

What Kind of Advocacy Do Americans with Disabilities Really Need?
An Open Letter to the Disability Rights Constituency
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Ever since Sarah Palin's acceptance speech, the "needs" of children with disabilities have gotten a lot of press. Palin pledged to be a "friend and advocate" for those children. News stories have reported the excitement of parents and other people in the disability rights constituency that disability issues are finally getting some attention. Some of them have decided to support the election of Palin and John McCain. But do the Republican candidates offer the kind of advocacy Americans with disabilities really need? I don't believe they do, and I want to explain why I am voting for Barack Obama and Joe Biden instead.

Before that, I should probably explain a bit about myself. I know what it is like to grow up as a child with a significant disability. And I've certainly known how hard it can be as an adult. I had polio as a boy. I've used a ventilator for many decades now and driven a power wheelchair for the last seven years. I have no use of my arms. I employ personal assistants to do housekeeping and aid me with basic personal needs. I struggled for years with oppressive bureaucracies and unfair public policies such as work disincentives. I recounted those battles in *Why I Burned My Book and Other Essays on Disability* (2003). Because of the disability rights movement and despite most government policies, I finally achieved my main goal and became a professor of American history at San Francisco State University. Because of what I've had to deal with, I also became a disability rights activist and a disability studies scholar.

Looking back, I can see how difficult it all was for my parents and what little support they got. It is understandable that parents of children with disabilities would

clutch at Sarah Palin's promise to be an "advocate." Many of them are increasingly desperate. Last month a University of North Carolina at Chapel Hill study documented the "chilling" rates of "hardship" among middle class as well as poor families with disabled children. They "are struggling to keep food on the table, a roof over their heads, and to pay for needed health and dental care."¹ Large numbers of adults with disabilities face the same economic hardships.

We've made a lot of progress in disability rights, but in some ways it's even harder financially for people with disabilities and their families than it was when I was a child, a youth, and a young adult. From both my personal experience and professional work, I understand what it's like for a lot of us. And I think I have some grasp on what sort of advocacy we need.

Would Palin provide that kind of advocacy? Would a President John McCain support the needs, interests, and rights of Americans with disabilities? What about Barack Obama and Joe Biden?

In their convention speeches, Palin, John, and even Cindy McCain focused only on children. The media have talked almost exclusively about children too. What so many people seem to forget is that children with disabilities grow up to become adults. Ninety percent of the 54 million Americans with disabilities are adults. Most acquired their disabilities after childhood.

In addition, the media talk has mostly been about "compassion" not about "issues." There has been little discussion about issues that matter to people with disabilities of all ages, issues such as health insurance, community-based personal assistance services, education, employment, and civil rights. Research has repeatedly

found that voters in the disability constituency---adults with disabilities, parents, and many professionals---decide how they will vote based on candidates' positions on disability issues. But they are often frustrated in trying to get that information.

In what follows, I summarize and critically examine the information I have gathered about the candidates' stands. I have gleaned it from online and printed sources as well as contacting some of the leading experts in the various communities that compose the disability rights constituency. Some of the information out there in the blogosphere is wrong. I've tried to get accurate and reliable information instead. Sometimes those experts I mentioned set me straight about things I had thought were true that they said were incorrect. It strikes me as significant that as far as I can tell the vast majority of those experts and other disability rights leaders are supporting the Obama-Biden ticket.

I want to make clear that I'm not speaking for that campaign. The analysis below represents my assessments, my conclusions, about the candidates' positions on issues. Here's what I've found out:

Obama and Biden have a set of detailed policy proposals called their "Plan to Empower Americans with Disabilities." You can find it on their campaign website.² In contrast, the McCain-Palin website's single page on "Americans with Disabilities for McCain" offers no policy positions.³ Elsewhere, that website mentions autism and disabled veterans but no other issues.⁴ (The Obama-Biden website also lays out policy proposals regarding both autism and disabled veterans.) So I've tried to glean McCain's and Palin's stands from their speeches, votes, and actions.

Here are some of the policy positions of the two pairs of candidates:

Medicare Obama co-sponsored legislation to end the two-year wait for recently disabled persons to qualify for Medicare after qualifying for Social Security Disability Insurance. This proposal is important because that waiting period is a time when many people with disabilities have no health insurance. McCain has not taken a position on that bill.

Mental Health Parity Obama also co-sponsored the Mental Health Parity Act. This legislation would prohibit health plans from requiring higher deductibles or co-pays while offering mental health benefits more limited than the medical coverage they provide. McCain has not taken position on that bill.

Health Insurance The McCain-Palin website seeks to refute the “myth” that under his healthcare plan, people “with pre-existing conditions would be denied insurance.” In fact, that is not the criticism being made. Rather, the criticism is that McCain’s healthcare plan would not *ban* insurance discrimination against individuals with disabilities and pre-existing health conditions.

As further refutation, the website points out that McCain supported the Health Insurance Portability and Accountability Act of 1996 which did provide “some protection against exclusion of pre-existing conditions.” In fact, that protection is both expensive and limited.

The website also declares that “nothing in John McCain’s plan changes the fact that if you are employed and insured you will build protection against the cost of any pre-existing condition.” This is a very complicated issue, but putting it as simply as possible this defense of McCain’s plan ignores the difficulties many people with disabilities and pre-existing conditions have in getting and maintaining both employment and insurance.

It also implicitly assumes that they have the financial resources to purchase insurance.

Finally, the website promises that “as President, John McCain would work with governors to find the solutions necessary to ensure those with pre-existing conditions are able to easily access care.” This language is a euphemism for the creation of high risk pools that have high premiums, high deductibles, time limited coverage, and often long waiting lists. Elsewhere, the website promises that McCain will “limit premiums” and provide assistance to families below a certain income level. But this market-driven approach has not worked in states that have established high risk pools.

By way of contrast, here is the comparable section of the Obama-Biden “Plan”:

“Guaranteeing Health Care Coverage: Many people with disabilities do not seek work or leave the workforce because they need the guaranteed health insurance that the federal government’s benefit programs provide. As a result, many stay on Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI), which include Medicare or Medicaid coverage, rather than take a job that might jeopardize their health care coverage. Barack Obama has pledged to sign universal health care legislation by the end of his first term in office that will assure that Americans with disabilities will have quality, affordable, portable coverage that will allow them to take a job without fear of losing coverage. People with disabilities who lose their Medicare or Medicaid eligibility by taking a job, but still cannot afford coverage, will be provided a subsidy in order to purchase coverage. Moreover, under Obama’s plan, insurers will not be able to deny coverage on the basis of pre-existing conditions.”

In addition, Obama co-sponsored legislation that would allow states to enroll families with incomes up to 300% of the poverty level in the State Children’s Health

Insurance Program (SCHIP). This policy is vital for families with children who have expensive disability-related healthcare needs, children like Sarah Palin's son. McCain and his fellow Republicans in the Senate opposed the bill. Gov. Palin, reported the *Wall Street Journal*, was "reluctant to support significant expansion" of Alaska's version of SCHIP, so she chose to accept families with incomes only "up to 175% of the poverty level." The *Journal* called Palin's policy "stingy compared with other states."⁵ Nor has she restored the state's mental health program that was essentially dismantled several years ago. Nor has she reduced the state's "Developmental Disabilities Waiting List, a list of individuals whose needs qualify them for assistance, but that the state doesn't have adequate funding to help."⁶ Or so the Alaska administration says. This at a time when the state government is awash in oil revenues.

Palin has "never elucidated a health care plan or vision or any kind of connection to the disability community," said Jim Beck, executive director of Access Alaska, an advocacy and independent living services agency for people with disabilities. "We're really suffering from not having a big plan."⁷ Palin has not made "health care one of her top priorities," reported the *Wall Street Journal*, but she does strongly support a "market- and business-driven" approach. Expanding health insurance "was less of an issue for Gov. Palin, much as it is less significant for Sen. McCain."⁸ Nonetheless, McCain too embraces the ideological dogma that profit-oriented businesses will resolve the inequities in the U.S. health insurance system and somehow cover those who are currently uninsured or underinsured. Among those Americans struggling the most desperately are people with disabilities and families.

Many adults with disabilities and parents of children with disabilities confront

another particularly harsh and unjust situation caused by public policies. Medicaid “long-term care” funding is skewed toward institutionalization or nursing home placement. But most of those adults and parents want people with disabilities of all ages to have the option to live in the community, with or near family and friends. Agreeing with them, Obama and Biden are co-sponsoring the Community Choice Act (CCA) to allow individuals to decide where they will live by funding community-based personal assistance services. McCain opposes the bill. He assumes it would cost too much.⁹ But studies have shown that community-based or independent living is almost always cheaper than institutionalization. It also ensures the self-determination prized by people with disabilities, including many people with Down syndrome. These competing policies will have a major impact on Palin’s son. Will she endorse CCA? Can she persuade her running mate to vote for it?

Education In 1975 after years of strenuous lobbying mostly by parents, Congress passed the Education for All Handicapped Children Act (since renamed the Individuals with Disabilities Education Act). Up until then, most such children were barred from public schools and got little or no education. Nowadays, most go to school and graduate. Congress promised to provide up to 40% of the funding for this mandate but has never done so. Obama and Biden favor full funding. McCain nowadays says he does too, though in past years he voted against it.

The Obama-Biden “Plan to Empower Americans with Disabilities” lays out a comprehensive policy agenda to enhance educational opportunities for young people with disabilities from early childhood through college. It also includes consideration of transition from school to work. It is too detailed for me to go into here, but if you are a

parent, professional, or person with a disability concerned about educational opportunities I would urge to go online and look at that portion of the “Plan.”

As far as I can tell, the McCain-Palin website’s several pages on education include nothing about the education of children and youths with disabilities.¹⁰ (I can’t be certain because, unlike the Obama-Biden website, the McCain-Palin website has no “Search” capability.)

Biden, an original cosponsor of the Individuals with Disabilities Education Act, has a long record of supporting the educational rights of children with disabilities and the civil rights of all Americans with disabilities. He came to his advocacy from personal knowledge of the prejudice youngsters with disabilities come up against. As a boy who stuttered severely, he experienced ridicule and abuse firsthand.

Some news outlets and blogs erroneously reported that as governor Sarah Palin slashed special education funding. Others are now incorrectly saying that she increased such funding 300%. The funding was indeed increased, but Palin only signed a bill developed by others. CNN reported that the bill’s actual co-sponsors felt “frustrated... by [her] stepping in only at the last minute.” Meanwhile, Sonya Kerr, an Anchorage attorney specializing in disability rights, sued the state and Palin for failing to provide adequate services for children with disabilities.¹¹

Palin also cut \$125,000 in funding for assistive technology for people with disabilities. According to Alaskan disability rights advocates, before her acceptance speech she showed little interest in disability issues. “I can tell you she wasn’t a champion for disabled children as governor,” said one State Senator.¹² It’s not that Palin only became aware of these matters after her son’s birth in April. Her sister’s son has

autism.¹³

Employment The Obama-Biden “Plan” to “increase the employment rate of workers with disabilities” encompasses several major innovations. Perhaps most notable, they pledge to implement Section 503 of the 1973 Rehabilitation Act. That provision requires all federal agencies and federal contractors to “take affirmative action to employ and advance in employment qualified individuals with disabilities.” Section 503’s affirmative action mandate has never been enforced. “Affirmative action in employment for adults with disabilities,” notes the “Plan,” “is not enforced with goals and timetables like the affirmative action requirements for people of color and women found in Executive Order No. 11246 and its progeny.” As president, Obama will direct the Secretary of Labor to bring the regulations implementing Section 503 more into line with that executive order. In other words, he recognizes disability as a civil rights category comparable to race and gender.

Just as important, Obama promises to establish a National Commission on People with Disabilities, Employment, and Social Security. He will charge this commission to undertake, at long last, the elimination of work disincentives in Social Security Disability Insurance, Supplemental Security Income, Medicare, and Medicaid policies.

In addition, Obama pledges to increase substantially federal hiring of workers with disabilities. He will also provide private-sector employers with resources to accommodate workers with disabilities and encourage them to use tax incentives to hire more workers with disabilities. Moreover, federal programs will provide support for small businesses owned by persons with disabilities. Finally, administration policies will assure “flexibility at work” to both workers with disabilities and nondisabled workers

who have responsibilities at home to provide assistance to family members with disability-related and healthcare needs.

In contrast to this comprehensive plan regarding employment, I can find no mention of employment and people with disabilities on the McCain-Palin website.

Civil Rights McCain and Biden voted for the Americans with Disabilities Act. They and Obama voted for the ADA Amendments Act. All three declare their support of anti-discrimination protections and guarantees of equal access and reasonable accommodations. But disability rights leaders point out that the Amendments Act is necessary because, contrary to Congress's intent, federal courts dominated by right-wing judicial activists decided that millions of Americans with disabilities---people with epilepsy, diabetes, mental health disabilities, HIV-AIDS, and other disabilities---do not match the ADA's definition of "disability" and therefore do not qualify for its protections. McCain and Palin pledge to appoint more judges like Scalia and Thomas, Roberts and Alito, the very jurists whose rulings have left 70% of Americans with disabilities without civil rights protections.

In contrast, Obama has declared that as president he will appoint "Judges and Justices who respect laws designed to protect people with disabilities [...]...The Supreme Court's interpretations of the ADA have shown disrespect for Congress' intent and frustrated the law's goals of fully integrating people with disabilities into society." "As a former civil rights lawyer and a strong advocate for workplace diversity, Barack Obama understands the critical importance of reducing workplace and labor market discrimination against people with disabilities...." Reversing the Bush administration's cutbacks in funding for the Equal Employment Opportunity Commission (EEOC) and the

Department of Labor's Office of Federal Contract Compliance Programs (OFCCP), "the agencies tasked with enforcing anti-discrimination laws that protect workers with disabilities," he pledges full funding and increased staffing to reduce the backlog of discrimination complaints and "prosecute efforts to remedy systemic discrimination."

McCain and Palin have made no comparable pledge. Indeed, with their philosophy of disengaged government they could not. Perhaps after a few years "experience" raising a child with a disability, Palin will see things differently. But people with disabilities have already waited an awfully long time for their civil rights and the vital services they need.

These are just some of the issues that concern the disability constituency. Disabled veterans' needs are a complex issue I am studying. I may write about it at a later date. Suffice it to say for now that Sen. McCain has apparently favorably talked about a voucher system, essentially a privatization of at least elements of the veterans' benefits system. This proposal is provoking deep concern among many veterans with disabilities.

The American Association of People with Disabilities estimates that there are some 36 million potential voters with disabilities. If we conservatively reckon that for every voter with a disability there is at least one nondisabled voter concerned about disability issues (a family member or professional), we are talking about a voting bloc comprising tens of millions of Americans. That voting constituency could determine the outcome of a close election. Yet despite all of the talk in the last couple of weeks about compassion toward children with disabilities, our issues still get only limited attention

from the news media and most politicians. I have concluded that Barack Obama and Joe Biden are paying attention. That's why I'm going to vote for them.

¹ "UNC study: 'chilling' hardship rates among families raising disabled children," August 18, 2008, <http://uncnews.unc.edu/news/health-and-medicine/unc-study-chilling-hardship-rates-among-families-raising-disabled-children.html>.

² <http://www.barackobama.com/issues/disabilities>.

³ <http://americanswithdisabilities.johnmccain.com/AmericansWithDisabilities.htm>.

⁴ <http://www.johnmccain.com/Informing/Issues>.

⁵ Jim Carlton, Michael M. Phillips, Elizabeth Williamson and Laura Meckler, "In Alaska, a Nuanced Record," *Wall Street Journal*, (September 4, 2008), A1.

⁶ Brendan Joel Kelley, "Sarah and the kids," *Anchorage Press*, (September 11, 2008), <http://www.anchoragepress.com/site/basicarticle.asp?ID=831>.

⁷ Kelley, "Sarah and the kids."

⁸ Carlton, et al., "In Alaska, a Nuanced Record."

⁹ National Forum on Disability Issues, Columbus, Ohio, July 26, 2008, <http://www.aapd.com/News/election/080726forumtrans.htm>.

¹⁰ See also the Council for Exceptional Children's Voter Education Guide, Election 2008, Meet the 2008 Candidates, available at <http://www.cec.sped.org/AM/Template.cfm?Section=Home&TEMPLATE=/CM/ContentDisplay.cfm&CONTENTID=10557>.

¹¹ CNN, "Biden's comments on special needs kids called 'new low'," September 10, 2008, <http://www.cnn.com/2008/POLITICS/09/09/biden.special.needs/index.html#cnnSTCText>

¹² Kelley, "Sarah and the kids."

¹³ CNN, "Biden's comments."