

Amplifying Your Voice

Four case studies examining the impact of social media and online grassroots activism in effecting change in individual cases and public policy on disability rights issues

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INTRODUCTION

On 26 October 2011, a special education teacher in Hamilton, Alabama physically restrained a fourteen year old non-speaking Autistic student for fifty-five minutes, prompting the girl, Emily Holcomb, to hit and push the teacher in self-defense in an attempt to escape being forcibly held down.

Barely a month later, in the first week of December, had sheriff's deputies appeared at the Holcomb household to serve papers to Emily charging her with first degree assault—a felony charge. The family reported that this came shortly after the school had already reached an agreement to provide the full cost of funding an autism specialist for Emily amid speculation that the filing of the criminal charge was an attempt to avoid responsibility for paying for this specialist by diverting Emily from the public education system to the juvenile justice system.¹

After this was reported in the local news outlet, Emily's mother, Jenny, contacted an Autistic who'd left her contact information in a comment on the original news article online.² They subsequently coauthored a petition addressed to the board of education demanding redress for the use of unnecessary physical restraint as well as the choice to file charges.

The petition, which was published on Change.org and publicized across Facebook, gained close to 1,200 signatures in roughly a week, while garnering significant attention to Emily's plight from the autism blogosphere, particularly among Autistic-run sites such as Aspies for Freedom³ and ThAutcast^{4,5}. Emily's case also became the primary subject of a user-created group on Facebook called "Support Justice for Emily Holcomb, 14 Autistic Student Charged with Felony Assault," which later relocated content and members to the more general user-run page on Facebook called "Stand Against Restraint, Seclusion, and Bullying by Teachers."

¹ Harper, I. (2011, December 7). School accuses 14-year old non-verbal autistic girl of felony assault. ABC 33/40. Retrieved from <http://www.abc3340.com/story/16203555/school-accuses-14-year-old-non-verbal-autistic-girl-of-felony-assault>

² Ibid.

³ Aspies for Freedom. (2011, December 10). Nonverbal autistic girl defends self against teacher, gets criminal charges. Retrieved from <http://www.aspiesforfreedom.com/showthread.php?tid=23640>

⁴ Bryce, L. (2011, December 9). School files felony assault charges against nonverbal autistic girl. Retrieved from <http://thautcast.com/drupal5/content/school-files-felony-assault-charges-against-nonverbal-autistic-girl>

⁵ Bryce, L. (2011, December 12). Charges against autistic girl dropped; please sign petition to help Emily Holcomb. Retrieved from <http://thautcast.com/drupal5/content/charges-against-autistic-girl-dropped-please-sign-petition-help-emily-holcomb>

Within seven days, not only were charges dropped, but Jenny reported a successful outcome from a scheduled mediation meeting with school officials, in which they rescinded the demand for residential or institutionalized placement in favor of an inclusive option.⁶

The family's lawyer, James Gallini, who also has an Autistic child and specializes in special education law, cited the influence of the petition in driving the school officials' decision during mediation, saying that it played a significant role.⁷

Though Emily's case merited very little attention from the mainstream media, and none from the national media at the time that it occurred⁸, it provides an excellent example of the possibilities for social media in augmenting traditional activist and advocate strategies.

USING SOCIAL MEDIA

What is social media?

Social media are technologies and platforms intended to transform communications into ongoing, interactive dialogue among participants with particular focus on user-generated content. Of the six major categories of social media, applications and platforms can range from virtual realities or games to social networking sites, content-based sites, collaborative media, and blogs and microblogs.⁹ The common denominator among these types of social media is their reliance and emphasis on user-generated innovation and interactions among users rather than untouchable, inaccessible industrial or commercial media forms, such as traditional news media or filmmakers, which are primarily controlled by producers rather than consumers.

Social media is based around internet and mobile applications, with significant overlap between the two. Some examples of popular social media applications and platforms, many of which are directly or indirectly relevant to the topic of this paper, include Blogger, LiveJournal, YouTube, Facebook, Tumblr, Twitter, Google Plus, LinkedIn, WordPress, IndieGoGo, StumbleUpon, Reddit, and Foursquare.

Social media have become ubiquitous enough to merit regular references and stories in the mainstream media as well as examinations by prospective employers when probing candidates' backgrounds. No longer the exclusive domain of in-vogue youth or geeky adults, social media have become all-pervasive in the twenty-first century, interacting with and reflecting every facet of life, society, and culture. We live in an age obsessed with information, and social media provide the perfect avenue to access, create, share, and disseminate information across the broadest possible spectrum of audiences and communities.

⁶ Holcomb, J. P. (2012, December 19). Personal communication, phone.

⁷ Gallini, J. (2012, January 27). Personal communication, electronic message.

⁸ Emily's case was discussed in a March NPR broadcast, which can be cited as follows: *Petitions are going viral, sometimes to great success.* (2012, March 16). Morning Edition. [Radio News Program]. Retrieved from <http://www.npr.org/2012/03/16/148556371/petitions-are-going-viral-sometimes-to-great-success>

⁹ Kaplan, A. M., & Haenlein, M. (2010). Users of the world, unite! The challenges and opportunities of social media. *Business Horizons*, 53(1), 59–68.

Who uses social media?

Increasing numbers of people, organizations, and communities have taken to using social media to create and share content, facilitate conversations, and explore new interests or areas of curiosity. Youth and adults have been among the largest consumers of social media, though children are increasingly a part of the social media community. Autistics, other disabled people or people with disabilities, and allies of the disability rights community are frequently joined in social media usage by nondisabled and disabled parents, professionals, service providers, researchers, teachers and other education professionals, legislators, government officials, political organizations, corporations and businesses, nonprofit organizations, civic groups, religious groups, academic institutions and research centers, and special interest organizations.

The two major categories of entities that use social media are individuals and organizations. Most businesses today have a website, and those that are technologically savvy or attuned to the interests and activities of customers and clients frequently have pages or accounts on social media websites, especially blogs, social networking sites, and content-based sites. Politicians, whether elected or appointed officials, are also increasingly likely to have a presence on social media where they can easily disseminate information and interact with constituents and community stakeholders. Nonprofit organizations have joined this trend, with many nonprofits owning accounts on sites like Facebook and Twitter.^{10,11} Academic institutions and research centers are only beginning to recognize the potential benefits of establishing a presence on social media.¹²

Among individuals, the reasons for using social media may vary, but many people nowadays have more than one profile or account on social media platforms because different social media platforms perform different functions. The networking functionality of many social media applications has also improved significantly, allowing users on different platforms to easily link accounts to cross-share content and identify connected profiles for other users to follow their postings across multiple platforms.

While organizations are more likely to use social media as a means of self-promotion and consumer, client, or stakeholder engagement, individuals may use social media for a number of purposes, including but not limited to, showcasing artistic creativity, establishing social connections with friends or family, sharing articles or information on particular topics, or disseminating a professional profile for use in a job search.

¹⁰ For example, the Autistic Self Advocacy Network (ASAN) can be found on YouTube at <http://www.youtube.com/autselfadvocacyntwk>, Twitter as @autselfadvocacy, and Facebook at <https://www.facebook.com/AutisticAdvocacy>. ASAN also maintains a presence on Flickr and Google Plus.

¹¹ Obar, J. A., Zube, P., & Lampe, C. (2012). Advocacy 2.0: An analysis of how advocacy groups in the United States perceive and use social media as tools for facilitating civic engagement and collective action. *Journal of Information Policy*, 2, 1-25.

¹² The National Collaborative on Workforce and Disability for Youth (NCWD/Youth) began to increase its presence on both Facebook (<https://www.facebook.com/NCWDforYouth>) and Twitter (@ncwdyouth_iel) in 2012, while the Georgetown University Center for Child and Human Development (GUCCHD) has only begun to create and maintain a presence on Facebook.

What are the benefits of social media?

Activists and advocates, corporations and businesses, special interest groups and research centers, and political institutions and government officials can all use social media to gain a larger audience for a cause or topic, build a larger returning audience, make a plethora of connections with individuals and organizations that have similar interests, create content accessible in multiple formats and at a user's convenience, disseminate materials more widely and for lower cost and more minimized effort than traditional paper-mailings, and especially target the enormous youth population with a presence on social media.

Social media provide an excellent means of creating, developing, and maintaining networks of people with loose or no ties to one another. Social media facilitate the ability to rapidly access, share, and disseminate information with friends and family, colleagues, acquaintances, and strangers with an interest in particular topics or causes in ways that were not possible before the advent of the internet. With the advent of web and mobile-based technologies to generate and share content, users can access information from nearly anywhere and nearly anytime.

What can you do with social media?

Social media have facilitated the ability of individuals to share their and others' pictures, videos, articles and essays; give constant, real-time updates about their activities, thoughts, or ideas; promote their own work, the work of friends, and the work of those whom they admire; publicize meetings, social activities, events related to particular causes or communities, and other gatherings; follow the professional and personal activities of family, friends, colleagues, and acquaintances; and draw attention to specific publications, reports, and guides around topics of professional, academic, and personal interest.

Depending on the specific application or platform, users may be encouraged to upload and share documents such as a resume or curriculum vitae, published papers or articles, or other writing samples (such as on LinkedIn or Academia.edu); creative content such as self-produced films or music (such as on YouTube, Flickr, or DeviantArt); or regular posts around personal or professional activities or interests (such as on LiveJournal, Blogger, or WordPress). Particularly with regard to social networking platforms, users of social media are frequently encouraged to share personal information about themselves, including biodata and personal interests, to facilitate forming connections with other users who share similar backgrounds or interests. The "user profile" of web-based discussion forums has become ubiquitous to any website or community in which users create and maintain accounts.

In collaborative projects such as Wikipedia or other Wiki-enabled sites and communities¹³, users are encouraged to collectively produce and maintain content for use or reference either internally or externally to a broader audience. Communities such as RolePlayGateway, which is a web-based community with over 45,000 total members and around two thousand members who are active on a monthly basis,¹⁴ foster collaborative writing and other creative activities with an emphasis on collaborative production over individually-produced content, and may facilitate

¹³ These can be user-created around specific topics of special interest, or even as resources for specific projects.

¹⁴ Martindale, E. (2011, November 22). Personal communication.

interactions among people with specific shared interests that represent a small segment of the general population. Such online communities formed around specific or special interest areas provide excellent forum space for discussion, debate, and news around their topic areas, and may draw discussion about unrelated topics depending on the other interests of members.

Anecdotally, web-based communities like RolePlayGateway and social networking sites like Facebook have facilitated and fostered the development of many close friendships and romantic relationships between users who first became acquainted online.¹⁵ A similar practice exists in a more professional form through platforms such as LinkedIn and Academia.edu, which encourage networking among people with shared, similar, or related professional or academic interests who may not otherwise have had opportunities for interaction or communication.

What can social media do for activism?

Fifty years ago, activism in the public sphere was strongly identified with activities such as public marches and rallies in main city streets, sit-ins in protest of unjust and discriminatory practices, and demonstrations demanding change at and inside government buildings—activist actions that were frequently dangerous with immediate risk of harm to life, liberty, health, or property because they overtly and directly challenged the direct power status quo maintained through systemically embedded injustices and prejudices across policy and practice. The protest culture sunk its roots onto college campuses across America, energizing and uniting youth activists throughout the sixties and seventies in protests of everything from inaccessible buildings to the Vietnam War.

Today, it is possible to do nearly everything online that once had to be done in person, whether shopping for groceries, looking at apartments for rent, speaking to friends, job searching, or even reading books. Like all else, activism too has begun to move online, migrating into the realm of cyberspace where it has even earned the snide nicknames “slacktivism” and “clicktivism” as a criticism of the perceived attitudes of political passivity encouraged by a commercialization of social justice causes overtaking a genuine commitment to activism against injustices.^{16,17,18} The criticism is particularly potent because of those who compare activism that carried real risks of danger to participants to activism that carries very little risk of danger to life, liberty, health, property, *or* reputation, and may in fact serve to do little else for an individual other than bolstering his or her reputation among friends for supporting a cause perceived as worthwhile.

Responses to these criticisms, however, point to cases such as the use of social media to facilitate the mass mobilization of individuals against the SOPA and PIPA legislation, which threatened free speech, in early 2012, the Susan G. Komen Foundation’s withdrawal of funding for Planned

¹⁵ The author knows of several romantic relationships, engagements, and marriages that began after the partners met online, including many from web-based communities like RolePlayGateway and social networks like Facebook.

¹⁶ White, M. (2010, August 12). Clicktivism is ruining leftist activism. *The Guardian*. Retrieved from <http://www.guardian.co.uk/commentisfree/2010/aug/12/clicktivism-ruining-leftist-activism>

¹⁷ Morozov, E. (2009, May 18). The brave new work of slacktivism. *Foreign Policy*. Retrieved from http://neteffect.foreignpolicy.com/posts/2009/05/19/the_brave_new_world_of_slacktivism

¹⁸ Gladwell, M. (2010, October 4). Small change: Why the revolution will not be tweeted. *The New Yorker*. Retrieved from http://www.newyorker.com/reporting/2010/10/04/101004fa_fact_gladwell?currentPage=all

Parenthood, and the Motion Picture Association’s decision to give the documentary *Bully* an R rating¹⁹, all of which resulted in material changes according to the demands of online activists.²⁰

A 2011 Georgetown Center for Social Impact Communications study that collected data on the interaction between the digital revolution and cause involvement showed that those who engage in online activism or support for a cause are equally likely to donate money to a cause and twice as likely to volunteer time for a cause than those who are not engaged in cause promotion over social media, suggesting that the negative reputation often attributed to online-based activism is unfounded and unfair.²¹ The authors of a 2012 study (Obar, J. A., et al., 2012) further argue that social media directly enables more traditional organizers and activists to accomplish advocacy goals by facilitating and encouraging “various forms of political communication.” The same study describes three significant benefits that social media can have for advocacy groups—strengthening outreach efforts by disseminating group messages and facilitating organization growth, engaging feedback loops by providing multiple levels of interaction and engagement between individuals and an organization, and strengthening “collective action efforts through an increased speed of communication.”²²

In order to promote civic engagement and collective action, individual activists and advocacy organizations can use social media to draw attention to particular causes and campaigns, highlight seminal writings relevant to the organization or individual’s goals or platform, disseminate action alerts about specific campaigns and action items, mobilize the “silent majority” who might otherwise lack motivation or willpower to engage in any supportive action, create and expand networks with other individuals and organizations that share interests or goals, target an increasingly connected youth population, and connect to organizations formed around similar interests or principle statements. Most importantly, however, social media can be used to mobilize online supporters and followers to commit to engagement in offline action, such as letter or phone campaigns, protests or rallies, monetary donations, organization-sponsored events, or giving testimony at public hearings or other forms of public comments to government.

How do you create and develop a network?

When creating, sharing, or promoting content, it is imperative to strategically consider the use and impact of keywords and tags, search engine optimization, identifying relevant people and organizations, frequency of posting or sharing, interaction with and on pages belonging to other individuals or organizations, responses to comments and content shared by other individuals or

¹⁹ One of the bullying victims in *Bully* who took his own life, Tyler Long, was Autistic. The filmmakers chose to entirely omit this fact from the documentary for fear it would increase stigma, which has been criticized as hypocritical and dangerous because diversity education about LGBTQ youth, who are featured in the film extensively, can reduce bullying because of a youth’s sexual orientation; likewise it is wrong to tell Tyler’s story without explaining why he was bullied.

²⁰ Carr, D. (2012, March 25). Hashtag activism, and its limits. *The New York Times*. Retrieved from http://www.nytimes.com/2012/03/26/business/media/hashtag-activism-and-its-limits.html?_r=1

²¹ Keyes, D., Dixon, J., Weyler, A., Buchy, J., Arnold, D., Wayman, J., Temple, S., Friedman, K., Patterson, J., D’Agostini, H., Liang, A., & Gusikoff, J. (2011, November). Dynamics of cause engagement: Understanding the impact of the digital revolution on cause involvement: Exploring the connection between cause engagement and behavior change. Washington DC: Ogilvy Public Relations and Georgetown Center for Social Impact Communications.

²² Obar, J. A., Zube, P., & Lampe, C. (2012).

organizations, and generative (self-produced or created) versus reactive content. Use of hashtags on sites like Twitter can easily draw users who may be interested in particular topics related to your content or goals,²³ while tagging the public or personal pages of individuals or organizations with relevant interests or goals on Facebook can increase the amount of attention that your content will receive, as well as the likelihood that it will in turn be shared again by those individuals or organizations, or by individuals or organizations with connections to them.

Images and other types of visual or graphic content can both draw and retain viewers by grounding text-based content with a dose of reality—or artistry, depending on your preference. More important, however, is directly connecting with other individuals and organizations and actively promoting their content and work. Regularly promoting the work and content of others serves to offset perceptions of narcissism or shameless self-promotion created by regularly promoting one’s own content and work in addition to casting a wider net for establishing more connections with other individuals and organizations whose interests may be similar or tangentially relevant to yours through their interactions with content that you share and promote. This in turn can increase web traffic to your own materials or site, which can draw further attention to specific causes or campaigns.

CASE STUDY: MIA RIVERA

On 12 January 2012, Chrissy Rivera wrote a blog post entitled “Brick Walls”²⁴ for the website wolfhirschhorn.org, a web-based community dedicated to parents of children with Wolf-Hirschhorn Syndrome, about a conversation she and her husband had had only two days earlier with a physician and a social worker at Children’s Hospital of Philadelphia (CHOP) about their daughter, Amelia, who has Wolf-Hirschhorn Syndrome.

Amelia, affectionately known as Mia, had her regular nephrology appointment because she needed a kidney transplant. After the doctor came to the examination room to speak with the parents, he told them that Mia was ineligible to receive a kidney transplant solely on the basis of her intellectual disability, which is one component of Wolf-Hirschhorn Syndrome. The doctor explicitly stated that there was no other medical reason to deny eligibility for a transplant, and both he and a social worker in attendance attempted to convince the Riveras that Mia’s “mental delays” would inhibit her quality of life because she is “mentally retarded.”²⁵ The family even explained that they had identified a relative who was a match for a transplant and who



had agreed to provide the kidney, but the doctor insisted that he would not recommend Mia for receipt of a kidney because of her intellectual disability.

²³ For those who may not be as familiar with Twitter functionality, some examples of hashtags related to disability include the following: #disability, #ableism, #crip, #actuallyautistic, #palsy, #adhd, #specialied, and #disabilityrights.

²⁴ Rivera, C. (2012, January 12). Brick walls. [Wolfhirschhorn.org](http://wolfhirschhorn.org). Retrieved from <http://wolfhirschhorn.org/2012/01/amelia/brick-walls/>

²⁵ Ibid.

Within a period of only twenty-four hours, the site administrators reported an unprecedented traffic influx of over 62,000 visitors to that one article alone.²⁶ (Their average number of site views prior to “Brick Walls” was 165 visits per day.)²⁷ Over the next few days, another 250,000 visitors had read “Brick Walls.”²⁸ The Riveras’ article was directly linked in over 500 places within the seven days immediately after it was posted.²⁹ Site owner Kevin O’Brien stated that 91% of referrals to “Brick Walls” in the first twenty-four hours were from Facebook.³⁰

The CHOP Facebook page was inundated with comments posted in support of Mia and her family, resulting in the issuance of a perfunctory statement from hospital officials claiming no knowledge of the incident and no discriminatory policy against the disabled with regard to transplant eligibility.

Sunday Stilwell, the mother of two Autistic sons who blogs at Extreme Parenthood, wrote a petition via Change.org directed to the directors and administrators at CHOP requesting immediate reconsideration of the physician’s decision in Mia’s case as well as the implementation of an explicit nondiscriminatory policy in regards to disability.³¹ Petitions created via the platform Change.org will generate a unique email containing the text of the petition letter for each virtual signature and send those emails to designated targets of the petition if their email addresses are provided by the petition author.³² Within 24 hours, the petition had over 10,000 signatures. In 72 hours, it had gathered over 20,000 signatures, and over the next 27 days, there were over 40,000 total signatures.³³

An early June 2012 web search using keywords related to Mia’s case through Google found the following numbers in search results:

- 155,000 Google blog search results for “Mia Rivera transplant”
- 170,000 Blogspot.com-hosted only results for “Mia Rivera transplant”
- 526,000 total Google results for “Mia Rivera transplant”
- 2,390 Twitter results for “Amelia Rivera transplant”
- 7,690 Twitter results “Mia Rivera transplant”
- 5,110 Tumblr results “Mia Rivera transplant”
- 2,690 Tumblr results “Amelia Rivera transplant”

²⁶ O’Brien, K. (2012, January 30). A life changing event... for a greater population. Wolfhirschhorn.org. Retrieved from <http://wolfhirschhorn.org/2012/01/amelia/a-life-changing-event-for-a-greater-population/>

²⁷ Ibid.

²⁸ Ibid.

²⁹ Ibid.

³⁰ Ibid.

³¹ Stilwell, S. (2012, January 14). Children’s Hospital of Philadelphia: Allow the kidney transplant Amelia Rivera needs to survive. Change.org. Retrieved from <http://www.change.org/petitions/director-of-public-relations-allow-the-kidney-transplant-amelia-rivera-needs-to-survive>

³² Change.org. (n.d.). Start your online petition: Create an online petition in three easy steps. Retrieved from <http://www.change.org/guides/start-your-online-petition>

³³ These numbers are from the petition’s updates page.

Nearly every major news media outlet, including ABC, USA Today, and CNN, covered Mia's story, and wolfhirschhorn.org reported over forty interview requests for Chrissy within days of the publication of "Brick Walls."³⁴ Only seventeen days after "Brick Walls" had been published on wolfhirschhorn.org, CHOP issued another statement cross-posted to their Facebook page in which they announced that they would be meeting with the Riveras again regarding Mia's eligibility to receive a kidney transplant. On 15 February 2012, the family issued a joint press release with CHOP stating that no eligibility decision had been made, and that final determination comes after a comprehensive evaluation over multiple visits.³⁵

After Chrissy Rivera's viral blog post, and Sunday Stilwell's petition, Mia's case gained national attention far beyond the expectations of long-time wolfhirschhorn.org community members. The case gained extensive exposure throughout the disability community, where the doctor's comments as related by Chrissy stoked significant indignation and outrage over the blatant ableism. Disability rights advocates, particularly those with developmental and intellectual disabilities, held a personal stake in Mia's case—if her right to live could be abrogated on the basis of her intellectual disability, the rights of all disabled people to be recognized as human and worthy of life would be not only endangered but directly targeted for revocation. Disabled activists and advocates found themselves aligned with non-disabled parents and family members as well as medical and service professionals as Mia's story spread throughout special interest and mainstream web-based communities and social networking sites.

The factors most important in the ultimate success in Mia's case were the broad appeal of one individual's personal story, that strange alliance among stakeholders who are frequently at odds within and among themselves, and the spontaneous mobilization of hundreds of thousands of people to share Mia's story, sign the petition, contact CHOP directly, and express support for the Riveras. The power of an individual's personal story to grip someone's attention cannot be underestimated. Statistics and figures tell a dry tale; personal stories and experiences speak to people and can elicit happiness, rage, or sorrow, as appropriate.

CASE STUDY: CHRIS BAKER



On 14 December 2012, nine year old Autistic student Christopher Baker of Louisville, Kentucky, was instructed to climb inside an Abilitations BagOBalls, which is intended to be used for sensory integration therapy, as a punishment for disobedience and refusal to do work in class at his Harrodsburg school.³⁶ The teacher's aide closed the drawstring so that he was unable to escape from the bag, and placed him in the hallway. The school called Chris's mother, Sandra Baker, to ask her to take Chris home. When she arrived, she saw a wriggling mass inside the bag, which she said

³⁴ O'Brien, K. (2012).

³⁵ Apkon, M., Rivera, J., & Rivera, C. (2012, February 15). Joint statement of the Rivera family and The Children's Hospital of Philadelphia. Retrieved from http://www.philly.com/philly/blogs/what_happened/Transplant-Family-and-CHOP-Release-a-Joint-Statement.html

³⁶ Hoff, J. (2011, December 16). Mercer Co. mother upset over son's punishment. Lex18. Retrieved from <http://www.lex18.com/news/mercer-co-mother-upset-over-son-s-punishment>

looked like a duffel bag of some sort. Sandra demanded that Chris be removed from the bag immediately, and observed that he appeared to be extremely agitated—not the way one would appear or behave after genuinely beneficial and calming sensory integration therapy—only to learn that this was not the first time that he had been placed inside a tool intended for therapeutic purposes as a punishment and disciplinary measure.³⁷

Five days after the story broke, Sandra collaborated with the same Autistic advocate who had worked with Emily Holcomb's mother to write a similar petition via Change.org, this time directed to the Mercer County Board of Education and requesting four actions both in response to the incident and to prevent future, similar incidents³⁸:

1) That the teacher(s) responsible for confining and restraining Christopher Baker inside the Abilitations BagOBalls bag be dismissed from position for abusing a vulnerable person (a person with a disability) OR be required to successfully complete extensive continuing education professional training in interacting with and educating Autistic students and students with other disabilities, not to be fewer than at least the equivalent of a semester-long graduate level course developed using existing standards and best practices in model state systems, and which shall specifically include techniques for appropriate de-escalation and crisis intervention;

2) That all current and future special education teachers, including aides or educational assistants, in Mercer County be required to successfully complete extensive continuing education professional training in interacting with and educating Autistic students and students with other disabilities, not to be fewer than at least the equivalent of a semester-long graduate level course developed using existing standards and best practices in model state systems, and which shall specifically include techniques for appropriate de-escalation and crisis intervention;

3) That all current and future non-special education teachers, including aides or educational assistants, in Mercer County be required to successfully complete basic continuing education professional training in interacting with and educating Autistic students and students with other disabilities, not to be fewer than at least eight classroom hours of instruction developed using existing standards and best practices in model state systems; and

4) That use of any type of restraint or seclusion on any student be explicitly prohibited except in brief, temporary, and emergency interventions when there is imminent and immediate threat of harm to self or others, that are carefully and completely documented and reviewed with a full debriefing including the student and parent(s) or guardian(s) afterward.

One day after the petition had been publicized via Facebook, initially targeting the group of supporters who had rallied around Emily Holcomb, there were 500 signatures; two days after it was published, there were 1,000.³⁹ On 23 December, the interim superintendent issued a statement

³⁷ Ibid.

³⁸ Brown, L. (2011, December 21). End abuse of autistic students in Mercer County, Kentucky. Change.org. Retrieved from <http://www.change.org/petitions/end-abuse-of-autistic-students-in-mercer-county-kentucky>

³⁹ These numbers are from the petition's updates page.

that essentially promised no action and took no responsibility for the school's actions.⁴⁰ Over Christmas weekend, a national holiday, an unprecedented 11,500 *additional* people signed the petition in a new record for Change.org, according to Change.org staff member Benjamin Joffe-Wolt.⁴¹ This occurred immediately following the publication of an Associated Press article on Chris's story that was republished in major news outlets both in print and online across the country. Only two days after Christmas, the signature total was 50,000.

Sandra was interviewed by national news outlets, including CNN⁴², as well as local and state-based news outlets. She stated that Chris had never been the same since the incident, and after the holidays, chose to homeschool him along with his sister.⁴³ On 19 January 2012, Sandra, her mother, and other supportive friends attended a public school board meeting bearing two heavy boxes containing the printed petition—there were over 170,000 signatures.⁴⁴ She gave a prepared statement through her tears requesting redress of the situation only to be directly rebuffed by the interim superintendent and a spokesperson from the school board members.⁴⁵ In another statement given during the school board meeting, an elementary teacher expressed contempt for people whom she saw as merely trying to disrespect or maliciously malign the school, receiving applause for her statement.⁴⁶ To date, school officials have failed to accept responsibility or take any actions of redress in the situation.

⁴⁰ Davis, D. (2011, December 22). Personal email. The statement, which was sent to many individuals who signed the petition (though interestingly, not to me), read as follows: *"I want to thank you for your concern. The Mercer County School District is aware of recent reports of conduct directed by staff toward a student in one of our schools. Federal and State confidentiality laws prohibit the release of specific student information, and prevent the School District from even confirming or denying the specific allegations which are being raised in the public. Upon learning of the allegations, the school system reviewed the incident immediately, and the matter is being handled consistently with School District policies and with State and Federal law. The employees of the Mercer County Public Schools are qualified professionals who treat students with respect and dignity while providing a safe and nurturing learning environment. The well-being and safety of our students is our primary concern, while we strive to provide a quality education for student success. Often conclusions are jumped-to and snap judgments are made by people who do not possess all of the facts. Due to the confidentiality rights afforded to all students, I am not empowered to correct misinformation and misconception. I am therefore left to give my assurance that our School District strives to use appropriate educational procedures and techniques which are designed or approved by licensed professionals and that our employees receive appropriate trainings and certifications to prepare and equip them with the skills necessary to educate our children. Whenever the school is addressed with a concern, we review that concern to ensure that our policies and procedures have been followed, and we take corrective action when necessary and appropriate. The School District desires to have open lines of communication, and we encourage parents to visit our schools and talk with our staff whenever there is a question or concern."*

⁴¹ Schreiner, B. (2012, January 4). Mom wants changes before she'll let autistic son return to Mercer school. Associated Press. Retrieved from <http://www.kentucky.com/2012/01/04/2015169/mom-wants-changes-before-shell.html>

⁴² Sandra, Chris, and I were also invited for an appearance on *Anderson Cooper* to discuss Chris's story and the school's continuing inaction, but a last minute scheduling change placed different guests on the show instead.

⁴³ Schreiner, B. (2012).

⁴⁴ Kocher, G. (2012, January 20). Mercer County mom whose son was put in bag delivers 170,000 signatures to school board. Lexington-Herald Leader. Retrieved from <http://www.kentucky.com/2012/01/20/2035478/mercercounty-mom-whose-son-was.html#storylink=cpy>

⁴⁵ Ibid.

⁴⁶ Wilma Thomas's words, as quoted in Kocher, G. (2012). *"The allegations brought against the teacher in question serve only the purpose of depriving students of an experienced, high-qualified individual. The negative media reports have been fed by frustration, misunderstanding and a lack of communication. Our system is dedicated to meeting students at their level of need, and as members of this community, I challenge you to support our schools. Do not allow them to become targets of disrespect or rumor."*

The petition gained huge amounts of attention in the autism and Autistic communities, where Autistic self-advocates and advocates expressed increasing frustration with the type of dehumanizing and abusive treatment that Chris and other Autistics routinely receive in schools, alongside parents who were upset at the continued use of inappropriate restraints, seclusions, and aversives as punishments and disciplinary measures against their Autistic children. Chris's story was discussed throughout the Autistic blogosphere, and extensively covered on the popular ThAutcast blogazine site^{47,48,49,50}.

As of June 2012, the petition, which is still open and collecting new signatures, has over 200,000 signatures, but has yet to reap any results. One potential reason that the campaign to seek a proactive response from school officials has failed may be that the members of the school board felt distinctly threatened by the sudden attention from the national media; however, there is no objective evidence to support this theory. Publicity and attention to Chris's story and family have largely died, with relatively few references to the story and case since Sandra's failed presentation before the school board.

Nevertheless, the publicity for Chris's story occurred around the same time as Senator Tom Harkin reintroduced legislation in December 2011 that would enact nationwide restrictions on the use of all types of restraint and seclusion.⁵¹ It may be that the attention given to Chris's case by the national media and blogosphere, propelled by a Change.org campaign and the mobilization of members of a page on Facebook, brought the issue of restraint and seclusion to broader consciousness beyond the often insular disability community.

CASE STUDY: EMILY HOLCOMB



Discussed earlier in the introduction, Emily Holcomb's case was one of the two in this paper that resulted in a positive or successful outcome in large part due to the influence of social media and online activism in her case.

The Holcombs' attorney, James Gallini, stated, "I was in the mediation meeting in Alabama and the first request from the District was to stop the petition as they were getting overwhelmed (the Board of Education members were also unaware of what was happening and the Superintendent got into some trouble). They have provided Emily everything we asked for and the Court

⁴⁷ Bryce, L. (2011, December 23). How you can help stop autistic children from being put in bags. ThAutcast. Retrieved from <http://thautcast.com/drupal5/content/how-you-can-help-stop-autistic-children-being-put-bags>

⁴⁸ Bryce, L. (2011, December 22). Superintendent responds to petition for autistic boy placed in ball bag. ThAutcast. Retrieved from <http://thautcast.com/drupal5/content/superintendent-responds-petition-autistic-boy-placed-ball-bag>

⁴⁹ Bryce, L. (2011, December 21). Please help: Sign petition for boy placed in ball bag. ThAutcast. Retrieved from <http://thautcast.com/drupal5/content/please-help-sign-petition-boy-placed-ball-bag>

⁵⁰ Bryce, L. (2011, December 23). See kind of "ball bag" autistic boy was confined to. ThAutcast. Retrieved from <http://thautcast.com/drupal5/content/see-kind-ball-bag-autistic-boy-was-confined>

⁵¹ This is Senate Bill 2020, Keeping All Students Safe Act.

immediately dropped the charges. You were a very real part to the success we were able to achieve in that case.”⁵²

The Bakers and Holcombs both live in Southern, small town communities. The tactics that proved effective in Emily’s case ultimately failed to effect any lasting change in Chris’s case, though Chris’s story received significantly more news media coverage—particularly from outsiders—than Emily’s did. Interestingly, there was no mass convergence of activists and supporters for Emily (though her mother did hand-deliver a copy of the petition with over 1,000 signatures during mediation), while the petition delivery in Chris’s case was covered by the state news media and reported by the Associated Press.⁵³

Although online activism can prove effective in bringing greater awareness of particular causes or issues as well as mobilizing users to commit to offline activist activities, it should not be substituted for more traditional forms of activism and advocacy, and should be considered cautiously. It may be that had Chris’s case *not* received national media attention, the school officials may have been more amenable to hearing Sandra’s concerns and requests for redress, although the petition organizer had no control over when and how the media would take notice of the petition written on Chris’s behalf.

CASE STUDY: ANDRE McCOLLINS, GREG MILLER, AND OCCUPY JRC

In April 2012, the nation’s only institution that subjects disabled people to electric shock as punishment was taken to civil trial after Cheryl McCollins sued the Canton, Massachusetts based Judge Rotenberg Center for torturing her son Andre.



In 2002, JRC staff asked then-eighteen year old Andre, an Autistic youth, to remove his jacket.⁵⁴ When he refused, he was shocked with a device more painful and powerful than a police taser, while screaming and trying to hide under a table to escape further shocks. Staff forcibly removed him from the table and physically held him on a four-point restraint board, where he was tied facedown, and would receive thirty-one shocks over a period of seven hours.⁵⁵

Almost all of those shocks were punishment for every time Andre tensed or screamed for fear of receiving another shock. Andre was taken to a hospital after three days, where his mother described him as catatonic. He was diagnosed with acute stress response and catatonia post-traumatic stress disorder caused by the shocks.⁵⁶

⁵² Gallini, J. (2012).

⁵³ Schreiner, B. (2012).

⁵⁴ Beaudet, M. (2012, April). State raised concerns at shock school; trial of youth shocked for seven hours starts Monday. My Fox Boston. Retrieved from <http://www.myfoxboston.com/story/17409776/state-raised-concerns-at-shock-school-trial-of-youth-shocked-for-seven-hours-starts-monday>

⁵⁵ Ibid.

⁵⁶ Goddard, J. (2012, June 21). USA: Mother of autistic youth pleads for ban on electric shock ‘therapy.’ Scotsman.com. Retrieved from <http://www.scotsman.com/news/international/usa-mother-of-autistic-youth-pleads-for-ban-on-electric-shock-therapy-1-2365730>

During the trial, surveillance footage of Andre's torture was aired in open court after eight years of court-suppression at the request of JRC attorneys. Though the trial ultimately resulted in an undisclosed settlement, it brought national attention to the JRC's decades' long history of abusing and torturing disabled people in the name of treatment. One user's upload of the shock footage to YouTube has over 233,000 views,⁵⁷ a number which only includes users who watched the entire video, and which may therefore be a modest estimate of the number of people who have seen the footage.

Around the same time that the trial was occurring, a former employee of the JRC, Greg Miller, wrote a petition via Change.org that that demands the end of electric shock as a form of



treatment for people with the most significant disabilities or any disability at all⁵⁸. That petition has nearly 250,000 signatures.

Both the current and previous United Nations Special Rapporteurs on Torture have declared the use of electric shock at the JRC to be torture^{59,60}, and the U.S. Department of Justice initiated a civil rights investigation into the JRC's practices in 2010. The JRC's founder, Matthew Israel, was forced to resign in Spring 2010 after facing charges for destroying video evidence of abuses of the GED electric

shock device after ordered not to destroy the tapes from a 2007 incident in which a former resident prank called a group home, resulting in staff rousing two residents from sleep and shocking them dozens of times.⁶¹

Contrary to the JRC's claims, not only do students receive electric shocks for relatively minor behaviors such as standing up from a desk or swearing as well as for potentially dangerous behaviors (i.e. severe self-injurious or destructive behavior), but the most challenging behavior problems can be successfully treated without the use of aversives like electric shock. In legislative hearings each year on legislation that would ban the shocks, professionals with expertise in developmental and intellectual disabilities testify about the ineffectiveness of electric shock and the myriad options for addressing problematic behavior other than electric shocking.

⁵⁷ My Fox Boston. (2012, April 10). Footage of Judge Rotenberg Center torturing a person with a disability aired in court (graphic). Retrieved from <http://www.youtube.com/watch?v=aAj9W0ntUMI>

⁵⁸ Miller, G. J. (2012, May 5). Judge Rotenberg Educational Center: Please stop painful electric shocks on your students. Change.org. Retrieved from <http://www.change.org/shock>

⁵⁹ Boehmke, M. (2010, June 30). U.N. finds shock treatments at Judge Rotenberg Center in Canton to be torture. Retrieved from <http://brianajoyce.com/pressreleases/un-finds-shock-treatments-judge-rotenberg-center-canton-be-torture>

⁶⁰ Beaudet, M., & Rothstein, K. (2012, June 20). U.N. investigating Judge Rotenberg Center's use of shocks. My Fox Boston. Retrieved from <http://www.myfoxboston.com/story/18840703/2012/06/20/un-investigating-judge-rotenberg-centers-use-of-shocks>

⁶¹ Quraishi, J. (2011, May 27). "School of shock" founder forced to resign. Mother Jones. Retrieved from <http://www.motherjones.com/blue-marble/2011/05/judge-rotenberg-forced-resign-school-shocks>

There are no scientific, peer-reviewed studies that show any long-term efficacy of electric shock as a treatment for severe behavioral challenges.⁶²

In 1977, Matthew Israel first founded what was then called the Behavior Research Institute in California, where his aversive techniques included deep muscle pinching, forced inhalation of ammonia, excessive use of physical restraints, and withholding of food.⁶³ After a fourteen year old student died in 1981, the California government banned the use of aversive punishments.⁶⁴ Israel relocated the BRI to Rhode Island, but did not stay long because the Rhode Island government refused to allow the use of electric shock as an aversive therapy. Almost immediately after moving from Rhode Island to Massachusetts, Israel faced a lawsuit after the 1985 death of twenty-two year old Vincent Milletich, an Autistic resident at one of his group homes whom Israel had shackled and forced to wear a helmet that blasted him with white noise as punishment.⁶⁵

When in the 1990's, Massachusetts attempted to close the BRI again, Israel filed a lawsuit against the then Department of Mental Retardation, resulting in a court decision that has enabled the JRC to continue its operations unfettered to this day. The DMR was forced to pay attorney's fees, the commissioner and assistant commissioner were forced to resign, and the DMR lost its power to regulate Israel's facility.⁶⁶ In 2011, the renamed Department of Developmental Services issued a prospective ban on the use of the electric shocks for students admitted after September 2011, which has prompted resistance from the JRC's lawyers, who argue that the nearly twenty-year old court decision prevents the DDS from being able to legally enact those regulations.⁶⁷

Since the 1980's, disability rights advocates have repeatedly failed to see legislation that would enact a complete ban on aversives pass through the Massachusetts Legislature, in part because of the political support of State Representative Jeffrey Sanchez, whose nephew, Brandon, has been a resident of the JRC for over two decades.⁶⁸ In every legislative session, a complete ban on aversives goes to a hearing in which the JRC parades employees, family members, and current students—who are usually wearing the GED shock device while testifying—in front of the members of the legislative committee.^{69,70} State Senator Brian Joyce later said that “many of

⁶² Preaching hate; Romney's business experience; school defends shock treatments. (2012, May 22). *Anderson Cooper 360 Degrees*. [Television News Program]. Retrieved from <http://transcripts.cnn.com/TRANSCRIPTS/1205/22/acd.02.html>

⁶³ Ahern, L., & Rosenthal, E. (2010). *Torture not treatment: Electric shock and long-term restraint in the United States on children and adults with disabilities at the Judge Rotenberg Center*. Washington DC: Mental Disability Rights International.

⁶⁴ Ibid.

⁶⁵ The New York Times. (1987, January 24). Negligence is cited in death: Correction appended. Retrieved from <http://www.nytimes.com/1987/01/08/us/negligence-is-cited-in-death.html>

⁶⁶ Gonnerman, J. (2007, August 20). Why can't Massachusetts shut Matthew Israel down? *Mother Jones*. Retrieved from <http://www.motherjones.com/politics/2007/08/why-cant-massachusetts-shut-matthew-israel-down>

⁶⁷ Howe, E. M. (2011, October 14). Department of Developmental Services's response to testimony and comments on proposed amendments to behavior modification regulations: 115 CMR 5.14. Retrieved from <http://www.mass.gov/eohhs/docs/dmr/regs/reg-115cmr514-comments.rtf>

⁶⁸ Gonnerman, J. (2007)

⁶⁹ Cheney, K. (2011, July 26). Lawmakers again debate over Canton shock therapy school. *State House News Service*. Retrieved from <http://www.wickedlocal.com/canton/news/x2014914288/Lawmakers-again-debate-over-Canton-shock-therapy-school#ixzz1yUW4LK59>

these students who were testifying actually had GED devices attached to their bodies while giving testimony, [and] were fearful of saying the ‘wrong’ thing and being shocked.”⁷¹

Currently, there are two major legislative initiatives aimed at ending the use of contingent electric shock. In Massachusetts, Senator Joyce filed Amendment #548 to the Senate version of the fiscal year 2013 budget. Amendment #548 is a complete ban on contingent electric shock in Massachusetts. The Senate passed Amendment #548 into the budget, which at the time of this writing has gone to a budgetary conference committee, where the House and Senate versions of the budget must be reconciled for final approval by each body.⁷²

In New York, Senator Martin Golden and Assemblywoman Joan Millman filed legislation (S6294A-2011 and A9084A-2011) that would revise the current social services laws to prohibit any state or public funding to any school or program that uses aversive interventions; this bill specifically names contingent electric shock.⁷³ In 2006, the state of New York banned the use of contingent electric shock on any student from New York,⁷⁴ but New York residents still comprise a significant percentage (at least 50%, and perhaps as many as 60% or more) of JRC residents, whose tuition is paid by public funding.⁷⁵

Either the Massachusetts budget amendment or the New York proposed legislation could potentially result in the permanent closure of the JRC. The majority of the JRC’s revenue comes directly from New York, and if New York permanently cuts funding to any facility, school, or program that uses aversives such as electric shock, which is explicitly named in the legislation. Efforts to support both legislative campaigns have been widely publicized and disseminated online through specific interest web-based communities and social networking media.

Exemplifying the marriage of online activism with offline action, individuals (many of them disabled and survivors of institutional abuse) and organizations committed to protecting the human rights of the JRC’s residents organized into a massive grassroots organization called Occupy the Judge Rotenberg Center (www.occupyjrc.org), which held a national day of action on 2 June 2012 to demand the passage of Amendment #548 in the Massachusetts legislature. The June 2 event consisted of a rally in front of the Massachusetts State House featuring several speakers, including Greg Miller and Cheryl McCollins, followed by a march past the JRC site in

⁷⁰ Carroll-Bergman, M. (Ed.) (2012, June 1). Transcript of live chat Friday with Sen. Brian A. Joyce on the Judge Rotenberg Center. Retrieved from <http://canton.patch.com/articles/test-455894c4>

⁷¹ Ibid.

⁷² The Autistic Self Advocacy Network. (2012, June 6). Joint letter to the Massachusetts conference committee. Retrieved from <http://autisticadvocacy.org/2012/06/joint-letter-to-the-massachusetts-conference-committee/>

⁷³ The Autistic Self Advocacy Network. (2012, May 23). The Governor of NY: Stop the flow of taxpayer dollars to support torture. Change.org. Retrieved from <https://www.change.org/petitions/the-governor-of-ny-stop-the-flow-of-taxpayer-dollars-to-support-torture>

⁷⁴ CNN. (2006, June 21). New York education officials ban shock therapy. Retrieved from http://articles.cnn.com/2006-06-21/politics/shock.therapy.school_1_shock-therapy-electric-shock-geds?_s=PM:EDUCATION

⁷⁵ Esposito, J. C. (n.d.). Skin-shock therapies continue at JRC in spite of controversy. Retrieved from <http://www.judgerc.org/nepsycharicle.pdf>

Canton, which was attended by close to or more than one hundred people despite inclement weather.⁷⁶

Unlike the other three cases, two of which ended with positive outcomes and one of which is extremely unlikely to result in a positive outcome, this fourth case study is still in progress, as at the time of this paper, both the Massachusetts and New York state legislatures have opportunities to enact legislation that could end the JRC. Organizers associated with Occupy JRC and several other disability rights organizations, including the Autistic Self Advocacy Network (ASAN) and the Community Alliance for the Ethical Treatment of Youth (CAFETY), have been milking social media for all their worth, using social networking and blogging tools to keep followers and supporters updated about the latest events in the campaign to close the JRC and informing them of specific actions they can take, such as calling or writing legislators.

Within seven days after the protest, ASAN published a joint letter addressed to the members of the conference committee urging them to ensure that Amendment #548 is included in the final version of the budget sent back to both the Senate and the House. This letter was signed by over thirty organizations, including all of the major autism-related organizations, many disability rights organizations, parent and education organizations, and community and youth organizations, offering a glimpse into the broad array of organizations—and the individuals whom they represent—who have a stake in the continued operation of the JRC.⁷⁷ Without social media, would this type of organizing have been possible? Maybe, but with the plethora of social media platforms and applications, it has certainly become easier and faster to identify and connect with interested individuals and organizations.

CONCLUSION

I am no idealist, and I pride myself on my ability to avoid deluding myself with irrational, illogical, or nonsensical ideas.

The criticisms of social media for promoting a culture of political passivity are not unfounded; however, social media do have the potential to give individuals and organizations access to augmentative tools to promote and support causes and campaigns by promoting offline civic engagement and collective engagement. It is critically important for individuals and organizations to recognize both the limitations and potentials for social media to contribute to activism and advocacy. As with traditional or conventional actions for activism and advocacy, any means of recruiting, engaging, and organizing supporters will have both benefits and downsides.

Extensive use of social media can contribute to the feeling that activism has been overtaken by a commercialized or marketing spin, as well as activism fatigue—when individuals lose motivation or willpower to participate in meaningful action around a particular cause or campaign because they feel that their efforts are worthless and do not contribute much toward an

⁷⁶ Berrington, L. (2012, June 3). Time for Mass. lawmakers to close abusive Judge Rotenberg Center. Boston.com: The Angle. Retrieved from

http://www.boston.com/bostonglobe/editorial_opinion/blogs/the_angle/2012/06/time_for_mass_1.html

⁷⁷ The Autistic Self Advocacy Network. (2012, June).

overall cause. While social media can provide the means to access and engage others anytime, anywhere, that same fact can cause individuals to feel spammed or solicited rather than meaningfully engaged. Constant connectivity has its drawbacks. This is why people continue to enjoy retreats, especially those for which they must temporarily withdraw from communication using social media via the internet or phone.

Too much emphasis on the use and role of social media in one's causes and campaigns can unfortunately detract from the overall principles, message, or objectives, as opponents and critics may look to the extensive use of social media and conclude that your cause or campaign is not as legitimate or worthwhile as those that focus more on traditional or conventional means of action. While it can be positive to avoid succumbing to the pitfall of peer pressure, public opinion can make or break a campaign—with the right amount of good press and public support, a little-known cause or campaign can easily be placed in the spotlight where negative publicity would certainly undermine the value of the cause or campaign.

On the other hand, the advent of ubiquity in social media has allowed greater opportunities for individuals and organizations to make connections and foster an environment that encourages civic engagement and offline collective action. If used wisely and appropriately, social media can give an individual or organization the tools necessary to gain much broader exposure to one's ideas, content, and calls to action, as well as to forge connections and engage with like-minded individuals and organizations. Social media is effective at *amplifying* one's voice, but not necessarily in increasing its impact.

In the absence of well-organized, highly planned structure, grassroots movements built around a loose association of ideas but lacking a concrete leadership are doomed to fail. Yet with the right supports—whether for the disinterested citizen who generally takes no active role in public life or the well-seasoned community organizer—grassroots movements formed around common interest in a topic, cause, or campaign highlighted in the news media, can elicit support from a broad spectrum of people, which in turn can be engaged and transformed into the basis of a group of people who can be called upon to participate in legislative visits, protests, public hearings, or other public events. This too is a form of social media—the ability to communicate en masse with one's followers or supporters.

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