

Navigating the Web of Children's Advocacy Sites

by Deborah Hornstra, M.A.

Children's needs often straddle more than one system, so advocating on their behalf can involve dealing with not only the health care system, but quite possibly the educational system, the legal system, the custodial (foster care) system, and even the penal system. This makes advocating for children different from advocating for adults, and it can be hard to find the information you need to do the job, whether you find yourself advocating for a single child, many children or, on the policy level, all children in need.

If you are advocating for a child or children, here are some of the best places to start looking for information and advice. *Technical note:* Many of these sites post their research results and other publications in Adobe Acrobat (*.pdf) format, which is fast becoming the standard for such materials. To view these materials, you will need to download and install the free Acrobat Reader from Adobe at <http://www.adobe.com/prodindex/acrobat/readstep.html>. This format is fully searchable and prints out beautifully, just like the document in its paper incarnation.

Also, as a general rule, realize that most of these organizations offer the results of their research and other publications on the web *only in summary form*, and many charge a fee (often nominal) for hard copies of the full text reports, which you can often easily order through the web site itself.

Families USA

www.familiesusa.org

The premier Internet clearinghouse for children's issues. Go here first.

U.S. Bureau of the Census

www.census.gov

When it's data you're after, this is THE place for demographic statistics on the population of the United States. They've got it broken down (almost) every way you could possibly need. Bookmark your favorite tables so you can go there directly and not have to "drill down" many levels. I would even recommend

saving the tables you use most often to your hard drive or printing them out (and actually reading the stats off *real paper*), because this site deservedly gets LOTS of traffic.

The Urban Institute's Health Policy Center

<http://www.urban.org/centers/hpc.html>

A beautifully designed website, easy to navigate and filled with useful and relevant research.

National Health Law Program

<http://nhelp.org>

Abstracts of many useful documents, well organized.

National Governors' Association

<http://www.nga.org/>

See their 1998 *Annual Report on the State Children's Health Insurance Program (S-CHIP)*, published March 22, 1999.

Healthfinder's Children's Health Page

<http://www.healthfinder.gov/justforyou/children.htm>

Excellent DHHS-sponsored search "portal," or starting point. Go to the "children" category under "just for you." Each site listed was chosen for its utility and credibility by actual intelligent human beings, not robots or spiders.

Institute for Child Health Policy

<http://www.ichp.edu>

Examine their purchaser's tool, "Evaluating Managed Care Plans for Children with Special Health Care Needs," which is deliberately NOT copyright protected; its authors and sponsors (including the American Academy of Pediatrics, Family Voices, and the National Association of Children's Hospitals and Related Institutions) want people to use it and distribute it freely.

Electronic Policy Network

<http://www.epn.org/>

This is the brainchild of Paul Starr, Princeton professor and author of *The Social Transformation of American Medicine*. Tons of provocative essays and analyses and another very well organized web site to emulate, with my fa-

vorite site map on the whole web (it looks like a subway map!)

Duke Health Policy Cyberexchange

<http://www.hpolicy.duke.edu/cyberexchange/>

This is probably the single best place to start a search on any health policy-related topic. I met the webmaster in November at a meeting convened by the Institutes of Medicine, the purpose of which was to determine whether the IOM should set up a "health policy gateway" site on the web. It was basically decided that Duke had already done so with this site. You won't be disappointed.

Policy.com

<http://www.policy.com>

Check out the children's health section of their issues library for 25 pages of links to excellent resources.

David and Lucile Packard Foundation's The Future of Children

<http://www.futureofchildren.org/>

A great quarterly journal, worth checking out every issue if children's advocacy is your passion. Full text of each article is online in Adobe Acrobat (*.pdf) format — see above for how to get the free reader.

Medline

<http://www.nlm.nih.gov/databases/freemedl.html>

This is the way to access Medline for free if you're not affiliated with a university. You get access only to abstracts; most of the journals indexed will make you pay to access full-text articles, and some will even make you buy a subscription (this is usually cost-prohibitive — then you have to go to a good library!) From here you can search not only Medline proper, but also Aidsline, Bioethicsline, Popline, and Toxline, among others.

Children's Defense Fund

<http://www.childrensdefense.org/>

Excellent, well designed page filled with useful resources. Very topical reports and a great page of annotated links. Good site index and search engine add

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user-friendliness to this essential site.

Child Welfare League of America

<http://www.cwla.org/>

Not as useful as some sites because they don't even put up summaries of their excellent publications, though they do make it extra-easy to order them through the website. Check out the quick and current stats on their fact sheet *Children '99: Countdown to the Millennium*.

Google!

<http://www.google.com>

My new favorite search engine, Google! is the brainchild of two Stanford grad students. They use a completely different method for ranking web sites: unlike all other search mechanisms, they take into account the quantity and quality of all OTHER sites that link to any particular site. Therefore you tend to get the better pages near the top of your "hit list," rather than just the ones that have done a thorough job keywording and metatagging their site and submitting it aggressively to the other search engines.

Google! is not good for looking for a specific person's home page, because there probably aren't that many other pages out there linking to it, but it's very good for research, as it points you to sites deemed worthy by other deemed-worthy sites. If you need the other kind of search, try Hotbot at <http://www.hotbot.com>. They have the most web pages in their database and their robot is usually lightning-fast.

U.S. Department of Health and Human Services

Check out their *Profile of America's Youth* at <http://youth.os.dhhs.gov/youthinf.htm#profile>.

Other recent DHHS reports on children and youth are listed (and hot-linked) here: <http://youth.os.dhhs.gov/youthinf.htm#reports>.

Center on Budget and Policy Priorities

<http://www.cbpp.org/>

Excellent body of research. I especially recommend the recently published *Employed but Not Insured: A State-by-State Analysis of the Number of Low-Income Working Parents who Lack Health Insurance* (February 1999).

Kaiser Family Foundation

<http://www.kff.org>

Another beautifully designed site where it's very easy to find what you need. You can sign up for e-mail notification of new publications on just the topics that interest you, a great idea more sites are (and should be) offering. You can read all their surveys, click on a map of the US to get instant health facts about any state, or browse the web starting from their annotated link library on Reproductive and Children's issues, at <http://www.kff.org/links/linkrh.html>. Tons of resource material.

Annie E. Casey Foundation

<http://www.aecf.org>

Named in honor of the mother of the man who founded UPS, Jim Casey, Baltimore-based AECF, which is a major funder of children's health care initiatives, which is the entire mission of the organization. This is mainly interesting if you are looking for grant money and want to learn about the kinds of projects they fund.

Wisconsin Department of Health & Family Services

<http://www.dhfs.state.wi.us/>

A good example of how a state itself can put up a useful, comprehensive, and friendly web site.

The California HealthCare Foundation

<http://www.chcf.org/>

A fantastic website put together by a state-centered foundation. See the fascinating article from January 1999, *The Future of the Internet in Health Care*. To get access to some of the articles, you have to give them a California address. (I gave them the one I lived at 15 years ago, and it worked just fine....)

Voices for Illinois Children

<http://www.voices4kids.org>

Another good example of an advocacy site put up by a state-centered non-profit organization. Lots of Illinois-focused information, well organized.

The Commonwealth Fund

<http://www.cmwf.org>

Lots of good research, with a special focus on New York City.

National Data Archive on Child Abuse and Neglect

<http://www.ndacan.cornell.edu>

If your subject is child abuse and neglect, start here at this site, run by Cornell University. Also see the fact sheet on this subject from DHHS at <http://www.acf.dhhs.gov/programs/cb/ncanprob.htm>.

Bookmark the list of health advocacy links on our own HAP web site at <http://www.slc.edu/pages/h/health/halinks.htm>, which includes many organizations working in children's health advocacy. You can find another good list of links to child advocacy sites at <http://www.childadvocacy.org/imptxt.html>. Also bookmark the very comprehensive list of health advocacy organizations (including many which are not yet on the web), including phone numbers and URLs (web pages) if they exist, posted by Johns Hopkins at <http://infonet.welch.jhu.edu/advocacy.html>.

Health A-Z (<http://www.healthatoz.com>) is my favorite health-only search engine. When I'm doing serious research, I like to start where the pros start: the reference page of links on the *New York Times* site, which can be found at <http://www.nytimes.com/library/tech/reference/cynavi.html>. (They might make you register before they let you in, but it's free.) This has links to all kinds of sources of information and is in fact a good page to make your home page.

If you still can't find what you're looking for, send me an e-mail and I'll be happy to try to help!

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