

## Introduction

**The Future of Disability in Alaska Summit** was held in Anchorage in the summer of 2013, May 9-10. The purpose was to gather perspectives from a diverse group of stakeholders to inform a vision of the future for people with disabilities in Alaska. A task force comprised of individuals from UAA and Hope Community Resources planned and organized the summit:

- Herb Bischoff, Hope Community Resources
- Heather Chord, LEND (Leadership Education in Neurodevelopmental & Related Disabilities) Fellow, University of Alaska Anchorage (UAA)
- Michele Girault, Hope Community Resources
- Stephanie Johnson, Master's of Social Work Candidate, UAA
- Karen Ward, UAA Center for Human Development

The format of the summit consisted of a keynote speaker, opening remarks, and a series of presentations by recognized Alaskan leaders in the disability field, followed by working group discussions.

- **Keynote Speaker:** Katherine McDonald, PhD, FAAIDD from Syracuse University
- **Opening Remarks:** Steve Lesko, Executive Director of Hope Community Resources

It is acknowledged that there are many very important topical areas that should be examined in this type of forum. The limited time for this summit required narrowing the discussion to five areas. Listed below are the topics that were chosen and the presenters who introduced them.

1. **Housing Arrangements:** Roy Scheller, PhD, Deputy Executive Director of Hope Community Resources
2. **Advocacy:** Kara Thrasher-Livingston, State of Alaska, Senior & Disabilities Services
3. **Relationships:** Karen Ward, EdD, Director of the UAA Center for Human Development
4. **Economic Wellbeing:** Millie Ryan, then Executive Director of the Governor's Council on Disabilities and Special Education
5. **Health:** William Browner, MD, Alaska Native Medical Center

Based on findings from a qualitative analysis of the stakeholder perspectives gathered at the summit, a follow-up online survey was designed and implemented. The purpose of the survey was to gather perspectives from a broader range of stakeholders and to get a sense of the highest priorities in each topical area.

# Method

## Summit

Following each of the five topical presentations, participants in [The Future of Disability in Alaska Summit](#) broke into seven working groups. Group membership was randomly assigned at registration. Though there was flexibility to accommodate individual needs and latecomers, group membership remained mostly constant for the duration of the summit.

Facilitators for working groups were engaged prior to the summit and prepared with a set of guidelines for group process. Facilitators were responsible to help groups establish and follow ground rules. They ensured groups chose note takers and timekeepers. Facilitators introduced a pre-established set of questions and helped to keep discussion moving and on topic, but otherwise they did not control the direction of discussion. They encouraged equity in participation, kept a record of off-topic issues, and intervened if necessary when there were conflicts.

Working groups addressed the following questions in each topical area (Housing Arrangements, Advocacy, Relationships, Economic Wellbeing, or Health):

- What is your vision of the future in [topic]?
- Looking at different stages of life, what are your desires/needs to achieve your vision of the future in [topic]?
  - Young children
  - Adolescence
  - Adulthood
  - Seniors
- What do you not want to see in the future?

## Qualitative Analysis of Summit Responses

The task force continued to meet after the summit to determine what process would be used to analyze the large quantity of qualitative data collected, and how to garner broader input from Alaskan stakeholders who were not able to attend the summit. Dr. Katherine McDonald from Syracuse University continued to work as a consultant in this process. Three people were chosen to conduct a qualitative analysis along with Dr. McDonald: Dr. Karen Ward, Rain Van Den Berg, and Roxann Lamar from the UAA Center for Human Development (“the analysts”). The original task force reviewed findings and had opportunities to weigh in at the completion of each major step described below.

**Step 1:** The notes from each of the seven working groups were transcribed from the flip charts used during the summit, and a document was prepared for each topical area combining the responses for that topic across the 7 working groups. Within each topic, responses were organized under 1) Vision of the

Future, 2) Stages of Life, 3) What We Don't Want to See, and 4) Points for Discussion (other). This pattern of grouping responses basically followed the pattern of questions that were asked of summit participants.

**Step 2:** The four analysts worked in two pairs, dividing up topics to conduct an initial sort of responses into themes that were specific to each topical area. Across themes, responses were further sorted by: 1) Vision, 2) Needs, and 3) Strategies. The sorting of responses went through a primary review by one pair of analysts until they reached consensus, then it went through a secondary review by the other pair of analysts. This process continued until there was consensus across analysts on how responses were categorized and sorted in each topical area. At this stage of the process, all data was maintained in its raw form, but categorizing started a process of interpretation.

**Step 3:** The four analysts continued the same consensual process with primary and secondary reviews in pairs to synthesize comments into summary statements, the next level of interpretation. Within each theme category in each topical area, the information under Vision and Needs was combined into a series of summary statements. Strategies were combined in summary statements that aligned with themes and vision/needs statements.

**Step 4:** Two of the analysts continued a consensual process to reduce the Vision/Needs statements as much as possible to series of bulleted phrases representing main ideas for drafting survey items. The draft survey was reviewed by the other pair of analysts and members of the task force, and revised according to their feedback. The draft survey was tested separately by two individuals with I/DD, one who had attended the summit and one who had not. Items were revised for understandability based on their feedback.

## Follow-up Survey

The purpose of conducting a follow-up survey was two-fold: to hear from a broader range of stakeholders and to get a sense of the highest priorities. The survey used the five topical areas from the summit. However, Economic Wellbeing and Health each had a markedly larger number of ideas. These two topics were broken into subthemes to make them more manageable in a survey format. This resulted in eight sections for an online survey:

1. Housing Arrangements
2. Advocacy
3. Relationships
4. Economic Wellbeing Across the Lifespan
5. Economic Wellbeing Awareness & Policy
6. Quality of Healthcare
7. Health & Wellness
8. Health Access & Policy

Within each of the eight sections of the survey, respondents were asked to choose what they thought was MOST important from a list of ideas. Usually they could choose up to three ideas from a list, but in two subareas with fewer options they could choose only one or two. Each prioritization item was followed by an opportunity to note any needs that were not yet included. The last section of the survey asked for demographic data to summarize types of respondents and areas of residence. When respondents submitted the survey, they were directed to a separate online survey where they had an opportunity to enter into a drawing for \$25 gift cards if they wished.

The survey invitation was sent out on October 15, initially utilizing the listserv resources of the UAA Center for Human Development, Hope Community Resources, and the Governor’s Council on Disabilities and Special Education. The invitation encouraged recipients to share the invitation with others, and offered accommodations and assistance through the UAA Center for Human Development. The deadline for response was October 31, but an examination of preliminary results indicated there was not as much response as desired from persons with disabilities and family members. Organizations working with these populations were encouraged to make more effort to get the survey out to individuals and families, and the deadline was extended to November 15.

This report combines the results from both the qualitative analysis process of [The Future of Disability in Alaska Summit](#) with results from the follow-up survey. It includes vision summary statements, and also strategies suggested by summit and survey participants that can be considered in making plans and working toward the vision.

## Participants

### Summit Participants

There were approximately 76 participants in the summit. Stakeholders included people with disabilities, family members, advocates, service providers, policymakers, and other people interested in the future for people with disabilities in Alaska.

### Survey Respondents

There were 285 respondents to the online follow-up survey. In demographic data respondents were asked to “check all that apply” from a list of types of respondents. Seventeen respondents skipped this item. Of those who answered the question ( $n = 268$ ), well over half (160 or 60%) indicated they were persons with disabilities or family members, over half indicated they were service providers (147 or 55%), and almost half indicated they were advocates (129 or 48%). Detailed results are listed in Table 1.

**Table 1: Types of survey respondents**

Type of Respondent	Number	Percent
Service provider	147	55%
Advocate	129	48%
Family member	114	43%
Educator	57	21%
Person with a disability	46	17%
Healthcare provider	41	15%
Self-advocate	25	9%
Academic/Researcher	15	6%
Policymaker	13	5%
Other	31	12%
<b>Total Respondents</b>	<b>268</b>	<b>100%</b>

Of the 31 respondents indicating “other,” 5 noted they were counseling, mental/behavioral health, or rehabilitation professionals; 4 caregivers of persons with disabilities; 4 administrators or government workers; 3 vocational rehabilitation workers; 3 case managers or care coordinators; 2 students; and 2 community members. The rest added clarifications, unique roles, or job positions.

Respondents were asked to provide a zip code for the place in Alaska where they lived most of the time. There were 47 (16%) respondents that skipped this item, and one who gave a zip code for another state. In Table 2, the Alaskan zip codes provided ( $n = 237$ ) were sorted by the economic regions of the state used by the Alaska Department of Labor and Workforce Development, as compared to the most current general population statistics from the same Department.

**Table 2: Regional response profile**

Region	Response (% AK zip codes)	General Population (%)
Anchorage/MatSu Region	148 (62%)	392,643 (54%)
Gulf Coast Region	27 (11%)	80,750 (11%)
Interior Region	17 (7%)	115,114 (16%)
Northern Region	5 (2%)	27,312 (4%)
Southeast Region	35 (15%)	74,423 (10%)
Southwest Region	5 (2%)	42,056 (6%)
<b>Total</b>	<b>237 (100%)</b>	<b>732,298 (100%)</b>

At first glance, there seems to be a disproportionate response by region to the survey, particularly an over-representation in the Anchorage/MatSu and Southeast Regions. However, the population of interest for this survey is not distributed the same as the general population. The vast majority of disability services, including highly specialized services are more available in urban areas. There are not only more providers, but it is also a known migration pattern that people with disabilities and their families relocate to larger population centers because they need access to specialized and intensive services. For example, the Alaska Division of Vocational Rehabilitation 2014 State Plan noted that Census data documents a definite rural to urban migration pattern for persons with disabilities in Alaska [see Attachments 4.11(a) and (e)(3) of the State Plan]. With that in mind, the most questionable result in regional distribution of survey respondents is a low response from the Interior Region that includes Fairbanks.

There were 169 respondents who entered their names and addresses into the drawing for a gift card. After the conclusion of the survey, winners of the drawing were chosen using the random number assignment function in Excel. The five entrants with the highest random numbers were awarded \$25 gift cards to popular shopping vendors. Gift cards were donated by the UAA Center for Human Development.

**A note about comments added to surveys:** The intent of adding a comment space after each priority ranking question was to gather any “missing” ideas, especially from people who did not have a voice in the summit. However, many respondents used the comment space to repeat items from the list provided, beyond the ones they chose as the most important. This reflects the difficulty of choosing only a few things when everything is important.

There were hundreds of comments added to surveys and each was checked against information recorded from the summit to evaluate if an idea expressed in a survey comment was already sufficiently covered, particularly in the wealth of suggested strategies (not presented in the survey). In this report, any new information from survey comments was integrated with the information gathered at the summit. A few quotes from survey comments are also included to help remind readers this is about people’s lives.

**A note about interpreting results for priorities:** Anything that was endorsed as most important by a third or more ( $\geq 33\%$ ) of respondents was considered meaningful.

Results are organized in the following sections by topical area.