Executive Summary

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 in five broad topical areas: 1) Housing Arrangements, 2) Advocacy, 3) Relationships, 4) Economic Wellbeing, and 5) Health. 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 making some choices and focusing the discussion.

About 76 stakeholders participated in the summit including people with disabilities, family members, advocates, service providers, policymakers, and others. A follow-up online survey was conducted to gather information from a broader range of stakeholders and to get a sense of the highest priorities in each topical area. There were 285 survey respondents. In addition to other overlapping roles, about half were persons with disabilities or family members, and about half were service providers.

The purpose of this report and other products coming out of this effort is to inspire stakeholders to periodically reflect, individually and in groups, on how they are working toward the vision in a relevant topical area and taking action in the context of advocacy, policy/regulation, funding, and services/resources. Please see the body of the report for full elaborations of the vision for each topical area, and the many suggested strategies to accomplish it.

What is the vision of the future for Housing Arrangements?

The vision for quality housing incorporates affordability, stability, safety, integration, choice, accessibility, and well-trained staff. Inclusion is interdependent relationships characterized by respect, appreciation, support, and belonging. The vision calls for personal choice and access to supports with diverse options in both urban and rural areas, flexibility in funding and supports, and the right of individuals to have a meaningful voice.

The first priority is for 1) *affordable, stable housing in safe neighborhoods*, followed by 2) well-trained staff and consistent services. The following were each endorsed by 46% of respondents: housing in a community of choice that respects independence, freedom, and culture; flexibility in funding and supports; and individuals have a meaningful say in activities, routines, and who lives with them.

What is the vision of the future for Advocacy?

The vision for advocacy includes public awareness, greater accessibility, and inclusion as a respected member of the community. The vision calls for a strong self-advocacy system, safe places and support to learn self-advocacy, and leadership roles. It calls for unity in advocacy and collaboration, greater involvement in civic engagement and policy development, and greater awareness and equality in the legal system.

The priority that rose to the top is 1) the *choice, desires, and opinions of individuals are valued and respected*, followed closely by 2) greater public

awareness and accessibility, and 3) unity in advocacy across agencies, types of disabilities, and the lifespan.

What is the vision of the future for Relationships?

The vision for relationships is a society that takes it for granted that people with disabilities have the same human needs and desires as people without disabilities and the same human rights. It includes safety and inclusion in social environments, and access to relevant education and supports. The vision calls for the same rights to make choices as people without disabilities, and the removal of barriers to healthy relationships imposed by policy and regulation.

The top priority is 1) *safety from abuse, violence, unfair treatment, and exploitation*. This is followed by 2) flexible supports driven by individual needs and priorities; 3) staff respect the dignity of risk, boundaries, and the balance among individual choice, safety, and privacy; and 4) recognition of equal human needs for healthy relationships and equal human rights.

What is the vision of the future for Economic Wellbeing?

The vision for economic wellbeing starts at a young age with the economic stability of families, increasing awareness and capacity of parents, schools, doctors, and others providing services for children. It continues along the lifespan into the expectation for employment and access to the same opportunities in preparation for employment and financial security utilized by other adolescents and adults, resulting in meaningful employment and careers. It extends to financial security for seniors along with options that respect independence and choice in housing, employment, and activities. The vision calls for community awareness and involvement, as well as policy and regulations that support economic wellbeing from the individual perspective without penalties for being successful.

This area was broken into two subareas for setting priorities. The top priority for economic wellbeing across the lifespan is 1) *long-term planning for economic wellbeing across the lifespan,* followed by 2) opportunities to work full-time and earn a living wage, and 3) equal opportunity for job skill development and career exploration. The top priority for economic wellbeing awareness and policy is *no penalties for gaining employment.*

What is the vision of the future for Health?

The vision for quality of healthcare includes more individualized, flexible approaches and greater continuity of care, using a team approach for transition from pediatric to adult services. It calls for improved professional standards, greater accountability, better training, and incentives for health professionals to work with people with disabilities. The vision includes better overall management of medication, with increased access to alternative approaches. It addresses wellness with a holistic approach to an overall quality of life, with more access to facilities, transportation, information, prevention, and resources. To facilitate choice, there is more individual and family involvement in setting goals and making decisions, more education about evidence-based

information, and shared responsibility. The vision calls for strong self-advocates, more family practice providers, and respect for the right of individuals to make decisions about their own bodies. Flexible policies, regulations, and funding support care-driven services, with both standard and holistic approaches, that promote health and integrate healthcare.

This area was broken into three subareas for setting priorities. The top priority in quality of healthcare is 1) *coordination and continuity of care among providers,* followed by 2) providers trained to work with individuals with disabilities, and 3) services are individualized and flexible. The top priority in health and wellness is 1) *a whole person, quality of life approach,* followed by 2) a focus on wellness and prevention, and 3) individuals and teams share responsibility for choices in health goals, plans, and decisions. The top priority in health access and policy is 1) *affordable, quality healthcare,* followed by 2) policy supports care-driven services.

What improvements could have impact across areas?

In working with the volume of stakeholder perspectives gathered in the summit and in the follow-up survey, it became apparent there were issues that crossed all topical areas. These Universal Themes include:

- Transportation
- Inclusion
- Advocacy
- Equality
- Accessibility
- Choice
- Flexibility
- Safety
- Public Awareness

It can be concluded that considering the above issues and making improvements whenever possible could have broad impact. Please see the full report for a discussion of how these issues came up under each topical area.

Reflection Questions

In any topical area…

- How does advocacy support the vision and priorities?
  - If it is weak, how can it be strengthened?

- How do policies and regulations support the vision and priorities?
  - If they create barriers, how can they be changed?

- How do sources of funding support the vision and priorities?
  - If they are in conflict, what other funding can be used?

- How do services and resources support the vision and priorities?
  - If they fall short, how can they be improved?