

**ANNUAL REPORT**

**DD Shared Vision**

**FY18**

*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.*

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# Executive Summary

This report describes the first full year of work toward operationalizing the Shared Vision for Developmental Disabilities.

The DD Shared Vision project started with conversations in the Fall of 2016 about how to sustain support for people with developmental disabilities in the midst of significant reforms and financial constraints.

Between October 2016 and January 2017, the Alaska Mental Health Trust Authority 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. Once the vision was articulated, a steering committee comprised of DD systems “thought leaders” came together to collectively work toward making the Vision real.

The steering committee (referred to as the DD Systems Collaborative -see Appendix D for roster) met in May 2017 to create a strategic action plan. The plan identified five focus areas. In July 2017 the Collaborative launched a recruitment effort inviting stakeholders from many perspectives to participate on project teams – one team per focus area – to develop goals and begin the work of change.

The five project teams included:

- *Person-Directed Culture Change*: How can we ensure people of all abilities are in control of the services they are receiving?
- *DSP Workforce Development*: How do we create a workforce with the skills needed to support the Vision?
- *Community Awareness & Engagement*: How will we change the way people with disabilities are perceived?
- *Legislative Engagement*: Who will champion our Vision with Alaska Leaders?
- *Measuring Success*: How will we know we are succeeding?

The project team members included people with disabilities, family members, care coordinators, and non-profit leaders as well as State of Alaska and university employees. Each team created an action plan and worked toward implementation. The DD Systems Collaborative met quarterly to review the action plans and provide input.

In April, a community outreach effort involving focus groups and an online survey invited input. Over 200 stakeholders shared their thoughts on the success of current efforts and next steps.

A critical aspect of this work has been establishing a truly collective effort; the Shared Vision is not “owned” or driven by a particular entity. Currently the Trust is funding consultant Kim Champney in the role of network coordinator. But the work of the Vision relies on the commitment of all stakeholders to embed this paradigm shift within organizations, relationships and systems moving forward.

This report provides more details on FY18 including input received regarding next steps both from the community outreach as well as an all-day strategic planning session held May 22 by the DD Systems Collaborative.

# 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.

# FY18 Action Items and Progress

The work of the DD Vision occurred via five Project Teams that met at least monthly. (For list of Project Team Members, see Appendix D)

## **Person-Directed Culture Change**

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### **Goals**

**Goal #1:** A concise, clear definition of person-directed culture will be developed and shared.

**Goal #2:** DD service providers will shift to a person-directed paradigm.

**Goal #3:** Alaska will adopt a more strengths-based person-directed service delivery model.

### **Accomplishments**

1. Created working definition of person-directed:
  - *I live the life I choose with the support I direct.*
2. Developed Talking Points
  - Discussed different perspectives based on role within system – how to individualize the message and stay consistent

### **In Progress**

1. Education – service providers, families, people who receive support, guardians
2. Document Stories to Share

## **DSP Workforce Development**

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### **Goals**

**Goal #1:** Alaska DD service providers commit to building a professional\*\* workforce.

**Goal #2:** Design a professional development system for this workforce that promotes professionalism, career mobility and qualified pool of workers.

**Goal #3:** Build provider capacity to support a more professional workforce.

### **Accomplishments**

1. Presented a formal request to AADD to adopt the NADSP Code of Ethics
2. Surveyed DSPs attending the Full Lives conference
3. Mapped out the “DSP Journey”

### **In Progress**

1. Pursue increasing training requirements

- Behavior basics
  - Person-Directed support
2. Develop Ready-to-Work applicant process
  3. Design a coordinated recruitment process
  4. Collaborate with entrepreneurial community on Workforce Catalyzer initiative

## **Community Awareness and Engagement** ---

### **Goals**

**Goal #1:** Educate and empower Alaskan communities through knowledge and relationship building to make meaningful connections with individuals and their families. Outreach emphasizes the gifts and individual abilities of people with disabilities.

**Goal #2:** Family members will increase understanding and have an ongoing awareness of:

1. The shift from person-centered to person-directed support and supported decision-making (reflecting the unique abilities and needs as well as the dignity of risk for the individual)
2. Importance of natural supports, collaboration, and role of families as advocates
3. Fluctuating amount of services across lifetime as individual abilities and needs change

**Goal #3:** Foster and maintain natural supports to connect Alaskans with disabilities to their communities so they can be not just in their communities but of their communities where individuals are encouraged to pursue their own interests and passions.

### **Accomplishments**

1. First Annual Disability Pride Alaska Celebration – July 21, 2018

### **In Progress**

1. Welcome Video that promotes the Shared Vision
  - For families – collaboration with the Disability Law Center
  - For educators – collaboration with the Stone Soup Group

## **Legislative Engagement** ---

### **Goals**

**Goal 1:** Embed the Shared Vision in state statute to ensure it endures.

**Goal 2:** Promote consistent messaging across the many groups which will meet with legislators this session.

## **Accomplishments**

1. Updated and distributed DD infographic
2. Priority of the Key Campaign
3. Successful passage of Shared Vision into state statute!

## **Measuring Success** \_\_\_\_\_

### **Goal**

Goal: To develop a coordinated approach to measuring quality of Alaska's DD service delivery system as described by the DD Shared Vision.

### **In Progress**

1. Contract with Effective Health Design– assess current practices and assist with recommendations
2. SDS renewed exploration of feasibility of National Core Indicators' participation

# Community Outreach

## Introduction

In anticipation of the strategic plan development retreat scheduled for May 23, the DD Systems Collaborative designed an outreach plan to gather input on the work being done during the first year of “operationalizing” the Shared Vision. This report describes this outreach process which took place in April 2018 and shares the input and trends.

## Methodology

There were two facets of the outreach process: an online survey and five community focus groups. This is the same process that was used to develop the Shared Vision in January 2017.

Questions asked via online survey:

1. Have you been aware of activities related to the Shared Vision this past year?
2. Do you believe the value of having a Shared Vision is understood or should there be more education/information regarding the purpose of the Shared Vision?
3. From your perspective, in which of these FY18 focus areas is there the greatest need for change in order to make the Shared Vision real? (Rank from 1 = Greatest Need to 5 = Least Need)
4. If we are successful in making the Shared Vision a reality, what three things would change in your life or the lives of people with disabilities?
5. My role related to this survey is ...
6. Additional thoughts to share (optional)

Outline for Focus Group discussion:

- Introductions
- Review handout (see Appendix C) that included the Shared Vision and Five Priorities as well as highlights from the five project teams.
- How would life change for you/people you work with if the Vision became Real?
- Is there a priority that is missing from the list?

The online survey and focus groups were publicized in the following ways:

- Email sent to participants from previous year’s focus groups
- SDS e-alert
- Alaska Association on Developmental Disabilities monthly meetings and via email
- The Governor’s Council on Disabilities and Special Education Facebook and email
- Local provider associations in communities where focus groups were planned
- Local care coordinators
- Other partners – i.e. Stone Soup Group

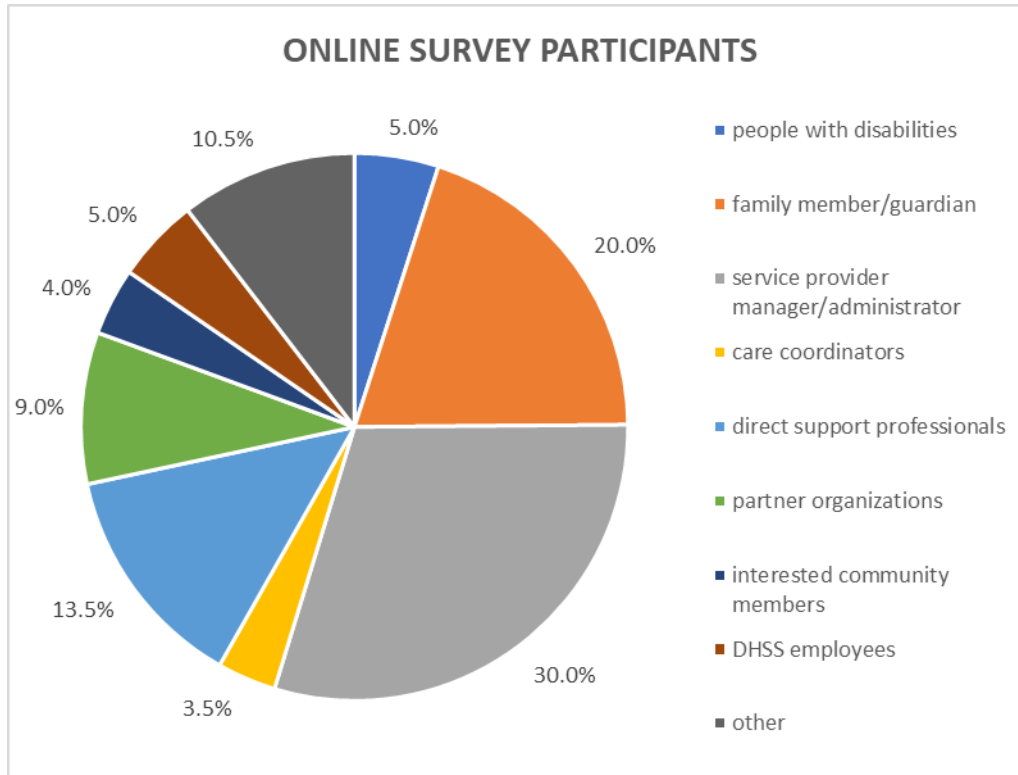
Community focus groups were held Anchorage, Kodiak, Kenai, Wasilla and Juneau. The gatherings were held in community locations not managed by service providers except in the case of Kenai – the Hope Kenai Community Center was the most accessible location for that community.



# Online Survey Results

## Who Participated

171 people completed an online survey.



## What They Said

*Question 1: Have you been aware of activities specific to the Shared Vision this past year?*

62% of the respondents have been aware of the activities specific to the Shared Vision this past year.

*Question 2: Do you believe more education is needed regarding the purpose of the DD Shared Vision?*

82% responded there should be more education regarding the purpose of the Vision.

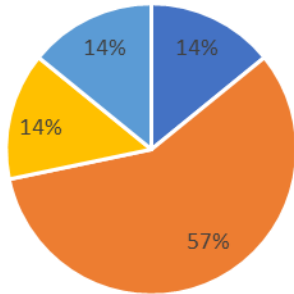
*Question 3: Out of the five current focus areas, which area do you believe is in need of the greatest change in order to realize the Shared Vision?*

Overwhelmingly Person-Directed Culture Change, followed closely by DSP Workforce, were identified as the two areas needing the greatest change. The charts below depict interesting differences across respondent categories. While people who receive services identified DSP Workforce Development as the area of greatest need by a significant percentage, this wasn't on the radar of "interested community members" – people outside of the service delivery system.

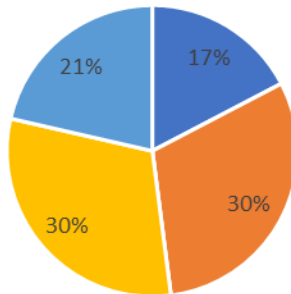
These charts reflect which of the five focus areas needs the greatest change:

■ DSP Workforce 
 ■ Person-Directed Culture 
 ■ Community Awareness 
 ■ Legislative 
 ■ Measuring Success

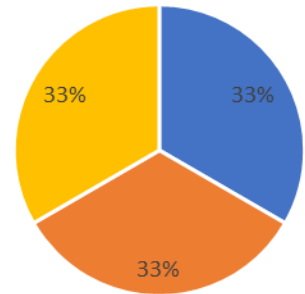
People who receive Services



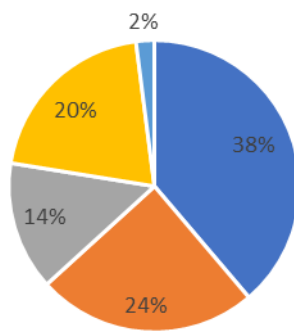
Direct Support Professionals



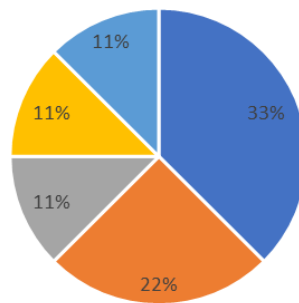
Care Coordinators



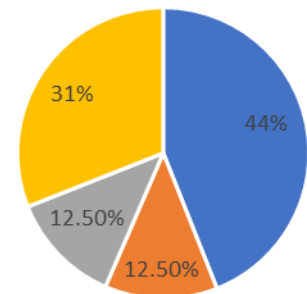
Service Provider Management



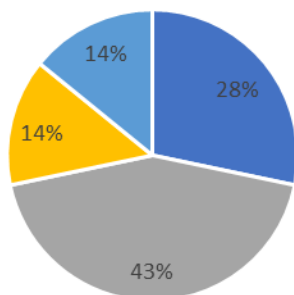
DHSS staff



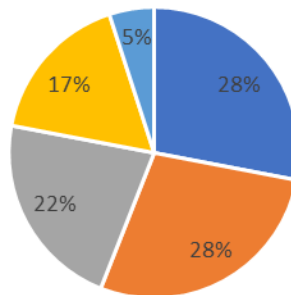
Partners



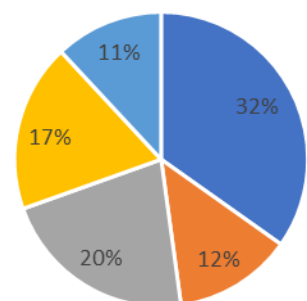
Interested Community Member



"Other"



Family Members & Guardians



*Question 4: If we are successful in making the Shared Vision a reality, what three things would change?*

The following are the general themes; the actual responses are included at the end of this report (Appendix A).

1. Workforce: DSPs are paid more and better qualified
2. Person-Directed: People are more in control of their lives and their services
3. Rural: Services more available across Alaska
4. Quality of Life: Quality of life for people with disabilities is improved
5. Access: Services would be more widely available to people who need them
6. System: The DD system processes align with the Vision
7. Community: Community members will be more aware of the value and needs of people with disabilities
8. Employment: More employment options for people with disabilities

*Question 5: What additional comments or recommendations do you have for the steering committee?*

The following are several impactful statements to consider. All comments are provided at the end of this report.

- I applaud the effort, and hope it can be implemented effectively so it's not just lip service
- More press and public awareness of the lives of Alaskans with disabilities highlighting the programs and funding that are vital to the quality of those lives.
- Until funding and hours are available to give DSPs a consistent schedule, a true living wage and benefits, the people needing services will continue to struggle with unacceptable turnover rates. You can't professionalize a workforce if you can't keep the DSPs in a position long enough to further their education and training.
- I believe in the shared vision and am on a committee...and...the need for continual education, information sharing (especially with families and DSPs) is essential. Also...TEACHING about advocacy to people with disabilities is going to be essential for this to fully take hold. Especially when looking at older PWD's....there is a "culture" embedded that is a barrier to the Vision. Changing that Culture will take time and continual work within our community.

## **Community Forum Results**

52 people participated in community forums.

The community forums allowed for more of a dialogue around the Vision priorities. All comments are included at the end of this report (Appendix B). Generally participants were enthusiastic and appreciated the opportunity to share their thoughts. Here are some comments that reflect themes of the conversations or may be helpful when considering next steps:

- There's a disconnect between the vision and the current system
- Community awareness is important so that we can achieve true inclusion – be in the community with or without paid staff.

- “My daughter is nonverbal – will count on people around her. This Vision doesn’t take away from that, does it?” (*similar statements were made at nearly all the community meetings*)
- School is the first introduction to the disability system
- Also medical providers are key – have doctors telling parents of a 2-year-old child to plan on long-term care, low expectations.
- From a self-advocate: Plan of Care meetings can make you feel like crap
- Multiculturalism – important, we are missing participation at this meeting from AK Native, Hispanic, Filipino (*this was true of all community meetings*)
- Families with young children – missing from the vision
- Fear of losing services (*multiple statements*)

In summary, providing opportunities for community input is a worthwhile investment with two important achievements: first, it ensures that the activities of the DD Shared Vision align with current challenges and priorities being experienced by stakeholders and second, it increases the number of people who are aware of this work and engaged with this change.

# Strategic Planning Session – 5.23.18

The following information was generated at an all-day planning session of the DD System Collaborative members. The session included reviewing accomplishments of the previous year as well as input from community outreach. Kim Champney facilitated a “pre-mortem” discussion which involved imagining we had failed in our efforts to make our Vision real – everyone was asked to imagine what went wrong. This generated a good list of things to pay attention to as we move forward (see Appendix E for the details). Lastly the group brainstormed tasks and issues to work on in the upcoming year.

Information specific to current Project Teams will be passed along to team leaders to consider in action planning for FY19. Recommendations outside of current teams will be considered as plans evolve.

## **Themes generated during “pre-mortem” activity:**

- Lack of national advocacy
- Lack of true collaboration (trust, mutual understanding)
- Lack of legislative support
- Workforce falls short
- Not enough training
- Funding concerns
- Medical model prevailed
- Vision not clearly understood
- Self-advocates not engaged
- Close-mindedness/people fail to embrace the new culture
- Vision becomes too structured – feels like compliance
- No tools to measure progress
- Lack of ownership/host/champion

## **Recommendations for action items in the upcoming year:**

New priority: To advocate for additional position/s within SDS to develop capacity for a review of systems barriers to operationalizing the Vision

- SDS does not have capacity to conduct identify and address policies and procedures within its system which are barriers.
- *Potential goal of the Legislative Engagement project team*

## Person-Directed Culture Change

- Outreach to young children – children with disabilities are empowered
  - Three E’s: empowerment, engagement and Education – include civic involvement
- Ongoing regular meetings of self-advocates
  - Start with personal challenges – unify advocates across the state around shared experiences
  - Bring in the Shared Vision (relate to personal challenges)
  - Partner with IL centers

- Teach teachers and guardians about person-directed thinking/culture
- Visualize the Vision
  - Videos, role plays
- Review the capacity of care coordinators to facilitate person-directed planning
  - Implement use of tools like pictures, other people (peers) helping with the plan
  - How to increase capacity of care coordinators
  - Re-visit role of care coordinators – what if the care coordinators don't write plans
- Celebrate independence from/reduction in paid services (address people's fears around this)

### DSP Workforce Development

- Create collaboratives with existing resources
  - Example: collaborate on training for school and community-based support staff
- Workforce holds the power! Inform, Infuse and Embrace
  - Standardize training for DSPs (also offer similar training to families and people who receive support)
  - Explore funding options for DSP training – possibly Medicaid admin funds

### Community Awareness and Engagement

- Break down barriers related to relationships in communities
  - Fear/uncertainty keeps naturally occurring support from developing (example: churches)
- Continuing education of community

### *Additional suggestions outside of current project teams:*

- Identify future host, champion – what structures do we need to create to ensure the Shared Vision continues to guide our work and support systems?
- Expand the Shared Vision to include seniors
- Increase understanding/clarification re. person-directed support
  - Ensure people are aware there's limited resources
  - Vision is not tied to money
  - Consider developing a white paper – what do we mean by person-directed services?
- Create a process for self-pay/purchase of services
  - Potentially provide seed \$\$ to ABLE accounts for people to purchase support
- Create a process for sharing un-used service units
- Identify creative solutions like using technology (both in administration and direct support)

# **Appendix A**

## **Online Survey Responses by Category**

### **Workforce**

- better staff training
- a more highly trained workforce to support people
- As a parent of special needs children, I would have enough direct support staff that my small children would be safe while I am at work so there can be food on the table and a roof over our heads. I am in constant fear of losing my job due to me having to be absent from work so often.
- better qualified and trained DSPs
- better trained staff
- Better training for DSP's
- better training and wages for direct support staff.
- Better wages
- Better wages for DSPs
- Care providers will get a living wage
- competitive salaries and benefits for direct support professionals
- DSPs might get paid a professional wage, keeping them engaged in the field instead of passing through on their way to something else
- DSP's would be better trained.
- DSPs would be seen as a real profession
- Evaluation and wages for direct support employees.
- Greater number of qualified service providers
- Improved work force - skilled workers
- Increased skilled and knowledgeable professionalized workforce that provides better quality services
- increased training and accredited workforce training like a CNA course for disabilities
- Increased wages for direct service professionals
- Legislative and state support for the professionalization of the DSP workforce benefits everyone
- Less staff turnover
- Less turnover with in home supports
- More community education opportunities for caregivers and professionals
- More competitive wage
- more competitive wages for DSPs
- More qualified direct support professionals earning competitive salaries.
- more support for direct support professionals
- More training for DSP's would be available and required.
- Needed well trained workforce/commitment to employment
- Qualified and skilled workforce
- Services would be improved if staff were more professionally trained which would increase quality for individuals receiving services and staff
- Standardized foundational training
- Sufficient # of professional DSPs to deliver the services requested
- Talented individuals are compensated with a live-able wage, and progressive career.
- training for dsp focusing on person directed care
- Wage increase for direct support staff would increase the longevity of staff
- Wage increases for DSPs & Clients who have a job.

- Wages
- Wages for direct care available
- Wages for Direct Support Professions must be more competitive and available
- Wages for DSP's would be more competitive
- wages more competitive, would provide higher skilled staff
- Wages/Benefits/Education for support professionals would be more competitive and available.
- Respite hours would be paid at the same rate at Dayhab/Supported Living to allow for these hours to actually be filled.
- While the need for DSP's may increase, I see that DSP positions themselves will find it even harder to attain full time employment and benefit eligibility.
- "caregivers" could make a livable wage so they could excel at the cares rather than be so physically/emotionally drained by 2+ jobs
- A shift in perspective would make working in the field more attractive - so a more stable workforce!
- Better pay for DSP's
- Better resources for DSP training.
- Better selection of direct support professionals
- better wages for direct support professionals
- Better wages for DSPs
- Better, competitive wages for DSP's/PCA's
- Collaborative training
- Competitive wages for DSP
- Consistent, well trained staff to provide those supports
- dedicated support professionals
- direct care staff wages be more competitive
- Direct care workers would have access to quality training opportunities to better prepare them to support program participants in achieving their individual goals
- Direct service providers able to make a living and have a career in this field
- direct support professionals more available
- Direct Support Professionals would be trained and compensated enough to make it an attractive career instead of a training job that requires anyone who chooses it to live below the poverty line.
- DSP jobs will be more competitive drawing more experienced applicates
- DSP pay would be more competitive
- DSP wage increase
- DSPs are exposed to "teaching Environments." - applying special education or teaching Principles after ACT/ACE
- DSPs might be able to organize independently, or be shared employees with a DSP-only agency that would prevent DSPs from having to jump around to multiple agencies just to keep a full schedule of clients
- DSP's would be educated
- DSP's would be paid enough to want to stay in their jobs.
- DSP's would have adequate training and support to be successful
- enhanced staff professionalism and competency
- Establish group of professionals to meet monthly
- Front line staff would be professionalized, certified and ready to work. Rate Reimbursements would allow provider agencies or independent markets to be able to afford to pay a higher living wage and compete with other industry markets that take from our work force. Recruitment/Retention would be a strong focus of the field.
- Good pay/health insurance for DSP's-front line after all



- Greater access to qualified service providers
- greater access to training for DSPs
- Having educated Staff for documentation and service
- higher caliber of direct support professionals available
- Higher wages and better retention of quality staff.
- Increase in training for direct supports that includes developing a ladder or progression to include wage so these are not considered entry level positions but career choices
- Increased wages for DSPs who have completed the accredited training
- Job openings for direct support professionals will be more available
- job positions for direct support professionals made available
- less of a turnover rate of staff in the field
- making the wage more competitive for workers
- minimum standards of performance
- More and better trained DSP workers available
- more competitive staff pay
- More direct support at the home
- More funding, support and education for service providers and support professionals.
- More professional development opportunities
- More supports and training are always needed for DSP's and the community.
- More trained DSPs & More trained supervision who want to do the job
- My children would have direct support staff who are familiar with their specific needs and can provide appropriate support more quickly. The staff would be able to do this because they have been working with my children longer than a few months. The current personnel turnover is high because the staff are not paid enough to stick to the job.
- My staff would be paid well, and get real training
- Presenting direct services as a dignified and respected position-a partner in care rather than an adult baby sitter
- Professional training would increase community/legislative opinion of the DSP field in a positive manner
- Providers would have sufficient DSP's (and living wages for them)
- qualified direct service providers are available in every part of Alaska
- Realization of desired services/supports because of workforce
- staff would be trained and supervised
- Standardized and Consistent trained work force
- Training for DSP's would be consistent nationwide
- Wages
- Wages for direct support professionals paid through state/Medicaid money would be competitive and significant.
- Wages for DSPs could be equal to the job they do.
- A clear career path would be articulated for direct service professionals with incentives for continued professional development.
- Accessibility to more trainings
- better trained and compensated workforce
- Better training for direct support professionals in regions (working VTC, trainer makers trip, etc)
- Create a consortium whereby agencies share a trading center, develop a uniform set of standards, and access to behavior and ongoing training; develop a certificated program
- Direct Service Professionals would received the acknowledgement they deserve
- direct support staff would teach self-determination

- DSPs would be universally trained on this model
- focus of the dsp as a professional
- improved DSP workforce
- including DSP's in goal planning
- Increased pay for direct care staff
- More accountability, flexibility for dsp's
- More competitive wages for DSPs
- More training opportunities for DSP to respond to the new trends and needs of the people with disabilities
- Offer specialized training in the field
- offering professional livable wages for DSP's
- recruiting for more qualified DSPs
- The opportunity for direct support professionals to advance or be eligible for raises.
- Wages
- wages for all disability services professionals would be more competitive

### **Person-Directed**

- All individuals that need services would receive services in a manner they have chosen
- alternatives to full guardianship are utilized
- availability of services is based on what the person wants/chooses
- Empowering the person to create change from within their immediate and primary focus and spread to all areas of their life and community
- People with disabilities would be treated as equals.
- person focused support
- Getting professionals to understand this idea.
- Greater team work client directed
- I would be respected
- improved choice and control
- plans of care would be written with objectives that are meaningful to recipients
- More meaningful person-centered choice
- Paradigm shift to acknowledge the capabilities within each person.
- People experiencing disabilities would feel more empowered to direct their care
- People living lives they want to live
- People make their own choices (good and bad)
- people should be able to direct their own services
- People who receive services have more control over their life
- People with Disabilities are not going to be overlooked and increase their value in our society
- People with Disabilities would recognize the power of their own voice
- People would be able to do the things that they want or need to do
- People would have more choices
- Person first language will be empowering for those who experience disabilities.
- Review of Personal Choice vs. Guardianship, more emphasis on the individual vs. power of guardianship
- Self advocates would report they direct their plan
- services that are better aligned with the wishes of people with disabilities
- Services will be more individualized.
- The ability to hire their own support or at least to be part of the process

- The biggest change would be people actually directing their services - being IN CHARGE of their own lives, taken seriously, valued by their communities, enhancing their self-worth... and so on!
- The system was truly Person-Directed – regulations, oversight of the system, rules, COP's etc would all be aligned with the vision and supportive to the person supported as well as to the provider communities. This would be a statewide change.
- True partnerships between individuals and providers to promote health and wellness
- Clients get more person centered care
- clients would be aware of resources
- Guardians would clearly understand their boundaries and support the vision
- The individuals receiving the services would be a greater part of the process
- Individual's actually becoming recognized self-advocates
- individuals having a direct say in their care and services allowing them to live a life that is meaningful to them
- More control of one's own life
- More meaningful, person-directed services (goals, etc)
- more person centered means, in part, less provider directed services which has never been the intent of these services
- more self advocacy for people with disabilities
- More self-determination
- People served will be the leaders in their own lives
- People with Disabilities would direct their services
- person centered services
- Ability to choose for affected individuals
- An agency wide commitment to people directing their own services and having the resources to do so benefits all stakeholders
- An attitude of being in charge of change
- clarification of the intent of these services so that they are not misused by providers as a profit making machine; they are for the individuals who need them
- clients having more of a voice
- Clients who choose there guardian
- Consumers might have REAL control over their services
- every plan of care identifies and builds goals or tasks around informal supports and community activities
- Families would be able to get the TYPE of service they need, without a cap. There could be a dollar cap, but within that cap, they could specify the type of service they wanted.
- I would have my choices listened to
- learn more varied skills
- People receiving services would be and feel in more control of what services they receive, how and when they receive them, and from whom they receive them.
- People with disabilities being treated respectfully and with dignity
- People with disabilities would be offered choices and have natural consequences as a result of their choices.
- Person centered decision making
- Person centered driven
- The same respect for people with and without disabilities
- there would be greater emphasis of getting recipients connected in their communities

## **Rural**

- availability of services
- Choice of providers in remote communities.
- more resources and attention would be given to Hope's non-Anchorage regions
- More services in our rural area
- More services remotely is great
- People in communities without bus systems will be better supported
- Services available in remote communities
- services in remote communities
- Services in rural Alaska
- Services would be available for more people statewide, and particularly in rural areas.
- Supports for rural communities including villages
- More and better supports to our consumers all around the state including rural and remote communities
- more job openings for professionals in rural areas
- Options for services in remote areas
- Remote communities would have ample support providers
- services available throughout the state - increase in rural AK

## **Quality of Life**

- Better outcomes with person-directed goals
- clients will be happier
- Clients would have freedom
- Comfortable care within the home
- Dreams for Individuals becoming recognized and implemented
- Higher quality services with measurable outcomes.
- Improved Quality of Services
- quality of life
- Better outcomes for person centered choices and services for recipients and their families
- Everyone would be happier.
- Families could stay together.
- greater equality of social status, regardless of ability level
- Have individuals with disabilities the chance to work with minimal supervision.
- I will be happier because the people I work with will be happier
- Improved community integration
- more people would have meaningful jobs
- People get skills to succeed
- People would have quality services
- quality services for those dually diagnosed with long term tx options
- better evaluation of success
- Better treatment of clients
- Clients would receive better more complete care
- Doing all we can to provide a super safe place for folks to live and flourish
- more care and support of the individuals served
- People receiving support would receive higher quality of care.
- People will be able to do more with their lives
- people with disabilities a more integral part of the community

- People with disabilities will be included in community
- Quality of life would be better.
- We could show quality measurements for meaningful lives
- Well-supported service recipients experiencing full lives

### Access

- Access to needed supports
- Everyone will have a better understanding of the limitations and parameters of these services so that any one person doesn't take more than they need which leaves others with nothing or less
- Greater Access to services
- Independent living supports are easy to get
- Individual would have access to needed services
- Individuals with FASDs are included in receiving supportive services
- It wouldn't be so hard to know whether we'll keep receiving services next year.
- all services to the consumers would be utilized
- More agencies would be able to afford to provide Respite (as opposed to Habilitation services)
- More appropriate services
- More employer resources-job coaches, etc. statewide
- more services available to clients
- No PDD left behind with no services
- Services have no waiting lists
- Services would be able to meet everyone's needs
- Services would be available to all and would focus on person choice in who their "caregiver" was
- services would be available with less of a waiting period
- Funding enabling people with disabilities more support.
- Increased funding for programs would allow more services to be provided.
- Safety for those who suffer without help.
- Service availability
- services to reflect more challenging individuals
- there would be more options for those that don't meet LOC
- Broader services
- Increase in day hab hours allowed by waivers
- increased access to goal directed supports
- Increased funding for employment
- Increased funding through the AK state legislation not cookie cutter CUTS to SERVICES that help IDD folks access the community
- More quality services throughout Alaska
- more work/community involvement for people w/disabilities
- Our family would be supported well enough that we are not looking for other states to move to which have better DD support infrastructure.
- people would get what they need without having to fight as much
- Real transportation options
- services available more readily
- Sufficient funding to run organizations to support this Shared Vision
- The process of getting services could be simplified.
- There would be a supported employment program for individuals who are more severely impacted by development disabilities and require additional supports.

## **System**

- better funding for needed services
- Companionship would be a billable service
- fiscal prioritization for supports needed for community engagement
- Get rid of the habilitative goals to justify services
- More flexibility in how services are provided.
- Services would support inclusive services--pay less for group home and site-based day hab
- Day hab hours would be increased to allow people with disabilities to be more active and engaged in their communities.
- DVR would fund temporary positions not just permanent as the employment in most of AK is seasonal
- Families would have greater flexibility in their services
- Hopefully less bureaucracy and more time to work with individuals
- Increased collaboration and shared resources among providers
- individualized and meaningful services
- Living like the rest of us not having to work on the same goals everyday all day long
- more creative service options/solutions across the state & cultures
- more effective services being delivered
- Simpler system
- enhanced partnership between primary stakeholders and funders
- Improved communication between SDS and providers
- less bureaucracy
- Level of services would be based on individual need and not capped by budget constraints
- Service Providers would be more educated and informed about "what" the shared vision truly means and how systems need to be modified to support the shared Vision
- There's too much paperwork!
- Wider knowledge of services available

## **Community**

- Community would be more supportive and accepting of people with disabilities
- Greater awareness
- Increased community support
- Legislators should be more aware of the DD population and its needs.
- More community involvement: media, Chamber of Commerce
- Community at large would be more aware of people who experience DD and would have a better understanding of how people with DD are assets to the community
- Community Awareness
- Developing community opportunities to engage with disabled folks
- having the opportunity to know where you can get involved
- More accessible buildings/parking lots/bathrooms
- Consistent expectations
- Creative housing options - or available housing in general
- Strengthen Community Awareness and Participation
- better communication about mtgs for community input
- Better community awareness
- better legislative support and advocacy
- broader understanding of disability and inclusiveness

- Community Advocacy
- Community awareness and understanding could lead to more inclusive programing.
- Community involvement
- Community support through funding, volunteerism, etc.
- community would be more knowledgeable and supportive
- Community would step up to support persons served and "caregivers"
- Greater appreciation for people with disabilities
- Greater public awareness, greater opportunities and supports for those affected, and realization that all in our society have worth if only given the chance.
- Inclusive communities to create opportunities for success
- Legislative advocacy would lead to better funding - improving service for recipients & pay for our DSP
- Making sure that legislators know that when they make decisions about programs and funding, they are dealing with real people and not numbers in a spreadsheet
- More community centers and events would be available.
- more community engagement with individuals
- More community support would allow individuals with disabilities to have more opportunities for inclusion and acceptance
- More educational materials and classes would be available to facilitate natural supports. These would be targeted at parents and at the broader community, to educate them on how best to support relatives and peers who experience disabilities. An excellent example is the packet "Bringing Home a Technology-Dependent Child", distributed by the Children's Hospital at Providence and targeted at parents. It is extremely empowering but I know many parents and staff who don't even know it exists. I wish it was better distributed, and I wish there was a behavioral equivalent. I think there are some classes at the Iona village which might be informative and I wish such relevant disabilities-related information could be accessible in one place.
- More inclusive communities.
- More natural engagement in the broader community.
- More opportunities for community engagement
- More opportunities for community involvement
- Statewide opportunities to be involved/included in the community
- The community would be aware of needed systems change (and the reduction of services Alaskans with disabilities are facing).
- The legislature would...hopefully...recognize the importance of helping to fund programs that recognize an individual's need for independence and the role that organizations play in helping to achieve those goals to become productive members of society.
- these services and how crucial they are would be better understood and funded
- Voices being heard

### **Employment**

- Finding volunteer activities or job to help with people's self-worth
- more job opportunities for people with disabilities
- job availability for individuals with DD
- greater access to jobs for Alaskans experiencing disabilities
- Increased employment opportunities
- job coach working pretty closely with my daughter
- Jobs for beneficiaries
- jobs more available for people with disabilities
- More jobs would be available to people who experience DD

- Allow individuals with disabilities the opportunity to work at a job they enjoy.
- real jobs for people with DD

### **Last Question: Additional Comments**

- "Self-directed services and supports led by knowledgeable guiding hands..."
- I worked for a non-profit in another state, and this nonprofit paid staff .50-\$1.00 higher than competing agencies. This agency was full staffed most of the time! Better services, happier staff and families.
- More press and public awareness of the lives of Alaskans with disabilities highlighting the programs and funding that are vital to the quality of those lives.
- Making the public more aware that inclusion is necessary regardless of where you live.
- Thank you for distributing this survey. I thought the questions allowed me to express my thoughts and feelings fully.
- I am interested in the National Association of Direct Support Professionals
- Until funding and hours are available to give DSPs a consistent schedule, a true living wage and benefits the people needed services will continue to struggle with unacceptable turnover rates. You can't professionalize a workforce if you can't keep the DSPs in a position long enough to further their education and training.
- Just do the right thing - this is the right thing
- Transportation in smaller communities
- A real life example: A family wants NO In-Home (or Supported Living), and only want Day Hab, but due to "soft" cap, they are unable to have the services of choice. The total cost would not increase, if they could choose what they actually wanted.
- There needs to be a concerted effort to help people with disabilities connect with all services
- The staff providing supports to people with disabilities are often unskilled, if wages were increased for those with more experience and training a more quality workforce would result.
- It has become increasingly difficult to get support to repair/maintain mobility devices after they are purchased.
- DSP's in Alaska should create a Union
- Great work
- Keep going. The DD vision is clear and needed.
- When Shared Vision becomes a reality, people with disabilities can have more meaningful and productive lives.
- As a professional in disability supports and the biological parent of 3 adult sons who experience autism spectrum disorder, it is necessary to recognize the hopes and dreams of all individuals who experience a disability. I have raised my own sons to be strong self advocates and to believe and know themselves. It is true among ALL of us that only we know what we truly want and dream of in our lives. ALL people want a purpose and to be validated. It is not acceptable to take away the dreams of anyone. Life in itself regulates limitations on its own; people do not need imposed limitations regulated by laws. People who experience disabilities already experience challenges and limitations in their lives. As teams and supporters of Individual's we should believe in them, recognize them and value them as Individual People, not documents, data and numbers. Please understand that I have been passionate in raising my sons to be proud of who they are and to always be there very best. I believe all people need to surround themselves with people in their lives that will LISTEN and UNDERSTAND that challenges and barriers do not always result in dead ends.
- My son's care giver has lived with him for 22 years. His daily stipend has not increased in all that time. That is a huge problem in recruiting and keeping good people.
- We all need each other, we can all give!
- Thank you for all the work to improve the lives of differently abled and highly valued individuals
- This seems to have historical reoccurring, but never implemented work that is being redone and resubmitted.



- How do people in rural Alaska. People without access to computers/internet. People with DD or their family members have a voice in this?
- we are at a tipping point for many- \$ can't drive our values but without sustainable fiscal support reaching the vision will be compromised
- It would be more beneficial to the livelihood of the consumers as well as the staff providing the supports if we were more involved with who makes the decisions about how much care they are allowed to receive.
- I applaud the effort, and hope it can be implemented effectively so it's not just lip service
- Wish we had better education in SDS about the application (not just language) of person directed
- The vision will require system change in SDS and OPA guardians
- I believe in the shared vision and am on a committee...and...the need for continual education, information sharing (especially with families and DSP's is essential) Also...TEACHING about advocacy to people with disabilities is going to be essential for this to fully take hold. Especially when looking at older PWD's....there is a "culture" embedded that is a barrier to the Vision. Changing that Culture will take time and continual work within our community.
- The Vision is great in Writing, however as we write the Vision, DD grant services are being cut and Medicaid is not forever. It's a risk. More efforts in keeping state funding for DD grants would have been more realistic to meet about for the last 2 years. Words on paper, are just words. You cannot make people share the vision.
- This is extremely important work!
- Let's keep up the GOOD work on the shared DD vision!
- The vision is great, but how the heck are we going to secure sustainable funding "into the future" and develop the rural workforce?!
- fragmented services for people in the system; not enough resources in Alaska to meet the need; families, individuals and professionals not trained on person centered; too much paper time and less people time
- Developing a career path in this area that would focus directly on professional disabilities support providers with compensation to match skills might create a more stable as well as inclusive connectedness to the foundational support provided by this component to supporting individuals who experience disabilities and needs for support people who are not in transition to other employment opportunities, but secured in this opportunity with competencies and compensation to match the service provision.
- Where does the funding for all these items come from? The State (and this Vision) is implementing changes with no obvious provision for the increased costs of implementing these changes.

## ***Appendix B***

### **Community Forums**

#### **Total of 52 participants**

##### **Kodiak (10 participants), Held 4.2.18 at Kodiak Public Library**

- Disconnect between the vision and the system
- Ready to work DSP good idea – filter people out who aren't a good fit
- Use mentors – get a feel for new DSPs, help with retention, help with matches
- Connection between DSP recruitment and community awareness
- Young children are important, partner with ILP, great to have stories of successful older kids to share
- “Their” measurement of success – how does the person define success
- What's meaningful to them?
- Degrading when someone says to a DSP “You are such an angel to be doing this”. I'm a better person for the lessons they've taught me
- Include DSPs in the development of the plan of care
- Multiculturalism – important, we are missing participation at this meeting from AK Native, Hispanic, Filipino
- Families with young children – missing from the vision
- BHAs – good network for supports for people with disabilities
- When people are empowered, guardians are uncomfortable
- Culture is a big barrier to families being engaged. Willie at Hope in Kodiak – great link between community/services and Filipino community.
- Need translators – support from churches?

##### **Input from Kenai (19 participants), Held 4.3.18 at Kenai Hope Community Center**

- Consider a registry/tracking system of poor staff – beyond what BCU tracks.
- Need to start with the goals in the plan of care – need to be more meaningful, based on person-centered planning
- More compatible staff, not so judgmental
- In past funding not so driven by Medicaid, didn't need to work on goals for 8 hours to get a day of support.
- Vision at same time as system changes that don't align with the vision
- “I'm afraid of being too independent for services,” making too much progress.
- Social security needs reform – had issue with eligibility, had to prove my son didn't outgrow Down Syndrome.
- Social security, public assistance and OPA guardians need education
- Fear of losing services (multiple statements)
- We need non-habilitative services that can be more flexible
- Community awareness is important, so we can achieve true inclusion – be in the community with or without paid staff.
- Transportation is a barrier
- Need homes that don't feel like an institution, group homes that follow the vision
- “If they want to go to Wal-Mart, they should be able to go anytime they want – I see my friends' pain and struggles.”
- People have been programmed to be compliant
- Advocate and ally in Sen. Micciche, especially in a numbers way (use data)
- State is implementing so many things to save money but without a vision
- In past, state program specialist would visit with a person to understand needs

- We are ahead of some states

### **Input from Wasilla (9 participants), Held 4.4.18 at LINKS**

- How do we get people more invested – to show up? Social media?
- Mat-Su Health Foundation may be a resource
- Use technology to spread the word, hire youth to develop videos
- Start with recruiting/outreach to youth – easier to shift their thinking
- From a self-advocate: People don't talk to us, think we don't know much, set us apart even though we want to be just like everyone else.
- From a self-advocate: Ticks me off, people don't hear me, understanding is a big thing. If everyone understood everyone, everything would be good.
- Story about an 8-year-old using Google translate to communicate with a person who he was having a difficult time understanding. – very generational, all kids talk to text.
- Flexibility versus person-directed (example: current system doesn't support this – person couldn't choose to have an all DH plan versus a cap)
- Parent shared its difficult when workers have training during times when they are needed to work with someone. There needs to be a back-up system – maybe highly skilled subs?
- Transportation is difficult. Example of flexibility – parent shared that her son has taxi rides written into his waiver so he can get around.
- Employers need education that people with disabilities can work, info re. ADA accommodations
- How do you support person-directed lives with conflicting choices – example: someone wants to stay home all the time but also wants friends? What about someone who can't learn?
- DSP jobs do require training & education but low paid – would be helpful to have a loan forgiveness program/benefit
- Need wages that back up level of training – “caregivers are never going to get ahead”
- Need to advocate for services with the governor/state – so plans don't get cut down further
- My daughter is nonverbal – will count on people around her. This Vision doesn't take away from that, does it?

### **Anchorage (8 participants), Held 4.12.18 at Stone Soup Group**

- Education system is so important, transition from school to adult, participation in IEPs
- Special ed teachers have the same workforce issues – don't see students' abilities. Parents turn to teachers for guidance but teachers don't have any training on system
- IEPs are deficit-based
- Teachers so focused on classroom – but there's a disconnect re. supports at home and afterschool/community supports.
- Teachers are intimidated, afraid to get involved. Don't want to identify needs or options – afraid to say too much because may have to pay for something.
- IEP team – source of information
- Special ed training (inservices) for teachers is often not relevant,
- Parent: my daughter has a diagnosis but I don't have buy-in from the school. Listen to me as the parent!”
- School is the first introduction to the disability system
- SESA gets lots of frustrated calls from parents.
- There's lots of turnover of Sped teachers – don't know what training they've had. A video would be helpful – make it mandatory.
- Too often we “dumb down” our training for DSPs and teachers.
- Need for a comprehensive database – place to go for info about resources, who does what (example: there's a misunderstanding about the role off the Stone Soup Group – people think they are connected with Disability Law Center)
- Way of connecting with each other, centralized communication system. The Autism Resource Center has a database.

- Help Me Grow is a new program, focuses on early childhood but could expand – a big part of it is a database, housed at the All-Alaska Pediatric Partnership. Intent is to create a hotline specific to child development, parents could get their questions answered by master’s level specialists
- Gov’s Council transition handbook is a good resource
- If you don’t know how to ask the question, you won’t ask.
- Also medical providers are key – have doctors telling parents of a 2-year-old child to plan on long-term care, low expectations.
- Need for more culturally responsive programs – in villages, doesn’t have to be complicated
- How do families get connected with Tefra? Not good system for this.
- Anne Applegate is Gov Council rep to Special Ed
- What are the resources for people who don’t qualify for DD services
- Would be good to have a one-page document listing resources – widely available

**Input from Juneau (6 participants), Held 4.28.18 at Mendenhall Valley Public Library**

- I do miss the more person-centered planful meetings for Plans of Care; now it seems rushed, cut and dried.
- From a self-advocate: Plan of Care meetings can make you feel like crap
- Helpful to have a pre-planning meeting with the care coordinator
- Why don’t DD providers collaborate with school district – i.e. Mandt training?
- Organizations should focus on bottom up – most important to focus on DSPs and individuals – everything else supports that
- Proactive training is important, like the idea of more required training
- % of Medicaid funding should go to DSP wages
- Person-directed needs to accommodate different cognitive levels, my daughter can’t make decisions – needs others to help her. Don’t want to exclude people who need help on an elemental level.
- We should share the stories of people who benefit from services, highlight the value of services - \$\$ doesn’t just go in a dark hole, this could counter the current message about Medicaid.
- Niall shared a story about supporting Reggie on the bus, important relationship and connection no longer occurring due to funding cuts.
- Suggestion for the legislative engagement committee: rating card on legislators, other political candidates re. their voting record on issues related to people with disabilities.
- Organize a Town Hall meeting where candidates answer questions specific to support for people with disabilities; partner with the League of Women Voters ...
- Sabrina shared loss of an accessible smokehouse – the house where it was located was sold and it’s no longer available for community use. Someone suggested perhaps Sealaska would support creating another accessible smokehouse.
- Suggestion: increase recognition of businesses who do invest in/support people with disabilities
- Jessie shared that in her high school in Oregon they received high school credit for completing CNA training, great partnership opportunity.
- Support people with disabilities volunteering – giving back, changing perception so not seen just as a burden
- Shared that Niall is excellent with children, therapeutic for children and good exercise for Niall. What about regular volunteer opportunity? Build on individual strengths.

## ***Appendix C***

*(This handout was provided at the community forums along with a copy of the Vision & Priorities)*

### **FY18 Focus Areas & Action Items**

#### **Focus Area #1: Person-Directed Culture Change**

- Develop definition of Person-Directed: *I live the life I choose with the support I direct*
- Identify key principles important to include in training and presentations

#### **Focus Area #2: DSP Workforce Development**

- Formally adopt the NADSP Code of Ethics statewide
- Increase core training requirements beyond health and safety
- Develop process to support “Ready-to-Work” applicant
- Coordinate recruitment efforts

#### **Focus Area #3: Community Awareness & Engagement**

- Create a short video welcoming families and individuals with disabilities to the system and introducing the Vision
- Establish a statewide event to celebrate the strengths and abilities of people with disabilities
- Conduct a public awareness campaign: “You Know Me, Include Me”

#### **Focus Area #4: Legislative Engagement**

- Embed the Shared Vision in state statute to guide future program planning and system change

#### **Focus Area #5: Measuring Success**

- Develop a more coordinated meaningful way to measure the quality of services

## ***Appendix D***

### **DD Systems Collaborative Members as of May 2018**

<b>Name</b>	<b>Organization/Role</b>
(Chair) Roy Scheller	Hope Community Resources
Amanda Faulkner	Frontier Community Services, AADD
Barb Rath	The Arc of Anchorage
Caitlin Rogers	Senior and Disabilities Services
Corey Gilmore	Beneficiary
David Fleurant	Disability Law Center
Duane Mayes	Senior and Disabilities Services
Emily Ennis	Fairbanks Resource Agency
Gina Bastien	Division of Vocational Rehabilitation
Jimael Johnson	Alaska Mental Health Trust Authority
Joni Stumpe	Division of Behavioral Health
Joyanna Geisler	Kenai Independent Living Center
Karen Ward	UAA Center for Human Development
Kathy Craft	University of Alaska Anchorage
Kathy Fitzgerald	Family Member, Key Coalition
Kelda Barstad	Alaska Mental Health Trust Authority
Kristin Vandagriff	Governor's Council on Disabilities and Special Education
Lizette Stiehr	Alaska Association on Developmental Disabilities
Mallory Hamilton	Family Member
Mary Middleton	Stone Soup Group
Michael Bailey	Hope, AADD
Nishama Srur	Maniilaq Association, care coordinator
Patrick Reinhart	Governor's Council on Disabilities and Special Education
Ric Nelson	Governor's Council on Disabilities and Special Education
Sandra Heffern	Effective Health Design, Community Care Coalition
Shelly Vendetti-Vuckovich	Family Member
Travis Noah	Beneficiary

## Project Team Members FY18

Person-Directed Culture Team		
<b>Travis Noah (co-chair)</b>	advocate	Hope
<b>Joyanna Geisler (co-chair)</b>	IL provider	Kenai Independent Living
Kimberly Adkison	care coordinator	ARA
Faith Kelly	service provider (management)	Cindy & Vic's
Anne Applegate	DD council	Governor's Council
Amanda Wilcox	service provider (management)	Frontier
Jennifer Bertolini	parent	Anchorage
Leah Solberg	service provider (management)	The Arc
Heather Mountcastle	direct support professional	TIDES
Jacquelyn McArthur	care coordinator	Anchorage
Maggie Winston	advocate	Kenai, Governor's Council
Mark West	advocate	Anchorage
Cindy Hensley	service provider (management)	Cindy & Vic's
Kara Thrasher-Livingston	state government, family member	SDS
Mary Middleton	parent organization	Stone Soup Group

DSP Workforce Development Team		
<b>Barb Rath (co-chair)</b>	service provider (management)	The Arc
<b>Joni Stumpe (co-chair)</b>	state government	Division of Beh. Health/CBC
Lisa Cauble	university	Alaska Training Cooperative
Kathy Craft	university	UAA School of Health
Phil Tafs	behavior specialist/service provider	PCR
Summer Lefebvre	behavior specialist	UAA Center for Human Development
Robin Siverson	service provider (management)	Hope
Nikki Franzoni	service provider (management)	TIDES
Michelle Watson	direct support professional	REACH
Nicki Nelson	service provider (management)	Crossroads
Corey Gilmore	advocate	Juneau
Betsy Chivers	university	Alaska Training Cooperative
Ann WingQuest	direct support professional	The Arc
Carrie Grice	service provider (human resources)	The Arc
Lisa Harbold-Pitta	service provider (management)	Pride/SPBH

### Community Awareness & Engagement Team

<b>Lizette Stiehr (co-chair)</b>	provider association	AADD
<b>Kristin Vandagriff (co-chair)</b>	DD council	Governor's Council
Patricia Lange	service provider (management)	Consumer Direct
Annie Geselle	advocate	Juneau
Maria Delrosario	state government, family member	SDS
Nikki Marcano	service provider (management)	Frontier Community Services
Maria Davies	STAR Coordinator	SAIL
Karla Wright	ADRC	Anchorage Muni
Michelle McManus	service provider (management)	Hope
Jill Doyle	advocate	Anchorage
Caryn Brunello	service provider (management)	The Arc
Art Delaune	independent living	Access Alaska

### Legislative Engagement Team

<b>Ric Nelson (chair)</b>	DD council	Governor's Council
Kathy Fitzgerald	parent	Key Coalition board
Patrick Reinhart	DD council	Governor's Council
Roy Scheller	service provider (management)	Hope Community Resources

### Measuring Success Team

<b>Sandra Heffern (chair)</b>	consultant	Effective Health Design
Karen Ward/Karen Heath	university	UAA Center for Human Development
Karen Heath	University	UAA Center for Human Development
Lanny Mommsen	DD council	Governor's Council
Britteny Howell	service provider (management)	Hope
Caroline Hogan	state government	SDS
Heidi Young	care coordinator	Island Care Services
Anita Wilson	service provider (management)	The Arc
Ellie Fitzjarrald	parent	Juneau



## ***Appendix E***

### **DD Vision Strategic Planning Pre-Mortem Activity**

During the DD Systems Collaborative strategic planning meeting held 5.23.18, the group participated in a “pre-mortem” exercise. Participants were each invited to imagine that we failed to achieve our Shared Vision and to consider what may have caused our failure. The results are listed below, organized around themes:

- Lack of national advocacy
  - Asleep at the wheel and not paying attention as the national level crashes our system
  - Somehow Trump manages to get re-elected
  - Trump gets re-elected
- Lack of true collaboration (trust, mutual understanding)
  - Not having enough “groups” involved in the conversation – i.e. foster families, rural service providers
  - Service agencies not cooperative/work together for training, certification of DSPs
  - Didn’t understand what the State had the capacity or willingness to do
  - Lack of collaboration
  - Seeing the State as the obstructionist further divides us and the system crashes
  - Failure of SDS and providers to remain aligned in implementing the Vision
  - Agencies are not willing to cooperate to share costs around workforce development/other shared services
- Lack of legislative support
  - Have to convince the legislature to fund the Vision – Would having a state legislative participant help?
  - Political community indifference
  - Legislature - doesn’t require accountability
- Workforce falls short
  - No family or living wage for DSPs
  - Didn’t improve DSP recruitment, training and pay
  - DSP workforce enhancements/compensation unmet by funding sources
  - Need to look for workforce innovations like unionizing DSPs
  - DSPs aren’t valued
  - No workforce
  - Workforce concerns in relation to Maslow’s hierarchy of needs – how do we develop the workforce capacity to provide more than assistance/support for meeting BASIC needs – and also meet the “higher” needs of life satisfaction and meaning?
- Not enough training
  - Increased training requirements are not put into regulation
  - Lack of training and direction for front-line staff (eg care coordinators) and at the same time over reliance on those staff to carry the message
  - Lack of coordinated system in training, staffing
  - It would be very interesting to see homemade videos specific to individuals to show DSPs exactly what they’re jumping into while also giving some prior knowledge about that individual

- Funding concerns
  - Backwards slide in Medicaid funding
  - System does not allocate resources (in a strengths-based manner) in response to an accurate assessment of support need
  - Cost was left solely to the State to figure out
  - State fiscal situation does not improve
  - Funding structure does not change to reflect the demand for and value of in-home services
- Medical model prevailed
  - State (SDS/DHSS) doesn't embrace person-centered – goes back to medical model
  - Failure to break the medical model regulations and philosophy
  - Too dependent on Medicaid/medical model
  - State policies do not accommodate needed changes
  - The plan of care policies, forms and process does not change
  - Failure to move from medical model mindset to human/person centered
  - Regulations choke out flexibility/choice
  - Funding tied to “Medicaid” – medical model on focusing on deficit-based model
  - Unable to get person-direct plans of care approved
- Vision not clearly understood
  - Lack of clarification, people thought it was something it wasn't
  - Failure to communicate that the Vision was not about funding
  - Failure to share a visualization of the desired outcomes possible from the Vision
  - Greed for more instead of correcting what we have will break the system
  - The perception that person-centered planning is an open checkbook will break the system
- Self-advocates not engaged
  - Individuals with disabilities must have a voice and financial stake in their own life (i.e. employment expectations – the option to pay for some care when appropriate), take some pressure off the state, give ownership
  - Need significant outreach to individuals with disabilities RE: Vision and engaging them more
  - Not focusing on individuals dreams and wishes
  - Parents/Guardians/schools fail to empower persons with significant disabilities to strive for a meaningful life
  - The group of self-advocates was too limited – not diverse enough to inspire full statewide engagement
  - Self-advocates don't choose to take self-responsibility
  - Self-advocates were shunned and could not speak up
  - Didn't educate self-advocates and families about what it means to be person-directed
- Close-mindedness/people fail to embrace the new culture
  - Guardians refuse to allow individuals self-direction
  - The will to really change was only lip services. We rearranged the deck chairs rather than changing direction/course of the ship.
  - Didn't incorporate person-directed into the culture
  - Being close-minded

- Getting everyone (Feds included) on board with consistent language person-directed vs. person-centered
- Providers refuse to embrace person-directed services
- Providers fail to embrace culture change to person-centered/directedness
- Stigma
- Non-acceptance of people with disabilities by the community
- SDS didn't believe in the Vision
- Lack of taking a risk
- Community rejects the dignity of risk
- Vision becomes too structured – feels like compliance
  - The Vision became too structured and took on a compliance flavor
- No tools to measure progress
  - Didn't develop tools to monitor and measure success
- Lack of ownership/host/champion
  - Didn't have centralized "host" for our work and work products
  - It didn't have a champion who passed the torch
  - Lost sustainability – no host to maintain momentum
  - Lack of presence/momentum/ownership