Annual Update
October 2017 – September 2018
Creating change that improves the lives of Alaskans with disabilities
The Council is now in the 3rd year of its 5-Year State Plan

- **GOAL #1** — Community Inclusion, Supports, and Services: Improve service delivery to empower individuals with intellectual and developmental disabilities (IDDs) to live and thrive in their communities with formal and informal supports and services that promote independence.

- **GOAL #2** — Employment: Alaskans with disabilities and their families will receive the necessary employment services and supports needed to become competitively employed in an integrated setting.

- **GOAL #3** — Early Intervention: Strengthen policies and programs so that infants and toddlers with disabilities, their families, and caregivers receive appropriate early intervention services and supports.

- **GOAL #4** — Education: Participate in activities that lead to enhanced practices so that children and youth with disabilities have access to appropriate qualified professionals, curriculum, inclusion, support, and resources to ensure they have the skills they need for educational success and future independence.

- **GOAL #5** — Health Care: Alaskans with disabilities will have greater access to needed health care services that will improve their quality of life.

**Council Committees Include:**

- Developmental Disabilities Committee
- Legislative Committee
- Education Committee (Special Education Advisory Panel – SEAP)
- Early Intervention Committee (Interagency Coordinating Council on Infants and Toddlers with Disabilities – ICC)
- Employment and Transportation Ad Hoc Committee
- Medicaid Ad Hoc Committee
- Autism Ad Hoc Committee
- FASD Workgroup

If you are interested in participating in the day-to-day work of the Council by becoming a public member on one of the Council’s committees, please contact us: [http://dhss.alaska.gov/gcdse/Pages/contacts/](http://dhss.alaska.gov/gcdse/Pages/contacts/)
ADVOCACY AND LEADERSHIP

Advocacy on behalf of Alaskans with disabilities and their families is one of the primary responsibilities of the Council. The Council conducts its advocacy efforts on both state and federal levels due to its multiple roles.

State Advocacy

The Council:
- Held its annual Juneau Council meeting along with meetings with Alaska legislators
- Presented to the House Health, Education and Social Services Committee
- Presented to the Senate Health and Social Services Committee
- Presented the Council’s priorities to Governor

The Council serves as Alaska’s Developmental Disabilities Council, a federally required role of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act); a unique responsibility to engage in “advocacy, capacity building, and systemic change activities” without interference by the State (42 USC 15024(c)(5)(I).

2018 Advocacy Priorities

1. HB 336 Supported Decision Making Agreements Act

This bill provides equal access to decision-making for adults with disabilities by authorizing written agreements between an adult and supporters which describe a process for making life decisions; including decisions related to a person’s finances, where and with whom the person wants to live, the services, supports, and medical care the person wants to receive, and where the person wants to work. Supported Decision Making Agreements are a legal alternative to full or partial guardianship. This alternative actively engages people with disabilities in creating the decision-making structures and tools that serve their lives and autonomy. This bill formalizes a support process, describes eligible supporters, creates a blueprint for valid written agreements, and provides safeguards to protect the well-being and independence of adults with disabilities. The bill passed the House and Senate and was signed into law by Governor Walker in September 2018.

2. SB 174 Developmental Disabilities Shared Vision Bill

This bill places aspirational language into statute that will provide a solid platform for how services are provided throughout the state. This ensures that individuals with developmental disabilities will receive services that lead to meaningful lives — for current and future generations of Alaskans. It solidifies a spirit of self-determination for individuals with developmental disabilities within the Alaska service system. This bill passed the House and Senate and was signed into law by the Governor in August 2018.

Shared DD Vision:
“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.”
3. Key Campaign

- Staff support to the Key Coalition on planning the statewide developmental disabilities educational “fly in” to Juneau in February 2018.

- The Council and Key Campaign continued to provide information to state legislators on both the importance of Medicaid Home and Community Based Services (HCBS), as well as the cost savings when compared with institutional care.

<table>
<thead>
<tr>
<th>Cost of Intellectual/Developmental Disabilities (I/DD)</th>
<th>$186,909</th>
</tr>
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<tbody>
<tr>
<td>Home &amp; Community Based Services (HCBS)</td>
<td>$87,718</td>
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2,069 individuals currently receive I/DD waiver services for a total annual cost of $181 million. If the same individuals were in an institution the cost to provide services could easily cost upwards of $386 million. By allowing waivered services, the state and federal government saves $205 million dollars per year.

Federal Advocacy

The Council hosted an Alaska visit with U.S. Congressman Don Young, discussing issues important to Alaskans with developmental disabilities. At this meeting, the Council presented Rep. Young with a Friends of the Alaska DD Network Award, recognizing his ongoing support of the DD Network.

The Council has continued to be in close contact with Alaska’s U.S. Congressional Delegation, sending comment letters educating them on potential impacts of healthcare, special education, and employment legislation or policy changes.

The Council would like to thank

The Council thanks U.S. Senator Lisa Murkowski for introducing a bill to delay the Electronic Visit Verification (EVV) provision contained in the 21st Century Cures Act law to allow states adequate time to set up effective EVV systems. Thanks also to U.S. Senator Dan Sullivan who co-sponsored this bill and to U.S. Congressman Don Young who sponsored the companion legislation in the House. This legislation was signed into law July of 2018.
Self-Advocacy Support

Peer Power Alaska

The Council has continued to support Alaska’s statewide self-advocacy organization for individuals with I/DD:

- Peer Power now has 350 members statewide.
- Peer Power held the second annual statewide Self-Advocacy Summit for Alaskans with I/DD with 105 attendees (65 self-advocates and 40 supporters).
- The next Self-Advocacy Summit will be held in Anchorage on September 28-29, 2019. For more information, contact Ric.Nelson@alaska.gov or at (907) 269-8989.

Get engaged in self advocacy through Peer Power’s website or Facebook page:
- www.peerpower907.wixsite.com/peer-power
- www.facebook.com/Peer-Power-of-Alaska-1404232596476441/

Community Inclusion Supports & Services

The Council Awarded New Federal Living Well Grant

In September of 2018, the Council was awarded a $1.96 million dollar 5-year federal grant by the Administration on Community Living to develop model approaches to: 1) community monitoring, and 2) community capacity building.

The overarching goal of this project is to increase the community integration, health, safety, independence, and well-being of individuals with developmental disabilities through realization of our DD vision.

Objectives

1. Improve health and safety as well as independence and employment
2. Improve workforce sustainability and training
3. Increase leadership opportunities for self-advocates
4. Improve rights

Supported Decision-Making Agreement (SDMA)

- The Council provided 26 presentations in 9 communities, reaching over 1,705 individuals over the past year.
- Instructional how-to videos were created with actors featuring step-by-step instruction on developing a Supported Decision-Making Agreement. This effort was accomplished through a collaborative effort between the Council, the Trust, AARP, the Disability Law Center, and HOPE Community Resources: http://alaska.gov/go/RB8S

Disability Pride Events Across the State

The Council partnered with the Alaska DD Collaborative in implementing the Shared DD Vision, resulting in 5 communities across Alaska holding Disability Pride events (Anchorage, Kenai, Fairbanks, Kodiak, and Juneau) with hundreds in attendance. The Kenai event included an accessible slip and slide – big thanks to Senator Micciche for celebrating too! The Anchorage event included Mayor
Berkowitz, two Paralympic athletes as well as lots of interactive vendor booths and performances. Fairbanks joined the Golden Days Parade with Disability Pride T-shirts and signs. Juneau’s celebration included a Tlingit dance group as well as other performers, a cookout, and two local movie options about disability issues. Be on the lookout for how you can get involved in the 2019 Disability Pride events which will be held on July 20th close to the anniversary of the Americans with Disabilities Act (ADA).

**Autism Ad Hoc Committee**

- **Autism Regulations:** The Council provided comments on the final regulations that have been implemented in June 2018 regarding the composition of the team that will be reviewing clinical records.

- **5-Year Plan on Autism Focus Areas:** The work plan has been updated to include suggestions following the September meeting, including support of the Tiered Model in diagnosing autism, and suggestions on expanding the practice beyond certified professionals such as BCBA's and RBTs. Also, a work group to research other evidence-based practices for autism will be convened.

- **Adult services discussion:** The Council will be researching adult programs in other states (including reduction of barriers to employment and capacity building) as it initiates an ad hoc working group around this area per stakeholder feedback.

- **Pediatric Neurodevelopmental (PND) Specialists:** The Council is pleased to report that Alaska now has four PND specialists! In addition to Dr. Siv Fasci with Providence Alaska Medical Center, Dr. Randy Zernzach and one more of his colleagues with Southcentral Foundation — which sees Tribal beneficiaries and military members — there is still a visiting PND specialist from Washington slated to conduct clinics in rural Alaska for at least one more year.

**Fetal Alcohol Spectrum Disorders (FASD)**

- **5-Year Plan on FASD:** Over 50 stakeholders from around the state have helped to develop a robust 5-year plan around FASD with the following priority areas: Primary Prevention of FASDs, Screening for and Diagnosis of FASD, Early Childhood and Education, System Transformation and Navigation: Youth and Adults, and Community Outreach and Engagement. Work groups have continued to meet regularly and to work on the 2018-2019 activities.

- **FASD Day (9/9) Awareness:**
  - Social Media Toolkit & Campaign
  - Worked with Senator Kevin Meyer’s office to have a Governor’s Proclamation for Fetal Alcohol Spectrum Disorders Awareness Day on 9/9/2018
Employment

Employer Engagement Efforts

The Council continues to lead the Business Employment Services Team (BEST) which is a collaboration between the Departments of Health and Social Services and Labor and Workforce Development with the mission of meeting the workforce needs of Alaska businesses and improve hiring outcomes for individuals with disabilities and veterans.

- The Council led the planning for the 4th Annual BEST Employment First Job Fair in partnership with Department of Labor staff. In 2018, over 800 job seekers attended, visiting 67 employers. Individuals attended with job coaches, and the local paratransit entity was continually bringing and picking up job seekers throughout the Job Fair.
- The Council again co-sponsored the Alaska Society of Human Resource Management (SHRM) annual conference keynote, bringing up Lou Orslene with the Job Accommodation Network.
- Council staff presented nationally with the CEO of the U.S. Business Leadership Network as part of the TASH/ANCOR employment webinar series on employer engagement.

National Governor’s Association (NGA) Employment Learning Lab:
The Council was selected to attend the NGA employment learning lab in Wisconsin which resulted in four core recommendations to enhance Alaska’s system to support improved employment outcomes for individuals with disabilities:

1. Enhance State As a Model Employer (SAME) efforts within Alaska state government.
2. Enhance apprenticeship opportunities for Alaskans with disabilities
3. Initiate an Employment First Work Group or Commission called “Alaska Work Matters”.
4. Enhance Alaska’s re-entry process and system (making employment/work experience an area of even stronger focus).

Alaska Achieving a Better Life Experience (ABLE) Act:

- Becoming law in 2016, this act allows qualified individuals with disabilities the opportunity to save without jeopardizing vital public benefits (such as SSI and Medicaid).
- As of August 2018, there were almost 197 open Alaska ABLE accounts with total assets amounting to $839,887.
- The Council led the #ABLEtoSave campaign for Alaska in the month of August and gave numerous presentations. If your entity is interested in a presentation, contact Ric.Nelson@alaska.gov.
- Learn more: savewithable.com/ak/home/plan-benefits.html

Alaska Project SEARCH

The Council now supports five Alaska Project SEARCH sites statewide, allowing youth with disabilities to gain transferable
employability skills in hospitals in Anchorage, Fairbanks, Mat-Su, Kenai, and Juneau.

To learn more, as well as access 2019-2020 school year application and deadlines, visit: [http://alaska.gov/go/F4VS](http://alaska.gov/go/F4VS).

**Alaska Disability Benefits 101 Website (AK DB 101):**
- The AK DB 101 website is free and assists individuals with disabilities and those supporting them to navigate through questions around how benefits are impacted by work.
- To learn more and use this website which includes plain language articles with interactive tools and a benefits to work calculator, visit: [http://ak.db101.org](http://ak.db101.org).
- For videos and additional tools on how to best use this exciting new employment tool, visit: [http://alaska.gov/go/HZD3](http://alaska.gov/go/HZD3).

**Alaska Subminimum Wage Regulation Repeal:**
The Council commends the Alaska Department of Labor and Workforce Development for its repeal of subminimum wage in Alaska as of February 2018, making Alaska only the third state in the nation to do so. Alaska has been an Employment First state since 2014, and this effort placed Alaska as a leader in implementing the principles of Employment First.

**Alaska Integrated Employment Initiative’s (AIEI) Impact on Alaska:**
Funded through the Administration on Community Living, as a Partnerships in Employment effort, the Council worked on enhancing employment outcomes for youth and young adults with developmental disabilities through this grant.

This 6-year grant work resulted in a myriad of systems change outcomes:

**Policy Outcomes:**
- 2014 – Alaska became an Employment First state (prioritizing competitive and integrated employment for all)
- 2014 – High School Graduation Qualifying Exam was repealed with retroactive provision (removing a barrier to employment for youth with disabilities)
- 2016 – Alaska ABLE Act passed (allowing greater self-sufficiency through options for individuals with disabilities to save)
- 2018 – Subminimum wage regulation was repealed in Alaska (removing a barrier to competitive employment for Alaskans with disabilities)
- 2018 – Alaska’s Shared DD Vision Bill was passed (elevating employment as a key facet of leading a meaningful life)

**Capacity Building Outcomes:**
- Over 1,000 trained on employment best and promising practices through training offered in partnership with the Center for Human Development.
- Employment First Job Fair initiated, bringing together 3,094 job seekers and 267 employers since it began.
• Over 3,311 reached through the grants employment resources presentations.
• Business Employment Services Team initiated creating a DHSS and DOL employer engagement collaboration.
• Alaska Disability Benefits 101 tool developed and launched.
• Five Project SEARCH transition sites across the state teaching transferable employability skills.
• “Alaska Transition Handbook Pathway to Adulthood and Employment” developed and disseminated statewide to thousands in print and online formats. Find it online at: http://alaska.gov/go/9M28.

This Alaska specific resource assists individuals with disabilities and those who support them in successful transitions. It is a culmination of the five-year AIEI grants work around transition and was a collaborative project with input from stakeholders statewide. It includes success stories, information on state agency resources, benefits and work, savings, and employment support services.

_The Council wishes to thank all the stakeholders engaged in this employment systems change grant work over the past six years, including: the Center for Human Development, the Disability Law Center of Alaska, Senior and Disabilities Services, the Department of Education and Early Development, Division of Vocational Rehabilitation, Division of Employment and Training Services, Alaska Mental Health Trust Authority, Peer Power Alaska, Alaska Association on Developmental Disabilities, as well as countless self-advocates, family members, service providers, educators, and community members._

**Continued Trust Collaboration:** The Council has continued to partner with the Trust on the Microenterprise grant program, the Beneficiary Employment Engagement Initiative, the DD mini-grants, and many other projects related to services for individuals with a developmental disability.

**Interested in self-employment and being your own boss?** The Council administers the Trust Microenterprise Grant with the UAA Center for Human Development. Learn more about this _exciting self-employment resource for Trust beneficiaries._

**Early Intervention**

**Universal Developmental Screening:** The Council, working with the state office of Women’s, Children’s and Family Health, continued hosting a Universal Developmental Screening task force comprised of health professionals and stakeholders from around the state. Exciting recent work:

• Ages and Stages Questionnaire (ASQ) addendum to Alaska Community Health Aide/Practitioner Manual (CHAM).
• ASQ conversation on data and establishing centralized tool for evaluating how many children were screened.
• The Council coordinated the start-up of a “branding” campaign for universal developmental screening; “Look at me and where I’ll be!”, focuses on ages 0-3 as the “wonder years” where early childhood and brain development and developmental screening are pivotal.

**LEND Project:** The Council secured two Alaska LEND (Leadership Education in Neurodevelopmental and related Disabilities) Fellows who took on research into Increased Family Engagement in Developmental Screening.

**Child Care:** The Council supported the early childhood expulsion survey conducted by Learn & Grow, Alaska’s Quality Recognition & Improvement System (QRIS) aiming at advancing the quality of early care and learning.
State Interagency Coordinating Council on Infants and Toddlers with Disabilities (ICC): The Council completed an annual review of the performance report and parent satisfaction survey, and wrote a letter with comments and recommendations to be included with the report to the federal Office of Special Education Programs (OSEP) and the Governor.

Early Intervention/Infant Learning Program: The State Early Intervention/Infant Learning Program (EI/ILP) staff are active members of the Council and provide a monthly update to the Early Intervention Committee (EIC). The Program underwent fiscal monitoring by the Office of Special Education Programs and has just been provided with the outcomes of the on-site visit. The Council also provided necessary stakeholder input for EI/ILP (including fiscal monitoring preparation issue) and meets regularly with the director and her staff on issues relating to reporting, workforce development and fiscal sustainability.

Education

The Rural Transition Work Group defined a measurable goal and benchmark objectives, with the first two objectives being the increase of curriculum units available for teaching foundational self-employment skills, and the increase of curriculum units for teaching skills for work safety in rural environments.

Alaska State Special Education Conference (ASSEC) 2018: The Council had a resource table with Council staff giving several presentations, including supported decision-making in transition plans, transition resources, and trauma-informed education.

State Education Advisory Panel (SEAP) duties:

• Attended monthly Department of Education and Early Development (DEED) leadership calls with DEED Commissioner.
• Submitted comprehensive annual report on SEAP activities and recommendations to Commissioner of Education and Early Development, and to OSEP.
• Held stakeholder meeting with leaders of Alexander Graham Bell Society and the Alaska Deaf Council on Deaf Children’s Bill of Rights to discuss unmet needs for special education.

Stone Soup Group Parent Conference: Council members and staff had several trainings at the Stone Soup Group Conference, including sessions on transitions to adulthood, supported decision-making, and self-advocacy from the perspective of an adult with autism.

Public Comment: The Council completed several comment letters regarding special education on both a state and federal level, including making recommendations on the state Every Student Succeeds Act (ESSA) Plan, on collecting data on the number of students with an Individual Education Plan (IEP) who use the Alaska Performance Scholarship, renewing support for the creation of a Dyslexia Task Force, and responding to federal delay of Significant Disproportionality Methodology deadlines.

Inclusive Practice Award 2018: There were eight teams of educators nominated for the 2018 Inclusive Practice Award. The winners were two exceptional educators, Ben Griese and Nicole Wagner, of Chief Ivan Blunka School in New Stuyahok, Southwest Region School District. They were recognized as having embraced inclusive practices so that students with disabilities are integrated into the entire school and community.
Health

Emergency Preparedness:

• **GetReady! Toolkits:** This past year, over 1,000 toolkits have been distributed throughout the state. To access the GetReady Toolkit, visit: [http://alaska.gov/go/AQ73](http://alaska.gov/go/AQ73).

• **Safety Kept in Place (SKIP) kits:** Over 500 starter emergency kits were distributed to families across the state.

• **Emergency Preparedness Presentations:** More than 300 people were trained by Council staff through 10 emergency preparedness presentations.

Health Promotion:

• **Annual Aging and Disability Summit:** The Council supported this third (October 12-14, 2017) and 4th annual (September 26 & 27, 2018) event by having staff on the steering committee, completing a summit presentation, and having a resource table. Over 100 individuals were in attendance each year with over 50 agencies/groups represented from all across the state.

• **Inclusive Play Dates:** The Council again partnered with inclusive play champions Anchorage Park Foundation to hold five inclusive play dates around Anchorage in 2018. These play dates combined drew more than 300 attendees. Partners included Stone Soup Group, Alaska Center for the Blind, Hope Community Resources, Anchorage Museum, Arc of Anchorage and others. To learn more about inclusive parks in Anchorage, visit: [http://anchorageparkfoundation.org/programs/inclusiveplay/](http://anchorageparkfoundation.org/programs/inclusiveplay/).

In Memory Of Banarsi Lal

Banarsi Lal, 86, and long-time resident of Fairbanks, passed away on the morning of Friday, December 28, 2018 at Fairbanks Memorial Hospital surrounded by his loving family. Banarsi was a great advocate for persons with disabilities and seniors, having served as both a member of the Governor’s Council on Disabilities and Special Education and the Alaska Commission on Aging.

Banarsi will be lovingly remembered by his wife of 62 years, Asha, children Jyotsna (Steve), Sanjiv (Denise), Nandita (Dan), and grandchildren Daniel, Andrew, Chloe, Maya, Kavya and Kaushal. He will also be fondly remembered by his sisters Tara, Sheela, Padma, and brothers Kamal and Ravi.

**Memorial donations may be made in remembrance of Banarsi to the Banarsi Lal Social Work Scholarship at UAF, or the American Cancer Society.**
Council Members

1. Anthony Cravalho – Kotzebue
2. Art Delaune – Fairbanks
3. Donald Enoch – Juneau
4. David Fleurant – Anchorage
5. Jeanne Gerhardt-Cyrus – Kiana
6. Mallory Hamilton – Anchorage
7. Maureen Harwood - Fairbanks
8. Alexis Henning – Anchorage
9. Elizabeth Joseph - Kongiganak
10. David Kohler – Anchorage
12. Shelly Vendetti-Vuckovich – Anchorage
13. Maggie Winston – Kenai
14. Anna Atla – Anchorage
15. Meghan Clark – Anchorage
16. Christian Muntean – Anchorage
17. Corey Gilmore – Juneau
18. Margaret Evans – Anchorage
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20. Heidi Lieb-Williams – Anchorage
22. Molly McManamin – Anchorage
23. Cindy Murphy-Fox – Anchorage
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