

University of Massachusetts Medical School

Community Health Clerkship
Health Advocacy

**CHILDREN LIVING WITH MULTIPLE DISABILITIES AT THE
 MASSACHUSETTS HOSPITAL SCHOOL FOR CHILDREN (MHS)**

Advocacy Organizations	
What are some Local organizations that do advocacy work?	United Cerebral Palsy (UCP) of MetroBoston, located in Watertown Disability Law Center (DLC), Boston branch
What are some State level organizations that do advocacy work?	Cerebral Palsy of Massachusetts (CPMA), located in Quincy Programs for Children with Special Health Care Needs—a division of the Department of Public Health, located in Boston
What are some National level organizations that do advocacy work?	United Cerebral Palsy Associations (UCPA), based in Washington, DC National Dissemination Center for Children with Disabilities (NICHCY), based in Washington, DC
What are some International organizations that do advocacy work?	International Cerebral Palsy Association (ICPA), based in British Columbia, Canada Cerebral Palsy Association, based in Sydney, Australia
Advocacy Issue	
Looking at the State, National, and/or International level, at the websites or information from the organizations above, what is a major area of advocacy at this time? <i>Try to choose an advocacy issue that will in some way affect the local community.</i> Advocacy specifically refers to promoting legislation, policies or specific budgetary appropriations that positively affect a health issue. This may occur through decreasing barriers to accessing health services, providing an infrastructure conducive to effective health promotion programs, or directly increasing the resources and infrastructure of the public health system.	Boston Center for Independent Living (BCIL) is looking at a number of accessibility issues that are prevalent in Boston’s many healthcare facilities: improper transfers onto examination tables, denied use of accessible inpatient rooms, architectural barriers within the facilities, and poor overall quality of care.
What specific law, policy or appropriation is being advocated for?	
Who is doing the advocating? (Which organizations?)	Boston Center for Independent Living (BCIL), in collaboration with Greater Boston Legal Services
Who is being lobbied?	At present, BCIL is advocating this issue on a grass-roots level and gathering information from individuals with disabilities who have experienced such issues personally. As such, no litigious action or lobbying has yet to actively begin. However, BCIL and Greater Boston Legal Services have a storied history

	together: they won a class action lawsuit against the Massachusetts Bay Transportation Authority in April of 2006. This resulted in MBTA placing a total monetary value of \$310 million on the planned cost of improving accessibility of public transport for those with disabilities. As such, we are very optimistic that their advocacy efforts, this time on behalf of improved accessibility to healthcare, will be successful.
Whom will this issue affect?	People with disabilities, including those with Cerebral Palsy.
Were they or will they (in your opinion) be successful?	Yes
Why or why not? What do they need to be more successful?	If BCIL is again successful in its advocacy endeavors, many individuals with disabilities throughout the state of Massachusetts could benefit from increased accessibility to healthcare.
What are the consequences if they are not successful?	If these advocacy efforts fall short, however, those individuals would continue to live with the very real consequences of not receiving proper care. For many people living with CP, frustration and embarrassment are often an expected result of visiting their healthcare facility, and many are hesitant to seek the care they need. And those who do seek care often find it to be inadequate.
If they are not successful, what other strategies can be used to achieve the same goal?	If BCIL fails to achieve legislative action against those hospitals and practices that fail to accommodate their disabled patients, the fight should not simply disappear. Other organizations, both on the state and national level, should take up the cause and lobby legislators to instate high standards for healthcare practices that require improved accessibilities for those with disabilities.
How can physicians and/or nurses be involved in this advocacy issue?	Individual physicians and nurses should step forth in support of the cause, and be cognizant of their surroundings in order to make their services as accommodating to those living with disabilities as possible.

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