

## Research Article

**“Every Vote Matters:” Experiences of People with Intellectual and Developmental Disabilities in the 2016 United States General Election**

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**Abstract:** This study explores the experiences of people with intellectual and developmental disabilities voting in the 2016 United States general election. Although the majority of participants voted, they still faced a number of barriers that point to larger problems with the United States’ election process and discrimination against people with disabilities.

**Keywords:** 2016 general election; people with intellectual and developmental disabilities; civic engagement

The United Nations General Assembly (2011) asserts “the right to vote is arguably the most important political right” (p. 4). Voting allows citizens to shape decisions that can indirectly and directly effect their quality of life (Agran, MacLean, & Andren, 2015). For this reason, Agran et al. (2015) call voting “the ultimate act of American citizenship” (p. 388).

Although election results can have many direct consequences for people with disabilities, historically they have been disenfranchised (Beckman, 2007). In the past, many people with disabilities in the United States were denied the right to vote because of a requirement of independence, a concept intertwined with ideas of competence and guardianship (Beckman, 2007). Even today, people with intellectual and developmental disabilities (IDD) and/or psychiatric disabilities are often denied voting rights based on restrictions at the state level (Beckman, 2014). As a result, the application of voting rights for people with IDD is inconsistent across the United States (Bell, McKay, & Phillips, 2001).

States can bar people with disabilities from voting based on ‘competence’ standards. This disenfranchisement occurs through four main methods: (1) the use of general guardianship status or a determination of general incapacity conferred by the court; (2) the court’s restriction of voting eligibility for specific individuals; (3) the application of outdated descriptors like “idiots” or “insane persons” to justify voting restrictions; or (4) the attribution of the status *non compos mentis* (i.e. not sane or in one’s right mind) as defined by individual states (Bazelon Center for, 2008, p. 6). As of 2016, 10 states barred voting by individuals under guardianship, 25 by a voting specific court determination, and four by *non compos mentis*. Eleven states had no disability-related restrictions (Bazelon Center for et al., 2016). People who lost the right to vote based on a state voter competence requirement may be able to challenge the requirement on the ground that it violates federal law. Laws that bar people who are ‘mentally incompetent’ or under guardianship from voting generally violate the Constitution and the Americans with Disabilities Act if they are used to take away a person’s

right to vote based on disability even if the person has the capacity to vote. These laws, however, typically require certain people—usually those who are the subject of guardianship proceedings—to meet standards that are not imposed on other voters. Probate courts in these states sometimes ask individuals who are the subject of guardianship proceedings to demonstrate an understanding of elections and politics that goes far beyond what is expected of the general public before they are permitted to vote (Bazon Center for, 2008, p. 12-13).

Recently, however, there has been state-by-state momentum to ensure people with IDD have voting rights (Bazon Center, 2008; 2012; Beckman, 2014; Bell, McKay, & Phillips, 2001). The voting rights of people with disabilities have changed over time through legislation and court decisions. For example, successful litigation against voting restrictions often uses arguments that competence ineligibility violates the Equal Protection and Due Process Clauses of the Fourteenth Amendment (Bazon Center for et al., 2016). The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act also bar discrimination against people with disabilities, including the denial of a citizen's right to vote. However, both the ADA and Section 504 "require an individualized assessment to determine if a person with a disability is qualified" (Bazon Center for et al., 2016, p. 8). Self-advocates have also been pushing to increase people with IDD's access to voting. Self Advocates Becoming Empowered (SABE), the largest self-advocacy group for and by people with IDD, spearheaded the Go Voter movement, providing training about voting for people with IDD and technical assistance to make voting accessible for everyone (Go Voter, n.d.). Further, the United Nations Convention of the Rights on Persons with Disabilities (CRPD) recently reaffirmed the right to vote for people with disabilities, including those with IDD (Beckman, 2014; Kjellberg & Hemmingsson, 2013). Unfortunately, even when people with IDD possess or secure the right to vote, doing so can still be difficult because of barriers. Large disparities exist between disabled and nondisabled people, with people with IDD having one of the largest voting gaps (Schur, Adya, & Kruse, 2013). According to the United States Election Assistance Commission, these disparities largely derive from barriers to access (Government Accountability Office, 2009; Schur, Adya, & Kruse, 2013). Of voters with IDD in the 2012 general election, approximately half reported polling place difficulties (Schur, Adya, & Kruse, 2013).

Various barriers may make voting difficult for people with IDD, or prevent them from voting altogether. With regards to physical barriers, people with IDD may have trouble getting to a polling place as transportation is a large need for people with disabilities (Agran et al., 2015; Bell et al., 2001; Belt, 2016; Schur et al., 2013). Not all polling places are physically accessible for people with IDD who use wheelchairs or mobility devices either (Schur et al., 2013). Moreover, without accessible materials people with IDD may have difficulties understanding ballots or voting machines because of their cognitive impairments (Agran et al., 2015; Bell et al., 2001; Keeley et al., 2008; Schur et al., 2013; Weiss, 1988). Attitudinal barriers may also negatively affect people with IDD's ability to vote. Service providers may not see voting as a priority for people with IDD because of low expectations about their abilities. However, research has found people of IDD are capable of making

informed decisions regarding voting (Agran & Hughes, 2013; Agran et al., 2015; Schriener et al., 2000).

Millions of people in the United States have intellectual and developmental disabilities (Boyle et al., 2011). They have the ability to be a powerful voting block that can direct attention to disability issues that affect millions of United States residents. Yet, people with IDD remain largely an untapped resource. For these reasons, this study aims to explore the experiences of people with IDD in the 2016 United States (U.S.) general election. The 2016 U.S. general election, noted for its heated presidential contest between Donald J. Trump (Republican) and Hillary R. Clinton (Democratic), was one of the most polarized U.S. elections to date (Huang et al., 2016). To reinforce that people with IDD are important constituents who are interested in and capable of engaging in the election system, our central intent was to explore people with IDD's engagement – both as citizens in anticipation of the voting process, and their ideology about the voting process in general – and to determine the barriers and facilitators to voting participation for people with IDD as they are key to expanding access and engagement of people with IDD. Rather than engaging in a discussion of which political ideology of people with IDD in the 2016 election, the subject of another study (see Friedman (2017), this manuscript focuses on the broader analytical points of this process, linking them to systems and attitudes.

## Methods

### Participants

This study took place in Chicago, Illinois. The location was beneficial for such an exploration of voting experiences because Chicago is complex and multifaced, both in terms of the general climate and disability community. The study took place in urban environment in a left-leaning city but one that is located in a generally conservative state. Chicago is portrayed as a mix of liberal politics and 'midwestern sensibilities'; it is also very diverse yet very segregated. According to the 2000 census, approximately 23% of Chicagoans had a disability (Facts and Figures, n.d.). However, despite a longstanding and persistent disability rights and advocacy movement in Chicago, Illinois consistently ranks as one of the worst states for institutionalization of people with IDD (Braddock et al., 2015).

Participants were recruited via flyers, distributed through self-advocacy organizations, organizations that serve people with IDD, and the state protection and advocacy agency. Study information was also distributed through word of mouth. To participate, people needed to self-identify as having an intellectual and/or developmental disability, be 18 years old or older, and speak English. Participants received \$30 compensation to help pay for transportation and time.

Thirty-four people with IDD participated in this study; demographics are presented in Table 1. About three-quarters of participants ( $n = 26$ , 76.5%) voted in the 2016 general election. Most participants ( $n = 24$ , 70.6%) had voted in a government election prior to 2016.

Although participants were not asked about the severity of their impairments, as a proxy measure they were asked about some of the skills that can make civic engagement more challenging. The majority of participants (61.8%,  $n = 21$ ) reported having trouble understanding complicated information; about half of the participants (47.1%,  $n = 16$ ) also had trouble reading.

Table 1

Demographics ( $n = 34$ )		
	%	<i>N</i>
Age		
18 to 24	17.6	6
25 to 34	55.9	19
35 to 44	5.9	2
45 to 54	5.9	2
55 to 64	8.8	3
Gender Identity		
Man	64.7	22
Woman	32.4	11
Race		
Asian or Pacific Islander	5.9	2
Black or African American	26.5	9
Hispanic or Latinx	44.1	15
Middle Eastern	5.9	2
Native American or Indigenous	2.9	1
White	17.6	6
Other	5.9	2
Where do you live?		
Own home or apartment	8.8	3
With parents or family	61.8	21
With a foster family	2.9	1
In a group home	23.5	8
Guardianship		
Own guardian	44.1	15
Has legal guardian	52.9	18

## Process

Focus groups were held three days after the 2016 general election, November 11, 2016. Participants first completed informed consent forms and surveys about demographics. While the majority did so independently, a portion of participants were supported by the research team or their support person, most often by having the items read aloud. They were then divided into four focus groups held simultaneously in separate rooms. A researcher with a doctorate in disability studies, Carli Friedman and three advanced doctoral students in disability studies facilitated the focus groups, which lasted approximately one to one and a

half hours. All facilitators had experience doing research with and/or working with people with IDD. The focus group questions especially focused on participants' experiences with voting the 2016 general election, including any barriers they may have faced trying to vote. Examples of topics and prompts included:

- For those of you that voted in the general election what did you like about voting?
- Were there any difficulties while trying to vote? If so, what were they?
- Based on what we just talked about and some of the things that were hard to do, what changes should be made to make it easier for people with disabilities to vote?
- How do you think we can get more people with disabilities to vote?

The facilitators did permit participants to bring support people (e.g., personal attendants, family, etc.) if they wanted (only a handful did so), but reminded support people of their role to only support the participants and not participate in the research.

## Analysis

I analyzed demographic data using descriptive statistics. Focus group data were analyzed using thematic analysis (Braun & Clarke, 2006). First, the researcher listened to the audio recordings of the focus groups and read the verbatim transcripts becoming immersed in the data. The transcripts were then examined again for patterns; initial codes were generated based on these patterns. Codes were grouped into major and minor themes (described below) and revised when necessary.

## Findings

Findings fell into three major themes: 1) Leading up to the election: decision making; 2) Participating in the election: barriers and supports; and 3) Future elections: the importance of voting.

### Leading Up to the Election: Decision Making

Leading up to the 2016 general election, participants used a variety of different methods to gather information to make informed decisions when they voted. An overwhelming majority of participants watched the presidential debates for the general election. One participant acknowledged, "That's how I knew what to vote for, and then I saw the debates I was like 'okay, now I know who to vote for'. They really helped me to figure out who I want to vote for." In addition to watching the debates, other participants spoke with family and friends. Others used other media, such as newspapers, local news, and the radio. Social media also affected the decision making processes of participants. For example, a number of participants read the articles they found on their Facebook newsfeeds. Another participant explained YouTube helped him make a decision in the 2016 presidential election. He added, "YouTube...I was just scrolling down to see...There are some good videos about what...judging about Trump or Hillary and all that. I wasn't sure which one should I pick so that helped me a lot."

## Participating in the Election: Barriers and Supports

Participants faced a number of barriers when trying to participate in the election process, though some were not necessarily disability specific. For example, a handful of participants experienced long lines when trying to vote. One participant noted their were “long lines, like unemployment.” Another general problem was the lack of information in languages other than English. Staff had to help a handful of participants translate some of the text into Spanish because although they spoke both English and Spanish, reading in English was difficult. However, the majority of the barriers faced by the participants with IDD were more specific to people with disabilities. A number of participants were unable to register to vote because they did not have state identification. In many states voters can register with other forms of identification, such as a birth certificate or a utility bill that includes name and address. People with IDD, however, are less likely to have access to these types of items, particularly if they live in a provider-managed group home.

Although the majority of participants found voting in the 2016 general election to be easy overall, they did note a number of basic accessibility barriers. One participant recommended, “Maybe if they had more places with wheelchair ramps that would make it easier for people with disabilities.” A group of participants who went to the polls together also mentioned a lack of signs, which made it difficult for them to locate their polling place. In addition to being more physically accessible, the participants also believed that a greater number of more conveniently located polling places with longer hours would facilitate voting for people with disabilities.

Despite a number of physical barriers, the majority of participants who used voting machines found them very easy to operate (e.g., “It was easy for me. It was the machine;” “I think it was pretty straightforward”). One participant even noted the machine made things more accessible for her. She explained the machine “was better” because “my hands shake. I have endpoint trembles [that make writing difficult].” Another complained that in comparison to the voting machines the paper versions of ballots can be difficult; the participant explained, paper ballots “sometimes can be a little confusing or hard. If I mess up I have to cross it out and get a new one.” Only two participants had trouble with the voting machines. One participant’s machine kept getting “stuck” and “breaking down,” while another had trouble because there was a lot of typing required.

Attitudinal barriers also played a role in the voting process of the participants in the 2016 general election. One participant had a negative interaction with the poll workers that were supposed to help him. He said, the poll workers “were giving us attitude. They were giving me and my stepmom attitude... I wanted to ask a question and they were giving me attitude. I was like, ‘I just wanted to ask a question.’” Ultimately, he decided not to ask his question because of the experience. Meanwhile, other participants described barriers that were both institutional and attitudinal. For example, one participant was unable to vote because his agency support staff did not bring him on Election Day or during early voting. Although he told his staff ahead of time that he wanted to vote and the organization was aware of his plans

to do so and agreed to facilitate, on the day of the election his group home staff did not drive him to his polling place. He explains, “They actually didn’t think it was important to me.” Although he believed voting was important “to make a change” when asked if this experience frustrated him he explained, “I didn’t think it would be nothing to be frustrated about” as if the problem was out of his hands. It is not uncommon for people with IDD to not be seen as experts about their own lives; for example, proxy research with family or staff instead of people with IDD themselves is still prominent in the IDD field. Undervaluing the knowledge and expertise of people with IDD, whether in research or in their personal decision making, is common, particularly when it comes to dignity of risk (Perske, 1972). However, people with IDD have unique experiences and understandings to which others many not have access; it is critical that staff and other support people recognize this moving forward.

Other participant comments also nodded to the idea that the reason many people with IDD do not vote is because of low expectations, that is they are not encouraged to vote because of the attitudes of the abilities of people with IDD. One participant noted, “They’re probably scared. Not scared but ‘look I don’t know if I can do it or not...It’s like ‘no try it, you know.’ That’s all that matters. You need to try and vote, that’s all that matters.”

In fact, with the right support, barriers were not a problem for participants and they voted successfully in the 2016 general election. Staff supported many of the participants in the study by helping them complete paperwork, finding the polling places, and getting to their polling places. For example, one participant said, “It was my first time voting and I wasn’t really registered. So I registered and voted. It was pretty cool. They [staff] were really good at explaining it. It was really cool.” Another participant noted, “If you can’t use your hands to vote, you can tell your staff to help you. Do you see what I mean? Making it for people to make it more easier for them to vote.” A number of other participants also went voting with their family members such as one participant who recounted, “When I went to the library [to vote] I had to put a card in [the voting machine]. I didn’t have no problem with mine, no problem whatsoever. She [my sister] helped me, and I thanked her for helping me”

### **Future Elections: The Importance of Voting**

Participants agreed it is important to continue to vote in future elections. One participant instructed, “You have the right to vote, and you’re supposed to vote. If you don’t vote, your vote won’t count.” Another participant proclaimed, “Spread the word so lots of people with disabilities can be like your vote matters. It will matter. Or it does matter.” In addition to announcing the importance of voting, participants also went on to discuss why this is the case. Participants recognized voting as a mechanism to voice their opinions, captured in statements such as: “We have the right to speak!”; “You can get your voice”; and “You ain’t voting for who somebody else told you to vote. You vote because you want to vote.” They also recognized the role voting plays in shaping the government. As one participant explained, “[People] just need to get out there and vote for who they believe in. Who they feel would make the country stronger.” Another conceded, “We don’t want the president to suck...I didn’t want to vote at first but I said ‘You know what? I’m going to vote because every vote

matters. You don't be missing the vote.'" Participants also recognized that the election's victor would impact the issues they care about as well as them directly. Many discussed key issues such as services and supports, domestic violence, and international relations as factors that determined who they voted for in the 2016 presidential election (see Friedman (2017)).

## Discussion

With the proper supports, people with IDD are willing and able to participate in the voting process. Participants with IDD in our study actively engaged with the 2016 U.S. general election. They watched the debates, they spoke with their families and friends, and they researched candidates via new and old media. In other words, they participated in very similar ways as the general population. The participants also understood the impact the election could have on both their lives personally and the larger direction of the country.

The majority of participants had few problems when voting in the 2016 general election. However, parallel with previous research (e.g., Agran et al., 2015; Bell et al., 2001; Keeley et al., 2008; Schur et al., 2013; Weiss, 1988), people with IDD faced accessibility barriers in the 2016 general election. Some of these barriers point to larger problems with the U.S. election process, such as long wait times or a lack of non-English language information, while others specifically relate to inaccessibility and discrimination against people with disabilities. Although the majority of participants did not have trouble with the voting machines or the voting itself, attitudes, both individual and institutional, served as barriers for some participants. Support professionals and organizations that serve people with disabilities either have the ability to facilitate election participation of people with IDD or serve as gatekeepers that make voting more difficult. In fact, research has found that organizations can play a key role in increasing people with disabilities' ability to exercise voting rights (Friedman & Rizzolo, 2017). As shown in this study, for many people with IDD, the ability to vote may hinge on the organization's commitment to bringing them to the polls. Unfortunately, because of societal attitudes about people with IDD, organizations and direct support professionals may not recognize that people with IDD are not only capable of voting but also are interested in doing so. Historically, the voting rights of people with disabilities were denied because of competence. Prior to suffrage women were denied the right to vote under similar pretenses (Baynton, 2001). However, suffragettes reinforced people with disabilities' exclusion in order to win the right to vote, arguing, "They [women] were not disabled...and therefore were not proper subjects for discrimination" (Baynton, 2001, p. 34).

IDD's etiology is and always has been intertwined with ideas of competence. Early constructions of IDD in the United States were tied to "a failure of the will" (Trent, 1994, p. 16). As a result, IDD was not only pathologized but also people with IDD were institutionalized and later sterilized (Trent, 1994). While today there are more complex understandings of people with IDD, the devaluation of people with IDD is still explicitly and implicitly evident in the ways that persons with IDD are characterized and discussed (Carlson, 2010). Such constructions and their overwhelming emphasis on impairment "give rise to

further discourses of *personal pathology*, of *individual difficulties* and of *dependency* in the face of *care* (Goodley, 1997, p. 369).

These stereotypes regarding the presumed competence of people with disabilities carry forward even today as many states deny voting rights based on ‘competence’ standards (Bell et al, 2001). One self-advocate explains, people:

“Quickly assume that people [with IDD] don’t have the capacity to understand or know what’s happening in their lives, or somebody has to help them, or somebody has to explain it. And that’s not the case. Sometimes that kind of thinking gets you riled up. We are always needing to explain to people that people are capable. You know, most other disabilities, people look at people as, ‘Oh, look what they can do, that’s wonderful. Oh.’ They sort of get amazed. You say a [intellectual or] developmental disability and, ‘Oh! There’s something wrong, or that’s dangerous’” (Caldwell, 2011, p. 319).

Thus, it is not enough for organizational structures to be changed or physical barriers to be addressed. Stereotypes about the abilities and interests of people with IDD need also to be dismantled in order for more people with IDD to have the ability to exercise their voting rights. As their effects can trickle down to smaller acts such as voting participation, more attention to systemic barriers is also needed, not only regarding competence (and by extension guardianship) but also community integration. Although deinstitutionalization of people with IDD has reached an all-time high, for many people with IDD community integration is still rare (Braddock et al., 2015; Friedman & Spassiani, 2017). However, changes to these systems are necessary, especially as with community integration comes choice making opportunities. For example, when people with IDD have choices about their support staff, they are twice as likely to vote (Friedman & Rizzolo, 2017).

Our study has a number of limitations which should be noted, particularly regarding our sample. Although I paid subjects for participating in focus groups, they volunteered to participate based on flyers distributed mainly by word of mouth. As a result, there is a chance of self-selection bias. Moreover, because of the design of my study participants were required to communicate verbally. Thus, the experiences and views of people who use nonverbal communication, or have more severe impairments were not necessarily captured. This study was limited by a lack of member checking or data review by additional researchers. It should also be noted that participants were from a large urban area and its suburbs. Although diverse, the city is solidly Democratic. Moreover, there are contextual factors, such as the state’s bias towards institutionalization (Braddock et al., 2015), that may have impacted participant’s ability to and interest in voting. The 2016 U.S. general election in particular was noted for its heated presidential contest; as such, participants’ enthusiasm may have been unique to the 2016 general election. It remains to be seen if the participants’ enthusiasm for future elections will continue. This passion, however, is certainly reflected in large segments of the American populace at the very outset of the Trump Administration. Within the first 100 days of Trump taking office, the nation has already seen its largest collective protest in U.S. history, The

Women's March, as well as a surge of people, particularly women, registering to run for office (Cauterucci, 2017; Gajanan, 2016).

Despite enjoying participating in the 2016 general election and having an interest in voting in the 2018 general election, participants had mixed responses when asked if they would vote in the next local election. While some participants said they would, others did not think they would. When asked why, one participant said: "I don't know [why]. It's because... I mean not concern me, but it doesn't really. I don't know how you say it, [it isn't as] interesting to me." This finding suggests more education is needed so that people with IDD, like the general public, understand the important role of non-presidential elections. Perhaps if the election process is more accessible and relatable for people with IDD, it will help more people with IDD become engaged. As one participant admitted, "I wasn't relating to politics until this election, [then] I was like 'okay, pretty interesting!'"

Voting is a critical form of civic engagement because it allows people with IDD to contribute to decisions that will both directly and indirectly impact their lives. As one of the largest social minority groups in the United States, if actively engaged, people with disabilities have enough collective power to draw attention to issues that could directly facilitate their empowerment and equity of opportunity. Yet, even among the disability community, people with IDD's opinions and participation are often devalued (Charlton, 1998). This study was influenced by the understanding that people with IDD are legitimate producers of knowledge, especially about their own experiences and perceptions, they are important constituents in the election system. Yet, because of power imbalances people with IDD often need to advocate for their rights, especially rights many nondisabled people take for granted. Facilitating equity of access to voting and other forms of civic engagement requires attention to barriers including structural power inequalities and entrenched ideas about competence "because every vote matters."

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