

## **DD Systems Assessment Project: Phase One**



***If you were describing the ideal DD system, what are some of the words you would use?***

Trust  
Alaska Mental Health  
Trust Authority

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## INTRODUCTION

Alaska's publicly-funded developmental disabilities (DD) system is undergoing transformation. Medicaid reform, a national and local paradigm shift toward person-centered care, and Alaska's fiscal challenges are propelling Alaska's DD service system to a new, as yet to be determined, place.

By state statute (AS 47.30.660), the Department of Health and Social Services is tasked with developing and periodically revising a plan for a comprehensive integrated mental health program (which includes services to people with developmental disabilities) in conjunction with the Alaska Mental Health Trust Authority. Given the current degree of change and uncertainty, the Trust and its partners initiated a deeper look into the system of support for people with developmental disabilities.

Between October 2016 and January 2017, the Trust sponsored a statewide outreach process to gather input on what the future developmental disability service system should look like. This process resulted in a Shared Vision and Five Priorities. This report summarizes data collected during this initial phase which will inform the next steps in the assessment process.

Under the Trust's leadership, a steering committee comprised of DD systems "thought leaders" came together to guide the development of a comprehensive systems assessment process. Early on leaders recognized the value of a Shared Vision that would shape systems change.

There are three primary motivations behind the development of a Shared Vision statement regarding services and supports for Alaskan citizens experiencing intellectual and developmental disabilities:

1. A desire to have a unified Vision guiding us in times of strong fiscal resources as well as in times of fiscal shortfalls. The Vision statement is absent any fiscal note or language. Whether we have ample fiscal resources or not, our Vision will still be followed.
2. In the past few decades, the model of service delivery in Alaska has shifted from a medical model to a supports model and then back to a medical model. This Vision statement will drive the State of Alaska toward the supports model approach and guide major system transformation underway due to SB74 as well as future changes. The supports model is anchored in person-centered thinking, self-determination and individualized funding.
3. A unified Vision statement supported by stakeholders begins a healthy, healing process for people involved in supports for Alaskan citizens experiencing an intellectual/developmental disability. Support recipients, support providers, and support funders/regulators sharing a unified Vision will have common ground to act from. This common ground will provide a focus of healing and trust-building as we all move forward together.

As part of this process, there was significant recognition that this Vision will provide guidance not only for today but into the future and withstand changes in administrations.

The Vision and Priorities are playing a key role in legislative activities this year. In anticipation of the legislative session, members of the DD Vision Steering Committee, along with representatives from the Key Coalition of Alaska and the Statewide Independent Living Council, designed an infographic. The infographic included the new Shared Vision and Priorities along with historical and current information describing

Alaska's DD system. Members of the Governor's Council on Disabilities and Special Education shared the infographic at legislative meetings in Juneau. The Key Coalition plans to use this tool as well during its annual Key Campaign.

The Trust is leading this project in collaboration with the Alaska Association on Developmental Disabilities (AADD), the Alaska Department of Health and Social Services (DHSS) Senior and Disabilities Services (SDS) and the Governor's Council on Disabilities and Special Education.

On behalf of the Trust and its partners we thank everyone who took the time to share your thoughts, either by participating in a focus group, a webinar or the online survey. Each comment has been documented and will contribute to shaping the direction of things to come.

Members of the DD Vision Steering Committee included:

<b>Name</b>	<b>Role</b>	<b>Organization</b>
Roy Scheller, Chair	Executive Director	Hope Community Resources
Amanda Lofgren	Program Officer	Alaska Mental Health Trust
Heidi Wailand	Data and Policy Planning Officer	Alaska Mental Health Trust
Michael Bailey	President	Alaska Association on Developmental Disabilities
Amanda Faulkner	Vice President	Alaska Association on Developmental Disabilities
Lizette Stiehr	Executive Director	Alaska Association on Developmental Disabilities
Travis Noah	Beneficiary	
Joyanna Geisler	Executive Director	Kenai Peninsula Independent Living Center
Mallory Hamilton	Parent	Governor's Council on Disabilities and Special Education
Patrick Reinhart	Executive Director	Governor's Council on Disabilities and Special Education
Kristin Vandagriff	Program Manager	Governor's Council on Disabilities and Special Education
Shelly Vendetti-Vuckavich	Parent	Governor's Council on Disabilities and Special Education
Duane Mayes	Director	DHSS Senior and Disabilities Services
Caitlin Rogers	Waiver Unit Supervisor	DHSS Senior and Disabilities Services
Kim Champney	Contract Support	Kim Champney Consulting

## **SHARED VISION STATEMENT FOR THE DEVELOPMENTAL DISABILITY SYSTEM IN ALASKA**

***Alaskans share a Vision of a flexible system in which each person directs their own supports, based on their strengths and abilities, toward a meaningful life in their home, their job and their community. Our Vision includes supported families, professional staff and services available throughout the state now and into the future.***

### **Five priorities based on community input:**

**Priority #1 - Every person directs their own supports:** Based on his or her strengths and abilities, the person receiving services will decide when, who and how services are provided. Families and other team members will help with supported decision making so that the person can direct services as much as they are able. This includes a commitment to making services available in the community where the person chooses to live as well as honoring the family's role in the lives of children receiving services.

**Priority #2 - Services will support lives with meaning:** Our system helps people create lives with meaning, purpose and inclusion as well as respecting individual choices. This will look different for each person. Opportunities for meaningful relationships and natural supports are highly valued. As Alaskans, we will support the diversity of cultures of people receiving services in our state.

**Priority #3 - Our system values the role of direct support professionals:** Direct support professionals will have the knowledge, skills, and abilities to perform job duties. This includes access to education and supportive supervision. A good direct support professional is engaged and assists the person to lead a meaningful self-directed life which includes helping the person develop and maintain a variety of respectful and authentic relationships.

**Priority #4 - Our system is flexible and simple:** Our system is responsive to needs and preferences throughout life. It is as simple and clear as possible so individuals and families understand how to get their needs met. Information is available in a clear, concise, and consistent manner. Also, the person understands the variety of services available and is assisted as needed to make an informed choice.

**Priority #5 - Our system uses resources wisely and measures outcomes focused on quality of life:** Alaska is committed to the Vision above regardless of available resources. This Vision drives quality improvement. In order to ensure the system is available into the future, resources are used wisely while innovation and creative problem-solving are encouraged.

## DESCRIPTION OF OUTREACH ACTIVITIES

The outreach process kicked off with an interactive presentation at the Alaska Association on Developmental Disabilities annual meeting November 3, 2016. Amanda Lofgren and Heidi Wailand from the Trust introduced 50 attendees representing DD provider agencies large and small to the systems assessment project. Participants provided input using Audience Response Technology.



In preparation for this presentation, the Trust developed a graphic (attached to this report) illustrating the myriad of forces currently influencing the DD system. Providers shared their perspective on the most significant forces impacting service delivery:

### *Top three environmental factors impacting providers*

1. Increasing pressures to do more with less
2. Compliance and liability drive up costs
3. Workforce challenges

### *Top three reform forces impacting providers*

1. New staff training and provider certification requirements
2. Conflict-free case management as catalyst for reform
3. Changing role of day habilitation services

Providers were also asked to imagine how beneficiaries experience the system today and then, after some discussion about the qualities of a true person-centered system, providers repeated the activity using a fresh person-centered lens. The results of this activity are attached to this report.

In discussing the many current and anticipated systems changes, not surprisingly providers expressed feeling more uncertain and negative than positive:

Generally Positive = 34%	Generally Negative = 64%
22% feel Optimistic	30% feel Anxious
6% feel Inspired	14% feel Discouraged
4% feel Trusting	14% feel Frustrated
2% feel Confident	6% feel Overwhelmed

Following the DD provider gathering, the Steering Committee held a series of meetings to discuss the development of a unifying Vision for the DD system. With skilled facilitation provided by Roy Scheller, executive director at Hope Community Resources, the committee



identified five key components as well as an initial draft Vision statement. The committee designed an outreach process, carefully considering how to provide opportunities for all stakeholders to provide input with equal voice. These stakeholders included beneficiaries, family members, direct support professionals, other service provider representatives, care coordinators, community partners and State of Alaska staff. Due to timing of the legislative session, the outreach was limited to a three-week period.

Between December 5 and December 31, 2016, the team gathered input through multiple facilitated meetings as well as an online Survey Monkey. All participants were asked the same questions:

- If you were describing the ideal DD system, what are some of the words you would use?
- What does “able to be sustained over time” mean to you?
- What does “person and family-directed supports” mean to you?
- What does “life of meaning” mean to you?
- What does “flexible services” mean to you?
- What does “skilled workforce” mean to you?
- Are there any concepts that you really think are missing?
- What do you like about this Vision?
- What do you not like about this Vision?
- Is this a Vision that you think would help you or your family member?

Community focus groups were held in Kenai, Kodiak, Juneau, Wasilla and Anchorage. Project representatives also facilitated discussions with the Governor’s Council DD Committee and Senior & Disabilities key staff.

The DD Vision Steering Committee reviewed the input and revised the Vision Statement and Five Priorities in response.

A total of **212** people provided input on the Vision.



*++Some DSPs identified as DD Service Providers in the online survey.*

*\*\*Other includes SDS staff, friend, health care professional, other state government, university staff, hospital social worker, tribal vocational rehabilitation, special education provider, advocate*

In January, the Trust presented at the Care Coordinator Conference organized by Senior and Disabilities Services. Ninety participants, primarily care coordinators, were introduced to the Vision Statement and Five Priorities. Using Audience Response Technology, attendees provided input on the Vision Statement and Priorities as well as several other questions, several which were also asked of providers at the AADD gathering in November.

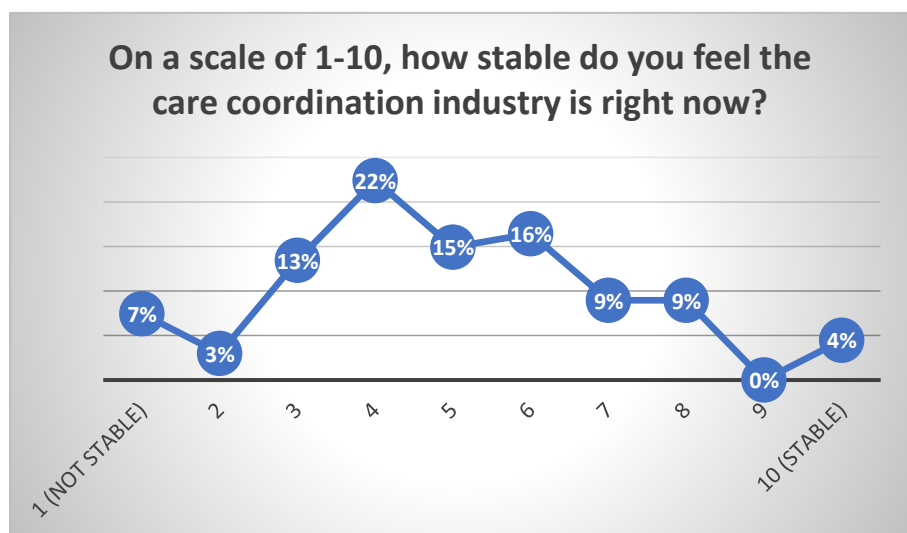


For example, care coordinators were also asked how they felt about current and upcoming changes in the system and were slightly more anxious and overwhelmed than the provider community:

<b>Generally Positive = 25%</b>	<b>Generally Negative = 75%</b>
21% feel Optimistic	28% feel Anxious
4% feel Confident	23% feel Overwhelmed
1% feel Trusting	13% feel Frustrated
0 feel Inspired	11% feel Discouraged

Care coordinators were also asked questions about the stability of the industry. Given that the transition to conflict-free care coordination was finalized July 2016, this particular segment of the DD system has had significant recent upheaval. Out of the 90 care coordinators in the room, 46 percent had been a care coordinator for less than four years; 30 percent had changed employers in the past year. *(This number may have been higher if the question had asked employment change in the past two years.)*

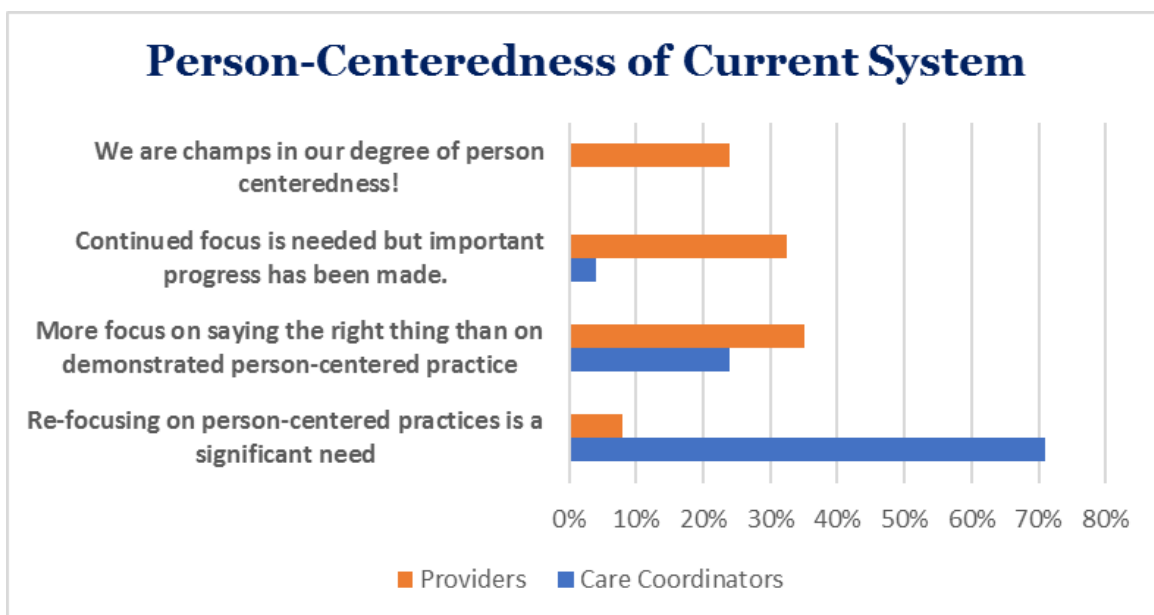
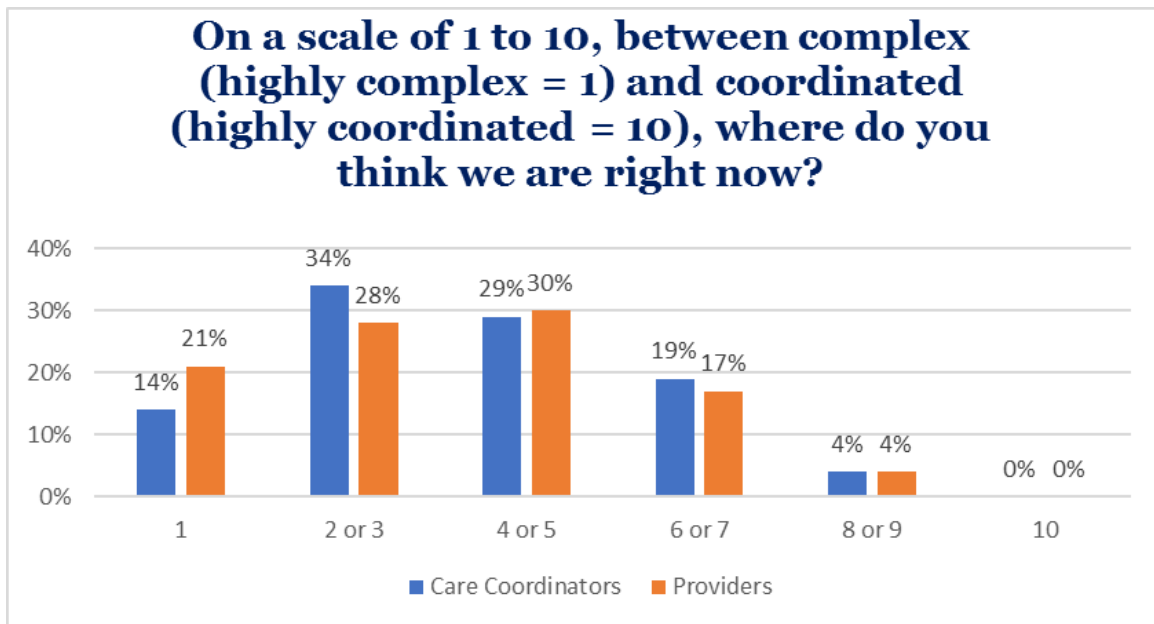
The chart to the right illustrates, from the care coordinator perspective, how stable the profession feels at this time.





## NOTABLE TRENDS

Automated Response Technology provides a unique data opportunity. Providers and care coordinators were asked their impressions of the current system in two different gatherings. While both groups were aligned on the current level of the system's complexity – generally leaning toward the DD system is highly complex - the two groups had significantly differing perceptions of the current system's degree of person-centeredness. Providers were much more positive about person-centered practice in today's service delivery system. Another noteworthy comment made during the care coordinator presentation: all recipients of long-term care services in Alaska would be well-served by this Vision, not just people with developmental disabilities.



The outreach process specific to the draft Vision statement and key concepts elicited many thoughtful comments. A level playing field was an important element of the process – family members, service recipients, direct support professionals, providers and advocates had equal voice in development of the Vision.

When reviewing input from participants in the online survey and various focus groups, the following trends and comments impacted the final draft Vision statement:

- Overwhelmingly participants liked the draft Vision statement and were aligned with the key concepts.
- The concept of “sustained over time” was challenging for some people to understand. Also, several people shared they were concerned that it was code for funding cuts.
- Several people were confused about “skilled workforce” – it wasn’t clear whether this described service providers or increasing the skills of people with disabilities related to employment.
- There was lots of energy around the importance of direct support professionals – the need for training and better pay – and how key this is to the success of an individual.
- Also, there were many comments about the need to simplify the system. Descriptors included cumbersome, broken, inconsistent, inaccessible, and confusing.
- There were multiple comments about lack of access to services in rural areas.
- There was some concern regarding person-directed services. Some participants struggled to understand how certain recipients could direct their services and were concerned they would be left out of the Vision. Also, concerns were expressed about the need for safety and protection of people who are vulnerable. Quote from a family member: “Blatantly unfair to place responsibility totally on the disabled person if their disability handicaps them in any way from receiving information or services or action or advocacy.”
- There were multiple comments around innovation, technology, up-to-date information, and training
- “Flexible services are important but very undefined ... creates all manner of expectations unless all manner of defining "flexible" are addressed.” There were several comments about the difficult reality of this with paid staff if interpretation means services are flexed daily.

## SUMMARY OF COMMENTS

Comments received on each of the key concept areas discussed during the outreach process were sorted into themes. Below, the major themes are listed under each outreach question in order beginning with the most prevalent. *(All comments were documented and are available at [www.mhtrust.org](http://www.mhtrust.org)).*

### **What does “able to be sustained over time” mean to you?**

1. Adequate funding is available on an ongoing basis.
2. The system is well-planned.
3. There is a culture of collaboration across stakeholders.
4. Services continue ongoing in a stable and predictable manner.
5. There’s a high level of understanding which results in a more resilient system.

### **What does “person and family-directed supports” mean to you?**

1. The choices of individuals receiving services are respected.
2. The person is in control of their services.
3. Services are designed based on individual needs.
4. Service providers and others listen carefully to the individual receiving services.

5. There's a process in place that allows for differences of opinion and conflict management.
6. Person-directed is different from person-centered.

**What does "life of meaning" mean to you?**

1. Having choices – in how a person defines a life of meaning as well as choices in daily life.
2. Having a purpose which includes contributing to a person's community.
3. Having a range of relationships with others.
4. Being included in the community.
5. Experiencing happiness or joy with life.

**What does "flexible services" mean to you?**

1. Services are responsive to changing needs.
2. Services are individualized based on the person's choices and needs.
3. The system is simplified to allow easier navigation and understanding of options.
4. The system allows for "outside the box" solutions.

**What does "skilled workforce" mean to you?**

1. Staff receive meaningful and effective training that prepares them for providing quality services.
2. The direct support workforce is professionalized; for example, promotes professional development, expects professional behavior and skills, and provides a career ladder with increasing pay opportunities.
3. The number of people providing services to people with disabilities is greatly increased.
4. Direct support professionals are paid wages that reflect the value of the work.
5. Not clear if skilled workforce means employment for people with disabilities or people providing services.

Participants were also asked what they liked or didn't like about the draft Vision statement. Here's a sample of the responses:

What Do You Like About This Vision?	What Do You Not Like About This Vision?
<ul style="list-style-type: none"> <li>• I like the whole thing.</li> <li>• It sounds good—dreamy ... utopia ... can we make it reality?</li> <li>• Short, specific, and provides an image of where we want to be.</li> <li>• I believe it includes elements of what most people want in their lives.</li> <li>• Good beginning.</li> <li>• The part about "meaning" really resonates with me. It doesn't dictate what "meaning" is, while still making that a focus, and extending "meaning" into private and public realms of life.</li> <li>• That it places the people receiving supports in the forefront.</li> <li>• I like the hopefulness of the Vision.</li> </ul>	<ul style="list-style-type: none"> <li>• It doesn't address the accessibility of the system - what about the individual that needs services, but cannot access them - difficult process to receive waiver services.</li> <li>• How does this Vision get maintained?</li> <li>• No described plan of action to support the words.</li> <li>• Not all persons can direct own supports and need representation</li> <li>• The definitions behind each concept is what will be crucial.</li> <li>• There also has to be a part that speaks to the supports needed for provider agencies to sustain their work to uphold this Vision.</li> <li>• Does not include education of the public enrollment for support.</li> </ul>

## CONSIDERATIONS FOR FUTURE PLANNING

Development of the Shared Vision is the first phase of the DD Comprehensive Systems Assessment. Ultimately this process will result in operationalizing the Shared Vision along with the Five Priorities.

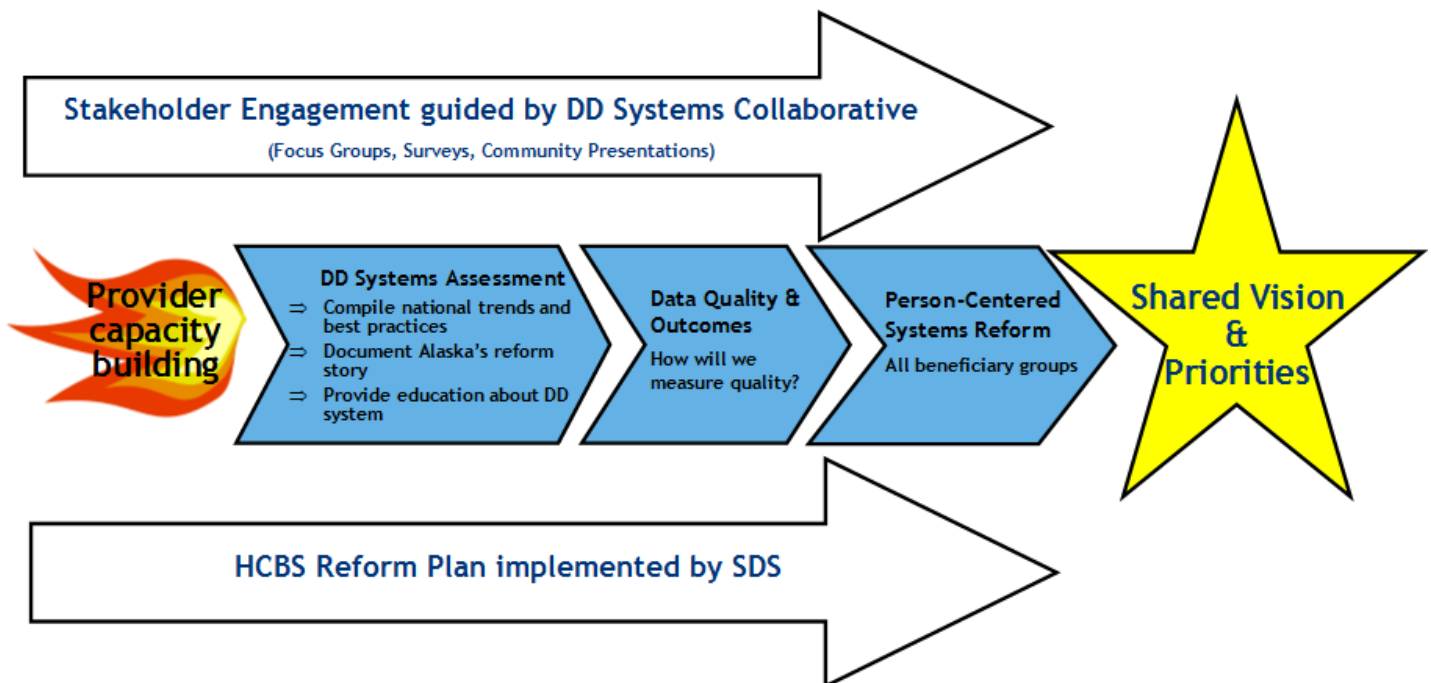
Members of the DD Vision Steering Committee, initially formed as an ad-hoc group to guide development of the Vision, have made a long-term commitment to the systems assessment process. The group changed its name to reflect this new role: the DD Systems Collaborative. This group, which includes several leaders from Senior and Disabilities Services including Director Duane Mayes, recognizes the value of aligning efforts with the current HCBS reform plan SDS is managing.

The next phase of this project will focus on moving the Vision and Priorities into practical steps. Careful collaboration will ensure this project strengthens system reform efforts while not adding additional work to an already overburdened infrastructure.

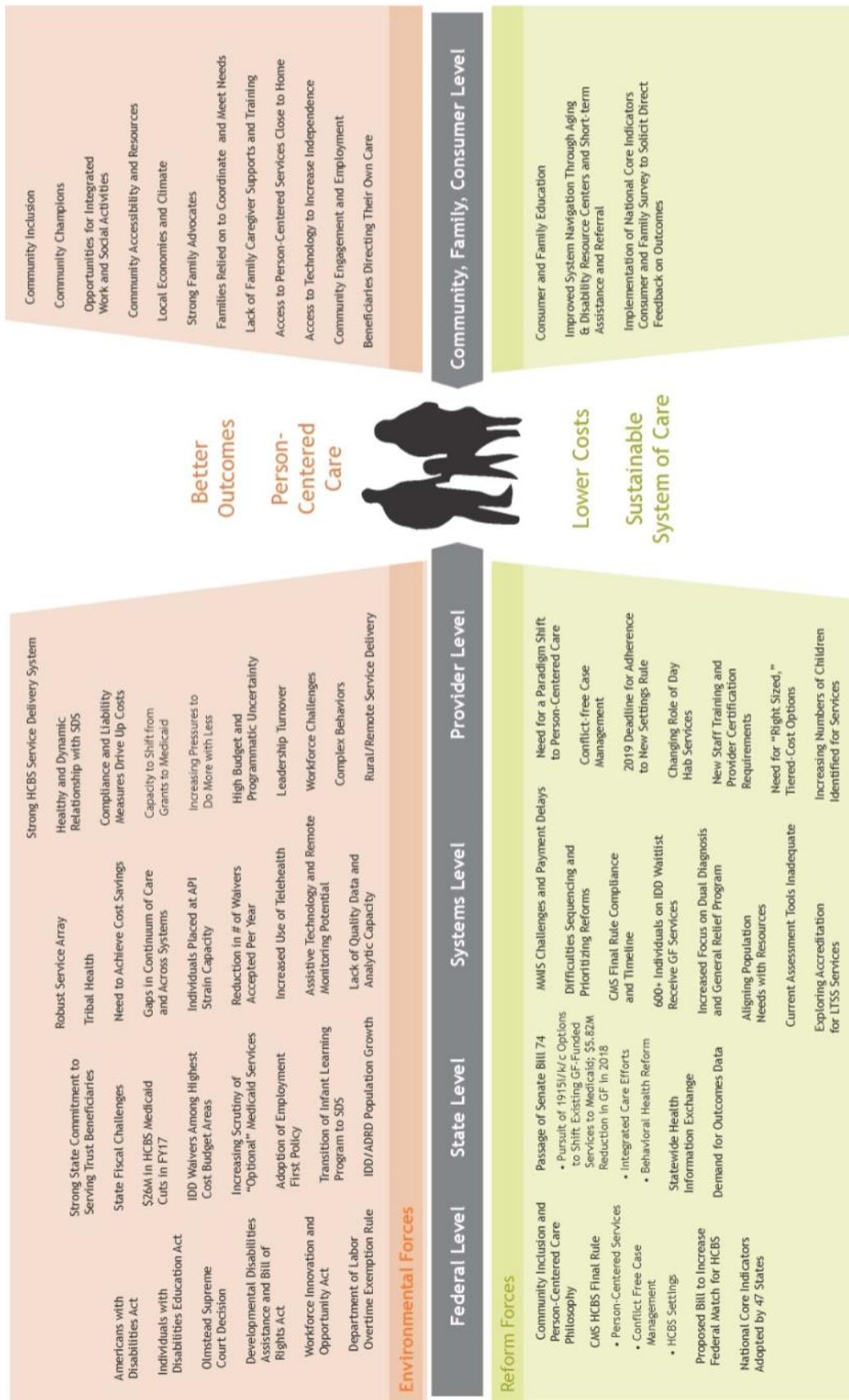
As the graphic below illustrates, the DD Systems Collaborative will provide a vehicle for continuing to engage Alaskans in reform. Using outreach methods described in this report, input from recipients, families, providers and other stakeholders will continue to inform the process.

The next steps include three parallel and complementary tasks: 1) continuing to assess the current DD system to inform the change process, 2) to develop capacity to gather data that measures outcomes based on quality of life and 3) to shift the current paradigm to a more person-centered culture of service. This includes changing the expectations and skills of people receiving services as well as those providing services, and applies across beneficiary groups.

Essential to successfully reaching the Vision is ensuring service providers – including care coordinators - have what they need to keep the fire (passion) fueled – passion not only for moving through the system transformation but also to continue to meet people’s needs every day.



## Intellectual and Development Disabilities (IDD) Systems Assessment: Positive and Negative Forces Influencing the IDD System in Alaska





# Beneficiary System Experience Mapping

Alaska Association on Developmental Disabilities (AADD) Face-to-Face Meeting 11/3/2016



**How do beneficiaries experience the system today?**

**How would the experience change if the system were person-centered?**



ASSESSMENT AND PLAN OF CARE DEVELOPMENT	
Challenging to get connected to system, complex paperwork, deficit-approach, need services now but big delays, bumpy entry into system when families are in crisis  <i>Emotions: frustration, negative focus, overwhelming</i>	STAR (Short-Term Assistance and Referral) coordinator conducts eligibility, person tells story one time, once eligible—focus is on goals & services (not re-evaluating if the person continues to have a disability), process is simpler, people get immediate access to support  <i>Emotions: relief, listened to, hopeful, empowered</i>
INITIAL ENTRY INTO SYSTEM	
Choosing a care coordinator is overwhelming, ICAP (Inventory for Client and Agency Planning) process is consuming—necessity and purpose isn't clear, deficit-driven process, difficult to choose a provider, focus is on what provider can do instead of collaboration  <i>Emotions: confusion, trapped, lost, lack of understanding</i>	Materials target different learners (i.e. videos to help choose care coordinators/providers), there's a road map to guide people through process, first question asked: what do you want and how can we help you get there?  <i>Emotions: ease, understanding</i>
SERVICE DELIVERY	
Beneficiary may or may not participate in staff selection process, difficult if poor staff match—lack of relationship or low quality, often lack of alternative staff options, plan of care process is directed by the care coordinator  <i>Emotions: frustration</i>	Person-centered planning takes several days, outcomes are meaningful lives, providers focus on staff/recipient relationship, staff is guide/voice/support/mentor  <i>Emotions: going in the direction person wants to go</i>
EMPLOYMENT	
Where beneficiaries work is usually determined by agencies, beneficiaries don't have a lot of say in where they want to work—limited choices, comes down to providers connecting them to a job  <i>Emotions: disempowered, dependent</i>	Expectation is that people will work, information is gathered about hopes and dreams, people are allowed the opportunity to fail—not kept in a bubble, concerns about people losing benefits are addressed  <i>Emotions: motivated</i>
OVERALL	
No voice, we say person-centered but the beneficiary needs to think this way too, lack of information about self-determination, professionals make decisions instead of decisions driven by family and person  <i>Emotions: powerless, confused</i>	A person's voice is translated into services with realistic expectations, providers are system translators—inform and then allow decisions to be made, supported decision-making empowers adults  <i>Emotions: empowered, shared responsibility, respected</i>



*Providers of disability services discuss the current beneficiary experience and envision what a truly person-centered experience would look like.*