GRASSROOTS PROJECT
ENGAGE CONNECT ADVOCATE

Year-End Report

Fiscal Year 2025

About this Report

The Grassroots Project Year-End Report for Fiscal Year 2025 was prepared by Project Co-Directors Kate Brady and Alixe Bonardi of Human Services Research Institute (HSRI), and Project Evaluator Amie Lulinski, Ph.D.

Special thanks to Laura Bernas, Lindsay DuBois, Monique Stamps, and Carole Rosen, who supported data analysis and report preparation.

Cover art: “Untitled 03/07/2009” by Barry Kahn, Pure Vision Arts.

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Executive Summary

Project Overview and Membership

The Grassroots Project is co-directed by Kate Brady, PhD, ABD, and Alixe Bonardi OTR, MHA, and administered by HSRI with funding from the Administration for Community Living (ACL). After one year of bridge funding, the project has completed the first year and is embarking on the first option year of this novel and impactful initiative designed to strengthen cross-disability and cross-generational leadership in home and community based services (HCBS) systems. The project supports advocates with disabilities and their allies to connect, learn, and influence how services are designed and delivered—advancing a vision of communities where people with disabilities actively participate and lead in shaping high-quality, inclusive supports.

Throughout the project year (October 2024–September 2025), the Grassroots Project brought together a robust and diverse membership base. The National Action and Advocacy Coalition (NAAC) includes 14 national organizations representing a wide range of disability communities and policy perspectives—from independent living and self-advocacy networks to family and cross-disability alliances. Complementing this national membership are 11 State and Local Action and Advocacy Coalitions (StAACs and LAACs) spanning 10 states and territories, each building local leadership and organizing networks of people with disabilities and family members. Together, these groups form the foundation of a growing national network committed to advancing disability-led systems change through shared learning, collaboration, and coordinated advocacy.

The Grassroots Project's FY 2025 evaluation reflects a year of deepening capacity, connection, and influence across disability-led networks at the national, state, and local levels. Grounded in a participatory *Most Significant Change* (MSC) approach, the evaluation team gathered data through monthly reports, supplemental reflections, engagement and project surveys, and structured story-sharing sessions. These multiple methods captured not only the scope of activities but also the lived experiences and priorities of the advocates driving this work.

Data Collection Overview

Over the 2024-2025 project year, the membership of the National Action and Advocacy Coalitions (NAAC) and the State and Local Action and Advocacy Coalitions (StAACs and LAACs) submitted structured reports documenting technical assistance, leadership training, partnerships, and policy engagement. Surveys collected feedback from more than 500 participants. Quantitative data highlighted strong advocacy engagement and learning outcomes, while qualitative stories offered a deeper view into how advocates and coalition members are shaping change within home- and community-based services (HCBS) systems.

Key Findings

Across all levels of the Grassroots Project network, three major themes stood out:

1. **Collaboration and Connection:** Members consistently reported that the most significant changes stemmed from strengthened collaboration and the evolution of networks into cohesive communities with shared purpose. This year saw members moving from coordination to co-creation—building trust, shared goals, and unified strategies that amplify lived experience at every level.
2. **Leadership and Influence:** Members with disabilities reported increased visibility, confidence, and active participation in policymaking spaces. Survey data show that 93% of participants learned something useful for their advocacy, 91% felt more confident, and 94% were likely to take future advocacy action. Members are now leading meetings, providing legislative testimony, and shaping policy campaigns within and beyond their home states.
3. **Knowledge Translation and Systems Impact:** Members used education and plain-language communication to translate complex HCBS and Medicaid topics for both advocates and policymakers. These efforts improved understanding of community-based supports and helped bridge information gaps that often limit participation and impact.

Across the network, members highlighted shared strengths: the creation of inclusive communities, the development of accessible educational tools, and the advancement of disability leadership within advocacy infrastructures. Consistent opportunities for connection—through regular meetings, retreats, and shared campaigns—helped sustain engagement and momentum.

Challenges and Continued Commitment

Members also acknowledged ongoing challenges—competing priorities, limited funding and staffing, shifting policy landscapes, and difficulties engaging lawmakers or rural communities. Many noted the fatigue that comes from persistent advocacy in the face of slow change. Yet, in the spirit of disability justice and community care, members continue to engage in advocacy work.

They described intentionally building new partnerships, finding creative ways to stay connected, and using accessible formats to maintain communication and visibility. Some coalitions established peer support circles or informal mentoring groups to sustain one another's energy. Others turned to storytelling, public education, and local advocacy campaigns as ways to keep disability issues visible. This resilience underscores one of the central findings of the evaluation: the movement's strength lies in its adaptability and in members' collective determination to keep working toward equity and inclusion, especially when systems are slow to change.

Looking Ahead

The findings point to strategic opportunities for the next phase of the Grassroots Project:

- Expand structured leadership and peer-led "train-the-trainer" programs.
- Increase civic-engagement training focused on legislative testimony, public comment, and media advocacy.
- Strengthen outreach to long-term supports and services (LTSS)/HCBS users, youth, and underrepresented communities through plain-language and culturally responsive engagement.
- Continue investing in infrastructure, relationship-building, and peer support to sustain participation and mitigate burnout.

This project year demonstrates meaningful progress toward a disability advocacy ecosystem led by people with disabilities, informed by shared learning, and grounded in community. Despite barriers, members across the Grassroots network are continuing to show up, organize, and lead—reminding us that advocacy is sustained not only by resources, but by persistence, connection, and shared purpose.

Overview

Participatory Action Framework

HSRI employed a mixed methods approach to the evaluation of this project. Specifically, the participatory storytelling approach of Most Significant Change (MSC) was used to capture and analyze stories of significant impact or change brought about by a program or intervention. Developed in the 1990s by Rick Davies, MSC focuses on identifying and evaluating the most meaningful outcomes from the perspectives of the people affected by a project. The MSC approach was incorporated into evaluation of the impact of the Grassroots Project because "policy change is political, nonlinear, and inclusive of opposing forces. Policy change occurs as part of an 'infinite' game, where players come and go, the rules are changeable, and there is no defined endpoint" (Raynor, Coffman, & Stachowiak, 2021). The MSC framework allows for evaluation to be responsive to the varied areas of change and connect with individual's priorities, aligning well with the context-specific nature of the grassroots organizations.

Self-Evaluation Process

HSRI created a logic model based off the 27 specified outcomes of the Grassroots Project. For each outcome, the HSRI team identified or created a suitable data source (see Appendix A for the crosswalk of project outcomes and data sources). This step was the foundation for a comprehensive evaluation process designed to assess the project's impact at the individual, local, state, and national levels. The following section provides an overview of each data source used in the evaluation.

Project Data Sources

Monthly Report

Each grantee submitted a monthly report (see Appendix B for NAAC Monthly Report and Appendix C for StAAC/LAAC Monthly Report) that included quantitative and qualitative information. Quantitative information included the number of technical assistance events offered, the number and type of resources shared, number of office hours offered, the number and types of waivers commented on, and number of advocacy groups supported. Qualitative information included links to training events, resources shared, and organizational partnerships and collaborative activities.

Supplemental Report

This project year, grantees were asked about most significant changes in a Supplemental Report. The members of the NAAC completed and submitted a Supplemental Report in May (see Appendix D) and again in September 2025 (see Appendix E). The StAACs/LAACs completed and submitted a Supplemental Report in September 2025 (see Appendix F). The Supplemental Report provided an opportunity for grantees to reflect on what is going well, challenges, impact, observations of rights restrictions and responses, and most significant changes.

Engagement Survey

To evaluate the impact of activities conducted by the NAAC, StAACs, and LAACs, each grantee was encouraged to distribute a post-event survey via Survey Monkey participating individuals (see Appendix G). In addition to collecting information about the overall satisfaction with and accessibility of the event, participants were asked how likely they were to take action in their own advocacy, collaborate with new people, and engage with Grassroots Project in the future. Participants were also asked whether they felt more comfortable and confident in advocating as a result of their involvement in the activity.

Project Survey

Project outcomes focused on increasing knowledge, strengthening advocacy and civic engagement, using knowledge to inform state and local systems, and leveraging resources to create new coalitions and sustain them. Many outcomes relate to individual experience which required surveying at the level of the individual. There was, however, not an existing survey to use that would meet project needs.

HSRI developed a Project Survey (see Appendix H), informed by research literature (see Appendix I), to assess individual-level advocacy knowledge and civic engagement. The Grassroots Project team added additional project-specific questions to align with the identified outcomes. The Project Survey, initially intended to be fielded twice during the project period, was fielded once from May 15 to July 25, 2025, using Survey Monkey.

Miscellaneous Data Sources

In addition to formalized methods of collecting project specific data, we used virtual means in virtual meetings to receive input. This was done using Menti polls to ask specific questions.

In an end-of-project-year meeting on September 13, 2025, grantees shared highlights and reflections on their coalition's experience with grassroots advocacy successes and challenges for the purpose of cross-coalition learning. Grantees' reflections are included in this report.

Findings

All survey and report responses were collected using Survey Monkey, which allowed download of data to an Excel workbook where the data was cleaned, coded, and analyzed for key themes. Detailed below are findings from the four main project data sources—Monthly Reports, Supplemental Reports, Engagement Surveys, and Project Surveys.

Monthly Report Findings

Monthly reports requested both quantitative and qualitative information on the following general areas:

1. New organizations engaged and/or partnered
2. TA tools and resources shared (with specific interest in those resources related to leadership).
3. TA events (with specific interest in those events addressing leadership training and/or train-the-trainer activities)
4. Advocacy groups supported via TA
5. Materials disseminated
6. Policy areas addressed (with a specific interest in HCBS Waivers comments)

National Action and Advocacy Coalitions

Ten NAAC members were contracted as of January 2025, with four more joining in March. This resulted in nine monthly reports for each NAAC (with the exception of those contracted in March). Over the course of the project year the 14 NAAC members met outcomes of increasing the degree to which Grassroots Project networks represent the breadth of the disability community: NAAC members, engaged 45 new organizations, 20 of which broadened the spectrum of representation. Additionally, some NAAC members formally partnered with 25 organizations, 15 which expanded the spectrum of representation. NAAC members shared 210 technical assistance resources, 21 of which addressed leadership engaging 5,118 participants. NAAC members held a total of 235 office hours with 2,226 people in attendance. There were 120 hosted leadership activities—17 of which were provided in a train-the-trainer format. NAAC members also continued to disseminate materials (449 products shared) and support StAACs/LAACs

(407) with technical assistance. There were no CMS site calls or site visits, however, 19 waivers were commented on.

NAAC members covered a broad range of policies that fall under the umbrella of the seven designated ACL “Priority Areas”: caregiver crisis (39), civil rights (65), community inclusion (65), health and safety in community living (57), HCBS Settings Rule (32), person-centered planning, consumer direction, and self-direction (52), and technology (18).

Tables 1 and 2 show NAAC monthly report data and ACL Priority Areas addressed.

Table 1. National Action and Advocacy Coalition: Monthly Report Data by the Numbers

	Jan/Feb	March	April	May	June	July	Aug	Sept	Total
New organizations engaged	5	2	8	7	4	7	6	6	45
New organizations expanding diversity	3	2	3	2	1	2	3	4	20
New coalitions partnered with	2	2	4	5	2	3	1	6	25
Organizations partnered with expanded diversity	1	1	3	4	1	2	1	2	15
TA tools	18	3	23	33	29	40	30	34	210
TA tools addressing leadership	0	0	3	3	3	3	5	4	21
TA events	16	2	46	32	25	29	29	24	203
TA events addressing leadership	3	1	5	3	5	4	6	2	29
Participants in TA leadership activity	16	0	1512	387	490	879	978	856	5118
Office hour sessions	24	12	29	40	26	37	46	21	235
Attendees at office hour sessions	204	160	154	338	276	433	442	219	2226
Hosted leadership activities	10	3	26	19	15	18	12	17	120
Leadership activities that were "train the trainer"	1	0	2	2	5	2	4	1	17
Policies actively addressed	23	20	56	48	23	37	23	44	274
CMS site calls	0	0	0	0	0	0	0	0	0
Materials disseminated	28	3	153	56	30	54	65	60	449
Waivers commented on	8	1	3	4	0	1	1	1	19
StAACs/LAACs supported via TA	23	5	119	132	34	31	30	33	407

Table 2. National Action and Advocacy Coalition: ACL Priority Areas Addressed

Which of the following ACL Priority Areas has your Grassroots Project addressed this reporting period?	Jan/ Feb	March	April	May	June	July	Aug	Sept	Total
Caregiver crisis	4	2	6	6	6	6	5	4	39
Civil rights	7	1	11	8	10	11	7	10	65
Community inclusion	6	1	10	9	12	10	7	10	65
Health and safety in community living	4	1	10	8	10	10	7	7	57
HCBS settings rule	2	2	7	4	4	6	2	5	32
Person-centered planning, consumer direction, or self-direction	5	2	10	8	7	8	6	6	52
Technology	0	0	4	3	3	4	2	2	18

NAAC grantees reported monthly, including open-ended questions. Key themes are summarized below.

1. **New advocacy organizations or/or advocacy and action coalitions engaged.** Over the course of the project period, NAAC members engaged with nearly 80 grassroots and disability organizations representing local (14), state (24), national (35), and international organizations (2). These organizations engaged in work on a variety of topics including addiction and wellness, advocacy, aging, autism, brain injury, caregiving, disability (health, policy, advocacy, rights, inclusion, and services), education, hunger and food insecurity, independent living, intellectual and developmental disabilities, mental health and wellness, access to services, housing, law, and sexual violence.
2. **Partnerships with new advocacy organizations and/or action and advocacy coalitions.** During the project period, NAAC members partnered with nearly 50 organizations representing local (6), state (7), national (27), and international (3). Organizations represented expertise and work in the areas of aging, autism, caregiving, independent living, intellectual and developmental disabilities, disability (health, rights, policy, advocacy, and services), mental health, addiction, law, and public policy.
3. **StAACs/LAACs supported through the provision of technical assistance.** NAAC members supported nearly 50 state and/or local advocacy groups through the provision of technical assistance. Target populations of the groups supported included advocacy, disabilities (including autism, IDD, and brain injury), aging, and Medicaid (specifically those groups representing 1115 re-entry waivers).
4. **Technical assistance tools and resources shared.** During the project period, NAAC members provided over 130 technical assistance tools and resources, with topics including the federal budget process and program funding, advocacy, employment, family support, Medicaid and HCBS, mental health, paralysis, plain language resources, and 1115 re-entry waivers.
5. **Technical assistance tools and resources that support leadership training.** Combined, the NAAC provided approximately 20 technical assistance tools and resources that included advocacy, how to get involved on boards and advisory committees, developing easy read resources, and conflict management. Many of the resources developed were specific to people with intellectual and developmental disabilities. Additional target audiences included autistic people and nonprofit organizations.

6. **Technical assistance events provided.** NAAC members held more than 80 TA events addressing a myriad of topics including the Americans with Disabilities Act, advocacy, aging, disability, autism, HR 1 (OBBBA), coalition building, communities of practice, easy read content, employment, education, family support, federal government structure, leadership, legislation, and Medicaid. TA was provided to groups including: advocacy groups, community partners, service providers, students, parents and family caregivers, and self-advocates.
7. **Dissemination of materials.** NAAC members disseminated nearly 90 resources over the course of the project reporting period via newsletters, listservs, social media posts, webinars, position statements, and more. Topics included advocacy, civic engagement, the federal budget process and HR 1, disability awareness and policy, education, sub-minimum wage, Medicaid HCBS and final settings rule, Medicaid waiver comments, Make America Healthy Again proposals, long COVID, mental health, opportunities for story-sharing, and voting. Resources were intended to be useful by a wide range of audiences, including the general citizenry as well as people with disabilities and Medicaid program participants.
8. **Leadership activities hosted.** Over 30 TA events specifically addressing leadership were held during the project reporting period. The target audience was self-advocates/those with lived experience and allies. Topics covered advocacy, federal funding of DD Act partners, Medicaid, and mental health.
9. **Train-the-trainer leadership activities provided.** Nearly 20 technical assistance events involved a “train-the-trainer” approach in which participants were trained to become a trainer of the topic covered. The target audience was advocates with lived experience and allies. Topics included Medicaid, advocacy, federal budget, and state budget processes, with the goal of empowering grassroots organizations with information needed to work effectively.
10. **Hot topics discussed.** The Grassroots Project grantees hosted regularly scheduled office hours and regularly prompted the NAAC membership to raise priority topic areas for their membership. Based on a thematic analysis of items reported, priority topics included: advocacy (e.g., educating legislators regarding the importance of funding using data), the caregiver crisis, education, implementation electronic visit verification, EVV, federal and state appropriations/budget, HHS reorganization, and Medicaid (funding, eligibility, HCBS, waitlists).

11. **National, state, and/or local policy addressed.** An analysis of themes resulted in the following key categories of policies addressed. This is not an exhaustive list, however, represents a large proportion of policy topics such as autism, caregiver crisis, education, employment, federal budget, federal agency reorganization, Medicaid, person-centered practices and self-direction, and voting.

State and Local Action and Advocacy Coalitions

Eleven StAACs/LACCs were under contract by March 2025. This resulted in seven monthly reports for each StAAC/LAAC. Overall, StAACs and LAACs reported engaging with 36 new organizations, 14 of which expanded diversity. Additionally, they reported formally partnering with 16, nine which expanded the degree to which Grassroots Project networks represent the breadth of the disability community diversity. Ten StAACs/LAACs reported an increase in coalition members who use LTSS/HCBS. Seventy-two leadership activities were hosted for 1,293 participants. Six of the activities were in a train-the-trainer format. During the reporting period, 20 StAACs/LAACs reported an increase in the number of participants with lived experience serving in leadership roles. Additionally, 28 StAACs/LAACs identified up-and-coming leaders. Thirty-eight indicated an increase in the number of peer support and/or networking activities addressing advocacy on ACL priority areas. Eighty state and/or local policies were addressed. No CMS site calls occurred; however, StAACs/LAACs reported commenting on two waivers during the public comment period.

Like the NAAC members, StAACs/LAACs discussed a wide range of policy topics falling under ACL “Priority Areas”: caregiver crisis (32), civil rights (35), community inclusion (61), health and safety in community living (41), HCBS Settings Rule (27), person-centered planning, consumer direction, and self-direction (39), and technology (12).

Table 3. State and Local Action and Advocacy Coalitions: Monthly Report Data

	March / April	May	June	July	Aug	Sept	Total
StAACs/LAACs that engaged new organizations	9	5	6	6	4	6	36
StAACs/LAACs that engaged with organizations which expanded diversity	5	4	1	1	1	2	14
StAACs/LAACs that partnered with new coalitions	4	3	1	4	2	2	16
StAACs/LAACs that partnered with new coalitions which expanded diversity	2	2	1	1	1	2	9
StAACs/LAACs that saw an increase in coalition members who receive LTSS/HCBS	2	2	3	1	1	1	10
Hosted leadership activities	12	10	15	9	10	16	72
Participants in leadership training	609	70	149	87	31	347	1293
Leadership activities that were "train the trainer"	1	1	1	2	0	1	6
Policies actively addressed	22	14	11	13	11	9	80
CMS site calls	0	0	0	0	0	0	0
Waivers commented on	2	0	0	0	0	0	2
StAACs/LAACs that engaged in identification and support of up-and-coming leaders	7	4	3	4	5	5	28
StAACs/LAACs reporting an increase in number of advocates with lived experience serving in coalition leadership roles	5	2	1	4	3	5	20
StAACs/LAACs reporting an increase in number of peer support and/or networking activities addressing advocacy on ACL priority areas	9	5	6	6	4	8	38

Table 4. State and Local Action and Advocacy Coalitions: ACL Priority Areas Addressed

Which of the following ACL Priority Areas has your Grassroots Project addressed this reporting period?	March / April	May	June	July	Aug	Sept	Total
Caregiver crisis	7	7	6	5	3	4	32
Civil rights	7	7	6	7	3	5	35
Community inclusion	12	11	9	10	9	10	61
Health and safety in community living	9	8	9	7	3	5	41
HCBS settings rule	6	5	4	4	4	4	27
Person-centered planning, consumer direction, or self-direction	6	7	6	7	6	7	39
Technology	3	2	1	2	2	2	12

In addition to responses requiring quantitative responses, several open-ended questions were also included in StAAC/NAAC monthly reports. Key themes are summarized below.

1. **New advocacy organizations or/or advocacy and action coalitions engaged.** StAACs and LAACs engaged over 80 organizations representing people with disabilities (including autism and brain injuries), caregivers, deafblind, and veterans on the topics of accessibility, advocacy, aging, autism, brain injury, community living, disability rights, Medicaid, mental health, sexual violence transportation.
2. **New advocacy organizations and/or action and advocacy coalitions partnered with.** StAACs and LAACs partnered with over 15 advocacy organizations focused on brain injury, caregivers, Medicaid, DSP wages, and IDD.
3. **Hot topics discussed.** The Grassroots Project grantees hosted regularly scheduled office hours and regularly prompted the STAAC/LAAC membership to raise priority topic areas for their networks. A thematic analysis of responses to this question revealed key themes discussed during office hours which included advocacy, autism, community building, community inclusion, education, emergency preparedness, employment, government funding (e.g., DSP wages, HCBS Waiver, and DD Act Network partners), SNAP, affordable and accessible housing, Social Security benefits, transportation, and voting rights.
4. **Leadership activities hosted.** StAACs and LAACs hosted nearly 20 leadership activities covering topics such as preparing for a press conference, writing letters to the editor, self-advocacy, entrepreneurship, resume writing, interviewing, systems change, how to start a podcast, and how to contribute to board and /or advisory committees.
5. **Train-the-trainer leadership activities provided.** While grantees provided answers to this question, those answers did not contain train-the-trainer curricula. Rather, responses noted that aspects of leadership training were included in a conference program, for example. Others provided informal titles for trainings provided that are not formal programs.
6. **National, state, and/or local policy addressed.** An analysis of themes resulted in an array of policies addressed by STAAC/LAAC membership, including preservation of the ACA, access to supports and services, waitlists, caregiver crisis (DSP wages), civil rights, community inclusion, community living, education, employment, state and federal funding bills, guardianship, health and safety,

Medicaid, person-centered planning and self-determination, policy implementation, proposed changes to federal programs, transportation, and voting rights.

Supplemental Report Findings

The Supplemental Report provided an opportunity for grantees to reflect on what is going well, challenges, impact, observations of rights restrictions and responses, and most significant change.

Findings from the National Action and Advocacy Coalition Supplemental Reports

NAAC membership completed two Supplemental Reports. A thematic analysis was done of the NAAC Supplemental Reports, and combined results (May and September) are presented below.

1. **What has been going well in your Grassroots Project efforts?** Overall, NAAC members reported three main categories: collaboration and networking, knowledge sharing and translation, and advocacy and community mobilization.
    a. **Collaboration & networking** as demonstrated by cross-organizational collaboration with a focus on building partnerships at state and national levels. NAAC members appreciated the opportunities for networking through regularly scheduled meetings, which fostered relationship building: "*Several of us have been dialoguing outside of the meetings, I truly believe that it has facilitated engagement with organizations [t]hat may not have in the past seen the cross-community collaboration opportunities along with intersectionality of local and state organizations. For this, I'm very grateful."*
    b. **Knowledge sharing and translation** through development of toolkits, webinars, templates, and other materials and resources allowed for knowledge translation. Bi-directional information sharing informed NAAC members of the concerns of constituents and in turn, information and feedback was provided to individuals and groups at the state and local levels. Training and skill building was highlighted – supporting advocacy and leadership. One NAAC representative commented: *"Really positive engagement with our graphics and reels explaining advocacy issues on social media. Good feedback from colleagues and self-advocates on our plain language roundups."*

c. **Advocacy and community mobilization** Expansion of leadership opportunities (such as Regional Champions, ASAN mini-grants, and the Autism Campus Inclusion programs) led to empowering individual advocates to share their lived experience with elected officials. One grantee commented: "*Our portion of this project has allowed self-advocates to share their experiences and continue to feel heard within their HCBS Medicaid waiver services."*

2. **What has been challenging in your Grassroots Project work?** NAAC members reported five major areas of challenges: communication, capacity, burnout, reaching underserved communities, and shifting policy landscapes.

   a. **Communication** was challenging during the project period due, in part, to federal restrictions on public-facing communications and led to confusion and a delayed project start. One NAAC member commented: *"The freeze on public-facing communications has remained an ongoing challenge for engaging beyond our existing networks."*

   b. **Capacity** strain due to concerns over current and future policy environment, which sapped time and resources as well as contributed to staff turnover. One person commented: *"Many of our affiliate groups have faced increase[ed] challenges under the current administration's cuts to Medicaid and other attacks on autism research and health care. This has damaged morale, raised anxieties in affiliate group members, and caused strain on resources."*

   c. **Burnout** of staff due to competing priorities, fear of retaliation for speaking up by individual service recipients, and fatigue from ongoing stress related to systemic challenges and communication barriers. One grantee commented: "*Many long-term advocates in our program have explained to me that they are feeling burnt out by repeated advocacy efforts, particularly when change is slow or when sharing traumatic experiences with lawmakers. [For example, one person] shared privately that after a Hill meeting where their concerns were dismissed, they needed to take a step back from advocacy for a bit due to the emotional toll."* Another commented: *"Our team has struggled with advocates having fear of sharing their true concerns without fear of retaliation by staff or agencies."*

   d. **Reaching underserved and rural communities**, particularly rural areas in the Midwest and South, is difficult in part due to lack of transportation and

infrastructure. One NAAC member commented: *"[S]ome rural and underserved areas remain underrepresented, particularly in parts of the Midwest and South. Transportation barriers, and a lack of established disability service organization connections in these areas make outreach more difficult."*

e. **Shifting policy landscapes** proved a deterrent to engaging in non-critical work beyond advocating for the continued funding of existing federal programs, such as DD Act programs and Medicaid. As one person noted, *"This has been a challenging year for much of our advocacy work due to loss of funding and changing priorities that has made it difficult for many of our partner organizations to participate with us at their normal level.*

3. **What impact has your work had on expanding advocate influence on the HCBS system?** NAAC members reported many ways in which their work was having an impact and included cross-organizational collaboration, connection, and relationship building; knowledge translation and education; increased reach; and empowered advocacy.

   a. **Cross-organizational collaboration, connection, and relationship-building** through increased partnerships between disability and non-disability organizations because of shared advocacy efforts and regular touchpoints and other ongoing engagement through structured opportunities to come together. One NAAC member commented: *"Through our weekly meetings, we have heard from multiple states of successes that are resulting in creating collaboration with other disability and non-disability partners to strengthen networks and advocacy efforts for HCBS systems."*

   b. **Knowledge translation and education** through webinars, toolkits, and office hours. Identification of knowledge gaps and needed resources. One person commented: *"'Sometimes you don't know what you don't know'—this is what we have heard from individuals who have been receiving [HCBS] but who didn't realize that this was what they were receiving. Family leaders had no idea that they could go to a CMS website and actually review their state's Medicaid Waiver application and check to see if what is written is what is actually happening in practice."*

   c. **Increased reach** through expansion of digital presence via social media to amplify issues of concern, share individual stories, and enhance visibility. One NAAC member commented: *"Our peer-to-peer education through our*

monthly Medicaid workgroup has shared model practices throughout states and (we are) learning how state systems work for advocates to engage with to advocate for waivers."

d. **Empowered advocacy** through sharing one's story, use of plain language resources, and direct policy engagement. One member of the NAAC commented: *"[The project] has inspired self-advocates to get more involved in options for their services and getting their stories out to people that could help impact services in their state. We found that many advocates were not aware that there was a public comment period for each state's waiver program or that they were encouraged to comment and share their stories."*

4. **What ways have you seen people's rights being restricted in the context of HCBS?** NAAC members were asked this question in the May supplemental reports only. Answers included categories such as funding cuts, program elimination, and systemic barriers.

    a. **Funding cuts and program elimination** impact the ability of people with disabilities to maintain choice of community-based services and avoid long waiting lists and bring about fear of potential institutionalization and/or vital service interruptions. One person commented: *"We've seen people's rights restricted in HCBS when they are forced into institutions due to long waitlists or lack of in-home care options. Some individuals report being denied the right to self-direct their services, limiting their ability to choose who provides their care, and how it's delivered. Others face sudden service cuts without proper notice or due process, violating their right to appeal."*

    b. **Systemic barriers** impact access to benefits, redetermination timelines, etc., which have undue burden on service recipients. One NAAC member commented: *"Many CILs are reporting consumers having issues accessing their benefits, whether through Social Security office or representative payee programs, that is risking their ability to remain in the community."*

5. **Describe solutions and approaches to prevent, minimize, or remediate restriction or violations of rights.** NAAC members were asked in May to reflect on their organization's advocacy related to solutions and approaches to rights restrictions or violations. Responses fell into the following thematic areas.

a. **Training and education** related to supported decision making, end-of-life care, using grievance processes, and fostering collaboration and resource sharing across networks. One person on the NAAC commented: *"Many of our [affiliates] are implementing supportive decision making trainings and education for family/support circles and individuals. A lot of times, it is the lack of knowledge of the possibilities that can be the restriction."*

b. **Policy advocacy** aimed at funding Protection and Advocacy organizations, implementation of HCBS Final Settings Rule, and opposition to forced treatment. One person commented: *"[We] are working to create effective state grievance procedures so that people can report violations of [the Final Settings Rule] and to improve state licensing bodies' timely monitoring so that new facilities do not fail to comply, and older settings do not fall out of compliance. P&As provide education on peoples' rights during their monitoring visits and can assist individuals in making grievances."*

c. **Communication and collaboration** using clear and consistent messaging about legislative action and strengthening of advocacy infrastructure across networks. One person commented: *"We have identified that clear and consistent communication and information sharing about the impact of federal actions on individual advocates and CILs as vital."*

6. **What is the most significant change which has resulted from Grassroots Project work?** NAAC members reported three main categories of significant change: collaboration and resource sharing, empowered advocacy, and capacity building.

a. **Collaboration & resource sharing** occurred through dedicated spaces for advocates to share ideas and resources. One NAAC member commented: *"[A]ctual grassroots networking has significantly connected dots with local and regional, along with state-by-state connection points."*

b. **Empowered advocacy** was supported through the use of unified messaging, plain language resources, and knowledge translation. This knowledge mobilization supports an increase of advocates' confidence in and understanding of systems. As a result, advocates take informed action at a greater rate than previously. One member of the NAAC commented: *"[W]e saw a significant change of advocates strengthening their ability to deliver clear, consistent, and impactful messages to lawmakers."*

c. **Capacity building** resulting from regular office hours and other dedicated spaces for conversation and provision of technical assistance and peer learning. A NAAC member commented: *"The most significant change we have been able to enact as a result of our participation in the Grassroots Project work is the creation of a dedicated monthly TA meeting devoted to Medicaid and HCBS-related issues."*

Findings from the State and Local Action and Advocacy Coalition Supplemental Reports

1. **Please reflect here on what has been challenging in your Grassroots Project work? Share stories, name barriers, and describe your response to these challenges.** StAACs/LAACs reported challenges with collaboration and fostering of partnerships, communication and engagement, and competing priorities among limited resources.

    a. Grantees reported that **collaboration and fostering of partnerships** proved difficult due, in part, to scheduling. One person wrote, *"One of the most significant challenges we have faced while organizing our collaborative efforts has been effectively coordinating with other agencies. The task of aligning compatible schedules and identifying suitable locations that meet everyone's requirements has proven to be quite complex."*

    b. **Communication and engagement** with elected officials could be difficult. As one member commented, "Engaging with legislators has been much more difficult this year than in previous years. This year was a budget year for [our state] and legislators were not as responsive to disability issues as in the past. We were met with non-communication and disinterest for our [General Assembly Briefing (GAB)] Sessions. We believe it was due to the legislator schedules and their summer break…When getting little response from legislative offices, we tried to encourage staff to join our GAB Sessions to discuss more openly disability related issues in [our state], but that was also difficult."

    c. **Competing priorities and limited resources** made for slow progress in some cases. As one person succinctly shared, *"A challenge is having enough time to address all the issues coalition members would like to tackle."*

2. **Please share what has been going well in your Grassroots Project efforts. Include stories and as much detail as you can.** StAAC and LAAC members reported that communication (specifically amplification of advocate voices), connection, collaboration, and knowledge translation were all positive outcomes of project efforts.

    a. **Communication**, specifically amplification of advocate voices, was a common theme of what went well. Once person reported, "Self-advocates have reported greater confidence in public speaking and increased recognition in their communities. One self-advocate remarked after presenting, 'People listened to me as a leader for the first time in a public meeting.'"

    b. **Connection** and relationship building was identified as something going well. As one person wrote, "The leaders learned small groups of participants also met outside of the regular sessions to form friendships and community building."

    c. **Collaboration** was celebrated as a positive outcome of the Project. One grantee noted, "One of the most exciting milestones was hosting our first in-person coalition retreat after nearly two years of virtual collaboration. Leaders from across [the state] came together to break bread, deepen trust, and make key decisions about campaign strategy. Participants described it as "a turning point" where the coalition truly began to feel like an alliance rather than a network."

    d. **Knowledge translation** proved to be an important positive outcome. In some cases, new educational materials were created and shared, though not all were intended for people with disabilities. In fact, elected officials were in receipt of some Grassroots Project knowledge translation efforts. As one person noted, *"… through our ongoing discussions and actions, we identified that many policy makers do not understand our policy "Asks" because they do not understand the basics of the issue. This has helped us pave a path forward… Each Committee is working on educational materials in different formats to educate policy makers (legislators, legislative staff, and agency employees) on the foundations of our issues."*

3. **Please reflect on the impact your work has had on expanding advocate influence on the home and community-based services system.** StAACs/LAACs reported six key themes related to impact: communication, enhancing outreach and partnerships, facilitation of collaboration and

connection, increased enthusiasm, knowledge translation, and support of advocacy efforts.

a. Communication, facilitation of collaboration and connection, and enhancing partnerships Coalitions reported that their work has strengthened the voice and visibility of advocates in the HCBS system. Through improved communication and growing partnerships, advocates have built stronger relationships with policymakers and community organizations. One grantee shared, *"Our coalition model ensures that disabled people themselves are directly shaping the strategies, policies, and campaigns we advance. The collaborative design of the…campaign centers disabled residents' voices, particularly those from underserved communities, and explicitly positions them as experts in defining what accessible and equitable HCBS should look like. This approach expands influence beyond traditional 'service provider voices' and moves disabled advocates into decision-making spaces and leadership in systems change."*

b. Increased enthusiasm: These connections have sparked new collaboration, shared learning, and increased enthusiasm for collective advocacy. As one person wrote, *"There is a lot more excitement and I think that people have more tools and a better understanding of the system."*

c. Knowledge translation and support of advocacy efforts Many noted that their efforts to share information and translate complex policy topics have helped others better understand disability issues and the importance of community based supports. One grantee explained, *"…we have chosen an educational/"Back to Basics" strategy moving forward. This has allowed us to identify real barriers in policies and service delivery-lack of understanding of the basics of the system. Both policy makers and recipients of services must understand the systems that provide critical community based services…"*

4. **What ways have you seen people's rights being restricted in the context of HCBS? Please share details about the situations, the violations, and any remedies you are aware of that are underway.** Grantees reflected on their observations of rights violations among their constituents and noted workforce

shortages, service accessibility, bureaucracy and program rules, and lack of inclusive leadership.

a. **Workforce shortages** lead to absence of support leaving people with disabilities at risk of institutionalization at worst. In addition, workforce shortages can significantly impact a person with a disability's ability to participate in their own life. As one person summarized, *"Chronic underpayment of direct care workers leads to instability, high turnover, and unfilled shifts. This leaves many without essential supports, effectively institutionalizing people in their own homes and stripping them of dignity and independence."*

b. **Lack of access to services** that one is eligible for has been observed as a negative result of administrative barriers and lack of affordable housing. One person noted, *"[State] delays in authorizations leave people without services they qualify for."* Another person commented, *"Many disabled residents who qualify for HCBS cannot find accessible or affordable housing. As a result, people are forced into group homes or restrictive settings that feel like "mini-institutions," violating the HCBS settings rule that promises integration."*

c. **Bureaucracy and program rules/policies** continue to violate the rights of people receiving formalized services. One grantee commented: *"We've worked with a family who was no long[er] permitted to visit with their son in his own room. The team worked with the administration to find an alternative place for the family to visit in private."* Another grantee commented: *"We have also seen situations where service coordinators or MCO representatives steer individuals toward specific providers or services rather than presenting the full range of options. This limits informed consent and denies people true choice in who delivers their care and how supports are structured. Survivors have shared that this practice makes them feel like decisions are being made for them rather than with them, which directly undermines the principles of person-centered planning."*

d. **Lack of inclusive leadership** was noted as a recurring rights violation. One member commented: *"Coalition members have observed: People with I/DD being excluded from leadership tables where community or service decisions are made."* As another grantee commented: *"HCBS policies are often developed without meaningful participation of disabled people, resulting in rules that miss lived realities. This exclusion is a systemic rights restriction."*

5. **Please describe solutions and approaches to prevent, minimize, or remediate restrictions or violations of rights.** StAAC and LAAC members reported use of a myriad of approaches to preventing, minimizing, or remediating restrictions or rights violations. These included: enhanced outreach and partnerships, facilitation of collaboration and connections, promotion of legislative and/or regulatory policy changes, improved accessibility, knowledge translation, and supporting choice and autonomy.

    a. **Enhanced outreach** and partnerships, facilitation of collaboration and connection, promoting legislative/regulatory policy changes, and improved accessibility were all indicated as approaches used to counter rights restrictions. As one grantee commented: *"The 'Coffee with Your Legislator' initiative is making advocacy easier, warmer, and more personal—reducing intimidation and opening new doors for participation."*

    b. **Knowledge translation** provided a mechanism to inform customers of their rights and how to respond should they feel their rights were violated. One grantee commented: *"Many grievance systems are overly technical or inaccessible, effectively silencing disabled residents. [The Coalition] is committed to advocating for streamlined … and accessible grievance and appeal mechanisms, so that individuals can exercise their rights without additional barriers. This includes ensuring materials are available in multiple formats (ASL, plain language, translated) and that people have support navigating the process."*

    c. **Supporting choice and autonomy** through education was noted. One grantee commented: *"Education of individuals with disabilities on their rights, including supported decision making, is core way to prevent and remediate HCBS violations. If the people most impacted do not know their rights and the appeal/grievance process, they cannot to advocate for themself or inform entities such as [their P & A] of the problems."*

6. **Please share here the most significant change that has resulted from your Grassroots Project work.** Grantees provided information on what they perceive as being the most significant change to occur as a result of Grassroots Project engagement. Five key themes emerged: communication and increased bi-directional outreach; empowerment; facilitation of collaboration and connection; increased skills and knowledge; and inclusive leadership.

a. **Communication and increased bi-directional outreach** led to tightened structure which enabled continued work. One grantee commented: *"The [Coalition] has gathered and developed a shared vision and goals that reflect the collective priorities of our members and the communities we serve. This impactful work enabled us to formalize a plan and structure that has a built-in governance and structure that will move our work forward."*

b. **Empowerment** of advocates increased through recognition as leaders. One grantee commented: *"The most significant change has been the shift in visibility and recognition of self-advocates as community leaders. … Its impact is both symbolic and structural: self-advocates are no longer only telling their stories, but are being invited into decision-making roles that influence local systems and HCBS alignment."*

c. **Facilitation of collaboration and connection** emerged through a recognition of shared values and intent. As one grantee commented: *"The most significant change from our Grassroots Project work is [the shift] from being a loose network into a true coalition with shared values, agreements, and leadership. … We chose to slow down and intentionally build trust, governance structures, and collective capacity before launching a statewide campaign. The impact of this change is profound: disabled leaders across [our state] are now not only coordinating but co-creating strategy, [and] training one another."*

d. **Increased skills and knowledge** were noted by advocates, which led to increased engagement with elected officials. As one grantee commented: *"We've received positive feedback on advocates feeling more comfortable with reaching out to their legislators to share their stories and their issues."*

e. **Inclusive leadership** through opportunities for advocates to lead proved powerful. One person commented: *"The most powerful change we've seen is the confidence of survivors finding their voices. From standing with pies in hand at the [state] Capitol, to leading discussions during support groups, to testifying at state hearings—survivors are no longer just participants. They are leaders. We've also noticed a shift in how policymakers respond. They're listening differently when they hear stories not from professionals, but directly from people living with brain injury and their families."*

Engagement Survey Findings

The Grassroots Project Team provided a link to a web-based survey and encouraged Grassroots coalition members to use the link at the end of public-facing educational, outreach, and technical assistance activities. Participants were invited to respond to the anonymous survey. Over the course of the project period, 319 Engagement Surveys were submitted[1] by individuals who participated in an activity hosted by one of the NAAC members, StAACs, or LAACs (see Appendix J for full results).

The initial item in the survey was, "Please select the hosting organization for the activity you participated in" (n = 315). Responses ranged from zero (n = 5, no organization) to 41 (n = 1, 41 completed surveys for one organization). Twenty-two individuals indicated the hosting organization as "other" than those listed.

Questions 2-4 are listed in Table 5 along with responses. Niney-four percent indicated that they were "likely" or "very likely" to take action in the next six months in their own advocacy; 92% reported that they were "likely" or "very likely" to connect and collaborate with new people as a result of the activity; 86% answered that they were "likely/very likely" to engage with the Grassroots Project in the next six months.

[1] HSRI does not have accurate information about the number of people who received the survey, so a response rate cannot be calculated.

Table 5. Engagement Survey: Likelihood to take action, connect and collaborate, and engage (n = 318)

Questions 2 - 4	Very Likely/Likely	Neither Likely nor Unlikely	Unlikely/ Very Unlikely	Not Applicable
2. How likely are you to take action in your own advocacy in the next six months as a result of today's activity?	94%	4%	1%	1%
3. How likely are you to connect and collaborate with new people in the next six months as a result of this activity?	92%	6%	2%	0%
4. How likely are you to engage with the Grassroots Project in the next six months?	86%	10%	2%	2%

In response to question five, *"Do you feel more comfortable and confident in advocating as a result of participating in this activity?"* (n = 315), 91% indicated "yes," 2% indicated "no," 2% preferred not to say, and 5% indicated "not applicable."

In response to question six, *"How accessible was this activity for you?"* (n = 315), 93% indicated "very accessible," 7% indicated "somewhat accessible," while no one indicated "not at all accessible."

In response to question seven, "*Did you learn anything useful for your advocacy about state systems, policies, funding, or state agencies overseeing disability services from*

this activity?" (n =312), 93% indicated "yes," 3% indicated "no," 1% indicated "prefer not to say," and 4% indicated "not applicable."

In question eight, survey participants were asked, "*In what ways do you primarily identify with the disability community?"* and were instructed to check all that apply. Thus, responses are duplicative; one person could have more than one role. Table 6 illustrates responses (n = 244). The top three roles people indicated that they had was as advocate (62%), a person working in a disability organization (61%), and a person with a disability/disabled person (58%). Given the percentages of disabled peoples' participation in this survey, it is notable that only 7% of respondents identified as receiving LTSS or HCBS. This may be, in part, due to nomenclature. Anecdotally, we heard from members that LTSS/HCBS users may not be aware that the supports they are receiving are funded via Medicaid HCBS. This may be due to state HCBS Medicaid waiver funded programs not having a single program name across the nation, rather they are referred to as a state-based programs, each with a different name. To support aligned communication and education related to program design and access, NACDD created a list of states and the names of the related Medicaid programs.

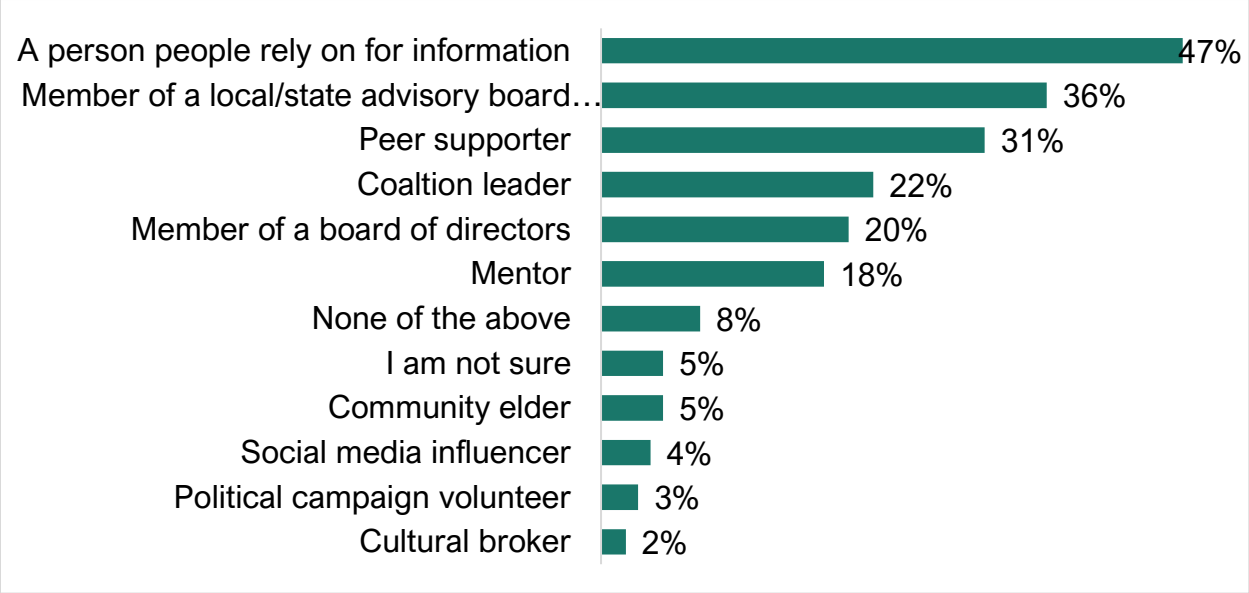
Table 6. Engagement Survey: Respondent relationship to disability community (n = 244)

Role	Percent
Advocate	62%
Person working in a disability organization	61%
Person with a disability/a disabled person	58%
Family member or loved one of a person with a disability (disabled person)	34%
Person who uses LTSS or HCBS	7%
Caregiver or staff supporting a person with a disability/disabled person	7%
None of the above	0%

Additionally, in question nine, participants were asked to indicate what leadership roles they played (and were invited to check all that apply). Figure 1 illustrates the range of responses (n = 249). The top three roles that respondents indicated playing were a

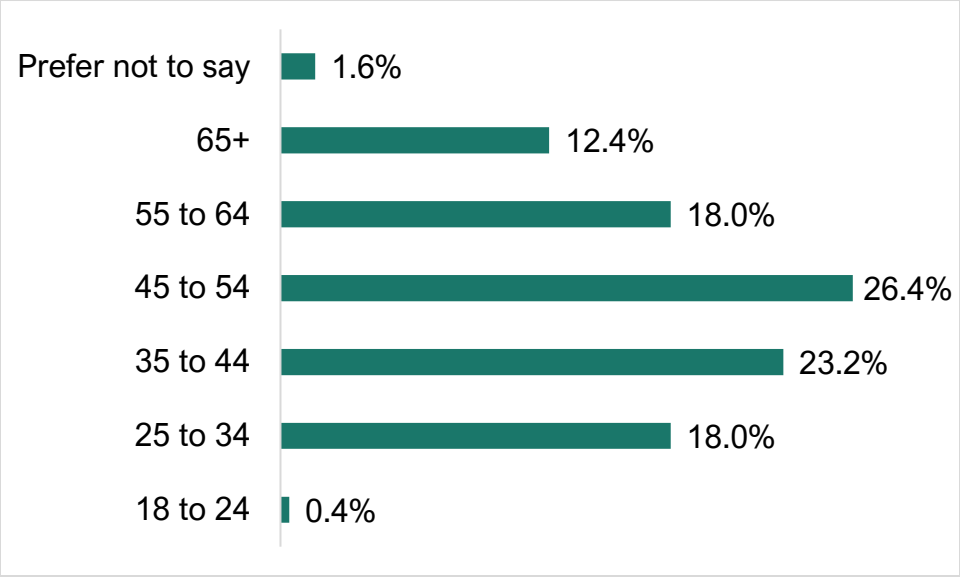
person that people rely on for information (47%), a member of a local/state advisory board or committee (36%), and peer supporter (31%). Approximately one-fifth of respondents indicated they play the role of coalition leader (22%), member of a board of directors (20%) and mentors (18%). Less than 10% indicated they were none of the above (8%), not sure (5%), a community elder (5%), social media influencer (4%), political campaign volunteer (3%), and cultural broker (2%).

Figure 1. Engagement Survey: Respondent Role (n = 249)



Question 10 addressed age (n = 250). Results can be found in Figure 2. The majority (26%) of respondents indicated they were 45–54 years old, followed by those aged 35–44 (23%). Respondents ages 25–34 and 55–64 accounted for 18% each. Twelve percent of respondents indicated they were 65-plus, while 2% preferred not to say. Only one respondent indicated an age range of 18–24.

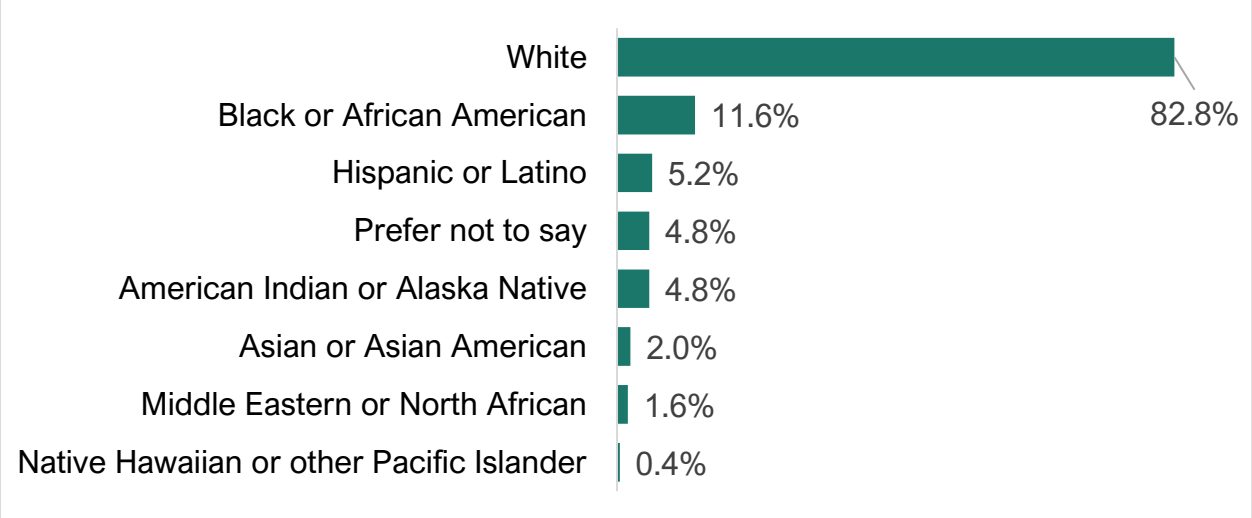
Figure 2. Engagement Survey: Respondent Age (n = 250)



Seven percent of respondents (n = 249) relayed that they identify as Hispanic or Latino, while 89% did not. Four percent preferred not to say.

The majority of all respondents (n = 250) 83% identified as white, 12% as Black or African American, and those who preferred not to say, Hispanic or Latino, and American Indian or Alaska Native each represented 5%. Two percent identified as Middle Eastern or North African, and 2% as Asian or Asian American. Less than 1% identified as Native Hawaiian or other Pacific Islander.

Figure 3. Engagement Survey: Respondent Race (n = 250)



Project Survey Findings

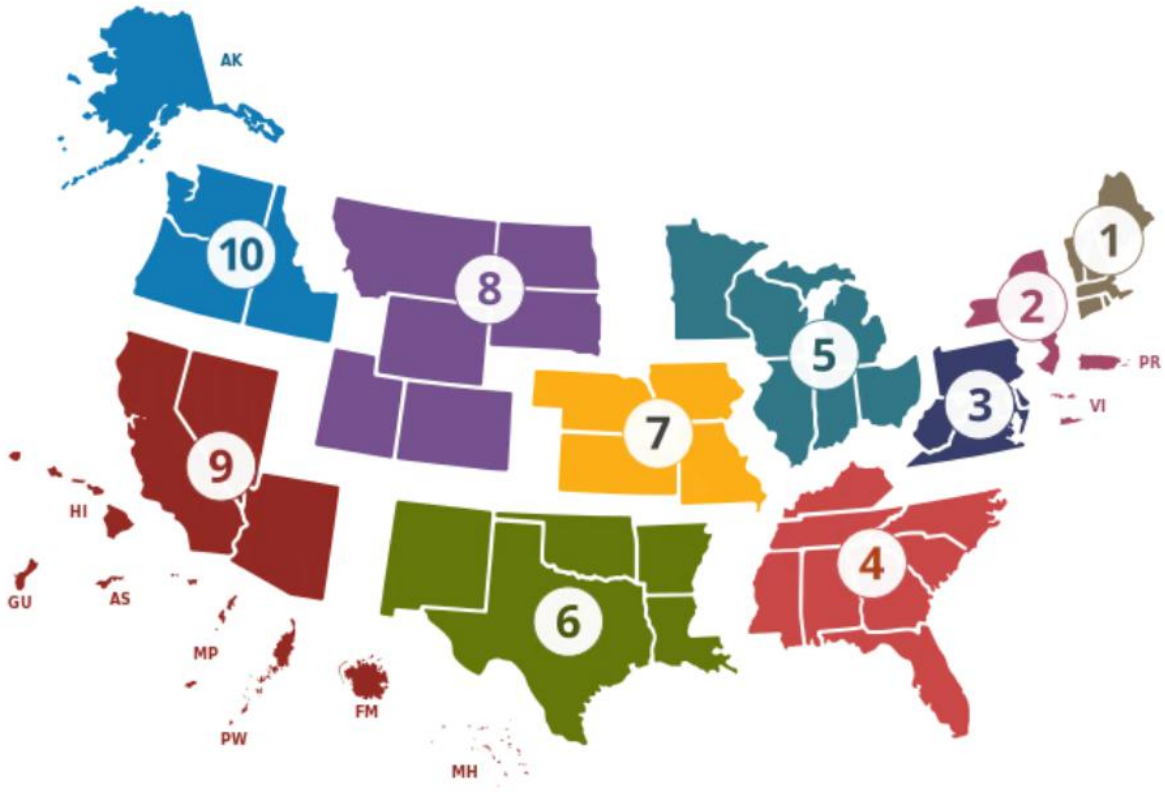
Survey questions and full results are available in Appendix K. The following is an abbreviated overview of key survey data.

Demographics

We received 230 completed surveys. The majority of the respondents indicated that they identified as a person with a disability/disabled person (77.7%), followed by advocate (74.4%), person working in a disability organization (58.1%), and family member or loved one of a person with a disability/disabled person (45.1%). Caregivers or staff supporting a person with a disability/disabled person represented 17.2% of respondents, while people who use LTSS or HCBS represented 16.3%. Of the responses, 7.4% indicated they had a role of "other," which included mainly volunteers and independent consultants.

The states with the top three total number of survey responses were Illinois (7.9%), Massachusetts (7.0%), and California (6.1%). Two states received 12 responses each, while two received 11 each. The remaining 36 states received less than 10 responses, and specifically, five states had one respondent each. No responses were received from the District of Columbia or the US Territories. In terms of geographic location, we used HHS Regions (displayed in Figure 4) to gain an understanding of geographic representation. Region 5 received the highest number of responses at 29 (22.4%) while Region 10 received the fewest at eight (3.7%). Table 7 displays totals for each region.

Figure 4. HHS Regional Offices[2]



[2] https://www.hhs.gov/about/agencies/iea/regional-offices/index.html

Table 7. Total Responses by HHS Region

HHS Region	States	# of Responses	%
1	CT, ME, MA, NH, RI, VT	30	14.0%
2	NJ, NY, PR, USVI	14	6.5%
3	DE, DC, MD, PA, VA, WV	29	13.6%
4	AL, FL, GA, KY, MS, NC, SC, TN	29	13.6%
5	IL, IN, MI, MN, OH, WI	48	22.4%
6	AR, LA, NM, OK, NM	10	4.7%
7	IA, KS, MO, NE	16	7.5%
8	CO, MT, ND, SD, UT, WY	10	4.7%
9	AS, AZ, CA, CNMI, Guam, HI, NE	20	9.3%
10	AK, ID, OR, WA	8	3.7%

The largest proportion of respondents indicated their age as 45–54 years old (25.1%), followed by 55–64 (21.4%), and 35–44 (20.0%). Regarding ethnicity, 6.5% of respondents indicated they identify as Hispanic/Latino, while 4.7% preferred not to say. The largest category of race selected by respondents was white (78.5%), followed by Black or African American (8.4%). Nearly 70% of respondents indicated that one of the roles that they play is “a person people rely on for information or advice” (69.7%). Nearly half indicated that they are a peer supporter (47.8%), and 40.8% indicated they are a member of a local/state advisory board. About a third indicated they serve as a mentor (32.8%) and/or a member of a board of directors (28.9%).

With regard to education level, nearly half (48.6%) indicated they had a certificate/some college/associate’s degree, 38.3% had a bachelor’s degree, and 32.7% had a master’s or terminal degree. Nearly 76% indicated they work, while 17.7% indicated that they are not seeking employment and 6.5% were seeking employment.

Table 8. Project Survey: Responses to Knowledge and Perception Statements

Statement	n	Strongly agree / agree	Neither agree nor disagree	Disagree
I believe people with disabilities and I can influence services for people with disabilities.	227	94.3%	4.0%	1.8%
I feel that I am a good disability rights activist.	230	83.0%	12.6%	4.3%
I think about new policies for improving the life of people with disabilities.	230	83.5%	13.9%	2.6%
I know who my local legislators are.	229	83.4%	6.1%	10.4%
I know how to contact my local legislators.	230	85.2%	6.5%	8.3%
I know how to participate in legislative testimony.	231	58.0%	22.1%	19.9%
I feel supported to advocate and make my own choices.	227	81.9%	12.8%	5.3%
I am aware of opportunities for public comment on proposed rules and regulations.	230	70.4%	17.0%	12.6%

Table 9. Project Survey: Responses to Action-Oriented Statements

Statement	n	Always/ usually	Sometimes	Rarely/ never
I stay informed of events in my local community.	220	78.6%	19.5%	1.8%
I participate in opportunities for public comment on proposed rules and regulations.	219	44.7%	35.2%	20.1%
I attend conferences to increase my knowledge of advocating for legislative change.	219	50.2%	27.9%	21.9%

I frequently discuss bills and legislative issues that are important to the disability community.	219	53.4%	27.9%	18.7%
I participate in disability-related marches and/or rallies.	220	28.6%	29.5%	41.8%
I work with disability organizations and/or other people with disabilities to increase public awareness of disability issues	220	79.1%	13.6%	7.3%
I am involved in structured volunteer positions in the disability community (e.g., formal role, elected position, committee chair/co-chair, active volunteer role).	219	54.8%	17.4%	27.9%
I am an active member of at least one disability-related group	219	80.8%	8.7%	10.5%
I use mass media (e.g., newspapers, TV, radio) to express my support or objection to a bill.	220	28.6%	22.7%	48.6%
I use social media (e.g., Facebook, Instagram, X, Bluesky, Pixeled, Mastadon) to express my thoughts and opinions about disability issues.	220	42.3%	20.5%	37.3%
I provide training to others to increase their legislative advocacy knowledge.	220	44.5%	19.1%	36.4%
I communicate with members of my local community (e.g., friends, family, and neighbors) about disability issues important to me.	219	74.9%	15.5%	9.6%
I talk to member(s) of the press (e.g., journalists, reporters, talk show hosts, podcasters) about disability issues important to me.	218	22.0%	22.9%	55.0%
I communicate (by phone, email, or visit) with legislators or their staffers about my stand on disability rights.	219	52.5%	20.1%	27.4%
I contact the Governor's office to urge them to sign or not sign a passed bill.	219	36.1%	28.3%	35.6%
I attend legislative hearings.	217	22.6%	24.4%	53.0%
I participate in legislative hearings by giving testimonies.	220	18.6%	18.6%	62.7%

Discussion

Overview of Key Findings

The evaluation of the Grassroots Project demonstrates significant progress in strengthening disability advocacy networks, leadership capacity, and systems-level influence at the national, state, and local levels. Through the participatory MSC framework and a mixed-methods approach, this project captured both quantitative metrics and rich qualitative insights into how advocates and coalitions mobilized, learned, and led.

Across all data sources, evidence shows that the Grassroots Project has contributed meaningfully to increased knowledge, empowerment, and connection among advocates with disabilities and their allies. Engagement Survey findings reveal that 93% of participants learned something useful for their advocacy, 91% reported increased confidence and comfort in advocating, and 94% were likely to take advocacy action in the next six months. These outcomes reflect the success of project-supported training, peer learning, and technical assistance in cultivating practical advocacy skills and confidence.

At the systems level, the NAAC and StAACs/LAACs expanded their reach and diversity, engaging more than 80 new organizations across multiple issue areas including HCBS, civil rights, community inclusion, and person-centered planning. Coalitions reported enhanced collaboration, strengthened relationships, and the emergence of new advocates stepping into leadership roles. Importantly, many grantees described a transition from isolated networks into cohesive coalitions that share values, co-create strategy, and influence policy conversations in new ways.

Qualitative data provide a view into particular areas of impact—the most significant change—as identified by Grassroots Coalition members. Narrative responses described self-advocates who now lead coalitions of advocates, present publicly, and contribute directly to policymaking. The shift from advocacy “for” people with disabilities to advocacy “by and with” people with disabilities represents a foundational systems change. Active state and local coalitions have amplified advocates’ voices, supported and demonstrated best practices in accessible communication, and advanced inclusive leadership models that embed lived experience into decision-making.

Factors Influencing Results

Several contextual and methodological factors influenced the Grassroots Project's evaluation outcomes.

- First, **limited participation from people who use LTSS or HCBS** emerged as a notable limitation. Only 7% of Engagement Survey respondents and 16% of Project Survey respondents identified as receiving HCBS. This underrepresentation likely reflects both systemic and linguistic barriers—many individuals may not recognize the terminology "LTSS" or "HCBS," as states often use program-specific names that obscure the federal connection. This gap underscores a need for clearer communication and plain-language education around Medicaid-funded supports, as a foundation for aligned education and communications among advocates and with public managers and policymakers.
- Second, **variability in defining leadership and train-the-trainer activities** affected the consistency of data. Some coalitions interpreted "leadership" broadly to include public speaking or peer mentoring, while others referred to structured advocacy curricula. Similarly, "train-the-trainer" events were inconsistently documented, ranging from informal mentoring sessions to formalized training models. Future evaluation efforts would benefit from standardized definitions and clearer documentation of leadership outcomes.
- Third, **survey representativeness** was limited. Participation skewed toward older (35–64) and White respondents, with relatively few respondents aged 18–24 or from racially and ethnically diverse communities. This demographic imbalance suggests that additional outreach strategies are needed to engage younger and more diverse advocates in project activities and data collection.
- Finally, **external contextual factors** such as shifting policy landscapes, funding uncertainties, and federal communication restrictions impacted coalition capacity and timelines. Many grantees cited burnout, resource constraints, and communication challenges as barriers to consistent engagement—reflecting broader systemic pressures within the disability advocacy ecosystem.

Implications for Future Efforts

The findings point to clear implications for strengthening future grassroots disability advocacy initiatives:

1. **Expand leadership and "train-the-trainer" programming.** Leadership development emerged as both a strength and a need. Expanding structured leadership curricula—including mentoring and peer-led "train-the-trainer" models—can further build sustainable advocacy capacity and create pathways for advocates with lived experience to train others.
2. **Enhance civic engagement and legislative skills training.** While most participants felt confident advocating, fewer reported knowing how to influence state administration, give testimony, or engage in legislative hearings. Future programming should include targeted modules on policy influence, public comment processes, working with the press, and legislative testimony.
3. **Increase participation among people who use LTSS/HCBS.** Addressing the terminology barrier and enhancing outreach through plain language, trusted messengers, and accessible formats can ensure greater inclusion of those directly impacted by HCBS systems.
4. **Prioritize youth engagement and broaden the representativeness of coalitions.** Strategies to engage younger advocates and advocates of color—through partnerships with youth networks, culturally responsive outreach, and mentorship programs—are essential for sustaining the movement's future and ensuring that leadership reflects the diversity of the disability community.
5. **Support coalition infrastructure and capacity.** The evaluation underscores the importance of consistent convening spaces, technical assistance, and relationship-building. Ongoing investment in these supports will help maintain momentum and mitigate burnout among advocates.
6. **Increase training.** Find ways to influence state administration, provide testimony, provide public comments, public relations/press training, how to contact a legislator, increase attendance at and participation in legislative hearings.

Limitations and Reflections

The participatory and iterative nature of the MSC approach aligns with the complex, nonlinear reality of policy change. While not intended to produce generalizable findings, this evaluation offers credible and compelling evidence of progress toward systemic empowerment and inclusion. Still, the limitations—particularly regarding representativeness and definitional consistency—warrant careful attention in designing the next phase of the Grassroots Project.

Overall, the data reflect a powerful story of transformation: people with disabilities gaining the skills, confidence, and connections to lead, and coalitions evolving into more inclusive, coordinated, and influential advocacy bodies. As one participant summarized, “People listened to me as a leader for the first time.” That shift—from being heard to leading change—embodies the core impact of the Grassroots Project.

Appendix A: Crosswalk of project outcomes and data sources

Table 10. Immediate, Intermediate, and Long-term Outcomes and Data Sources

Immediate Outcomes	Source
1. Increase in the knowledge state and local grassroots advocates have of state systems, policies, and funding for services and supports, and the state and local agencies that oversee / fund them.	- ACL Grassroots Project Engagement Survey; - Project Survey
2. Increase in the knowledge support circle members (parents, siblings, other family members, providers, teachers, etc.) have of the independent living philosophy and disability rights.	- ACL Grassroots Project Engagement Survey - Project Survey
3. Increase in the number and diversity of individuals actively advocating and participating in StAACs/LAACs.	- ACL Grassroots Project Engagement Survey - Project Survey
4. Increase in the number and diversity of people participating in coalitions and associated activities who are also enrolled in LTSS and/or HCBS waivers.	- ACL Grassroots Project Engagement Survey - Project Survey - NAAC/StAAC/LAAC monthly progress reports
5. Increase in the number and diversity of people enrolled in HCBS waivers who are leaders in StAACs/LAACs and other coalitions.	- ACL Grassroots Project Engagement Survey - Project Survey
6. Increase in the number of advocates serving in leadership roles.	- ACL Grassroots Project Engagement Survey - Project Survey
7. Increase in the diversity of advocates serving in leadership roles.	- ACL Grassroots Project Engagement Survey - Project Survey
8. Increase in the number of advocates participating in leadership training.	- ACL Grassroots Project Engagement Survey - NAAC/StAAC/LAAC monthly progress reports - Project Survey
9. Increase in the diversity of advocates participating in leadership training.	- ACL Grassroots Project Engagement Survey - Project Survey
10. Increase in the number of advocacy and action coalitions representing diverse populations.	- StAAC/LAAC descriptive survey/application - StAAC/LAAC monthly reports - Project Survey - Engagement Survey
11. Increase in the number of StAACs & LAACs	StAAC/LAAC monthly reports

12. Increase in the number of peer networks which provide training on how to advocate in the 7 focus areas.	StAAC/LAAC monthly reports
13. Increased ability of advocates to engage in state level system advocacy.	- ACL Grassroots Project Engagement Survey - Project Survey
14. Increase in the number of advocates actively working to affect system and policy changes at the state level in the 7 focus areas to improve quality of life and community living opportunities for people with disabilities.	- ACL Grassroots Project Engagement Survey - Project Survey
15. Increase in the number of grassroots advocacy partnerships formed.	- monthly reports from NAAC/StAACs/LAACs
16. Increase in the number of state and local policies addressed within 7 focus areas.	- monthly reports from NAAC/StAACs/LAACs
17. Increase in the number of grassroots advocates who become trainers of the Project/train others (e.g., train the trainers).	- monthly reports from NAAC/StAACs/LAACs - Engagement Survey - Project Survey
Intermediate Outcomes	
1. Grassroots advocates use their knowledge of states services to hold states / providers accountable and responsive to stakeholder input.	- NAAC/StAAC/LAAC supplemental reports - Project Survey
2. Grassroots advocates use their knowledge of state systems and funding streams to navigate to the right state and local systems and advocate for changes in state and local level policies and services.	- NAAC/StAAC/LAAC supplemental reports - Engagement Survey - Project Survey
3. Grassroots advocates leverage state and other resources to create new coalitions / new programs / new organizations to do peer to peer outreach and training on how to advocate for community living.	- StAAC/LAAC supplemental - Engagement Survey - Project Survey
4. Grassroots advocates understand how services are funded, provided, and know the state and local agencies that fund services and supports.	- Engagement Survey - Project Survey
5. Grassroots advocates are organized in the state and have a strategy for how to identify areas where change is needed at the state or local level and acting to affect that change.	- StAAC/LAAC monthly reports
6. People with disabilities are supported (including by individuals in their support circle) to advocate and make their own choices.	- Engagement Survey - Project Survey
7. State and local advocacy and action coalitions are sustained.	- StAAC monthly reports

8. State coalition relationships with grassroots advocacy coalitions are sustained.	- LAAC monthly reports
Long-term Outcomes	
1. The next generation of cross-disability, cross-generational, and culturally diverse leaders are strongly positioned within the advocacy movement.	
2. Networks of grassroots advocacy and action coalitions are supporting each other and have the skills and knowledge to advocate for improvements in the quality of community living because they have grown, are connected and are strong.	

Appendix B: NAAC Monthly Report

NAAC Monthly Progress Report

Let us know what you have been up to! Please update HSRI on activities, outputs, and impact of this month's activities and Grassroots Project efforts. (Please complete each question and do not use "see #4" etc.)

* 1. **Reporting period** (please select the LAST day of the month you are reporting on. If you are completing the monthly report for March, enter 3/31/2025.*

Last day of reporting period

Date

MM/DD/YYYY

* 2. **Name of organiziation**

* 3. **Name of person completing report**

* 4. **Has your organization engaged with any NEW advocacy and action coalitions this reporting period?** (Be sure to only include NEW organizations, not returning or current partners. Here, we are seeking new connections.)

- Yes
- No

5. **Please specify NEW organizations with whom your organization engaged.**

* 6. **Do any of the NEW organizations/groups you engaged with expand the ethnic and/or racial diversity of your coalition?**

- Yes
- No

7. **If yes, please list which organizations you engaged with that expand the ethnic and/or racial diversity of your coalition.**

* 8. **Has your organization formally partnered with any NEW advocacy and action coalitions this reporting period?** (We are specifically looking to see formal partnerships such as co-hosting an event, co-creating a toolkit, co-authoring a fact sheet, or cross-posting action alerts. Formal partnership indicate an agreed upon set of deliverables from each party and can be in the form of a contract or a memorandum of understanding and can be legally binding or not.)

- Yes
- No

9. **Please specify NEW organizations with whom your organization has partnered.**

* 10. **Do any of the NEW organizations/groups you partnered with and listed expand the ethnic and/or racial diversity of your coalition?**

- Yes
- No

11. **Please list which organizations you partnered with expand the ethnic and/or racial diversity of your coalition.**

12. **Number of technical assistance (TA) tools and resources used in your Grassroots Project work this reporting period.** (TA tools and resources may include guidance documents, translational resources, informational summaries, best practice briefs, toolkits, etc.)

- 0
- 1
- 2
- 3
- 4
- Other (please specify)

13. **Please list, describe, and share link to the TA tools and resources you have counted.**

14. **Did any of the TA tools and/or resources listed address leadership training?** (By leadership training, we mean training that specifically focuses on developing essential skills for effective leadership such as communication, decision making, conflict resolution, and coaching.)

- ○ Yes
- ○ No

15. **Please specify which of the tools and/or resources counted above address leadership training.** [List the specific leadership training curriculum/program used (e.g., 7 Habits of Highly Effective People based on Stephen Covey's book by the same name)].

16. **Number of TA events hosted as part of your Grassroots Project work this reporting period.** (Events may include peer-to-peer activities, webinars, listening sessions, forums, and training. Please do not include office hours here as that will be captured below.)

- ○ 0
- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ Other (please specify)

17. **Please list and describe any TA events counted above this reporting period.** (Events may include peer-to-peer activities, webinars, listening sessions, forums, and trainings.)

18. **Did any of the TA events listed above address leadership training?** (Supply which of the TA events in Q17 specifically address leadership training)

- ○ Yes
- ○ No

19. **How many people participated in leadership training counted in #18?** (please just enter one number)

20. **Please specify which of the TA events addressed leadership training.**

* 21. **Number of office hour sessions hosted this reporting period** (e.g., if two office hours events are hosted and one event is 1 hour and another is 2 hours you will report 2 sessions and not 3 hours).

- ○ 0
- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ Other (please specify)

* 22. **Number of total attendees at all office hour sessions held this reporting period.** (It is acceptable for this number to be duplicative meaning that if Joy attended four office hour sessions, she will be counted four times.)

23. **List any hot topics discussed in office hours this reporting period.** Hot topics include discussion items that are pressing and/or timely, such as major waiver amendments, state budget, etc.

* 24. **How many leadership activities were hosted this reporting period?**

- 0
- 1
- 2
- 3
- 4
- Other (please specify)

25. **Did any of the leadership activities listed include "train the trainer" type education?** (By "train the trainer", we mean a curriculum aimed at training people to become subject matter experts and who will deliver training to others on the topic in which they have been supported to learn.)

- Yes
- No

26. **Please specify which of the leadership activities above include "train the trainer" type education.**

27. **How many national, state and/or local policies were actively addressed this reporting period?** By "actively addressing" we mean taking proactive and deliberate steps to address a topic or situation (e.g., creating a fact sheet, testifying to the state legislature, etc.).

- 0
- 1
- 2
- 3
- 4
- Other (please specify)

28. **Of the national, state and/or local policies counted above, please indicate whether they addressed any of the following seven ACL priority areas.**

	Yes	No
Caregiver crisis	○	○
Civil rights	○	○
Community inclusion	○	○
Health and safety in community living	○	○
HCBS settings rule	○	○
Person-centered planning, consumer direction, or self-direction	○	○
Technology	○	○

29. **Of the "yes" responses to #27 above, describe the national, state, and/or local policy addressed.**

30. **Number of CMS site visit calls that your organization or state affiliates participated in.**

- ○ 0
- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ Other (please specify)

31. **Please provide a list of CMS site visit calls in which your coalition participated.**

32. **Number of materials disseminated that support grassroots disability advocates.** (Disseminated materials may include newsletters with content relevant to grassroots advocates or dissemination of announcements or training events.)

- ○ 0
- ○ 1
- ○ 2
- ○ 3
- ○ 4
- ○ Other (please specify)

33. **Please list and describe materials disseminated.** Include to whom (e.g., individual members, list serve) and number of people. Please share links to those materials here and consider posting to Basecamp. (e.g., HCBS Fact Sheet to coalition list serve, 75 members)

34. **Number of HCBS waivers that your organization or its state level affiliates have commented on this reporting period.**

- ◯ 0
- ◯ 1
- ◯ 2
- ◯ 3
- ◯ 4
- ◯ Other (please specify)

35. **Please describe the waivers your organization or its state level affiliates have commented on this reporting period. Please provide the state, the name and type of waiver, and a summary of and/or link to comments.** (e.g., KS 1915c Brain Injury Waiver, DSP rate increase; comments at: www.pagelink.xyz)

36. **Number of state and/or local grassroots disability advocacy groups supported through TA this reporting period.** This question is specific to groups to whom your organization is providing technical assistance and differs from previous questions asking about engaging and partnering.

- ◯ 0
- ◯ 1
- ◯ 2
- ◯ 3
- ◯ 4
- ◯ Other (please specify)

37. **Please list and describe the grassroots disability groups counted for this reporting period** (e.g., Self Advocacy Group of State, TA provided on voter access, www.abc.xyz).

38. **Which of the following ACL Priority Areas has your Grassroots Project addressed this reporting period?** (check all that apply)

	Yes	No
Caregiver crisis	☐	☐
Civil rights	☐	☐
Community inclusion	☐	☐
Health and safety in community living	☐	☐
HCBS settings rule	☐	☐
Person-centered planning, consumer direction, or self-direction	☐	☐
Technology	☐	☐

Appendix C: StAAC/LAAC Monthly Report

StAAC & LAAC Monthly Report

Let us know what you have been up to! Please update HSRI on activities, outputs, and impact of this reporting period's activities and Grassroots Project efforts. (Please complete each question and do not use "see #4" etc.)

* 1. **Reporting period** (please select the month for which you are reporting, not the month it currently is).

- March 2025
- April 2025
- May 2025
- June 2025
- July 2025
- August 2025
- September 2025

* 2. **Name of coalition**

* 3. **Name of person completing report**

* 4. **Has your coaltion engaged with any NEW advocacy organizations or/or advocacy and action coalitions this reporting period?** Be sure to only include NEW organizations, not returning or current partners. Here, we are seeking new connections made.

- Yes
- No

If yes, list the NEW advocacy organizations and/or advocacy and action coalitions your coalition engaged with.

* 5. **Do any of the NEW organizations/coalitions you engaged with and listed in #4 expand the ethnic and/or racial diversity of your coalition?**

- ◯ Yes
- ◯ No

If yes, please list which organizations you engaged with expand the diversity of your coalition.

* 6. **Has your coalition formally partnered with any NEW advocacy organizations and/or action and advocacy coalitions this reporting period?** We are specifically looking to see formal partnerships such as co-hosting an event, co-creating a toolkit, co-authoring a fact sheet, or cross-posting action alerts. Formal partnership indicate an agreed upon set of deliverables from each party and can be in the form of a contract or a memorandum of understanding and can be legally binding or not.

- ◯ Yes
- ◯ No

If yes, please specify the NEW organizations/coaltions your coalition partnered with.

* 7. **Do any of the NEW organizations/groups you partnered with and listed in #6 expand the ethnic and/or racial diversity of your coalition?**

- ◯ Yes
- ◯ No

If yes, please list which organizations/coalitions you partnered with expand the diversity of your coalition.

* 8. **Are you seeing an increase in the number of individual coalition members who receive long-term supports and services or home and community-based services?**

- ◯ Yes
- ◯ No

If yes, please briefly indicate how you are obtaining this information (e.g., member survey, self-disclosures, other).

9. **List any 'hot topics' discussed this reporting period. Hot topics include discussion items that are pressing and/or timely** (e.g., a major waiver amendment, state budget, new regulations, etc.).

* 10. **How many leadership activities were hosted this reporting period?** By leadership activities, we mean activities that specifically focuses on developing essential skills for effective leadership such as communication, decision making, conflict resolution, and coaching.

- ◯ 0
- ◯ 1
- ◯ 2
- ◯ 3
- ◯ 4
- ◯ Other (please specify)

11. **Please describe the type of leadership activity hosted and its focus (e.g., webinar on grassroots communications strategies with XYZ Product Name) entered into #10**. List the specific leadership training curriculum/program used (e.g., 7 Habits of Highly Effective People based on Stephen Covey's book by the same name) if applicable.

12. **How many people participated in leadership training counted in question 10?**

* 13. **Did any of the leadership activities listed in #11 include "train the trainer" type education?** By train the trainer, we mean a curriculum aimed at training people to become subject matter experts and who will deliver training to others on the topic in which they have been supported to learn.

- ◯ Yes
- ◯ No

If so, please briefly describe.

* 14. **How many national, state and/or local policies were actively addressed this reporting period?** By "actively addressing" we mean taking proactive and deliberate steps to address a topic or situation (e.g., creating a fact sheet, testifying to the state legislature, etc.).

- ◯ 0
- ◯ 1
- ◯ 2
- ◯ 3
- ◯ 4
- ◯ Other (please specify)

* 15. **Of the national, state and/or local policies counted in #12, please indicate whether they addressed any of the following seven ACL priority areas.**

	Yes	No
Caregiver crisis	◯	◯
Civil rights	◯	◯
Community inclusion	◯	◯
Health and safety in community living	◯	◯
HCBS settings rule	◯	◯
Person-centered planning, consumer direction, or self-direction	◯	◯
Technology	◯	◯

16. **Of the "yes" responses to #15 above, describe the national, state, and/or local policy addressed.** If none, enter n/a.

* 17. **Number of CMS site visit calls that your coalition participated in.**

- ◯ 0
- ◯ 1
- ◯ 2
- ◯ 3
- ◯ Other (please specify)

* 18. **Number of HCBS waivers that your coalition commented on this reporting period.**

- ◯ 0
- ◯ 1
- ◯ 2
- ◯ 3
- ◯ 4
- ◯ Other (please specify)

19. **Please describe the waiver(s) your coalition commented on this reporting period.** Please provide the state, the name and type of waiver, and a summary of and/or link to comments. (e.g., KS 1915c Brain Injury Waiver, DSP rate increase; comments at: www.pagelink.xyz)

* 20. **Which of the following ACL Priority Areas has your coalition addressed this reporting period?** (check all that apply)

	Yes	No
Caregiver crisis	☐	☐
Civil rights	☐	☐
Community inclusion	☐	☐
Health and safety in community living	☐	☐
HCBS settings rule	☐	☐
Person-centered planning, consumer direction, or self-direction	☐	☐
Technology	☐	☐

* 21. **Did your coalition engage in identification and support of up-and-coming leaders this reporting period** (e.g., provision of leadership training, a mentorship program, etc.)?

- ◯ Yes
- ◯ No

If yes, please list and briefly describe.

* 22. **Was there an increase in the number of advocates with lived experience serving in coalition leadership roles this reporting period?**

- ◯ Yes
- ◯ No

If yes, please briefly describe the position, how the person was supported in pursuing this position, and/or how they are being supported in the duties of this position.

* 23. **Was there an increase in peer support and/or networking activities that addressed how to advocate on the seven ACL priorities this reporting period?**

- ◯ Yes
- ◯ No

If yes, please describe.

Appendix D: NAAC Supplemental Report, May 2025

NAAC Supplemental Report

Please update HSRI on your accomplishments, challenges, strategies and impacts through your Grassroots Project efforts since January of 2025. These questions are meant to spark reflection and invite storytelling.

* 1. Please enter the date

Date

Date

MM/DD/YYYY

* 2. Name of organiziation

* 3. Name of person completing report

* 4. Please share what has been going well in your Grassroots Project efforts. Include stories and as much detail as you can.

* 5. Please reflect here on what has been challenging in your Grassroots Project work? Share stories, name barriers, and describe your response to these challenges.

* 6. Please reflect on the impact your work has had on expanding advocate influence on the home and community-based services system.

* 7. What ways have you seen people's rights being restricted in the context of HCBS? Please share details about the situations, the violations and any remedies you are aware of that are underway.

8. Please describe solutions and approaches to prevent, minimize, or remediate restrictions or violations of rights (including supportive decision making, HCBS Settings Rule implementation, alternatives to forced treatment, grievance and appeal processes, and legal action) that you have identified.

* 9. Please share here the most significant change which has resulted from your Grassroots Project work. Be specific about the origin and impact of the change.

Appendix E: NAAC Supplemental Report, Sept 2025

NAAC Supplemental Report - September 2025

Please update HSRI on your accomplishments, challenges, strategies, and impacts through your Grassroots Project efforts since mid-May/June of 2025. These questions are meant to spark reflection and invite storytelling.

* 1. Please enter the date

Date

Date

MM/DD/YYYY

* 2. Name of organiziation

* 3. Name of person completing report

* 4. Please share what has been going well in your Grassroots Project efforts. Include stories and as much detail as you can.

* 5. Please reflect here on what has been challenging in your Grassroots Project work? Share stories, name barriers, and describe your response to these challenges.

* 6. Please reflect on the impact your work has had on expanding advocate influence on the home and community-based services system.

* 7. Please share here the most significant change which has resulted from your Grassroots Project work. Be specific about the origin and impact of the change.

Appendix F: StAAC/LAAC Supplemental Report, Sept 2025

StAAC/LAAC Supplemental Report

Please update HSRI on your accomplishments, challenges, strategies and impacts through your Grassroots Project efforts since March of 2025. These questions are meant to spark reflection and invite storytelling.

* 1. Name of coalition

- ◯ Allied Help Coalition Virgin Islands
- ◯ Arizona Achieve
- ◯ Brain Injury of America, Maine Chapter
- ◯ Coalition Advocating for New Directions in Legislation, Empowerment, & Services (CANDLES)
- ◯ Disability Justice Alliance
- ◯ Going Home Coalition
- ◯ LifeStreams Coalition
- ◯ MA Accessible Transportation Coalition
- ◯ Ohio Olmstead Task Force
- ◯ Rise Up, Speak Out
- ◯ Virginia Autism Coalition

* 2. Name of person completing report

* 3. Please share what has been going well in your Grassroots Project efforts. Include stories and as much detail as you can.

* 4. Please reflect here on what has been challenging in your Grassroots Project work? Share stories, name barriers, and describe your response to these challenges.

* 5. Please reflect on the impact your work has had on expanding advocate influence on the home and community-based services system.

* 6. What ways have you seen people's rights being restricted in the context of HCBS? Please share details about the situations, the violations and any remedies you are aware of that are underway.

7. Please describe solutions and approaches to prevent, minimize, or remediate restrictions or violations of rights (including supportive decision making, HCBS Settings Rule implementation, alternatives to forced treatment, grievance and appeal processes, and legal action) that you have identified.

* 8. Please share here the most significant change which has resulted from your Grassroots Project work. Be specific about the origin and impact of the change.

Appendix G: Engagement Survey

ACL Grassroots Project Engagement Survey

Thank you for participating! All of your responses to this survey are voluntary and all information collected is for the purpose of program evaluation. None of the information you provide will be linked to you. All results will be shared in aggregate, meaning the results will be presented in a way that does not identify any specific people. Information provided will remain private and used to inform the program going forward.

With appreciation for the diversity of the disability community's orientation toward terminology we use both identity first (disabled person) and person-first (person with a disability) throughout all of our work.

1. Please select the hosting organization for the activity you participated in.

2. How likely are you to take action in your own advocacy work in the next six months as a result of today's activity?

- ◯ Very likely
- ◯ Likely
- ◯ Neither likely nor unlikely
- ◯ Unlikely
- ◯ Very unlikely
- ◯ Not applicable

3. How likely are you to connect and collaborate with new people in the next six months as a result of this activity?

- ◯ Very likely
- ◯ Likely
- ◯ Neither likely nor unlikely
- ◯ Unlikely
- ◯ Very unlikely
- ◯ Not applicable

4. How likely are you to engage with the Grassroots Project in the next six months?

- ◯ Very likely
- ◯ Likely
- ◯ Neither likely nor unlikely
- ◯ Unlikely
- ◯ Very unlikely
- ◯ Not applicable

5. Do you feel more comfortable and confident in advocating as a result of participating in this activity?

- ◯ Yes
- ◯ No
- ◯ Prefer not to say
- ◯ Not applicable

6. How accessible was this activity for you?

- ◯ Very accessible
- ◯ Somewhat accessible
- ◯ Not at all accessible

7. Did you learn anything useful for your advocacy about state systems, policies, funding, or state agencies overseeing disability services from this activity?

- ◯ Yes
- ◯ No
- ◯ Prefer not to say
- ◯ Not applicable

8. In what ways do you primarily identify with the disability community? (check all that apply)

- [ ] Person with a disability/disabled person
- [ ] Advocate
- [ ] Family member or loved one of a person with a disability/disabled person
- [ ] Person who uses long-term services and supports and/or home and community-based services
- [ ] Person working in a disability organization
- [ ] Caregiver or staff supporting a person with a disability
- [ ] Other (please specify)

- [ ] None of the above

9. Which of the following leadership roles to you play? (select all that apply)

- [ ] Coaltion leader
- [ ] Community elder
- [ ] Cultural broker
- [ ] Member of a local/state advisory board or committee
- [ ] Member of a board of directors
- [ ] Mentor
- [ ] Peer supporter
- [ ] A person people rely on for information
- [ ] Political campaign volunteer
- [ ] Social media influencer
- [ ] None of the above
- [ ] I am not sure
- [ ] Other (please specify)

10. What is your age?

- ○ 18 to 24
- ○ 25 to 34
- ○ 35 to 44
- ○ 45 to 54
- ○ 55 to 64
- ○ 65+
- ○ Prefer not to say

11. Are you Hispanic or Latino?

- ○ No, not Hispanic or Latino
- ○ Yes, Hispanic or Latino
- ○ Prefer not to say

12. What is your race? (check all that apply)

- ☐ American Indian or Alaska Native
- ☐ Asian or Asian American
- ☐ Black or African American
- ☐ Hispanic or Latino
- ☐ Middle Eastern or North African
- ☐ Native Hawaiian or other Pacific Islander
- ☐ White
- ☐ Prefer not to say

13. To which of the following national organizations are you connected? (check all that apply)

- [ ] Alliance for Rights & Recovery
- [ ] Association of Programs for Rural Independent Living (APRIL)
- [ ] Autistic Self Advocacy Network (ASAN)
- [ ] Association of University Centers on Disability (AUCD)
- [ ] #MEAction (The Myalgic Encephalomyelitis Action Network)
- [ ] Mindfreedom International
- [ ] National Association of Councils on Developmental Disabilities (NACDD)
- [ ] National Association of State Head Injury Administrators (NASHIA)
- [ ] National Association of Statewide Independent Living Councils (NASILC)
- [ ] National Council on Independent Living (NCIL)
- [ ] National Disability Family Networks
- [ ] National Disability Rights Network (NDRN)
- [ ] National Paralysis Resource Center (NPRC)
- [ ] Self Advocates Becoming Empowered - Self Advocacy Resource and Technical Assistance Center (SABE-SARTAC)\
- [ ] I don't know/I am not sure
- [ ] Prefer not to say

Other (please specify)

14. You indicated in a previous question that the activity was not accessible to you. Please share why.

Appendix H: Project Survey

ACL Grassroots Project Survey

Thank you for participating! All of your responses are voluntary and all information collected is for the purpose of program evaluation. None of the information you provide will be linked to you. All results will be shared in aggregate, meaning the results will be presented in a way that does not identify any specific people. Information provided will remain private and used to inform the program going forward.

With appreciation for the diversity of the disability community's orientation toward terminology we use both identity first (disabled person) and person-first (person with a disability) throughout all of our work.

Knowledge/Perception Related Outcomes

1. I believe that it is important to be informed of community issues.

- ○ Strongly agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

2. My opinion is important in deciding what people with disabilities need.

- ○ Strongly agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

3. I feel comfortable telling agencies and government staff how services for people with disabilities can be improved.

- ○ Strongly agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

4. I know how to get agency state administrators or legislators to listen to me.

- ○ Strongly agree
- ○ Agree
- ○ Neither agree nor disagree
- ○ Disagree
- ○ Strongly disagree

5. I have a good understanding of the disability rights movement.

- ◯ Strongly agree
- ◯ Agree
- ◯ Neither agree nor disagree
- ◯ Disagree
- ◯ Strongly disagree

6. I know what the rights of disabled people are under the Americans with Disabilities Act.

- ◯ Strongly agree
- ◯ Agree
- ◯ Neither agree nor disagree
- ◯ Disagree
- ◯ Strongly disagree

7. I believe people with disabilities and I can influence services for people with disabilities.

- ◯ Strongly agree
- ◯ Agree
- ◯ Neither agree nor disagree
- ◯ Disagree
- ◯ Strongly disagree

8. I feel that I am a good disability rights activist.

- ◯ Strongly agree
- ◯ Agree
- ◯ Neither agree nor disagree
- ◯ Disagree
- ◯ Strongly disagree

9. I think about new policies for improving the life of people with disabilities.

- ◯ Strongly agree
- ◯ Agree
- ◯ Neither agree nor disagree
- ◯ Disagree
- ◯ Strongly disagree

10. I know who my local legislators are.

- ◯ Strongly agree
- ◯ Agree
- ◯ Neither agree nor disagree
- ◯ Disagree
- ◯ Strongly disagree

11. I know how to contact my local legislators.

- ◯ Strongly agree
- ◯ Agree
- ◯ Neither agree nor disagree
- ◯ Disagree
- ◯ Strongly disagree

12. I know how to participate in legislative testimony.

- ◯ Strongly agree
- ◯ Agree
- ◯ Neither agree nor disagree
- ◯ Disagree
- ◯ Strongly disagree

13. I feel supported to advocate and make my own choices.

- ◯ Strongly agree
- ◯ Agree
- ◯ Neither agree nor disagree
- ◯ Disagree
- ◯ Strongly disagree

14. I am aware of opportunities for public comment on proposed rules and regulations.

- ◯ Strongly agree
- ◯ Agree
- ◯ Neither agree nor disagree
- ◯ Disagree
- ◯ Strongly disagree

Action-Oriented Outcomes

Please answer the following questions reflecting on the past 6 months.

15. I stay informed of events in my local community.

- ◯ Always
- ◯ Usually
- ◯ Sometimes
- ◯ Rarely
- ◯ Never

16. I participate in opportunities for public comment on proposed rules and regulations.

- ◯ Always
- ◯ Usually
- ◯ Sometimes
- ◯ Rarely
- ◯ Never

17. I attend conferences to increase my knowledge of advocating for legislative change.

- ◯ Always
- ◯ Usually
- ◯ Sometimes
- ◯ Rarely
- ◯ Never

18. I frequently discuss bills and legislative issues that are important to the disability community.

- ◯ Always
- ◯ Usually
- ◯ Sometimes
- ◯ Rarely
- ◯ Never

19. I participate in disability-related marches and/or rallies.

- Always
- Usually
- Sometimes
- Rarely
- Never

20. I work with disability organizations and/or other people with disabilities to increase public awareness of disability issues

- Always
- Usually
- Sometimes
- Rarely
- Never

21. I am involved in structured volunteer positions in the disability community.

- Always
- Usually
- Sometimes
- Rarely
- Never

22. I am an active member of at least one disability-related group

- Always
- Usually
- Sometimes
- Rarely
- Never

23. I use mass media (e.g., newspapers, TV, radio) to express my support or objection to a bill.

- Always
- Usually
- Sometimes
- Rarely
- Never

24. I use social media (e.g., Facebook, Instagram, X, Bluesky, Pixeled, Mastadon) to express my thoughts and opinions about disability issues.

- ◯ Always
- ◯ Usually
- ◯ Sometimes
- ◯ Rarely
- ◯ Never

25. I provide training to others to increase their legislative advocacy knowledge.

- ◯ Always
- ◯ Usually
- ◯ Sometimes
- ◯ Rarely
- ◯ Never

26. I communicate with members of my local community (e.g., friends, family, and neighbors) about disability issues important to me.

- ◯ Always
- ◯ Usually
- ◯ Sometimes
- ◯ Rarely
- ◯ Never

27. I talk to member(s) of the press (e.g., journalists, reporters, talk show hosts, podcasters) about disability issues important to me.

- ◯ Always
- ◯ Usually
- ◯ Sometimes
- ◯ Rarely
- ◯ Never

28. I communicate (by phone, email, or visit) with legislators or their staffers about my stand on disability rights.

- ◯ Always
- ◯ Usually
- ◯ Sometimes
- ◯ Rarely
- ◯ Never

29. I contact the Governor's office to urge them to sign or not sign a passed bill.

- ○ Always
- ○ Usually
- ○ Sometimes
- ○ Rarely
- ○ Never

30. I attend legislative hearings.

- ○ Always
- ○ Usually
- ○ Sometimes
- ○ Rarely
- ○ Never

31. I participate in legislative hearings by giving testimonies.

- ○ Always
- ○ Usually
- ○ Sometimes
- ○ Rarely
- ○ Never

Demographic information

32. In what ways do you identify with the disability community? (check all that apply)

- ☐ Person with a disability/disabled person
- ☐ Advocate
- ☐ Family member or loved one of a person with a disability /disabled person
- ☐ Person who uses long term support and services (LTSS) or home and community-based services (HCBS)
- ☐ Person working in a disability organization
- ☐ Caregiver or staff supporting a person with a disability
- ☐ Other (please specify)

33. In what state or territory do you live?

34. What age group do you belong to

- ○ Under 18
- ○ 18-24
- ○ 25-34
- ○ 35-44
- ○ 45-54
- ○ 55-64
- ○ 65+
- ○ Prefer not to say

35. Are you Hispanic or Latino?

- ○ No, not Hispanic or Latino
- ○ Yes, not Hispanic or Latino
- ○ Prefer not to say

36. What is your race (check all that apply)?

- ☐ American Indian or Alaska Native
- ☐ Asian or Asian American
- ☐ Black or African American
- ☐ Hispanic or Latino
- ☐ Middle Eastern or North African
- ☐ Native Hawaiian or other Pacific Islander
- ☐ White
- ☐ Prefer not to say
- ☐ Other (please specify)

37. Please indicate any formalized leadership positions you have held over the past six months (select all that apply)

- ☐ Coalition leader
- ☐ Community elder
- ☐ Cultural broker
- ☐ Member of local/state advisory board
- ☐ Member of a board of directors
- ☐ Mentor
- ☐ Peer supporter
- ☐ A person people rely on me for information or advice
- ☐ Political campaign volunteer
- ☐ Social media influencer
- ☐ Prefer not to say
- ☐ Other (please specify)

38. Please mark completed levels of education (select all that apply).

- [ ] Less than high school
- [ ] High school/GED
- [ ] Some college
- [ ] Associate's degree
- [ ] Bachelor's degree
- [ ] Master's degree
- [ ] Doctoral or other terminal degree
- [ ] Certificate
- [ ] Prefer not to say
- [ ] Other (please specify)

39. What is your employment status? (select all that apply)

- [ ] Part-time employment
- [ ] Full-time employment
- [ ] Self-employed
- [ ] Seeking employment
- [ ] Not seeking employment
- [ ] Retired
- [ ] Full-time student
- [ ] Prefer not to say
- [ ] Other (please specify)

40. Which of the following organizations are you primarily affiliated with?

- [ ] Association of Programs for Rural Independent Living (APRIL)
- [ ] Autistic Self Advocacy Network (ASAN)
- [ ] Association of University Centers on Disability (AUCD)
- [ ] National Association of Councils on Developmental Disabilities (NACDD)
- [ ] National Association of State Head Injury Administrators (NASHIA)
- [ ] National Association of Statewide Independent Living Councils (NASILC)
- [ ] National Council on Independent Living (NCIL)
- [ ] National Disability Rights Network (NDRN)
- [ ] Paralysis Resource Center (PRC)
- [ ] Self Advocates Becoming Empowered - Self Advocacy Resource and Technical Assistance Center (SABE-SARTAC)
- [ ] Prefer not to say
- [ ] Other (please specify)

Appendix I: Project Survey References

Grassroots Project Survey (with citations; not including demographics)

Knowledge/perception-related

1. I believe that it is important to be informed of community issues. (Doolittle & Faul, 2013)
    - Strongly Agree
    - Agree
    - Neutral
    - Disagree
    - Strongly Disagree
2. My opinion is important in deciding what people with disabilities need. (based on Sharp et al, 2017)
3. I feel comfortable telling agencies and government staff how services for people with disabilities can be improved. (Sharp et al, 2017)
4. I know how to get agency state administrators or legislators to listen to me. (Sharp et al, 2017)
5. I have a good understanding of the disability rights movement. (Sharp et al)
6. I know what the rights of disabled people are under the Americans with Disabilities Act. (Sharp et al, 2017)
7. I believe people with disabilities and I can influence services for people with disabilities. (Sharp et al, 2017)
8. I feel that I am a good disability rights activist. (Sharp et al, 2017)
9. I think about new policies for improving the life of people with disabilities. (Landmark et al, 2017)
10. I know who my local legislators are. (Landmark et al, 2017)
11. I know how to contact my local legislators. (Landmark et al, 2017)
12. I know how to participate in legislative testimony. (Landmark et al, 2017)
13. **NEW** I feel supported to advocate and make my own choices.
14. **NEW** I am aware of opportunities for public comment on proposed rules and regulations.

Action-oriented outcomes (Please answer reflecting on the past 6 months)

15. I stay informed of events in my local community. (based on Doolittle & Faul 2013, added "local")
    - Always
    - Often

- Sometimes
- Never
- Not applicable

16. **NEW** I am aware of opportunities for public comment on proposed rules and regulations.
17. **NEW** I participate in opportunities for public comment on proposed rules and regulations.
18. I attend conferences to increase my knowledge of advocating for legislative change. (Landmark et al, 2017)
19. I frequently discuss bills and legislative issues that are important to the disability community. (Landmark et al, 2017)
20. I participate in disability-related marches and/or rallies. (Landmark et al, 2017)
21. I work with disability organizations and/or other people with disabilities to increase public awareness of disability issues (Landmark et al, 2017)
22. I am involved in structured volunteer positions in the [disability] community. (based on Doolittle & Faul, 2013)
23. [I am an] Active member of at least one [disability-related] group (based on Lopez & Marcelo, 2008)
24. I use mass media (e.g., newspapers, TV, radio) to express my support or objection to a bill. (based on Landmark et al, 2017)
25. I use social media (e.g., Facebook, Instagram, X, Bluesky, Pixeled, Mastadon) to express my thoughts and opinions about disability issues. (based on Landmark et al, 2017)
26. I provide training to others to increase their legislative advocacy knowledge. (Landmark et al, 2017)
27. **NEW** I communicate with members of my local community (e.g., friends, family, and neighbors) about disability issues important to me.
28. **NEW** I talk to member(s) of the press (e.g., journalists, reporters, talk show hosts, podcasters) about disability issues important to me.
29. I communicate (by phone, email, or visit) with legislators or their staffers about my stand on disability rights. (Landmark et al, 2017)
30. I contact the Governor's office to urge [them] to sign or not sign a passed bill. (Landmark et al, 2017)
31. I attend legislative hearings. (Landmark et al, 2017)
32. I participate in legislative hearings by giving testimonies. (Landmark et al, 2017)

References:

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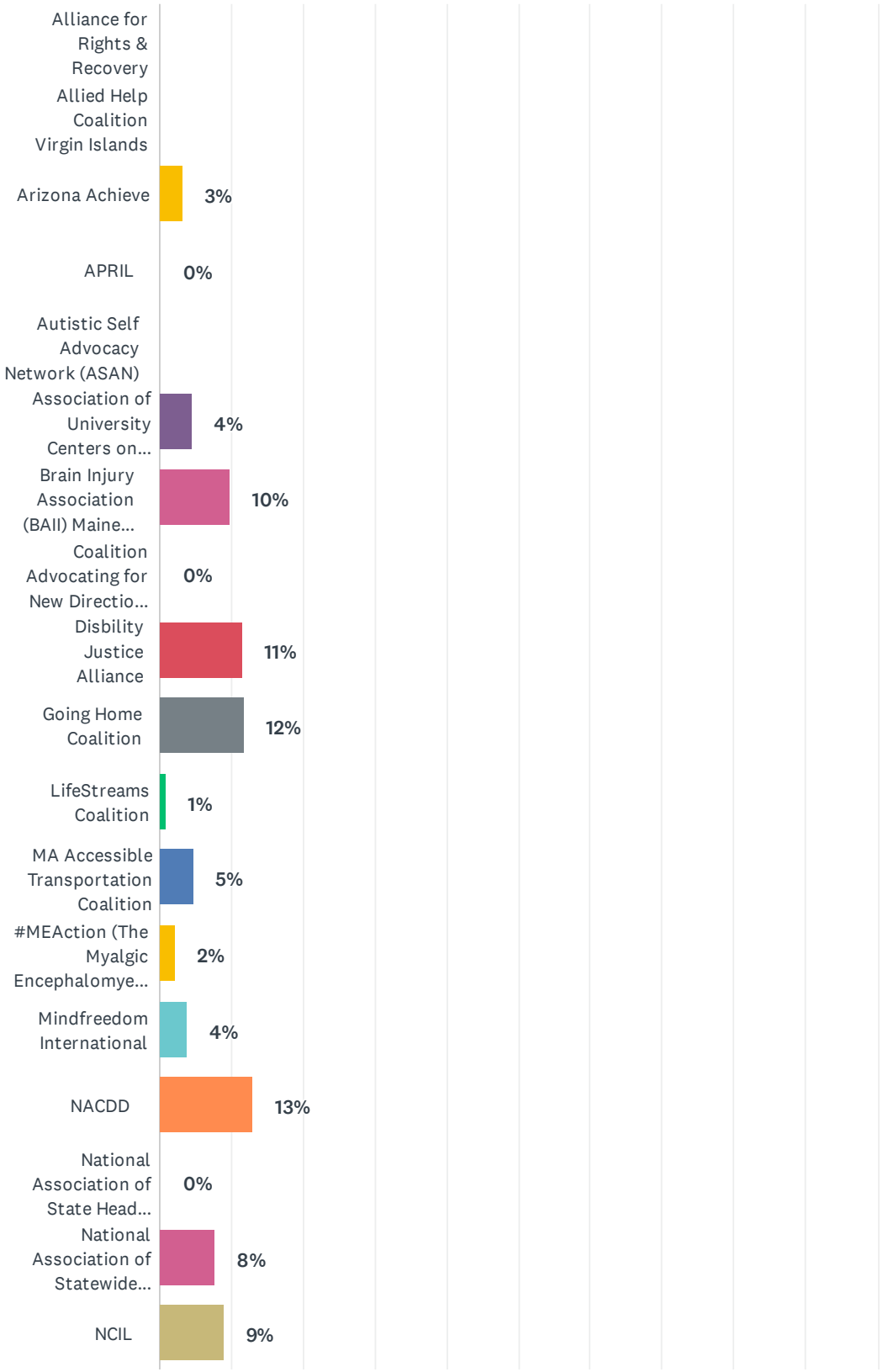
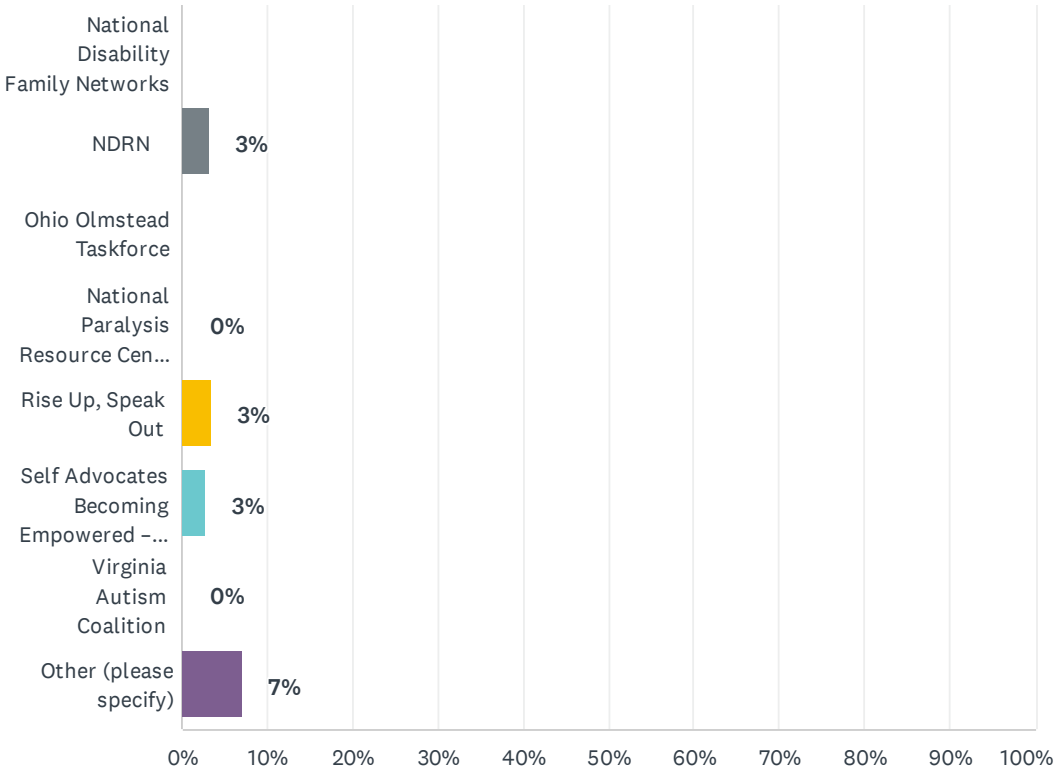
Appendix J: Engagement Survey Results

Q1 Please select the hosting organization for the activity you participated in.

Answered: 315 Skipped: 4




National Disability Family Networks
NDRN
3%
Ohio Olmstead Taskforce
National Paralysis Resource Cen...
0%
Rise Up, Speak Out
3%
Self Advocates Becoming Empowered –...
3%
Virginia Autism Coalition
0%
Other (please specify)
7%
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%

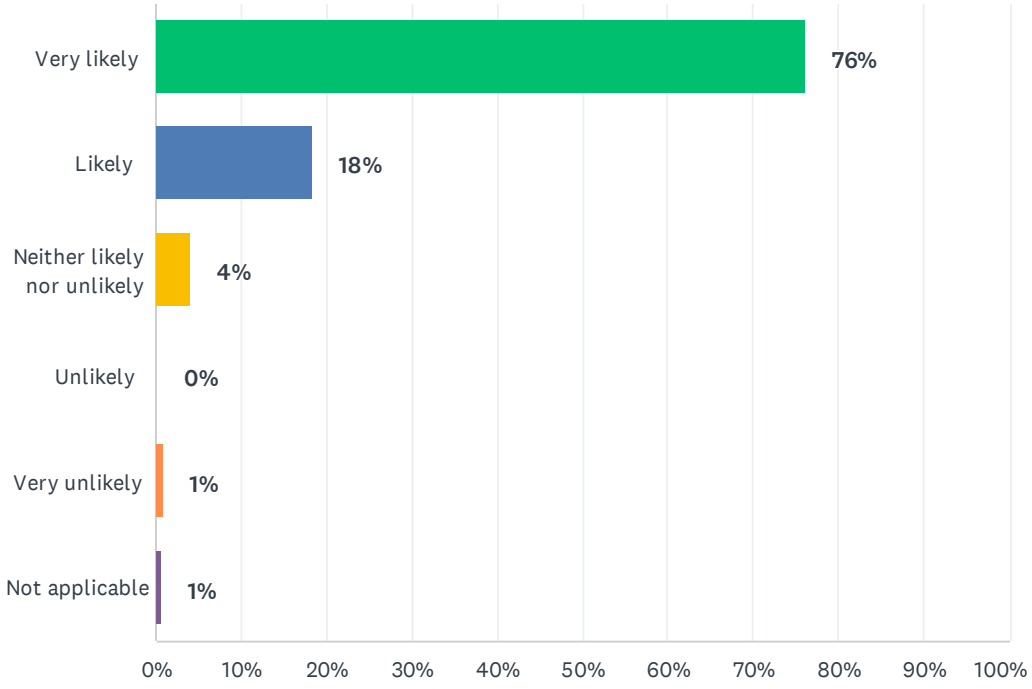
ANSWER CHOICES	RESPONSES	
Alliance for Rights & Recovery	0%	0
Allied Help Coalition Virgin Islands	0%	0
Arizona Achieve	3%	10
APRIL	0%	1
Autistic Self Advocacy Network (ASAN)	0%	0
Association of University Centers on Disability (AUCD)	4%	14
Brain Injury Association (BAII) Maine Chapter	10%	31
Coalition Advocating for New Directions in Legislation, Empowerment, & Services (CANDLES)	0%	1
Disbility Justice Alliance	11%	36
Going Home Coalition	12%	37
LifeStreams Coalition	1%	3
MA Accessible Transportation Coalition	5%	15
#MEAction (The Myalgic Encephalomyelitis Action Network)	2%	7
Mindfreedom International	4%	12
NACDD	13%	41
National Association of State Head Injury Administrators (NASHIA)	0%	1
National Association of Statewide Independent Living Councils (NASILC)	8%	24
NCIL	9%	28
National Disability Family Networks	0%	0
NDRN	3%	10
Ohio Olmstead Taskforce	0%	0
National Paralysis Resource Center (NPRC)	0%	1
Rise Up, Speak Out	3%	11
Self Advocates Becoming Empowered – Self Advocacy Resource and Technical Assistance Center (SABE-SARTAC)	3%	9
Virginia Autism Coalition	0%	1
Other (please specify)	7%	22
TOTAL		315

#	OTHER (PLEASE SPECIFY)	DATE
1	MA statewide independent living conference	9/16/2025 12:58 PM
2	HCBS	8/27/2025 8:09 PM
3	Self-Advocacy Association of New York State (SANYS)	8/27/2025 1:17 PM
4	Self-Advocacy Association of New York State	8/27/2025 1:16 PM
5	Self-Advocacy Association of New York State	8/27/2025 1:13 PM

6	National Collaborative for Supporting Families	8/21/2025 2:37 PM
7	National Community of Practice	8/21/2025 2:23 PM
8	UMKC Supporting Families Best Practice Series	8/21/2025 2:21 PM
9	Families as allies, advocates, and partners and grassroots systems changes	8/21/2025 2:18 PM
10	National Collaborative for Supporting Families	8/21/2025 2:18 PM
11	Human Services Resource Institute	8/21/2025 2:17 PM
12	FSRTC	8/21/2025 2:15 PM
13	Judi's Room	8/6/2025 6:21 PM
14	Thresholds	7/8/2025 5:28 PM
15	parent	7/8/2025 5:07 PM
16	Grassroots Project	7/2/2025 12:10 PM
17	Special olympics arizona athletes leadership program	6/20/2025 3:51 PM
18	Rev UP	5/14/2025 6:45 PM
19	Rev up Illinois	5/14/2025 6:08 PM
20	ÇSPD	4/7/2025 5:25 PM
21	Center for Independent living	4/7/2025 3:01 PM
22	Self-Advocates of Michigan	4/7/2025 10:42 AM

Q2 How likely are you to take action in your own advocacy work in the next six months as a result of today's activity?

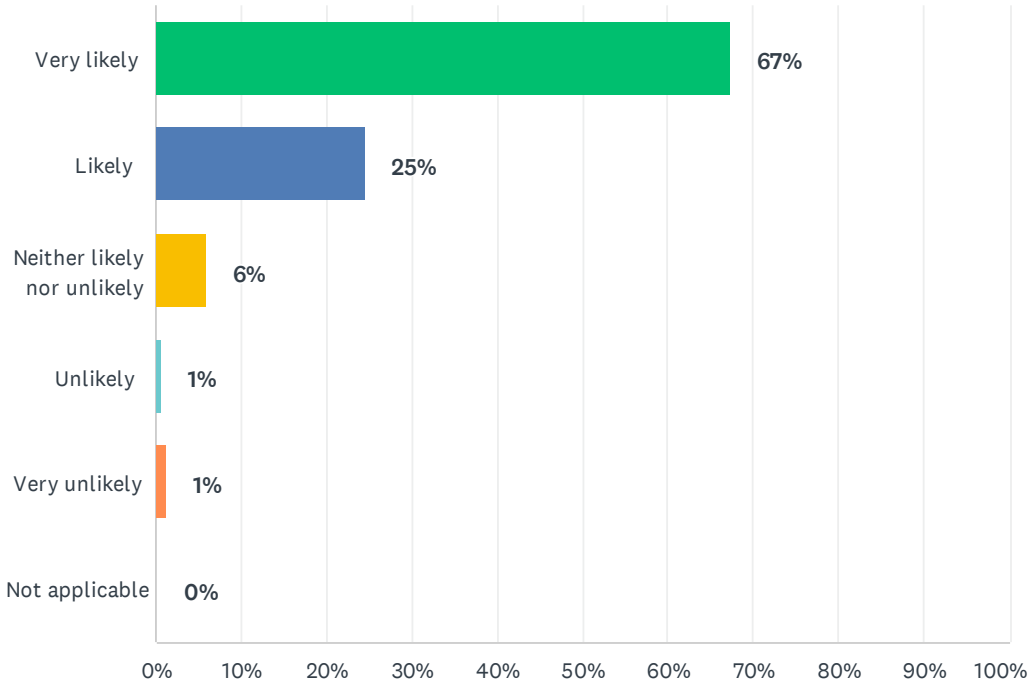
Answered: 318 Skipped: 1



ANSWER CHOICES	RESPONSES	
Very likely	76%	242
Likely	18%	58
Neither likely nor unlikely	4%	13
Unlikely	0%	1
Very unlikely	1%	3
Not applicable	1%	2
TOTAL		318

Q3 How likely are you to connect and collaborate with new people in the next six months as a result of this activity?

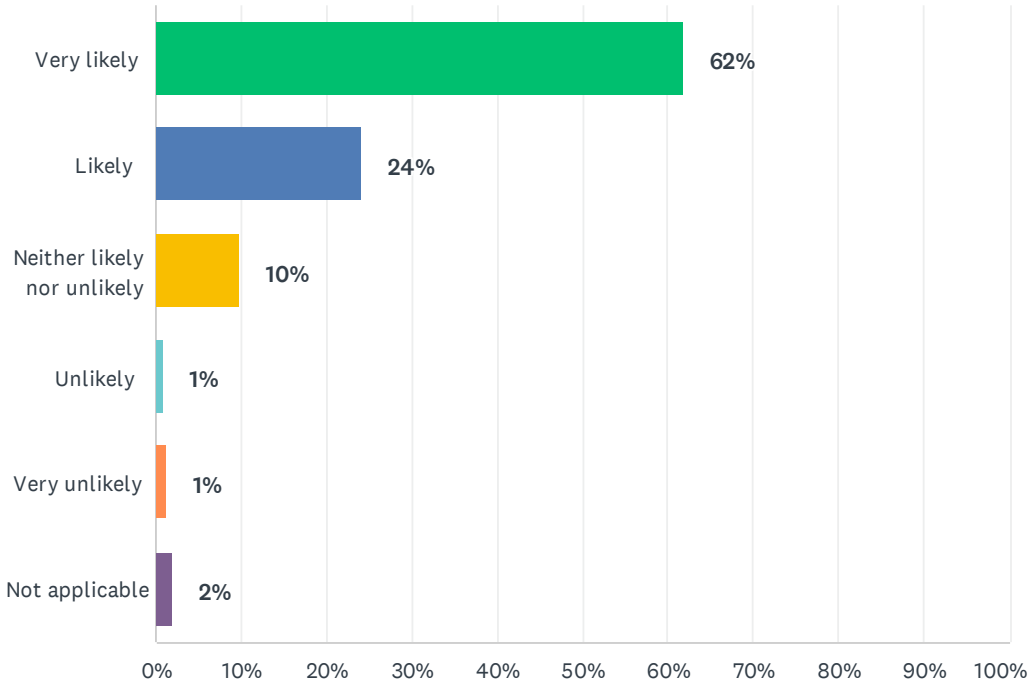
Answered: 318 Skipped: 1



ANSWER CHOICES	RESPONSES	
Very likely	67%	214
Likely	25%	78
Neither likely nor unlikely	6%	19
Unlikely	1%	2
Very unlikely	1%	4
Not applicable	0%	1
TOTAL		318

Q4 How likely are you to engage with the Grassroots Project in the next six months?

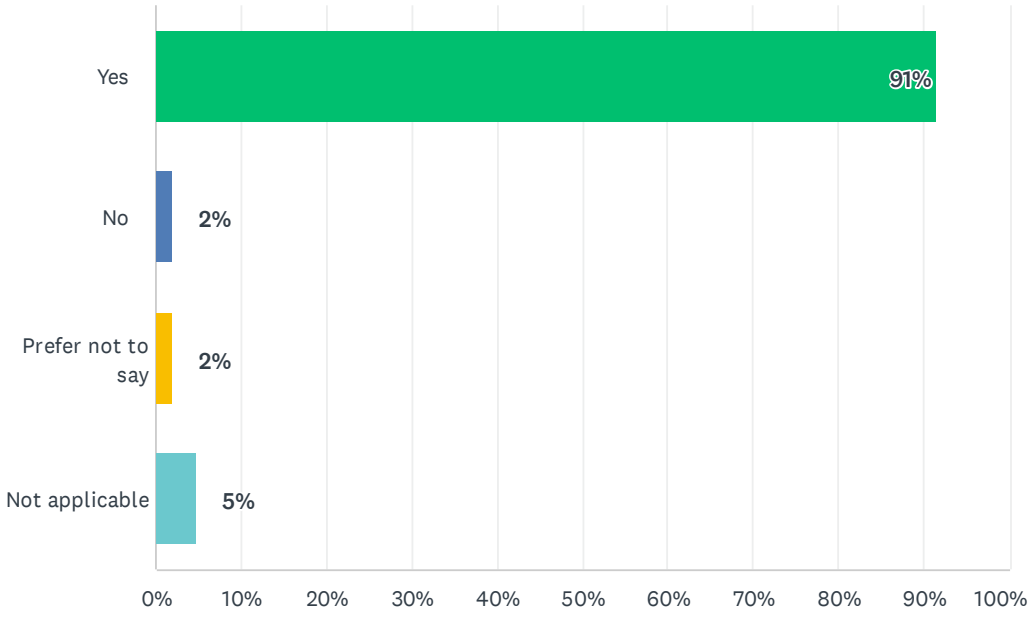
Answered: 315 Skipped: 4



ANSWER CHOICES	RESPONSES	
Very likely	62%	195
Likely	24%	76
Neither likely nor unlikely	10%	31
Unlikely	1%	3
Very unlikely	1%	4
Not applicable	2%	6
TOTAL		315

Q5 Do you feel more comfortable and confident in advocating as a result of participating in this activity?

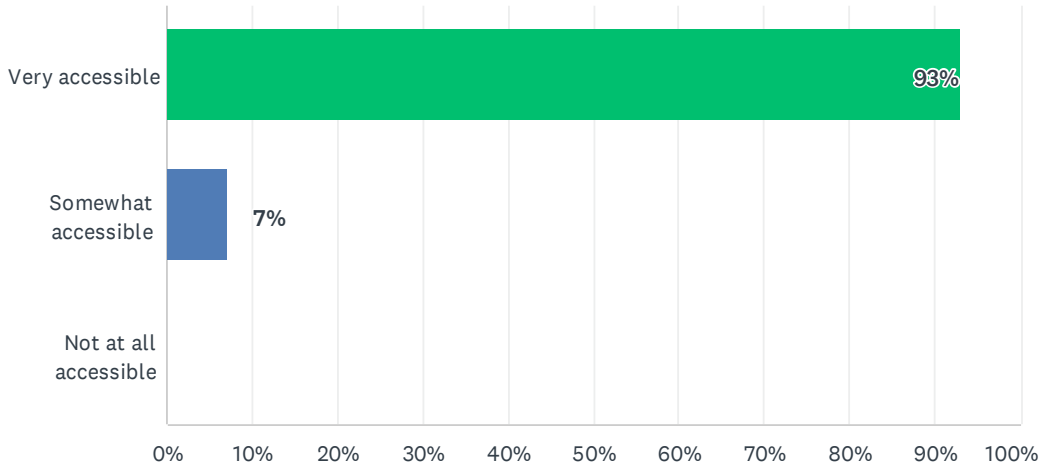
Answered: 315 Skipped: 4



ANSWER CHOICES	RESPONSES	
Yes	91%	288
No	2%	6
Prefer not to say	2%	6
Not applicable	5%	15
TOTAL		315

Q6 How accessible was this activity for you?

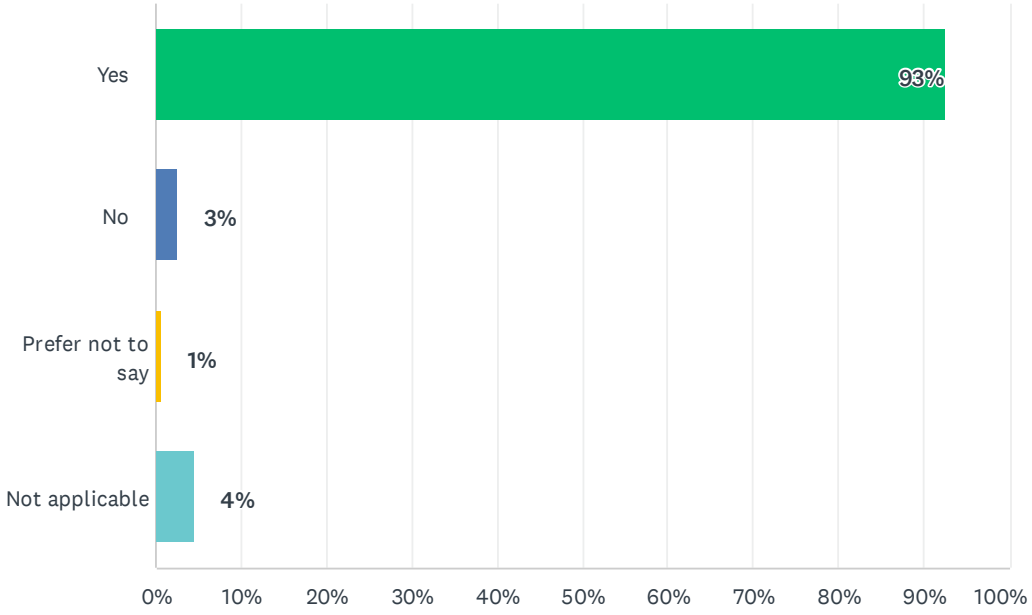
Answered: 315 Skipped: 4



ANSWER CHOICES	RESPONSES	
Very accessible	93%	293
Somewhat accessible	7%	22
Not at all accessible	0%	0
TOTAL		315

Q7 Did you learn anything useful for your advocacy about state systems, policies, funding, or state agencies overseeing disability services from this activity?

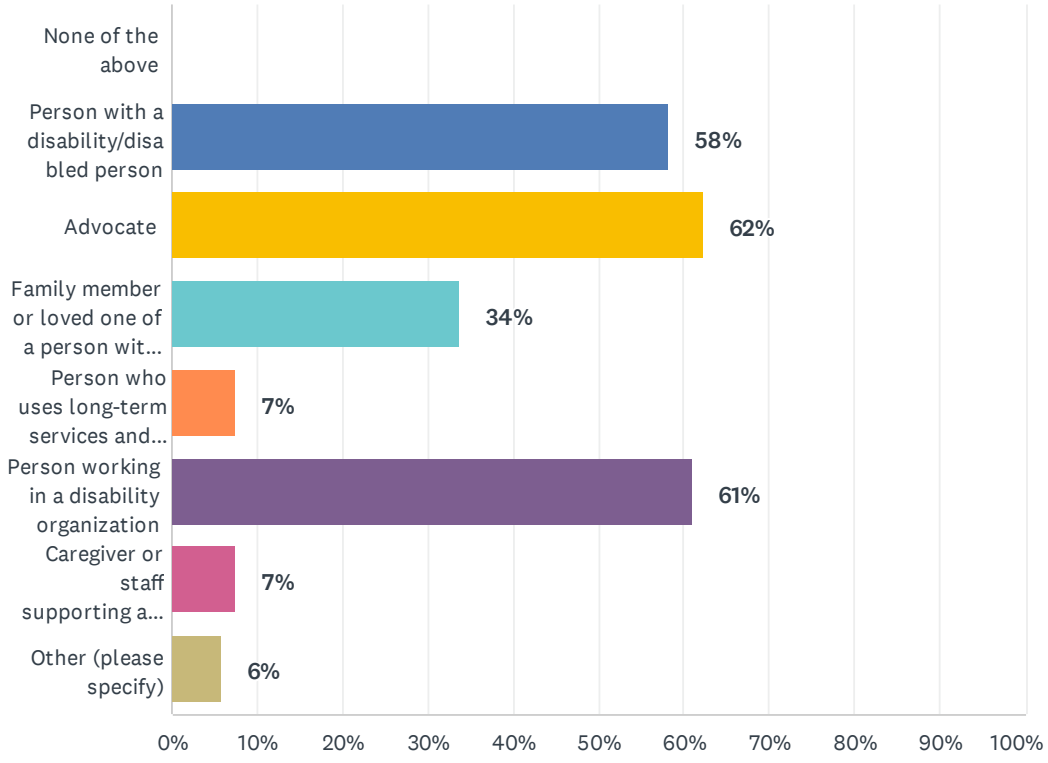
Answered: 312 Skipped: 7



ANSWER CHOICES	RESPONSES	
Yes	93%	289
No	3%	8
Prefer not to say	1%	2
Not applicable	4%	14
TOTAL		312

Q8 In what ways do you primarily identify with the disability community? (check all that apply)

Answered: 244 Skipped: 75

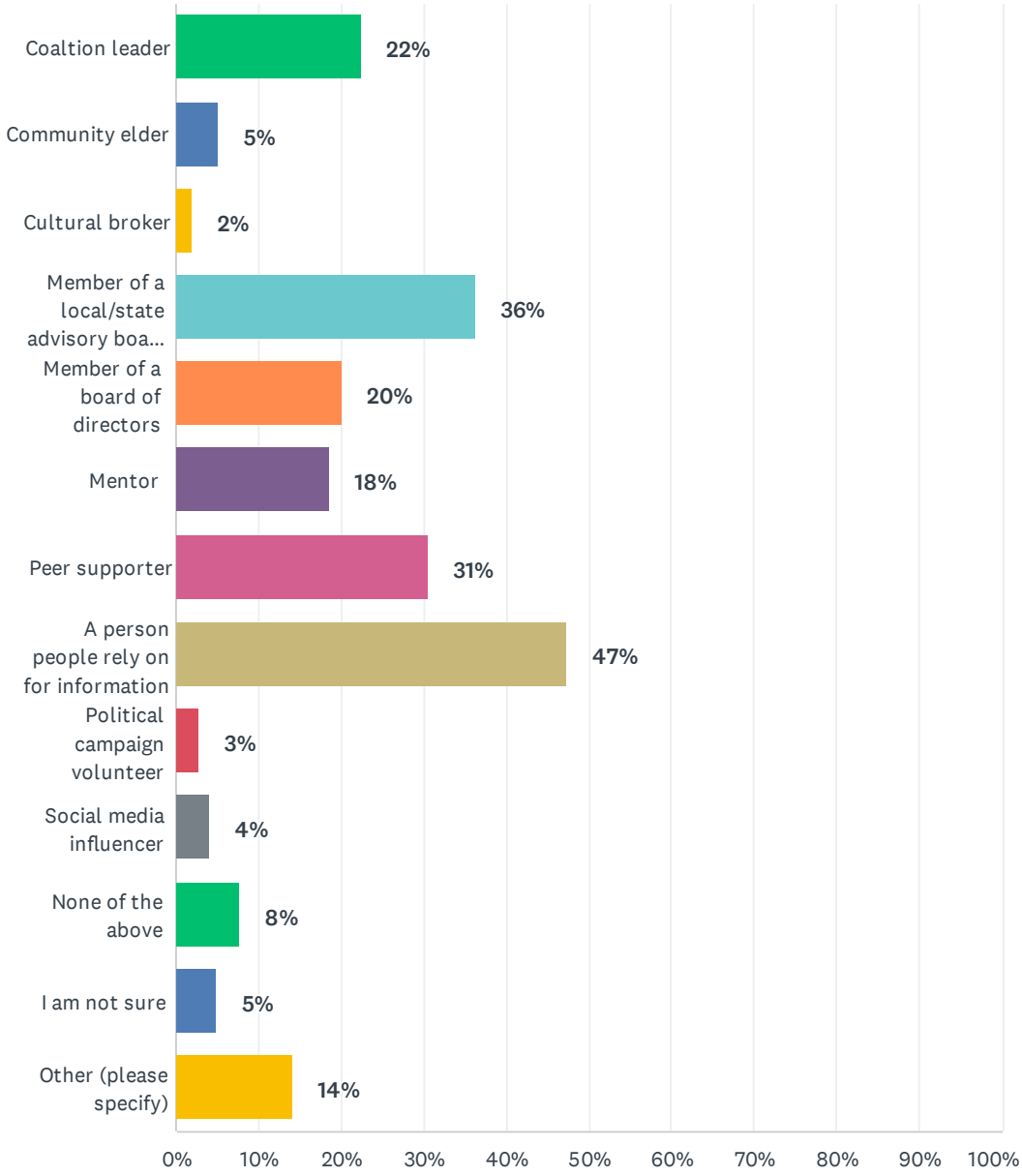


ANSWER CHOICES	RESPONSES	
None of the above	0%	0
Person with a disability/disabled person	58%	142
Advocate	62%	152
Family member or loved one of a person with a disability/disabled person	34%	82
Person who uses long-term services and supports and/or home and community-based services	7%	18
Person working in a disability organization	61%	149
Caregiver or staff supporting a person with a disability	7%	18
Other (please specify)	6%	14
Total Respondents: 244		

#	OTHER (PLEASE SPECIFY)	DATE
1	Owner/Operator Wheels on the Bus Private Transportation Service for persons with a a disability.	9/22/2025 10:34 AM
2	Executive Director of Nebraska DD Council	9/17/2025 4:11 PM
3	Psychiatric Survivor (I don't identify as being disabled)	9/11/2025 5:59 PM
4	Psychologist and Psych Survivor	9/11/2025 5:22 PM
5	disabled person	8/11/2025 12:44 PM
6	Activist working to change the thrust of how the work is appraoched.	8/6/2025 6:40 PM
7	Mentor for the Writers Guild Initiative, community builder	8/6/2025 1:21 PM
8	Work with students at a public school in special education.	6/20/2025 6:52 PM
9	I am a board member or active member in 6 local, state, and federal disability and healthcare organizations.	5/16/2025 11:46 AM
10	Legislative Assistant	5/15/2025 1:29 PM
11	Volunteer moderator of Illinois Parents of Adults with Developmental Disabilities Facebook group (7,800 members)	5/14/2025 8:23 PM
12	Work	5/2/2025 5:34 PM
13	MDDC	4/7/2025 10:48 AM
14	Business owner with a disability	3/7/2025 2:06 PM

Q9 Which of the following leadership roles to you play? (select all that apply)

Answered: 249 Skipped: 70


Coaltion leader
22%
Community elder
5%
Cultural broker
2%
Member of a local/state advisory boa...
36%
Member of a board of directors
20%
Mentor
18%
Peer supporter
31%
A person people rely on for information
47%
Political campaign volunteer
3%
Social media influencer
4%
None of the above
8%
I am not sure
5%
Other (please specify)
14%
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%

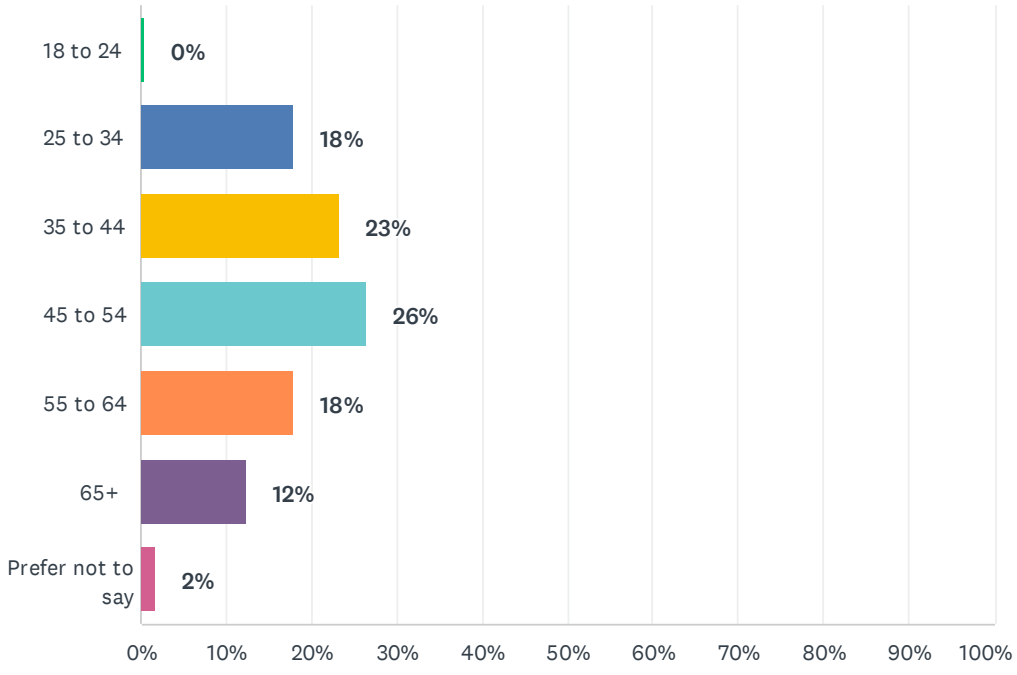
ANSWER CHOICES	RESPONSES	
Coaltion leader	22%	56
Community elder	5%	13
Cultural broker	2%	5
Member of a local/state advisory board or committee	36%	90
Member of a board of directors	20%	50
Mentor	18%	46
Peer supporter	31%	76
A person people rely on for information	47%	118
Political campaign volunteer	3%	7
Social media influencer	4%	10
None of the above	8%	19
I am not sure	5%	12
Other (please specify)	14%	35
Total Respondents: 249		

#	OTHER (PLEASE SPECIFY)	DATE
1	Executive Director	9/23/2025 3:18 PM
2	Executive Director of State DD Council	9/17/2025 4:11 PM
3	Executive Director	9/17/2025 4:00 PM
4	Manager	9/16/2025 1:01 PM
5	Technical and other supports	9/12/2025 1:18 PM
6	Agency Program Coordinator	9/11/2025 5:22 PM
7	SILC	9/9/2025 6:17 PM
8	Executive Director	9/2/2025 7:35 AM
9	staff at disability organization/agency	8/28/2025 8:51 AM
10	Self Advocate leader	8/21/2025 2:21 PM
11	Executive Director of Statewide Independent Living Council	8/20/2025 6:17 AM
12	trade Union member, with the Writers Guild of America	8/6/2025 1:21 PM
13	Disability organization CEO	7/28/2025 1:59 PM
14	workgroup leader	7/2/2025 12:09 PM
15	leadership in a social services agency	6/26/2025 9:51 AM
16	Special Olympics	6/22/2025 12:24 AM
17	Hospital Administrator	6/20/2025 9:22 AM
18	clinical administrator for state government	6/19/2025 2:51 PM
19	Transition Coordinator at a state CIL	6/18/2025 10:36 AM
20	administrator	6/2/2025 2:52 PM

21	administrator	6/2/2025 2:51 PM
22	Pastor	5/3/2025 4:24 PM
23	Administrative support to a cross-disability non-profit org	5/2/2025 6:16 PM
24	Executive Director	4/7/2025 3:02 PM
25	Director of DD Council	4/7/2025 12:34 PM
26	Council on developmental disabilities staff	4/7/2025 11:14 AM
27	Executive Director of the WV DD Council, advocate, mentor	4/7/2025 10:52 AM
28	director of a disability organization	4/7/2025 10:51 AM
29	self-advocate	4/7/2025 10:43 AM
30	New to working in a disability organization but have many years of lived experience as a person who has a disability..	4/4/2025 2:01 PM
31	Systems Change Advocate	4/4/2025 1:59 PM
32	Systems Change	3/7/2025 2:06 PM
33	Support programs/projects that involved advocacy	3/7/2025 2:05 PM
34	Systems change advocate	3/7/2025 2:03 PM
35	CIL Systems Advocate	3/7/2025 2:02 PM

Q10 What is your age?

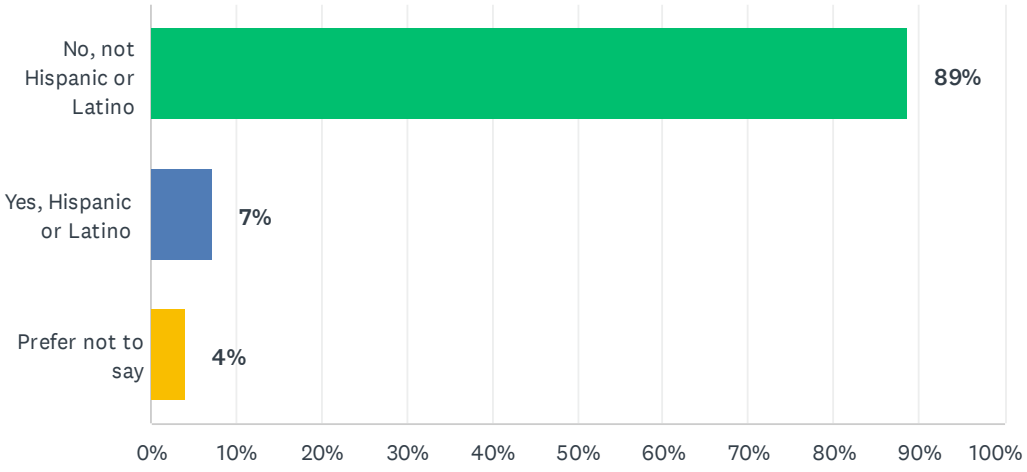
Answered: 250 Skipped: 69



ANSWER CHOICES	RESPONSES	
18 to 24	0%	1
25 to 34	18%	45
35 to 44	23%	58
45 to 54	26%	66
55 to 64	18%	45
65+	12%	31
Prefer not to say	2%	4
TOTAL		250

Q11 Are you Hispanic or Latino?

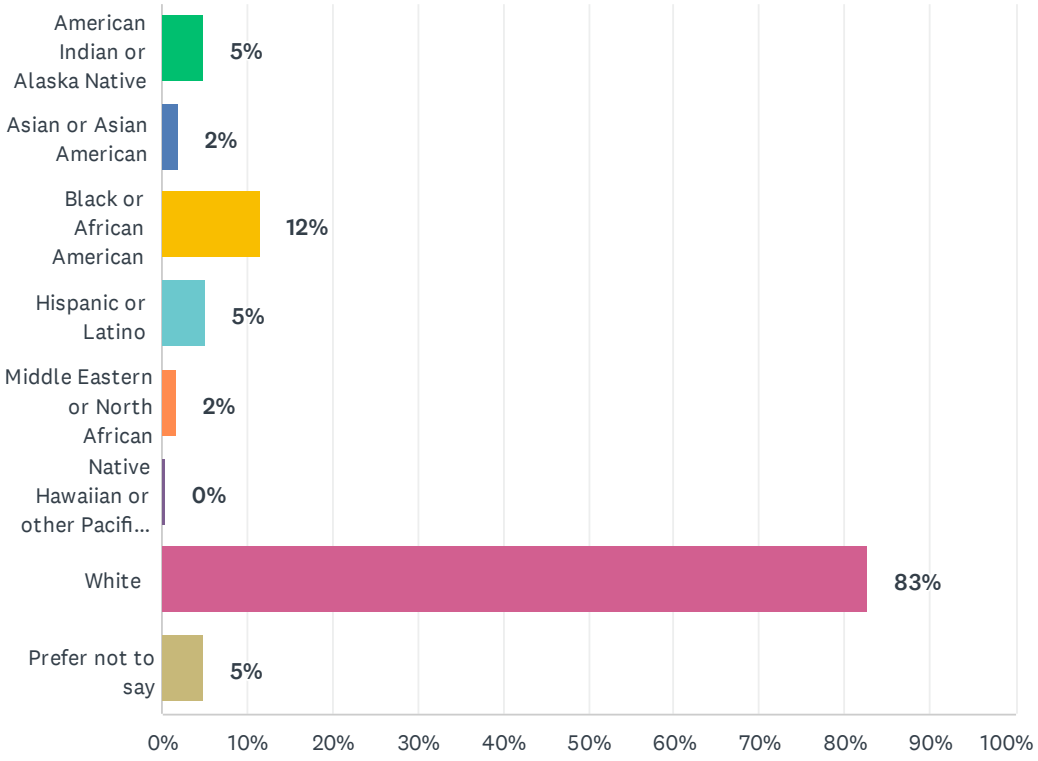
Answered: 249 Skipped: 70



ANSWER CHOICES	RESPONSES	
No, not Hispanic or Latino	89%	221
Yes, Hispanic or Latino	7%	18
Prefer not to say	4%	10
TOTAL		249

Q12 What is your race? (check all that apply)

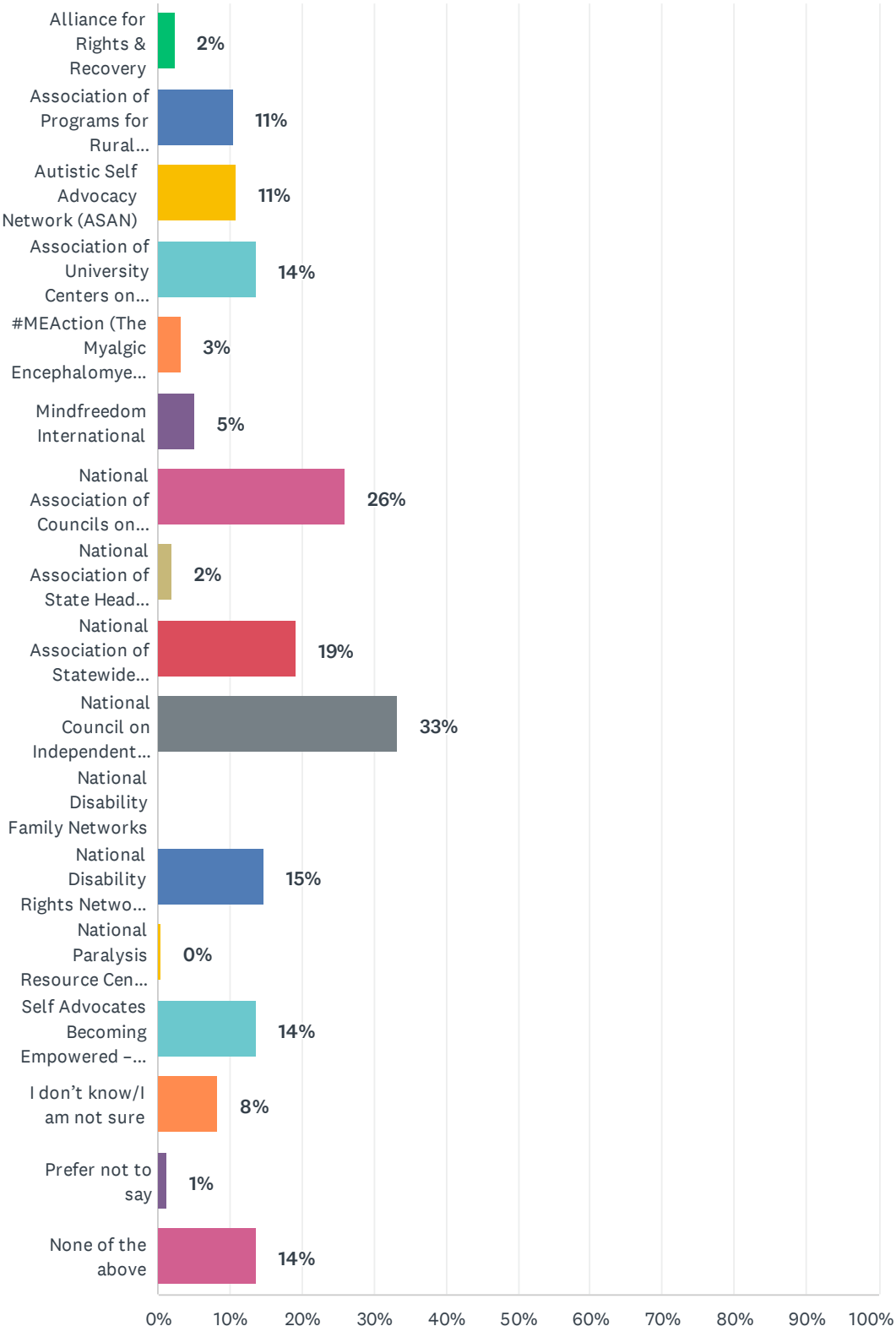
Answered: 250 Skipped: 69



ANSWER CHOICES	RESPONSES	
American Indian or Alaska Native	5%	12
Asian or Asian American	2%	5
Black or African American	12%	29
Hispanic or Latino	5%	13
Middle Eastern or North African	2%	4
Native Hawaiian or other Pacific Islander	0%	1
White	83%	207
Prefer not to say	5%	12
Total Respondents: 250		

Q13 To which of the following national organizations are you connected? (check all that apply)

Answered: 219 Skipped: 100


Alliance for Rights & Recovery
2%
Association of Programs for Rural...
11%
Autistic Self Advocacy Network (ASAN)
11%
Association of University Centers on...
14%
#MEAction (The Myalgic Encephalomye...
3%
Mindfreedom International
5%
National Association of Councils on...
26%
National Association of State Head...
2%
National Association of Statewide...
19%
National Council on Independent...
33%
National Disability Family Networks
National Disability Rights Netwo...
15%
National Paralysis Resource Cen...
0%
Self Advocates Becoming Empowered –...
14%
I don't know/I am not sure
8%
Prefer not to say
1%
None of the above
14%
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%

ANSWER CHOICES	RESPONSES	
Alliance for Rights & Recovery	2%	5
Association of Programs for Rural Independent Living (APRIL)	11%	23
Autistic Self Advocacy Network (ASAN)	11%	24
Association of University Centers on Disability (AUCD)	14%	30
#MEAction (The Myalgic Encephalomyelitis Action Network)	3%	7
Mindfreedom International	5%	11
National Association of Councils on Developmental Disabilities (NACDD)	26%	57
National Association of State Head Injury Administrators (NASHIA)	2%	4
National Association of Statewide Independent Living Councils (NASILC)	19%	42
National Council on Independent Living (NCIL)	33%	73
National Disability Family Networks	0%	0
National Disability Rights Network (NDRN)	15%	32
National Paralysis Resource Center (NPRC)	0%	1
Self Advocates Becoming Empowered – Self Advocacy Resource and Technical Assistance Center (SABE-SARTAC)\	14%	30
I don’t know/I am not sure	8%	18
Prefer not to say	1%	3
None of the above	14%	30
Total Respondents: 219		

#	OTHER (PLEASE SPECIFY)	DATE
1	Caring Across Generations	9/23/2025 3:23 PM
2	UCEDD	9/23/2025 3:19 PM
3	Mental Health America; National Alliance on Mental Illness	9/23/2025 3:19 PM
4	UMass medical school	9/16/2025 1:01 PM
5	Mental Health America in Michigan, National Alliance on Mental Illness	9/16/2025 9:20 AM
6	NARPA, DRVT, Another Way	9/15/2025 6:09 PM
7	SAFE	9/12/2025 1:18 PM
8	PIDs	9/9/2025 6:17 PM
9	National Alliance on Mental Illness; Mental Health America in Michigan	8/26/2025 3:26 PM
10	Caring Across Generations, Justice in Aging, FamiliesUSA	8/22/2025 10:24 AM
11	National Community of Practice fir Supporting Families	8/21/2025 2:25 PM
12	National Sibling Leadership Network	8/21/2025 2:22 PM
13	Self Advocates United as 1	8/21/2025 2:21 PM
14	National Alliance on Mental Illness county affiliate; Mental Health Assoc in Michigan	8/18/2025 1:11 PM
15	United Spinal	8/15/2025 11:26 AM

16	Disability Justice Alliance	8/11/2025 9:49 AM
17	The Arc U.S.	8/11/2025 9:40 AM
18	ABIAC	7/25/2025 12:54 PM
19	ABIAC	7/25/2025 12:51 PM
20	BIAA	6/28/2025 11:23 AM
21	Brain Injury Association of America, Maine chapter	6/26/2025 9:51 AM
22	Special Olympics	6/22/2025 12:24 AM
23	ARC of Tempe	6/20/2025 6:52 PM
24	United for change	6/17/2025 1:14 PM
25	United for change	6/17/2025 1:10 PM
26	United for change	6/17/2025 1:05 PM
27	na	5/22/2025 1:33 PM
28	none	5/15/2025 1:29 PM
29	Nads, engage ill	5/14/2025 7:33 PM
30	The Arc of the United States	5/14/2025 6:58 PM
31	The Arc of the United States	5/14/2025 6:56 PM
32	partners in policymaking	5/14/2025 6:53 PM
33	advocate for individuals that I support and have supported in the past.	5/14/2025 6:45 PM
34	SHPA	5/14/2025 6:10 PM
35	Long Term Care Ombudsman	5/3/2025 4:24 PM
36	Nsac	5/2/2025 6:02 PM
37	United States International Council on Disabilities	5/2/2025 1:54 PM
38	ÇSPD	4/7/2025 5:27 PM
39	TASH member	4/7/2025 3:20 PM
40	center for independence	4/7/2025 3:02 PM
41	TASH	4/7/2025 11:58 AM
42	none of these	3/7/2025 2:06 PM
43	CIL	3/7/2025 2:05 PM
44	NYSILC; NASW: New York State Rehabilitation Council Board	3/7/2025 1:17 PM

Q14 You indicated in a previous question that the activity was not accessible to you. Please share why.

Answered: 154 Skipped: 165

#	RESPONSES	DATE
1	I did not say that, and it won't let me go back to the question to fix it	9/24/2025 2:40 PM
2	None	9/24/2025 1:09 PM
3	was	9/24/2025 1:07 PM

4	n/a	9/24/2025 1:04 PM
5	I did not say this, I said it was "very accessible"	9/24/2025 7:20 AM
6	I did not have accessibility problems.	9/23/2025 3:24 PM
7	got this message in error again. activity was accessible	9/23/2025 3:20 PM
8	I did not. For #6 I answered that it was accessible.	9/23/2025 3:20 PM
9	Did not meant to put. It was very accessible	9/23/2025 3:20 PM
10	did not indicate that	9/23/2025 3:19 PM
11	NA i dont know why it says this, i just double checked and i answered that i had no problems with accessiblity	9/23/2025 3:19 PM
12	It was accessible, my mistake!	9/23/2025 3:18 PM
13	It was accessible, must have made a wrong choice sorry	9/23/2025 5:23 AM
14	I was too ill to take much in / participate and had to leave early. I appreciated the the opportunity and will look for similar programs in future.	9/22/2025 4:43 PM
15	Unable to bring up info regarding script.	9/22/2025 3:14 PM
16	It was accessible	9/22/2025 10:51 AM
17	hard to get in the isles with my wheelchair. had to sit in back of workshops	9/22/2025 10:36 AM
18	If activities require money of any sort, then I'm unable to attend due to costs.	9/19/2025 2:41 PM
19	That is not what I indicated. Activity was accessible. I checked my answer.	9/17/2025 5:04 PM
20	This must be a mistake in the survey. I indicated that the activity was accessible.	9/17/2025 4:11 PM
21	Didn't mean to - using a track ball because of shoulder injury - my apologies. everything was good	9/17/2025 4:02 PM
22	I indicated it was very accessible.	9/17/2025 4:02 PM
23	I do not think this is correct- I checked that this activity was accessible to me.	9/17/2025 4:01 PM
24	That was a mistake	9/17/2025 4:00 PM
25	My survey response was the activity was accessible	9/17/2025 3:59 PM
26	Difficulties with CART	9/16/2025 12:59 PM
27	This is not correct. For question #6 I checked "very accessible".	9/16/2025 9:21 AM
28	I did not do so - activity is accesible	9/15/2025 6:10 PM
29	Marked in error. All activities were accessible to me. The survey would not let me return to correct it.	9/15/2025 1:58 PM
30	not sure why this was indicated - had indicated that all activities were accessible	9/15/2025 12:40 PM
31	N/A - did not indicate this, I think it is a glitch	9/13/2025 10:05 AM
32	I did not indicate that	9/12/2025 2:54 PM
33	I'm not sure what activity the question was referring to.	9/12/2025 1:19 PM
34	I don't recall answering that way. It is not an issue.	9/11/2025 5:59 PM
35	That was not the answer I intended. It was accessible for me	9/11/2025 5:22 PM
36	The activity WAS accessible to me. You are mistaken.	9/11/2025 3:19 PM
37	I am not sure what question you are referring to. maybe I mis understood the question.	9/10/2025 3:58 PM
38	This must be a mistake because everything was accessible to me.	9/10/2025 3:26 PM
39	N/A	9/10/2025 1:46 PM

40	Everything was accessible to me	9/10/2025 10:31 AM
41	Sorry that was an error	9/10/2025 10:06 AM
42	That was an error on my part. Every session was made accessible to me in every.	9/10/2025 10:05 AM
43	This is an error, all activities were accessible.	9/10/2025 9:36 AM
44	This activity was very accessible to me.	9/10/2025 8:21 AM
45	Everything was accessible to me. If I indicated that something was no accessible that was an error.	9/10/2025 4:39 AM
46	I was fairly certain I marked this WAS accessible to me, but it won't let me go back far enough to double check. Sorry if I marked that question incorrectly	9/9/2025 9:08 PM
47	I did not experience any accessibility issues.	9/9/2025 6:37 PM
48	I did not indicate this. I believe there is something wrong with the survey. The activity WAS accessible and very much appreciated.	9/9/2025 6:24 PM
49	It was accessible	9/9/2025 12:47 PM
50	It was difficult to use technology that I was unfamiliar with	9/9/2025 12:38 PM
51	That was a mistake, it was very accessible!	9/3/2025 9:12 PM
52	I don't think that I did? Everything has been accessible to me.	9/3/2025 4:09 PM
53	I meant it was	9/2/2025 6:49 PM
54	I did not indicate any inaccessibility in my responses. Please check your data collector for errors.	9/2/2025 7:36 AM
55	I indicated that the activity was accessible.	8/31/2025 3:52 PM
56	it was accessible.	8/28/2025 8:52 AM
57	Yes it's acceptable to me.	8/27/2025 8:36 PM
58	n/a	8/27/2025 1:18 PM
59	difficult for some people to put info in the chat or fill out surveys by typing	8/27/2025 1:16 PM
60	N.a	8/27/2025 1:13 PM
61	it was accessible to me	8/27/2025 8:44 AM
62	I did not. I checked "very accessible".	8/26/2025 3:27 PM
63	If I did that was a mistake on my part - meeting was accessible	8/26/2025 3:25 PM
64	Sorry, but I checked the wrong answer. The activity was fully accessible to me.	8/22/2025 10:25 AM
65	That must have been an error in my part. Fat fingers I guess I thought I hit that I was able to access the program	8/21/2025 2:41 PM
66	I must have clicked that in error. It was easily accessible to me.	8/21/2025 2:22 PM
67	I could not enable captions on zoom	8/21/2025 2:22 PM
68	sorry, that was an error and I cannot go back and fix it. The activity was accessible.	8/20/2025 10:30 AM
69	I made a mistake and cant find how to undo it. This program was accessible and incredible	8/20/2025 10:30 AM
70	I did not indicate an activity was not accessible to me.	8/20/2025 6:18 AM
71	If so, that is not correct. It was accessible. There was no way to go back and correct the response.	8/18/2025 1:12 PM
72	That was a mistake. It was very accessible.	8/15/2025 11:26 AM
73	If I answered that way it was a mistake and I cannot go back to that particular question to change my answer.	8/13/2025 2:12 PM

74	We were working on internal planning and advocacy next steps.	8/13/2025 1:13 PM
75	google docs can be a little difficult to manage with a screen reader, though not impossible.	8/11/2025 12:44 PM
76	must have been a mistake, it was accessible	8/11/2025 10:46 AM
77	It must have been on error	8/11/2025 9:50 AM
78	That was a mistake, all is accessible.	8/11/2025 9:41 AM
79	Countless questions are never addressed.Genuine dissent isn't tolerated.	8/6/2025 6:41 PM
80	That was an accident and I can't go back and change my answer for some reason - the activities are always accessible to me.	8/6/2025 2:09 PM
81	The organizers did a great job with the #MillionsMissing event in DC. The only difficulties I found were financial, and changes to my body's capacity day-to-day. #MEAction are good folks!	8/6/2025 1:29 PM
82	That is incorrect	8/6/2025 1:01 PM
83	That was a mistake	7/29/2025 1:08 PM
84	Activity is accessible	7/28/2025 1:59 PM
85	N/A	7/25/2025 12:54 PM
86	All activities were accessible to me	6/28/2025 11:23 AM
87	I believe it was an accidental answer. I found all of our module meetings quite easily accessible.	6/26/2025 11:50 AM
88	I pressed this button in error, sorry!	6/26/2025 9:51 AM
89	This statement is not true. I clicked very accessible.	6/22/2025 7:19 PM
90	None	6/22/2025 12:25 AM
91	There was communication in the break out activity and the conference.	6/20/2025 6:53 PM
92	N/A	6/20/2025 6:09 PM
93	I am new to this whole thing	6/20/2025 3:54 PM
94	I must have put the wrong answer? It was accessible	6/19/2025 2:51 PM
95	If that is what I checked it is wrong. This was completely accessible to me	6/18/2025 10:37 AM
96	This seems to be an error. I reviewed my answers and did not indicate that the activity was not accessible.	6/18/2025 10:25 AM
97	That was an error--it was accessible!	6/18/2025 10:23 AM
98	I never said the activity was not accessible?	6/17/2025 3:40 PM
99	Everything was accessible	6/17/2025 1:10 PM
100	i said it accessible	6/17/2025 1:06 PM
101	It was accessible to me	6/15/2025 6:46 PM
102	Not true. It was accessible.	6/2/2025 3:03 PM
103	That must have been an error - this was very accessible for me.	6/2/2025 2:53 PM
104	I did not indicate that it was not accessible. This may be an error in your form.	6/2/2025 2:42 PM
105	mistake it was accessible	5/28/2025 7:16 PM
106	The meeting was very packed with information, which was a great thing. Because it was a very packed meeting, there was less ability for individuals to read aloud important points from the chat, which is not easily accessible to me.	5/16/2025 11:48 AM
107	I did not mark that the activity was not accessible. In fact, the meeting seemed very accessible. If it was marked not accessible, then it was a mistake.	5/15/2025 8:45 AM

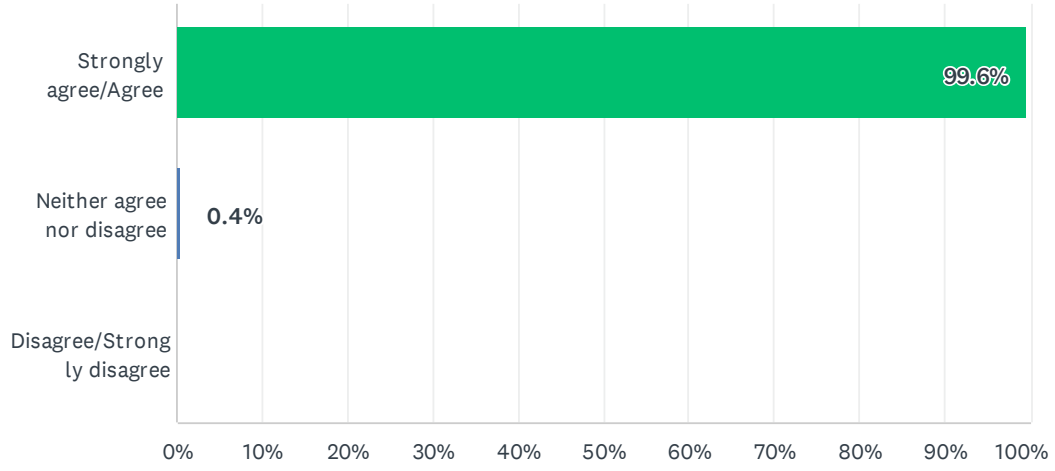
108	I thought I indicated it was accessible. I had no problems accessing the meeting. I can't seem to go back and check the answer.	5/14/2025 8:24 PM
109	Error - I intended to say it was accessible	5/14/2025 8:16 PM
110	Not in my network of advocacy	5/14/2025 8:12 PM
111	I don’t have anything about accessibility to offer	5/14/2025 7:34 PM
112	I said it was very accessible.	5/14/2025 6:58 PM
113	oops! that was a mistake. The even was very accessible! I appreciated being able to have the CART running on another monitor so that the captioning didn't cover the speakers' faces during the zoom event.	5/14/2025 6:54 PM
114	I did not mean to mark that. Very accessible via zoom	5/14/2025 6:46 PM
115	I'm not sure what activity	5/14/2025 6:02 PM
116	I did not select that answer	5/7/2025 12:10 PM
117	mistake—activity was accessible	5/7/2025 12:10 PM
118	yes it was	5/2/2025 10:16 PM
119	I do not believe I did, it was indeed accessible to me.	5/2/2025 6:16 PM
120	I am sorry, that my answer is incorrect- it should be yes. I didn't need anything.	5/2/2025 5:35 PM
121	No, I didn't. I am unable to go back to that page to correct if needed, but I'm fairly sure I said the event was accessible.	5/2/2025 1:56 PM
122	Hit the wrong button- sorry!	4/15/2025 1:57 PM
123	I apologize, that must have been a mistake. It was very accessible, a sign language interpreter was provided for those requiring it. Captions could be helpful.	4/15/2025 1:57 PM
124	N/A	4/8/2025 12:36 PM
125	that was a mistake. It was accessible	4/8/2025 10:22 AM
126	this was accessible to me. there were no issues. captions help with electronic communication.	4/8/2025 8:23 AM
127	Meant to say that it was accessible, must have made a mistake.	4/7/2025 5:28 PM
128	I did not indicate that. Went back and checked my answer. Activities were extremely accessible. Thanks.	4/7/2025 3:21 PM
129	I indicated the activity was very accessible.	4/7/2025 3:20 PM
130	I checked the box that the meeting was very accessible. I had no issues.	4/7/2025 3:08 PM
131	I actually believe that this activity was very accessible.	4/7/2025 3:06 PM
132	I indicated that it was very accessible and I had no issues.	4/7/2025 3:04 PM
133	That's incorrect. This activity was accessible to me.	4/7/2025 3:03 PM
134	the activity was accessible, i clicked "very accessible"	4/7/2025 3:02 PM
135	This seems to be an error - I indicated the event was very accessible in Q6.	4/7/2025 2:56 PM
136	I indicated the activity was accessible.	4/7/2025 1:38 PM
137	I indicated it was accessible.	4/7/2025 12:34 PM
138	Need more information	4/7/2025 12:14 PM
139	I checked "Very Accessible" - I didn't have any issues.	4/7/2025 11:58 AM
140	I have not indicated that an activity was not accessible to me.	4/7/2025 11:44 AM
141	I'm not sure if the activity being "inaccessible" is accurate but I've felt that NACDD events have sometimes been challenging to participate in because a lot of information is shared very	4/7/2025 11:17 AM

	quickly, verbally, and sometimes the meetings run long - I would benefit from a slower pace with an agenda shared during the call or in advance and we stick to the topics/time limits.	
142	I did not check that it was not. All trainings are very accessible, but I do not need any accommodations.	4/7/2025 10:57 AM
143	I didn't answer that particular question, because I do not need accessibility accommodations.	4/7/2025 10:53 AM
144	I did not. I answered very accessible.	4/7/2025 10:48 AM
145	N/A	4/7/2025 10:46 AM
146	The activity was accessible to me.	4/7/2025 10:43 AM
147	That must be an error, it was accessible.	4/4/2025 2:01 PM
148	I stated that it was accessible	4/4/2025 1:59 PM
149	It was very accessible, I'm not sure where I indicated otherwise.	4/4/2025 1:56 PM
150	I just went back and looked. I don't think I indicated that anywhere. If I did, it was in error.	3/21/2025 1:24 PM
151	The chat feature was not enabled. Could not save chat content.	3/7/2025 2:08 PM
152	*This question does not apply - the meeting was very accessible*	3/7/2025 2:06 PM
153	I don't know what you mean. For the question that inquired about accessibility, I indicated "very accessible". I don't understand this question since I responded that way.	3/7/2025 2:04 PM
154	couldn't get the captions going like I wanted; could be user error	3/7/2025 1:17 PM

Appendix K: Project Survey Results

Q1 I believe that it is important to be informed of community issues.

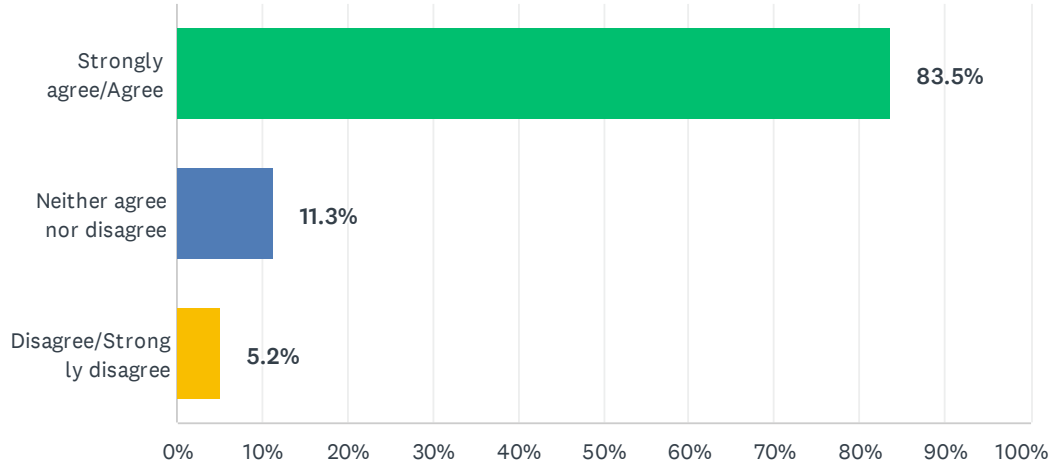
Answered: 230 Skipped: 1



ANSWER CHOICES	RESPONSES	
Strongly agree/Agree	99.6%	229
Neither agree nor disagree	0.4%	1
Disagree/Strongly disagree	0.0%	0
TOTAL		230

Q2 My opinion is important in deciding what people with disabilities need.

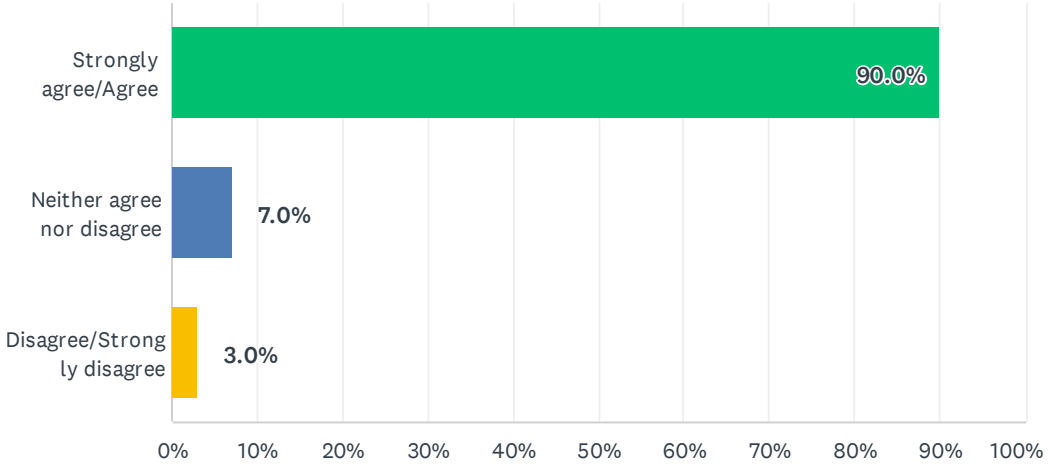
Answered: 230 Skipped: 1



ANSWER CHOICES	RESPONSES	
Strongly agree/Agree	83.5%	192
Neither agree nor disagree	11.3%	26
Disagree/Strongly disagree	5.2%	12
TOTAL		230

Q3 I feel comfortable telling agencies and government staff how services for people with disabilities can be improved.

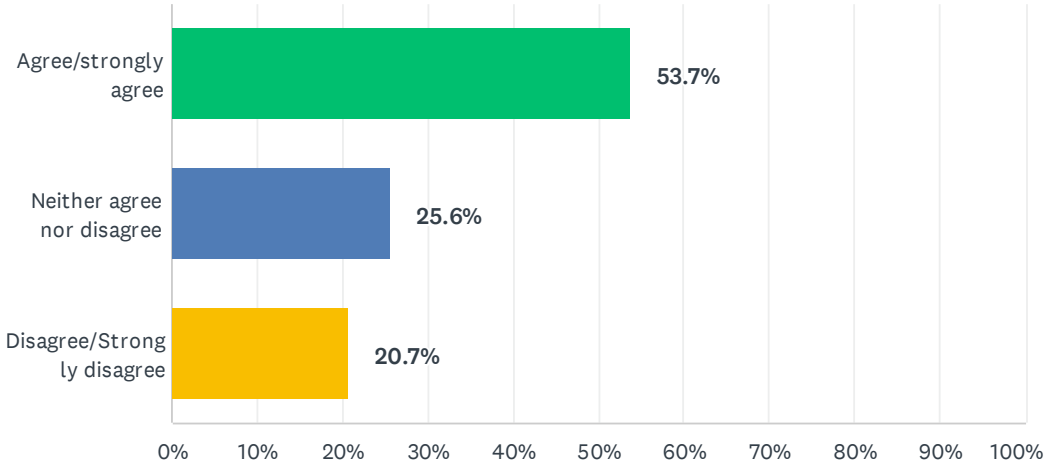
Answered: 230 Skipped: 1



ANSWER CHOICES	RESPONSES	
Strongly agree/Agree	90.0%	207
Neither agree nor disagree	7.0%	16
Disagree/Strongly disagree	3.0%	7
TOTAL		230

Q4 I know how to get state agency administrators or legislators to listen to me.

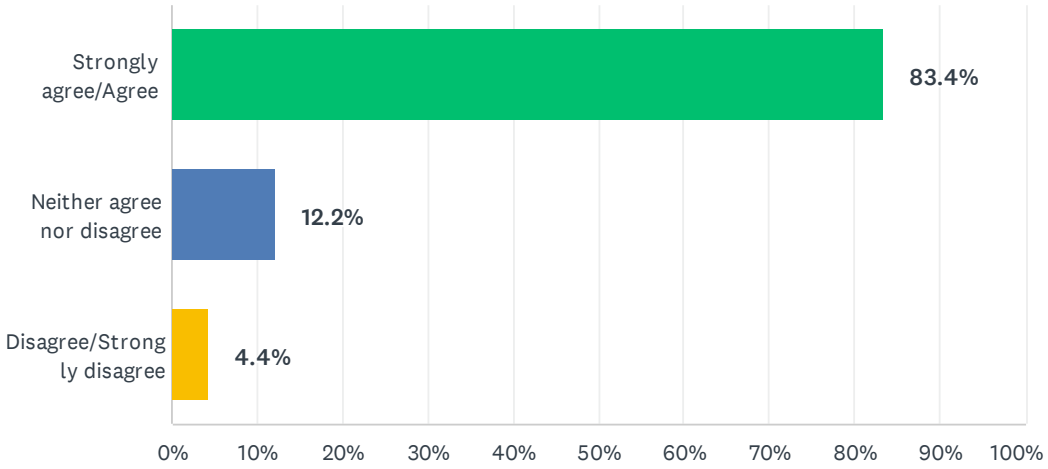
Answered: 227 Skipped: 4



ANSWER CHOICES	RESPONSES	
Agree/strongly agree	53.7%	122
Neither agree nor disagree	25.6%	58
Disagree/Strongly disagree	20.7%	47
TOTAL		227

Q5 I have a good understanding of the disability rights movement.

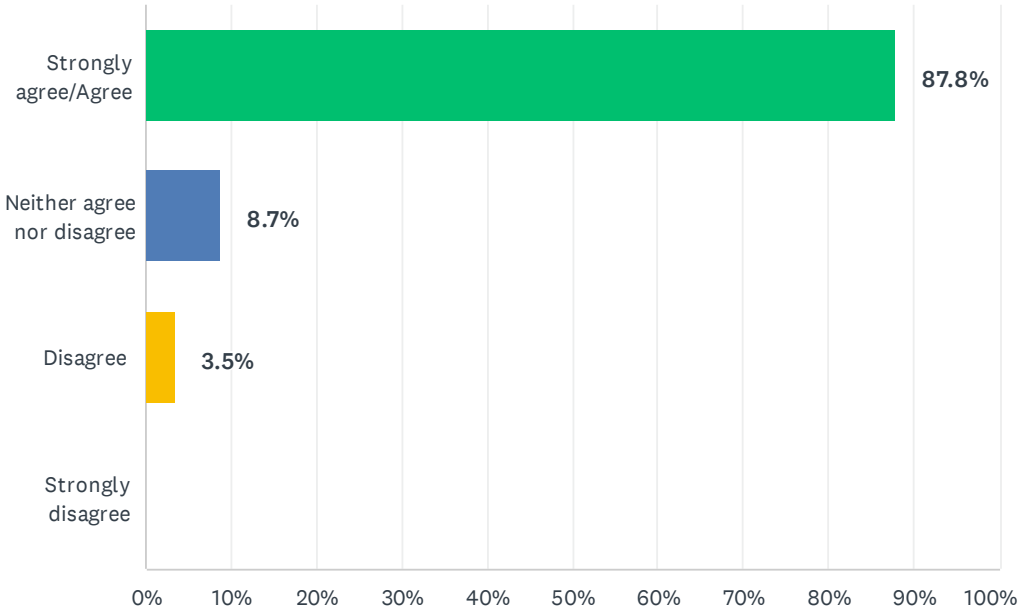
Answered: 229 Skipped: 2



ANSWER CHOICES	RESPONSES	
Strongly agree/Agree	83.4%	191
Neither agree nor disagree	12.2%	28
Disagree/Strongly disagree	4.4%	10
TOTAL		229

Q6 I know what the rights of disabled people are under the Americans with Disabilities Act.

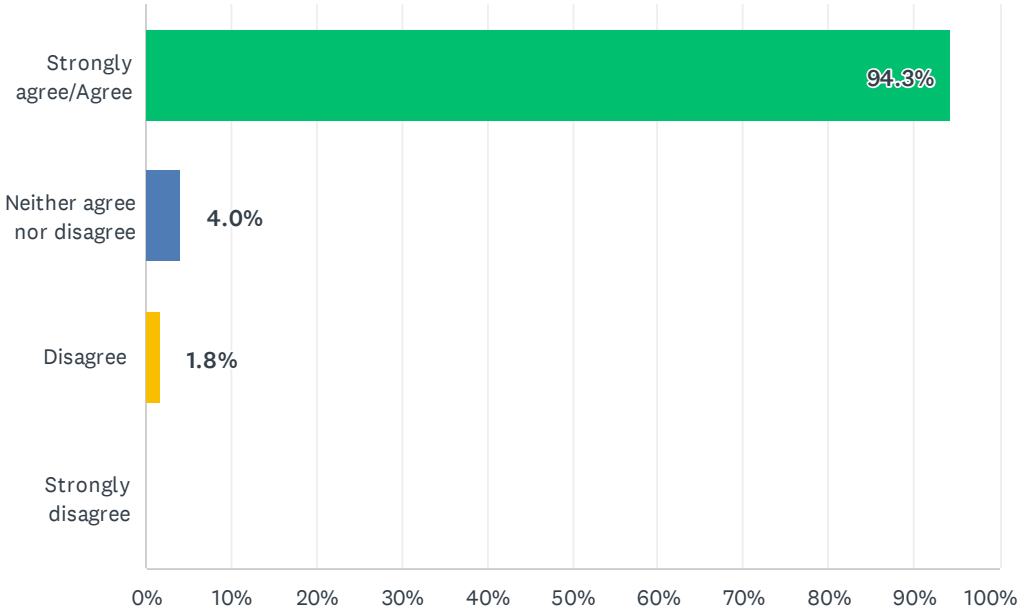
Answered: 230 Skipped: 1



ANSWER CHOICES	RESPONSES	
Strongly agree/Agree	87.8%	202
Neither agree nor disagree	8.7%	20
Disagree	3.5%	8
Strongly disagree	0.0%	0
TOTAL		230

Q7 I believe people with disabilities and I can influence services for people with disabilities.

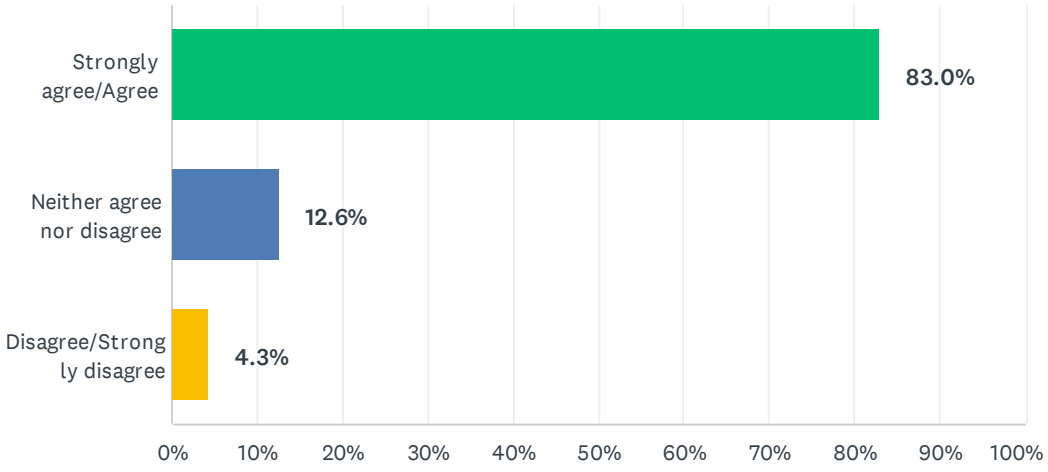
Answered: 227 Skipped: 4



ANSWER CHOICES	RESPONSES	
Strongly agree/Agree	94.3%	214
Neither agree nor disagree	4.0%	9
Disagree	1.8%	4
Strongly disagree	0.0%	0
TOTAL		227

Q8 I feel that I am a good disability rights activist.

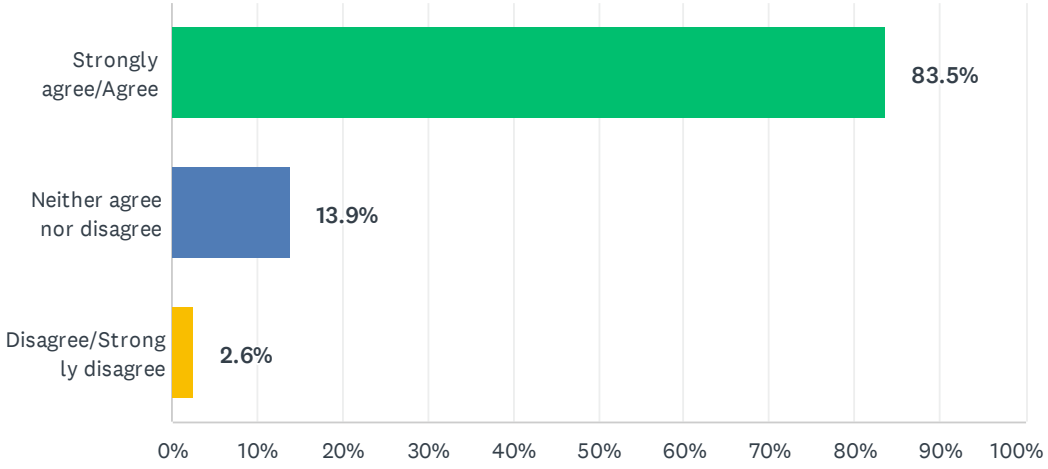
Answered: 230 Skipped: 1



ANSWER CHOICES	RESPONSES	
Strongly agree/Agree	83.0%	191
Neither agree nor disagree	12.6%	29
Disagree/Strongly disagree	4.3%	10
TOTAL		230

Q9 I think about new policies for improving the life of people with disabilities.

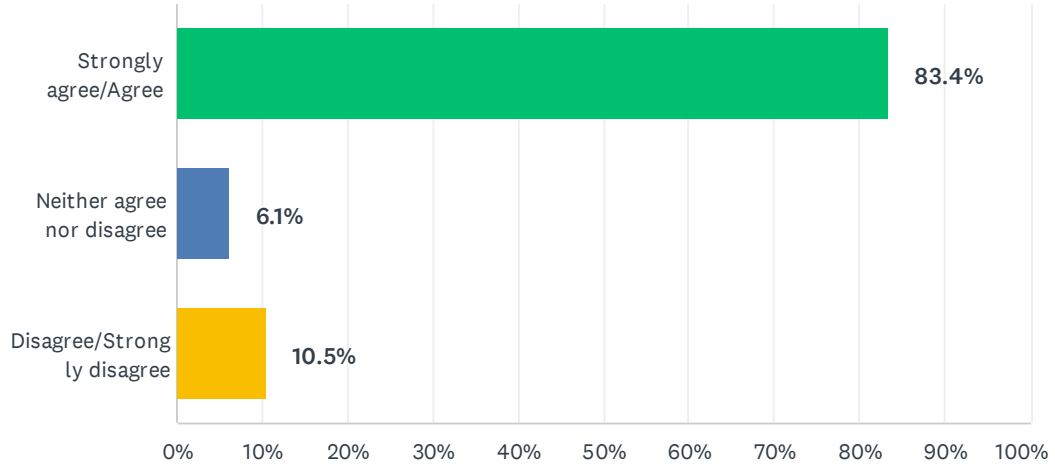
Answered: 230 Skipped: 1



ANSWER CHOICES	RESPONSES	
Strongly agree/Agree	83.5%	192
Neither agree nor disagree	13.9%	32
Disagree/Strongly disagree	2.6%	6
TOTAL		230

Q10 I know who my local legislators are.

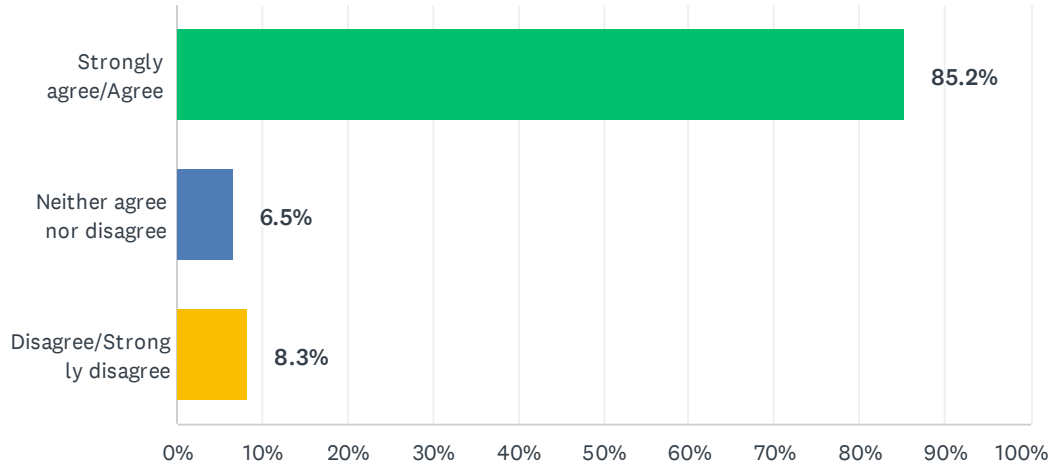
Answered: 229 Skipped: 2



ANSWER CHOICES	RESPONSES	
Strongly agree/Agree	83.4%	191
Neither agree nor disagree	6.1%	14
Disagree/Strongly disagree	10.5%	24
TOTAL		229

Q11 I know how to contact my local legislators.

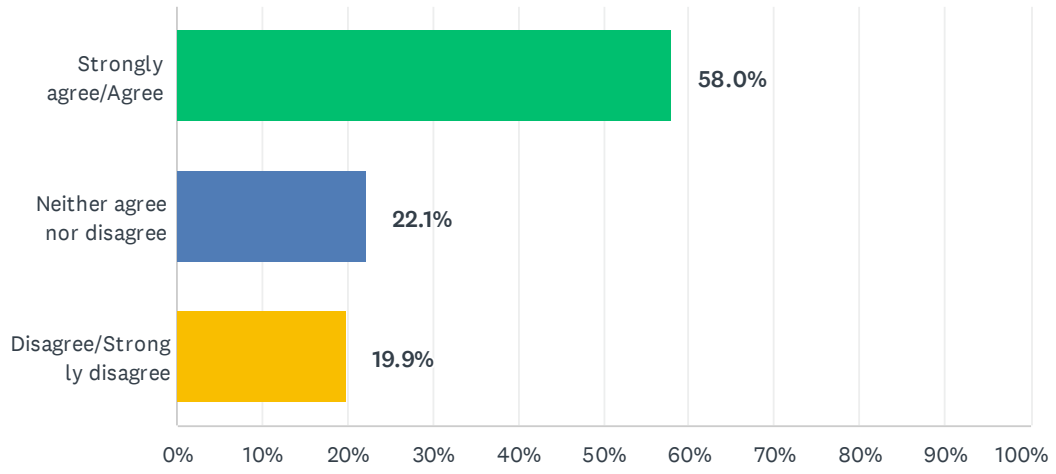
Answered: 230 Skipped: 1



ANSWER CHOICES	RESPONSES	
Strongly agree/Agree	85.2%	196
Neither agree nor disagree	6.5%	15
Disagree/Strongly disagree	8.3%	19
TOTAL		230

Q12 I know how to participate in legislative testimony.

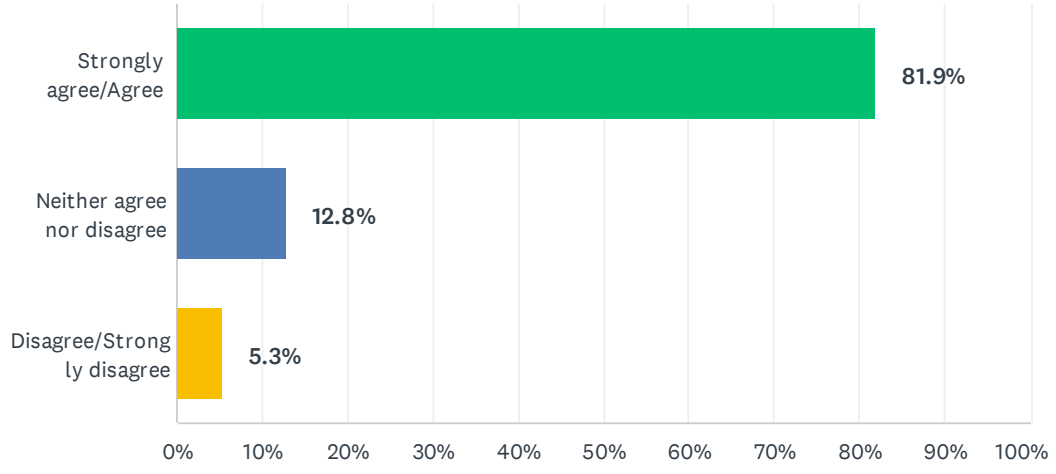
Answered: 231 Skipped: 0



ANSWER CHOICES	RESPONSES	
Strongly agree/Agree	58.0%	134
Neither agree nor disagree	22.1%	51
Disagree/Strongly disagree	19.9%	46
TOTAL		231

Q13 I feel supported to advocate and make my own choices.

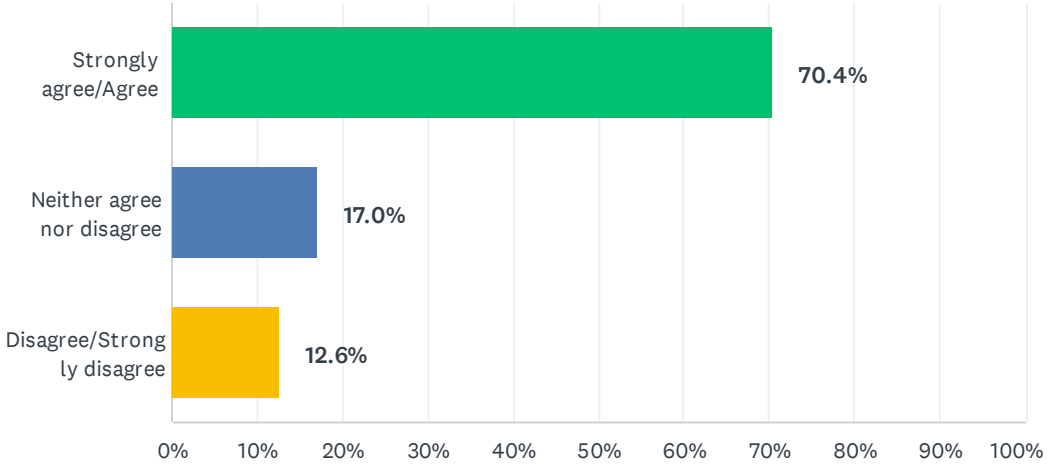
Answered: 227 Skipped: 4



ANSWER CHOICES	RESPONSES	
Strongly agree/Agree	81.9%	186
Neither agree nor disagree	12.8%	29
Disagree/Strongly disagree	5.3%	12
TOTAL		227

Q14 I am aware of opportunities for public comment on proposed rules and regulations.

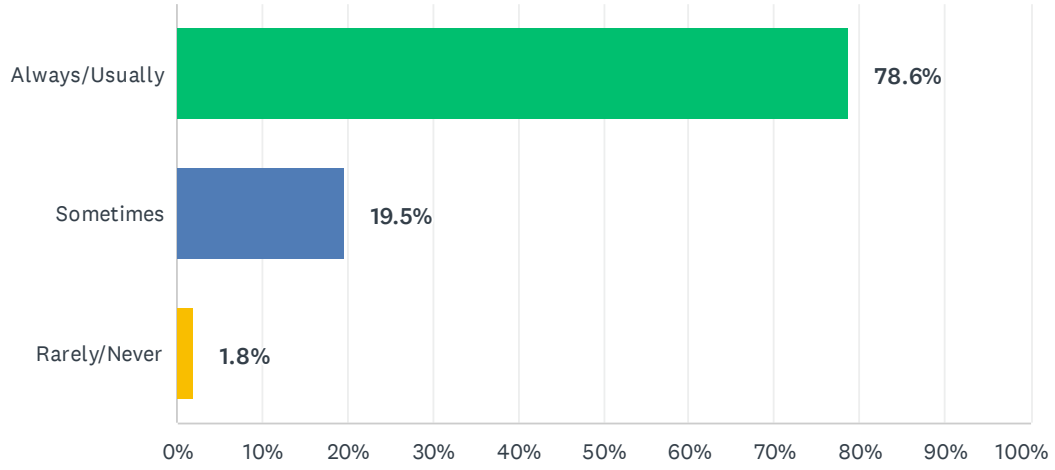
Answered: 230 Skipped: 1



ANSWER CHOICES	RESPONSES	
Strongly agree/Agree	70.4%	162
Neither agree nor disagree	17.0%	39
Disagree/Strongly disagree	12.6%	29
TOTAL		230

Q15 I stay informed of events in my local community.

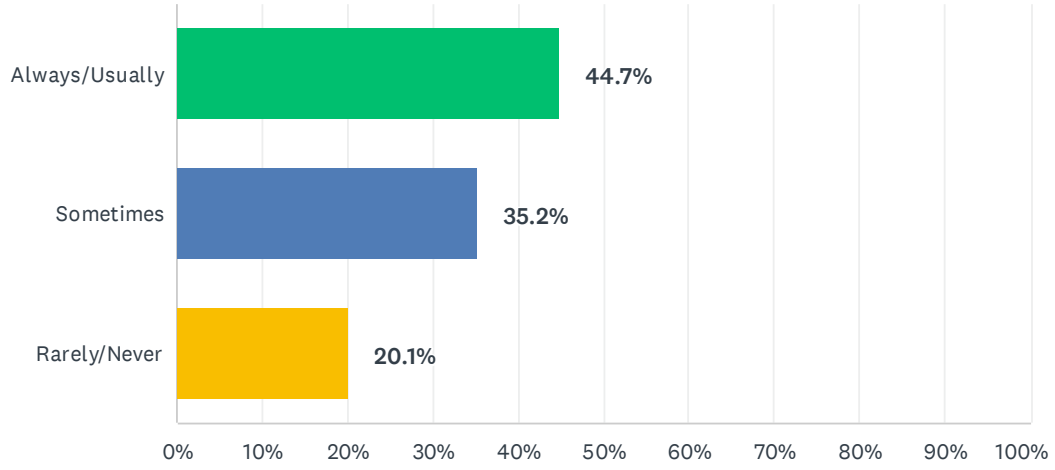
Answered: 220 Skipped: 11



ANSWER CHOICES	RESPONSES	
Always/Usually	78.6%	173
Sometimes	19.5%	43
Rarely/Never	1.8%	4
TOTAL		220

Q16 I participate in opportunities for public comment on proposed rules and regulations.

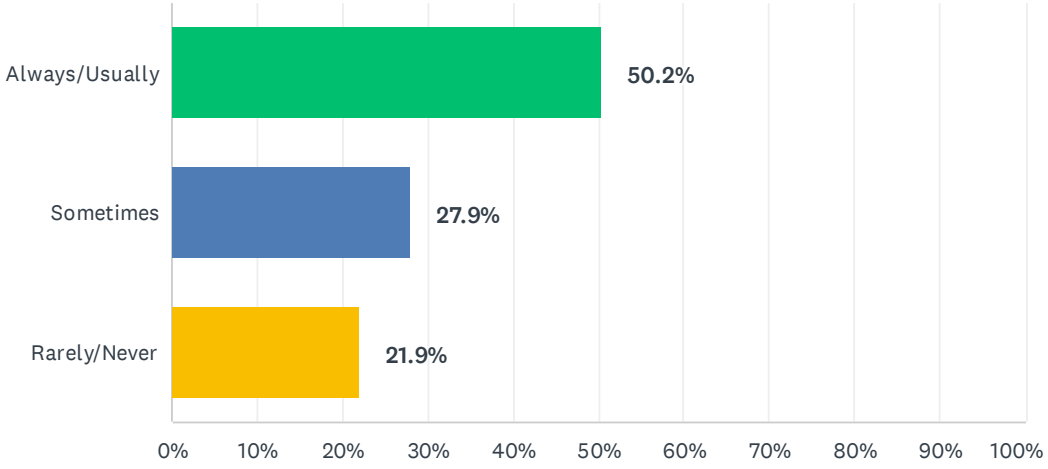
Answered: 219 Skipped: 12



ANSWER CHOICES	RESPONSES	
Always/Usually	44.7%	98
Sometimes	35.2%	77
Rarely/Never	20.1%	44
TOTAL		219

Q17 I attend conferences to increase my knowledge of advocating for legislative change.

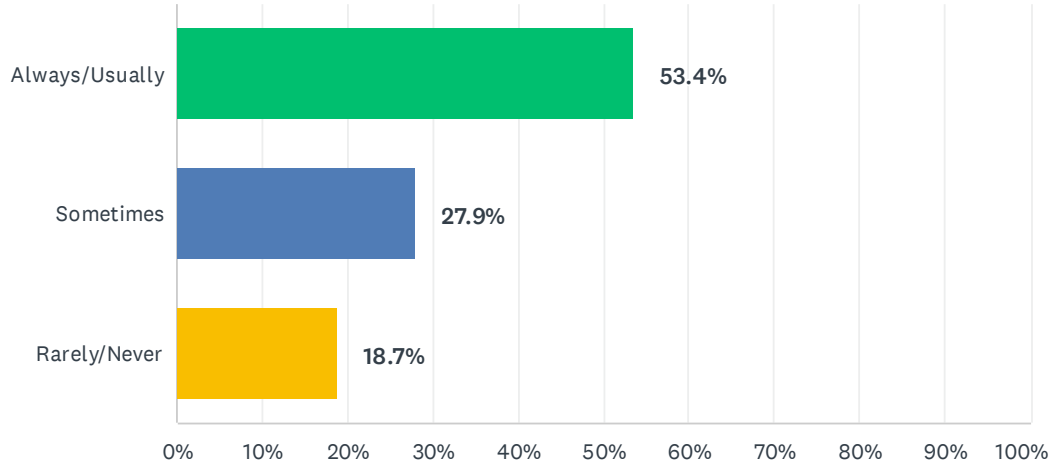
Answered: 219 Skipped: 12



ANSWER CHOICES	RESPONSES	
Always/Usually	50.2%	110
Sometimes	27.9%	61
Rarely/Never	21.9%	48
TOTAL		219

Q18 I frequently discuss bills and legislative issues that are important to the disability community.

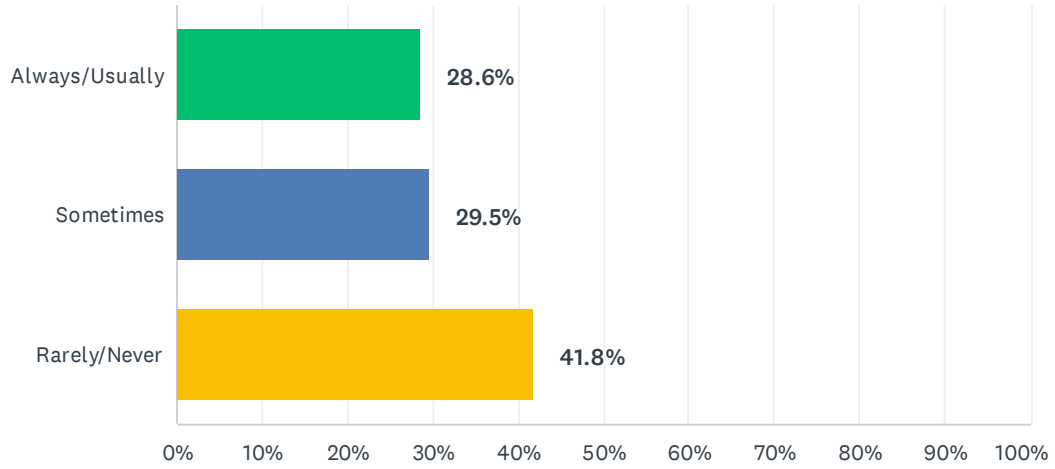
Answered: 219 Skipped: 12



ANSWER CHOICES	RESPONSES	
Always/Usually	53.4%	117
Sometimes	27.9%	61
Rarely/Never	18.7%	41
TOTAL		219

Q19 I participate in disability-related marches and/or rallies.

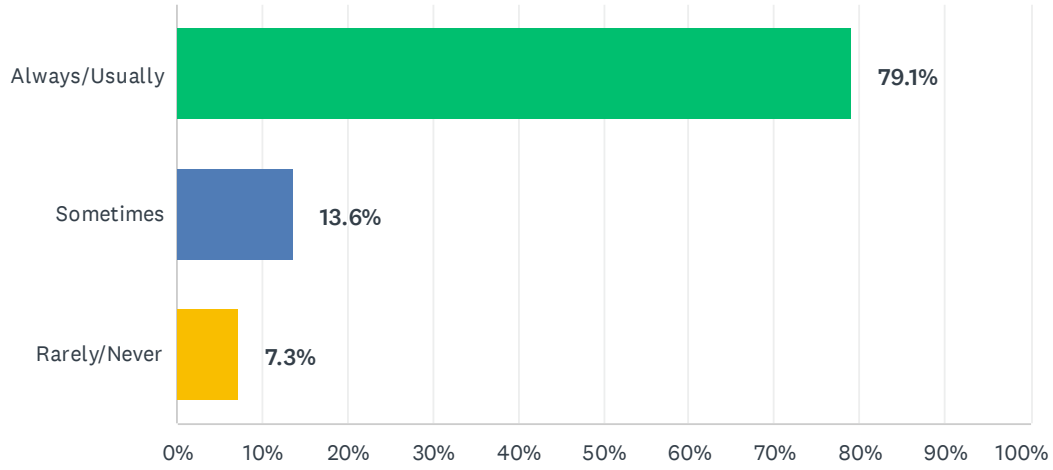
Answered: 220 Skipped: 11



ANSWER CHOICES	RESPONSES	
Always/Usually	28.6%	63
Sometimes	29.5%	65
Rarely/Never	41.8%	92
TOTAL		220

Q20 I work with disability organizations and/or other people with disabilities to increase public awareness of disability issues

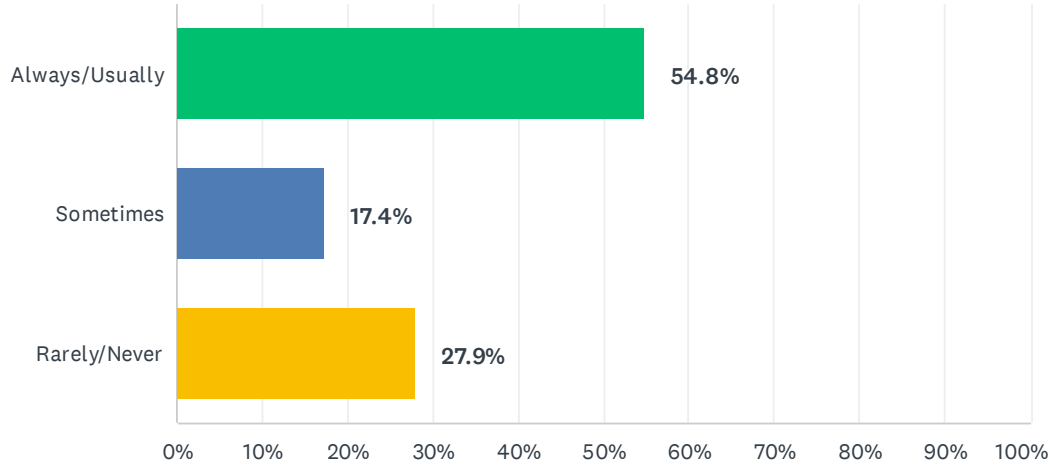
Answered: 220 Skipped: 11



ANSWER CHOICES	RESPONSES	
Always/Usually	79.1%	174
Sometimes	13.6%	30
Rarely/Never	7.3%	16
TOTAL		220

Q21 I am involved in structured volunteer positions in the disability community (e.g., formal role, elected position, committee chair/co-chair, active volunteer role).

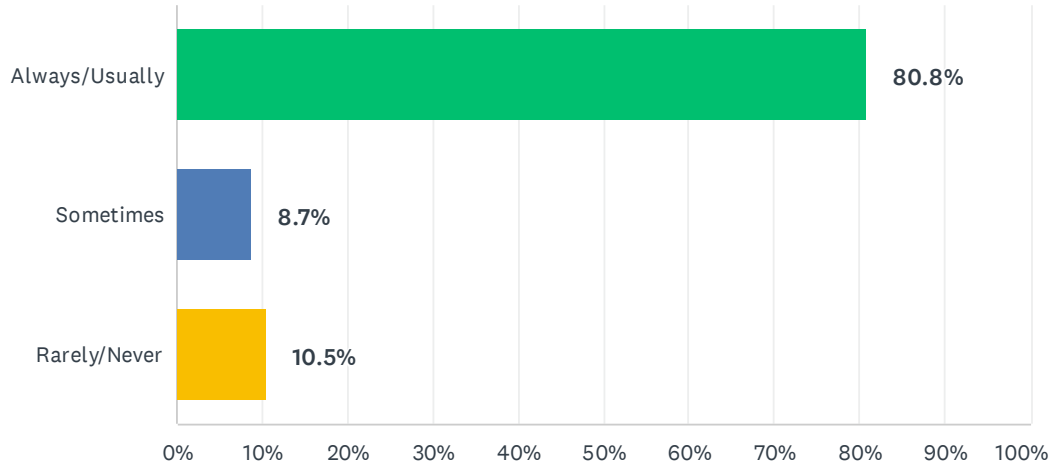
Answered: 219 Skipped: 12



ANSWER CHOICES	RESPONSES	
Always/Usually	54.8%	120
Sometimes	17.4%	38
Rarely/Never	27.9%	61
TOTAL		219

Q22 I am an active member of at least one disability-related group

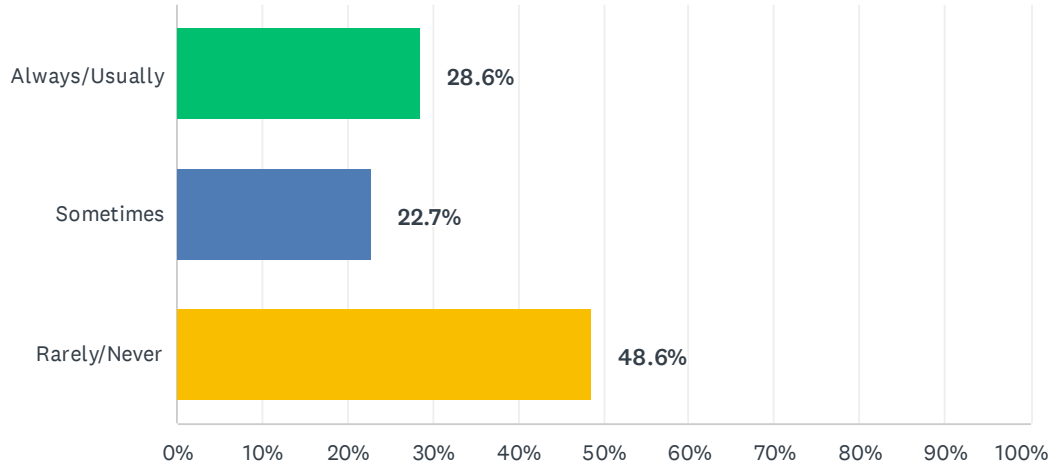
Answered: 219 Skipped: 12



ANSWER CHOICES	RESPONSES	
Always/Usually	80.8%	177
Sometimes	8.7%	19
Rarely/Never	10.5%	23
TOTAL		219

Q23 I use mass media (e.g., newspapers, TV, radio) to express my support or objection to a bill.

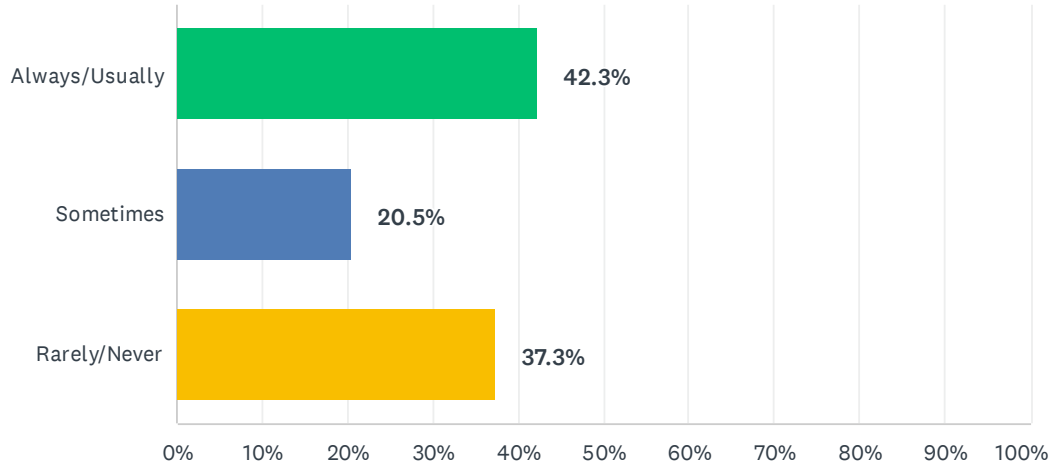
Answered: 220 Skipped: 11



ANSWER CHOICES	RESPONSES	
Always/Usually	28.6%	63
Sometimes	22.7%	50
Rarely/Never	48.6%	107
TOTAL		220

Q24 I use social media (e.g., Facebook, Instagram, X, Bluesky, Pixeled, Mastadon) to express my thoughts and opinions about disability issues.

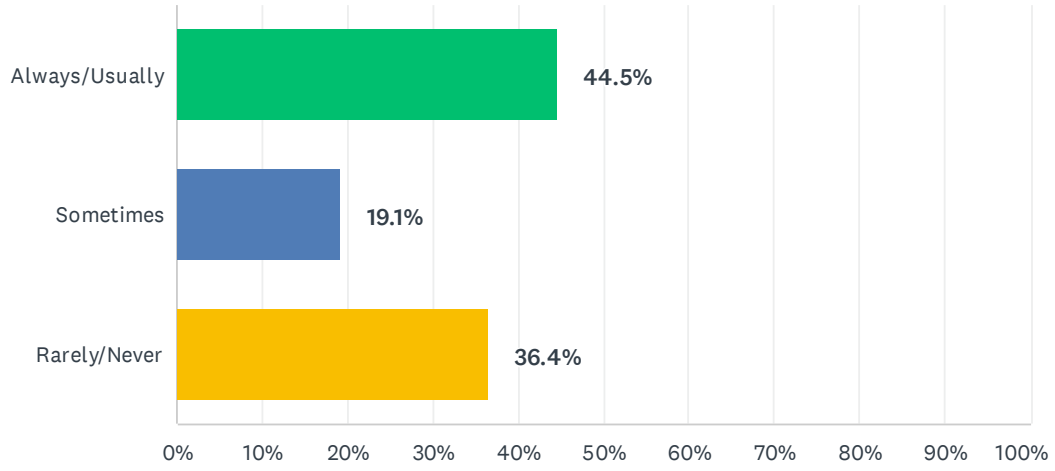
Answered: 220 Skipped: 11



ANSWER CHOICES	RESPONSES	
Always/Usually	42.3%	93
Sometimes	20.5%	45
Rarely/Never	37.3%	82
TOTAL		220

Q25 I provide training to others to increase their legislative advocacy knowledge.

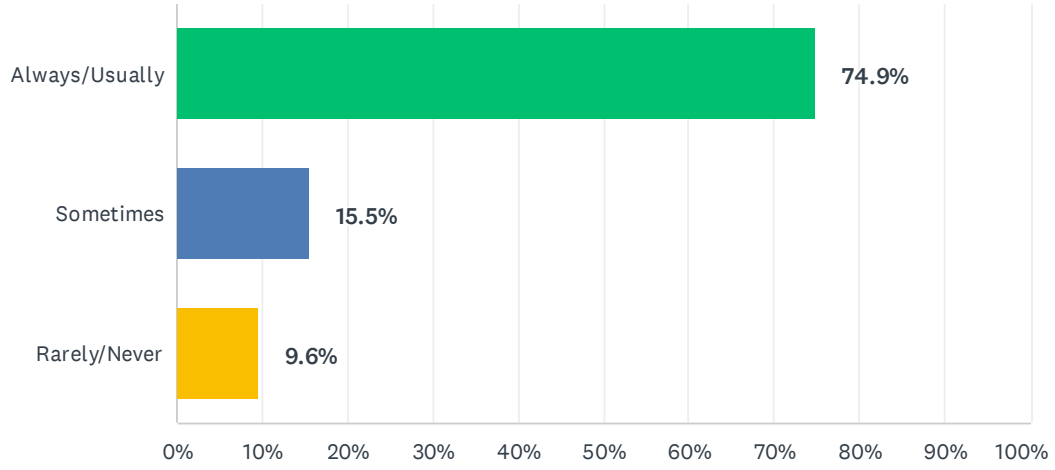
Answered: 220 Skipped: 11



ANSWER CHOICES	RESPONSES	
Always/Usually	44.5%	98
Sometimes	19.1%	42
Rarely/Never	36.4%	80
TOTAL		220

Q26 I communicate with members of my local community (e.g., friends, family, and neighbors) about disability issues important to me.

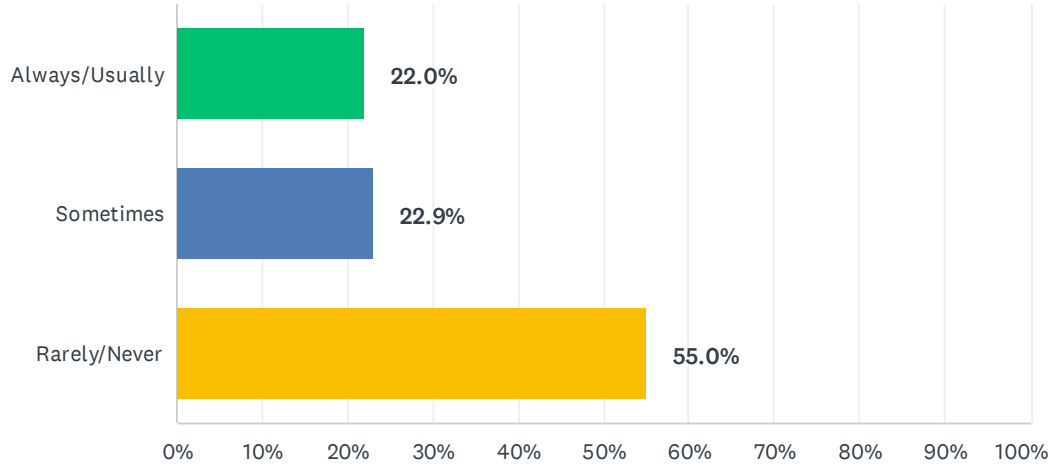
Answered: 219 Skipped: 12



ANSWER CHOICES	RESPONSES	
Always/Usually	74.9%	164
Sometimes	15.5%	34
Rarely/Never	9.6%	21
TOTAL		219

Q27 I talk to member(s) of the press (e.g., journalists, reporters, talk show hosts, podcasters) about disability issues important to me.

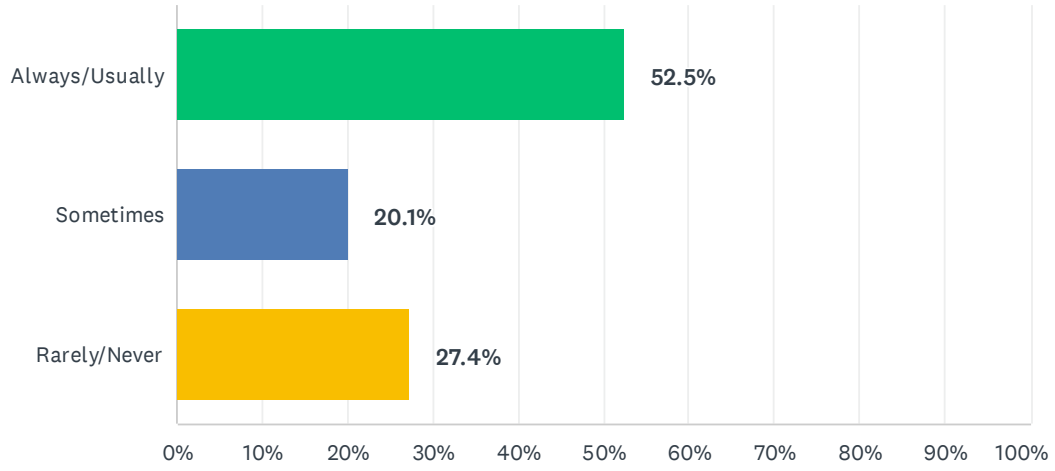
Answered: 218 Skipped: 13



ANSWER CHOICES	RESPONSES	
Always/Usually	22.0%	48
Sometimes	22.9%	50
Rarely/Never	55.0%	120
TOTAL		218

Q28 I communicate (by phone, email, or visit) with legislators or their staffers about my stand on disability rights.

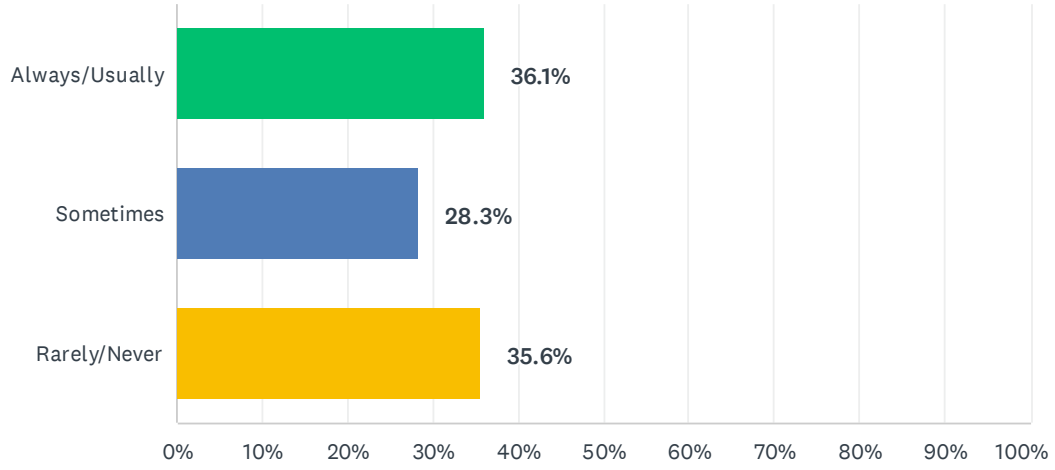
Answered: 219 Skipped: 12



ANSWER CHOICES	RESPONSES	
Always/Usually	52.5%	115
Sometimes	20.1%	44
Rarely/Never	27.4%	60
TOTAL		219

Q29 I contact the Governor’s office to urge them to sign or not sign a passed bill.

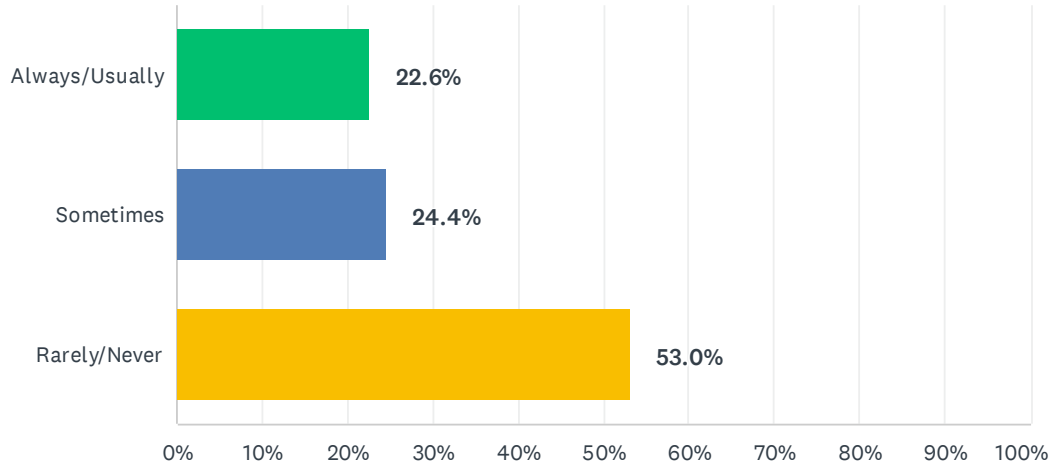
Answered: 219 Skipped: 12



ANSWER CHOICES	RESPONSES	
Always/Usually	36.1%	79
Sometimes	28.3%	62
Rarely/Never	35.6%	78
TOTAL		219

Q30 I attend legislative hearings.

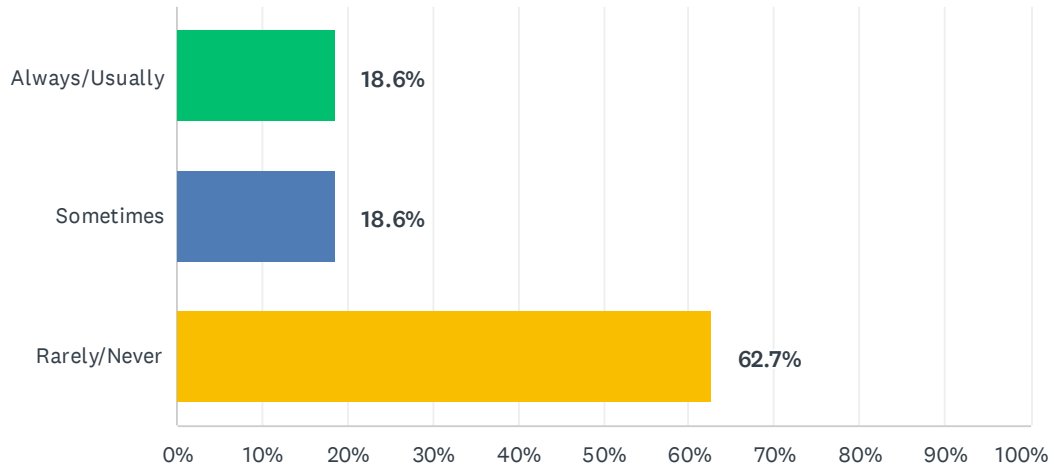
Answered: 217 Skipped: 14



ANSWER CHOICES	RESPONSES	
Always/Usually	22.6%	49
Sometimes	24.4%	53
Rarely/Never	53.0%	115
TOTAL		217

Q31 I participate in legislative hearings by giving testimonies.

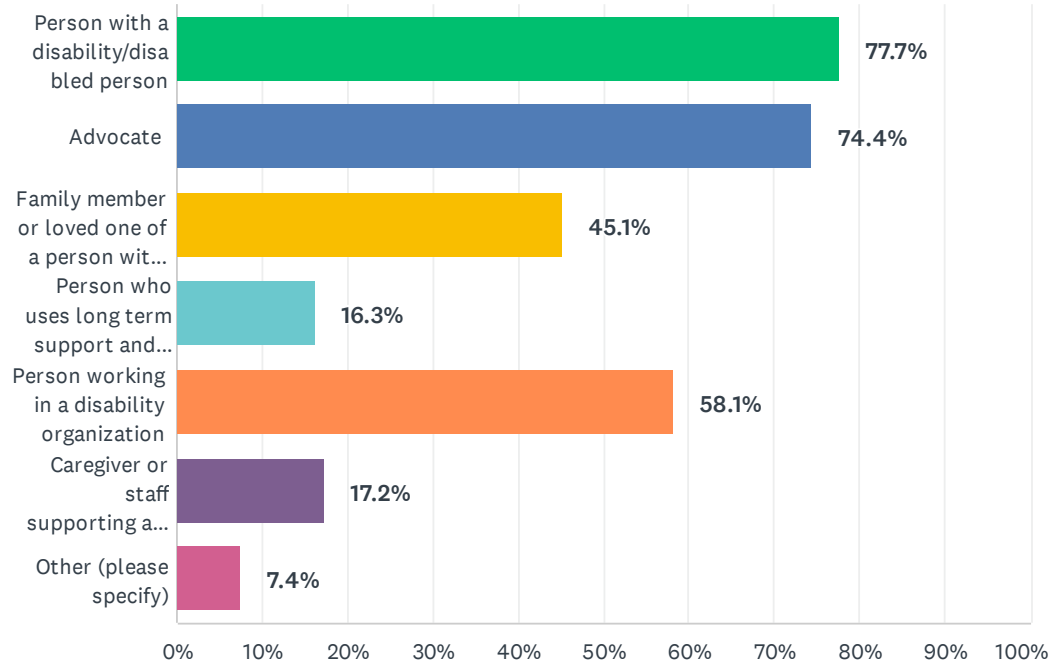
Answered: 220 Skipped: 11



ANSWER CHOICES	RESPONSES	
Always/Usually	18.6%	41
Sometimes	18.6%	41
Rarely/Never	62.7%	138
TOTAL		220

Q32 In what ways do you identify with the disability community? (check all that apply)

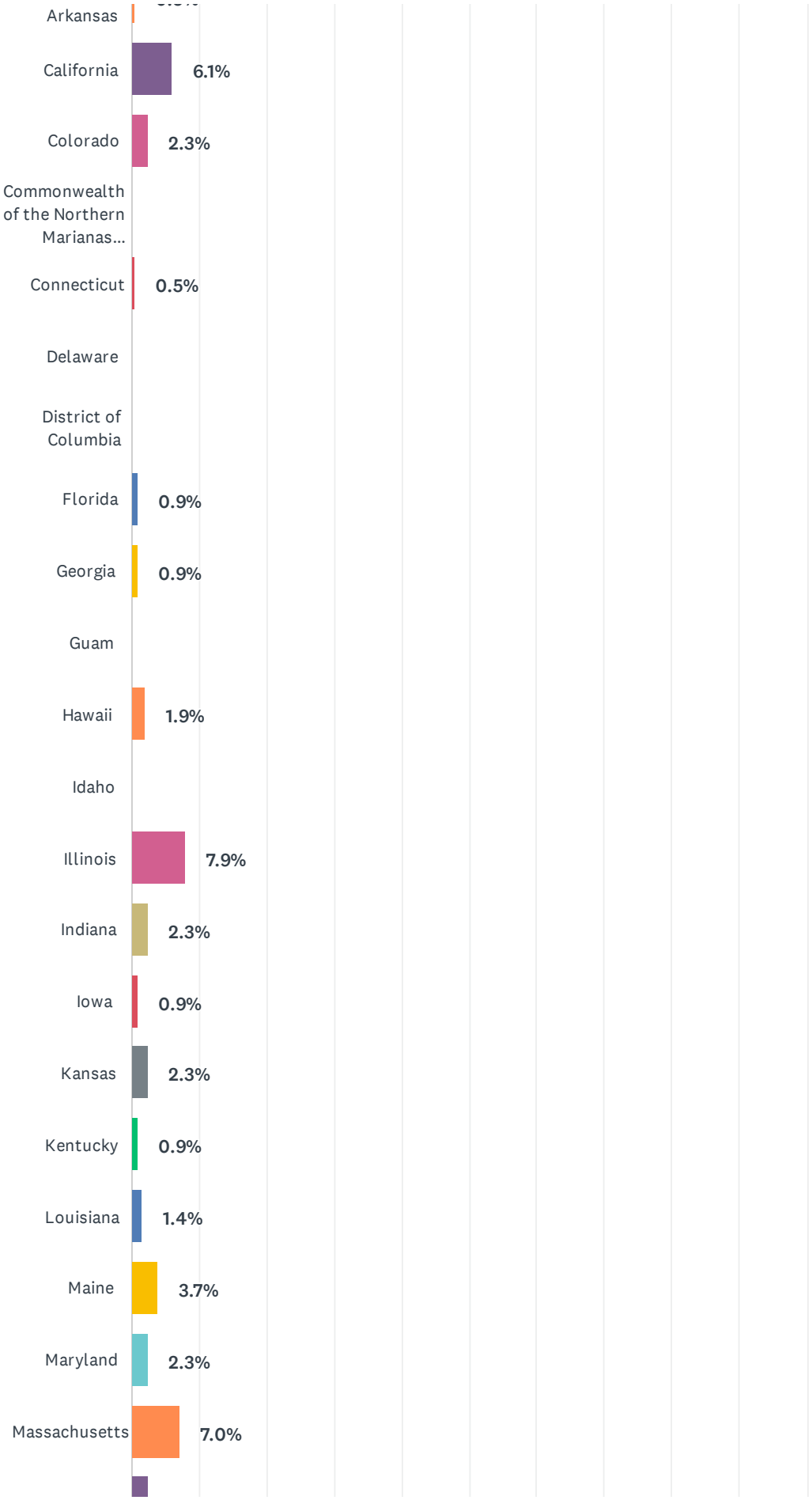
Answered: 215 Skipped: 16

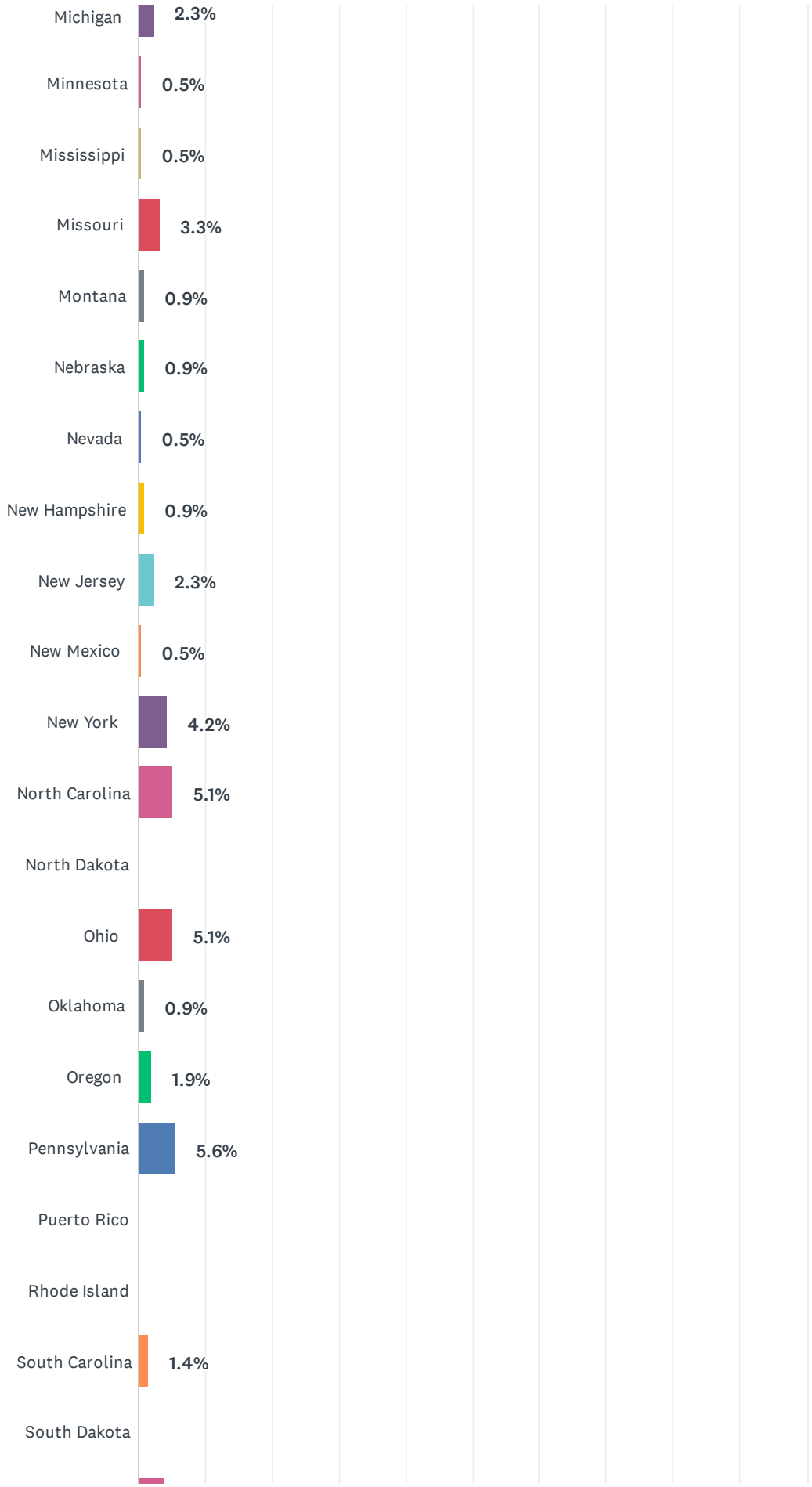


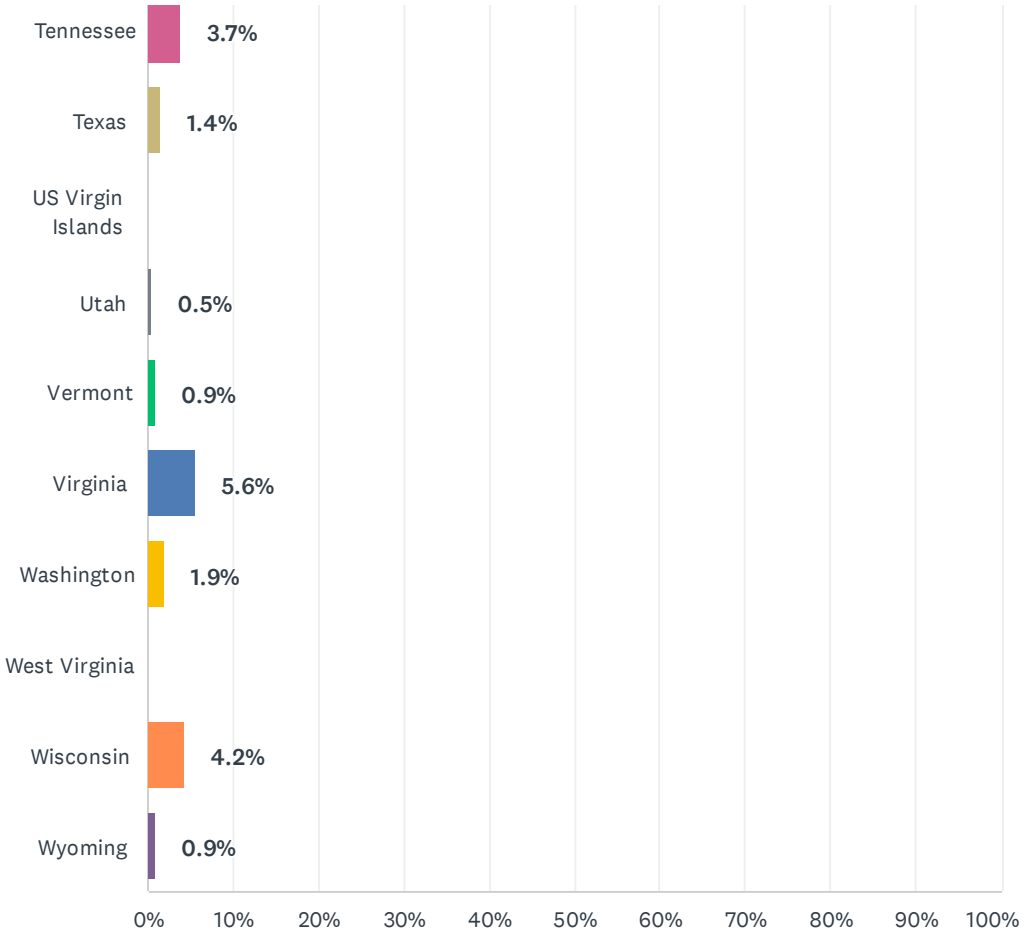
ANSWER CHOICES	RESPONSES	
Person with a disability/disabled person	77.7%	167
Advocate	74.4%	160
Family member or loved one of a person with a disability /disabled person	45.1%	97
Person who uses long term support and services (LTSS) or home and community-based services (HCBS)	16.3%	35
Person working in a disability organization	58.1%	125
Caregiver or staff supporting a person with a disability	17.2%	37
Other (please specify)	7.4%	16
Total Respondents: 215		

Q33 In what state or territory do you live?

Answered: 214 Skipped: 17


Arkansas
California
6.1%
Colorado
2.3%
Commonwealth of the Northern Marianas...
Connecticut
0.5%
Delaware
District of Columbia
Florida
0.9%
Georgia
0.9%
Guam
Hawaii
1.9%
Idaho
Illinois
7.9%
Indiana
2.3%
Iowa
0.9%
Kansas
2.3%
Kentucky
0.9%
Louisiana
1.4%
Maine
3.7%
Maryland
2.3%
Massachusetts
7.0%


Michigan 2.3%
Minnesota 0.5%
Mississippi 0.5%
Missouri 3.3%
Montana 0.9%
Nebraska 0.9%
Nevada 0.5%
New Hampshire 0.9%
New Jersey 2.3%
New Mexico 0.5%
New York 4.2%
North Carolina 5.1%
North Dakota
Ohio 5.1%
Oklahoma 0.9%
Oregon 1.9%
Pennsylvania 5.6%
Puerto Rico
Rhode Island
South Carolina 1.4%
South Dakota

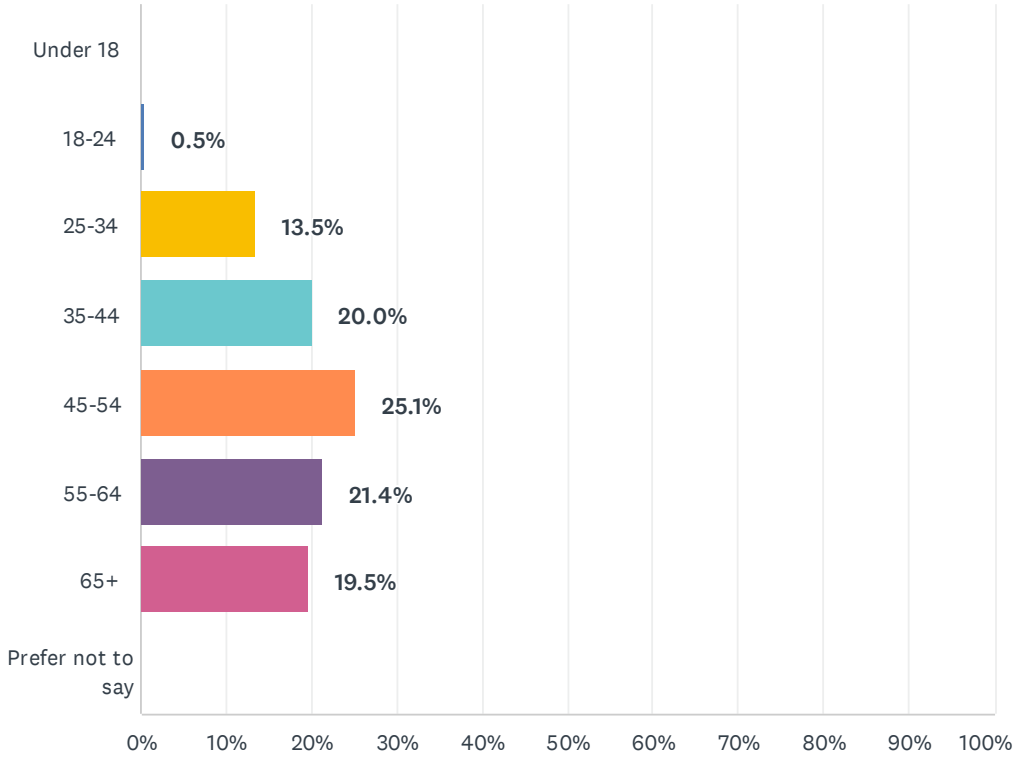

Tennessee
3.7%
Texas
1.4%
US Virgin Islands
Utah
0.5%
Vermont
0.9%
Virginia
5.6%
Washington
1.9%
West Virginia
Wisconsin
4.2%
Wyoming
0.9%
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%

ANSWER CHOICES	RESPONSES	
Alabama	0.0%	0
Alaska	0.9%	2
American Samoa	0.0%	0
Arizona	0.9%	2
Arkansas	0.5%	1
California	6.1%	13
Colorado	2.3%	5
Commonwealth of the Northern Marianas Islands	0.0%	0
Connecticut	0.5%	1
Delaware	0.0%	0
District of Columbia	0.0%	0
Florida	0.9%	2
Georgia	0.9%	2
Guam	0.0%	0
Hawaii	1.9%	4
Idaho	0.0%	0
Illinois	7.9%	17
Indiana	2.3%	5
Iowa	0.9%	2
Kansas	2.3%	5
Kentucky	0.9%	2
Louisiana	1.4%	3
Maine	3.7%	8
Maryland	2.3%	5
Massachusetts	7.0%	15
Michigan	2.3%	5
Minnesota	0.5%	1
Mississippi	0.5%	1
Missouri	3.3%	7
Montana	0.9%	2
Nebraska	0.9%	2
Nevada	0.5%	1

New Hampshire	0.9%	2
New Jersey	2.3%	5
New Mexico	0.5%	1
New York	4.2%	9
North Carolina	5.1%	11
North Dakota	0.0%	0
Ohio	5.1%	11
Oklahoma	0.9%	2
Oregon	1.9%	4
Pennsylvania	5.6%	12
Puerto Rico	0.0%	0
Rhode Island	0.0%	0
South Carolina	1.4%	3
South Dakota	0.0%	0
Tennessee	3.7%	8
Texas	1.4%	3
US Virgin Islands	0.0%	0
Utah	0.5%	1
Vermont	0.9%	2
Virginia	5.6%	12
Washington	1.9%	4
West Virginia	0.0%	0
Wisconsin	4.2%	9
Wyoming	0.9%	2
TOTAL		214

Q34 To what age group do you belong?

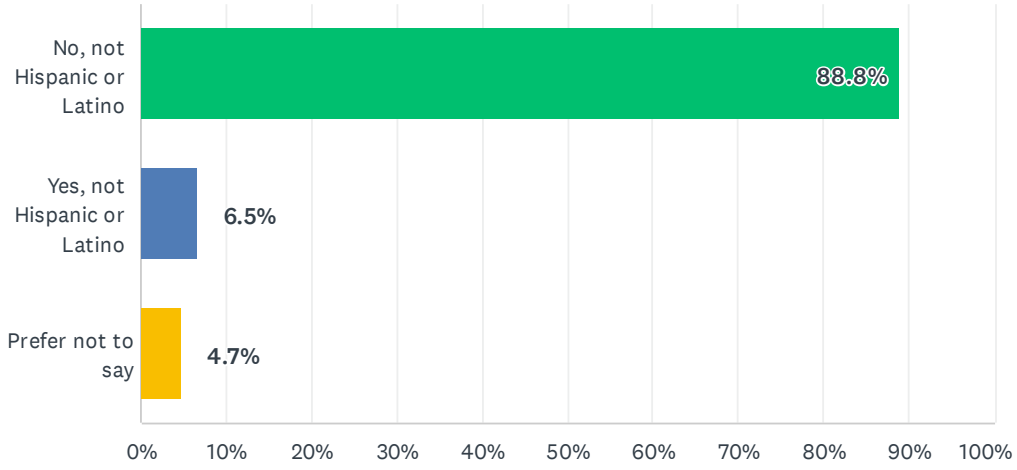
Answered: 215 Skipped: 16



ANSWER CHOICES	RESPONSES	
Under 18	0.0%	0
18-24	0.5%	1
25-34	13.5%	29
35-44	20.0%	43
45-54	25.1%	54
55-64	21.4%	46
65+	19.5%	42
Prefer not to say	0.0%	0
TOTAL		215

Q35 Are you Hispanic or Latino?

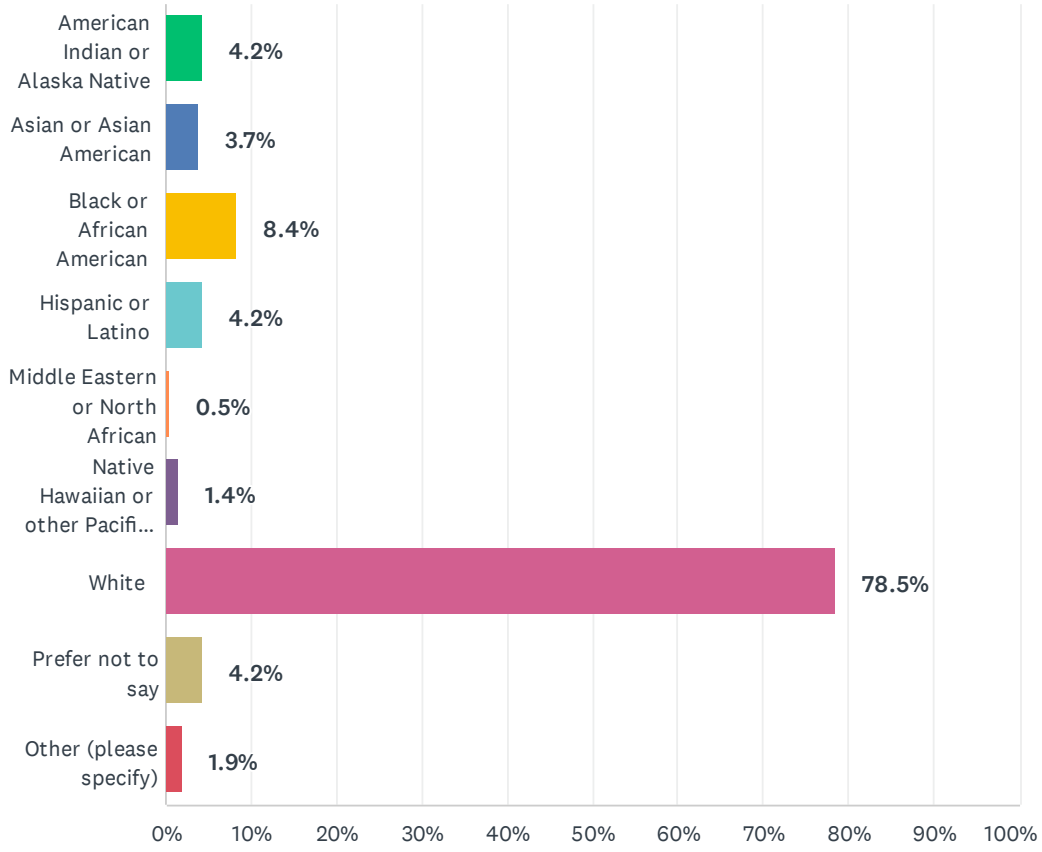
Answered: 215 Skipped: 16



ANSWER CHOICES	RESPONSES	
No, not Hispanic or Latino	88.8%	191
Yes, not Hispanic or Latino	6.5%	14
Prefer not to say	4.7%	10
TOTAL		215

Q36 What is your race (check all that apply)?

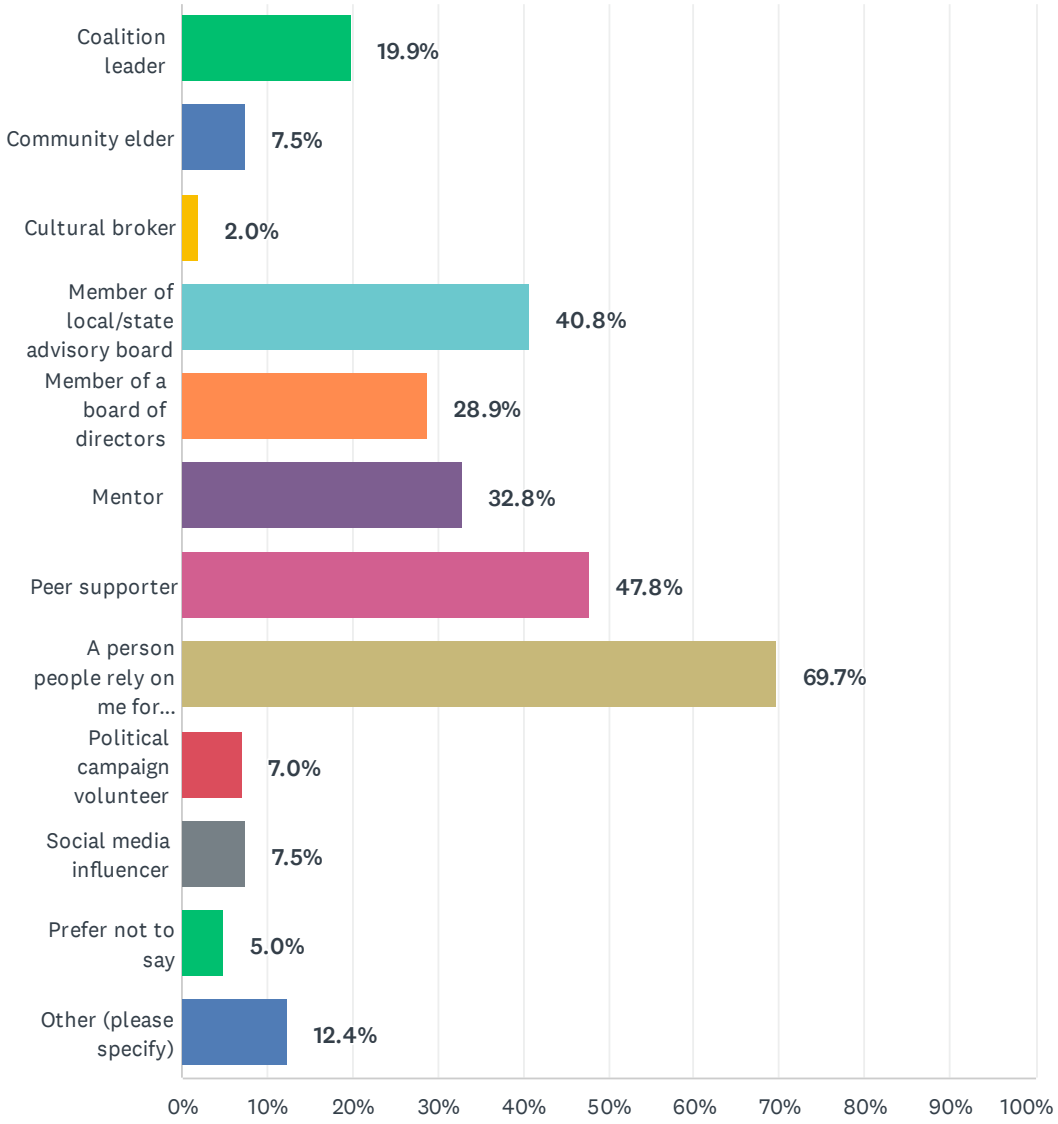
Answered: 214 Skipped: 17



ANSWER CHOICES	RESPONSES	
American Indian or Alaska Native	4.2%	9
Asian or Asian American	3.7%	8
Black or African American	8.4%	18
Hispanic or Latino	4.2%	9
Middle Eastern or North African	0.5%	1
Native Hawaiian or other Pacific Islander	1.4%	3
White	78.5%	168
Prefer not to say	4.2%	9
Other (please specify)	1.9%	4
Total Respondents: 214		

Q37 Please indicate any formalized leadership positions you have held over the past six months (select all that apply)

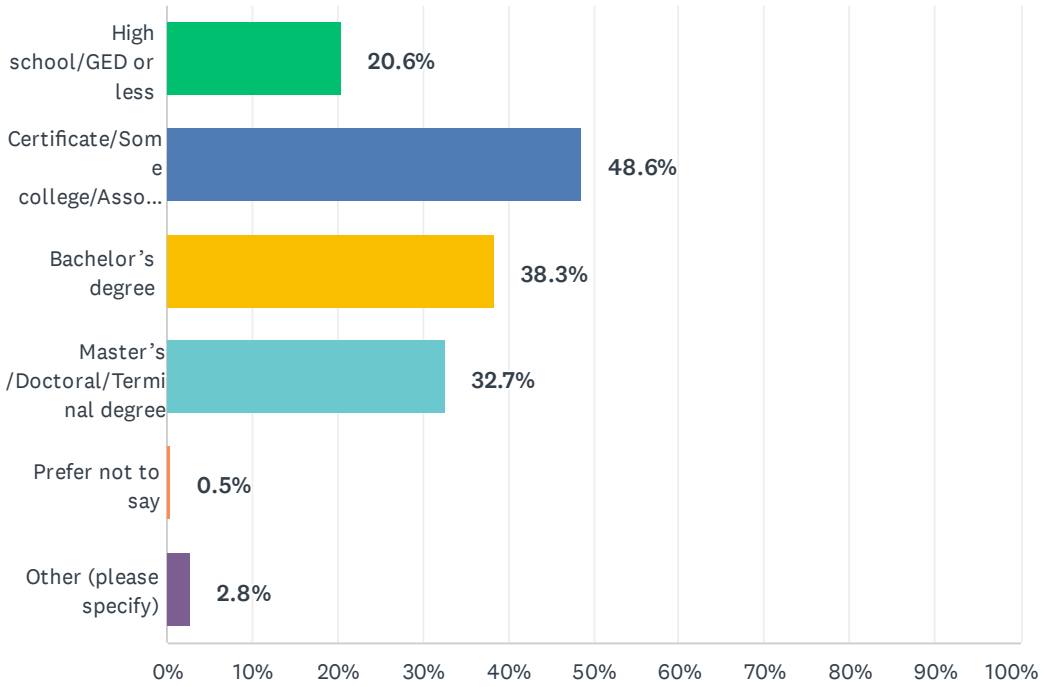
Answered: 201 Skipped: 30


Coalition leader
19.9%
Community elder
7.5%
Cultural broker
2.0%
Member of local/state advisory board
40.8%
Member of a board of directors
28.9%
Mentor
32.8%
Peer supporter
47.8%
A person people rely on me for...
69.7%
Political campaign volunteer
7.0%
Social media influencer
7.5%
Prefer not to say
5.0%
Other (please specify)
12.4%
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%

ANSWER CHOICES	RESPONSES	
Coalition leader	19.9%	40
Community elder	7.5%	15
Cultural broker	2.0%	4
Member of local/state advisory board	40.8%	82
Member of a board of directors	28.9%	58
Mentor	32.8%	66
Peer supporter	47.8%	96
A person people rely on me for information or advice	69.7%	140
Political campaign volunteer	7.0%	14
Social media influencer	7.5%	15
Prefer not to say	5.0%	10
Other (please specify)	12.4%	25
Total Respondents: 201		

Q38 Please mark completed levels of education (select all that apply).

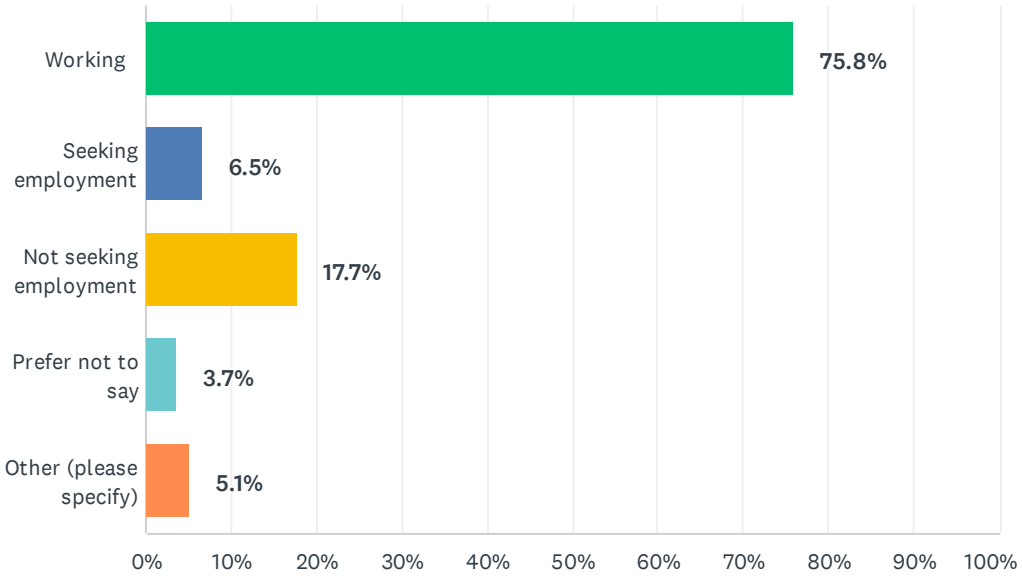
Answered: 214 Skipped: 17



ANSWER CHOICES	RESPONSES	
High school/GED or less	20.6%	44
Certificate/Some college/Associate's	48.6%	104
Bachelor's degree	38.3%	82
Master's /Doctoral/Terminal degree	32.7%	70
Prefer not to say	0.5%	1
Other (please specify)	2.8%	6
Total Respondents: 214		

Q39 What is your employment status? (select all that apply)

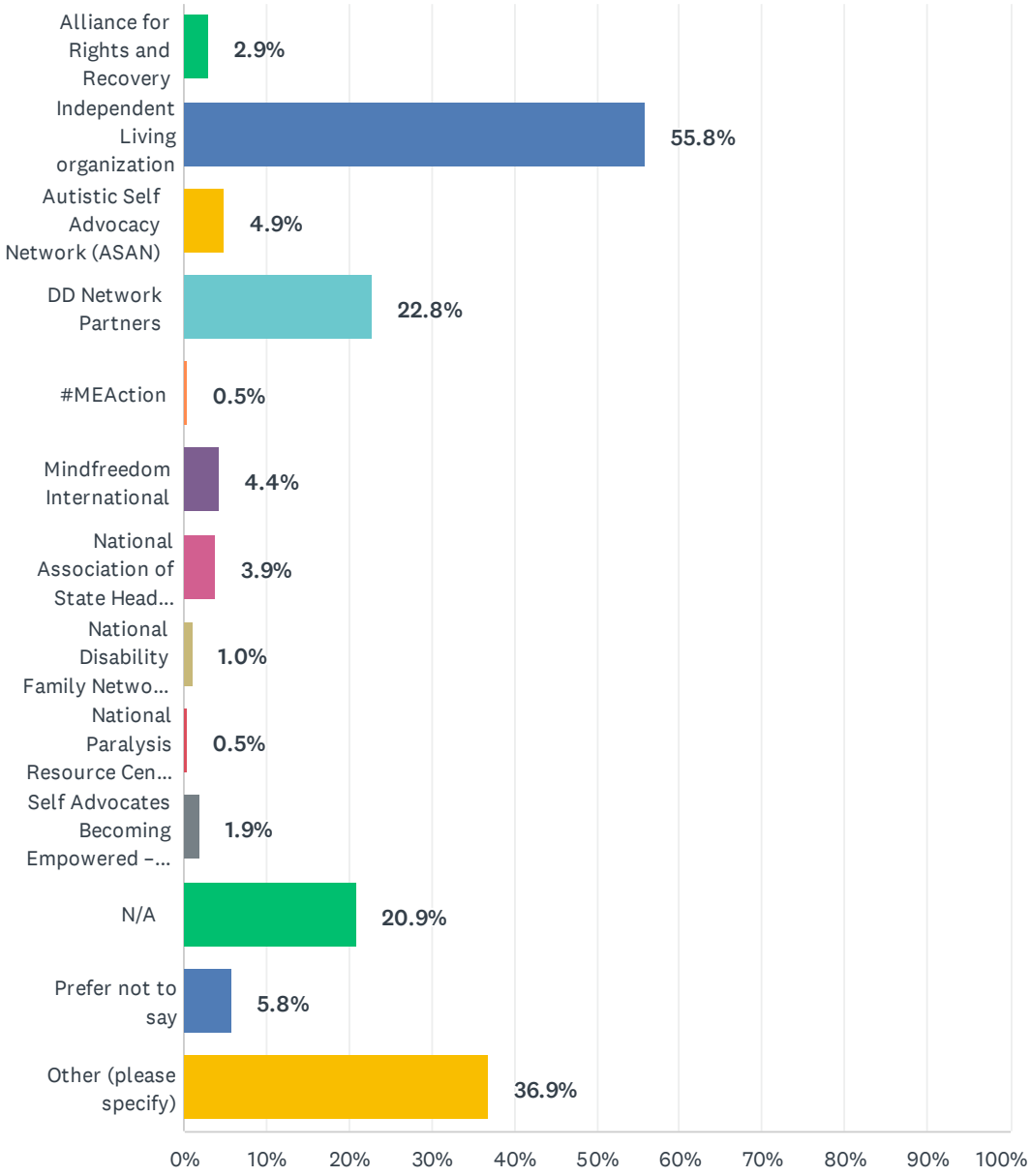
Answered: 215 Skipped: 16



ANSWER CHOICES	RESPONSES	
Working	75.8%	163
Seeking employment	6.5%	14
Not seeking employment	17.7%	38
Prefer not to say	3.7%	8
Other (please specify)	5.1%	11
Total Respondents: 215		

Q40 Which of the following organizations are you primarily affiliated with?

Answered: 206 Skipped: 25


Alliance for Rights and Recovery
2.9%
Independent Living organization
55.8%
Autistic Self Advocacy Network (ASAN)
4.9%
DD Network Partners
22.8%
#MEAction
0.5%
Mindfreedom International
4.4%
National Association of State Head...
3.9%
National Disability Family Netwo...
1.0%
National Paralysis Resource Cen...
0.5%
Self Advocates Becoming Empowered –...
1.9%
N/A
20.9%
Prefer not to say
5.8%
Other (please specify)
36.9%
0%
10%
20%
30%
40%
50%
60%
70%
80%
90%
100%

ANSWER CHOICES	RESPONSES	
Alliance for Rights and Recovery	2.9%	6
Independent Living organization	55.8%	115
Autistic Self Advocacy Network (ASAN)	4.9%	10
DD Network Partners	22.8%	47
#MEAction	0.5%	1
Mindfreedom International	4.4%	9
National Association of State Head Injury Administrators (NASHIA)	3.9%	8
National Disability Family Networks (facilitated by IHD)	1.0%	2
National Paralysis Resource Center (NPRC)	0.5%	1
Self Advocates Becoming Empowered – Self Advocacy Resource and Technical Assistance Center (SABE-SARTAC)	1.9%	4
N/A	20.9%	43
Prefer not to say	5.8%	12
Other (please specify)	36.9%	76
Total Respondents: 206		