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Emergency Preparedness for Alaskans Experiencing Disabilities: A Follow-up

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A Research Report for the Alaska Health and Disability Program

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Abstract

In June 2013, the Alaska Health and Disability Program released a report on the state of emergency preparedness among Alaskans with disabilities. That report established a baseline measure for emergency preparedness statewide and gathered data to inform the development and dissemination of resources. This survey is a one-year follow up to the original survey in an attempt replicate the results and test for change after the publication of the Get Ready! Alaska's Emergency Preparedness Toolkit for People with Disabilities (Get Ready! toolkit). The 2014 survey included basic demographic questions, queries around preparedness, the communication and information resources used, and familiarity with the Get Ready! toolkit among Alaskans with disabilities and their caregivers. In addition, the survey included questions about motivators and barriers related to emergency preparedness. Over a six-week period, surveyors collected 276 responses using a convenience sample. Results indicate that despite 86.1% feeling vulnerable to a disaster, less than one-fifth (19.2%) have a written plan for what to do in a natural disaster or emergency. Slightly more than half (57.7%) have emergency supplies. Only 3.8% have received the Get Ready! toolkit.

Background

A significant component of the Alaska Health and Disability Program is improving emergency preparedness for people with disabilities. As first reported in 2013, a keyword search of academic databases indicated that there is sparse research available that addresses preparedness for people with disabilities or related issues. The 2013 research report revealed that 18.8% of Alaskans with disabilities have an emergency or disaster plan (Rein), slightly under other national estimates (Eisenman et al, 2006, McClure et al, 2011, National Council on Disability, 2009, & Tomio, Sato, Mizumura, 2012). Previous research has shown that people with disabilities are less likely to have an emergency kit or supplies (Bethel, Forman, & Burke, 2011, Eisenman et al, 2006, & Smith, & Notaro, 2009). Our 2013 survey echoed this finding with 54.0% of Alaskans with disabilities reporting they have an emergency supply kit (Rein, 2013). A national survey of older adults indicated that 34.3% of sampled adults over 50 years of age had participated in education or read about disaster participation, and confirmed those with older age, disability, or low education were less likely to be prepared (Al-rousan, Rubenstein, & Wallace, 2014). Additionally, 15.0% of those older adults use medical devices that require power (Al-rousan et al, 2014).

In Alaska, the most commonly reported benefit of having an emergency plan among those with disabilities is continuity of care after a disaster (Rein, 2013). The perceived benefits cited in previous studies of confidence, self-reliance, and safety (Newport, & Jawahar, 2003), were also important to Alaskans (Rein, 2013). Reasons for not having an emergency plan or kit included a lack of time, financial constraints, the perception that a plan is not needed for safe evacuation, and a long list of needs on which emergency planning falls near the bottom (Rein, 2013; National Council on Disability, 2009), creating feelings similar to crisis fatigue. Literature indicates that emergency preparedness messages for people with disabilities need to be easy to understand and delivered in multiple methods by people viewed as knowledgeable (National Council on Disability, 2009 & Tierney et al, 2001). Additionally, materials need to be easy to locate, user-friendly, and available from a variety of disability- and health-related organizations (Rein, 2013).

Methodology

Data were collected using the web-based survey site, SurveyMonkey.com between November 3, 2014 and December 15, 2014 using a convenience sample composed of adults over age 18 in Alaska with any disability or the adult caregivers of any Alaskan with a disability. Multiple outreach opportunities with the Alaska Health and Disability Program, partners, and disability stakeholder organizations recruited survey participants using email, social media, internet, and meetings.

Email requests to distribute surveys were sent to a variety of state and local organizations including Adult Protective Services, Aging and Disability Resource Centers, Alaska Association of Developmental Disabilities Providers, Alaska Autism Resource Center, Alaska Brain Injury Network, Alaska Commission on Aging, Alaska Healthcare Commission, Alaska Mental Health Board, Alaska Mental Health Trust Authority, Anchorage School District Special Education Department, Division of Behavioral Health, Division of Healthcare Services, Division of Public Health, Division of Senior and Disabilities Services, Governor's Council on Disabilities and Special Education, Statewide Independent Living Council, University of Alaska Anchorage, and many other social service and non-profit agencies. Two social media messages were posted to the Alaska Health and Disability Program Facebook page at the beginning and end of the survey period. Additional social media exposure resulted from sharing of those messages to at least three other related groups. Both the Alaska Mental Health Trust Training Cooperative and the Alaska Division of Vocational Rehabilitation reported sharing the survey invitation with their large listservs.

Online collection was the primary collection method, although respondents had the opportunity to obtain alternate survey formats, such as paper or telephone. Surveyors emailed two PDF survey forms when requested. Surveyors received no paper surveys or requests for telephone survey.

Informed consent and study information comprised the introduction page of the survey. The University of Alaska Anchorage Institutional Review Board reviewed and approved this study. As a thank you for completing the survey, respondents had the opportunity to enter a drawing for one of four $25 gift cards to Fred Meyer. Drawing entries remained separate from survey responses.

Demographics

Two hundred and seventy-six (276) people responded to the survey. The survey invitation stated that people experiencing a disability could have someone help them complete the survey if they chose. Less than half of all respondents (44.5%) used the assistance of another person in completing the survey. If an individual indicated a role other than a person who experiences a disability, survey skip logic reminded proxy respondents that their answers should be on behalf of an individual with a disability and should not reflect the proxy's own information or experiences. More

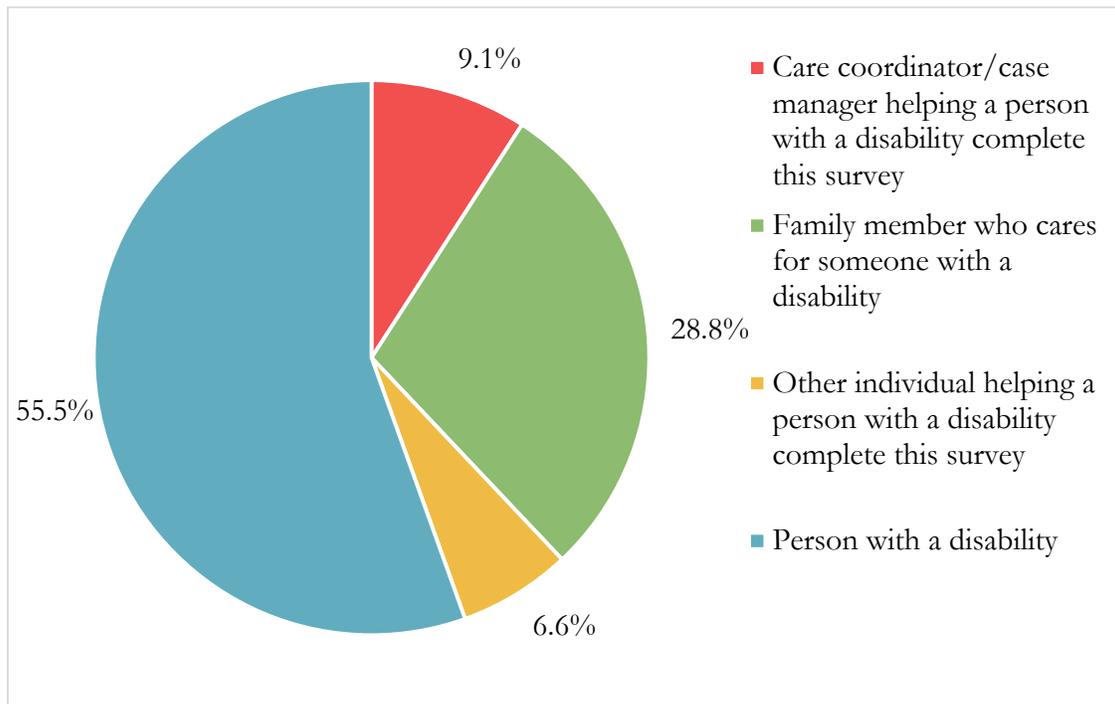than half (55.5%) of respondents with a disability and completed the survey themselves (see Figure 1).

Figure 1. The proportion of survey respondents' different roles

Survey respondents were asked six standard questions used in the American Community Survey to identify their disability. Interestingly, twenty-three respondents who identified themselves as having a disability answered "no" to each of the six disability screener questions. More than two thirds (71.5%) of those with disabilities reported multiple disabilities. Approximately half (51.6%) of those surveyed reported a physical disability, and one quarter (25.3%) reported a sensory disability. The most common single disability reported was difficulty concentrating, remembering, or making decisions (see Figure 2).
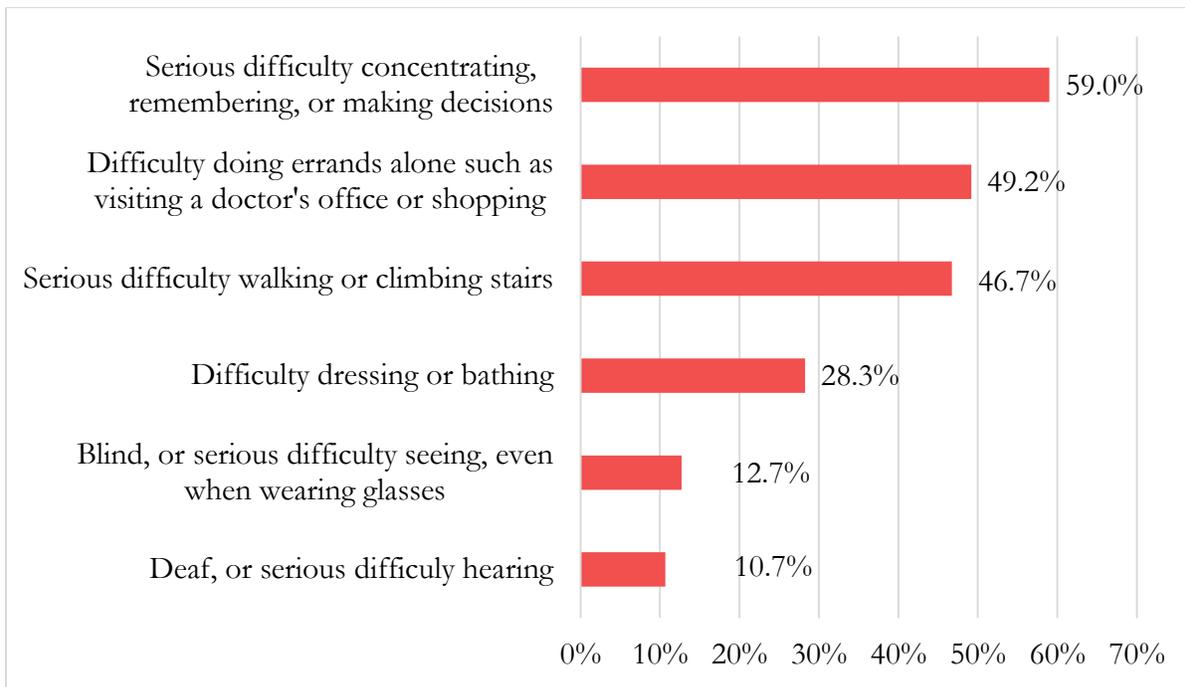
Figure 2. Proportion of disability types reported by respondents

The age of those responding to the survey was not evenly distributed, or representative of the population distribution in Alaska, either with or without a disability. Survey results were over-representative of those 55-64 years old and older than 65 years, and under-representative of those younger than 18 years (see Figure 3). An adult completed responses for children younger than 18 years.
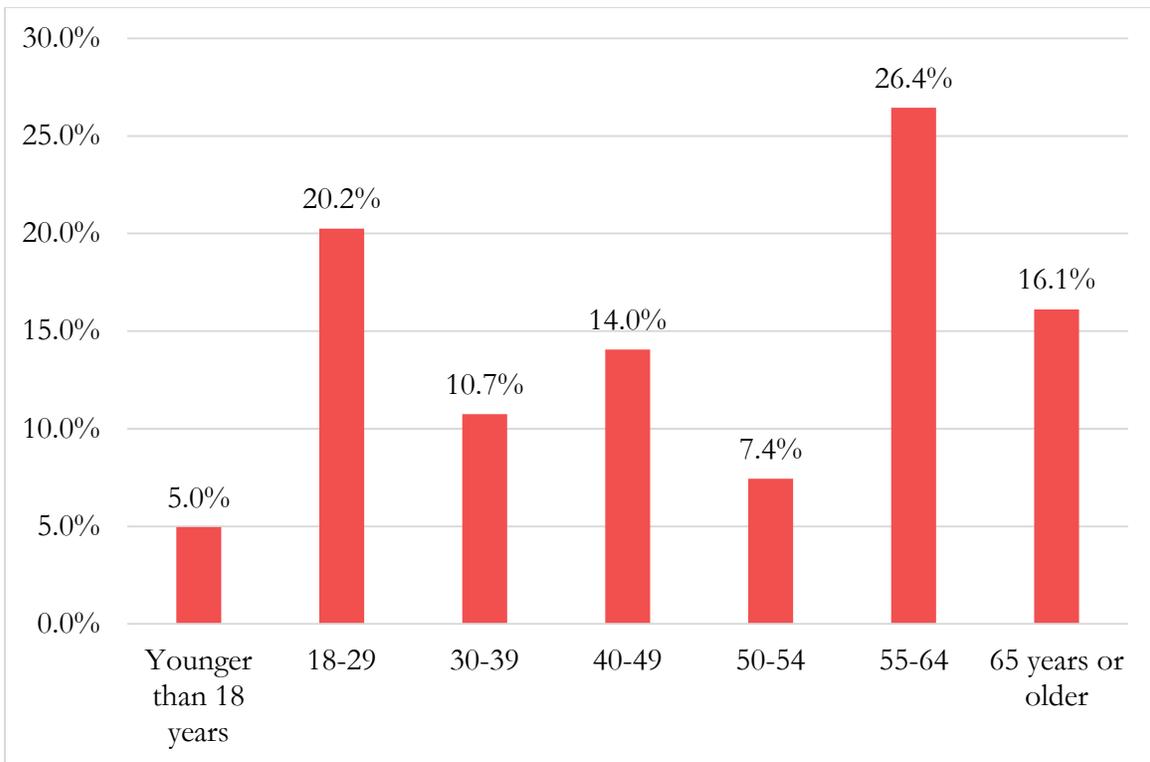
Figure 3. Age distribution of survey respondents

While approximately 45% of Alaskans who experience disabilities are female, women were more likely to respond to this survey (see Figure 4).
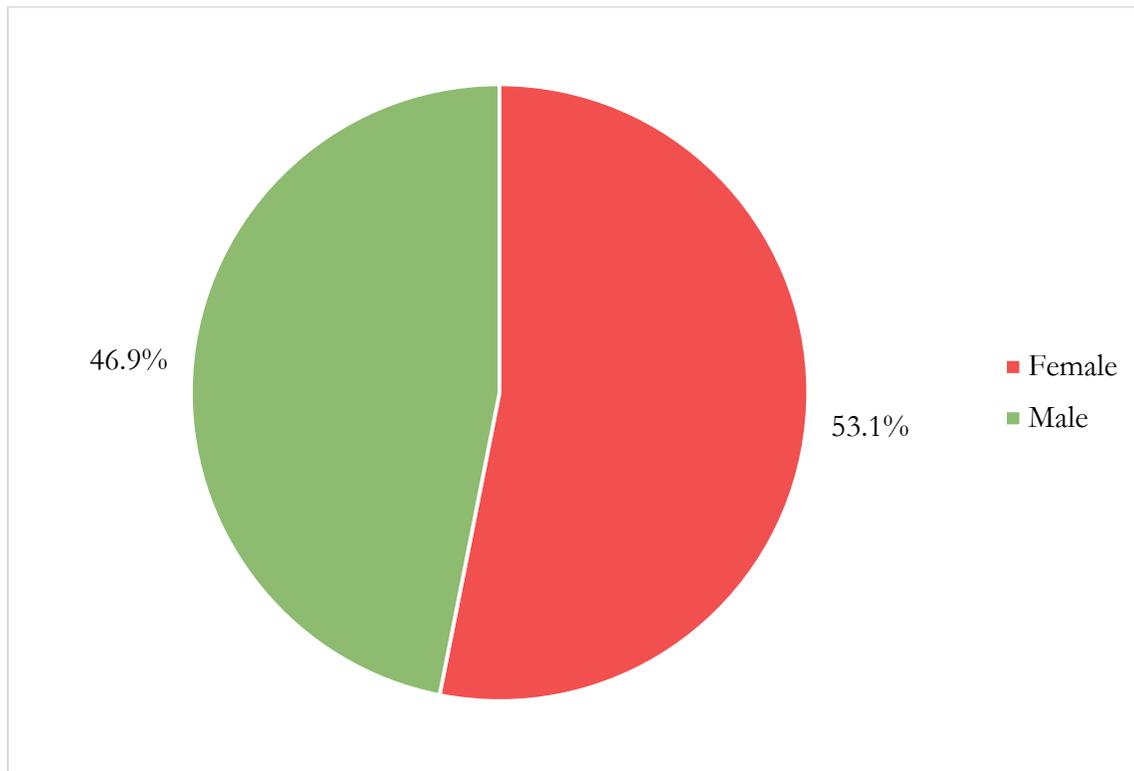
Figure 4. Gender distribution of survey respondents

Most of those responding to the survey described their living situation as living independently (33.5%), or with family who provide daily support (48.8%) (See Figure 5). No respondents reported living in a nursing home or skilled nursing facility. Six respondents reported being homeless. Nearly two-thirds (63.2%) of respondents report some daily support from others to meet their needs. Nearly eight percent (7.9%) live in group homes or assisted living homes that licensed by the State of Alaska and whose regulations require some level of emergency planning. Someone other than the person with a disability completed all of the responses indicating residence in a group home or assisted living home.
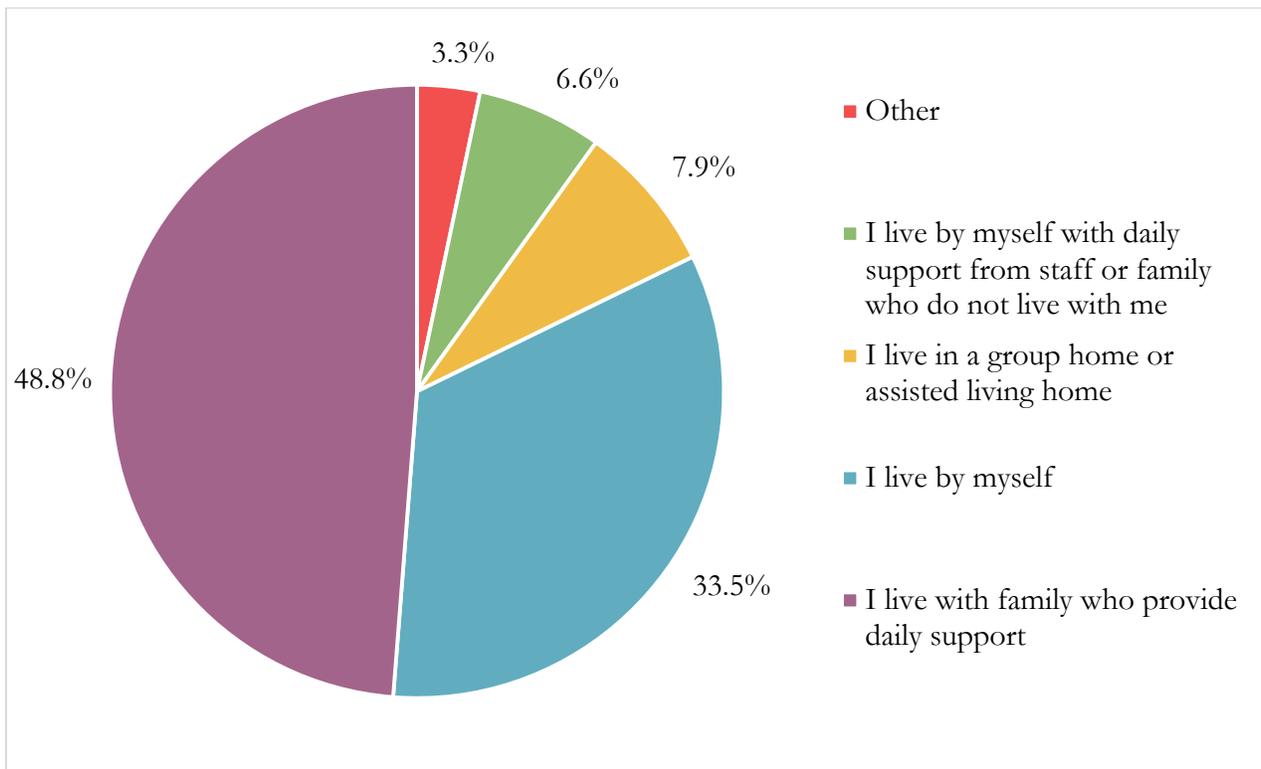

Figure 5. Distribution of the living situations of the survey respondents

Survey responders, asked to provide their zip code, indicated that they live in 37 communities throughout the state. Consistent with state population centers, respondents were primarily located in south-central Alaska (see Figure 6). The highest numbers of responses were from Anchorage (28.2%), Wasilla (19.9%), Juneau (9.1%) and Fairbanks (8.3%). Other resident communities included Adak, Anchor Point, Barrow, Chugiak, Douglas, Eagle River, Ester, Gustavus, Haines, Homer, Hooper Bay, Indian, Kake, Kenai, Ketchikan, Kiana, Klawock, Kodiak, Kotzebue, Nome, North Pole, Palmer, Petersburg, Salcha, Seward, Sitka, Soldotna, Sterling, Sutton, Tok, Valdez, Ward Cove, and Willow.
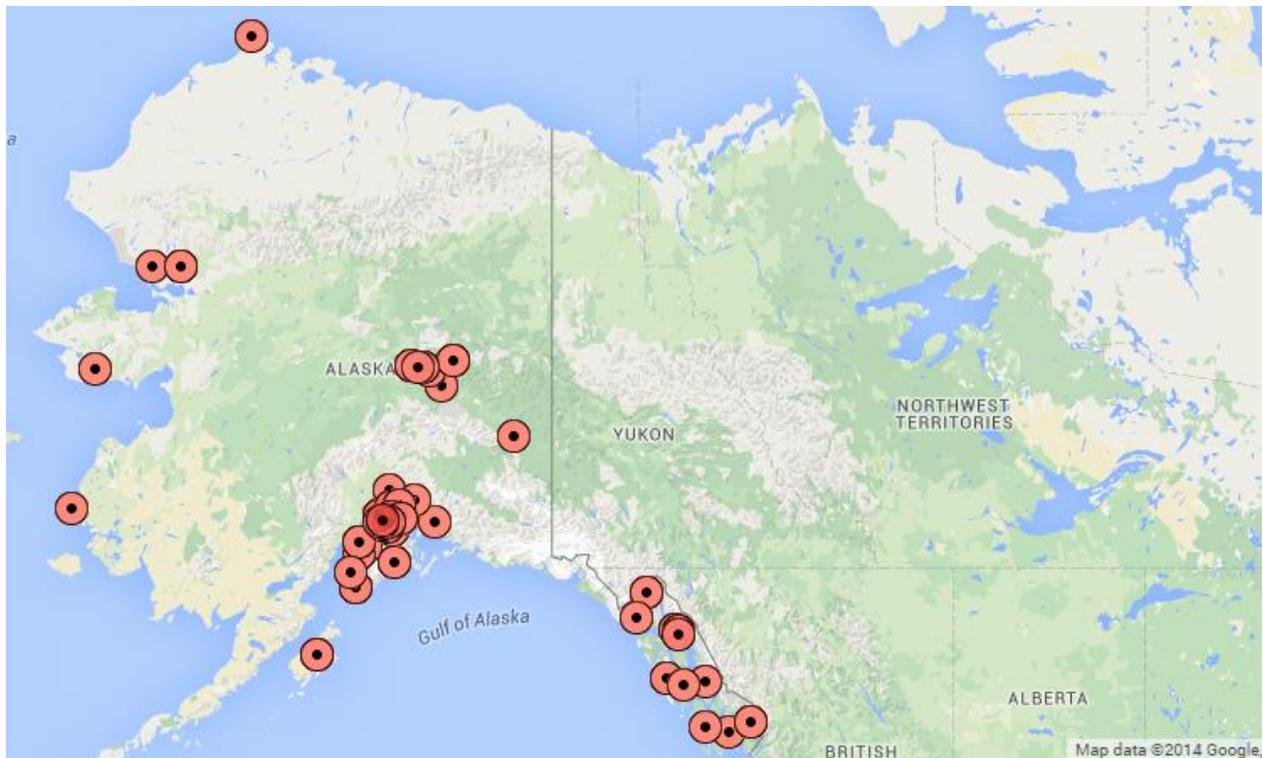

Figure 6. Geographic distribution of survey respondent locations. Map by BatchGeo, LLC.

A variety of survey questions related to the respondent's perceived vulnerability to a disaster, their level of preparedness, and their motivations and preferences related to preparedness. The online survey tool included skip logic to allow for categorization of responses.

Vulnerability

Most (86.1%) of respondents indicated that they felt like a natural disaster or emergency could happen to them. Most respondents (73.9% and 62.9%, respectively) felt that having a written plan for what to do in case of a disaster or emergency either 1) makes them feel safer (of respondents who already have a written plan) or 2) would make them feel safer (among respondents who do not yet have a written plan) (see Figure 7). The proportion of those who feel safer is higher if they already have a written plan.
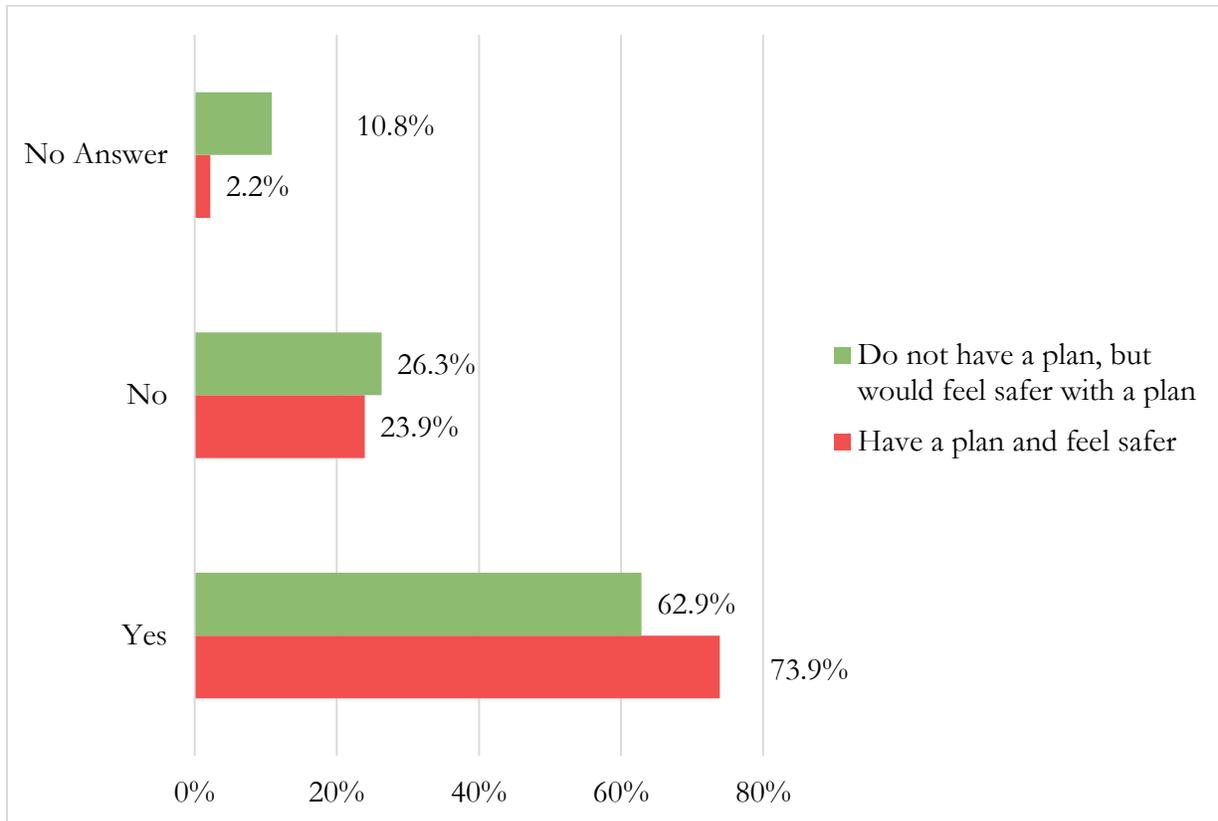

Figure 7. Proportion of survey respondents who feel, or would feel, safer with a written emergency plan, by plan status.

Level of Preparedness

Although 86.1% of respondents feel vulnerable to a disaster, and a majority express a belief that a written plan would make them safer, a much smaller percentage (19.2%) of respondents have a written plan for what to do in a natural disaster or emergency. Respondents were more likely to have a "go kit" in case of evacuation, and even more report having enough emergency supplies, such as a flashlight, batteries, and medicines, to shelter in place for five to seven days (see Figure 8).
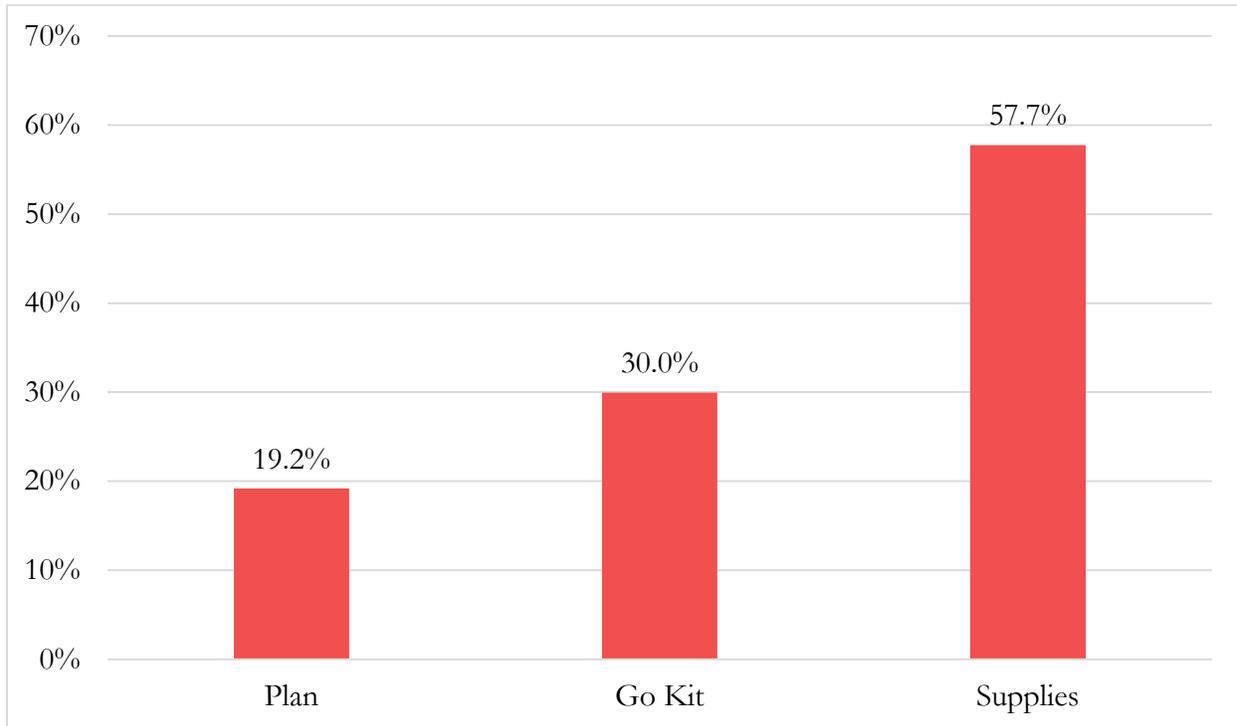

Figure 8. Proportion of survey respondents with a written plan, go kit, or emergency supplies

Nearly half (47.9%) of those with a "go kit" also have a written plan. Nearly one-third (28.3%) of those who have shelter-in-place emergency supplies also have a written plan. Thirty-four individuals (14.2%) report having a written plan, a go kit, and emergency supplies (see Figure 9).
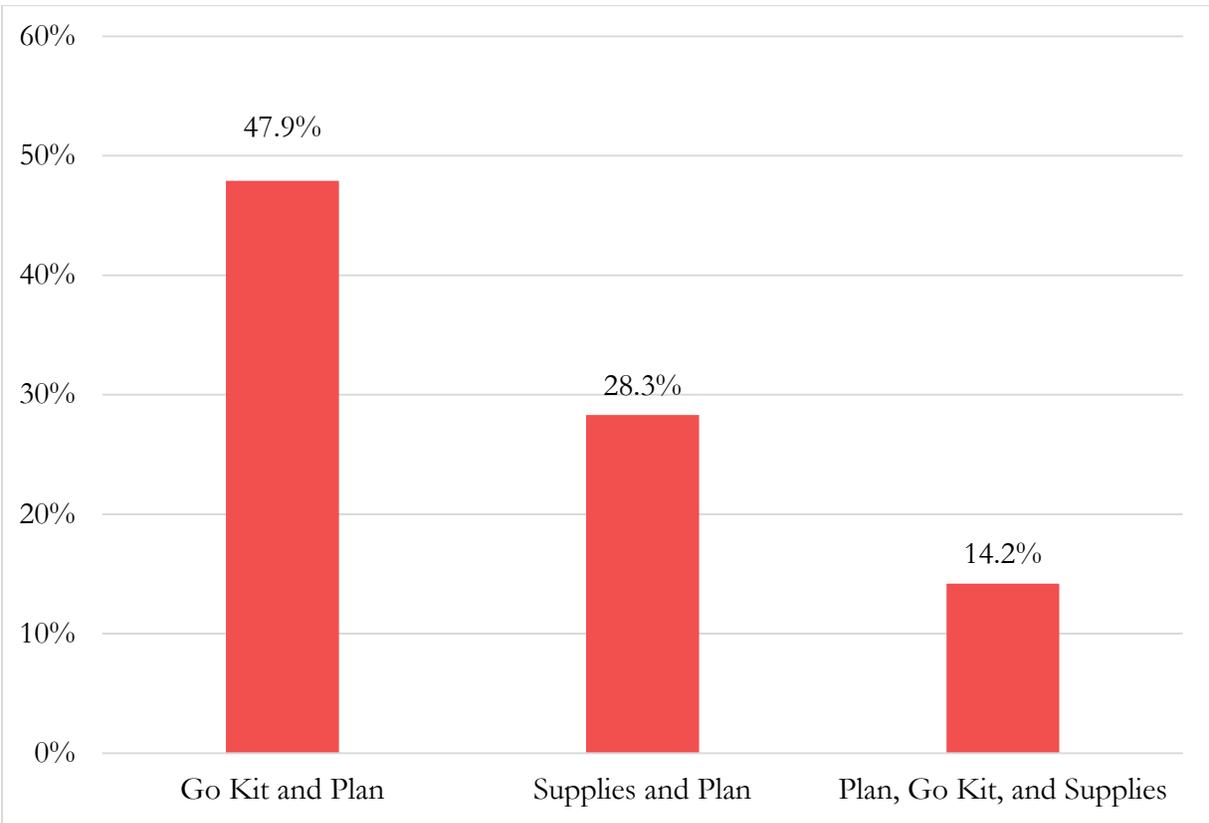
Figure 9. Proportion of survey respondents who have multiple areas of emergency preparation.

Nearly two-thirds (60.0%) of those who feel like a disaster could happen to them also have either a "go kit" or shelter-in-place supplies. When looking only at respondents who feel like a disaster could happen to them, still only 18.0% have a written plan.

Nearly half (46.7%) of respondents with emergency plan reported their plans were written by someone other than the person with a disability. Of those with no written emergency plan, most (77.6%) reported it was not someone else's responsibility to write one (see Figure 10). Of those who did identify someone responsible for writing a plan, most cited a parent, guardian, or immediate family member.

Figure 10. Proportion of survey respondents for whom someone wrote an emergency plan or someone else is responsible for writing an emergency plan.

Motivators

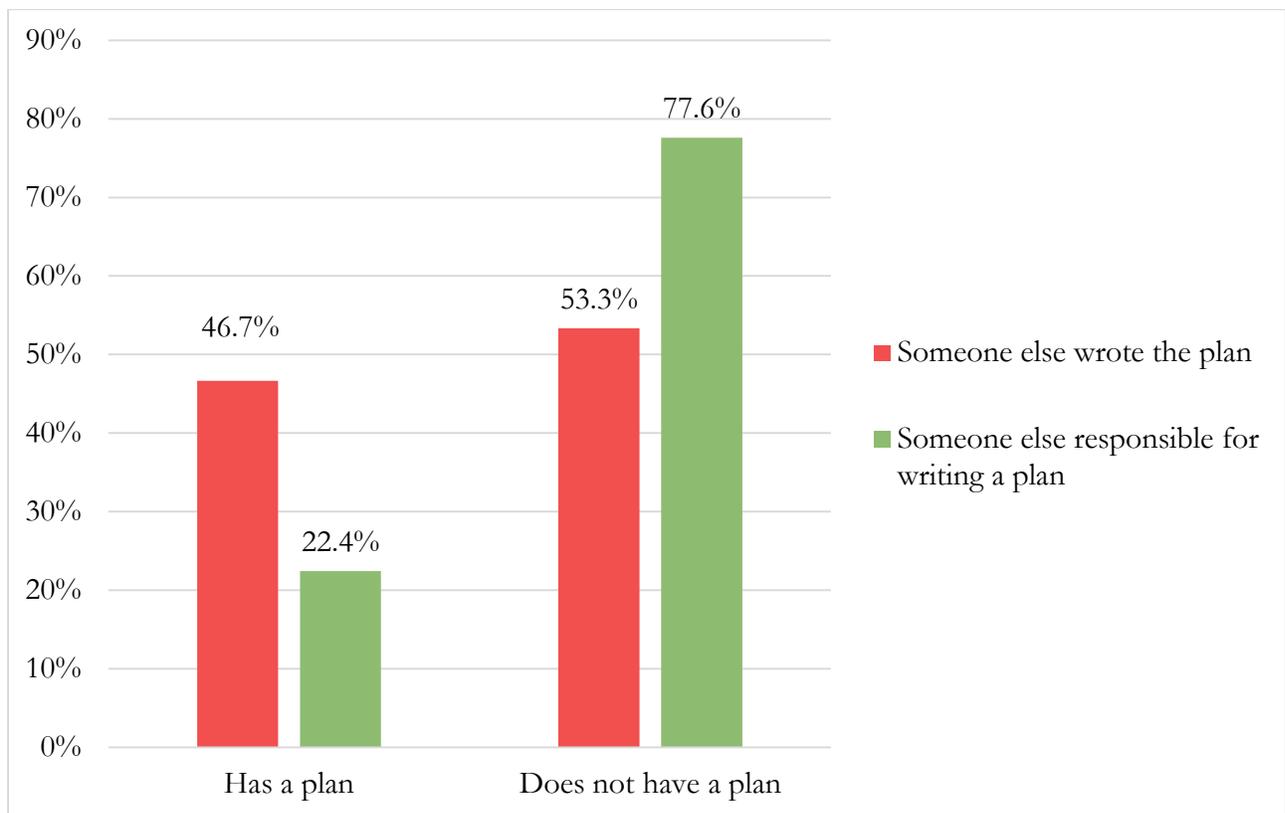The survey included several questions that aimed to explore the motivators and barriers involved in writing an emergency plan. Respondents identified their perceived benefits to having a written emergency plan both for themselves and for other people in their lives. Clustering similar themes together allowed analysis of responses. Overall, simply knowing what to do in an emergency was most important to respondents. One person stated I, "…practice because I can't remember things unless it's long term so mom makes me every month go over my safety plan in case of earthquake." Knowing what to do is particularly important for those who do not yet have a plan. Continuity of care, or the assurance that their needs can be met after a disaster, was particularly important to those who already had a written plan. Several respondents stated they did not know of a benefit to having a plan, including one individual who has a plan in place. Several additional respondents specifically stated that there was no benefit to having a written plan (see Table 1). One respondent commented, "I all ready [sic] live day to day-what is one more challenge?" Another respondent felt that if they had a plan, "it could be integrated…into [the family's] emergency plan so that I would not be forgotten about during a time of emergency."

Table 1. Proportion of benefits mentioned in having written emergency plan, by plan status and beneficiary

	Respondents with plan (%)			Respondents without a plan (%)			Total (%)
	For self	For others	Subtotal	For self	For others	Subtotal	
Know what to do	21.2	7.9	14.1	23.2	12.7	18.2	17.4
Feel safe/alleviate fear	9.1	21.1	15.5	10.4	8.7	9.6	10.6
Continuity of care	33.3	7.9	19.7	7.9	8.7	8.3	10.4
Maintain family connectedness/reassurance	-	21.1	11.3	2.4	16.0	8.9	9.4
Feel ready/organized	6.1	2.6	4.2	11.6	6.0	8.9	8.1
Know where to go	3.0	13.2	8.5	1.8	13.3	7.3	7.5
Prompting/remembering	-	-	-	12.8	1.3	7.3	6.0
Less stress/remain calm	-	-	-	9.1	2.7	6.1	4.9
Know who will help	6.1	7.9	7.0	4.3	4.0	4.1	4.7
Don't know	3.0	-	1.4	3.7	4.7	4.1	3.6
None	12.1	2.6	7.0	2.4	2.7	2.5	3.4
Know how to help	-	-	-	-	8.7	4.1	3.4
Know where to find supplies/equipment		5.3	2.8	3.0	2.7	2.9	2.9
Solve problems ahead of time	-	-	-	4.3	0.7	2.5	2.1
Understanding of own needs	6.1	7.9	7.0	0.6	-	0.3	1.6
Faster response to emergency	-	2.6	1.4	1.2	2.0	1.6	1.0
Independence/self-reliance	-	-	-	-	3.3	1.6	1.3
Know what will be happening	-	-	-	1.2	1.3	1.3	1.0
Use less resources	-	-	-	-	0.7	0.3	0.3

Respondents identified resources or assistance that have, or would be, helpful in writing a plan. The responses to this open-ended question mirrored some of the other questions related to motivators, barriers, and information sources. Most frequently mentioned included having access to templates, checklists, or examples of emergency plans, particularly by those who do not have a plan. Training was the most cited influence on those who have a written plan. The internet is clearly an important resource to all respondents. While other factors play a role in whether a person writes a plan, availability of resources is clearly important (see Table 2).

Table 2. Proportion of resources that were indicated as helpful in writing an emergency plan, by plan status

	Respondents with a plan (%)	Respondents without a plan (%)	Total (%)
Template, checklist or example	5.0	14.9	12.3
Information/Where to start/List of resources	-	15.8	11.7
Internet	10.0	11.4	11.0
Supplies (where to get, financial assistance)	5.0	8.8	7.8
Family	7.5	6.1	6.5
Hands-on assistance	7.5	5.3	5.8
Training/class	12.5	1.8	4.5
Personal data (phone numbers, medication lists)	-	6.1	4.5
Care providers	7.5	2.6	3.9
Community/Local Government	5.0	2.6	3.2
American Red Cross	2.5	3.5	3.2
Money	2.5	3.5	3.2
Federal Emergency Management Agency (FEMA)	7.5	0.9	2.6
Time	-	3.5	2.6
State of Alaska disability resources	2.5	1.8	1.9
Brochure	2.5	1.8	1.9
Local emergency plans	-	2.6	1.9
Mandate/Legal requirements	5.0	-	1.3
Primary care physician	2.5	0.9	1.3
Fire department	2.5	0.9	1.3
Common sense	2.5	0.9	1.3
Help problem-solving disability issues related to disasters	-	1.8	1.3
Acceptance of need	-	1.8	1.3
Faith Community	2.5	-	0.6
Media	2.5	-	0.6
Legal aid	2.5	-	0.6
Amateur radio community	2.5	-	0.6
Utility companies	-	0.9	0.6

In addition to what people feel they need in order to write a plan, respondents identified who they would like to help them. Family was the most frequently cited and healthcare providers were the least important source of assistance cited. Many respondents also said they did not want anyone to help them write a plan (see Figure 11). Those that identified other sources of help mentioned school, people with expertise in emergency preparedness, a neighbor, a housemate, a therapist, and a group at a senior center. One stated, "Linking up with neighbors/neighborhood associations has been helpful in becoming acquainted and welcomed for initial support in the event of need to be supported until emergency resoureces [sic] become available."
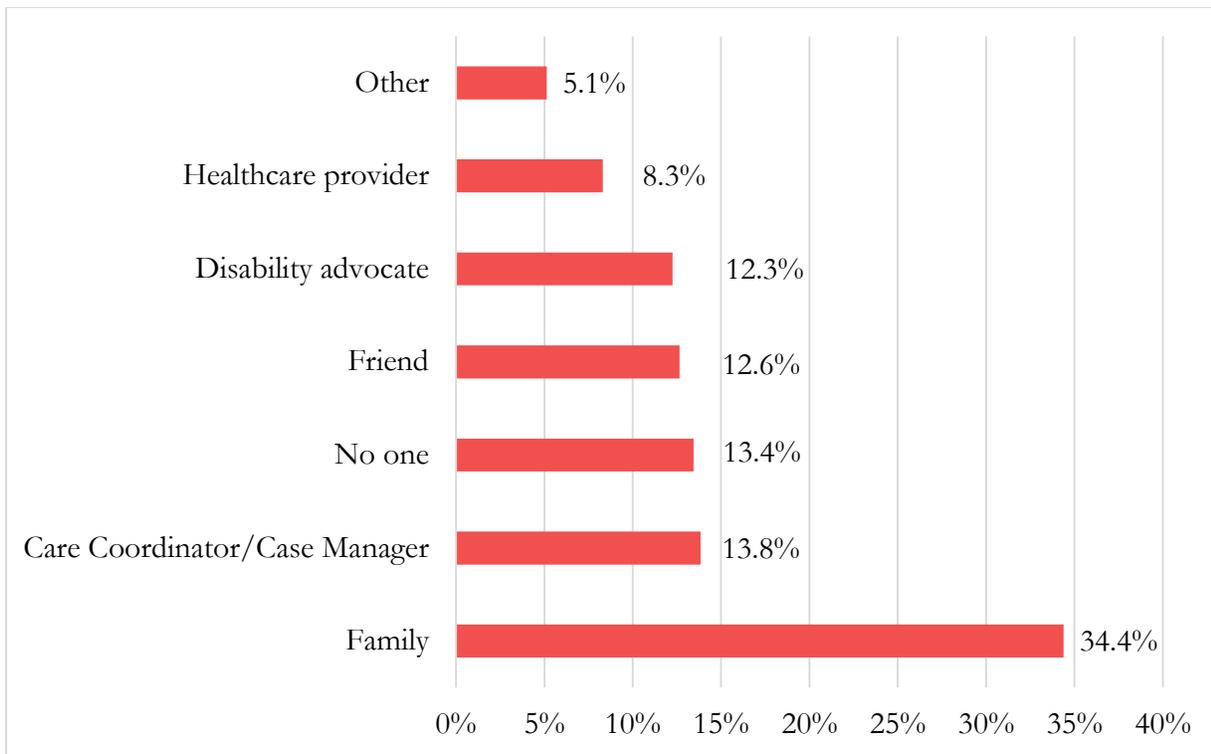
Figure 11. Proportion of individuals from who survey respondents would like help writing an emergency plan

Barriers

The survey included questions aimed at determining the barriers or obstacles that respondents have encountered to writing a plan. Most frequently, respondents reported not knowing how to go about writing a plan. In a separate question, 72.0% indicated that they do not know what to put in a written plan or where to access this type of information. One respondent reported, "There is a major lack of resources available in rural villages." There also appeared to be a general lack of knowledge related to awareness of the need to plan. Respondents reported a lack of time and procrastination or disorganization as well as the severity of disability or poor health as hindering a person's ability to participate in planning. A few respondents mentioned there is no need for a plan (see Table 3). Nearly all (88.6%) respondents said they feel like writing a plan is possible to do with help. Of those who reported not having a written plan, 31.8% said keeping it up to date is a challenge as their life or personal needs change.

Table 3. Proportion of barriers reported by survey respondents that make writing an emergency plan difficult or impossible to do

	Proportion of barriers reported (%)
Do not know how to do it	19.3
Did not think about it	18.6
Lack of time	8.3
Procrastination/Disorganization	8.3
Ability to participate in planning due to disability/poor health	7.6
Nothing	6.9
Need help from someone	6.9
No need for a plan	4.8
Do not have the financial resources	4.1
To many other things have priority	4.1
Don't know	4.1
Do not want to think about it	2.8
Currently feel safe	2.8
Disinterested	1.4

A few respondents described a sense of being overwhelmed by emergency preparedness and all that it entails. One respondent stated:

> I have environmental health problems with chemicals and molds, diesel fumes and wood smoke, to name a few. I do not know where I could go that I would not get in a health crisis and I am very poor so I am not sure how to buy emergency things or store organic food for emergency

Another stated, "It is difficult to put together an emergency pack when you live in an apartment with limited space and very limited dollars."

Information and Communication

In addition to determining the level of preparedness and the motivators and barriers associated with emergency preparedness for Alaskans experiencing disabilities, the survey included questions regarding where respondents get information and what resources they use, both to get information about emergency preparedness and non-emergency preparedness information. Questions about the use of the Get Ready! toolkit were also included.

Information about emergency preparedness

Survey respondents selected the sources they currently access for information about emergency preparedness from a list of potential information sources. Respondents were also able to add any additional sources not listed. The most frequently cited resources respondents currently use to obtain information about emergency preparedness were the internet using a computer, followed by family and television.

The survey included questions to identify where respondents would like to get more information about emergency preparedness. The Get Ready! toolkit was the most frequently selected resource (38.7%). Internet accessed on a computer or PC and the Alaska Health and Disability Program were also frequently selected (33.7% and 30.4% respectively).

In comparing the sources they currently access with those respondents would like more information from, respondents indicated a desire for more information about emergency preparedness from health fairs, healthcare providers, and disability advocacy groups. The results indicated there is significant interest in obtaining more information from the Get Ready! toolkit and the Alaska Health and Disability Program. While obtaining information from family, friends, internet, and television is important, there does not appear to be a desire for substantially more information from those sources (see Figure 11).
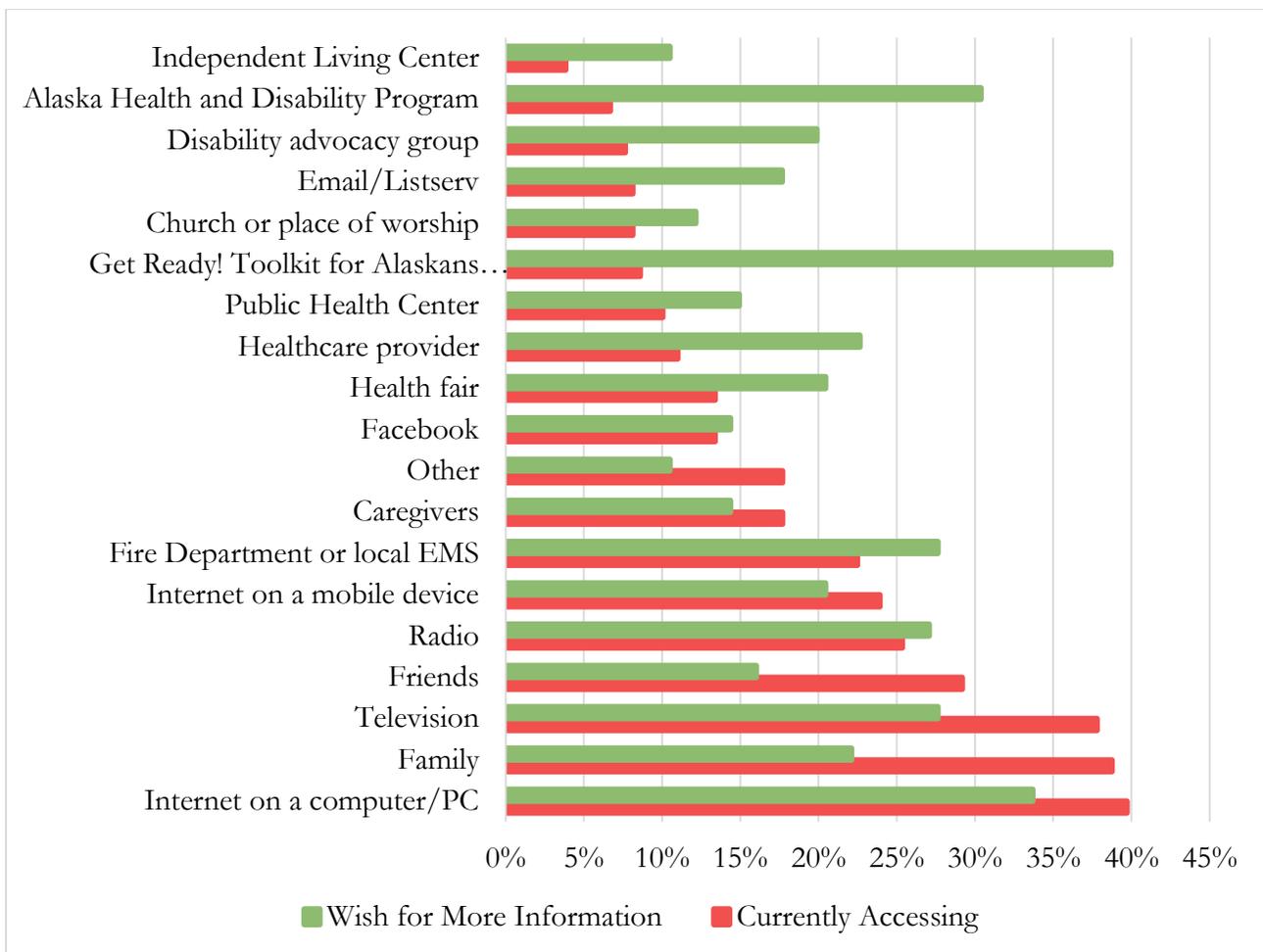
Figure 11. Graphic comparison of relative interest in obtaining information on emergency preparedness from various sources

Frequently used resources

The survey included questions about the frequency that respondents generally use certain resources. Respondents reported using electronic resources, such as email, internet, and social media very frequently, with the exception of Twitter. Nearly 14% utilizes an Independent Living Center once a month or more. Nearly 25% utilizes a public health center once a month or more (see Table 4).

Table 4. Proportion of use of resources by survey respondents

	At least once a day (%)	About once a week (%)	About once a month (%)	Never (%)
Internet on a computer/PC	61.1	18.8	8.2	12.0
Email	58.1	23.7	3.0	15.3
Internet on a mobile device	47.5	13.9	5.9	32.7
Facebook	35.2	14.6	10.6	39.7
Twitter	4.2	1.1	3.7	91.1
Independent Living Center	2.7	3.7	7.4	86.2
Public Health Center	1.1	2.7	20.7	75.5

Get Ready! Toolkit for Alaskans Experiencing Disabilities

Only 3.8% of respondents reported receiving the Get Ready! toolkit. Most (40.0%) of those whom have the Get Ready! Toolkit received it from a care coordinator, case manager, or other direct service provider. No respondents indicated that they had downloaded the Get Ready! Toolkit from the Alaska Health and Disability Program website (see Figure 12).
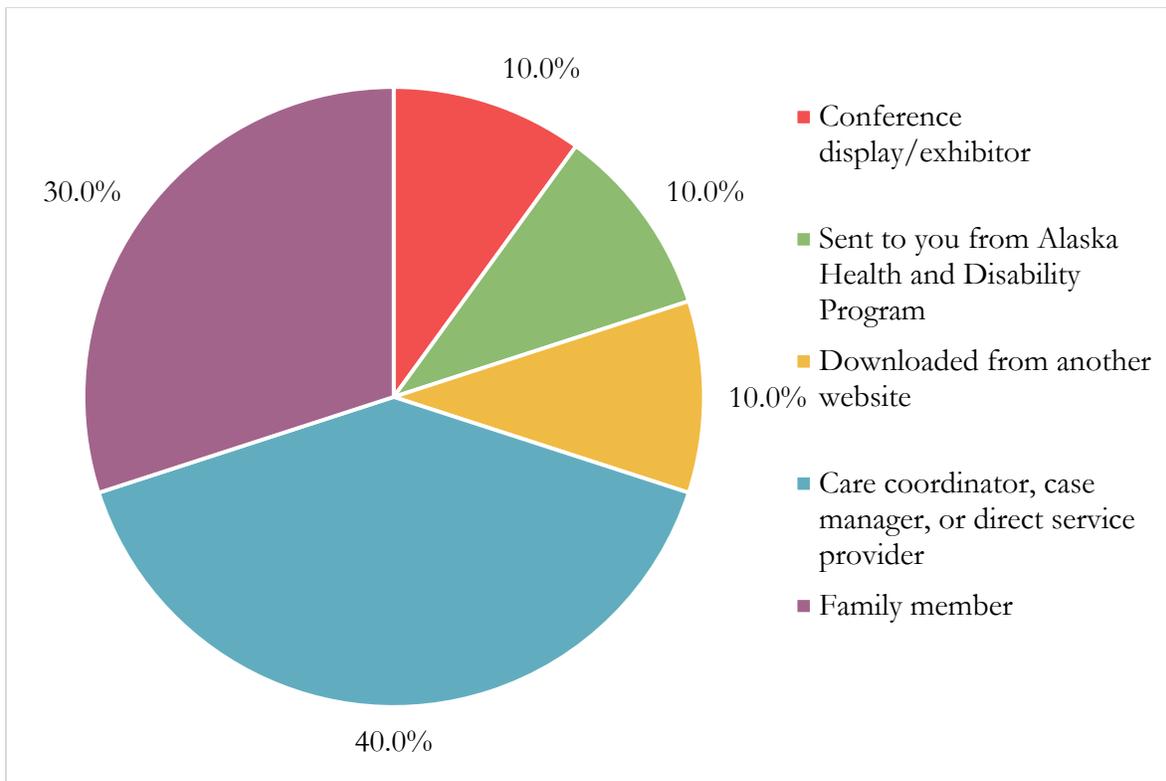
Figure 12. Proportion of respondents who had received the Get Ready! toolkit, by source of the Toolkit

One-third of respondents with the Get Ready! toolkit used it without help from others and an additional one-third used it with help from family. While most of the respondents received the Toolkit from a care coordinator, case manager, or direct service provider, no respondents reported receiving help using the Toolkit from a care coordinator or case manager. Ten percent of respondents reported receiving help using the Toolkit from a Boy Scout Troop (see Figure 13).
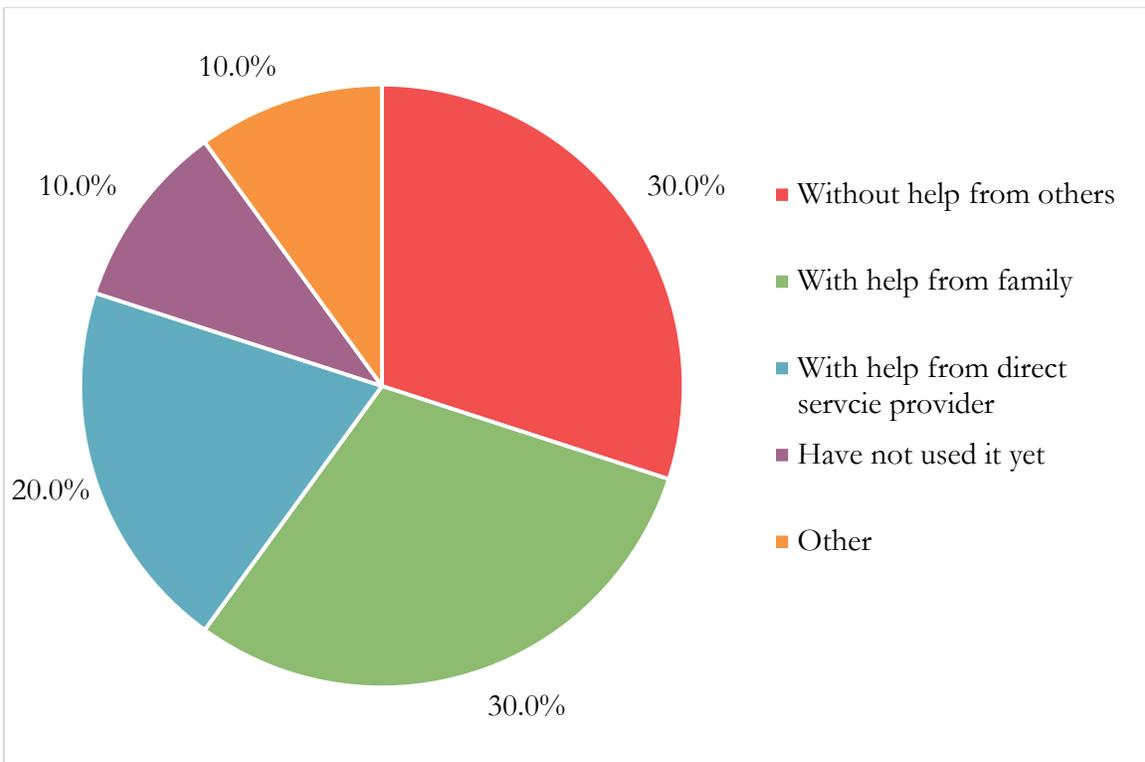
Figure 13. Proportion of uses of the Get Ready! toolkit

Forty percent of respondents reported the most useful section of the Get Ready! toolkit was "Making a plan". Seventy five percent reported "Resources" and "Should I stay or should I go" as the least useful sections of the toolkit (see Figure 14).
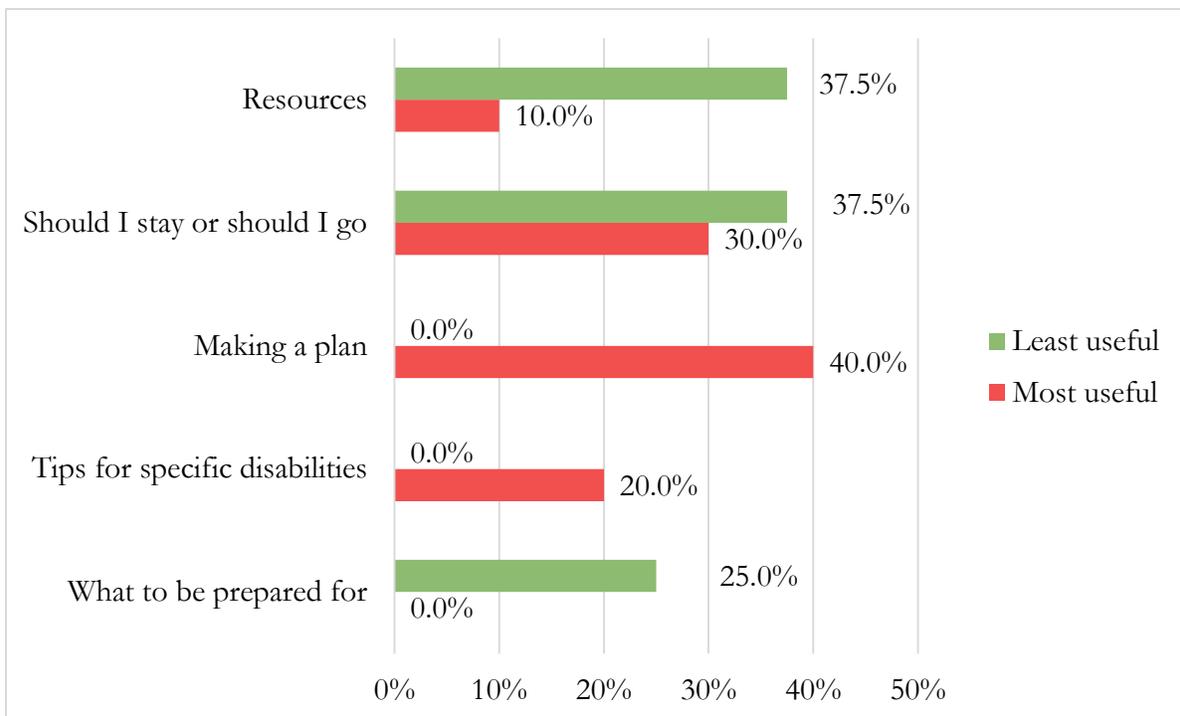
Figure 14. Proportion of Get Ready! toolkit sections, by least useful and most useful

One respondent reported that the best thing is that the Get Ready! Toolkit has, "so many resources in one place". Additional respondents reported that they liked that it is Alaskan. Suggestions for changes in the Get Ready! toolkit include bigger print, particularly in the Resources section, and a child version of the toolkit. Another respondent stated, "…resources are very fragmented. IF there was ONE website that I could go to it would be easier…Then everybody can know where to go to get help instead of looking for each individual organization which is hard for someone with limited energy."

Analysis and Recommendations

The results of this study provided valuable information about the importance of promoting emergency preparedness to Alaskans experiencing disabilities and confirmed the need for additional research. These findings can inform decisions about what information to distribute, how to distribute it, and to whom. The results also provide additional information from which to measure the Alaska Health and Disability Program's outreach and successes.

While the results do not indicate significant change in preparedness status due to intervention by the Alaska Health and Disability Program, they do support the original conclusions of the 2013 report. Twice the number of Alaskans with disabilities responded to this survey themselves, without the help of a proxy, compared with the 2013 survey. Disability type and gender distribution is similar to the 2013 survey, however, this study revealed more variability in the age of respondents. The number of communities represented by respondents increased by 68.2% and there was more representation from southeast Alaska with this survey. The level of preparedness among Alaskans with disabilities is 2.4% higher than reported in 2013. Only 14.2% of respondents have a plan, a go kit and supplies.

Nearly two-thirds (63.2%) of respondents report some daily support from others to meet their needs. This is significant as, in the case of emergency, those who may function adequately on a day-to-day basis may decompensate as their system of care experiences stress and disruption. Individuals with emergency plans are more likely to fair well because they have considered contingencies. Emergency systems are more likely to serve their communities successfully if they understand that people who experience disabilities require additional planning and consideration due to the vulnerability created by reliance upon others for care needs. More people wrote their own emergency plan in this survey, rather than having another person, such as a caregiver or family member write it. This is consistent with the fact that more people with disabilities completed the survey directly, rather than having a proxy complete it for them.

Continuity of care was a more important motivator for people with a plan than in the previous survey. In the 2013 survey, knowing what to do was more important. The differences in priority may again relate to a slightly increased level of independence in the current survey respondents. Those who are more independent may be less worried about who is going to take care of them. Knowing what to do was the most important motivator for people without a plan in this survey. Training or a class was the most important resource for those respondents with a plan. For those without a plan, information, where to start, or list of resources was most important. While a lack of time was the most important barrier to writing a plan in 2013, it was the third most frequently mentioned barrier in this survey. The most important barriers to writing a plan in this survey are not knowing how to do it and not thinking about it.

Overall, the most important resource is a template, checklist or example. People cannot make a plan or a kit if they do not know where to begin or how to find the information. Family is still the number one preferred resource in writing an emergency plan. Clearly, these results continue to support the importance of providing a variety of educational opportunities and planning tools to people with disabilities, and to include families of people with disabilities in the target audiences.

There continues to be a disconnect between understanding what communities, governments, and non-governmental agencies can, and should, be responsible for in an emergency compared to an individual's personal preparedness responsibility. Everyone must be prepared on an individual basis. Everyone, even those with severe disability or illness can participate in his or her own preparedness. This is consistent with strongly held beliefs in disability culture – inclusion and "nothing about me, without me." While care coordinators are responsible for writing annual plans of care that contain components of emergency planning, they are not mandated to write emergency preparedness plans for clients. Despite the requirement of an assisted living home to have a written emergency plan, it is home specific, and not individualized to resident needs.

Several respondents mentioned the need for, "A list of those that would have difficulty evacuating including addresses to be part of a larger community plan," or that, "Local and state [government] should plan for housing and feeding disabled citizens for at least one week." Another respondent stated:

> Agencies that provide supports for daily living should provide emergency
> preparedness for their clients with disabilities. Families can be so caught up in trying
> to help their family member survive that it is not realistic for anyone to expect them
> to even think about this, especially when they are battling just to get what they need
> to live just a normal day.

Individual responsibility is an ongoing theme in emergency preparedness and emergency planning, regardless of disability status. Managing expectations is an important part of emergency preparedness education. Increasing participation of people with disabilities in emergency preparedness drills and exercises may assist in demonstrating the need for individual responsibility and managing expectations.

Information about emergency preparedness continues be mostly obtained from the internet on a computer or pc as in 2013. Only 8.6% of respondents utilize the Get Ready! toolkit and 6.7% of respondents utilize the Alaska Health and Disability Program. Promisingly, respondents want more information from Get Ready! toolkit and the Alaska Health and Disability Program (38.7% and 30.4% respectively). Electronic information sources are frequently used on a daily basis. More than 5,000 Get Ready! toolkits have been distributed statewide. The reason for the low utilization of the toolkit may be that those toolkits are primarily going to disability related agencies and not making it

to individuals with disabilities. It may also be that distributed toolkits are being set aside rather than being implemented. Additional information through direct follow-up with those participating in training and those receiving toolkits would help obtain data regarding how the information is implemented.

Recommendations

- AHDP and partners such as the Statewide Independent Living Network should continue to encourage disability representation within local emergency planning committees (LEPCs) to encourage emergency managers to improve integration of the needs of people with disabilities into guidelines, policies, and surveillance methods. This could be accomplished by working with LEPCs to actively recruit membership from the disability community, as well as by providing information to people participating at emergency preparedness trainings about how to locate and get involved with their LEPC.

- AHDP and partners should continue to include family caregivers and paid caregivers in emergency preparedness education campaigns and trainings. This could be accomplished by continuing to present and exhibit at conferences and meetings where caregivers are a target audience, as well as by approaching family caregiver support agencies and organizations to directly target family caregiver presentations.

- AHDP and partners should continue to emphasize that individualized plans are important, even if there is a facility or community plan in place.

- AHDP and partners should continue to promote the message that there is benefit to completing a written plan, even if a person cannot afford all of the supplies.

- AHDP and partners should continue to promote the message that all Alaskans with disabilities can, and should, participate in emergency planning.

- Internet, email, and other social media networks are heavily used platforms for respondents, and AHDP and partners should continue to utilize them as integral points to disseminate emergency preparedness messages.

- Disability advocate and service organizations should take an active role in encouraging and providing assistance with emergency preparedness plans to Alaskans with disabilities by not only distributing Get Ready! toolkits, but providing hands-on assistance in using the toolkit.

- AHDP should continue ensure disability advocate and service organizations have the materials and support necessary to provide Get Ready! toolkits and assistance using them.

- AHDP should survey care coordinators to find out if or how they are utilizing Get Ready! toolkits to inform future training and dissemination needs.

- AHDP should survey disability advocate and service organizations to find out if or how they are utilizing Get Ready! toolkits to inform future training and dissemination needs.

- AHDP should add separate, individual links to the medication list, summary checklist, and FEMA forms to the AHDP web page to promote their use.

- AHDP should add an evaluation survey tool to the print and electronic version of the Get Ready! toolkit to monitor utilization and inform future program changes. This short survey could obtain basic demographic information (e.g. age, location, living situation, etc.) as well

as how the Get Ready! toolkit has been implemented and any thoughts on changes to the toolkit.

- AHDP should revise the resources section of the Get Ready! toolkit to allow for larger print of outsourced materials, or consider recreating the items in a readable and accessible format.
- AHDP should repeat a follow-up survey similar to the first two surveys in approximately five years. This length of time offers the ability to measure a more accurate level of saturation of the Get Ready! toolkit.
- AHDP should explore modifying any follow-up survey methodology to attempt to obtain a representative sample.

Strengths and Limitations

This research project has several strengths and limitations. It is the second survey of its kind in Alaska, confirming many of the original results. It continues to reinforce the need for additional attention and research in this area by other stakeholders. This report should encourage additional efforts to assess and evaluate preparedness across Alaska and among people with disabilities.

This survey was not a representative sample of Alaskans with disability. A convenience sampling, promoted and conducted through primarily electronic means, may have resulted in sampling bias. Conducted approximately one year after the launch of the Get Ready! toolkit, it was difficult to detect a change in preparedness levels among the target population.

This survey targeted adults with disabilities or adult caregivers of people with disabilities, which created two potential additional limitations. First, youth with disabilities were under-represented in responses. Second, despite clear instructions, caregivers may have responded as themselves, rather than as the person they take care of, potentially creating a proxy bias. There was no one-to-one correspondence between the first survey's respondents and this survey's respondents. This survey population, while similar to the first, may not provide good comparisons where demographics may be different.

Survey responses continue to support that Alaskans are interested in more information about emergency preparedness. Many respondents thanked the researcher for drawing attention to the topic. Many expressed interest in following up to improve their preparedness level. One respondent wisely reminded that emergency preparedness is an ongoing process where it is important to, "always be prepared and adding more to your kit." The information provided by the survey will continue to inform efforts to assist all Alaskans to always be prepared.

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