

Civic Engagement and People with Disabilities: The Role of Advocacy and Technology

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Abstract

Disability legislation acknowledges the right of people with disabilities to participate in political and public life on an equal basis with others, but there continue to be significant barriers in accessing all aspects of the policymaking process. Advocacy and technology are two core strategies used by the disability community to advance the rights of people with disabilities. Further understanding of how these strategies and tools empower people with disabilities to connect with government is needed. This research seeks to develop and enhance civic knowledge and practices of people with disabilities by conducting civic engagement training and evaluation and examining the role of four disability advocacy organizations. Using qualitative and quantitative data, the research explores the inclusion and participation of people with disabilities in civic society, with a focus on advocacy and technology.

Introduction

In the United States in the 1970s the civil rights model began to influence disability policy discourse and practices, which shifted from a charity approach to one that embodies human rights, self-determination, and empowerment. During this time there was a great deal of support for ending discrimination against people with disabilities (Scotch, 2001). However, unlike other civil rights movements, the disability rights movement was relatively invisible, which meant that political, social, and legal structures created to advance rights either were not applied or were applied with less rigor in the case of people with disabilities (Mezey, 2005; Stavis, 2005; Switzer, 2003). Despite strong disability legislation intended to increase the social and political participation of people with disabilities, there continues to be significant barriers in accessing all aspects of the policymaking process. The Americans with Disabilities Act and other legislation has not solved these problems for many of the 50 million people with disabilities in the United States (Blanck et al., 2004). Using empirical qualitative and quantitative data obtained through training, evaluation, and focus groups with people with disabilities and interviews with disability advocacy staff, the research examines how advocacy and technology can facilitate empowerment of people with disabilities to express and communicate their views and needs regarding disability policy.

People with Disabilities in Civic Society

Historically, people with disabilities have been isolated both from general society and from

each other, which has restricted opportunities to participate in public domains or to politically organize (Donoghue, 2003). Disability policies have typically been developed for people with disabilities, rather than with their direct participation (Braddock & Parish, 2001; Garcia-Iriarte et al., 2008). Furthermore, people with disabilities continue to be marginalized in all aspects of the policymaking process, including lobbying efforts, voting, and serving as elected representatives (Barnartt et al., 2001). Inequalities still exist in basic areas such as public accessibility and transportation, which prevents people with disabilities from full civic and social participation. Moreover, people with disabilities may have lower self-efficacy than others, and even when accounting for differences in employment and education, people with disabilities do not believe that they can impact the political system (Schur, Shields, & Schriener, 2003). Elected officials rarely solicit the input of people with disabilities, so it is important that people with disabilities are able to engage in public policy debate (Silverstein, 2010).

Research acknowledges the importance of direct involvement of people with disabilities in all aspects of policy debates, and civic engagement is one means in which to create or influence change. For people with disabilities, civic engagement can help to create self-efficacy, promote social integration, and develop personal interests (Barnartt et al., 2001; Hahn, 1985; Zola, 2005). Like other citizens, people with disabilities want an equal voice in democratic debates and the opportunity to advocate for change (Barnartt et al., 2001). Such participation and involvement in public

policy efforts can have an emancipatory effect, as marginalized groups are able to feel they are part of something, and in turn become more aware of their civic rights and responsibilities (Lewis, 2010). Disability advocate and scholar Jim Charlton cites civic engagement as a vital strategy for people with disabilities to develop a raised consciousness as they engage in grassroots advocacy for change in local communities. The title of his book, *Nothing About Us Without Us*, is a mantra frequently heard in disability rights movements and calls for people with disabilities to be involved in decisions made about them (Charlton, 2000). Increasing the engagement of people with disabilities will ensure that new policies do not continue the cycles of political marginalization historically experienced by this population.

Disability Advocacy

The use of advocacy by people with disabilities has been successful in changing policies and programs, most of which are associated with protests organized by the disability rights movement. A historical analysis of the number of protests by disability organizations between 1972 and 1999 shows growth in political activism over the years (Barnartt & Scotch, 2001). For instance, the group Disabled in Action developed strategies to block traffic to secure accessible public transportation in New York in 1977. That same year several groups of people with disabilities led sit-ins in 10 federal government offices until the government issued regulations for Section 504 of the Rehabilitation Act, and in 1988 deaf students at Gallaudet University protested until a deaf president was hired to lead them (Barnartt et al., 2001; Fleischer & Zames, 2001; Shapiro, 1994). In 2003 representatives from a group known as Mad Pride in California received national attention for a hunger strike organized to bring attention to the rights of people with mental health issues (Lewis, 2010). In Chicago, there is a strong history of grassroots disability advocacy being used to elicit change and connect citizens with government. Disability organizations, including Access Living and the Progress Center for Independent Living, have played a significant role in disability policy debates across Illinois. This included efforts toward deinstitutionalization, transportation accessibility, and securing access to sign language interpreters. In addition, the Mayor's Office for People with Disabilities in Chicago has been active in ensuring access around public sidewalks, voting, and schools.

Non-profit organizations face legal restrictions on the amount of lobbying they can engage in, but they still manage to make a significant impact in policymaking (Vaughan & Arsneault, 2008). In order to create widespread change, forming relationships between people with disabilities and state representatives is critical because it helps citizens gain power in the policy arena. However, people with disabilities face various barriers to full involvement. Most barriers fall into one of three categories: intrapersonal (skills and competence); interpersonal (team dynamics); or organizational (resources, decision-making processes) (Foster-Fishman, Jimenez, Valenti, & Kelly, 2007). One of the most common barriers is a lack of resources or funds to either purchase assistive devices or make trips to visit officials, so having a voice in policy decisions can be challenging. Other barriers that hinder the development of advocacy skills in individuals with disabilities include inaccessible buildings, a lack of training experiences, negative attitudes, and few opportunities to practice learned skills. Increasing safe environments, supporting advocacy trainings, and forming mentor relationships can help facilitate the development of self-advocacy skills for people with disabilities.

Technology for People with Disabilities

While advocacy has been an essential strategy for promoting the rights and participation of people with disabilities, further efforts are needed to encourage and facilitate people with disabilities in public policy domains. The use of adaptive technology is another vital strategy that empowers people with disabilities to connect with government, as it facilitates communication and allows for full expression in policy debates; and are, at times, the only means by which they can access public debate. Furthermore, people with disabilities often use technology to relate to the real world. This is especially true for people who use augmentative and alternative communication devices as people with severe communication impairments face significant additional barriers in participation, attaining self-determination, and realizing a high quality of life (Light et al., 2007). Research has demonstrated that such technology, when people are appropriately trained to use it, can help people with disabilities overcome barriers to full and equal participation, and develop socio-relational and problem-solving skills (Light et al., 2007; McCarthy et al., 2007). It is imperative that people with disabilities have opportunities for continued training and support in using technology, because

increased participation implies a greater range of communication environments (McNaughton & Bryen, 2007).

Adaptive technology is vital in allowing people with disabilities full participation in policy debates and the ability to become involved in the decision-making processes about policies that affect how they live in society. Aside from facilitating communication, technology can also be used as an organizational tool, it can help spark discussions about policy, and it can permit people with disabilities to find up-to-date information on government regulations and laws. Though seemingly all positive, some aspects of new technologies create additional barriers for people with disabilities who want to fully engage in civic society. There is a digital divide in society due to the fact that some individuals have access to internet and advanced technology and some do not (Rubaii-Barrett & Wise, 2008). Cost, availability, accessibility features, and lack of knowledge in effective usage are all barriers to people with disabilities taking full advantage of different forms of technology. There are regulations in place that address the issue of inaccessible technology, but states are either unable or unwilling to carry out federal mandates. Instead of focusing on increased spending, lobbying for greater enforcement of existing state and federal policies can be effective in bringing about positive changes in technology for those with disabilities (Rubaii-Barrett & Wise, 2008). Creating equal access to advanced technology for all people will help weaken the digital divide and increase opportunities for individuals with disabilities to become involved in policymaking processes.

Disability Rights

It is important to include people with disabilities in the decision-making process, particularly when those decisions affect them, so that people with disabilities are subjects of the political process rather than objects of policy decisions (Quinn and Degener, 2002). People with disabilities currently do not have an equal voice in the political process. For instance, voter turnout for the 2008 elections shows a gap of 7% between people with and without disabilities (57.3% and 64.5%) (American Association of People with Disabilities, 2010). Although this represents substantial improvement from 2000 and 1998 (gaps of 20 and 12 percentage points, respectively) (Schur, Kruse, Schriener, & Shields, 2000), additional strategies are needed to increase participation of the disability community

in the democratic process.

The need to increase political engagement of people with disabilities is reflected internationally in the United Nations Convention on the Rights of Persons with Disabilities (CRPD). People with disabilities played an active role in the development of the CRPD, which was unusual for a United Nations convention, which are typically negotiated solely by representatives from member states (Lang, 2009). The convention ensures that people with disabilities and disability organizations have a permanent voice pertaining to the convention to provide specialized expertise on disability issues and contribute to meaningful solutions (Melish & Perlin, 2007). The convention promotes the social model of disability and aims to remove barriers to the participation of people with disabilities and promote their inclusion in society.

Specifically related to civic engagement, Article 29 of the convention, "Participation in Political and Public Life," acknowledges the right of people with disabilities to participate in political and public life on an equal basis with others. This involves ensuring that voting procedures, facilities and materials are appropriate, accessible, and easy to understand; protecting the right to perform all public functions at all levels of government, including facilitating the use of assistive and new technologies where appropriate; and promoting an environment in which people with disabilities can effectively and fully participate in the conduct of public affairs (United Nations, 2006). The research draws on Article 29 to further understanding of the facilitators and barriers to civic engagement of people with disabilities and disabilities stakeholders. Advancing understanding of effective tools and strategies to increase involvement of people with disabilities in public life is necessary to ensure the rights of all citizens.

Methodology

Our aim is to examine how advocacy and technology can facilitate empowerment of people with disabilities to express and communicate their views and needs regarding disability policy and to do this in ways that influence the responsiveness of government. The research explores the following specific research questions:

1. How do people with disabilities engage with government, and what are the roles of policy knowledge, technology, and advocacy strategies in this engagement process?

2. What are the motivations of people with disabilities to engage in policy debate, and what are the perceived barriers and facilitators to increasing civic participation?
3. What is the role of technology in enabling and increasing access to government for people with disabilities?
4. How do disability organizations build advocacy knowledge, enhance civic awareness and responsibility, and increase development of technology skills to enable people with disabilities to participate in policy debates?

Research Design

This pilot study was conducted in Chicago from January to June 2011. The researchers worked in conjunction with the Assistive Technology Unit (ATU) and the Great Lakes Americans with Disabilities Act (ADA) Center—two disability organizations at the University of Illinois at Chicago that focus on engagement with and providing services to the community, as well as two disability community organizations, the Progress Center for Independent Living (PCIL) and Access Living (AL). In order to address the research questions, the project engaged with people with disabilities and these organizations in a participatory process to collect empirical data through community resource assessments, training sessions and evaluations, and focus groups/interviews with people with disabilities and/or disability stakeholders, as outlined below.

Community Resource Assessment

A community resource assessment was performed for each of the research project partners (ATU, ADA, PCIL, AL). This was a comprehensive appraisal and analysis of the advocacy and technology strategies that these organizations engaged in, which entailed a systematic critical review of secondary data, supplemented with interviews with key staff from each organization. Data for this part of the research included organizational material focused on public meetings and advisory boards; training and education programs; textual and promotional materials; teleconferences, webinars, and websites; and social networking and listservs. In additions informal interviews were conducted with a key staff member from each of the organizations to supplement the written materials. The goal of this stage of the

research was to gain a better understanding of the organization and how they facilitate inclusion of people with disabilities, especially related to the fourth research question: How do disability organizations build advocacy knowledge, enhance civic awareness and responsibility, and increase development of technology skills to enable people with disabilities to participate in policy debates?

Training and Evaluation

Three civic engagement trainings were conducted for groups of people with disabilities associated with the partner organizations. Each session was for people with disabilities of working age (18–64) who live in the Chicago area and are interested in becoming more involved in civic engagement activities. Each training session was unique, based on the organization it was conducted with, although each contained elements of five broad themes: general civic engagement, building policy knowledge, using advocacy, using technology, and becoming more involved with government. The five themes were used to structure each of the trainings similarly so that they are comparable on a broad level. Table 1 outlines each training session format.

Each participant was asked to complete an evaluation form prior to and 6–8 weeks after each training. Depending on availability and accessibility requirements, participants completed the evaluations in person, by email, or phone. The evaluations consisted of approximately 10 close-ended questions designed to measure policy knowledge and levels of engagement, and six open-ended questions designed to better understand the civic engagement of each individual. The qualitative data obtained from these questions are used alongside the data obtained from focus groups and interviews. The other results of these evaluations are used as a pre- and post-test analysis. [Note: because of time constraints and the poor completion rate of the pre-evaluation for the participants using alternative communication devices, people in the PCIL/ATU training were not asked to complete a post-evaluation]. The result of the training and evaluations provide insight into the following research questions: How do people with disabilities engage with government and what are the roles of policy knowledge, technology, and advocacy strategies in this engagement process? What is the role of technology in enabling and increasing access to government for people with disabilities?

Table 1: Training Sessions Format

	Access Living (AL)	Americans with Disabilities Act Center	Progress Center for Independent Living/ Assistive Technology Unit (PCIL/ATU)
Format	Series of two face-to-face trainings, one general and one focused on the experiences of a state lobbyist	One general webinar/ teleconference	Series of two face-to-face trainings, both general to account for the extra time needed for augmentative and alternative communication (AAC)
Participants	10 in the first session and 11 in the second; all with disabilities who were staff or volunteers of AL	Five people with disabilities who responded to a message posted to the Center’s listserv	Six people who used AAC, recruited by PCIL or ATU staff
Emphasis	Building capacity to organize and influence	Using technology like the Internet and social media to engage policymakers on policy and legislation	Using AAC effectively for advocacy

Focus Groups and Interviews

Six weeks following the trainings, follow-up focus groups and individual interviews were conducted with the training participants. Focus groups allow for a deep, rich understanding of how advocacy and technology can facilitate empowerment of people with disabilities in civic engagement. It provided a forum for hearing directly from people with disabilities on their perceptions and experiences in accessing government; increasing civic awareness and responsibility; the role of advocacy, the use of technology, and alternative communication devices in civic participation; strategies to increase responsiveness of government; and other general issues related to participation in policy debate. Participants in the AL training completed a focus group in person. The ADA training participants completed the focus group questions individually by participating in a short telephone interview because of difficulty completing the focus group remotely. Participants in the PCIL/ATU training also completed the focus group directly with one of the researchers on an individual basis.

Qualitative data was also obtained from key stakeholders in each disability organization (N = 8). These open-ended in-depth interviews allowed stakeholders to add to existing secondary materials (i.e. the Community Resource Assessment); share perceptions and experiences of strategies used to increase participation of people with disabilities in policy debates; and provide important insight into key structural and process barriers and facilitators to promoting civic engagement. Thus, these

interviews triangulate data on the civic engagement of people with disabilities. The qualitative data in this part of the research are useful for addressing all of the research questions, but they especially relate to the following research questions: Why do people with disabilities engage in policy debate, and what are the perceived barriers and facilitators to increasing civic participation? How do disability organizations build advocacy knowledge, enhance civic awareness and responsibility, and increase development of technology skills to enable people with disabilities to participate in policy debates?

Table 2 summarizes the number of participants in the various parts of this project.

Research Limitations

This project had three limitations: participant recruitment, technical difficulties, and participant response/dropout. Each of these are discussed below.

The majority of the participants in this research were identified by staff at the partner organizations. Although the project was advertised on listservs and distributed to people with disabilities, there was a very limited response. All of the participants were known to, or worked for, one of the partner organizations, suggesting they were already engaged with the disability community and actively seeking additional knowledge. Furthermore, one of the survey questions asked whether someone had voted in the last election, and 16/20 (80%) reported that they had. As reported earlier, only 57.3 per cent of people with disabilities voted in the 2008 elections (American Association of People with Disabilities,

Table 2. Summary of Research Participants

Data Collection Stage	ADA ¹	AL ²	PCIL ³	ATU ⁴	Total
Training participants	5	11*	6	—	22
Pre-evaluation	5	10	5	—	20
Post-evaluation	4	11	—	—	15
Focus group	4	9	6	—	19
Stakeholder interview	2	2	2	—	8

*10 in first session

¹Americans with Disabilities

²Access Living

³Progress Center for Independent Living

⁴Assistive Technology Unit

2010). These results suggest that the participants are not representative of people with disabilities as a whole, because they are already highly engaged. Therefore, it is unclear the extent to which the participants are representative of people with disabilities in general.

Technical difficulties limited many aspects of data collection and attendance at the trainings. This was especially an issue for the ADA webinar. On the morning of the training, only one participant was able to log into both the webinar and audio, despite detailed instructions provided by email and phone. The training session was rescheduled and the researchers worked one-on-one with each participant to ensure that they knew how to view the webinar on the re-scheduled date. While each participant was able to access the training on the second day, it is ironic that individual training on using technology was necessary for a civic engagement training that emphasized how technology can facilitate inclusion of people with disabilities in policymaking. Technical difficulty was also an issue for the PCIL/ATU training participants. All of these individuals used alternative communication devices, and it was cumbersome and tiring (e.g. one of them uses a foot pedal to compose communication) for them to communicate and participate in the training. Communication difficulties are evident in the limited responses people in this training session gave to the pre-evaluation questions. In order to accommodate the extra time needed for response, the researchers organized an email listserv as a method to conduct the follow-up focus group so responses did not have to be immediate. However, this approach did not get any responses from the participants, due to restricted access to a computer and internet with accessible software. This limitation is a key finding because it highlights the

difficulty that people who use alternative communication devices have communicating, which is likely to be exacerbated because policymakers rarely have much time to spend with a given individual or group.

Although there were only three dropouts from the trainings through the focus groups (one for the ADA Center and

two for AL), missing out on their perspectives and not having a reason for their dropout raises questions. A better understanding of why they dropped out would contribute a lot of valuable information to the research. Prior to the training two additional people with disabilities indicated that they wanted to participate, but stopped responding to the researchers. They did consent to the research, meaning that there were 24 total original participants, and only 19 (79.2%) completed the research. For a short-term pilot study, the number of dropouts warrants additional consideration. For the people with disabilities that did not drop out, the researchers had to maintain constant contact and frequent reminders, in order to secure their participation. A number of participants indicated that email was their preferred method of communication, but they seldom checked or responded to it. If not for the vigilance and flexibility of the research team, that dropout rate would have been much higher.

Results

Stage 1: Community Resource Assessment

This section contains brief organizational descriptions and summaries of how each community disability organization engage in advocacy and technology.

Great Lakes ADA Center

The Great Lakes American with Disabilities Act (ADA) Center is a program of the Department of Disability and Human Development at the University of Illinois at Chicago. The center prides itself on providing information, materials, technological assistance, and training on the ADA to Region 5, which covers Illinois, Indiana,

Michigan, Minnesota, Ohio, and Wisconsin. It offers a variety of training services in the form of audio conferences, online courses, podcasts, and webinars designed to build and enhance knowledge and facilitate discussion on the ADA. Through the Great Lakes Accessible Information Technology Initiative, the center is able to provide individuals and organizations with resources on information technology and its usage. They offer technical assistance, education, training, referrals, and materials via phone or online to those seeking information on technology accessibility. The Great Lakes ADA Center uses a range of media to share information, including through *The Great Lakes Chronicle*, employment legal briefs, the ADA document portal, an architectural compilation series, social networking sites, and smart phone applications.

Access Living

Access Living is a Center for Independent Living governed and staffed primarily by people with disabilities. It offers peer-oriented services, public education, awareness and development, teaching of advocacy skills, and the enforcement of civil rights on behalf of people with disabilities. Their mission is to “empower people with disabilities so they can lead dignified, independent lives and to foster an inclusive society for all people, with and without disabilities.” Advocacy is a major area for Access Living and they specialize in community development and organization, policy analysis, and civil rights. Access Living supports six grassroots groups that fight for social change in a specific area of interest. Through the Arts and Culture Project, AL helps to raise awareness and visibility of disability culture. As part of their policy work, Access Living staff network and build relationships with legislators to rally for policy change and creation. Access Living employs attorneys to provide legal counseling on civil rights issues such as education, housing, and discrimination concerns and to help educate consumers on their rights and how the legal system operates. Throughout its work, Access Living uses a peer-based philosophy to empower people with disabilities.

Progress Center for Independent Living Summary

The Progress Center for Independent Living (PCIL) is another community-based, non-profit Center for Independent Living focused on disability advocacy and is run by and for people with disabilities. The Progress Center believes that

“independence is the ability to control one’s own life by making responsible choices from acceptable options.” PCIL provides four core services: information and referral on disability related topics; advocacy and direct support for disability rights; independent living skills training including budgeting, travel, personal assistant management, and job seeking to help people successfully live on their own in the community; and peer counseling and problem solving for people with disabilities. PCIL also holds training sessions for people with disabilities and conducts community education presentations on disability issues and policy. Through social media, e-mail, pamphlets, and a weekly radio show, PCIL is able to reach a wide range of consumers to educate individuals about independent living.

Assistive Technology Unit

The Assistive Technology Unit (ATU) is an interdisciplinary clinic of the Department of Disability and Human Development at the University of Illinois of Chicago. As a community-based service delivery program, it serves more than 90 per cent of its clients in their own home, school, work, or recreational environment. ATU staffs occupational therapists, physical therapists, rehabilitation engineers, and speech-language pathologists who specialize in assistive technology. The ATU defines assistive technology as “the use of commercially available, modified, and custom devices used by individuals with disabilities to maximize independence” and it offers this service in eight areas: adaptive equipment (custom-designed), augmentative communication, computer access, environmental control, home modification, mobility, seating, and worksite modification. The ATU offers educational workshops and graduate-level courses and a certificate program for professionals to enhance their knowledge of assistive technology. The ATU spreads information about their services through word of mouth, newsletters, digital pamphlets, academic publications, and conferences.

Each of these organizations build advocacy knowledge, enhance civic awareness and responsibility, and increase development of technology skills to increase participation of people with disabilities in policy debates. Furthermore, the organizations meet the goals of Article 29 of the United Nations Convention on the Rights of Persons with Disabilities. Table 3 summarizes the community resource assessment in relation to the goals of this research.

Table 3. Summary of Community Resource Assessment

Organization	Increasing policy knowledge/ awareness	Building Advocacy	Developing Technology Skills	Meeting CRPD Article 29
Americans with Disabilities Act Center	Provides information, materials, technical assistance (phone line) and training on the ADA; produces audio conferences, online courses, webcasts, and webinars on current topics.	Provides information on civil rights and encourages advocating for rights.	Great Lakes Accessible Information Technology Initiative provides individuals and organizations with resources on information technology.	Information and resources on removing barriers to community participation, including national legislation relating to accessible voting.
Access Living	Civil rights attorneys; community organizing; peer support; network with legislators; training workshops; newsletter.	Advocacy is a core focus on community development and organizing; support six grassroots teams.	Use social networking; trainings; technology is part of independent living skills.	Focus on self-advocacy; community development teams encourage individual participation; attorneys assist with overcoming barriers.
Progress Center for Independent Living/ Assistive Technology Unit	Provides information and referral services; community education; consumer training.	Focus on advocacy and independence; community outreach, with a focus on action.	Uses social networking, email, and a weekly radio show; technology is part of independent living skills.	Focus on self-advocacy; consumer training; community education on disability issues and rights.
Assistive Technology Unit	Evaluation and implementation of service; graduate courses and research; academic publications and conferences.	Services promote independent living; skills training on using assistive technology efficiently.	Focus on assistive technology and working with individuals to procure and receive training in assistive technology; maintain networks with technology providers.	Services to individuals encourage their participation in society.

Stage 2: Training Evaluations

A major component of this pilot project was to conduct civic engagement trainings in partnership with the disability organizations described above. In order to assess the impact of the trainings, each participant was asked to complete an evaluation before and six to eight weeks after the training. Each evaluation was unique to the organization that conducted the training, although six questions were consistent across the groups. Table 4 contains the responses to each of these questions (as noted before, the PCIL/ATU group did not complete a post-evaluation).

Although the participants may have been more engaged than people with disabilities in general, the training still showed an impact. Agreement with each of the questions indicates greater levels of civic engagement or understanding of the policy process. The cumulative responses (referred to the shaded cells in Table 4) indicate that the trainings were positive and achieved their goals. A chi-square test of significance ($\chi^2=9.4$, $df=4$, $p\text{-value}=0.0517$) shows that the results for

each evaluation is independent of the other. These results are statistically significant at the 90 per cent confidence level, and very close to significant at the 95 per cent (which would be significant with a higher count). We can be confident that there is a different distribution of answers in the pre-and post-evaluations. More specifically, in the post-evaluation, participants were more likely to agree with the statements or agree more strongly.

The evaluations followed the same trend general when broken down into individual training sessions. However, given the small number of participants per training, statistics have less significance. Results from each question for each group show that participants were more likely to agree or agree more strongly with the various questions relating to their civic engagement and policy knowledge following the trainings.

Although this trend was consistent, questions about the validity of the responses are interesting. The results suggest the possibility of acquiescence, which refers to the tendency of survey and questionnaire respondents to answer “yes” or agree

Table 4. Evaluation Responses (Number of Responses by Possible Choice)

		I understand what civic engagement is.		I can identify areas where I can influence public policy.		I believe that my advocacy efforts can have an impact on public policy.		I know how to use technology effectively in my advocacy efforts.		I know how to obtain up-to-date information on policy issues that matter to me.		I know how bills are passed and become law.					
Response		Pre	Post	Pre		Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	%	Post	%
Americans with Disabilities Act Center	Strongly Agree	1	2	1	3	1	2	1	4	1	3			5	20.0	14	70.0
	Agree	3	1	2	1	3	2	3	0	4	1			15	60.0	5	25.0
	Neither	1	1	1										2	8.0	1	5.0
	Disagree			1		1		1						3	12.0	0	0.0
	Strongly Disagree													0	0.0	0	0.0
Progress Center for Independent Living	Strongly Agree	1		2		4		4		4		3		18	60.0		
	Agree	2		2				1						5	16.7		
	Neither											1		1	3.3		
	Disagree	1		1		1				1				4	13		
	Strongly Disagree	1										1		2	6.7		
Access Living	Strongly Agree	2	6	3	3	3	5	1	4	1	3	3	2	13	22.0	23	34.8
	Agree	7	5	6	8	6	6	7	6	7	8	2	6	35	59.3	39	59.1
	Neither	1		1				1	1	1		4	1	8	13.6	2	3.0
	Disagree							1		1		1	2	3	5.1	2	3.0
	Strongly Disagree													0	0.0	0	0.0
Cumulative	Strongly Agree	4	8	6	6	8	7	6	8	6	6	6	2	36	31.6	37	43.0
	Agree	12	6	10	9	9	8	11	6	11	9	2	6	55	48.2	44	51.2
	Neither	2	1	2	0	0	0	1	1	1	0	5	1	11	9.6	3	3.5
	Disagree	1	0	2	0	2	0	2	0	2	0	1	2	10	8.8	2	2.3
	Strongly Disagree	1	0	0	0	0	0	0	0	0	0	1	0	2	1.8	0	0.0

with items on a survey instrument during research (Finlay & Lyons, 2002). On the pre-evaluation, 79.8 percent of their responses were either agree or strongly agree, and that number was 94.2 percent on the post-evaluation. This research does not have a way to wholly validate those responses and determine whether or not people with disabilities can back up what they said. However, one of the questions does offer some insight. People with disabilities were asked if they understood what civic engagement is, and in the pre-evaluations 16 out of 20 (80%) agreed or strongly disagreed. In the post-evaluation, 14 of 15 (93.3%) answered this way. One of the short answer questions asked people to define civic engagement. The responses for this question, especially during the pre-evaluation do not show much clarity on understanding civic engagement. The group from PCIL illustrates this point. Although three people either agreed or strongly agreed with the statement, during the qualitative portion three people acknowledged that they did not know, and the only one that provided

a substantial answer talked only about voting. This does not mean that every participant was confused, or acquiesced to the question as it was asked, but future research needs to follow-up this pilot study with more robust ways of measuring the knowledge that people obtained from these trainings, and how they put it into practice.

Stage 3: Focus Groups and Interviews

The qualitative data help to triangulate the survey responses. The answers to the open-ended questions are more interesting and provide valuable depth and insight into the impact of civic engagement trainings and local disability organizations. This section presents results from the focus groups with people with disabilities and interviews with disability stakeholders in the four organizations (see Appendix A for more detailed context of the participants such as pseudonyms, organization, and role). Two main themes emerged from the qualitative data: advocacy and action and technology and these are discussed below.

Advocacy and Action

Advocacy takes many forms in the disability community, ranging from awareness raising and education to direct action. Participants described advocacy in terms of “knowing your rights and how to fight for them” (Kristen), and “having a voice” (Christina) and “do[ing] something for themselves” (Trevor). One staff member described advocacy as seeking to understand and alter both the root of oppression and its effects on the disability community (Allen). Because advocacy can take different forms depending on both the advocates and the audience, staff make it a priority to test and develop effective strategies for change. One staff member explained that his organization trains on a variety of strategies but “[w]hat doesn’t change is how advocates are going to organize and educate the consumers to take charge of their own lives (Brendan).

Advocacy via education was perhaps the most mentioned tool for empowering people with disabilities to participate in civic society. Advocacy staff believed that information translation was a key strategy for helping consumers understand advocacy strategies, as well as their rights and responsibilities. One participant described the importance of “educating [consumers] about an issue and letting them decide for themselves what stand they want to take, and pointing them in the direction to allow them to advocate for what they believe in” (Catie). Other staff members stressed the importance of enabling consumers to explore their own interests and values. Participants shared the effects of the awareness raising activities conducted through this project, saying “Now when I hear the news and hear them talk about budget cuts, my radar goes up when before I didn’t really care or know how it would affect me” (Christina). Another spoke of how the trainings prompted him to take direct action: “As a direct result of the training...I made a phone call to a politician. I called the governor’s office and said no budget cuts... I’m 51 and it was the first time in my life” (Evan).

Consumer education through advocacy training enables people with disabilities to have a stronger presence and a louder voice when interacting with the government. Staff described how the “contact of people in government with the people the programs are actually supposed to serve is a powerful thing” (Tim). Both advocacy staff and participants gave specific advice on the strategies they have found to be most useful and effective. Staff and participants generally prefer

to advocate face to face with legislators and policymakers, coupled with awareness-raising activities such as street action (e.g. protests). Other effective strategies, especially when transportation is a barrier to physical access, include aggressive letter-writing or emailing campaigns, and phone calls. Education efforts spread beyond the disability community, however. An Access Living staff member said that a key factor in the larger disability advocacy effort is “educating the public to convey the message that disability issues are social issues” (Evan). Disability organizations are striving to educate their communities, disabled and non-disabled, about the issues they face. Peer support is seen as a key facilitator to successful advocacy action, and advocates take action to educate potential allies. Participants and staff serve on advisory boards and committees to partner with the larger community in creating an accessible environment. In addition, staff saw disability organizations as having a major role in making their community more visible, placing people with disabilities “into the public eye and into the minds of decision-makers” (Allen). Advocates also pursued “getting local media involved on covering issues” so that their views are included in coverage (Jeremiah).

As with any grassroots effort, there is “power in numbers” (Lenny). Participants strongly urged one another to be bold self advocates. During a focus group, one participant encouraged the others, “you have to show your face. We are disabled and proud and here to stay. To maintain power, we need to exercise the power that we have” (Elizabeth). Another person, when discussing developing effective strategies, advised the group to practice, try different advocacy methods, and work with others in the disability community (Catie). However, even the most powerful voice is rendered null if policymakers are not willing to hear it. Participants and staff shared that the greatest barrier faced by advocates is a lack of understanding or a willingness to understand disability issues. In general, staff and participants viewed the government as largely unreceptive to their message, echoing one another in saying that the government makes virtually no effort to reach out to people with disabilities. They suggested that the government needs to take action not only to meet the requirements of disability laws, but also to match the spirit of these laws and let the disability community know they are being considered.

Government bodies need to provide not only physical, but also programmatic access to

people with disabilities to enable all to participate. This was largely seen as lacking, however. One participant shared that “it’s an issue of even if they are willing to listen to us...do they have other priorities?” (Dana). Often, disability community members felt powerless in government situations. Participants and staff felt disempowered because they felt the government only wants you to vote and are generally not receptive to receiving input on issues. Brendan shared:

Government and politicians don’t see our community as a threat. They don’t see us as a threat or an economic resource to help them. So we continue being left behind, unfortunately. We are breaking barriers though. It’s going to take a while before government puts us on their agenda. It takes great effort to be at the table, and not on the menu.

Technology and Civic Engagement

Although technology cannot put the concerns of people with disabilities on the political agenda, it is an integral factor for engaging with civic society. Many people with disabilities are largely unable to afford the technologies necessary for participation. Third party payers will typically fund basic communication devices and software, but participants stated that this was rarely adequate to meet their communication needs. Additionally, third party payers will not allow for these devices to be used as a computer with internet capabilities, so any potential for long-distance communication is eliminated. In the cases that people with disabilities are able to afford their own computers, they may not have regular access to the internet. According to a staff member: “The fact that so few of our consumers have regular access to the internet is a problem and we still rely so much on U.S. mail and on phone calls to reach a lot of our consumers. The technologies are not always readily available” (Tim).

People with disabilities also expressed their frustrations related to constantly changing technologies. One person complained that as technology advances, “older versions don’t work anymore and it becomes difficult or impossible to access [technology]. Staying up to date is expensive and a lot of people with disabilities are unemployed” (Paul). While some people saw constantly changing technology as a barrier, others viewed it as a future opportunity. Cassandra, of the Great Lakes ADA Center, noted that “we’ll be

looking at more mobile technology...We’re stuck right now because it’s a time of change, but our options are multiplying” (Cassandra).

While technology was often seen as a facilitator for engagement, many people with disabilities do not possess the necessary skills to effectively use it. People with disabilities expressed that more funding is needed for “speech-related services of course to help with communication and environmental controls” (Lenny). A major technological barrier to civic engagement was learning how to use the computer; staff remarked that getting everyone trained to be at the same skill level is a challenge. Staff saw their organizations as having a major role in helping people learn how to use technology and making people aware of the options available to them. Practical knowledge about technology can also be a gateway to a sense of belonging in the community. Learning about technology “helps people get in touch with interests they forgot they had, or discover new things out there that they didn’t know about. It makes a huge difference in a person’s perception of where they fit in the world” (Jeremiah).

Technology was found to play a gateway role in allowing people with disabilities to interact with the government and advocate for change. Though some argued that “nothing takes the place of old fashioned, one-on-one organizing” (Brendan), others strongly preferred online-only advocacy. The Internet enables a person to connect directly with legislators without having to face obstacles such as transportation and communication difficulties. Some participants commented that they prefer online interaction because “with a computer nobody knows [you have a disability] because you can type it, they can read it, and that barrier actually goes away” (Catie). Participants stressed that, ideally, an e-mail or phone call should receive the same attention as a face-to-face interaction. Technology facilitates independence and gives people a voice. It allows advocates to reach more people in less time and provide them with more information over time. Participants and staff agreed that technology is essential to allowing people with disabilities and policymakers to have a conversation on efforts for social change.

Having access to the Internet and other technology is of little use if the information available online is inaccessible. Staff remarked that “the amount of information accessible on the internet has exploded but when it’s not accessible, it doesn’t help. Ensuring that websites are designed and created accessibly and new technologies being

accessible is key” (Paul). They urged that accessibility needs to be at the forefront of design, rather than being an afterthought. According to participants, the government should have a responsibility to lead the way in accessible online information. One participant provided a suggestion to help create a more accessible online environment: “They [the government] could call and see how we use our computers, then we might give them some ideas about how they could make computers for people with disabilities, make telephones for disabled people” (Trevor). Participants and staff generally felt that the government’s technology is outdated and that they need to take steps to gain awareness of new technologies.

Conclusion

The research provides important policy, advocacy and technology insights into the civic engagement experiences of people with disabilities and disability advocacy organizations. The research draws on Article 29 of the CRPD to further our understanding of the effective tools and strategies so that people with disabilities can increase their involvement in public life.

People with disabilities require a range of informal and formal supports to engage in civic society, including: peer mentoring with experienced disability advocates (i.e. to address feelings of powerlessness, isolation, learn strategies); increasing opportunities for knowledge building through training/education (i.e. to help understand policy processes, how to engage with politicians); and better access to practical information (i.e. to learn about voting rights, how to register to vote) and accessible technology (i.e. to assist with communication, group empowerment). Increasing the political engagement of people with disabilities will ensure that new policies do not continue the cycles of oppression and marginalization historically experienced by this population.

Immediate solutions could involve developing ongoing training programs in conjunction with disability advocacy organizations, as well as setting up peer mentoring groups so that experienced disability advocates can share their strategies with other people with disabilities. Such programs can be modeled on the small scale trainings discussed in this research. A longer term challenge is addressing broader structural barriers facing people with disabilities, such as environmental barriers (i.e. inaccessible buildings, transportation and technologies), and attitudinal barriers (i.e., perceptions that people with disabilities are not

valuable constituency groups). Training and peer-mentoring would also be a first step in addressing these more complex barriers. Additional strategies could involve increasing the visibility of people with disabilities on advisory boards and in other public positions, and awareness raising through email/letter writing campaigns, face-to-face meetings, and phone calls with legislators.

Parity of participation in civic engagement enables marginalized groups to be agents of social change. Through a community resource assessment, civic engagement trainings and empirical data gathered through pre-post evaluations, interviews and focus groups, this project identified key facilitators and barriers to developing and enhancing civic knowledge and practices of people with disabilities. However, further research efforts on a larger scale are still needed. The collaboration between individuals, disability advocates, researchers, scholars and service providers both with and without disabilities enabled an important participatory approach to research; thereby offering a unique and diverse perspective on an important public policy issue. Involving a range of stakeholders is an essential component of any future efforts to better support civic participation. It is through advancing our understanding of the effective tools and strategies to increase involvement of people with disabilities, including adults who use augmentative and alternative communication devices, that we can ensure the rights of all citizens.

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