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Consulting and education to promote full participation of people experiencing disabilities wherever they choose...

# Emergency Preparedness for Alaskans Experiencing Disabilities

June 30, 2013

A Research Report for the Alaska Health and Disability  
Program

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# Executive Summary

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Adult Alaskans experiencing disabilities or their adult caregivers were asked to participate in an anonymous survey to help the Alaska Health and Disability Program establish a baseline measure for emergency preparedness statewide and to gather data to inform the development and dissemination of resources in year two of this Program. The survey included basic demographic questions, queries around preparedness, and the communication and information resources Alaskans with disabilities and their caregivers use most. In addition, it asked questions about motivators and barriers related to emergency preparedness. Over a six-week period, a total of 111 responses were collected using a convenience sample. Results indicate that despite 92% feeling vulnerable to a disaster, less than 20% (18.75%) have a written plan for what to do in a natural disaster or emergency. Slightly more than half (53.95%) have emergency supplies. Emergency preparedness materials need to be easy to find, easy to use, and available in multiple formats and from multiple disability and health-related organizations. Results also indicate that friends, family, and caregivers of Alaskans experiencing disabilities should be included in education and planning efforts.

# Background

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A significant component of the Alaska Health and Disability Program, funded by the Centers for Disease Control and Prevention State Health and Disability grant (FOA DD12-1204: Improving the Health of People with Disabilities Through State-Based Public Health Programs), is improving emergency preparedness for people experiencing disabilities. A keyword search of academic databases indicates that there is somewhat sparse research available that addresses preparedness for people experiencing disabilities or related issues. The studies available for review used widely varying methodologies, and suggested that between 22.3% and 64.3% of people with disabilities have an emergency or disaster plan (Eisenman, D.P. et al, 2006, McClure, L.A. et al, 2011, National Council on Disability, 2009, & Tomio, J., Sato, H., Mizumura, H., 2012). McClure et al reported that 51% of people who rely on a wheelchair require assistance with evacuation from their home, and 26.6% rely on assistive technology during an evacuation (2011). People with disabilities are also less likely to have an emergency kit or supplies (Bethel, J.W., Forman, A.N. & Burke, S.C., 2011, Eisenman, D.P. et al, 2006, & Smith, D.L. & Notaro, S.J., 2009). However, one study suggested that they are more likely to have at least a three day supply of medications available (Bethel, J.W. et al, 2011) as is recommended by federal and state planning initiatives. Some research indicates that people experiencing disabilities are more likely to live in an area at risk for an emergency or disaster (Renne, J.L., Sanchez, T.W., & Litman, T., 2008), but are “...poorly represented in emergency planning” (Fox, M.H., White, G.W., Rooney, C., & Rowland, J.L., 2007). Registry systems to assist with evacuation of people experiencing disabilities may be utilized inappropriately or ineffectively (Renne, J.L. et al, 2008). Natural disasters and emergencies can highlight gaps in support services for people with disabilities who might otherwise function adequately day-to-day, but require additional supports when social and civic services are disrupted (Fox, M.H., White, G.W., Rooney, C. & Cahill, A., 2010).

Previous studies indicate that the perceived benefits of having an emergency plan include confidence, self-reliance, and safety (Newport, J.K., & Jawahar, G.G., 2003). Reasons for not having an emergency plan or kit include financial constraints, a perception that a plan is not needed for safe evacuation, and a long list of needs on which emergency planning falls near the bottom (National Council on Disability, 2009), creating a kind of crisis fatigue. Some studies indicate a lack of immediate or near vulnerability, which may contribute to planning apathy (Tierney, K.J., Lindell, M.K., & Perry, R.W., 2001). Literature indicates that emergency preparedness messages for people with disabilities need to be easy to understand and delivered in multiple methods by people who are viewed as knowledgeable (National Council on Disability, 2009 & Tierney, K.J. et al, 2001). No data was located on specific preparedness needs or experiences of Alaskans experiencing disabilities.

This report is one component of a comprehensive needs assessment for the Alaska Health and Disability Program. Our research results are meant to provide baseline data regarding the number of Alaskans with disabilities who have an emergency plan or kit. It also helps identify new approaches

for developing and disseminating emergency planning resources to Alaskans with disabilities and their caregivers.

# Methodology

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Data was collected using the web-based survey site, SurveyMonkey.com between April 6, 2013 and May 31, 2013 using convenience sampling of adults over age 18 in Alaska with any disability or the adult caregivers of any Alaskan with any disability. Participants were recruited through multiple outreach opportunities with Alaska Health and Disability Program partners and disability stakeholder organizations using email, social media, internet, and meetings.

The opportunity to participate in the survey was promoted at the 2013 Partner Summit organized by the Alaska Health and Disability Program, the University of Alaska-Anchorage Center for Human Development's 2013 Full Lives Conference for Direct Support Professionals, and a variety of other disability-related meetings during the survey period. Email requests to distribute surveys were sent to a variety of state and local organizations including Adult Protective Services and Aging and Disability Resource Centers Units of the Division of Senior and Disabilities Services, Alaska Association of Developmental Disabilities Providers, Alaska Autism Resource Center, Alaska Brain Injury Network, Alaska Care Coordination Network, Alaska Center for Resource Families, Alaska Commission on Aging, Alaska Healthcare Commission, Alaska Mental Health Board, Alaska Mental Health Trust Authority, All Alaska Pediatric Partnership, Anchorage School District Special Education Department, Arc of Anchorage, Cancer Coalition, Division of Behavioral Health, Division of Healthcare Services, Division of Public Health's Breast and Cervical Health Program, Division of Public Health Section of Chronic Disease Prevention, Division of Public Health Section of Emergency Preparedness, Division of Public Health Section of Women's Children and Family Health, Division of Senior and Disabilities Services, Fairbanks Resource Agency, Governor's Council on Disabilities and Special Education, Hope Community Resources, Mat-Su LINKS, Mat-Su Services for Children and Adults, Mental Health Consumer Web, Programs for Infants and Children, Reach Alaska, Special Olympics Alaska, Statewide Independent Living Council, University of Alaska Anchorage Center for Human Development, and University of Alaska Anchorage Master in Public Health Program.

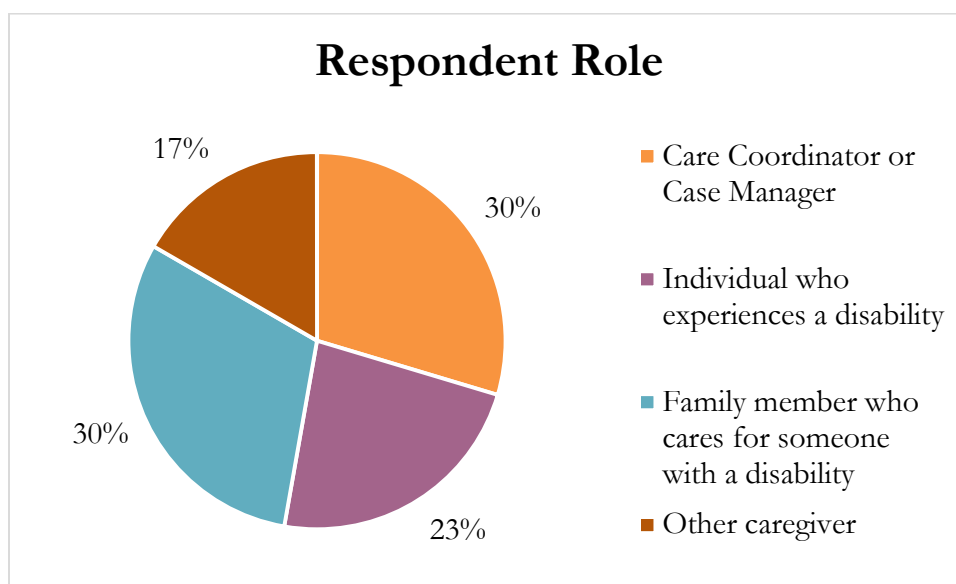
Responses were collected online although respondents were given the opportunity to obtain alternate survey formats, such as paper or telephone. Four PDF survey forms were distributed via email upon request by care coordinators to facilitate distribution to their clients. One paper survey was received by mail for manual input. No requests for telephone survey were received.

Informed consent and study information comprised the introduction page of the survey. The University of Alaska Anchorage Institutional Review Board reviewed the study design and materials, determining it exempt from full Board review and approving its implementation on April 5, 2013 (Project #449267-1). As a thank you for completing the survey, respondents were given the opportunity to enter a drawing for one of two \$50 gift cards to a store of their choice. Drawing entries were not linked to survey responses.

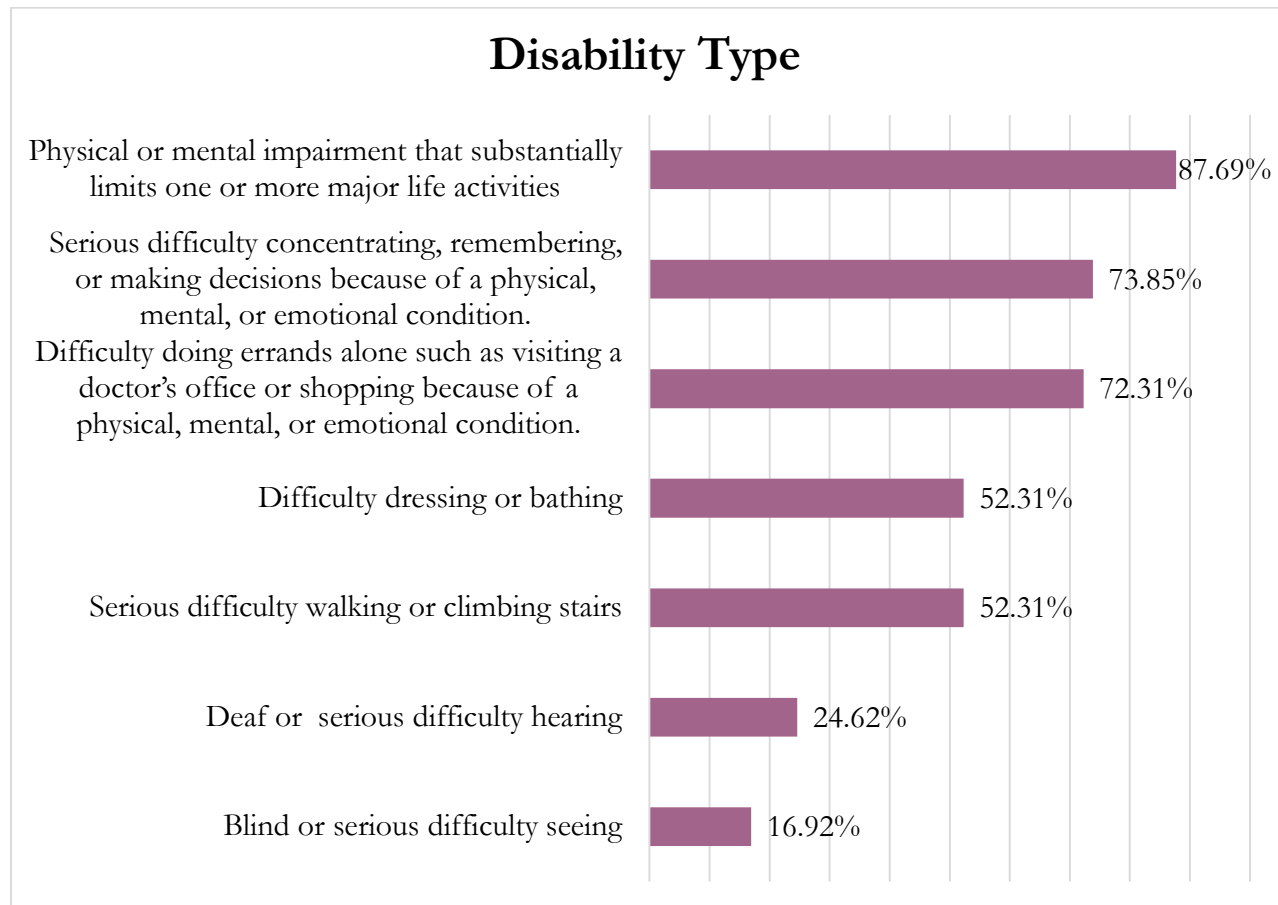
## Demographics

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A total of 111 people responded to the survey, 69 of whom indicated that they experience some disability or are responding on behalf of someone who experiences a disability. The survey invitation stated that people experiencing a disability could have someone help them complete the survey if they chose. Nearly half of all respondents 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 who experiences a disability and should not reflect the proxy's own information or experiences. Twenty-three percent of respondents experience a disability and completed the survey themselves.

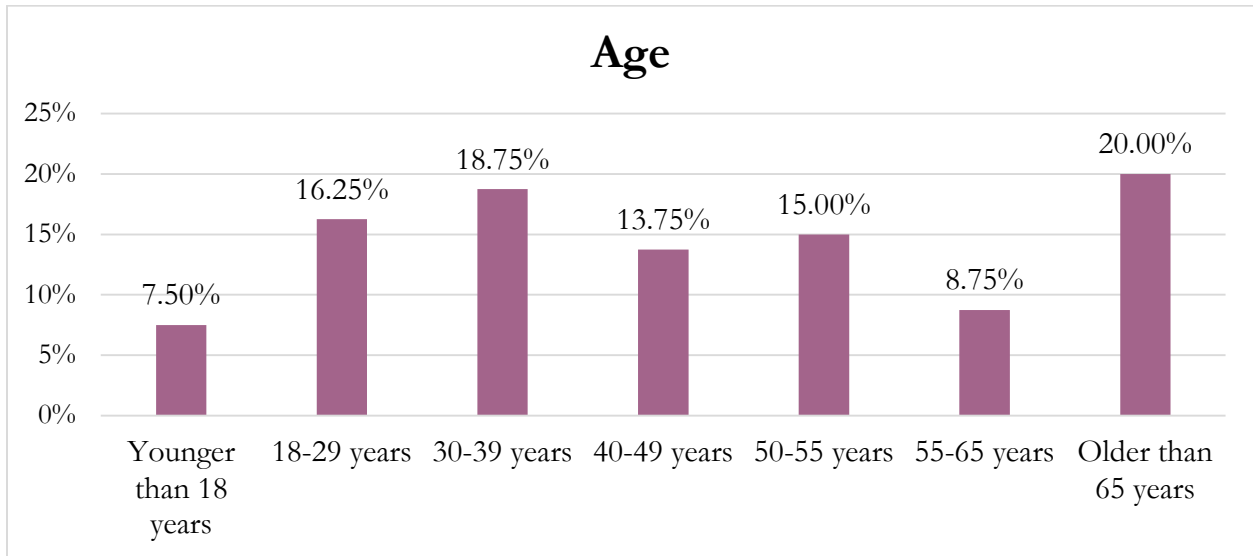


Survey respondents were asked six standard questions used in the American Community Survey to identify disability, as well as one question based on the Americans with Disabilities Act definition of disability. More than 81% of those with disabilities reported multiple disabilities. Almost two-thirds of those surveyed reported a physical disability, and more than one-third reported a sensory disability. The most common single disability reported was difficulty concentrating, remembering, or making decisions.

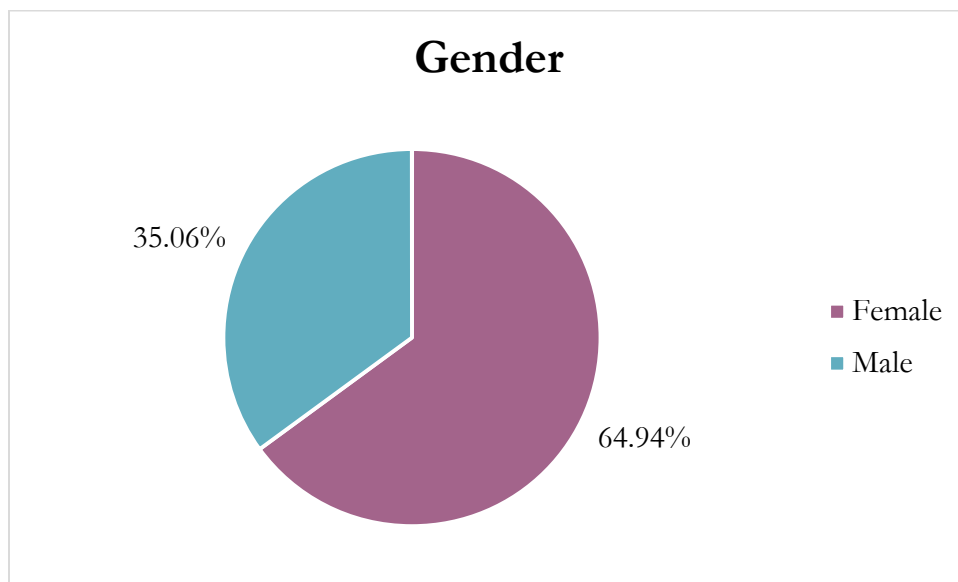




The age of those responding to the survey was generally evenly distributed, although not representative of the population in Alaska, either with or without a disability. Survey results are over-representative of those older than 65 years and under-representative of those younger than 18 years. Responses for children younger than 18 years were completed by an adult.

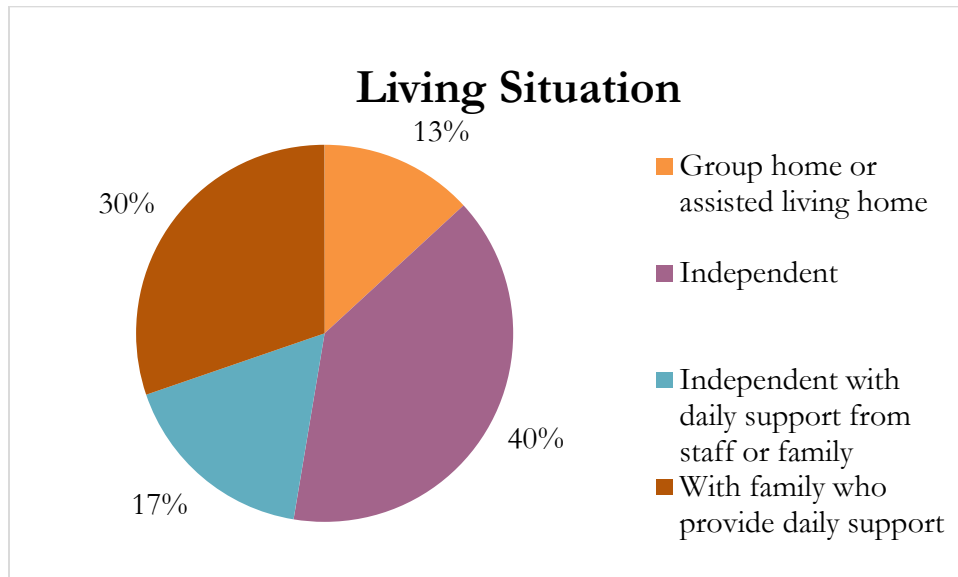


While approximately 45% of Alaskans who experience disabilities are female, women were more likely to respond to this survey.



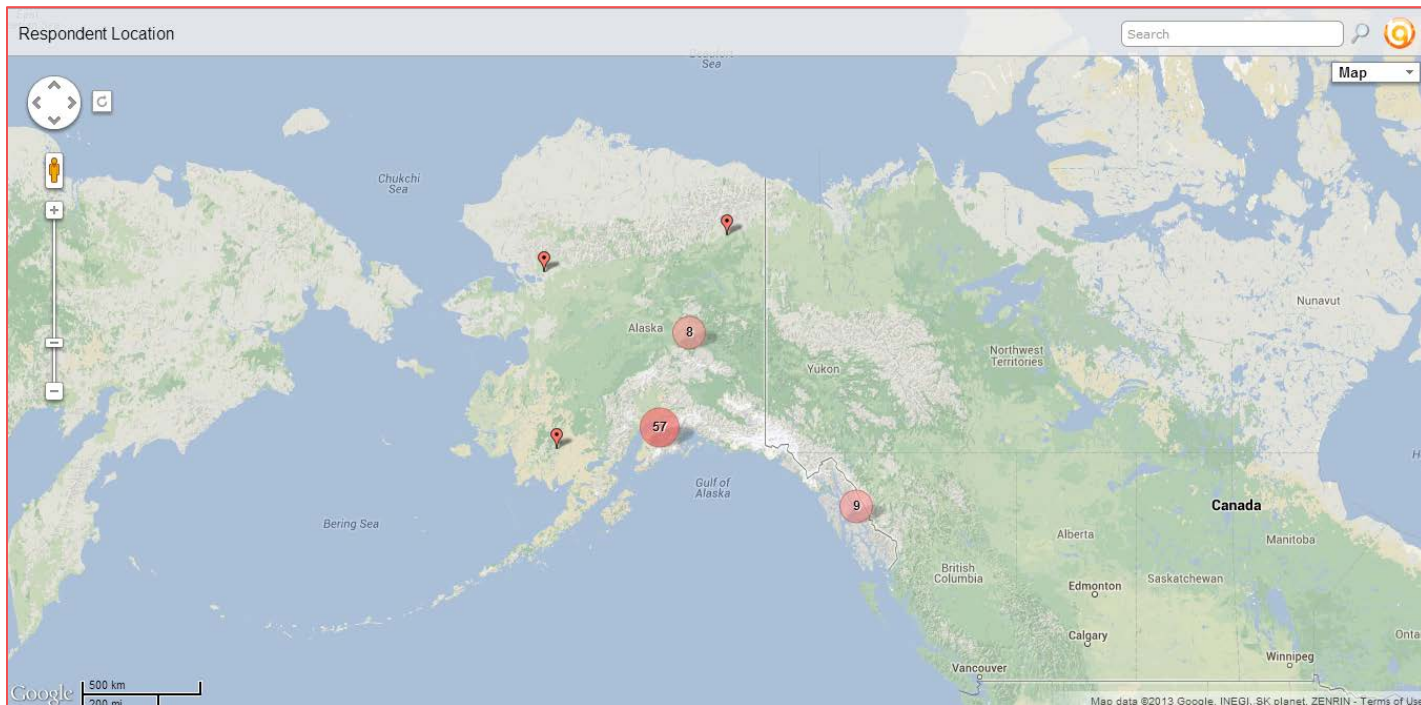
Most of those responding to the survey described their living situation as independent or partially independent with daily support from staff or family. No respondents reported living in a nursing home or skilled nursing facility.

Thirteen percent live in group homes or assisted living homes that are licensed by the State of Alaska and whose regulations require some level of emergency planning. Subsequent survey answers indicate that many group home and assisted living home residents and their caregivers are unaware that those emergency plans exist, or what they contain.



Survey responders, asked to provide their zip code, indicated that they live in 22 communities throughout the state. Consistent with state population centers, respondents were primarily located in south-central Alaska. Resident communities include Anchorage (31%), Chugiak (4%), Dillingham (1%), Douglas (3%), Eagle River (4%), Fairbanks (8%), Fort Yukon (1%), Haines (1%), Homer (4%), Juneau (4%), Kenai (3%), Ketchikan (3%), Moose Pass (1%), North Pole (1%), Palmer (5%), Petersburg (1%), Selawik (1%), Seward (3%), Soldotna (6%), Tok (1%), Wasilla (12%), and Willow (1%).

## Respondent Location

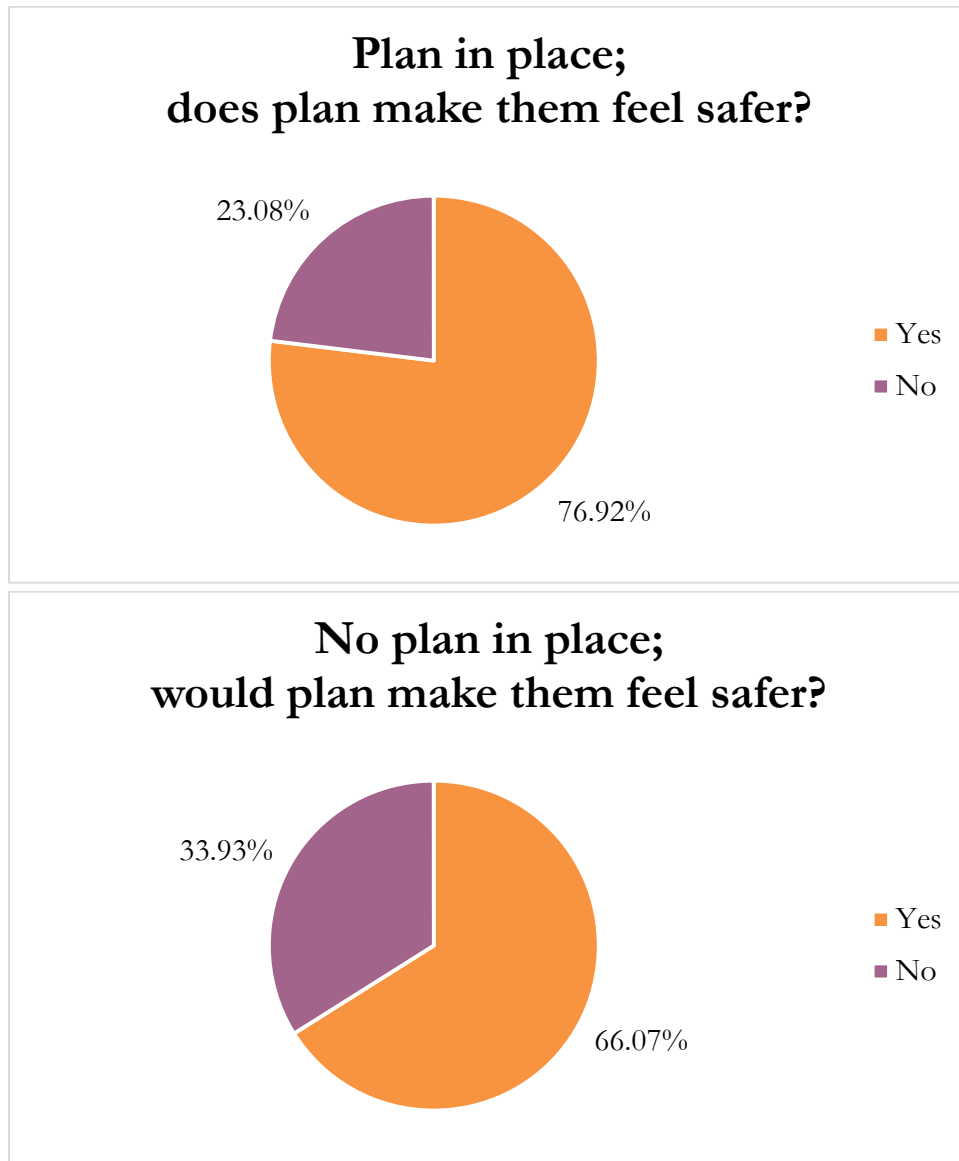


Mapping of respondent data by BatchGeo, LLC

Respondents were asked a variety of questions related to their 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.

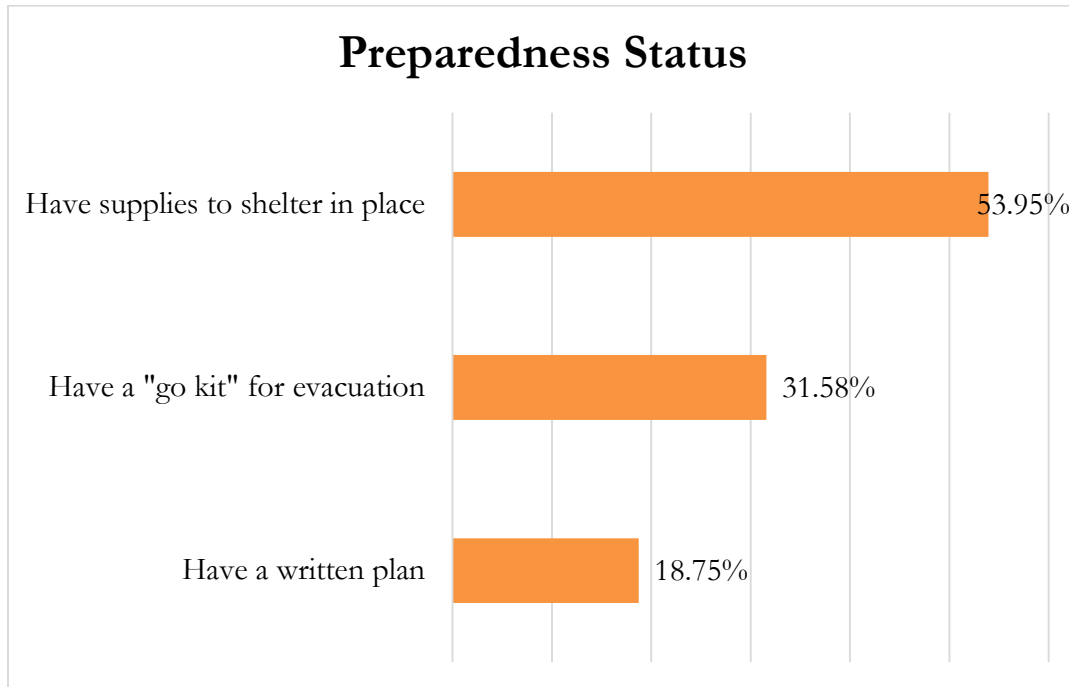
## Vulnerability

More than 92% of respondents indicated that they felt like a natural disaster or emergency could happen to them. Most respondents (76.92% and 66.07%, 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). The proportion of those who feel safer is higher if they already have a written plan.



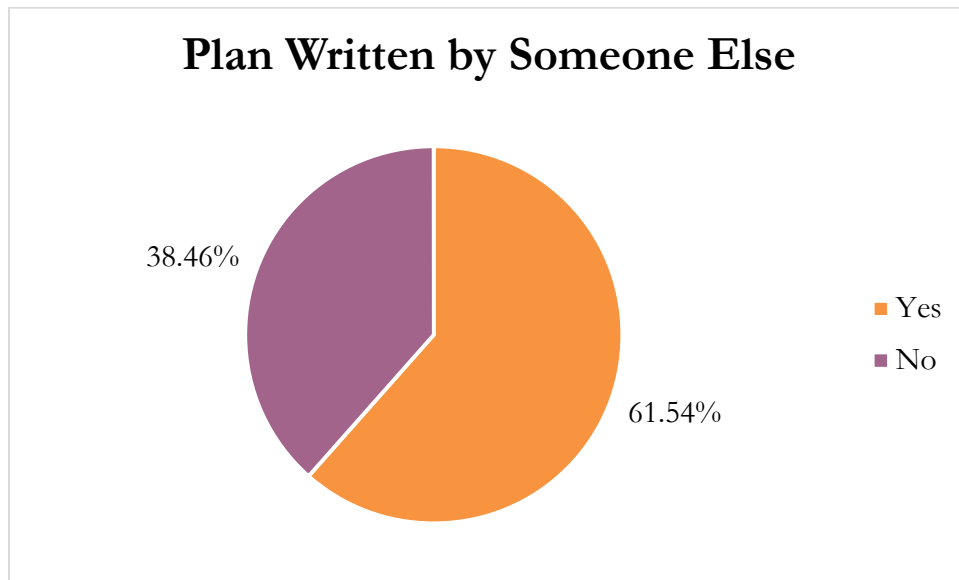
## Level of Preparedness

Although 92% 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 (18.75%) of respondents have a written plan for what to do in a natural disaster or emergency. Respondents are 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.

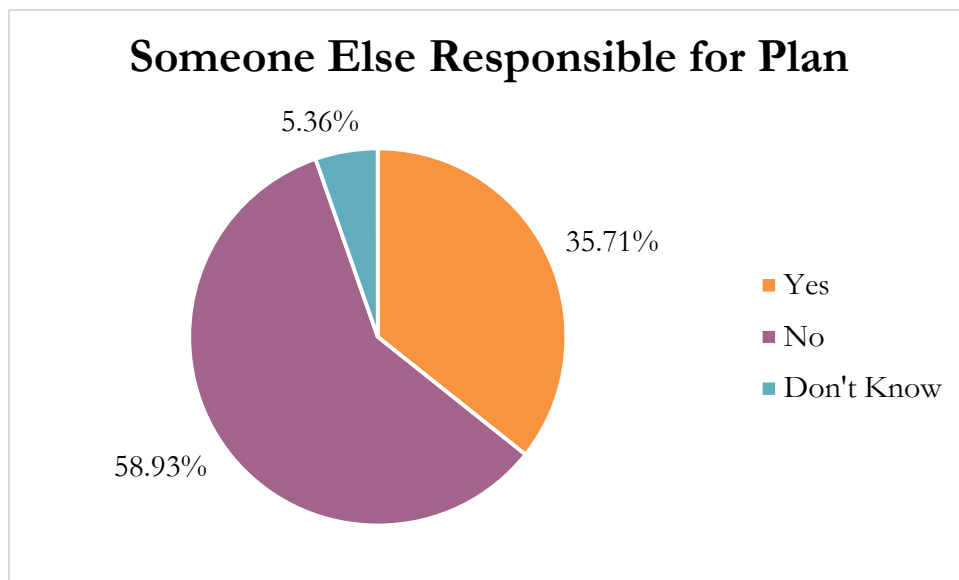


One third of those with a “go kit” also have a written plan. Slightly less, or 26.83%, of those who have shelter-in-place emergency supplies also have a written plan. More than half (58.57%) of those who feel like a disaster could happen to them also have either a “go kit” or shelter-in-place supplies. When looking only at respondents who feel like a disaster could happen to them, still only 20% have a written plan.

Most of the reported emergency plans were written by someone else, including a parent, care coordinator, tribal council, and local government.



Of those with no written emergency plan, most reported it was not someone else's responsibility to write one. Of those who did identify someone responsible for writing a plan, most cited a parent, guardian, or immediate family member. Two incorrectly identified their care coordinator as responsible for writing their emergency plan. While care coordinators are responsible for writing annual plans of care that contain components of emergency planning, they are not mandated to write emergency plans for their clients.



## Motivators

The survey asked several questions to explore the motivators and barriers involved in writing an emergency plan. Respondents were asked to identify what the benefits to having a written emergency plan are, or could be, both for themselves and for other people in their lives. Responses were analyzed by clustering similar themes together. Overall, the potential for continuity of care was most important to respondents, mentioned 29 times. Respondents wanted to know that their needs would continue to be met without disruption despite a natural disaster or emergency. Knowledge, including what to do and where to go, was also cited as extremely important, especially for those that already have a plan. One respondent wrote, “I know what to do and my village will help me.” Feeling safe and feeling ready were also particularly important to those who already had a written plan. This response is consistent with the previous response by those with a plan, indicating the plan made them safer. Eight respondents that do not have a written plan stated they did not know of a benefit to having a plan. An additional eight respondents specifically stated that there was no benefit to having a written plan. Interestingly, several mentioned that the process of completing the survey or writing a plan would encourage them to reflect on their readiness for an emergency, which they considered a benefit.

Benefits of Having a Plan	Respondents with Plan			Respondents without a Plan			Total
	<i>For Self</i>	<i>For Others</i>	<i>Sub Total</i>	<i>For Self</i>	<i>For Others</i>	<i>Sub Total</i>	
Continuity of care	2	1	3	16	10	26	29
Know what to do	3	1	4	8	8	16	20
Know where to go	1	1	1	6	9	15	16
Feel ready/organized	2	1	3	6	7	13	16
Feel safe/alleviate fear	1	2	3	7	4	11	14
Don't know	0	0	0	4	4	8	8
None	0	0	0	5	3	8	8
Avoid chaos	0	0	0	5	2	7	7
Reflect on readiness	1	0	1	2	0	2	3
Know where to find supplies/equipment	1	0	1	1	0	1	2
Know who will help	1	0	1	0	0	0	1
Comply with rules or regulations	1	0	1	0	0	0	1
Encourage community engagement	0	1	1	0	0	0	1

Respondents were asked to identify resources or help that are, or would be, important to write a plan. The responses to this open-ended question mirrored some of the other questions related to motivators, barriers, and information sources. The internet is clearly an important resource to respondents. Hands-on assistance in writing a plan as well as access to information about planning for emergencies that could be individualized based on a person’s needs was also cited as extremely important. One person stated they “wouldn’t know where to start.”

<b>Important Resources for Writing a Plan</b>	<b>Reported Frequency</b>
Internet	9
Hands-on Assistance	8
Training or information, especially individualized and Alaskanized	8
List of supplies; where to get low-cost, easy to obtain supplies; financial assistance resources for supplies	6
Family	5
Template or checklist of steps	5
Completed example	4
Care providers	3
Book	1
Previous experience with disasters	1
FEMA	1
Local government	1
Primary care physician	1
Red Cross	1
State of Alaska	1
Time	1

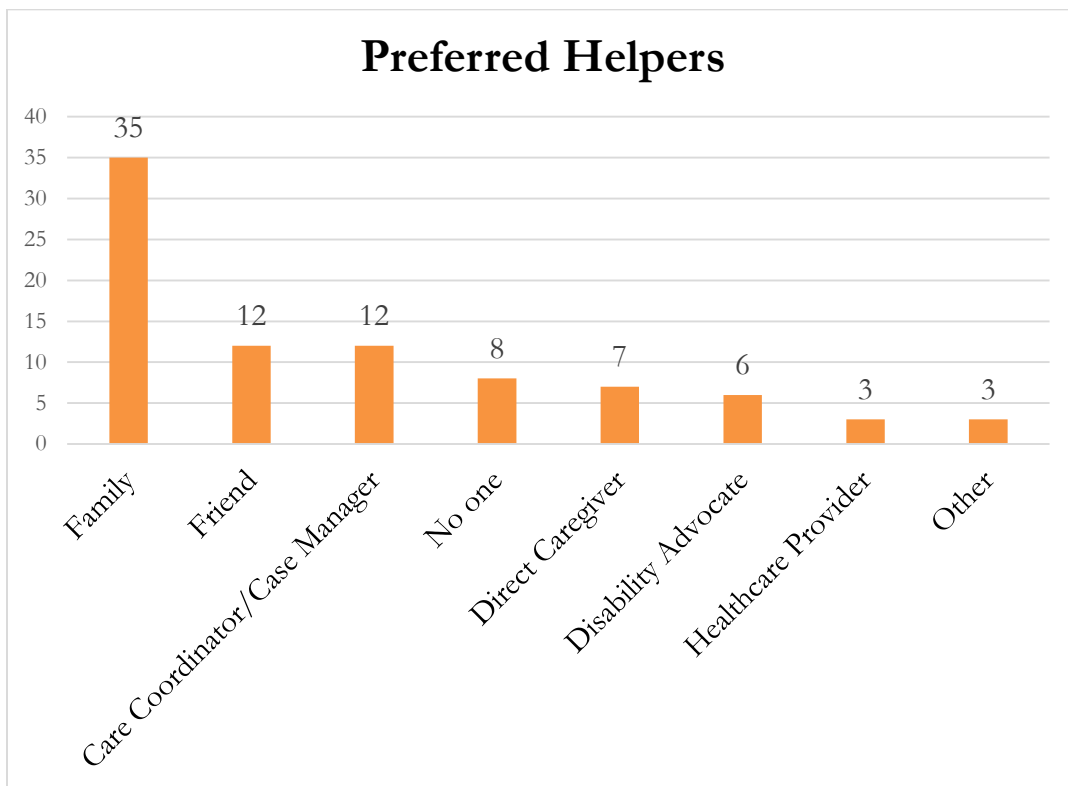


Respondents who did not already have a plan were asked what would encourage them to write a plan. The purpose of this question was to find out if writing a plan was resource-dependent, or if there were other factors that would encourage a person to write a plan. While other factors play a role in whether a person writes a plan, availability of resources is clearly important. As with the most frequently mentioned resource, the most frequently occurring theme in this question was a desire for hands-on assistance in writing a plan. Having a template available to use and feeling like a disaster could happen to them were also important themes for respondents. One person talked about how the experience of being without power for four days inspired them to plan. Another talked about being aware that many communities “only have enough food in the stores for four to five days if something stopped shipping carriers.”

<b>Encouragement to Write a Plan</b>	<b>Reported Frequency</b>
Hands-on Assistance	9
Template or example	6
Vulnerability to disaster	5
Awareness of the need	4
Instructions or a checklist of steps	4
Easy to find information	2
Internet	2
The thought of being without caregiver	2
Training	2
A need to communicate or coordinate family	2
Ability to shift priorities to make “room” for planning	1
Brochure	1
Encouragement	1
FEMA tools	1
Mandate	1
Money	1
Problem-solving	1
Schedule time	1
Supplies	1

In addition to what people feel they need in order to write a plan, respondents were asked who they would like to help them. Friends and family were the most frequently cited, mentioned 35 and 12 times respectively. Healthcare providers were not an important source of assistance, only mentioned three times.

Interestingly, eight people said they did not want anyone to help them write a plan. None of these individuals currently have a plan. All of them feel like a disaster or emergency could happen to them, although only half of them felt like having a plan would make them safer. Three thought they could write a plan with assistance, and only two could identify possible benefits of having a plan.



## Barriers

The survey asked what has made writing a plan difficult or impossible to do. The most frequently cited reason was a lack of time. There also appeared to be a general lack of knowledge related to awareness of the need to plan, how to go about writing a plan, or that writing a plan was possible in light of financial restraints. As one respondent stated, “I have to [sic] many things that I need to keep track of on any given day, throwing one more think [sic] into the mix is crazy!” Several providers responding indicated that they had difficulty getting all the people and family members involved with a person with a disability to come together or agree on emergency planning, creating a significant communication barrier. A couple of caregivers stated that people were too severely disabled for a plan to be useful, or for the person with the disability to participate in planning. This is concerning because it goes against the strongly held belief in disability culture – “Nothing about me, without me.”

While not knowing how to write a plan was cited four times by respondents, in a separate question, 58.15% indicated that they do not know what to put in a written plan or where to find out. Of those who do have a written plan, 53.84% said keeping it up to date is a challenge if their life or personal needs change.

<b>Reason Writing a Plan is Difficult or Impossible</b>	<b>Reported Frequency</b>
Lack of time	11
Nothing	8
Did not think about it	6
Do not have financial resources	4
Do not know how to do it	4
Too many other things have priority	4
Communication difficulties between interested parties	3
No need for a plan	3
Ability to participate due to disability	2
Need help from someone	1
Don't know	1
Do not want to think about it	1

## Information and Communication

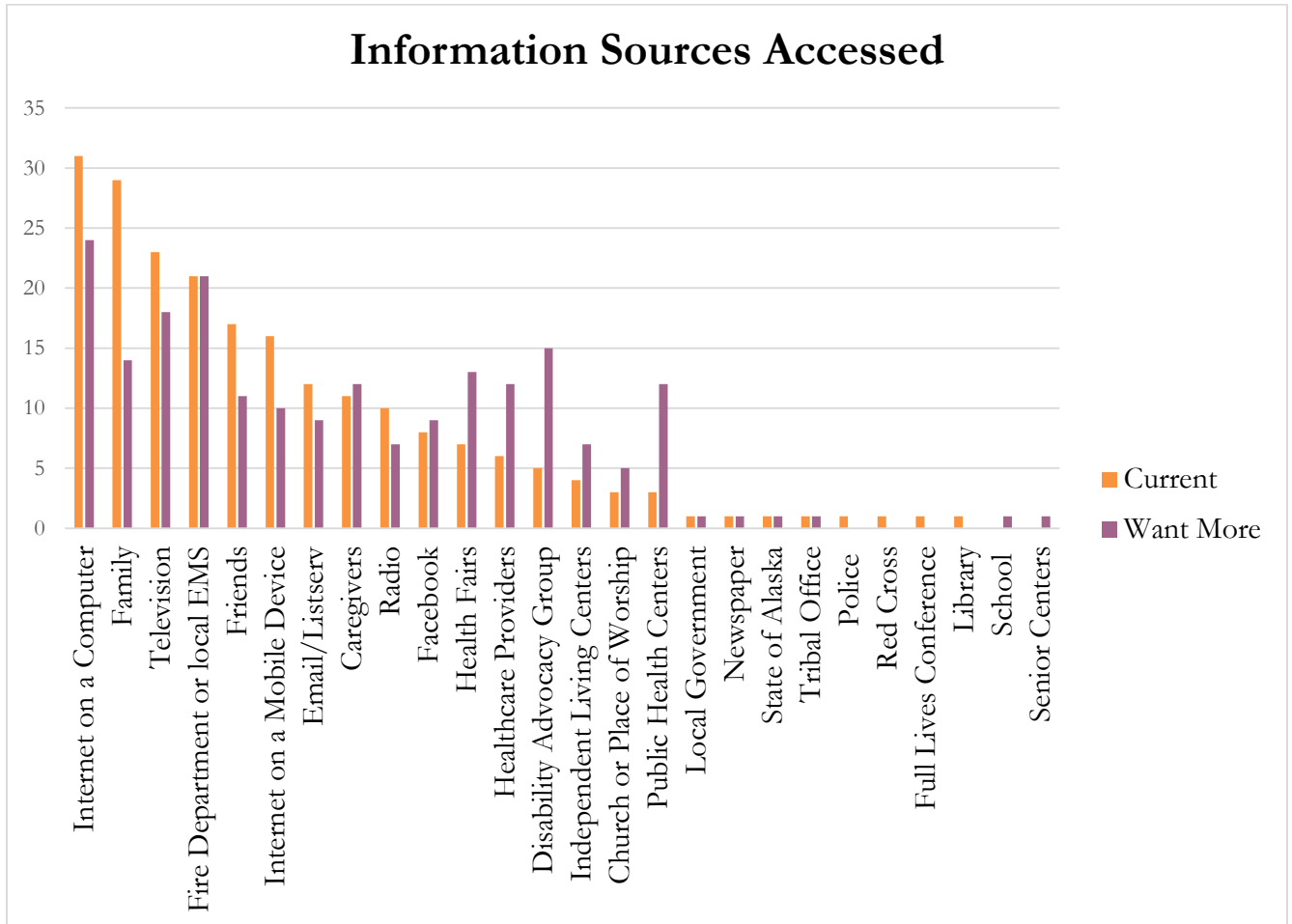
In addition to determining the level of preparedness and the motivators and barriers associated with emergency preparedness for Alaskans experiencing disabilities, the survey also asked questions about where respondents get information and what resources they use, both to get information about emergency preparedness and more generally. Survey respondents were given a list of potential information sources and were asked to select all the places that they currently get information about emergency preparedness. They were allowed to add any additional sources that were not listed. The most frequently cited resource was the internet using a computer, followed by family and television. Resources that are available and accessible on a daily basis are delivering more information than those that require transportation. Twitter appears to be unimportant as a source.

<b>Information Source</b>	<b>Currently Access</b>
Internet on a Computer	31
Family	29
Television	23
Fire Department or local EMS	21
Friends	17
Internet on a Mobile Device	16
Email/Listserv	12
Caregivers	11
Radio	10
Facebook	8
Health Fairs	7
Healthcare Providers	6
Disability Advocacy Group	5
Independent Living Centers	4
Church or Place of Worship	3
Public Health Centers	3
Local Government	1
Newspaper	1
State of Alaska	1
Tribal Office	1
Police	1
Red Cross	1
Full Lives Conference	1
Library	1

The survey then asked where they wanted to get more information about emergency preparedness. Again, internet (accessed through a computer) was the most frequently cited resource for more information. The Fire Department or Local EMS was also frequently selected, consistent with literature suggesting credible sources are important. Respondents also want more information from disability advocacy groups.

<b>Want More Information From</b>	<b>Frequency</b>
Internet on a Computer	24
Fire Department or Local EMS	21
Television	18
Disability Advocacy Groups	15
Family	14
Health Fairs	13
Caregivers	12
Healthcare Provider	12
Public Health Centers	12
Friends	11
Internet on a Mobile Device	10
Email/Listservs	9
Facebook	9
Independent Living Centers	7
Radio	7
Church or Place of Worship	5
Local Government	1
Newspapers	1
School	1
Senior and Disabilities Services	1
Senior Centers	1
Tribal Health Organization	1
Twitter	0

In comparing the sources they currently access with those respondents would like more information from, there appears to be a desire for more information about emergency preparedness from health fairs, healthcare providers, disability advocacy groups and public health centers. While obtaining information from family and friends is important, there does not appear to be a desire for substantially more information from those two sources.



Survey respondents were then asked about the frequency that they generally use certain resources. Electronic resources, such as email, internet, and social media are very frequently utilized with the exception of Twitter. Health fairs are the least frequently utilized resource, although the previous question seems to indicate a desire/interest in that resource.

<b>General Use of Information Resources</b>					
	<b>At least once a day</b>	<b>About once a week</b>	<b>About once a month</b>	<b>Never</b>	<b>Weighted Ranking</b>
<b>Email</b>	<b>57.8% (37)</b>	4.7% (3)	10.9% (7)	26.6% (17)	64
<b>Internet on a computer</b>	<b>66.7% (42)</b>	9.5% (6)	6.3% (4)	17.5% (11)	63
<b>Facebook</b>	<b>42.9% (27)</b>	14.3% (9)	7.9% (5)	34.9% (22)	63
<b>Independent Living Center</b>	6.5% (4)	9.7% (6)	4.8% (3)	<b>79.0% (49)</b>	62
<b>Internet on a mobile device</b>	<b>41.7% (25)</b>	8.3% (5)	8.3% (5)	<b>41.7% (25)</b>	60
<b>Public Health Center</b>	0.0% (0)	1.8% (1)	15.8% (9)	<b>82.5% (47)</b>	57
<b>Twitter</b>	3.6% (2)	3.6% (2)	5.5% (3)	<b>87.3% (48)</b>	55
<b>Health Fair</b>	0.0% (0)	0.0% (0)	14.8% (8)	<b>85.2% (46)</b>	54

# Analysis and Recommendations

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These results provide valuable information about the importance of promoting emergency preparedness to Alaskans experiencing disabilities. They also confirm the need for additional research. These results can be used to inform decisions about what information is distributed, how it is distributed, and to whom. They also provide a baseline from which to measure the Alaska Health and Disability Program's outreach and successes. Although the survey is not a representative sample, a wide variety of Alaskans – from different areas of the State and who experience different kinds of disabilities -- responded to it. Although some national surveys indicate that 46% of Americans, regardless of disability, have an emergency plan (Federal Signal Safety and Security Systems/Alerting & Notification, 2010), just 18.75% of surveyed Alaskans who experience disabilities indicated the same.

While physical and sensory disabilities were certainly present among our respondents and require the attention of emergency managers both in planning and education efforts, the most common disabilities among our respondents were related to 1) decision-making and 2) the ability to independently complete tasks outside the home. These are precisely the skills required to effectively respond to an emergency, especially during an evacuation. Ensuring that materials and education curriculum are universally designed to address many cognitive levels will support understanding and compliance with planning efforts for all Alaskans. Encouraging disability representation within local emergency planning committees will encourage emergency managers to improve integration of the needs of people with disabilities into guidelines, policies, and surveillance methods as well as encourage strength-based self-determination for Alaskans with disabilities.

Most respondents live independently. Survey respondents indicate that they often rely on others for assistance. This reliance may increase in times of stress or when routines are disrupted, both of which are likely to occur during a disaster or emergency. Including those supports - both family caregivers and paid caregivers - in emergency preparedness education campaigns is vital. Emphasizing that individualized plans are important, even if there is a facility plan in place may reduce confusion of those residing in licensed homes like assisted living homes or group homes.

There are few demographic differences among respondents who have a plan and those who do not. One exception is that those who have a written plan are more likely to live outside of Anchorage. This may indicate that individuals in smaller communities have developed personal support networks that would encourage and participate in planning, or because those individuals consider planning a part of general self-reliance strategies. No follow-up questions were included in this survey to address this possibility.

Survey creators initially assumed that respondents would be more likely to have a plan than to keep emergency supplies on hand. We assumed this because writing a plan for emergencies is



considerably cheaper than purchasing supplies. Our results, however, were somewhat contradictory. Interestingly, several mentioned cost as a barrier to writing a plan. A woman who lives independently said, “Financially I don't have the money for all the supplies I would need. So why write the plan when I don't have everything I need to implement that plan?” Moving forward, it will be important to emphasize that “something is better than nothing” with regards to planning. There is benefit to completing a written plan, even if a person cannot afford all of the supplies.

In addition to not planning due to limited funds, several caregivers questioned the need for a plan if the person experiences severe memory or behavior impairments. For someone who experiences dementia, some respondents indicated that they would “forget where it is when needed.” Two caregivers stated that the inability to read rendered a written plan ineffective. Education materials should make clear that a written plan is important, even for individuals with cognitive, memory, or communication complications, so that others can assist and ensure their needs are met in spite of a disaster or emergency.

Addressing respondents' perceived lack of time to plan is also important for program planners. While respondents feel vulnerable to disaster, a possible future disaster loses priority against the very real day-to-day challenges Alaskans experiencing disabilities face. Making planning easy with templates and suggestions in easy-to-find and accessible formats may mitigate some of the time concerns our respondents noted. Acknowledging respondents' potential lack of a plan - whether from apathy, crisis fatigue, or knowledge deficit - will require realistic materials and education that address caregivers as well as Alaskans experiencing disabilities.

Survey responses indicate that there are several things that can be done to improve dissemination of materials and ensure planning is implemented across Alaska. Internet, email, and other social media networks are heavily used platforms for our respondents. People with disabilities also state that they rely on, and want assistance from, family, friends, and various caregivers. Materials and education need to target not only Alaskans experiencing disabilities, but their caregivers, as well. Disability and health organizations need to take an active role in encouraging and providing assistance with emergency preparedness plans to Alaskans experiencing disabilities. The Alaska Health and Disability Program can ensure those organizations have the materials and support necessary to provide that assistance.

This research project has several strengths and limitations. It is the first attempt to establish a baseline, and as such, makes clear 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 experiencing disabilities. While respondents indicated they were more likely to have emergency supplies than a written plan, subsequent questions also indicated a lack of complete understanding of supply specifics. Respondents may have over-estimated their preparedness with respect to emergency supplies.

This survey was not a representative sample of Alaskans experiencing disability, thereby limiting its generalizability. We used a convenience sample and promoted and conducted this survey through primarily electronic means. Therefore, there may be sampling bias. This survey targeted adults experiencing disabilities or adult caregivers of people with disabilities which created two additional problems. Youth experiencing 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. Future research should consider a more representative sample that addresses these limitations.

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