

ADVOCACY CHECK LIST

ESSENTIAL HEALTH BENEFITS



Under the Affordable Care Act, all states must have an exchange by 2014, a marketplace where consumers can easily compare and buy health insurance plans.

Every plan in the exchange must cover “essential health benefits” (EHBs), but will these benefits include the full range of factor treatments? Will we have choice of pharmacy services?

This is now up to each state to decide, and through advocacy, you can make a difference in your state’s decision. Below is a checklist of nine straightforward steps you and/or your organization can take.

- 1. BECOME INFORMED
- 2. IDENTIFY YOUR PRINCIPLES AND PRIORITY INTERESTS WITH RESPECT TO EHBs
- 3. UNDERSTAND ANY COVERAGE MANDATES YOUR STATE HAS REGARDING BLEEDING DISORDERS
- 4. FIND OUT THE STATUS OF YOUR STATE’S EXCHANGE EFFORTS
- 5. ASSESS YOUR STATE’S POLITICAL LANDSCAPE WITH RESPECT TO THE EXCHANGE
- 6. BUILD RELATIONSHIPS CENTERED ON SHARED EHB INTERESTS AND CONSIDER COALITIONS
- 7. DEVELOP A BRIEF EHB POSITION STATEMENT
- 8. START WITH SMALL, FOCUSED ACTION
- 9. CELEBRATE AND SHARE

Let us know how HFA can help! Call or email us any time for individualized assistance on the issue of EHBs or on any other advocacy issue.

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1. BECOME INFORMED

Learn more about EHBs and the options your state has. For educational resources, visit our EHB webpage: <http://ehb.hemophiliafed.org>

2. IDENTIFY YOUR PRINCIPLES AND PRIORITY INTERESTS WITH RESPECT TO EHBs

What is motivating you and/or your organization to act? Examples of principles: Healthy families, Access, Fairness, Equality, Choice. Examples of interests:

- Our families are concerned they won't have access to their particular factor.
- Many in our community are poor. They should get the same benefits as others.
- We are in a rural area. It's already tough to get pharmacy services. Don't limit options.

Articulating your principles and knowing your interests will keep you focused, as well as help you develop talking points for your positions (see #7 below). In addition, shared principles and interests can serve as a foundation for strategic partnerships around the EHB issue.

3. UNDERSTAND ANY COVERAGE MANDATES YOUR STATE HAS REGARDING BLEEDING DISORDERS

The Affordable Care Act requires states to pay for their own mandates; however, if a state bases its EHB package on a benchmark plan already covering a mandate, then it does not have to pay for that coverage. Therefore, be sure to fully understand relevant mandates before your state begins debating EHB details.

Your state insurance and/or health department has more information. For contacts, visit Families USA's state page: <http://familiesusa.org/resources/state-information/> – Click "Government Links" for your state.

4. FIND OUT THE STATUS OF YOUR STATE'S EXCHANGE EFFORTS

So far, what has your state done (or not done) in developing the exchange? Possibilities:

- Enacted legislation or created rules on exchange governance and operations
- Is considering legislation or rules regarding the exchange
- Has received a federal grant related to the exchange
- In general, state leaders politically approve of the exchange, but they have not yet acted.
- In general, state leaders oppose the exchange. The federal government will likely run it.

For the status of your state's exchange, visit Kaiser Family Foundation's Exchange Monitor: <http://statehealthfacts.kff.org/comparemactable.jsp?ind=962&cat=17>

5. ASSESS YOUR STATE'S POLITICAL LANDSCAPE WITH RESPECT TO THE EXCHANGE

Identify who the state-level decision makers are on this issue. Consider:

- If your state has an exchange board, who are its members? Who appointed them?
- Who is sponsoring or co-sponsoring exchange bills before your legislature?
- Which state legislators serve on committees related to health and/or insurance?
- Who heads the state health department? Who is your state's insurance commissioner?

Your state administration's or legislature's website should help you identify these leaders. Visit <http://familiesusa.org/resources/state-information/>

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Identify other state-level political players on this issue. Consider:

- Who has spoken out on exchanges and EHBs? On health care reform in general?
- What are the largest insurance companies in your state? Business associations?
- What are the most active health advocacy organizations in your state?
- Which groups have issued press releases on this issue or on health care reform in general?
- What elections are coming up? Who are the candidates?

For assistance, visit HFA's Legislative Action Center – <http://hemophiliafed.org/what-we-do/advocacy/legislative-action-center/> – and see the resource tabs at the top.

Focus on state and local organizations; they will likely have the most influence over state legislators. Basic internet searches should yield results. Also, think about what's at stake in this issue for the above players.

6. BUILD RELATIONSHIPS CENTERED ON SHARED EHB INTERESTS, AND CONSIDER COALITIONS

You now have a list of decision makers and players regarding EHBs. Pick 3 whom you know fairly well but with whom you have not yet discussed EHBs. Reach out to listen and to learn their thoughts on this issue. You might even find yourself drawing on your own research (#1 above) and educating them about EHBs.

Also, consider working through existing coalitions in your state. Are there any that are already representing your EHB interests? Are there any that have the potential?

7. DEVELOP A BRIEF EHB POSITION STATEMENT

You are ready to craft a statement. Using your principles and interests as the base (# 2), referencing your state's mandates (if applicable, #3) and exchange status (#4), and benefitting from what you've learned from others (#6), write down the type of EHB package the bleeding disorders community needs in your state and why.

Your statement should consist of straightforward sentences that can also serve as individual talking points. Keep it to one page or less; it need not be detailed. In fact, the earlier it is in your state's EHB decision-making process, the better it might be for you to allow yourself some room for movement. For EHB talking points and sample statements specific to our community, visit <http://ehb.hemophiliafed.org>

8. START WITH SMALL, FOCUSED ACTION

It's time to take your views to more of the decision makers and players you listed – and to the public – but even the best advocacy groups have limits. So, start small and have specific, measurable goals such as:

- Meet with 3-4 key decision makers (for example, a legislator or exchange board member)
- Make your EHB talking points a part of your participation in a state Advocacy Day
- Attend a community meeting dealing with health care and bring up EHBs
- Generate 25 constituent emails on the EHB issue to 1-2 key decision makers

Remember, don't go it alone. Partner with other groups as much as possible. For more information, visit our Legislative Action Center: <http://hemophiliafed.org/what-we-do/advocacy/legislative-action-center/>

9. CELEBRATE AND SHARE

Policy victories do not happen overnight. Keep yourself and your allies positive and motivated by counting every step forward, no matter how small, a success. Talked with a state legislator about EHBs? Highlight it in your remarks at your next community meeting. Sent letters to the editor on the EHB issue? Post them on your website, whether or not the media took notice this time around.

KEEP MOVING – YOU ARE ON YOUR WAY!

HEMOPHILIA FEDERATION OF AMERICA

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