Other organisations that work with people with neurological conditions or disabilities may share many of your advocacy goals, and could prove to be important partners.

Assessing risk
The more you understand the political environment which you are working in, the more you can assess risk and the less likely you will be to make a mistake.

You do not need to be an expert in politics, but you are more likely to succeed and less likely to expose yourself and others to risk if you can answer the following questions:
• What are the key political debates, and who represents each side?
• Which issues (or people) have sparked political violence or community conflict in the past?
• Which issues (or people) have succeeded in reaching across ethnic, social or political boundaries?
• How is power exercised within the political system?
• Which groups in politics or government are respected, and which are disrespected or feared?
• How do the policies which you are concerned with relate to controversial topics?
• What are accepted forms of political dialogue and proper protocol for approaching policy makers?

It is important to remain impartial in political debates and party political issues so as not to compromise your position as an independent organisation or actor. Seek support from all sides and focus on achieving your policy change objectives.

Before you start any advocacy initiative, be sure that you understand the policy concerns of those who you represent, and that your involvement would be welcomed.
In the Irish health system, neurological diseases are misunderstood and under-funded. MS Ireland found that 30% of people with MS in Ireland wait over a year for diagnosis and 35% need improved access to physiotherapy. The Atlas of MS, produced by MSIF, found that Ireland has the lowest number of neurologists per capita in the EU – just 24 in the public health system compared to a recommended 42. Rehabilitation is also badly under-resourced, with a lack of consultants and rehabilitation beds.

MS Ireland identified several actors who had responsibility for relevant health system components: the Minister for Health and Children, the Director of the Health Services Executive (HSE), the Director of Quality and Clinical Care Directorate and the national leads in disability, rehabilitation, primary care and outpatient services.

The first and most important action in MS Ireland’s campaign was to join forces with other organisations through the Neurological Alliance of Ireland (NAI). More than 17% of the Irish population have neurological conditions, sharing many of the same concerns and issues regarding health services. The Chief Executive of MS Ireland became the Chairperson of NAI and the Communications Manager became a committee member of a working group.

Through the NAI, MS Ireland met with decision makers to propose solutions to these problems. The real-life experiences of people with MS were used to strengthen the case for change. A number of politicians were asked to support the campaign and prominent neurologists were also asked to get involved.

With the support of influential people and decision makers, a people-strong lobby, and a committed coalition of organisations working towards shared objectives, MS Ireland was able to achieve significant success; including a commitment from the HSE to increase outpatient neurology by 30% through the appointment of a number of new neurologists. MS Ireland was also represented on the development of the Neurorehabilitation Strategy, which is due to be published in May 2011.

“These are great achievements for us, but we know that we still need to keep the pressure on the HSE and the government. We are working with all of the charities from the NAI on the ‘Thinking Ahead’ campaign. It asks the government to continue to prioritise and invest in neurological care.”

Taragh Donohoe, Communications Manager, MS Ireland
Keeping Cool in Australia

Australia's climate ranges from temperate to tropical, so almost everyone with MS runs their air conditioner extensively to keep cool, as heat worsens their symptoms. Rapidly rising electricity prices mean that people with MS are having increasing difficulties paying their electricity bills.

In 2007 MS Australia began working to reduce this economic burden on low income MS households.

Two states already had government energy assistance schemes to assist those with a medical need to keep cool. MS Australia began working with MS organisations in other states and one territory to establish similar schemes, and to improve the Victoria scheme.

To provide evidence to underpin the advocacy work, MS Australia undertook a national survey about air conditioner use and the impact of getting too hot (as part of a wider study), and 2400 people with MS responded.

The same basic campaign strategy was used in each state, adapted to local conditions and coordinated by MS Australia. Materials for each campaign included a discussion paper, a proposal to treasury, tips for letter-writing and the Keeping Cool Survey report. Forming a ‘Keeping Cool Alliance’ with other heat-affected groups, such as Parkinson’s disease, spinal cord and brain injury, motor neurone disease and others, as well as organisations working on energy policy was also critical. Alliance work included developing an agreed policy position paper and campaign plan.

The discussion paper was sent to relevant government Ministers and public servants, and was followed up with face-to-face meetings. People with heat intolerant conditions were mobilised to write or meet with their local member of parliament. Media work was focused on human interest and heat intolerance rather than on the campaign itself.

Now rebates have been agreed in four of Australia's six states, and campaigns are underway or developing in the other two.

MS Australia Senior Policy Advisor Michael Summers said: “Alliances with other relevant organisations and their active participation in the campaigns were critical. Few public policy issues only affect people with MS, and involving others was essential to building a broad base of support and a sense of importance of the issue. This also has longer term benefits in relation to working together over time on other campaigns.”
Finalising an advocacy strategy

Identify key messages
Your key messages are what you will communicate with your target audience. Usually you will have a limited amount of time to convey your message so it is important to be clear about what you are asking for beforehand, and how you will ask for it. This way you have the best chance of convincing your target audience of your message.

A message is most effective when it is tailored to specific audiences. You should aim to understand what they already know and fill in the gaps with the additional information that they need.

Define advocacy activities
Now that you know who you will be addressing and what your message will be, you need to think about how you will target these audiences. It could be through letters, phone calls, face-to-face meetings, presentations or field visits. There are many different tools that you can use to engage your target audience. Field visits are a particularly powerful way to express the problem or to identify the solution. If your target audience cannot come to you, collect case studies to bring the problem to them.

Table 7: Identifying key messages

<table>
<thead>
<tr>
<th>Overall message</th>
<th>Message for Minister of Transport</th>
<th>Message for most powerful business leaders in the area of transport</th>
</tr>
</thead>
<tbody>
<tr>
<td>All people have a right to use public transport. Many people with disabilities cannot. Join our campaign in favour of ensuring that non-accessible buses are phased out of the transport system.</td>
<td>Policy change will ensure that transport companies only buy accessible buses in the future.</td>
<td>Buying accessible buses in the future will mean that your customer bases will widen and that your business practices are inline with our company ethos of inclusion and non-discrimination.</td>
</tr>
</tbody>
</table>

Essential elements of an advocacy message:
- What you want to achieve
- Why you want to achieve it (and why others should want to achieve it too)
- How you propose to achieve it
- What specific action you want the audience to take
Making a plan

Set a timeline
It is important to set a timeline at the beginning of the initiative but also to remain flexible. Political events can throw your timeline off course, so remember to revisit and adapt it as you meet challenges or successes.

React to opportunities as they emerge
You may be invited to speak at a meeting, or to act as an advisor. These kinds of opportunities can fit into your advocacy objectives. Monitor, add to and amend your activities accordingly. Remember to include other organisations or parties who you agreed to work with in the planning stage. They may be able to contribute additional advice or expertise in the light of this unplanned opportunity.

Prepare a budget
Estimating the cost of an advocacy project can be difficult. It may not cost anything if you are, or have volunteers to carry the project forward. Bear in mind that you may need additional financial resources for travel and meetings. You may want to invite actors to a lunch at a restaurant or café, or to a face-to-face meeting at your office. Base your budget around your activities and try to be realistic about the resources that you will need in order to reach your objectives. Include some contingency money in your budget to allow you to respond to unexpected opportunities as mentioned above.

This list will help you think about what additional resources you will need:
- Salaries and benefits for staff if you have them
- Supplies (stationery)
- Activities and events (conferences, briefings, lunches, meetings, press work)
- Printing and distribution (press materials, brochures, reports, fact sheets)
- Communications (telephone calls, fax, modem, internet access, postage)
- Office space (if you have it)
- Training
- Travel
- Contingencies
- Overheads

Once you have identified any additional funding that may be required to undertake your advocacy activities, you can begin to approach suitable donors. You may find that existing donors are willing to contribute to these additional costs if the objectives fit with those you have agreed for projects that they are already funding. Think about the connections between your existing projects and your advocacy initiative.
Prioritising access to treatment in Romania

In 2009 and early 2010, Claudia Torje, Executive Director of the Romanian MS Society (SSMR), became aware that severe problems in the public health system were having a negative effect on the health of people with MS. The national programme to address MS had suffered a cut in budget of more than 43% since 2009, which had affected access to necessary treatments for people with MS.

Claudia launched a campaign to ensure that people with MS had access to appropriate treatment. The first stage focused on generating public support online. The Society posted information on their website, in their printed publications and on social media sites. They worked with the media to feature the campaign in a number of local newspapers.

With public opinion behind them, Claudia harnessed the support of Mr Calin Potor, a Member of the Parliamentary Health Commission, to arrange a meeting with a Ministry of Health representative. She also sent a letter requesting an audience with the Romanian President.

In January 2010, SSMR was contacted by presidential advisor Virgil Paunescu, who invited them to attend a meeting at the presidential palace on 16 March. Claudia was given the opportunity to present the problems faced by people with MS. She made suggestions to solve these problems including changing the limit on the number of patients on the MS treatment programme, which has been fixed at 1,893 people in 2009. There were 300 people with MS on the waiting list who were in need of treatment, but for whom the treatment was not available.

In 2011 the treatment programme was extended as a result of Claudia’s work. Now more people with MS have access to the treatment that they need in Romania.

“Use the public to persuade policy makers that your cause is an important one. With public support behind you your voice will be louder.

“Be persistent and never give up, even if you don’t receive the support that you need and want at the beginning.”

Claudia Torje, Executive Director, Romanian MS Society.
Chapter 3
Implementing an advocacy initiative

Communicate effectively
Working with the media
Communicate effectively

Successful advocacy relies on being able to communicate your message effectively. Below are some tips about how to use two commonly used advocacy formats: letters and presentations.

Writing a letter
Writing a letter is a good way to deliver your message, especially if you do not have a relationship with your target audience. If you are writing on behalf of a group of organisations invite others to sign the letter. Think about how your audience is most likely to read the letter, by email, post or fax. Also consider whether you are expecting a response or if you are writing to share your opinion on an issue. You may also be writing to request further discussion or a meeting.

Remember to include:

1. **Proper salutation**: Address your audience using names and correct titles (Mr, Ms, Dr, Sir etc.)

2. **Leading paragraph**: Sum up your reason for writing and deliver your message in the opening few lines.

3. **Information about yourself**: Explain who you are, who you are representing and what your organisation does.

4. **Supporting arguments**: Make no more than three supporting arguments for your request. Use facts and positions taken by well known or respected groups. Show that others support your view.

5. **Request for action**: Be specific about what you want the reader to do. If you are writing to request a meeting tell them when you will be back in touch e.g. within one week.

6. **Acknowledgment of your audience**: Be sure to recognise your reader as someone whose opinion matters and invite them to give their perspective. Thank them for taking the time to read the letter and show appreciation for any past support.

7. **Include attachments** (optional) If you have particularly compelling information or research that supports your position include it as an attachment. Try to keep any additional information short; policy makers may be too busy to read long reports.
Clever communications lead to advocacy success in Canada

In the Canadian province of Newfoundland and Labrador, MS drugs were excluded from the Prescription Drug Program, leaving people with MS to face a dilemma: go without vital MS therapies, cut back on other necessities or leave their jobs and apply for social assistance.

The MS Society of Canada, Atlantic Division, decided to change that.

In November 2006, they launched a campaign to expand the Program to provide MS drugs to those who needed them. With few staff, limited volunteer time and a very small budget, the Society advocacy team created a campaign that was low cost and easy to deliver.

Firstly they identified the key actors in this policy area; the premier of Newfoundland and Labrador, and the Minister of Health, and decided that they would target their campaign at them. Using humour to convey their message, the Society used a series of light-hearted and non-confrontational messages on significant public dates and holidays:

- At Christmas, a news release proclaimed “Province gives lump of coal to MS patients”
- On Valentine’s Day, they presented the Premier with a giant heart-shaped cookie iced with the phrase “Premier, Have a Heart”
- At Easter, they met with the Minister of Health and Community Services and gave him a giant Easter bunny wearing a T-shirt that said “Premier, Hop to it!”

The media joined in with the campaign and were excited to see what the MS Society would do next. This generated significant public interest, and the issue of MS drugs became a hot topic on radio talk shows and in other media.

The media buzz was supported with an advocacy campaign with MS Society members writing letters and meeting with local members of provincial legislature to speak about the campaign.

On April 23, 2007, the government announced a significant expansion to the Newfoundland and Labrador Prescription Drug Program to the benefit of all people facing high drug costs.

“Be creative and don’t be afraid to use unusual tactics if it fits with the people you are trying to influence. Above all, don’t give up.”

Deanna Groetzinger, Head of Advocacy for the MS Society of Canada
Presenting to a group
Here are some suggestions for delivering an effective advocacy presentation:

1. Introduce yourself to the audience:
   Be clear about who you are and what your organisation does. If the audience has limited knowledge of your organisation, make it clear what the connection is between you and the issue to be discussed.

2. Tell the audience what you plan to present:
   Give an overview of your key points at the beginning of the presentation so they know what the structure of the presentation will be in advance. Tell them how long the presentation will take, and stick to it.

3. Deliver your advocacy message straight away:
   Don't wait until the end of the presentation to make your main point. Your audience should be thinking about it throughout your presentation. Support with your most compelling three arguments.

4. Tell your audience how they can help:
   Know your audience and the power that they have to help you achieve your goal.

5. Summarise your main points:
   Make sure that everyone leaves with a clear understanding of the main points of your presentation.

6. Thank your audience for attending:
   Recognise the time that they have taken to attend the presentation. If you can, take questions or discussion on key points at the end of your presentation.

Remember:
- Try not to read a script. It is not engaging for your audience.
- If you can, give a visual presentation include pictures and examples of how the issue affects people with MS.
- Use humour. Many people respond well to friendly interactive presentations.
- Try to allow for questions, or ask your audience questions throughout the presentation to keep them engaged.
Working with the media

If influencing the public is in your advocacy strategy, working with the media will be an important part of your plan. With the right connections you can reach a large number of people at little cost. Policy makers and others involved in the political process are also likely to be exposed to the media.

To ensure that your media coverage will enhance your advocacy initiative, make sure that you plan ahead. Think about which techniques you will use to interact with the media, which types of media you can use, what could go wrong (misrepresentation, or inaccurate information), and your own skills and experience in working with the media.

Planning your approach

The media is different in every country. Some media outlets are controlled by the government, others are privately owned. Some outlets have wide distribution, others have minimal distribution. Think about which media outlets are most likely to reach your target audiences; radio, print, television or online.

Once you have decided which kinds of media would be best suited to advancing your advocacy agenda, research key contacts who may be interested in featuring your story. Contact other like-minded organisations who may be willing to share their contacts with you.

Pitching your story

You may need to ‘pitch’ or make a case as to why your story should be featured in the media. Be prepared to make a strong case for why your story is important. Make your point concisely. Here are some tips for making a pitch:

- Explain why the story offers something new and relevant for here and now.
- If you are submitting something in text make sure you stick to word limits or any other guidance.
- Keep your scope narrow – don’t try to cover multiple topics.
- Present a positive aspect of the story.
- If it is a national story present a local focus when pitching to local outlets.
- If a reporter is needed to cover the story be flexible about how and when the coverage will occur.
- If you are approaching a visual media outlet such as television, newspaper, magazine or online, explain what kinds of supporting materials you have, or will make available. For example video or photographs.
Case studies
Case studies are a way to portray the human cost of the problem that you are advocating to change. Use them to highlight your message and to bring the reality of the problem to light. Policy makers often have little experience of the problems that people with MS face. It is your job to enlighten and engage them with the issues at hand.

Here are some tips for writing a case study:
- Write it in the first person, I feel, I think, I am. This keeps the story personal and will result in greater impact.
- Include a picture. Pictures speak louder than words and again will help to personalise the story.
- Keep the stories short and specific to your message. For example if you are addressing a problem with access to transport, the story should be about the problems that a person with MS faces in using public transport.
- Don’t forget to point to your suggested solution.

News advisory
A news advisory is sent to journalists and media outlets ahead of an event. You may be inviting a reporter to cover the event, or inviting them to write about the event ahead of time to attract other attendees.

You should always include Who, What, Where, When, and Why.

Follow up written advisories a day before the event as a reminder. Remember to include your contact details and a visual representation – pictures are a good way to get people interested.

News release
A news or press release is a written statement that alerts the press to a public announcement or an event. You may want to tell them about a report, research or a new project that you are launching. It is usually sent at the time of the event or immediately afterwards.

This release should include all of the information that a reporter would need to write a story. If you can, include quotations to support the story. Quotations from well known and/or respected people in the community will make the story particularly interesting to journalists.

Ensure that your contact information is clear and set apart from the body of the text and that you keep the main content of the press release to one side of A4. A press release should never exceed two sides of A4 including background information.
Sample press release

Use a short, clear headline focused on the audience: what’s in it for them? Don’t bother with clever or pun headlines. Your job is to get a simple message across.

Use a local or meaningful reference for the audience, rather than big numbers or hard-to-understand facts.

Use a quote within four paragraphs. Any quote you use should move the story on, not just repeat the story. Remember to focus on the benefit to the audience.

Use notes to editors to offer additional useful information, like information about images or availability of interviewees. Don’t use this space for your core story.

Get your contact details in right away. Don’t make the journalist hunt for them.

Date your release, so the journalist knows it’s current.

Families to get free trees, as children learn about woodlands in science lessons

Free tree saplings for pupils, with lessons on how to plan and care for them.

Norwich families are to receive enough free tree saplings to plant the pitch at Carrow Road 60 times over.

The giveaway is part of a drive by East Anglia nature charity The Woodland Foundation to teach conservation skills to school pupils and to spread interest in conserving threatened woodlands.

Pupils in all secondary schools across the city will be given saplings this month, with lessons on how to plant them at home or at school. Through follow-up lessons, pupils will measure, care for and learn about their trees.

Sally Jenkins, schools officer for The Woodland Foundation said: “Families will get a great-looking tree to help brighten up their garden. We want pupils and their families to learn about their tree and how best to care for it as it grows. We hope that will lead to a wider interest in conserving woodlands across East Anglia.”

Over 2,000 tree saplings will be given to pupils this month, with national curriculum-based lessons plans provided to science teachers.

Joseph Lines, head of science at St Christopher’s Secondary School on Juniper Way, said: “Our pupils got really excited when we handed out the saplings, challenging each other to grow the tallest, strongest tree. It’s a practical way to get families interested in conservation. Much better than another boring lesson.”

Notes to editors:
- Photo opportunity, 12th March - 10am: Pupils will be planting trees at Carlton Edge Secondary School on West Street, where staff from The Woodland Foundation will be available for face-to-face interviews.
- Pupils from St Christopher’s Secondary School are available for interview about the scheme, and press-ready photography from this school’s scheme is also available.
- The Woodland Foundation is Norfolk’s biggest environmental charity wholly dedicated to conserving woodland across East Anglia. It works with schools, local authorities and businesses across the region.

Contacts:
Working hours: Jess Smith, press officer 01234 567 8910, 07987 634 3154
Out of hours and weekends: Sally Jenkins, schools officer, 07887 654 3210

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You can make an impact

Now that you have learnt how to prepare, plan, and carry out an advocacy initiative, you have the tools that you need to make a positive impact on the lives of people with MS in your country.

Remember that you can make a difference through simple targeted advocacy.
Online campaigning resources

**Online campaigning resources**

**Advocacy Online** [www.advocacyonline.net](http://www.advocacyonline.net)

Advocacy Online is a leading provider of internet software that enables organisations to run effective e-campaigns, raise funds, and grow online communities in any language, in any country.

**Facebook** [www.facebook.com](http://www.facebook.com)

Join the largest online community in the world to raise awareness of the problem or to promote a solution. With more than 500 million active users in 190 countries worldwide this could be the platform you need to draw attention to your cause.

**Twitter** [www.twitter.com](http://www.twitter.com)

With 175 million users Twitter connects you to the latest information about what you find interesting. Simply find the public streams you find most compelling and follow the conversations. At the heart of Twitter are small bursts of information called tweets. Each tweet is 140 characters in length making it most ideally suited to campaigns which are building quickly and where there is a lot of ongoing activity. You can tweet about your own campaign or you can follow what politicians, journalists and other VIPs are saying about issues that affect you.

**Wordpress** [http://wordpress.com](http://wordpress.com)

Wordpress.com is a free blogging tool and site that will enable you to create a blog no matter how much (or little) online experience you have.

**Further reading**

Canadian MS Society, Advocacy and Government relations. [http://mssociety.ca/atlantic/socialaction.htm](http://mssociety.ca/atlantic/socialaction.htm)


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