Civic Engagement and Disability: using advocacy and technology to advance the political participation of people with disabilities

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Executive Summary

Background

Article 29 (Participation in Political and Public Life) of the United Nations Convention on the Rights of Persons with Disabilities acknowledges the right of people with disabilities to participate in political and public life on an equal basis with others. Despite a strong history of civil and human rights for people with disabilities there continues to be significant barriers in accessing all aspects of the policymaking process. Disability policies have typically been developed on behalf of people with disabilities, rather than with their direct participation, and people with disabilities continue to have restricted opportunities to participate in public domains. Advocacy and technology are two core strategies used by the disability community to advance the rights of people with disabilities, and to increase participation in public domains. While there have been important successes, further understanding of how these strategies and tools empower people with disabilities to connect government is needed.

Methodology

The research aimed to develop and enhance civic knowledge and practices of people with disabilities. It undertook empirical qualitative analysis examining the role of various advocacy strategies and use of technologies to facilitate the full expression and needs of people with disabilities in policy debates. Specifically, it explored the following specific questions:

- How do people with disabilities engage with government; and what is the role of policy knowledge, technology and advocacy strategies in this engagement process?
- Why do people with disabilities to engage in policy debate; and what are the perceived barriers and facilitators to increasing civic participation?
- What is the role of augmentative and alternative communicate devices, accessible information technology in enabling and increasing access to government for people with disabilities?
- 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?

To answer these questions, the researchers collaborated with four Chicago-based disability organizations to recruit people with disabilities and organization staff to join us in a participatory process to collect empirical data through multiple methods: community resource assessment involving informal interviews with key staff (n=3) and secondary analysis of organizational data (i.e. public meetings and advisory boards; training and education programs; textual and promotional materials; teleconferences, webinars and websites; social networking and listservs); civic engagement training, pre-post evaluation and focus groups with a broad range of adults with developmental, physical and sensory disabilities, including people who use augmentative and alternative communication devices (n=22); and interviews (n=8) with key stakeholders from disability organizations.

Results

After the training sessions, more participants reported understanding the policy process, including how they can become involved in making an impact in the decision making process. Participants also agreed that taking part in the training sessions strengthened their understanding and sense of efficacy related to civic engagement. Education and awareness raising were key strategies to encourage civic engagement in people with disabilities. The advocacy strategies cited as most successful for promoting empowerment and civic engagement included face-to-face meetings, letter writing/phone/e-mail campaigns, self-advocacy trainings, mentoring, and training in the use of technology. Major barriers included attitudinal obstacles such as lack of information about and receptiveness to the disability message, especially on the part of the government, and a lack of outreach to the disability community. Disability organizations were considered powerful facilitators for civic engagement, as was technology, provided people with disabilities could afford and use it. An individual summary of the three stages of data are presented below.

Community Resource Assessment: Disability organizations are a major facilitator to civic engagement and for application of the goals contained within Article 29 of the Convention on the Rights of Persons with Disabilities. The organizations in this research build advocacy knowledge through trainings, community education and organizing, technical assistance, and research publications. Advocacy is a core service for many of these organizations; advocacy efforts included education workshops, direct action, community outreach, and organizing interest groups. Direct action such as face-to-face meetings with legislators were viewed as most effective, though some preferred to utilize technology to reach a larger number of decision makers more efficiently. The organizations tended to utilize technology and social networking to communicate with consumers, build awareness, and coordinate efforts. Some organizations provided technical training workshops and assistance to consumers to help develop their skills.

Training Evaluations: Although a post-evaluation was not conducted for PCIL, for the others, training was shown to have a positive impact before and after. For the six statements that were used across the evaluations the number of people who either strongly agreed or agreed with each statement increased following the training. The results suggest that the trainings were successful in teaching people with disabilities about becoming more involved in policy. Across all of the post-evaluations, only two of the responses disagreed (2.3%) with and three (3.5%) responses neither agreed or disagreed. This means that, in the end, over 94 per cent of the responses either agreed or strongly disagreed with the statements that the trainings covered. To summarize:

- After the training, more people understood the policy process, how to be involved and had the belief that they could make an impact.
- For people who agreed with the statements before the training, participating in the training strengthened their understanding.
- The trainings were an effective way to bring groups up to the same level of understanding.

Focus Groups and Interviews: Civic engagement was viewed as an essential for participation in civic society. Because policy knowledge was seen as key for effecting change, advocacy efforts focused on educating and empowering consumers, and raising awareness among the general public through media outreach. Staff emphasized the role of mentoring in empowerment and shared advocacy strategies they have found successful. Staff and participants largely viewed the government as unreceptive to their message and generally lacking in knowledge about disability policy. Many participants preferred to advocate in person, though the enormous potential benefits of using technology in advocacy were discussed. A lack of accessible online media, inability to afford technology, and limited technology skills were seen as major barriers to civic engagement. To summarize:

- Education and awareness raising were key for increasing policy knowledge and reducing feelings of apathy and disempowerment among people with disabilities.
- Successful advocacy strategies included in-person direct action, self-advocacy skills training, mentoring systems, and using technology for outreach.
- A lack of government accessibility, awareness of disability issues, and outreach to the disability community were seen as major obstacles to civic engagement.
- Technology was widely considered a useful tool, provided that people with disabilities had access and skills to use it.

Conclusion

The research provides important policy, advocacy and technology insights into the civic engagement experiences of people with disabilities and disability advocacy organizations. It 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. 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. 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. 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. The research provides individuals, advocates, disability organizations and policymakers a better understanding of how to increase, advance and support civic participation of all citizens. 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.

Table of Contents

Introduction

The disability rights movement in the United States emerged in response to a variety of triggers, some of which included anger over exclusion from public domains on the grounds of disability; poor housing and transportation; lack of employment opportunities; discriminatory social attitudes; reduced government expenditure on services; growth of key lobby groups; and extensions of state action through struggles over legislation (Longmore, 2003; Meekosha & Jakubowicz, 1999; Wittenburg & Favreault, 2003). In the 1970s the civil rights model began to influence disability policy discourse and practices, which shifted from a medical or 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, 200). 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). Disability policies have typically been developed on behalf of people with disabilities, rather than with their direct participation, and people with disabilities continue to have restricted opportunities to participate in public domains. Despite strong disability legislation intended to increase the social and political participation of people with disabilities on an equal basis to others, there continues to be significant barriers in accessing all aspects of the policymaking process. Many of the 50 million people with disabilities in the United States continue to experience widespread problems that the Americans with Disabilities Act and other similar laws/policies have not solved (Blanck et al., 2004; United Nations, 2007).

Advocacy and technology are two core strategies used by the disability community to advance the rights of people with disabilities, and to increase participation in public domains. While there have been important successes, further understanding of how these strategies and tools empower people with disabilities to connect government is needed. This research seeks to develop and enhance civic knowledge and practices of people with disabilities through civic engagement training. It undertakes empirical qualitative analysis examining the role of various advocacy strategies and use of technologies to facilitate the full expression and needs of people with disabilities in policy debates. The research gatherers data from four disability advocacy organizations, people with disabilities and other disability stakeholders to explore the inclusion and participation of people with disabilities in civic society, as outlined by Article 29 in the United Nations Convention on the Rights of Persons with Disabilities. The report begins with a brief overview of key literature related to disability, advocacy, technology and civic rights. It outlines the methodology, including research aims, design and limitations of the study. The results are presented in three stages: (1) Community resource assessment of disability advocacy organizations; (2) Training evaluations with people with disabilities; and (3) Focus groups and interviews with people with disabilities and key disability stakeholders. The research provides individuals, advocates, disability organizations and policymakers a better understanding of how to increase, advance and support civic participation of all citizens.

Background

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 organization (Degener & Quinn, 2002; Donoghue, 2003). Disability policies have typically been developed on behalf of people with disabilities, rather than with their direct participation (Braddock & Parish, 2001; Garcia-Iriarte et al., 2008; Parish, 2005). 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 even 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 people without disabilities, 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, & Schriner, 2003). Elected officials rarely solicit the specific input of people with disabilities, so it is important that people with disabilities are able to engage in public policy debate alongside the rest of society (Silverstein, 2010).

Disability research has acknowledged 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 impact 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 as though 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 engagement of people with disabilities in all aspects of policy debate and processes 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 the amount of 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 ten federal government offices, which resulted in government issued regulations for Section 504 of the Rehabilitation Act; 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); and 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 also a strong history of grassroots disability advocacy being used to elicit change and connect citizens with government. Prominent disability organizations, such as Access Living and the Progress Center for Independent Living, have played a significant role in informing and influencing disability policy debates in Chicago and across Illinois. This has included efforts towards deinstitutionalization, transportation accessibility, and securing access to sign language interpreters. In addition, the City of Chicago's Mayor's Office for People with Disabilities has also been active in ensuring access around public sidewalks, voting and schools, amongst other initiatives.

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). By making an effort to change the perception of the policy problem so that it interests the public, non-profits can produce change at the national level. 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 in policymaking. Most barriers fall into one of three categories: intrapersonal (skills and competence); interpersonal (team dynamics); or organizational (resources, decision-making processes, historical practices) (Foster-Fishman, Jimenez, Valenti & Kelly, 2007). One of the most common barriers that prevents people with disabilities from becoming self-advocates in a lack of resources. With a lack of funds to either purchase assistive devices or make trips to visit state representatives, having a voice in policy decisions can be challenging. Other situational 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. By increasing safe environments, supporting advocacy trainings, forming mentor relationships, we can help facilitate the development of self-advocacy skills for people with disabilities. In addition, teaching advocacy skills at the young age will help build an overall stronger movement that can help impact the political processes and decision-making of policies that affect those 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: 56). 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). The advances and increased use of technology by people with disabilities has led to considerable improvements in overall quality of life; including improving access to education and employment, as well as community living and social interactions. (McNaughton & Bryen, 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 for those that use alternative communication devices, 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, that are some aspects of new technologies that 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). Fortunately, many federal government websites are already accessible which will hopefully set the norm for the future and influence all commercial websites to adapt complete accessibility as a standard policy (Jaegar, 2004). 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 and related processes.

Disability Rights

When addressing the rights of citizens in civic society it is important to include people with disabilities in the decision-making process, particularly when those decisions impact 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 show a gap of seven percentage points 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, Schriner, & Shields, 2000), additional strategies are needed to increase participation of the disability community.

The national public and policy recognition of the need to increase political engagement of people with disabilities is also reflected internationally in the United Nations Convention on the Rights of Person with Disabilities (CRPD). People with disabilities played an active role in the development of the CRPD, which was unusual for a United Nations Convention because they are typically negotiated solely by representatives from United Nations member states (Lang, 2009). However during development of the CRPD, people with disabilities were represented by the International Disability Caucus, which spoke for about 50 disability organizations. This representation enabled people with disabilities to have a strong presence in the policymaking process. The CRPD 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 CRPD promotes the social model of disability and aims to remove barriers to the participation of people with disabilities and promote their inclusion in aspects of society. In order to meet that goal, the CRPD identifies eight rights-based principles that nations should embody in their national policies: respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; non-discrimination; full and effective participation and inclusion in society; respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; equality of opportunity; accessibility; equality between men and women; and respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities (United Nations, 2006).

Specifically related to civic engagement, Article 29 "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, 2008). The research draws on Article 29 of the CRPD to further our understanding of the facilitators and barriers to civic engagement of people with disabilities and disabilities stakeholders. Advancing our understanding of the effective tools and strategies to increase involvement of people with disabilities in public life is necessary so that we can ensure the rights of all citizens.

Methodology

Aims

The aim of the research 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:

- How do people with disabilities engage with government; and what is the role of policy knowledge, technology and advocacy strategies in this engagement process?
- Why do people with disabilities to engage in policy debate; and what are the perceived barriers and facilitators to increasing civic participation?
- What is the role of augmentative and alternative communicate devices, accessible information technology in enabling and increasing access to government for people with disabilities?
- 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 ADA Center (ADA) - two disability organizations at UIC 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. The ethical conduct was monitored by the UIC Institutional Review Board (Research Protocol # 2010-1123). The following section outlines the three stages of data collection.

1. 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 that was supplemented with interviews with key staff members 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; 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 as it relates 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?

2. 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. Civic engagement training for Access Living consisted of a series of two face-to-face training sessions, one that was more broad and introductory on each theme, and one that focused on the experiences of a lobbyist working in the state capital. Ten people with disabilities participated in the first session and 11 participated in the second; the participants were staff or volunteers with AL, so they were already highly engaged with the disability community and organizations. The trainings lasted 2.5 and 1.5 hours, respectively. PCIL and ATU collaborated on the second training, which was designed for people who use alternative and augmentative communication (AAC) devices. The training covered each theme, with emphasis given to how to use AAC devices effectively for advocacy. Due to the increased time needed for communication with adults using AAC, this training was divided into two, two hour, face-to-face sessions. The six participants in this training were identified by staff at PCIL or ATU. The ADA Center conducted their training via webinar. It contained information on each of the five teams, and emphasized national legislation and policy and how to use technology (the Internet, social networking) in order to engage with policymakers. Five people with disabilities participated in the two-hour webinar, each of whom was identified by staff at ADA after they advertised the availability of the training on their listserv.

The five themes were used to structure each of the trainings similarly so that they are comparable on a broad level. Each participant was asked to complete a evaluation form prior to and six to eight after each training. Depending on availability and accessibility requirements, participants completed the evaluations in person, via email or via phone. The evaluations consisted of approximately 10 close-ended (yes/no, Likert scale agreement, multiple-choice) questions that were designed to policy knowledge and levels of engagement, and six open-ended questions designed to better understand the civic engagement, have each individual. The qualitative data contained in these open-ended questions is used alongside the qualitative 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 the time constraints and poor completion rate of the pre-evaluation for the participants using AAC, people in the PCIL/ATU training were not asked to complete a post-evaluation]. In general, the result of the training and evaluations provide insight into the following research questions: How do people with disabilities engage with government; and what is the role of policy knowledge, technology and advocacy strategies in this engagement process? What is the role of augmentative and alternative communicate devices, accessible information technology in enabling and increasing access to government for people with disabilities?

3. Focus Groups and Interviews

Following the trainings, follow-up focus groups and individual interviews were conducted. The focus groups were conducted with the training participants, and were held six to eight weeks after the training to provide an opportunity to assess how their knowledge and participation in civic engagement was impacted. 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 in which to hear directly from people with disabilities on their perceptions and experiences in accessing government; increasing civic awareness and responsibility; the role of advocacy, technology and ACC 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. In addition, participants in the PCIL/ATU training 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 provided by this part of the research is useful for addressing all of the research questions, but it is especially pertinent to following research questions: Why do people with disabilities to 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 1 summarizes the number of participants in the various parts of this research project.

Table 1: Summary of Research Participants

Data collection stage	**ADA**	**AL**	**PCIL**	**ATU**	**Total**
Training participant	5	11 (10 in first session)	6	-	22
Pre-evaluation	5	10	5	-	20
Post-evaluation	4	11	-	-	15
Focus Group	4	9	6	-	19
Stakeholder Interview	2	2	2	2	8

Research Limitations

This research project had three primary sources of limitation: participant recruitment, technical difficulties, and participant response/dropout. Each of these are discussed in detail 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. 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. This is despite detailed instructions provided via 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 AAC, 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 e-mail listserv as a method to conduct the follow-up focus group, so that 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 as well, because it highlights the difficulty that people who use AAC have communicating in general, which is likely to be exacerbated in the civic engagement process, where 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 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 e-mail was their preferred method of communication, but they seldom checked or responded to it. If not for the vigilance of the research team and the flexibility with which they obtained data, that dropout rate would have been much higher.

Results

The results are presented in three stages: (1) Community resource assessment; (2) Training Evaluations; and (3) Focus groups and Interviews.

STAGE 1. Community Resource Assessment

Four organizations participated in the research: The Great Lakes ADA Center, Access Living, Progress Center for Independent Living and the Assistive Technology Unit at UIC. Below are organizational descriptions and summaries of how they engage in advocacy and technology.

Great Lakes ADA Center

The Great Lakes ADA Center is a program of the Department of Disability and Human Development at the University of Illinois at Chicago. Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin are the six states that make up Region 5 and each state has an ADA Steering Committee that represents the business community, government agencies, and disability rights groups. The Center prides itself on providing information, materials, technological assistance, and training on the Americans with Disabilities Act of 1990 (ADA). It offers a variety of training services in the form of audio conferences, online courses, podcasts, and webinars. Audio conferences are ideal for those who already have some knowledge about the basics of the ADA and serve as an enhancement tool and discussion forum to provide additional information. Online courses typically offer an understanding of the basic concepts and principles of the ADA for individuals interested in learning more. Another way the Great Lakes ADA Center disseminates information about the ADA is through podcasts, which help organizations and individuals stay up to date on changes in regulations. Lastly, webinars are generally used to conduct training workshops to aid in professional development. 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 types to share information. *The Great Lakes Chronicle*, employment legal briefs, the ADA document portal, an architectural compilation series, social networking sites, and smart phone applications are different ways current information about the ADA is distributed which helps reach all types of audiences. The Great Lakes ADA Center is highly focused on helping individuals understand the ADA and its influence in the community. By organizing commemorative ADA anniversary events and participating in the annual Disability Pride Parade, the Center is able to reach out and educate the community.

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, a teaching of advocacy skills, and the enforcement of civil rights on behalf of people with disabilities. The mission of Access Living 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.” The organization believes people with disabilities are their own best advocates and advocating can help to tackle everyday problems such as the lack of housing, personal assistance, and transportation options. Advocacy is a major area for Access Living and they specialize in community development and organization, policy analysis, and civil rights.

Within community development, Access Living supports six grassroots groups that each fight for social change in a specific area of interest. The community organizing team also works with the Arts and Culture Project 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. They also bring back information to the community to help consumers understand what is happening. Access Living has attorneys on staff to provide legal counseling on civil rights issues such as education, housing, and discrimination concerns. The civil rights team also helps to educate consumers on their rights and how the legal system operates. The independent living department at Access Living uses a peer-based philosophy to empower people with disabilities to overcome barriers to equality and helps enable a smooth transition to autonomous community living. They conduct additional training workshops in the areas of accessibility, financial literacy, and decision making. Access Living provides services in the areas of education, housing, healthcare, community integration, women's issues, immigration work, and legal issues via social networking and a newsletter in order to help people with disabilities become their own best advocate.

Progress Center for Independent Living Summary

The Progress Center for Independent Living (PCIL) is a community-based, non-profit, non-residential service and advocacy organization run by and for people with disabilities. The Progress Center holds the belief that "independence is the ability to control one's own life by making responsible choices from acceptable options." The PCIL was founded as part of the independent living movement and operates on the following ten principles: civil rights, consumerism, deinstitutionalization, demedicalization, self-help, advocacy, barrier-removal, consumer control, peer role models, and cross-disability. There are four core services the Progress Center focuses on providing for the community. First, it offers information regarding any disability related topic and makes referrals to other specialty organizations if needed. Next, it provides advocacy and direct support for disability rights. Thirdly, it teaches independent living skills including budgeting, travel, personal assistant management, and job seeking to help people successfully live on their own in the community. Lastly, it offers peer counseling, sharing, and problem solving for people with disabilities. In addition to the above services, the PCIL also provides supplementary services. It holds training sessions on housing, personal assistant, and

Medicare issues and offers drop-in services where consumers can use the center’s computers, resource library, or receive informal support. The Progress Center regularly conducts community education presentations to groups regarding disability rights, disability policy, independent living, and disability culture as well as trains consumers to effectively participate in lobby days in Springfield. By using social media, e-mail, pamphlets, and a weekly radio show, the PCIL is able to reach a wide range of consumers to educate individuals about independent living and all that it entails.

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 is able to serve more than 90 per cent of its clients in their own home, school, work, or recreational environment. The staff at ATU is made up of occupational therapists, physical therapists, rehabilitation engineers, and speech-language pathologists, all of who hold assistive technology as their area of concentration. What makes the ATU unique is its ability to bring evaluation and implementation services to the consumer in their natural environment. 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. Aside from providing actual technology for individuals, the ATU also offers educational options for professionals aiming to enhance their knowledge of assistive technology. They offer master’s level courses through the Department of Disability and Human Development, a continuing education certificate program, individual one-day workshops, and in-services to schools. ATU staff dedicates time to research as well; developing and testing new or modified devices is a regular practice for the clinicians. The ATU spreads information about their services through word of mouth, newsletters, digital pamphlets, academic publications, and conferences. By maintaining strong networks with technology vendors and other service providers, the ATU can serve the greatest number of individuals in the most effective way possible.

Summary Table

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 2 summarizes the community resource assessment in relation to the goals of this research.

Table 2: Summary of Community Resource Assessment

Organization	*Increasing policy knowledge/ awareness*	*Building Advocacy*	*Developing technology skills*	*Meeting CRPD Article 29*
ADA	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 those 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 on national legislation relating to accessible voting.
AL	Civil rights attorneys; community organizing; peer support; network with legislators; training workshops; newsletter.	Advocacy is a core function; focus on community development and organizing; support six grassroots teams.	Use social networking; trainings; technology is part of IL skills.	Focus on self-advocacy; community development teams encourage individual participation; attorneys assist with overcoming barriers.
PCIL	Provides information and referral services; community education; consumer training.	Focus on advocacy and independence; community outreach, with a focus on action.	Uses social networking, e-mail and a weekly radio show; technology is part of IL skills.	Focus on self-advocacy; consumer training; community education on disability issues and rights.
ATU	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 on AT; maintain networks with technology providers.	Services to individuals encourage their participation in society.

STAGE 2. Training Evaluations

The second stage of the research conducted civic engagement trainings with three different groups. 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. The results of those evaluations are presented in this section.

Consolidated Training Results

The organizations that were partners in this research emphasize community inclusion and independent living. With regard to civic life, an important factor is political efficacy, which Schur (2002) argues consists of both internal political efficacy (the belief that an individual has competency to participate) and external political efficacy (the belief that though political system is responsive to an individual's actions). Schur's research created an efficacy scale, so her findings are not directly comparable to the findings of this research. Her research compared people with and without disabilities, which, again, is not possible from the findings of this research because people without disabilities were not included. However, she found that people with disabilities have efficacy than people without disabilities. The findings from this research show a high degree of political efficacy, both before and after the trainings. Two of the questions that were asked in the evaluation are relevant to the concepts of internal and external efficacy. These are important concepts for this research, especially because the participants are highly engaged with organizations that focus on independent living and self advocacy, which require efficacy to be effective.

The concept of internal political efficacy is related to one of the evaluation items, which asked people with disabilities their degree of agreement with the statement, "I can identify areas where I can influence public policy." Aggregating across the trainings, the pre-evaluations show that most people felt that they had a good understanding of how they can influence policy, only 10 per cent of the respondents disagreed and 10 per cent were not sure (see Table 3). Following the training, everybody who attended one of the trainings agreed that they could identify an area where they could influence public policy. While not a complete measure of internal political efficacy, these results do suggest that people with disabilities are confident in their ability to identify areas of the policy process that they can engage with. The training helped to increase confidence across the participants, either strengthening that confidence or providing it. This suggests that these trainings could be effective tools for increasing the civic engagement of people with disabilities by increasing their confidence to identify areas that they can participate in and are important to them.

Table 3: Internal Political Efficacy

Answer	*Pre-Training*	*Post-Training*
Strongly Agree	30%	40%
Agree	50%	60%
Neither	10%	0%
Disagree	10%	0%
Strongly Disagree	0%	0%

Similarly, the concept of external political efficacy is related to another of the evaluation items, which asked fair degree of agreement with the statement, "I believe that my advocacy efforts can have an impact on policy." Again, aggregating across the trainings, the pre-evaluations show that, only 10 per cent of people disagreed. Following the training, everybody agreed with that statement, and more people strongly agreed with it than before (see Table 4). This question is a simple matter of external political efficacy, but it does show that people believed that their efforts would have a real impact on policy and the policy process.

Table 4: External Political Efficacy

Answer	*Pre-Training*	*Post-Training*
Strongly Agree	40%	47%
Agree	50%	53%
Neither	0%	0%
Disagree	10%	0%
Strongly Disagree	0%	0%

The results for these questions (and for the others, which generally follow the same pattern; see Appendix A) suggest a high level of engagement to begin. Furthermore, one of the 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, 2010). These results suggest that the participants are not representative of people with disabilities as a whole, because they are already highly engaged.

Nonetheless, the training did have an impact on how people responded to the evaluation questions before and after. Table 5 shows the cumulative responses across the evaluations for the six questions that were consistent between the pre-and post-evaluations. A chi-square test of significance (χ^2=9.4, df=4, p-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 likely become significant with a higher count). This means that 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.

Table 5: Cumulative Responses

Answer	***Pre-Training***	***Post-Training***
Strongly Agree	36 (31.6%)	37 (43%)
Agree	55 (48.2%)	44 (51.2%)
Neither	11 (9.6%)	3 (3.5%)
Disagree	10 (8.8%)	2 (2.3%)
Strongly Disagree	2 (1.8%)	0

Individual Training Results

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. Their answers to the open-ended questions are more interesting. Evidence from each training session is presented below.

ADA Center

Five people with disabilities participated in a training webinar that was led by the Great Lakes ADA Center. They all completed pre-evaluations, although one dropped out after the study and did not complete a post-evaluation. For all of the questions that were consistent across the pre- and post-evaluations, there was a marginal positive effect. When asked if they agree with the statement, “I understand what civic engagement is”, their responses included strongly agree (1), agree (3), and neither agree or disagree (1). All of them were able to offer a definition for civic engagement, with the focus being involved in the community and civil rights, duties and obligations. Following the training, the answers shifted slightly so that two people strongly agreed, one person agreed, and one person neither agreed or disagreed with that statement. One person strongly agreed, two agreed, one person either agreed or disagreed, and one person disagreed that they could identify areas where they can influence public policy. Following the training, three people strongly agreed and person agreed. When asked if their advocacy efforts could have an impact on policy, one person strongly agreed, three people agreed, and one person neither agreed or disagreed. Two people strongly agreed and two people agreed following the training. Again, this was a slight improvement.

Regarding technology, when asked if they knew how to obtain information on policy one person strongly agreed, three people agreed, and one person neither agreed or disagreed. All four people strongly agreed following the training. When asked if they knew how to use technology effectively to advocate one person strongly agreed, three people agreed, and one person neither agreed or disagreed. Following the training, three people strongly agreed, and one person agreed. These results suggest a strong influence on knowledge and use of technology following the training. People with disabilities use many websites as tools to be involved, especially government websites. They found technology to be beneficial because it is an easy way of obtaining information, especially because you don’t have to physically go places. In the end, they defined civic engagement in terms of being involved, especially in terms of public policy and disability rights. Only one of the participants has increased the amount of activity she has done, and she imagined writing letters to government offices. Another said that she had been involved a little bit in helping people with local election. People with disabilities mentioned that they use Facebook to stay connected, both personally and to learn about local politics. They especially like the “notifications” feature.

Access Living

Ten people with disabilities who participated in training at Access Living completed the pre-evaluation, and 11 completed the post-evaluation (the extra person arrived in the middle of the first training). Initially when asked if they agree with the statement, “I understand what civic engagement is”, most people with disabilities agreed (7), while two strongly agreed and one did not agree or disagree. However, when asked to define the term only half of the people with disabilities even attempted to do so. Following the trainings, all 11 either agreed (5) or strongly agreed (6). Therefore, the trainings increase the knowledge of the participants on what civic engagement meant. The training also had an impact on whether people with disabilities agreed that their advocacy efforts could have an impact on policy. Before the training, seven people agreed with that statement and three people strongly agreed, and following the training six people agreed and five people strongly agreed. That these people work for a disability advocacy organization likely influenced the fact that people believe that their efforts could make a difference. Still, there was a slight shift in their responses indicating that the training had a positive impact.

The training also helped people with disabilities learn how to access up-to-date information on policy issues. Before the training, there was a range of responses on understanding how to get up-to-date information, with most (7) agreeing that they knew how to do so, one person disagreeing, one person strongly agreeing, and one person neither agreeing or disagreeing. Following the training, 8 people agreed and three people strongly agreed. These results indicate that the training helped to inform people on how to access up-to-date information.

Prior to the training, people with disabilities noted that technology helps them engage with others, because it makes everything easier. They no longer have to physically be in the same room, which saves time over meeting face-to-face. People with disabilities defined civic engagement as being empowered, interacting with policymakers and legislators, and involved in decisions that impact their lives. All of the people with disabilities said it was important for them to be engaged with public policy because they are issues that impact their lives and they need to speak up. Barriers to more participation that they identified include trouble accessing people with power, transportation, fatigue, policy knowledge and time constraints. Coalitions were seen as important, and were understood as people from other groups getting together behind a single issued to increase numbers and make a change. Some participants noted that it was beneficial to have a lobbyist who had direct access to an official who could advocate on their behalf. Participants thought it was most effective when their activities are something they could be measured, like a phone call or a letter or participation at a rally or meeting. Protests and demonstrations were also seen as effective, as was having a good relationship with a legislator or legislative staff. As highlighted in the Community Resource Assessment, these are activities that Access Living regularly participates in.

Following the training, 10 of the 11 people could define civic engagement. Most of the definitions were about being involved in making social change, a key theme in the disability rights movement. Advocacy and working in groups for key factors, as was engagement with policymakers and legislators. There was agreement that it meant being proactive. All 11 of the people with disabilities could identify things they had done to the training to be more involved. Some of these were cultural related, such as participating in a dance production about taking power. However, the majority involved meeting with legislators, going to the capital, and participating in rallies and protests. Many of these were about budget cuts and the impact that they would have on disability services. It was unclear whether people participated in these as part of their job or outside of it. Barriers that they mentioned to more participation include the lack of power (because of lack of experience or age), not having enough time notice, having to travel long distances, having to make priorities, not having publicity, their health, and not having enough knowledge. People with disabilities wish they had more contacts, experience, policy knowledge, more time and a better understanding of the political process in order to be more effective. All but one had regular access to the Internet and they did not discuss any barriers to being connected to the Internet or access to a computer.

Access Living hosted two training sessions. The first was general and in the second one, a speaker focused on a current legislative debate and how he was involved. People with disabilities found both of them helpful. They liked getting a general understanding and the first one and then being more focused on a specific issue in the second one. This finding shows that trainings can be more beneficial when they build on one another and can focus in detail on the specific aspects of civic engagement, particularly for this group that was already highly engaged with the disability community.

Progress Center for Independent Living

Five of the six people with disabilities who attended the training that was specific to AAC users completed the pre-evaluation. They were very mixed with regard to their knowledge about civic engagement; when asked if they agree with the statement, “I understand what civic engagement is”, their responses included strongly agree (1), agree (2), disagree (1), and strongly disagree (1). A qualitative question asked them to define civic engagement, but three of the respondents said they did not know, and the only response with content said it was about voting and being involved. Therefore, these results question the validity of the responses (see next subsection).

There was more agreement that their advocacy efforts could have an impact on policy and that they knew how to obtain information on policy: four people strongly agreed and the other disagreed. Similarly, two people strongly agreed and two agreed that they could identify areas where they can influence public policy. There was agreement that they knew how to use technology effectively to advocate as four people strongly agreed and the other agreed. Three people with disabilities strongly agreed that they understood how a bill becomes a law, while one strongly disagreed and one did not agree or disagree.

All of the people with disabilities were registered voters and had voted in the last election. The respondents were divided on policy knowledge; only three of them responded to the question about the number of representatives in the government of (all correctly said true), while four people tried to identify the three branches of government, and only two of them did so correctly. It would have been interesting to see if these answers changed following the training as those topics were covered in detail. However, a post-evaluation was not administered to this group, so comparisons to assess the impact of the training cannot be made.

Most of the responses to the open-ended questions were very short or not responded to. However, the one issue that all participants noted was that the use of AAC allowed them to call for transportation, which is essential to participate in civic society. The participants also noted additional barriers to being more engaged in civic society which is included a lack of patience by others when communicating with an AAC user, inadequate support (i.e. personal assistance) to be further engaged, and lack of opportunities for more training/education on policy issues.

Evaluation Limitations

The results suggest the possibility of acquiescence, which refers to the tendency of survey and questionnaire respondents to answer "yes" or agree 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 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.

The qualitative results from the focus groups, which follow, provide good empirical data about the effectiveness of the training and how people were able to use it.

STAGE 3. Focus Groups and Interviews

This section presents results from the focus groups with people with disabilities and interviews with disability stakeholders. (See Appendix B for participant table). Three main themes emerged from the qualitative data: empowerment and civic rights; advocacy and action; and technology. This are discussed below.

Theme I: Empowerment and Civic Rights

Civic engagement involves all aspects of participation in civic society, such as lobbying and advocacy efforts on key issues and voting for or serving as elected representatives. People with disabilities spoke about civic engagement in terms of being "being involved", and "effecting change". The ability to interact with the community, policymakers, and other organizations was an important factor. Some people noted that it was important to have a voice in the "everyday things that affect you on a personal level at home or at work or with your family or property" (Kelly), as well as having an impact, "from the local level all the way up to the federal level" (Paul). There are strong incentives for people to be involved more in civic society, one advocacy staff member spoke of the reasons why:

> The incentives for getting engaged in civic issues is that we're going to recognize that there are other people that have the same issues we do. The ultimate goal is to join as a single voice to create that change that will benefit the whole community. The bottom line, like with any ethnic group and racial group, is that we have to understand to fight as one. We have to believe that at the end we're gonna win (Brenden).

The disability advocacy staff agreed with this view of civic engagement but also spoke about how it is important to first have an awareness of public policy issues in order to actually work towards influencing the policy process. Some staff saw that personal experiences and expertise play a critical role in effecting positive change. As one person said: "People who are affected by a problem actually participating in finding a solution and working together as a group to figure out what the best solution is" (Dana). The people working in the organizations in general believed their role was to create facilitators to empower people with disabilities to change or have access to society on an equal basis to others. The advocacy staff spoke of the barriers to being more involved, noting that it people with disabilities often do not have the same opportunities to voice their opinions in policy. Some staff linked this back to not being out in the community, due to factors such as the long history of institutionalization and nursing home placements, and isolation when living in the community. This has been exacerbated with cuts to cuts to essential community support services and longer wait times for services. One staff member noted the importance engaging in the political process:

> We live in a society where if we don't show [the government] the harms they're doing by cutting services, training, and technology for people with disabilities, it won't change. We need to show our society, government, our own communities, that the need is there and the desire to move forward is there. We need them to know we have dreams and desires, just like anyone else (Brendan)

The advocacy stakeholders suggested specific strategies of how to increase involvement of people with disabilities and disability advocacy organizations, the main one being further education and knowledge building on civic issues. This included voting rights and registering to vote, understanding policy processes, being empowered to engage with politicians, and increasing knowledge of rights law, such as the ADA. The role of community educators, help-lines, seminars and workshops were seen as critical in facilitating education and providing information on specific strategies so people with disabilities can be better advocates in the community. One person said:

> It would be good to see more people in the disability community become policy experts and understand processes at the level of legislation and policy, and how these things actually get done. It seems like we're often on the outside of the real nitty-gritty of how these things get done, and it would be great to see more people with disabilities go through some level of education so they actually learn how legislation gets written, and be involved in that process and effect some real change there" (Jeremiah).

Others noted how it was important that people with disabilities be more knowledgeable and involved than average citizens, because many people rely on government services and their lived are affected by these services. One person said, “without significant participation, people with disabilities can become victims of their needs or policies” (Tim). Both advocacy staff and participants noted that advocacy action was an extremely powerful and effective tool for promoting empowerment in people with disabilities. Advocacy staff touted centers for independent living as one of the most promising facilitators of civic engagement for people with disabilities. One staff member noted that centers for independent living “have the role, in addition to advocating and assisting people in living independently, to educate people and assist in policy changes to make their communities more welcome for people with disabilities” (Paul). Staff and participants see the role of these centers as instrumental for educating and empowering consumers. One participant described disability organizations as an “in-route” for people with disabilities to reach out to the government (Catherine). These organizations also seek to use forums to “educate consumers about their rights and issues that impact them or need to be changed in order to make their quality of life better” (Tim). These centers advocate on behalf of their consumers by lobby with the government, build relationships with legislators, work with state agencies and the governor’s office. In sum, “We [centers for independent living] translate what we learn and put it out for the community” (Andrea).

Despite strong action on the part of centers for independent living, many people with disabilities remain disempowered and discouraged. Some advocacy staff attributed this disenfranchisement to a lack of action on the part of people with disabilities:

> If people with disabilities want policies to be inclusive for their population, they need to get out there and make sure their voices are heard... There are no reasons that people with disabilities are not fully engaged in the voting process. If they want change, they need to be involved in the process and ask policymakers what they can do for the disability community (Paul).

Staff members urged their consumers to take action, stating that voting every few years is not enough to elicit real change. If people with disabilities do not stand up and resist policies that are detrimental to them, they will continue to feel powerless. Tim, of Access Living, acknowledged that a high level of activity is “key to advancing disability concerns.” Others emphasized a need for changing the attitudes of people with disabilities. One advocacy staff member noted that some people with disabilities are apathetic, and that “unless they decide it’s good to be involved, they won’t listen. We need to change that mindset and we are, but slowly. We need to motivate people to be more involved in society” (Lenny). Participants tended to express a sense of fear, rather than apathy, as a major barrier to participation; people with disabilities tended to fear that they would be “wasting time” (Eric) or that “what you care about won’t get changed” (Christina). A staff member at access living proposed that “some people can be embarrassed or think they aren’t good enough to do this work” (Andrea) and thus do not participate at all.

Stakeholders also brought to light the barriers that are created when policymakers are apathetic or uninformed about disability issues. People with disabilities can play an enormous role in the political arena, “but it’s only as good as the policymaker’s knowledge is” (Cassandra). Government officials’ beliefs and attitudes toward people with disabilities can be a major barrier to empowerment as well; often, the social perception is that people with disabilities “aren’t looking to be part of the process, they’re just asking for a handout” (Jeremiah). Overall, advocacy staff members and participants alike agreed that the capacity for change and empowerment lies within the person. One organizer summarized this sentiment:

> People become powerful by claiming power and acting powerful… there’s no higher authority. People with disabilities were told for so long that we’re a burden and not important so we need to stop internalizing that oppression; we have to use our power to make things better (Allen).

A significant empowerment strategy identified by both participants and staff was peer mentoring. Peer support was a critical factor in whether a person with a disability showed interest or felt enabled to participate in the political arena. Staff shared that the use of peer modeling allows people with disabilities to understand that they can have an impact in their society; when people see others like them taking action on issues similar to their own, they show a stronger desire to get involved (Dana). Participants generally agreed that having a mentor is important to a person with disabilities. One participant expressed the importance of mentoring in advocacy, saying “You have to learn by example from someone who has more advocacy skills than you. If you have the opportunity, you should tag along with them and make sure your voice is heard" (Jennifer). This sense of camaraderie can act as an invitation for people with disabilities to join with others to unite under a common cause. One staff member reflected:

> If a person has a friend with a disability or similar life experience, it affects what they're interested in. All community change activities involve risk. Peer support is partly why Chicago has a successful disability community; we're a community, not a professional organization. They don't do this to get rich or that change is going to happen tomorrow, but they do it to make friends and feel like they're in charge and doing something (Andrea).

There is a prevalent perception in the disability community that their collective voice is not heard and peer modeling and mentoring provides a greater incentive for others to take action and believe that their actions can effect change. Tim, a staff member at Access Living, stated that "when people actually take part in some sort of activity they become much more convinced that they have power. Once they're convinced they have some power, then the road is open for things to change."

Theme 2: 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 "letting somebody do something for themselves (Trevor). One staff member at Access Living 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 drastically different forms depending on both the advocates and the audience, staff at these disability organizations make it a priority to test and develop effective strategies for change. Brendan, a key advocacy trainer at Access Living, said:

> We train individuals about disability oppression and action. Strategies vary with environment, political or economic environment. Sometimes strategies are to educate

> departments on what's going wrong. What 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. Staff led and participated in training sessions, developed curricula, provided legal education, and worked to train consumers in self-advocacy methods. 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 though 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, for the first time in my life, 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 [and] connected to consumers on 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, staff and participants noted that often advocacy is viewed too narrowly. As disability rights legislation is increasingly enforced, the focus moves toward advocating for a high quality of life and a sense of belonging. A staff member at access living put it this way:

> For anyone studying advocacy, keeping track of the moving, changing field is really important....things are going away from just disability advocacy. We don't just want laws, we want lives… a nice place to live, want to be able to travel, to go on dates, be treated with respect (Andrea).

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. Some felt that expecting the government to reach out was unrealistic, considering that many public officials still have inaccessible public offices. 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.

Participants and staff suggested the government seek to gain knowledge about the disability community to further include them. Some called on the government to employ a staff person focused on disability policy to help connect them to people with disabilities. Another common theme was a desire for the government to hire more people with disabilities to gain their input directly and help break down barriers. Some staff viewed the root of disenfranchisement as attitudinal barriers. Traditionally, the society and the government have viewed people with disabilities as individuals that need help rather than valuable and powerful members of society. In addition to attitudinal and political barriers, the physical environment and economic structures can also be extremely limiting to a person's civic engagement. Access to public transportation and buildings and limited income were cited as barriers to political engagement. Staff shared that often consumers would be willing to participate in the government but are forced to deal with more pressing concerns, such as food and housing, before thinking about taking political action. Participants and staff urged that removing these barriers is the first step toward civic engagement. Even after basic needs are met, larger societal barriers play a large role in preventing people with disabilities from engaging with the government, which was extremely discouraging to participants.

Beyond this, many shared a sense of disconnection from others in the disability community in terms of information sharing; people with disabilities are often "demobilized and uninformed" (Tim). Participants felt that the government does a poor job of disseminating information about relevant policy changes. People are often not aware of the potential connections they could have. A staff member at the progress center noted that with available information many more people would likely become involved in disability rights issues: "There are hundreds I'm sure who want to get involved, but they don't know who we are and we don't know who they are. That's the biggest barrier: getting people connected" (Jeremiah). Disability organizations are seen as a potential solution to this problem. Staff at these organizations can seek out potential consumers in need of services and help facilitate access to information. However, demand in the community is far greater than what the organizations are able to provide. The limited capacity of disability organizations can be a barrier to advocacy and action efforts because so many organizations are underfunded. Staff acknowledged that the centers tend to carry out more direct service work than advocacy or information sharing because it is easier to find funding for direct service work as opposed to advocacy work. Yet for many, the lack of funding only strengthens the need for advocacy and information sharing. Gregory, a staff member, stated: "Trying to maintain adequate funding is always a struggle so during cutbacks, being able to voice an opinion against those and why services need to be maintained is even more important".

Theme 3: Technology

Technology is an integral factor in engaging in civic society, however many people with disabilities are largely unable to afford the technologies necessary for participation. People with disabilities expressed that more funding is needed for "speech-related services of course to help with communication and environmental controls" (Lenny). 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. A staff member said: “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 others 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 by the change” (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. 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 have 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. Internet technology 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. Nobody knows what disability you have online unless you tell them” (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. Electronic communication 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 their government to have a united conversation and efforts for social change.

Having access to the internet is of little use if the information available online is inaccessible. If information is not accessible to those with visual or auditory impairments, it is essentially useless. 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. 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). The government should have a responsibility to lead the way in accessible online information, according to participants. They have a responsibility under the ADA, but this is not always recognized. 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. 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. 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. 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. The research provides individuals, advocates, disability organizations and policymakers a better understanding of how to increase, advance and support civic participation of all citizens. 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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Appendix A: 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 policy.		I know how to use technology effectively in my advocacy efforts.		I know how to obtain up to date information on the policy issues that matter to me.		I know how bills are passed and become law.		Total			
	Response	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	Post	Pre	%	Post	%
ADA 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%
PCIL	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	13.3%		
	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%
Total	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%

Appendix B: Participant Summary Table

Pseudonym	***Organization***	***Role***
Allen	Access Living	Participant
Christina	Access Living	Participant
Dolly	Access Living	Participant
Marissa	Access Living	Participant
Donna	Access Living	Participant
Mary	Access Living	Participant
Evan	Access Living	Participant
Elizabeth	Access Living	Participant
Eric	Access Living	Participant
Jennifer	Access Living	Participant
Kristen	Access Living	Participant
Brendan	Access Living	Interview
Tim	Access Living	Interview
Andrea	Access Living	Interview
Dana	Access Living	Interview
Bridget	PCIL	Participant
George	PCIL	Participant
Lindsey	PCIL	Participant
Trever	PCIL	Participant
Bailey	PCIL	Participant
Alex	PCIL	Participant
Lenny	PCIL	Interview
Jeremiah	PCIL	Interview
Caroline	ADA Center	Participant
Erin	ADA Center	Participant
Rebecca	ADA Center	Participant
Catherine	ADA Center	Participant
Paul	ADA Center	Interview
Cassandra	ADA Cetner	Interview
Kelly	ATU	Interview
Gregory	ATU	Interview