

TABLE OF CONTENTS

1. The Case for Parity
 - A New Chapter
 - Building a National Movement for Parity
2. Getting Started: The Basics
 - Forming Your Committee
 - Determining Your Goals
 - Writing Your Plan
 - Building Your Coalition
3. The Legislative Process
 - Overview
 - Resources
4. The Bill
 - Overview
 - Model Bill
 - Legislative Negotiating Principles
5. Funding Your Efforts
 - Budget
 - Steps
 - Fundraising Methods
 - Fundraising Tips
 - Follow-Up Methods
 - Follow-Up Tips
6. Organizing a Grassroots Effort
 - Why Do We Organize?
 - How to Lobby
 - Writing to Your Elected Officials
 - How to Plan an Event
 - How to Use Petitions
7. Working With the Media
 - Sources
 - Building Relationships With the Media
 - Designing and Delivering Your Message
 - Types of Media
 - Being Proactive With Your Media Plan
 - Managing Breaking News
 - Developing a Media List
 - Serving as a Media Spokesperson
8. Appendix (Sample Materials)

THE CASE FOR PARITY

Today, people with limb loss face more challenges than ever before. Growing healthcare costs and cuts by insurers' and employers' coverage of healthcare are putting increasing pressure on working families. This challenge is even more critical for people with limb loss. As benefits are cut, the very prostheses that they need to continue to participate in school activities, be an integral part of the work force and provide for their families are in jeopardy.

People living with the absence or loss of a limb face daunting obstacles when attempting to obtain appropriate prosthetic care. Some third-party payers place annual or lifetime caps on prosthetic devices. Others eliminate coverage altogether. These factors may very well prevent people with limb loss from living productive lives, lead to poor rehabilitation outcomes, and place amputees at risk for dangerous and costly secondary conditions.

Chronic secondary conditions such as depression, obesity and cardiovascular disease can lead to additional amputation. Each of these costly, devastating conditions exacts a tremendous emotional and economic toll on society, but they can be prevented by providing appropriate technology, support and education.

Companies are imposing unrealistic caps such as:

- One limb per lifetime
- \$2,500 per lifetime
- \$500 per year.

And some companies are eliminating orthotic and prosthetic coverage altogether!

A NEW CHAPTER

From its beginning in 1986, ACA has provided information and support to amputees, their families and healthcare providers in all 50 states. To further serve the needs of its constituency, ACA recently expanded its primary mission to include an advocacy program to influence public policy. This new focus is enabling the ACA to help local groups around the country and empower them to make the changes needed in their state legislature for access to prosthetic care.

BUILDING A NATIONAL MOVEMENT FOR PARITY

The Amputee Coalition of America (ACA) has assumed the challenge to address and improve prosthetic access for all amputees in the U.S., at both state and federal levels. The ACA is working to bring together patients and providers, trade groups and manufacturers through the Action Plan for People with Limb Loss (APPLL) to aggressively reverse these negative reimbursement trends and stem the emergency threats that could further erode coverage and access for prosthetic care.

Colorado was the first state to successfully pass a law mandating insurance coverage for prostheses, followed by Maine in 2003, New Hampshire in 2004, and Rhode Island, Massachusetts and California in 2006. ACA's APPLL program is providing the necessary guidance and assistance to local groups to facilitate the passage of prosthetic coverage legislation in additional states.

For more information or to get involved, contact the Advocacy Department at 202/742-1885 or apll@amputee-coalition.org

GETTING STARTED: THE BASICS

By requesting this toolkit, you've already taken the first step. You have decided to do something about the problems people with limb loss face in your state. Congratulations! So, what's next?

FORMING YOUR COMMITTEE

The core committee for your group will help drive every step of this process. This committee will be composed of folks who work hard and get the job done:

- People who have political or legislative knowledge and connections
- People with medical or prosthetic knowledge
- People who are impacted personally by this situation
- People who are committed to passing parity legislation
- People who have time to help.

There will be a lot to do in the months ahead. Your committee should have a plan to address the various areas it will take to succeed. People should volunteer for tasks that match their skill sets and backgrounds. It is likely that all of you will participate in all of the activities on one level or another, but, in order to use everyone's time most effectively, it is helpful to determine who will be primarily responsible for particular tasks, such as:

- Fundraising
- Conducting background research
- Writing the campaign plan
- Reaching out to your local media
- Contacting your state legislators
- Recruiting volunteers.

You may want to break down into subcommittees to help divide up the work and give people an opportunity to work on specific areas.

There will be times that one or more of your group will be quoted in the press. You'll want to make sure your name communicates an important message about your group. The Colorado group called themselves the "Colorado Coalition for Working Amputees." This name is "moderate" in nature and can appeal to people on all points of the political spectrum.



See: *"Funding Your Efforts," "Organizing a Grassroots Effort" and the Appendix.*

DETERMINING YOUR GOALS

The first thing your group must do is agree upon a goal, priorities and a timeline. It is critical that everyone agree upon the goal from the outset. You can have more than one goal, but it needs to be specific. For example:

Goal 1: *Pass parity legislation through the Assembly this year.*

Goal 2: *Pass parity legislation through the Senate next year.*

Goal 3: *Have parity legislation become law in two years.*

Once your group has agreed upon the goals, your next step is to put together a plan to achieve those goals. The plan is essentially the roadmap of how you intend to accomplish your goals and how you will use your resources to do so.

WRITING YOUR PLAN

1) Establish goals, priorities and timelines. Timelines are critical. First, you must find out when your legislature is in session and plan your timeline around that schedule.

2) Conduct background research to determine if other medical mandate legislation has been introduced in your state. Did it pass or fail? By how many votes? The answers to these questions will provide you with guidance on your chances and how to write a roadmap to victory.

3) Conduct a targeting exercise that will help you identify your allies. This will be very important to determine how difficult it will be to pass legislation. Start by identifying similar bills and use them as a benchmark. Then categorize each voting legislator as either likely supportive, likely opposed, or unsure/undecided. Use this as a base to determine how many votes you will need to pass.

This will be the roadmap you use for lobby meetings and grassroots outreach discussed later in this toolkit. If you have a legislator already lined up as a key sponsor, the legislator's staff can help you with your targeting.

4) Determine if the best approach is through a legislative solution or to seek solutions through the state insurance commission or insurance companies. If the background work leads you to believe that you can't pass a parity bill through your legislature, you should explore other ways to accomplish your goal. In some states, you may have a better chance of success by working through the state insurance commission.

5) Determine what is needed to pass parity legislation in your state. In Colorado, the state required the groups to submit financial impact data for the bill to be considered. Other states may have similar or more requirements. If you've already identified a sponsor for your bill, the sponsor may be able to help with this. Coalition partners that have worked to pass similar legislation may also provide you with some of these answers. Use your resources!

6) Decide if your group needs to hire a lobbyist. Lobbyists can be quite expensive. An alternative is to make sure your coalition includes other medically related nonprofits with an interest in passing coverage legislation. For example, the American Diabetes Association has much experience in passing legislation at the state level. Their state lobbyist may be able to help you for little or no cost.

If you have enough money and decide to hire a lobbyist, consider the following factors:

- Identify someone who is experienced and knowledgeable of health insurance issues.
- Select someone with a proven track record of working well with both Republicans and Democrats.
- Ask for a list of clients to make sure they don't have a conflict of interest.
- Be careful not to select someone whose reputation is based largely on supporting mandates.
- It may even be helpful to select a former health insurance or business lobbyist, as they can understand and represent both sides of the issue.
- Check references and ask legislators that you already know. You want someone with a solid reputation. A good lobbyist will be more than happy to provide you with a client list.

7) Assess your resources and determine where you need to reach out for additional help. In order to pass your bill, you will need to build a grassroots base. This is covered in more detail in section 6, "Organizing a Grassroots Effort." It is important for you to consider this when writing your plan. People will be your number one resource. Determine where you can gain access to people who may have an interest in supporting your efforts. Here are a few places to start:

- The ACA can send e-mail alerts and make phone calls to the members in your state.
- Local and national O&P groups that are supporting your efforts might be willing to contact their patients.
- Other coalition partners might be willing to reach out to their membership lists to build support.

8) Put together a detailed budget and fundraising plan to meet that budget. Passing legislation can be done on a shoestring budget, but it's much more difficult. The more money you have, the more resources you can bring to help pass the bill. You will need to determine all your possible costs. These may include:

- Lobbyist fees
- Costs for printing and mailing (postage) materials
- Costs for volunteers (food, etc.)
- Phones and computers
- Travel costs to transport people to testify at hearings or meet with legislators.

Once you've determined how much money you will need to achieve your goal, you must figure out how to raise the money to meet your budget.

9) Develop a communications plan. The media is one of the most important tools you'll have in your arsenal. You can use the media to raise awareness about your efforts and to educate both the public and legislators. Importantly, you can also employ media efforts to show support for your bill and to lobby legislators. Many elected officials regularly read the editorials and "Letters to the Editor" section of their local papers to keep up with issues of concern in their area.

BUILDING YOUR COALITION

You cannot do this alone. Coalition outreach is critical to your success. Coalition partners can contribute additional resources to your group in the way of research, activists and volunteers, media outreach, and experience with the legislative process, and enhance your group's credibility by enlisting respected groups and individuals within your state.

On a national level, ACA has joined forces with providers and like-minded organizations. In many cases, state chapters of the national coalition partners can provide you with additional support. Compile a list of groups within your state that you should approach for support. Examples include:

- State chapters of potential partners, such as:
 - American Diabetes Association
 - American Cancer Society
 - American Physical Therapy Association
 - American Nurses Association
 - American Medical Association
 - American Orthotic & Prosthetic Association
 - American Academy of Orthotists and Prosthetists
- State-based O&P providers
- Veteran's groups
- Independent Living Centers
- Communities of faith working on healthcare access
- State coalitions or groups working on:
 - Disability rights
 - Healthcare access
 - Insurance reform.