

**Promotion, Prevention, and Preparedness for Alaskans with  
Disabilities: Alaska's Disability & Health Program**

**Needs Assessment Report**

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## **Executive Summary**

In 2012, the State of Alaska Division of Public Health was awarded a Centers for Disease Control and Prevention (CDC) State Disability and Health Program grant to “promote equity in health, prevent chronic disease, and increase quality of life for people with disabilities” (CDC, State Disability and Health Programs, 2012). Alaska’s Health & Disability Program is a collaborative effort between the State of Alaska’s Section of Women’s, Children’s and Family Health, and the Governor’s Council on Disabilities and Special Education. The program aims to improve health across the lifespan of Alaskans experiencing disabilities.

The University of Alaska Anchorage (UAA) Center for Human Development (CHD) was contracted by the State of Alaska Division of Public Health to conduct a needs assessment regarding the health status of individuals with disabilities in Alaska for this program. The needs assessment consisted of four activities: 1) root cause analysis, 2) survey of health care providers, 3) survey of agency and support staff, and 4) focus group interviews with individuals with disabilities and family members. Data collected from the needs assessment activities will inform the Division of Public Health about health care services in Alaska to develop training and outreach activities to improve health across the lifespan of Alaskans experiencing disability.

### **Root Cause Analysis**

A root cause analysis (RCA) was used to gather information regarding health disparities, current practices, and barriers related to health care for people with disabilities in Alaska. Data was collected from health care providers, agency support staff, and family members of people with disabilities to inform the development of the survey questions and focus group guide for the subsequent needs assessment activities. Due to a lower than anticipated response rate, a literature review was conducted to identify additional topics not detected by the RCA. Key findings from the RCA and the literature review included: communication differences between providers and patients with disabilities; difficulty accessing health care services due to structural, financial, and personal barriers; lack of providers; limited support staff; varying comfort levels of health care providers; lack of person-centered services; and treatment for primary diagnosis only.

The information collected during the RCA interviews helped to provide a contextual framework for the survey and focus group questions. While the RCA provided critical insight as to why people with disabilities experience health disparities, the addition of the literature review improved and expanded the questions developed for the surveys and focus groups. Together the RCA and literature review provided a comprehensive foundation to draw from when developing the health care provider survey, agency and support staff survey, and focus group guide.

### **Health Care Provider Survey**

The health care provider survey gathered information from health care providers in Alaska about their experiences with health care services for people with disabilities. One hundred thirteen (113) health care providers completed the survey. The majority of respondents (82.3%) were physicians and most providers (83%) practiced in urban locations. The two most common areas of practice were specialty care (36.7%) and family practice (27.5%).

Key findings from the survey concluded that overall, health care providers in Alaska are comfortable working with people with disabilities. On average, they spent significantly more

time, nearly 40% more, with patients who experience disabilities than with patients without disabilities. Health care providers who received disability related trainings were more aware of the importance of accommodations and have made them available to their patients. When making health care decisions with patients, providers indicated they consulted with the individual over 90% of the time. However, there were a substantially lower percentage of providers who consulted with individuals who experienced memory or cognitive and developmental disabilities. Most health care providers, save those practicing in a specialty care setting, were interested in receiving disability related training. The most requested areas of training included legal requirements of the ADA, how to use TTY or Alaska Relay Service, disability specific training, and effective communication with people with disabilities.

### **Agency and Support Staff Survey**

The agency and support staff survey solicited information from staff about their experiences with health care services for people with disabilities. Agency and support staff in Alaska completed a total of 177 surveys. The most common respondents were administrators (23.1%) and direct service workers (22.5%). Respondents represented both urban (64.1%) and rural (35.9%) locations in Alaska and the majority (50.5%) of their time was spent working with adults.

Key findings from the survey found the size and diversity of support staff's caseload influenced their ability to attend health care appointments with their clients. Support staff who always attended health care appointments with patients with disabilities reported health care providers were more comfortable with their clients and spent significantly more time with providers during appointments than staff who sometimes or never attended appointments. Support staff who never attended health care appointments reported a greater number of barriers experienced by those they support in accessing health care services. Support staff in urban locations reported more difficulty in finding providers and services, reluctance of health care providers to serve people with disabilities, and a limited number of providers. Over half of the support staff who attended health care appointments with clients had not received training related to their role. Agency and support staff play a critical role in access to health care services for people with disabilities.

### **Focus Group Interviews**

The focus group interviews gathered information from individuals with disabilities and family members of people with disabilities about their experiences with health care services in Alaska. Focus groups were conducted in nine Alaskan communities representing a combination of urban and rural locations. Focus group interviews were held separately for individuals with disabilities and family members. A total of 19 focus groups were conducted. A total of 43 people participated in focus group interviews. Of the 43, 25 were individuals with disabilities (58.1%) and 18 were family members (41.9%).

Based upon the analysis of the focus group interviews, six key findings emerged from the data:

1. Public insurance plays a critical role for people with disabilities to attain health care services.
2. People with disabilities experience delays in the health care system which impact care.
3. People with disabilities have limited access to health care providers.
4. Behavioral health services are limited for people with disabilities in Alaska.

5. Inadequate health care options cause people with disabilities to seek services outside of their community.
6. People with disabilities and complex medical needs benefit from a coordinated, team approach when obtaining health care services.

The six key findings from focus group interviews overlap one another and add to the complexity of obtaining health care services for individuals with disabilities. The focus group interviews found that for some, their health care needs are being met at this time and they have been able to access services they need. However, the larger portion of the focus group participants reported challenges to accessing health care in Alaska.

### **Conclusion**

Given the overall findings of this needs assessment, there is much work to be done in Alaska to address health disparities for people with disabilities. It is imperative to have people with disabilities, families, disability stakeholders, health care providers, public and private health insurance representatives, State government, and other health care stakeholders working together to reduce the gaps in and barriers to accessing services by developing a statewide action plan. By working together as a health care system, improvement in the health outcomes of Alaskans with disabilities can be achieved.

## **Health Disparities Needs Assessment Report**

Over a quarter (26.9%) of Alaska's population over the age of 18 experience a disability (BRFSS, 2011). These individuals with disabilities face significant disparities compared to peers without disabilities in many core health indicators such as higher body mass index, limited physical activity, increased diabetes, increased asthma, increased heart disease, inability to seek health care due to cost, increased depression, and poor mental health. In 2012, the State of Alaska Division of Public Health was awarded a Centers for Disease Control and Prevention (CDC) State Disability and Health Program grant to "promote equity in health, prevent chronic disease, and increase quality of life for people with disabilities" (CDC, State Disability and Health Programs, 2012). Alaska's Disability & Health Program is a collaborative effort between the State of Alaska's Section of Women's, Children's and Family Health, and the Governor's Council on Disabilities and Special Education. The program aims to improve health across the lifespan of Alaskans experiencing disabilities.

One of the program goals was to conduct a statewide needs assessment regarding the health status of individuals with disabilities in Alaska. The University of Alaska Anchorage (UAA) Center for Human Development (CHD) was contracted by the State of Alaska Division of Public Health to conduct the needs assessment for this program. Established data sources regarding people with disabilities and health disparities, such as the BRFSS dataset, provide insight to incidence and prevalence data. However, there is limited information about the experience of people with disabilities and health disparities. The needs assessment gathered information on the health care system and access to health care services for people with disabilities to gain a better understanding of their experiences. The needs assessment consisted of four activities:

1. Root cause analysis,
2. Survey of health care providers,
3. Survey of agency and support staff, and
4. Focus group interviews with individuals with disabilities and family members.

Data collected in the needs assessment activities will inform the Division of Public Health about health care services in Alaska to develop training and outreach activities to improve health across the lifespan of Alaskans experiencing disability.

## **Root Cause Analysis**

### **Method**

Root cause analysis (RCA) is a method to examine the underlying causes of an event as a way to better understand why it has happened (Rooney & Vanden-Heuvel, 2004). For the purpose of the health disparities needs assessment, the RCA gathered information regarding health disparities, current health-related practices, and barriers associated to health programs for people with disabilities. RCA data was collected during interviews with health care providers, agency support staff, and family members of people with disabilities. The central statement for the 30-minute interview was "People with disabilities experience health disparities." Those interviewed were then asked "Why?" As respondents answer why to the central statement, the

interviewer continues to examine the line of thought by asking “Why,” ultimately revealing the “root cause.” Results of this RCA identified topics and content areas to develop questions for the subsequent needs assessment activities (i.e., the surveys and focus groups).

Although not in the original proposal, a literature review was conducted to detect additional topics and content areas for the development of survey and focus group questions. First, a search was conducted through the EBSCO and PubMed databases using the terms *health disparities, disability, health care, access, and barrier*. Articles were limited to studies in the United States, published after 2000, not specific to a disability category (e.g., autism, down syndrome, etc.), and that used survey or focus group methodologies. Next, a handful of published state needs assessment reports about health disparities and disability were reviewed. Reports were supplied by the program manager and identified through a Google search using the terms *health care, access, disability, and needs assessment*. Lastly, a search for existing survey questions of health care providers was conducted through Google using the key words *health care provider, disability, and survey*.

## **Results**

### ***Root Cause Analysis***

Invitations to participate in RCA interviews were distributed to known contacts by CHD, the Program Manager, and the Alaska Health & Disability Program Committee. The goal was to conduct between six and eight RCA interviews. A total of four RCA interviews were completed. Participants of the RCA interviews included health care providers (2), support staff (1), and family members (1). Key topics discussed during the RCA interviews included:

- Communication differences between people with disabilities and health care providers,
- Varying levels of comfort among health care providers,
- Lack of providers,
- Lack of general practitioner knowledge,
- Treatment for primary disability diagnosis only,
- Lack of access to health care services,
- Lack of support staff to assist with health care needs,
- Family role and considerations for people with disabilities,
- Reluctance to seek health care services, and
- Stigma.

### ***Literature Review***

Due to the lower than anticipated response rate during the RCA data collection, it was determined a literature review would aid in the identification of appropriate content for the development of focus group and survey questions. A total of 11 articles, reports, and surveys were examined as part of the literature review. Key findings from the literature review included:

- Lower rates of health care utilization among people with disabilities;
- Difficulty accessing health care due to structural (e.g., accessibility, policies and procedures, transportation, etc.), financial (e.g., medication, insurance, etc.), and personal (e.g., insensitivity, stigma, communication, etc.) barriers;
- Lack of person-centered services; and
- Areas of training for health care providers regarding people with disabilities.

## Discussion

Data gathered through the RCA interviews and literature review were examined and used to develop the health care provider survey, agency and support staff survey, and focus group question guides. The **health care provider survey** included specific questions regarding:

- Appointment length,
- Accommodation requests,
- Accessible health materials and forms,
- Physical accessibility of offices,
- Accessible medical equipment,
- Consultation practices,
- Comfort level, and
- Training related to people with disabilities.

The **agency and support staff survey** asked about:

- Preventative services,
- Physical activity,
- Emergency preparedness,
- Health care utilization,
- Barriers experienced when accessing health care,
- Health care management,
- Role of support staff during appointments,
- Comfort level of health care providers,
- Appointment length, and
- Training.

The **question guide for focus groups** with people with disabilities and family members focused on:

- Services are working well,
- Services that would be helpful to manage health,
- Barriers encountered and their impact,
- Decision-making process with providers, and
- Information dissemination of health promotion activities.

The information collected during the RCA interviews helped to provide a contextual framework for the survey and focus group questions. Given the unique nature of the State of Alaska, the RCA was able to capture the experience of health care providers, staff, and families in the state. For example, respondents discussed the need to seek services outside of Alaska. The RCA process also revealed the need to ask questions in relation to self-treatment and the priority of health and well-being for people with disabilities. While the RCA provided critical insight as to why people with disabilities experience health disparities, the addition of the literature review improved and expanded the questions developed for the surveys and focus groups. The literature review included topics not detected by the RCA. For example, the literature review included topics related to accessibility, types of accommodations, and importance of appointment length for people with disabilities in order to have a successful visit. Together the RCA and literature

review provided a comprehensive foundation to draw from when developing the health care provider survey, agency and support staff survey, and focus group guide.

## **Health Care Provider Survey Report**

### **Method**

Based upon the findings of the first activity of the needs assessment, the root cause analysis, and with the input of the Program Manager and the Alaska Health & Disability Program partners, CHD developed the Health Disparities Needs Assessment Survey for Health Care Providers. The survey solicited information from health care providers about their experiences with health care services for people with disabilities. The health care provider survey was an open-choice format, with some open-ended questions, making for a short survey with minimal typing necessary for completion. The survey data was collected using paper surveys and the web-based SurveyMonkey.com. A toll free telephone number was provided as an alternative to the paper and web-based survey. An incentive was offered for completing the survey. Participants were able to enter a drawing to win one of four \$50 gift cards at the completion of the survey. The health disparities needs assessment survey methods and protocol were reviewed and approved by the UAA Institutional Review Board.

### ***Recruitment and Sample***

CHD distributed the Health Disparities Needs Assessment Survey for Health Care Providers via email and paper invitation. The invitation explained the project, reviewed his/her rights as a research participant, and provided a link to, or a copy of, the survey. Paper versions of the health care provider survey were distributed with self-addressed, stamped envelopes for return. The paper survey was mailed to registered members of the Alaska State Medical Association. The online survey was distributed using a convenience sample of known contacts of: CHD personnel, members of the Alaska Health & Disability Program committee, and the Program Manager. Distribution also occurred through the Alaska Mental Health Trust Authority e-newsletter. A snowball sample was used to disseminate the email invitation with the online survey link.

The use of a convenience sample with a snowball sample does not lend itself to an accurate count of email invitations distributed. The paper survey was mailed to 568 health care providers in Alaska; 6 were not delivered and were returned (N = 562). The health care provider survey collected data from April 24, 2013 through June 28, 2013. A total of 113 surveys were completed during the two-month period. The response rate of paper surveys distributed through the Alaska State Medical Association was 16.5% (93/562).

### ***Analysis***

The information from returned health care provider paper surveys was entered into SurveyMonkey to centralize the data. Depending on the characteristics of the associated data, statistical analyses included the use of independent t-tests, chi-square tests, and various F-tests (e.g., analysis of variance (ANOVA), Welch test). Post hoc tests included Tukey's HSD and the Games-Howell pairwise comparison test. Any additional tests that were performed are clearly noted within the report. In all cases, the level of significance was  $\alpha = 0.05$ . For those chi-square tests that had statistically significant results, the summaries include one or two factors that contributed most to the overall association--i.e., had the largest standardized residuals (SR). All

statistical analyses were performed using SPSS16.0 and 17.0 for Windows (SPSS Inc., Chicago, IL).

## Results

### *Demographic Information*

Demographic information was collected from health care providers. The majority (82.3%) of the respondents to the health care provider survey were physicians. The two most common areas of primary area of practice were specialty care (36.7%) and family practice (27.5%). Specialty care included practice areas such as cardiology, neurology, oncology, or orthopedics. Most of the health care providers (83%) practiced in an urban location (i.e., the Municipality of Anchorage, the Fairbanks North Star Borough, and the City and Borough of Juneau). The mean number of years practicing in the field was 20.7 ( $SD = 11.0$ ). Health care providers reported serving a higher percentage of adults ( $M = 44.8$ ,  $SD = 23.7$ ), than seniors ( $M = 31.8$ ,  $SD = 21.8$ ) and children ( $M = 23.4$ ,  $SD = 31.1$ ). See Table 1 for a summary of health care provider demographic information.

Table 1. Health Care Provider Demographic Information

<b>Demographic Variable</b>	<b>#</b>	<b>%</b>	<b><i>M</i></b>	<b><i>SD</i></b>
Provider Type ( $n = 113$ )				
Physician	93	82.3		
Registered Nurse	7	6.2		
Nurse Practitioner	6	5.3		
Other	3	2.7		
Physician Assistant	2	1.8		
Dentist	1	0.9		
Mental Health	1	0.9		
Area of Practice ( $n = 109$ )				
Specialty Care	40	36.7		
Family Practice	30	27.5		
Obstetrics and gynecology	12	11.0		
Other	11	10.1		
Pediatric Primary Care	7	6.4		
Emergency Medicine	6	5.5		
Public Health Clinic	3	2.8		
Location ( $n = 100$ )				
Urban	83	83.0		
Rural	17	17.0		
Years in Practice ( $n = 106$ )			20.7	11.0
Percent Patients w/in Age Range ( $n = 105$ )				
Children and Youth (0-17)			23.4	31.1
Adults (18-54)			44.8	23.7
Seniors (55+)			31.8	21.8

### ***Appointment Length***

A paired-samples *t* test was run to determine statistical significance of the average length of time health care providers spent for a successful visit with patients with and without disabilities. This test concluded on average, to have a successful visit, providers spent significantly more time (35.47 minutes vs. 25.53 minutes) with a patient who has a disability ( $M = 35.47, SD = 15.21$ ) than a patient who has no disabilities ( $M = 25.53, SD = 10.90$ ),  $t(98) = -9.96, p = .000$ .

### ***Accommodations***

Nearly half (47.8%) of the survey respondents indicated they asked patients at intake or when scheduling appointments, if they need any accommodations. Two-thirds (66.7%) of providers documented accommodation requests for future appointments. Health care providers were asked to specify what types of accommodations their office provides for patients with disabilities. The most common accommodations included allowing support staff to accompany patients (91.2%), allowing service animals to accompany patients (83.3%), providing extended appointment times (77.5%), assisting with paperwork in accordance to HIPAA regulations (76.5%), and assisting with undressing, using restroom, lifting and positioning on exam table (73.5%). See Table 2 for a detailed list of accommodations provided to patients. A few health care providers (5) noted other accommodations provided such as, foreign language interpreter in the office and over the phone, house calls, and equipment (i.e., wheelchair transport).

Table 2. Accommodations provided by health care providers for people with disabilities

<b>Accommodation Provided</b>	<b>#</b>	<b>%</b>
Allow support staff to accompany patients	93	91.2
Allow service animals to accompany patients	85	83.3
Provide extended appointment times	79	77.5
Assistance with paperwork in accordance with HIPAA	78	76.5
Assistance undressing, using restroom, lifting and position on exam table	75	73.5
Flexible appointments to meet transportation needs	67	65.7
Assist with scheduling transportation	46	45.1
Communicate with patients using email	41	40.2
Provide sign language interpreters	28	27.5
Use of TTY machine to receive and make calls	16	15.7
Use of Alaska Relay Service to receive and make calls	14	13.7
Provide assistive listening devices during appointment	11	10.8
Text message reminders about appointments	9	8.8

$n = 102$

Results from an independent *t*-test showed those providers who asked patients if they need any accommodations worked in offices that provided significantly more of the specified accommodations ( $M = 6.89, SD = 2.13$ ) than providers who did not ask if accommodations were needed ( $M = 5.94, SD = 1.69$ ),  $t(95) = -2.45, p = .016$ . A similar analysis indicated those providers who documented accommodations worked in offices that provided significantly more of the specified accommodations ( $M = 6.68, SD = 1.98$ ) than providers who did not document accommodations ( $M = 5.81, SD = 1.91$ ),  $t(95) = -2.05, p = .043$ .

### ***Alternative Formats for Medical Forms***

The majority (77.7%) of health care providers reported they do not provide alternative formats for forms, medical information, medical instructions, and other health-related materials for patients who experience vision disabilities. Some health care offices (12.6%) provide alternative formats as standard practice and a few (9.7%) provide alternative formats upon request. Table 3 describes the types of formats and materials provided to patients with vision disabilities. One provider commented they provide patients with digital or optical magnifiers.

Table 3. Alternative Formats (provided by those who offer options other than standard print)

	<b>Health History</b>	<b>Education Materials</b>	<b>Care Instructions</b>	<b>Billing and Payment</b>
Enlarged Print	10 (45.5%)	12 (54.5%)	10 (45.5%)	9 (40.9%)
Electronic	10 (45.5%)	11 (50.0%)	9 (40.9%)	8 (36.4%)
Accessible Website	9 (40.9%)	12 (54.5%)	10 (45.5%)	9 (40.9%)
Picture-Based	2 (9.1%)	6 (27.3%)	4 (18.2%)	1 (4.5%)
Audio Recording	1 (4.5%)	2 (9.1%)	3 (13.6%)	2 (9.1%)
Braille	1 (4.5%)	1 (4.5%)	1 (4.5%)	1 (4.5%)

*n* = 22

### ***Accessible Building***

All (100%) of the health care providers replied their office was located in an accessible building. Table 4 summarizes the accessible building features. It is important to note this question did not include an N/A response choice. In retrospect, this question should have included an N/A choice to provide a more accurate depiction of accessible building features (e.g., an office could be in a one-story building and have no need for an elevator or if at street-level, ramps to an entrance are not necessary).

Table 4. Accessible Building Features

<b>Accessible Building Feature</b>	<b>#</b>	<b>%</b>
Accessible parking	99	97.1%
Restrooms (grab bars, etc.)	94	92.2%
Curb ramps	89	78.4%
Ramp to entrance	80	78.4%
Power assisted doors	72	70.6%
Elevator	66	64.7%

*n* = 102

### ***Accessible Medical Equipment***

Providers were asked a series of questions related to accessible medical equipment for people with disabilities. A majority (66.7%) of providers reported their office housed a height adjustable exam table. Relatively few (17.5%) of the provider offices had Hoyer-type life equipment to assist with patient transfers. A higher number (40.4%) of providers indicated they had access to trained lifters to assist patients on and off exam tables and other diagnostic equipment. Of offices with a need for diagnostic scans, 54.9% had in-house machines. Of those without accessible diagnostic machines (31.4%), the majority (75.9%) knew where to refer patients for such services. One-third (33.0%) of provider offices' with a need for wheelchair accessible weight scales, had them. Of those without (60.6%), the majority (62.5%) knew where

to refer patients to be weighed on a wheelchair accessible weight scale. See Table 5 for a summary of accessible medical equipment.

Table 5. Accessible Medical Equipment

Accessible Medical Equipment	<i>n</i>	Yes	No	N/A
Height adjustable exam table	102	66.7% (68)	28.4% (29)	4.9% (5)
Trained lifters	104	40.4% (42)	52.9% (55)	6.7% (7)
Accessible diagnostic scans	102	38.2% (39)	31.4% (32)	30.4% (31)
Referral for diagnostic scans	29	75.9% (22)	24.1% (7)	--
Wheelchair accessible weight scale	104	29.8% (31)	60.6% (63)	9.6% (10)
Referral for weight scale	56	62.5% (35)	37.5% (21)	--
Hoyer-type lift equipment	103	17.5% (18)	72.8% (75)	9.7% (10)

### Health Care Decisions

When providers make health care decisions with their patients, who they consulted with varied based upon the type of disability a patient may experience. For example, almost all (96.6%) providers consulted with individuals with chronic alcoholism and substance abuse disorders, whereas almost two-thirds (63.7%) consulted with individuals with intellectual and developmental disabilities when making health care decisions. In contrast, a higher majority (95.5% vs. 52.2%) of providers consulted with family members of people with intellectual and developmental disabilities versus family members of individuals who experienced chronic alcoholism or substance abuse disorders. Table 6 illustrates whom health care providers consulted with when making health care decisions based on disability category.

Table 6. Consultation When Making Health Care Decisions

Disability Category	<i>n</i>	Individual	Family/ Guardian	Support Staff
Substance abuse disorders	88	96.6% (85)	52.2% (59)	46.6% (41)
Physical disability	92	95.7% (88)	79.3% (73)	62.0% (57)
Mental health	87	93.1% (81)	79.3% (69)	58.6% (51)
Hearing impairment, including deafness	87	92.0% (80)	75.9% (66)	51.7% (45)
Visual impairment, including blindness	86	91.9% (79)	70.9% (61)	51.2% (44)
Memory or cognitive disability	88	70.5% (62)	93.2% (82)	68.2% (60)
Intellectual and development disability	88	63.7% (72)	95.5% (84)	73.9% (65)

A series of chi-square tests were run to determine significant associations between a provider's primary area of practice and consultation practices. There was a significant association between primary area of practice and whether support staff were consulted when making health care decisions with patients who had chronic alcoholism or other substance abuse disorders,  $\chi^2(4, N = 80) = 11.20, p = .024$ . The association was mostly influenced by the fact that there were fewer family practice providers who consulted with support staff under the above circumstances ( $SR = -1.6$ ) than would have been expected if there had been no association. There was also a significant association between primary area of practice and whether the family/guardian was consulted when making health care decisions with patients who had a mental health disability,  $\chi^2(4, N = 79) = 9.66, p = .046$ . The association was mostly influenced by the fact that there were fewer specialty care providers who consulted with the family/guardian under the above circumstances ( $SR = -1.6$ ) than would have been expected if there had been no association.

### ***Comfort Level***

Health care providers reported a mean overall comfort level, rated on a scale from 0 = very uncomfortable to 5 = very comfortable, of 4.01 when working with patients with disabilities ( $M = 4.01$ ,  $SD = 1.11$ ). Health care providers were asked to rank their level of comfort working with specified disability categories from 1 = most comfortable to 7 = least comfortable. The lower the mean ranking, the more comfortable providers were when working with a specific disability category. See Table 7 for a summary of mean comfort rankings. There were no statistically significant differences observed among the distributions of the comfort level rankings of working with patients in the specified disability categories,  $\chi^2(6) = 10.87$ ,  $p = .093$ .

Table 7. Mean Level of Comfort of Health Care Providers by Disability Category

<b>Disability Category</b>	<b><i>M</i></b>	<b><i>SD</i></b>
Physical disability	3.1	2.2
Intellectual and developmental disability	3.4	1.9
Hearing impairment, including deafness	4.0	1.9
Memory or cognitive disability	4.2	1.3
Mental health	4.3	1.9
Visual impairment, including blindness	4.4	2.1
Substance abuse disorders	4.5	2.4

$n = 31$

### ***Concerns Serving Patients with Disabilities***

Health care providers were asked about concerns they have when working with people with disabilities, to which 42 providers responded. Some providers commented they had concerns regarding effective communication and if “information is communicated adequately”. Others noted concerns with time constraints. Further, health care providers commented “the time it takes is much more than the compensation” and financial challenges include “poor reimbursement with Medicare.” Health care providers also stated the desire to “[meet] the needs [of their patients] appropriately” and provide quality care. They also pointed out concerns related to: a lack of access to equipment, resources, and materials; policies and procedures; provider knowledge; and the praised the benefit of family and support staff participation.

### ***Training***

Almost half (48.4%) of providers reported they had not received disability-related training within the past five years. Disability specific trainings were the most common (31.6%). The mean number of training categories received within the past five years was 1.4 ( $SD = 1.8$ ). Three providers commented on other types of trainings received including the UAA CHD Leadership Education in Neurodevelopmental and related Disabilities (LEND) fellowship, medical literature, and service dog laws. Approximately 73% of the providers indicated the desire to have disability related training. Providers most frequently (44.0%) reported the desire for training regarding the legal requirements of ADA to better serve individuals with disabilities. The mean number of training categories selected by health care providers was 2.5 ( $M = 2.5$ ,  $SD = 2.3$ ). A few providers indicated other areas of interest include planning ahead for visits, vocational evaluations, assistive technology, and service animals. See Figure 1 for a summary of training areas received within the past five years and desired areas of training.

Figure 1. Areas of Training Received within the Last 5 Years and Areas of Training Desired

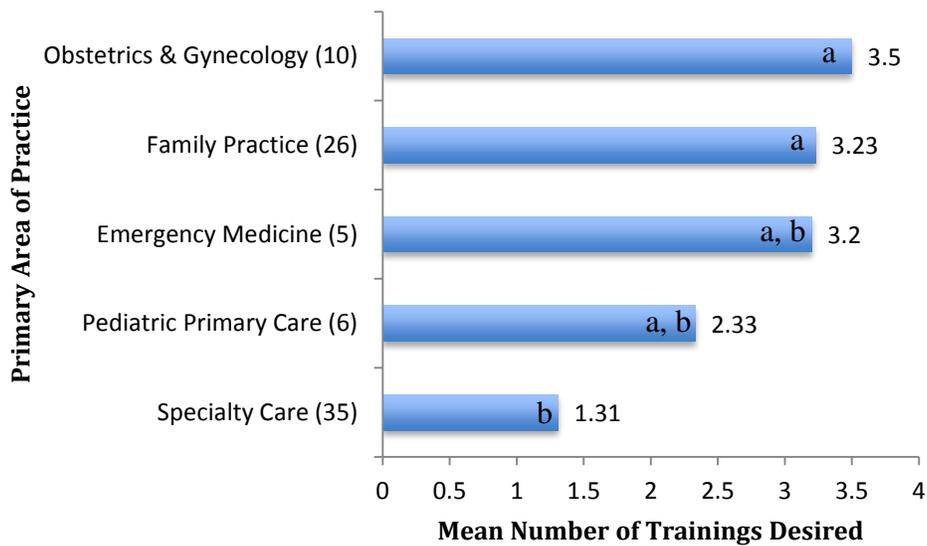
Received Training Areas (n = 95)		Desired Training Areas (n = 91)	
I have not received training	46 (48.4%)	ADA	40 (44.0%)
Disability specific training	30 (31.6%)	TTY or Alaska Relay Service	32 (35.2%)
ADA	25 (26.3%)	Disability specific training	30 (33.0%)
Effective communication	24 (25.3%)	Effective communication	30 (33.0%)
Disability awareness training	18 (18.9%)	Scheduling ASL interpreter	29 (31.9%)
Scheduling ASL interpreter	15 (15.8%)	Document accom. requests	27 (29.7%)
Accessible medical equipment	12 (12.6%)	I am not interested in training	21 (23.1%)
Document accom. requests	7 (7.4%)	Accessible medical equipment	19 (20.9%)
TTY or Alaska Relay Service	7 (7.4%)	Disability awareness training	17 (18.7%)

An independent *t*-test showed those providers who asked patients if they needed any accommodations received a significantly greater number of trainings ( $M = 2.16$ ,  $SD = 2.07$ ) than providers who did not ask if accommodations were needed ( $M = 0.91$ ,  $SD = 1.38$ ),  $t(87) = -3.37$ ,  $p = .001$ . A similar analysis indicated those providers who documented accommodations had received a significantly greater number of trainings ( $M = 1.82$ ,  $SD = 2.01$ ) than providers who did not document accommodations ( $M = 0.90$ ,  $SD = 1.26$ ),  $t(87) = -2.25$ ,  $p = .027$ .

A series of chi-square tests were run to determine significant associations between a provider's primary area of practice and desired training area. There was a significant association between primary area of practice and the desire for disability specific training,  $\chi^2(4, N = 82) = 19.38$ ,  $p = .001$ . The association was mostly influenced by the fact that there were more family practice providers ( $SR = 2.5$ ) and fewer specialty care providers ( $SR = -2.5$ ) who desired disability specific training than would have been expected if there had been no association. There was a significant association between primary area of practice and the desire for training on how to schedule a sign language interpreter,  $\chi^2(4, N = 82) = 19.07$ ,  $p = .001$ . The association was mostly influenced by the fact that there were more obstetrics and gynecology providers ( $SR = 2.3$ ) and fewer specialty care providers ( $SR = -2.3$ ) who desired training on how to schedule a sign language interpreter than would have been expected if there had been no association. There was a significant association between primary area of practice and the desire for training on effective communication with people with disabilities,  $\chi^2(4, N = 82) = 11.20$ ,  $p = .024$ . The association was mostly influenced by the fact that there were fewer specialty care providers ( $SR = -1.8$ ) who desired training on effective communication with people with disabilities than would have been expected if there had been no association.

Based on Welch's test, there was a significant effect of provider's primary area of practice on the number of trainings desired,  $F(4, 14.857) = 5.293$ ,  $p = .007$ . Pairwise comparisons using Games-Howell post hoc test showed that the number of trainings desired by obstetric and gynecological providers ( $M = 3.50$ ,  $SD = 1.84$ ) and family practice providers ( $M = 3.23$ ,  $SD = 2.30$ ) were significantly higher than the number of trainings desired by specialty care providers ( $M = 1.31$ ,  $SD = 1.32$ ). No other pairwise comparisons showed significant differences among the areas of practice as illustrated in Figure 2.

Figure 2. Number of Trainings Desired by Area of Practice (comparison of means)



*Note.* Groups that share one or more of the same letters outside their bars have means with no statistically significant differences.

### ***Improving Health Care Services in Alaska***

Providers were asked what could be done to improve health care services for people with disabilities in Alaska. Health care providers highlighted the need for training for both providers and staff. They commented on the importance of transportation services to offices, labs, and hospitals, and the lack of accessible taxis in Anchorage. Providers also cited the need for “better reimbursement for appointments” given the extended “time and extra overhead required for many patients with disabilities.” Providers noted a need for a “published list of available services” for referral purposes. Other suggestions included increased screening and diagnostic services, family participation, behavioral health telemedicine, care coordination, inclusion in planning, and feedback from people with disabilities to improve services.

### **Discussion**

The use of the Alaska State Medical Association mailing list was helpful to reach a higher number of health care professionals in Alaska. Health care providers are a harder population to reach for data collection efforts. While paper surveys are more expensive, in this case, they yielded a higher than anticipated response rate. Use of the mailing list is a good strategy to reach physicians in Alaska. Due to the fact the Alaska State Medical Association is an organization for physicians and physicians represented 82.3% of the responses, the results of the survey are more representative of their experience than the other types of health care providers.

On average, health care providers spent significantly more time, nearly 40% more, with patients who experience disabilities than with patients without disabilities. Extended appointment time was one of the most frequently provided accommodations. Health care providers expressed concern about time constraints and the desire for more time to see patients in order to serve their needs. Further, they conveyed frustration with reimbursement rates that do not take additional time into account.

Providers, who asked patients about accommodations at intake or when scheduling appointments, tended to offer a significantly higher number of accommodations to people with disabilities. This was also true for providers who documented accommodations. Further, these same providers had also received a significantly higher number of trainings related to people with disabilities within the past five years. Health care providers who received disability related trainings were more aware of the importance of accommodations and have made them available to their patients.

In line with the ADA, all provider offices were located in accessible buildings. Height adjustable exam tables were the most common type of accessible equipment for health care providers. When providers did not have accessible equipment at their office, they tended to know where to refer patients in order to meet their needs. For patients with vision impairments, alternative formats for medical forms and health-related materials were typically not utilized by providers.

When making health care decision with patients who experience disabilities, most health care providers (five of the seven disability categories) consulted with the individual over 90% of the time, although consultation with individuals who experience memory or cognitive and developmental disabilities was lower. When making decisions with patients with chronic alcoholism and substance abuse disorders, fewer family practitioners consulted with support staff compared to health care providers in other areas of practice. Fewer specialists consulted with families/guardians when making decisions with patients with mental health concerns compared to other areas of practice.

Most health care providers were interested in receiving disability related training. The most requested areas of training included legal requirements of the ADA, how to use TTY or Alaska Relay Service, disability specific training, and effective communication with people with disabilities. ADA trainings were most desired by family practitioners and least desired by specialists. Training related to scheduling sign language interpreters were most desired within obstetrics and gynecology and least desired among specialists. Training regarding effective communication with people with disabilities was least desired by specialists. Given these findings, training should be targeted to health care providers outside of specialty care settings. Specifically, trainings should be targeted to obstetrics and gynecology, and family practitioners, as they desired a significantly higher number of training areas than the other areas of practice.

Overall, health care providers in Alaska are comfortable working with people with disabilities. Providers spend more time with people with disabilities, yet they have to balance the extended amount of time with the approved reimbursement rate. From an advocacy perspective, individuals with disabilities need to be included in decision-making processes with health care providers. Providers recognize a need for more disability related training. Health care providers translate training into practice and are then able to better serve their patients with disabilities and to improve access to care.

## **Agency and Support Staff Survey Report**

### **Method**

Based upon the findings of the first activity of the needs assessment, the root cause analysis, and with the input of the Program Manager and the Alaska Health & Disability

Program partners, CHD developed the Health Disparities Needs Assessment Survey for Agency and Support Staff. The survey solicited information from agency and support staff about their experiences with health care services for people with disabilities. The survey was an open-choice format, with some open-ended questions, making for a short survey with minimal typing necessary for completion. The survey data was collected using the web-based SurveyMonkey.com. A toll free telephone number was provided as an alternative to the web-based survey. An incentive was offered for completing the survey. Participants were able to enter a drawing to win one of four \$50 gift cards at the completion of the survey. The health disparities needs assessment survey methods and protocol were reviewed and approved by the UAA Institutional Review Board.

### ***Recruitment and Sample***

CHD distributed the Health Disparities Needs Assessment Survey for Agency and Support Staff via email invitation. The invitation explained the project, reviewed their rights as a research participant, and provided a link to the survey. The online survey was distributed using a convenience sample consisting of the CHD listserv, Governor's Council on Disabilities and Special Education listserv, Alaska Mental Health Trust Authority e-newsletter, and known contacts of members of the Alaska Health & Disability Program committee and the Program Manager. A snowball sample was also used to disseminate the email invitation with the online survey link.

The use of a convenience sample with a snowball sample does not lend itself to an accurate count of email invitations distributed. CHD was able to determine the email invitation sent through the CHD listserv was opened by 454 people and the Alaska Mental Health Trust Authority e-newsletter was sent to 800+ people. The agency and support staff survey collected data from April 24, 2013 through June 28, 2013. A total of 177 surveys were completed during the two-month period.

### ***Analysis***

Depending on the characteristics of the associated data, statistical analyses included the use of independent t-tests, chi-square tests, and various F-tests (e.g., analysis of variance (ANOVA), Welch test). Post hoc tests included Tukey's HSD and the Games-Howell pairwise comparison test. Any additional tests that were performed are clearly noted within the report. In all cases, the level of significance was  $\alpha = 0.05$ . For those chi-square tests that had statistically significant results, the summaries include one or two factors that contributed most to the overall association--i.e., had the largest standardized residuals (SR). All statistical analyses were performed using SPSS16.0 and 17.0 for Windows (SPSS Inc., Chicago, IL).

## **Results**

### ***Demographic Information***

Respondents to the support staff survey most frequently identified their role as administrators (23.1%) or direct service workers (22.5%). Those who indicated their role as other specified they worked within education (5), law (4), justice (2), quality improvement (1), advocacy (1), and as an assistive technology specialist (1). The most common (31.5%) primary disability category staff worked with was intellectual and developmental disabilities. When asked to identify all disability categories worked with, staff reported working with intellectual and developmental disabilities (83.4%), mental health (78.7%), physical disabilities (76.4%), and

memory/cognitive disabilities (74.1%) most often. The mean number of disability categories staff worked with was 4.8 ( $M = 4.8, SD = 1.8$ ). The caseload size ranged from 0 to 100 and the mean number of clients on a staff member's caseload was 28.7 ( $SD = 31.1$ ). The median number of clients on a caseload was 15. The majority of support staff (64.1%) worked in an urban location (i.e., the Municipality of Anchorage, the Fairbanks North Star Borough, and the City and Borough of Juneau). Agency and support staff reported serving a higher percentage of adults ( $M = 50.5, SD = 34.8$ ) than seniors ( $M = 27.8, SD = 34.0$ ) and children ( $M = 21.7, SD = 34.8$ ). See Table 8 for a summary of agency and support staff demographic information.

Table 8. Agency and Support Staff Demographic Information

<b>Demographic Variable</b>	<b>#</b>	<b>%</b>	<b><i>M</i></b>	<b><i>SD</i></b>
Role ( $n = 173$ )				
Administrator	40	23.1		
Direct Service Worker	39	22.5		
Care Coordinator	22	12.7		
Case Manager	22	12.7		
Clinician	22	12.7		
Other	15	8.7		
Family Member/Guardian	13	7.5		
Primary Disability Supported ( $n = 168$ )				
Intellectual and Developmental	53	31.5		
Mental Health	43	25.6		
Physical	29	17.2		
Memory or Cognitive	19	11.3		
Chronic Alcoholism and Substance Abuse	18	10.3		
Hearing Impairment	4	2.4		
Visual Impairment	2	1.2		
All Disabilities Supported ( $n = 174$ )				
Intellectual and Developmental	146	83.4		
Mental Health	137	78.7		
Physical	133	76.4		
Memory or Cognitive	129	74.1		
Hearing Impairment	104	59.8		
Chronic Alcoholism and Substance Abuse	95	54.3		
Visual Impairment	93	53.4		
Location ( $n = 145$ )				
Urban	93	64.1		
Rural	52	35.9		
Average Caseload Size ( $n = 160$ )			28.7	31.1
Percent Clients w/in Age Range ( $n = 170$ )				
Children and Youth (0-17)			21.7	34.8
Adults (18-54)			50.5	36.8
Seniors (55+)			27.8	34.0

### ***Healthy Activities***

Support staff were asked about how those they supported engaged in health related activities. Staff reported on average, 60.8% ( $SD = 35.9$ ) of those they support accessed

preventative services such as a yearly exam, Pap smear, blood test, colonoscopy, prostate exam, or vaccines. The mean percentage of people with disabilities who engaged in regular physical activity (i.e., a minimum of 30 minutes of activity at least five days week) was 40.6 ( $SD = 33.0$ ). Agency and support staff indicated the mean percentage of those who had some preparedness for emergency or disaster situations was 38.8 ( $SD = 39.9$ ).

### **Health Care Utilization**

Table 9 displays health care utilization by type of health care accessed for people with disabilities. Staff reported people with disabilities utilized primary care most often; i.e., 0% reported primary care services were not sought. Health education services (e.g., healthy living, tobacco cessation) were utilized with less frequency; 29.1% of people did not seek health education services. As indicated by the bold percentages in Table 9, health care services were most frequently accessed on a yearly basis.

Table 9. Health Care Utilization for People with Disabilities

	Don't seek	> Every 2 years	Every 2 years	Yearly	Every 6 months	Monthly	Weekly	Don't know
Primary Care <i>n</i> = 141	0% (0)	7.1% (10)	5.0% (7)	<b>27.0%</b> <b>(38)</b>	26.2% (37)	15.6% (22)	4.3% (6)	14.9% (21)
Dental <i>n</i> = 143	2.1% (3)	18.2% (26)	7.0% (10)	<b>30.8%</b> <b>(44)</b>	17.5% (25)	1.4% (2)	2.8% (4)	20.3% (29)
Optical <i>n</i> = 142	2.1% (3)	15.5% (22)	17.6% (25)	<b>39.4%</b> <b>(56)</b>	2.8% (4)	0.7% (1)	1.4% (2)	20.4% (29)
Specialty Care <i>n</i> = 141	5.0% (7)	8.5% (12)	7.8% (11)	<b>24.1%</b> <b>(34)</b>	18.4% (26)	7.1% (10)	5.0% (7)	24.1% (34)
Med. ER <i>n</i> = 142	6.3% (9)	<b>19.0%</b> <b>(27)</b>	5.6% (8)	18.3% (26)	16.2% (23)	7.0% (10)	3.5% (5)	23.9% (34)
Preventative <i>n</i> = 142	7.0% (10)	16.2% (27)	7.0% (10)	<b>39.4%</b> <b>(56)</b>	7.0% (10)	1.4% (2)	0.7% (1)	21.1% (30)
Med. Hospital. <i>n</i> = 142	13.4% (19)	<b>23.2%</b> <b>(33)</b>	9.9% (14)	16.2% (23)	8.5% (12)	3.5% (5)	1.4% (2)	23.9% (34)
Psyc. ER <i>n</i> = 141	<b>17.7%</b> <b>(25)</b>	16.3% (23)	5.7% (8)	12.8% (18)	14.9% (21)	1.4% (2)	2.8% (4)	28.4% (40)
Psyc. Hospital. <i>n</i> = 142	<b>21.8%</b> <b>(31)</b>	<b>21.8%</b> <b>(31)</b>	8.5% (12)	12.0% (17)	5.6% (8)	2.1% (3)	1.4% (2)	26.8% (38)
Health Edu. <i>n</i> = 141	<b>29.1%</b> <b>(41)</b>	16.3% (23)	5.7% (8)	11.3% (16)	4.3% (6)	6.4% (9)	3.5% (5)	23.4% (33)

Note. Med. ER = Medical emergency room visit, Psyc. ER = Psychiatric emergency room visit, Med. Hospital. = Medical hospitalization, Psyc. Hospital. = Psychiatric hospitalization, Health Edu. = Health education services.

### **Managing Health Care Needs**

Agency and support staff indicated, on average, they were most responsible to manage health care needs of people with disabilities such as arranging transportation (50.4%), asking for

accommodations (41.4%), scheduling appointments (39.0%), and scheduling preventative services (34.8%). Table 10 describes who is most responsible for the management of health care needs for those who experience disabilities.

Table 10. Management of Health Care Needs

	<b>Support Staff</b>	<b>Family/Guardian</b>	<b>Individual</b>	<b>Health Provider</b>
Arranging transportation	50.4% (71)	24.8% (35)	22.0% (31)	2.8% (4)
Asking for accommodations	41.4% (58)	30.7% (43)	24.3% (34)	3.6% (5)
Scheduling appointments	39.0% (55)	22.9% (40)	27.0% (38)	5.7% (8)
Scheduling preventative services	34.8% (49)	31.2% (44)	22.7% (32)	11.3% (11)

*n* = 141

A series of chi-square tests were run to determine significant associations between the role of support staff and health care management needs. There was a significant association between support staff role and who was most responsible for asking for accommodations when managing health care needs,  $\chi^2(15, N = 156) = 34.59, p = .003$ . The association was mostly influenced by the fact that there were more support staff who were family/guardian and specified that the family/guardian was mostly responsible for asking for accommodations (*SR* = 3.8) than would have been expected if there had been no association.

### **Health Care Appointments**

Data were collected regarding health care appointments for people with disabilities. The majority (57.0%) of agency and support staff reported attending appointments with those they support either sometimes (38.9%) or always (18.1%). Staff who attended appointments rated the mean comfort level of health care providers when working with people with disabilities as 3.3 on a scale from 0 = very uncomfortable to 5 = very comfortable (*M* = 3.3, *SD* = 1.0). Support staff were asked on average how many minutes were necessary for a health care provider to have a successful visit with a person who experiences a disability; see Table 11 for a summary of responses.

Table 11. Mean Number of Minutes Needed for a Successful Visit with Health Care Provider

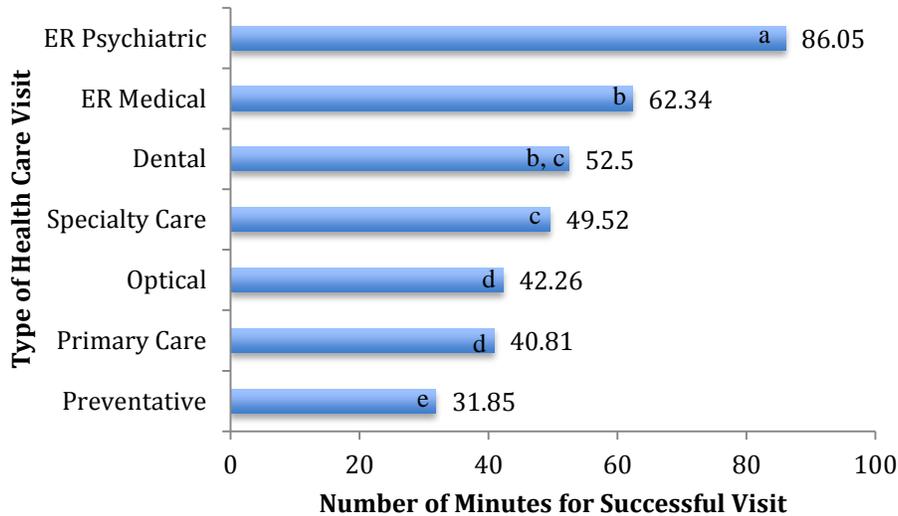
<b>Type of Visit</b>	<b><i>n</i></b>	<b><i>M</i></b>	<b><i>SD</i></b>
Psychiatric Emergency Room Visit	62	86.0	50.1
Medical Emergency Room Visit	67	72.7	72.3
Dental	76	50.7	21.7
Specialty Care	73	50.3	22.3
Optical	74	42.0	14.9
Primary Care	76	39.9	16.8
Preventative	75	31.5	16.3

Of staff members that attended health care appointments, almost half (48.8%) had received general training related to their support role. Training areas were related to advocacy, first aid, medication, lifting, adaptive equipment, health care paperwork, and disability specific information.

Based on a repeated measures ANOVA, there was a significant effect of length of a successful visit on the type of health care service received,  $F(2.14, 130.55) = 32.43, p = .000$ . Pairwise comparisons were made to determine where significant differences existed (See Figure

3). Holm-Bonferroni corrections were used to protect against family-wise errors from the pairwise post hoc comparisons.

Figure 3. Number of Minutes for Successful Visit by Type of Health Care Visit



*Note.* Groups that share one or more of the same letters outside their bars have means with no statistically significant differences.

A series of chi-square tests were run to determine significant associations between the role of support staff and frequency of attending health care appointments. There was a significant association between support staff role and the frequency with which support staff attended health care appointments with the individual(s) they supported,  $\chi^2(10, N = 156) = 35.26, p = .000$ . The association was mostly influenced by the fact that there were more support staff with the role of family/guardian who always attended appointments ( $SR = 3.2$ ) than would have been expected if there had been no association.

An independent *t*-test showed support staff who always attend health care appointments perceived health care providers as being significantly more comfortable ( $M = 3.39, SD = 1.01$ ) than staff who sometimes attended appointments ( $M = 3.09, SD = 1.00$ ),  $t(80) = -2.54, p = .013$ . A similar analysis indicated support staff who always attended health care appointments reported a significantly longer appointment time (in minutes) for a successful visit with a specialty care provider ( $M = 59.78, SD = 24.51$ ) than staff who sometimes attended appointments ( $M = 46.00, SD = 19.922$ ),  $t(71) = -2.55, p = .013$ .

A series of *F*-tests were conducted to determine the effects of support staff having attended health care appointments. Based on an ANOVA, there was a significant effect of appointment attendance on the number of disability categories supported,  $F(2, 141) = 3.58, p = .030$ . Pairwise comparisons using Tukey's post hoc test showed that the number of disability categories supported by those who did not attend health appointments ( $M = 5.11, SD = 1.64$ ) were significantly higher than those who always attended health care appointments ( $M = 3.96, SD = 2.14$ ). No other pairwise comparisons showed significant differences.

Based on Welch's test, there was a significant effect of support staff attendance of appointments on caseload sizes,  $F(2, 85.12) = 13.69, p = .000$ . Pairwise comparisons using

Games-Howell post hoc test showed that the caseload sizes of support staff who did not attend appointments ( $M = 33.52, SD = 33.45$ ) and those who sometimes attended appointments ( $M = 31.1, SD = 29.90$ ) were significantly higher than staff that always attended appointments ( $M = 10.24, SD = 14.83$ ). No other pairwise comparisons showed significant differences.

Based on an ANOVA, there was a significant effect of staff appointment attendance on the percentage of clients who access preventative health services,  $F(2, 134) = 6.77, p = .002$ . Pairwise comparisons using Tukey's post hoc test showed that the percentage of clients who accessed preventative services was significantly higher for those who were supported by staff who always attended appointments ( $M = 82.12, SD = 28.98$ ) compared to those who were supported by staff that either sometimes attended appointments ( $M = 59.52, SD = 36.09$ ) or did not attend appointments ( $M = 51.88, SD = 34.57$ ). No other pairwise comparisons showed significant differences.

### **Barriers**

Agency and support staff indicated the most frequent barriers experienced by people with disabilities, on a scale from 0 = never to 5 = always, included limited access to specialists ( $M = 3.6, SD = 1.3$ ), limited number of providers ( $M = 3.4, SD = 1.5$ ), and navigating the health care system ( $M = 3.4, SD = 1.4$ ). See Table 12 for a full list of barriers experienced by people with disabilities when trying to access health care. Other barriers included addiction, long waitlists, limited support from families, rural locations, lack of information, no insurance coverage, and lack of interdisciplinary services (e.g., developmental disability and behavioral health).

Table 12. Barriers Experienced by People with Disabilities when Accessing Health Care

<b>Barriers</b>	<b><i>n</i></b>	<b><i>M</i></b>	<b><i>SD</i></b>
Limited access to specialists	141	3.6	1.3
Limited number of providers	141	3.4	1.5
Navigating health care system	141	3.4	1.4
Client difficulty finding providers and services	140	3.3	1.5
Communication difficulties	140	3.3	1.2
Financial barriers	140	3.3	1.5
Health insurance/Medicare/Medicaid limits	139	3.1	1.5
Transportation challenges	140	3.0	1.6
Limited time with providers	137	2.9	1.5
Clients' distrust of providers	139	2.8	1.3
Health and well-being not seen as a priority by client	141	2.7	1.5
Reluctance from provider to serve PWD	139	2.4	1.5
Reliance upon self-treatment	134	2.3	1.5
Insensitivity and disrespect from providers	139	2.1	1.4
Lack of accessible medical equipment	138	2.0	1.5
Lack of physical accessible location	139	1.9	1.5
Other	28	1.9	2.2

The data showed clients experienced difficulty finding providers and services within urban locations ( $M = 3.46, SD = 1.43$ ) significantly more often than clients in rural locations ( $M = 2.76, SD = 1.55$ ),  $t(113) = 2.48, p = .015$ . Further, clients faced difficulty in regard to a limited number of providers within urban locations ( $M = 3.56, SD = 1.41$ ) significantly more often than clients in rural locations ( $M = 2.96, SD = 1.58$ ),  $t(114) = 2.14, p = .034$ . Clients experienced

reluctance from health care providers to provide care to people with disabilities significantly more often in urban locations ( $M = 2.59$ ,  $SD = 1.36$ ) than in rural locations ( $M = 1.72$ ,  $SD = 1.56$ ),  $t(112) = 3.16$ ,  $p = .002$ .

Based on an ANOVA, there was a significant effect of staff appointment attendance on the frequency rating of health insurance/Medicaid/Medicare limits,  $F(2, 136) = 5.77$ ,  $p = .004$ . Pairwise comparisons using Tukey's post hoc test showed that the mean health insurance/Medicaid/Medicare limitations rating for staff who did not attend appointments ( $M = 3.62$ ,  $SD = 1.32$ ) was significantly higher than the mean for staff who sometimes attended appointments ( $M = 2.71$ ,  $SD = 1.51$ ). No other pairwise comparisons showed significant differences.

Based on an ANOVA, there was a significant effect of staff appointment attendance on the frequency rating of difficulty navigating health care system,  $F(2, 138) = 4.05$ ,  $p = .020$ . Pairwise comparisons using Tukey's post hoc test showed that the mean health care system navigation difficulty rating for staff who did not attend appointments ( $M = 3.82$ ,  $SD = 1.26$ ) was significantly higher than the mean for staff who sometimes attended appointments ( $M = 3.20$ ,  $SD = 1.45$ ). No other pairwise comparisons showed significant differences.

Based on Welch's test, there was a significant effect of support staff attendance of appointments on the frequency rating of transportation difficulties,  $F(2, 62.65) = 6.89$ ,  $p = .002$ . Pairwise comparisons using Games-Howell post hoc test showed that the mean transportation difficulty ratings for staff who did not attend appointments ( $M = 3.47$ ,  $SD = 1.29$ ) and those who sometimes attended appointments ( $M = 3.04$ ,  $SD = 1.61$ ) were significantly higher than the mean for staff who always attended appointments ( $M = 2.04$ ,  $SD = 1.80$ ). No other pairwise comparisons showed significant differences.

Based on Welch's test, there was a significant effect of support staff attendance of appointments on the frequency rating of financial barriers,  $F(2, 59.21) = 12.09$ ,  $p = .000$ . Pairwise comparisons using Games-Howell post hoc test showed that the mean financial barrier rating for staff who did not attend appointments ( $M = 3.93$ ,  $SD = 1.02$ ) was significantly higher than the means for staff who sometimes attended appointments ( $M = 3.15$ ,  $SD = 1.50$ ) and staff who always attended appointments ( $M = 2.35$ ,  $SD = 1.77$ ). No other pairwise comparisons showed significant differences.

Based on Welch's test, there was a significant effect of support staff attendance of appointments on the frequency rating of health and well-being not seen as a priority by clients,  $F(2, 62.36) = 7.01$ ,  $p = .002$ . Pairwise comparisons using Games-Howell post hoc test showed that the mean health and well-being priority ratings for staff who did not attend appointments ( $M = 3.12$ ,  $SD = 1.19$ ) and those who sometimes attended appointments ( $M = 2.82$ ,  $SD = 1.54$ ) were significantly higher than the mean for staff who always attended appointments ( $M = 1.73$ ,  $SD = 1.71$ ). No other pairwise comparisons showed significant differences.

Based on Welch's test, there was a significant effect of support staff attendance of appointments on the frequency rating of clients' reliance on self-treatment,  $F(2, 62.89) = 8.88$ ,  $p = .000$ . Pairwise comparisons using Games-Howell post hoc test showed that the mean reliance on self-treatment ratings for staff who did not attend appointments ( $M = 2.55$ ,  $SD = 1.19$ ) and those who sometimes attended appointments ( $M = 2.44$ ,  $SD = 1.55$ ) were significantly higher than the mean for staff who always attended appointments ( $M = 1.16$ ,  $SD = 1.46$ ). No other pairwise comparisons showed significant differences.

### ***Improving Health Care Services in Alaska***

Support staff provided a variety of comments in response to the question, “What could be done in Alaska to improve health care services for people with disabilities?” Most of the comments focused on the following themes: access to services, lack of resources, transportation to/from medical care, training, staff turnover, and rural needs. Potentially identifiable information (e.g., agency name) was removed to protect the identity of the respondent.

Improving access to health care services was an area cited often by support staff. Survey respondents noted a need for additional medical professionals who are trained and willing to work with individuals with disabilities, especially those patients with complicated circumstances and/or challenging behaviors. Additionally, if the provider is unable to provide appropriate services, respondents noted he/she should make a referral to another provider. The need for additional providers who are willing to see patients on Medicaid/Medicare was also noted. As to availability, support staff suggested more weekend and evening hours; walk-in appointments; an increase in the number of sessions allowed (e.g. mental health sessions); longer appointments; and house calls and/or home health care. Finally, one respondent suggested the need for primary care providers being co-located in disability service organizations.

Support staff often cited concerns about lack of resources to cover the cost of healthcare, especially for those individuals who are not eligible for Medicaid/Medicare, are uninsured or are under-insured. Respondents also noted the need for additional providers who accept Medicaid and several suggestions were made to impact this challenge including: advocating for no funding reductions to Medicaid and Medicare, providing incentives to medical care providers who accept Medicaid, and encouraging the State of Alaska to embrace the Affordable Care Act. Respondents also suggested expanding Medicaid Choice Waiver and Medicaid eligibility. Respondents would also like to see universal health care, increased accessibility and funding for home health programs, simplified Medicaid/Medicare rules, and Medicaid coverage for vision, dental, and mental health services. Support staff cited the need for additional services in the areas of preventative care, mental health care, TBI medical care, specialist care, psychiatric care, early diagnostic care for developmental delays, and recovery care. In addition, respondents made the following suggestions: providing a health care service that specializes in providing health care for people with disabilities, increasing traveling clinics, increasing the number of occupational therapists, providing more financial support for peer support services, emphasizing continuity of care, providing more resources for wrap around services, and increasing outpatient psychiatric care and follow-up.

Support staff often cited the need to improve the availability of transportation to and from medical appointments both in terms of cost and accessibility. In rural areas, participants noted a need for travel funding for patients with disabilities to travel to regional or statewide health care providers. Also, respondents described the challenges with using Medicaid travel and the need to increase available transportation funding.

Training for health care professionals, people with disabilities and their families, the public, and law enforcement were cited often by support care staff as a way to improve health care services for people with disabilities. Specifically, respondents indicated training in the following areas: home health care and hospice; Mental Health First Aid; challenging behaviors; disability awareness/sensitivity; basic sign language; understanding non-verbal communication; effective communication with people with disabilities and the individuals who support them;

linkage between biological and psychosocial concerns; resources; healthy living, prevention of financial exploitation, and prevention of self-neglect.

Support staff cited the need to address staff turnover (through increased pay) for better continuity of care. Respondents also described a need for a liaison to help people with disabilities navigate the health care system by attending appointments, helping with communication, and helping understand and plan for treatment.

A number of needs specific to rural populations were noted by the survey respondents including: the need for more services, including specialty services, and outreach into small remote and rural communities; the need to address the expense and physical difficulty of rural travel; the need to address the unreliability of telephone use/access for medical consultation; the need to increase cultural knowledge, skills and health literacy of providers; and the need to increase medical services access via the internet. One respondent suggested developing a central database that alerts patients of needed care.

## **Discussion**

Several significant differences were detected when examining attendance of health care appointments by support staff. Staff who always attended appointments with their clients had significantly smaller caseloads than those who sometimes or never attended appointments. Further, staff that always attended appointments worked with fewer disability categories than those who did not attend appointments. The size and diversity of a support staff's caseload influences their ability to attend health care appointments with their clients. Always attending health care appointments with clients was most influenced by the family/guardian role compared to the other support staff roles (e.g., direct service worker, clinician, case manager).

Support staff members who always attended appointments felt health care providers were more comfortable with patients with disabilities than staff who sometimes attended appointments. These staff also reported significantly longer appointment times with specialty care providers. Staff members who always attend appointments may support individuals with more complex medical needs, who require the presence of staff at appointments, thus spending more time with specialty providers. Staff who always attended appointments reported their clients accessed preventative health services significantly more than those who sometimes or never attended appointments. Again, with smaller caseloads it is easier to help manage health care needs and follow-up of preventative services.

Support staff in urban locations reported more difficulty in finding providers and services, reluctance of health care providers to serve people with disabilities, and a limited number of providers. While urban areas have more health care resources, they also contain a larger number of people. Further, more health care resources also means people with disabilities and their supports have more services and providers to navigate, making it more difficult to determine what is available for an individual. Support staff expressed concern about the lack of providers who accept Medicaid/Medicare and the need for flexibility to provide services in non-traditional ways (e.g., weekend and evening hours, house calls, walk-in appointments).

Support staff who never attended health care appointments reported a number of barriers experienced by those they support in accessing health care services. Barriers included insurance/Medicaid/Medicare limitations, difficulty navigating the health care system, lack of transportation, financial burdens, health not being seen as a priority, and reliance upon self-treatment. Agency and support staff who never attended appointments had the largest caseload

size (approximately 34 people). Given these staff are supporting a larger number of clients, they may not be able to attend appointments and assist with health care management needs. Clients of those staff who never attend appointments face more barriers and as a result may access fewer health care services and/or may not require as many services.

Over half of the support staff who attended health care appointments with clients had not received training related to their role. Suggested areas of trainings for both support staff and health care providers include home health care and hospice; Mental Health First Aid; challenging behaviors; disability awareness/sensitivity; basic sign language; understanding non-verbal communication; effective communication with people with disabilities and the individuals who support them; linkage between biological and psychosocial concerns; resources; healthy living, prevention of financial exploitation, and prevention of self-neglect.

Agency and support staff play a critical role in access to health care services for people with disabilities. Support staff members who always attend health care appointments support individuals who experience fewer barriers. A staff's caseload size and caseload diversity impacts health care services for people with disabilities; the smaller and less diverse a caseload, the more a person accesses services. There is a clear need for more training with support staff who are attending appointments with people with disabilities. In conclusion, given the influence their support has on the lives of people with disabilities, agency and support staff members need to be involved in the health care management of the people they support.

## **Focus Group Interviews**

### **Method**

Based upon the findings of the first activity of the needs assessment, the root cause analysis, and with the input of the Program Manager and the Alaska Health & Disability Program partners, CHD developed the focus group interview guide. The focus group interviews solicited information from individuals with disabilities and family members of people with disabilities about their experiences with health care services in Alaska. The focus groups utilized standardized open-ended interviews where the question wording and the sequence of questions were predetermined. The standardized interview format allowed all respondents to answer the same questions and increased comparability of responses. This format also help to reduce interviewer bias as more than one interviewer was used to conduct the focus groups. See Figure 5 for focus group interview guides.

Figure 5. Focus Group Interview Guides

### People with Disabilities

- Why do you like living in your community?
- What has worked well for you, in your current healthcare experience? As you seek health care services what works?
- What supports and services are necessary for you to maintain your best possible health? (PCA, text message reminders, etc.)
- What types of assistance would be helpful as you manage your health. These may not be in place right now, but would help and make it easier to manage your health.
- What barriers have you encountered while trying to access healthcare? (equipment, transportation, scheduling, finding a provider, etc.)
- How have these barriers affected you?
- When making health care decisions, how does your healthcare provider involve you in making decisions about your healthcare?
- How do you find out about activities that can improve your health such as flu vaccine clinics or oral health screenings? (preventative services, annual exams, etc.)
- What could be done to improve access to healthcare and healthcare services in Alaska?

### Family Members of People with Disabilities

- Why do you like living in your community?
- What has worked well for your family member, in their current healthcare experience? As your family seeks health care services what works?
- What supports and services are necessary for your family member to maintain the best possible health? (PCA, text message reminders, etc.)
- What types of assistance would be helpful in managing the health of your family member? These may not be in place right now, but would help and make it easier to manage your family member's health.
- What barriers have you encountered while trying to access healthcare for your family member?
- How have these barriers affected your family?
- When making health care decisions for your family member, how does your healthcare provider involve you in making decisions? How do they involve your family member?
- How do you find out about health promotion activities, such as flu vaccine clinics, oral health screenings, or other preventative services that can be accessed by your family member? (annual exams)
- What could be done to improve access to healthcare and healthcare services for your family member in Alaska?

Focus groups were conducted in nine Alaskan communities representing a combination of urban and rural locations. Focus group interviews were held separately for individuals with disabilities and family members. Focus groups were limited to 10 people per group interview. An oral consent process was used to help ensure confidentiality of the participants. Focus group interviews were recorded after consent was obtained and written notes were also taken for analysis purposes. An incentive was offered for participating in the focus group interview. Participants were given a \$25 gift card as a thank you for their time. The health disparities needs assessment focus group methods and protocol were reviewed and approved by the UAA Institutional Review Board.

### ***Recruitment and Sample***

CHD distributed an email invitation to participate in the focus group interviews targeting people with disabilities and family members in the identified communities. The invitation was distributed using a convenience sample through the CHD listserv, the Governor's Council on

Disability and Special Education (GCDSE) listserv, the Stone Soup Group (SSG) listserv, and the Alaska Mental Health Trust Authority e-newsletter. A snowball sample was used to disseminate the email invitation. The invitation explained the project, reviewed research participant rights, and outlined the schedule for interviews in the identified communities. If people were interested in participating in the focus group interviews, they were asked to contact CHD. CHD gathered information relating to disability type and accommodation requests, described the consent process, obtained consent of legal guardians when applicable, and answered any questions participants had about the focus group interviews.

A total of 19 focus groups were conducted, and the interviews were approximately 90 minutes long.<sup>1</sup> Two CHD research team members were present at each focus group interview, one to facilitate the discussion and the other to assist and take notes. A total of four researchers from CHD took turns facilitating and assisting during the focus group interviews. Fifty-one individuals had contacted CHD to sign-up for the focus groups. A total of 43 people participated in focus group interviews. Of the 43, 25 were individuals with disabilities (58.1%) and 18 were family members (41.9%). The size of focus group interviews ranged from one to seven participants.

### ***Analysis***

A Consensual Qualitative Research Model (Hill, Thompson, & Williams, 1997; Hill, Knox, Thompson, Williams, Hess, & Ladany, 2005) was used to analyze the feedback gathered during focus group interviews. Consensual Qualitative Research (CQR) involves multiple researchers working together to code and analyze the data through a consensual process. Three of the researchers who were involved in conducting the interviews comprised the primary team. A fourth researcher who had not participated in the interview process served as an auditor to the CQR. Data analysis consisted of three steps: 1) identification of domains; 2) construction of core ideas; and 3) interpretation of key findings. During the first stage, team members each independently reviewed two transcriptions from the focus group interviews. Working from an established list of domains based on the Root Cause Analysis and literature review, researchers assigned established or new domains to the transcripts. After independently assigning domains, the team met to discuss the coding. The goal was to reach consensus about the coding of the data. Once a clear criterion was established for the domains, the researchers divided the work to finish coding the remaining nine transcriptions. The second stage of CQR was to summarize the content of the domains into clear, concise core ideas. Team members worked together using the abstraction process to summarize the data for each domain. In the final stage, similarities and variations were examined across transcriptions and domains to draw conclusions about the data. The auditor reviewed the work of the team at the end of each stage and provided feedback to the team.

### **Results**

Researchers began with a list of 26 domains based on the Root Cause Analysis and literature review findings. After the first round of coding two transcriptions, researchers removed three unused domains and added six new domains to the list, resulting in a list of 29 domains. Researchers then coded the remaining transcriptions. During the second stage of analysis, through a consensual process researchers reviewed the comments within each domain to identify

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<sup>1</sup> In one community with a large population, two focus groups were held for people with disabilities.

the core ideas discussed by the focus group participants. The process of developing core ideas helped researchers to distill the comments into clear, concise concepts. Researchers reviewed the comments, focusing on the original intent of the participants' statements and tried to avoid adding assumptions or interpretation of the data. Next, researchers reexamined the domains. Five domains were eliminated and were combined within more appropriate domains. At the end of the second stage 24 domains remained. Researchers then moved into the final stage of analysis, cross-analysis. The frequency of domains across the focus group interviews were examined to identify patterns, relationships, discrepancies, and essential themes. Domains were placed into three categories based on the commonality of their use - general, typical, and variant. General domains applied to all or all but one of the focus group interviews (14 or 15 interviews), typical applied to more than half of the interviews (8 to 13 interviews), and variant included at least two interviews up to half (2 to 7 interviews). See Figure 6 for the list of domains categorized into general, typical, and variant categories.

Figure 6. Final Focus Group Interview Domains

General	Typical	Variant
<ul style="list-style-type: none"> <li>• Access to Health Care</li> <li>• Alaska/Rural Specific</li> <li>• Confidence in Health Care Provider</li> <li>• Information Dissemination</li> <li>• Insurance</li> <li>• Provider/Patient Relationship</li> <li>• Quality of Life</li> <li>• Supports</li> </ul>	<ul style="list-style-type: none"> <li>• Advocacy</li> <li>• Behavioral Health Services**</li> <li>• CareCoordination/Continuity of Care*</li> <li>• Financial Burdens</li> <li>• Medication</li> <li>• Navigating the Health Care System</li> <li>• Personal Characteristics**</li> <li>• Provider Knowledge</li> </ul>	<ul style="list-style-type: none"> <li>• Dental Care</li> <li>• Diagnosis</li> <li>• Equipment, Supplies, and Repairs</li> <li>• Transportation**</li> <li>• Physical Activity</li> <li>• Provider Policies and Procedures</li> <li>• Rehabilitation Services</li> <li>• School District Services</li> </ul>

*Note.* \*Indicates typical domain overall, but was general to all focus groups with family members. \*\*Indicates typical or variant domain overall, but was general to all focus groups with people with disabilities.

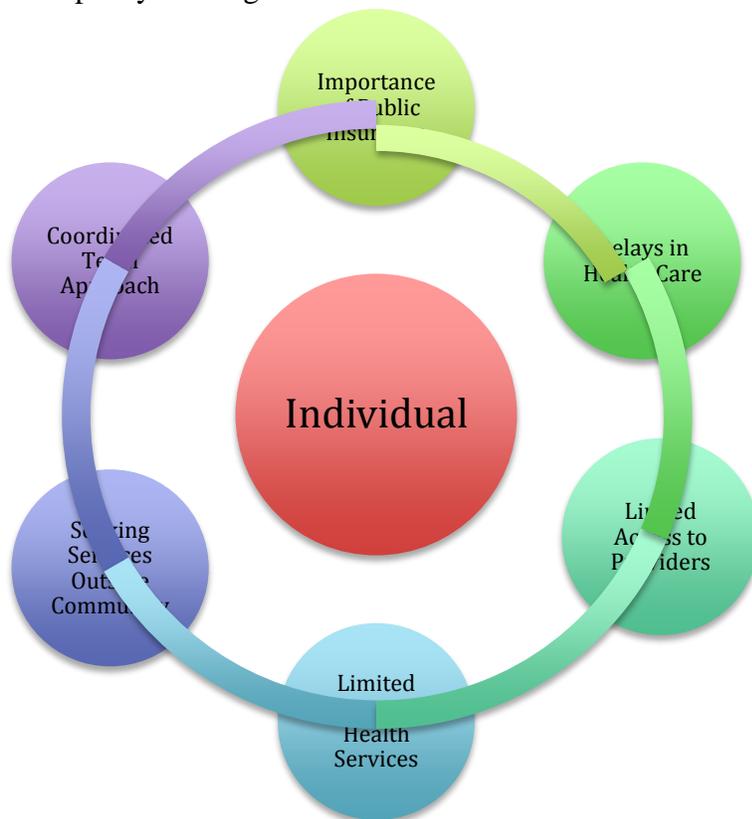
Based upon the analysis of the focus group interviews, six key findings emerged from the data:

1. Public insurance plays a critical role for people with disabilities to attain health care services.
2. People with disabilities experience delays in the health care system which impact care.
3. People with disabilities have limited access to health care providers.
4. Behavioral health services are limited for people with disabilities in Alaska.
5. Inadequate health care options cause people with disabilities to seek services outside of their community.
6. People with disabilities and complex medical needs benefit from a coordinated, team approach when obtaining health care services.

It is important to remember these key findings overlap with each other and at the core is an individual with a disability. People with disabilities have complex medical needs, which require

continuous care and attention. As they seek care to address their health needs, challenges related to their disabilities (e.g., cognition, mobility, sensory, communication) add to the complexity of their medical care. Figure 7 depicts the key findings of the focus group study.

Figure 7. Focus Group Key Findings



***Importance of Public Insurance***

Participants of the focus group interviews discussed the role of public insurance in their health care experiences. While many spoke of the challenges they have encountered, they were also able to articulate that public insurance plays a critical role for people with disabilities to attain health care services. This view was representative of all those who participated in the focus group interviews, both family members and people with disabilities. For some, public insurance was their only means of health insurance coverage, while others had dual coverage with private insurance. Regardless of their situation, public insurance programs provided access to many health care services that would otherwise be unattainable for people with disabilities including the coverage of travel costs to obtain services in other communities. It also helped to lessen the financial burdens people with complex medical needs face. For example, TEFRA directed a family to a program that reimbursed the premium for dependent coverage with their private insurance. The family said, “I could not have found this on my own. It has been a tremendous help financially.” See Figure 8 for quotes and summation of responses from focus group participants about the importance of public insurance.

Figure 8. The Importance of Public Insurance – Quotes and Summations

<b>People with Disabilities</b>
<ul style="list-style-type: none"><li>• Without long-term disability insurance I don't know how I would survive... Without Medicare I would not have that access.</li></ul>
<b>Family Members</b>
<ul style="list-style-type: none"><li>• Private insurance doesn't cover a lot of services and we rely upon Medicaid.</li><li>• I am grateful for the services provided to my [family member]. [He/she] wouldn't be here without it.</li><li>• The home and community based waiver has been wonderful.</li><li>• There are glitches but we have survived them so far and the services have been there for my [family member].</li><li>• Actually, Alaska is the first place that I feel [my family member] has gotten the best help.</li></ul>

Many focus group participants expressed their gratitude for specific publically funded programs like, Medicaid, Medicare, Tax Equity and Fiscal Responsibility Act (TEFRA), long-term disability insurance, Home and Community Based Services waiver, and Alaska Comprehensive Health Insurance Association (ACHIA). These programs make a real difference in the lives of people with disabilities.

### ***Delays in Health Care System***

In each focus group interview, people with disabilities and family members discussed their experiences with delays in the health care system and how those delays impacted their care. Common examples of delays within the system included:

- having to return to health care providers for prior authorization for medication or services;
- difficulty navigating the system due to terminology, not knowing what services are covered, or having to talking with several people before getting an answer;
- computer glitches;
- miscommunication;
- large amounts of paperwork;
- waitlists to see providers;
- coordinating private and public insurance payments; and
- trouble locating health care professionals.

Delays ranged from less than a week to return to a health care provider for prior authorization to months trying to locate a surgeon. Such delays impact the health care of individuals with disabilities because they are unable to receive immediate services to address their health care needs. For some, when the delays were not resolved in a timely manner, their health needs had escalated and necessitated new strategies. For example, one family stated, “for two years we fought with the State trying to get [equipment for my family member]. By the time we got it, my [family member] was not physically able to even use it. It was past its point of use.” See Figure 9 for additional illustrations of delays within the health care system.

Figure 9. Delays in Health Care System – Quotes and Summations

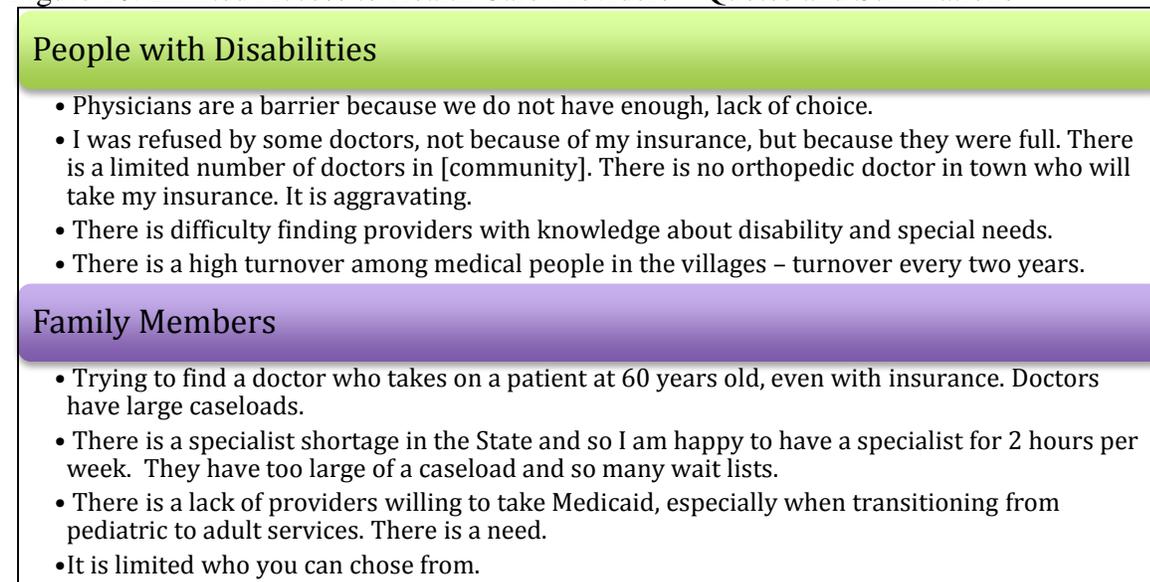
People with Disabilities
<ul style="list-style-type: none"><li>• I was dead [due to an error in Medicare records] and was not able to travel to get the testing needed. I didn't know what was going on. The computer glitches got in the way. It took over 6 months to try to get tests in [another community] because of the disconnect.</li><li>• Knowing what I qualify for with Medicaid [would be helpful]. I am having to go through five people before getting an answer.</li><li>• Medicaid is taking a long time to process claims. [Family member] applied in November for Medicaid and still has not been approved. Legally they have to make a decision in 4 months. They lost [his/her] paperwork.</li></ul>
Family Members
<ul style="list-style-type: none"><li>• [Family member] is on an enzyme prescribed by a specialist. We got the script and it was cut. Medicaid changed the prescription because they will only cover 40 per month. No one told me and we had to go back to the doctor to get prior authorization.</li><li>• It took us 3 months to get in for a needed surgery because we were looking for a specialist.</li></ul>

Individuals with disabilities and family members of people with disabilities expressed frustration with delays in health care system. Like everyone, people with disabilities want to access services in a timely manner. However, given their complex medical needs, delays in the health care system can have a compounding negative effect on an individual's well-being.

### ***Limited Access to Health Care Providers***

Family members and people with disabilities highlighted the limited access to health care providers in Alaska during the focus group interviews. Most spoke of limitations in regard to the number of providers within a community, the number of providers who accept their insurance, waitlists, providers who lack disability specific knowledge, turnover rates among providers, and large caseloads. Adults and family members of transition age youth most often cited these limitations. Family members of young children had mixed reports; some felt they could easily access health care providers and specialists, while others discussed the challenges of accessing services. Limited access to dental care and rehabilitation services were also discussed during the interviews. Rural communities specifically face the challenge of a limited number of providers. These participants discussed the importance to maintain their quality of life at the cost of a limited number of providers and services in their community. One family member shared, "families have to make a choice to tough it out without services or lose their identity and move to a city for services." See Figure 10 for quotes and summary responses from focus group participants about limited access to health care providers.

Figure 10. Limited Access to Health Care Providers – Quotes and Summations



Limited access to health care providers is a significant barrier for people with disabilities. Regardless of the type of disability experienced, size of a community, or type of insurance one has, people with disabilities across Alaska face obstacles when accessing health care providers. These limitations feed into the delays in the health care system by extending the time people are waiting to receive health care services. These limitations may also help to explain why health care utilization tends to be lower among people with disabilities.

### ***Limited Behavioral Health Services***

In the focus group interviews, participants expressed concern about limited behavioral health services for people with disabilities in Alaska. Both individuals and family members communicated this concern. One participant stated, “mental health is a big part of all disabilities.” Yet, most felt behavioral health needs had not been addressed for themselves or their family member. Participants discussed limitations such as not knowing how to access behavioral health services, facing long waitlists, providers not understanding co-occurring behavioral health and disability needs, and financial limitations. A few people discussed the at-times misplaced reliance on medication to address behavioral health concerns. One parent related his/her family member sees a therapist who believes medications will fix the problems and “they have continued to add medications, but it does not seem that they are helpful and now [he/she] has a cocktail of meds and all have potential side effects. It is a big deal – [he/she] is a developing young [person] and these are powerful, expensive medications.” See Figure 11 for illustrative quotes and summaries of limited access to behavioral health services.

Figure 11. Limited Behavioral Health Services – Quotes and Summations

### People with Disabilities

- Depression is common. I can't do what I used to be able to do. Things are falling apart. I am losing physical strength. Depression is related to health. I would like to have access to counseling services, but the wait is 4-6 months to see anyone.
- [Mental health providers] who accepted Medicare are no longer accepting Medicare patients and the out-of-pocket people are beyond my reach. This is really affecting me mentally, emotionally, and physically.
- It would help if [mental health provider] had more case managers, but there are budget shortfalls and low pay. It is hard to keep people there.

### Family Members

- We haven't been able to access behavioral [services]. Either we don't fit the right category or on paper we make too much money and we don't fit into certain boxes.
- Mental health has been difficult. I haven't figured that one out yet. Logistically I don't know if I am just fighting the wrong battle or haven't found the right avenue.
- There is only one place accepting Medicaid in town for mental health, but there is limited service for developmental disability/mental health co-occurring.
- A psychiatrist that really understands not just the mental health aspect but also the DD aspect and how that affects mental health. Without understanding the disability we ended up treating things that should not have been treated.

A few of the focus group participants were able to discuss the benefits of behavioral health services. For these individuals, behavioral health services have been critical to their overall well-being. One family member shared:

“Who [he/she] sees for counseling. The psychiatrist is supportive of [him/her] and doesn't degrade [him/her], understands [him/her] and what [he's/she's] going through, and understands what [he/she] has, and encourages [him/her] to do things instead of doing nothing all day. He's got [him/her] out hiking and talking to other people. [My family member is] becoming more of [him/her]self. They have [him/her] going back to school. All these positive things are happening for [him/her] and it's never been like that. There is positive reinforcement through the [behavioral health provider] and the [independent living center].”

The challenge of accessing behavioral health services impacts all people with disabilities. For many, behavioral health concerns are secondary conditions, which are not given the same priority as a primary condition. The complexity of co-occurring disorders also limits the number of providers with the ability to effectively work with people with disabilities. These limitations prevent people with disabilities from accessing behavioral health services and impact individuals' overall wellbeing.

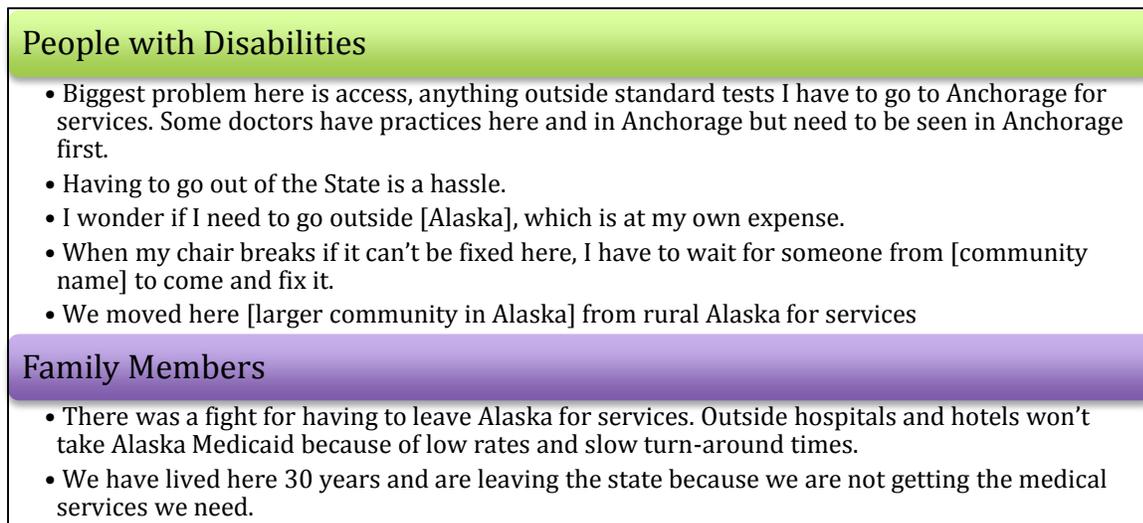
### *Seeking Services Outside of Community*

All of the focus groups discussed the challenge of living in a rural state and that inadequate health care options require them to seek services outside of their community. For some, services outside of the community meant the need to travel to a larger community within Alaska to receive the needed care. For others, services needed to be sought outside of Alaska. Participants described the challenges of traveling to other communities for services such as: economic burdens, time, approval processes, etc. For some, the limited services have resulted in the need to move outside of their community. One participant shared his/her family member had

to be moved from a small rural community, where he/she had lived his/her entire life, to a larger community to receive adequate care. They continued by saying, “[he/she] was moved when [he/she] needed the support of the community the most.” A few participants also shared they rely upon specialists to come to their community to provide care or repair equipment.

As participants in rural communities discussed seeking services outside of their community, this was not seen as overly problematic. In rural Alaska, most community members, regardless of disability status, have to also seek services outside of their community at times. It is accepted as a part of life when you live in a remote community. However, travel for individuals with disabilities is more cumbersome than those without disabilities. See Figure 12 for quotes and responses from focus group participants.

Figure 12. Seeking Services Outside of Community – Quotes and Summations



Having to seek services outside of one's community comes at a cost to people with disabilities and their families, whether it is financial or emotional. Alaska is unique, not only is it a rural state with much of the State not being connected by a road system, its remoteness from the lower 48 magnifies the challenges of seeking services outside.

### ***Coordinated Team Approach***

Focus group participants talked about the need for a coordinated team approach when managing their health care needs. Participants were able to discuss both positive and negative experiences in trying to coordinate care. Those who had positive experiences shared they had developed teams to work with them, their health care providers were able to link them to specialists, and they had developed strong relationships with their team members. For example, one family discussed a therapist who continued to work with their family member although they were not paid for a year because of a disconnect between private and public insurance. The therapist continued to work with the client because they did not want him/her to regress. Similarly, an individual upon returning from a trip was very ill, the doctor personally delivered [him/her] to the ER and [his/her] medical staff made daily visits until [his/her] discharge. Unfortunately, many other participants did not share similar experiences and expressed the desire to have a coordinated team approach. See Figure 13 for quotes and summations of participants' responses.

Figure 13. Coordinated Team Approach – Quotes and Summations

### People with Disabilities

- A bunch of people pushing me in the right direction, My treatment team, [program support], care coordinator, counselor, and assisted living home owner. People like that are the people we need in our lives.
- The other thing I do that really helps is I insist everything go through my primary care doctor, so that I have one gatekeeper. For me particularly it's important because of medications.
- I have found a neurologist in another community, which I literally stake my life on. I depend on her to keep me in the best health and manage my medication. She is just one person and this is a barrier. More people need to be involved.
- [What we] need more than anything is cohesive comprehensive care. A doctor to oversee all the specialists to have comprehensive service; oversight is not in place. That does not exist.

### Family Members

- A working medical home model takes a long time to develop – 10-15 years. We are close to this. The doctors work with specialists. This is important because they are working for the best outcomes. Sharing information for the best outcomes.
- We have been willing to move around services to find providers who treat us as if we're a team member. We have given up some things with some providers that we really liked but they didn't have that team mentality. They are 'We are the providers. This is the rule.' And that doesn't always work when you have a complex medical situation.
- Making sure there is a doctor who understands disabilities, I don't care if that's an eye doctor or dentist or medical specialist. That's something you are always searching for or can't find here.
- Somebody to coordinate some of the madness. 'Cause sometimes it gets, it gets a little much to try to keep track of everything and to try to get people to work together. Psychiatrist doesn't work with pediatrician. It is counter productive at times.

A coordinated team approach is beneficial for people with disabilities as they manage complex health care needs. For those without a team approach the responsibility of coordination tends to fall on the individual or family member. For most, this additional responsibility results in feeling overwhelmed or stressed and is magnified when individuals and family members do not know where to find services in their community. When services are not coordinated, their potential benefit is not maximized. Whereas, a coordinated team approach allows all of those involved in someone's health care, to work together for the best outcomes for an individual.

### Discussion

The key findings from this study are inseparably connected; none can be viewed in a silo. At the center of this complexity are individuals with disabilities trying to navigate and access health care services. For example, the inability to locate a provider may result in delays in treatment or may result in the need to travel outside of one's community to attain services. Without a coordinated team approach an individual may be on his or her own to find a provider. Although public insurance helps people to access services, there are still delays and glitches in the system. This study found that for some, their health care needs are being met. They are able to locate health care providers and access services they need. However, the larger portion of the focus group participants reported challenges to accessing health care in Alaska. It is not surprising people with disabilities experience health disparities given the challenges they encounter while accessing and navigating the health care system.

In addition to discussing their personal experiences accessing health care in Alaska, focus group participants also shared their opinions about what could be done to improve access within the State. Based upon the findings of this study, the following section outlines four recommendations to begin to address health disparities for people with disabilities.

### ***Training for Health Care Providers***

In order to address key findings related to limited access to health care providers, limitations in behavioral health services, inadequate health care options within communities, and benefits related to a coordinated team approach, training for health care providers is recommended. Training specific to people with disabilities could help increase health care provider knowledge and capacity. Areas of trainings suggested by focus group participants include diagnosis, co-occurring behavioral health/developmental disabilities concerns, disability awareness, developing relationships with clients who experience disabilities, the importance of working with teams, and person-centered services. These trainings could increase a health care professional's ability to provide services to a person with a disability. Further, this capacity could also increase the patients' confidence in their health care staff.

### ***Training for Individuals with Disabilities and Families***

In order to address key findings related to the benefits of a coordinated team approach, training for people with disabilities and their families is recommended. Participants of the focus group emphasized the importance of advocacy. One participant stated, "being a self-advocate is the best thing" when seeking services. Families shared their experiences advocating for their family members during health care visits and redirecting providers focus to the patient. It is essential to remember the individual is at the center of all of the services; services should be person-centered. People with disabilities and families could benefit from advocacy training. Such trainings could help people with disabilities and their families express their desires, goals, and needs related to health care. More often people who identified themselves as advocates tended to have coordinated teams of which they were active members.

### ***Reduce Barriers within the Health Care System***

In order to address key findings related to delays in the health care system, limited access to providers, and limitations of behavioral health services, a State action plan should be developed to reduce barriers within the health care system. Many of the focus group participants lamented over the challenges of navigating the health care system. One said, "it would be extremely helpful if the system was more user friendly." Another commented, "simplicity is never outdone. It's too complex. The systems should be simplified." Participants' suggestions to improve the health care system included:

- Simplify language and terminology.
- Make it easier to navigate the State website.
- Provide "a list of providers who accept Medicaid/Medicare" within a community.
- "At the first point of contact more information about where you could go for services."
- "When entering the system get a packet describing services, what is available to you and this is the number to call."
- Increase reimbursement rates for Medicare and Medicaid to increase the number of providers who accept patients.
- "Increase the number of providers to reduce waitlists."

- Provide “more community health centers all over the State.”

The suggestions by people with disabilities and family members reflect the need to increase access to health care services and reduce the delays in the system. The action plan should be developed through a participatory process, which includes people with disabilities, families, health care providers, public and private health insurance representatives, State government, and other health care stakeholders.

### ***Alternatives to Seeking Services Outside Communities***

In order to address key findings related to limited access to health care providers and having to seek services outside of community, it is recommended telehealth/telemedicine and itinerant health services be utilized. Many participants spoke about the burdens associated with traveling outside of a community for services. A few offered alternate ways to access services without having to leave their community. One participant suggested, “funding and technology for distance medical services [and] video conference instead of flying out of state” to access services. Telehealth services are offered within a limited scope in Alaska, but could be expanded. Telehealth services help increase access to timelier health care and keep people in their community. Another strategy that is used in Alaska is itinerant health care providers who travel to rural communities to provide services. Participants talked about providers who travel within the State and also those who come from outside of Alaska. Participants spoke of their reliance on these health care providers. The increased use of itinerant providers could also help reduce access barriers and allow people to stay in their home communities.

## **Conclusion**

Given the findings of this needs assessment, there is much work to be done in Alaska to address health disparities for people with disabilities. Health care providers expressed the desire for more disability related training and could improve consultation practices with individuals with intellectual and cognitive disabilities. Agency and support staff could also benefit from training related to their role when attending health care appointments. Focus group participants provided many examples of how the health care needs of Alaskans with disabilities are being met. In order to improve the system, these examples need to become the norm instead of the exception. It is imperative to have people with disabilities, families, health care providers, public and private health insurance representatives, State government, disability stakeholders, and other health care stakeholders working together to reduce the gaps in and barriers to accessing services by developing a statewide strategic plan. A strategic plan would help to focus the effort of eliminating health disparities for people with disabilities by bringing attention to the differences and providing solutions to overcome them. By working together as a health care system, improvement in the health outcomes of Alaskans with disabilities can be achieved.

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