

**GOVERNOR ' S
COUNCIL ON
DISABILITIES &
SPECIAL
EDUCATION
ANNUAL REPORT,
OCTOBER 2014 -
SEPTEMBER 2015**

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DISABILITIES and SPECIAL EDUCATION ANNUAL REPORT, OCTOBER
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Council members, partners, and staff, May 2015 (not pictured: Jeanne Gerhardt-Cyrus, Anthony Cravalho, Kristin Vandagriff)

CREATING CHANGE THAT IMPROVES THE LIVES OF ALASKANS WITH DISABILITIES

STATE COUNCIL ON
DEVELOPMENTAL DISABILITIES

SPECIAL EDUCATION ADVISORY
PANEL

INTERAGENCY COORDINATING
COUNCIL FOR INFANTS AND
TODDLERS WITH DISABILITIES

GOVERNING BOARD OF THE
SPECIAL EDUCATION SERVICE
AGENCY

BENEFICIARY BOARD FOR THE
ALASKA MENTAL HEALTH TRUST
AUTHORITY

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Department of Health & Social Services
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GOVERNOR'S COUNCIL
ON DISABILITIES &
SPECIAL EDUCATION

GOVERNOR'S COUNCIL ON DISABILITIES & SPECIAL EDUCATION ANNUAL REPORT FOR OCTOBER 2014-SEPTEMBER 2015

Council Mission

Creating change that improves the lives of Alaskans with disabilities.

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 state and federal levels.

Federal Advocacy – The Council's federal advocacy efforts centered around the rewrite and passage of the [Workforce Innovations and Opportunity Act](#) (WIOA) and the [Elementary and Secondary Education Act](#) (ESEA), both of which should have significant impact on persons with disabilities nationwide. With the passage of WIOA last year, we saw an increased emphasis on transition services for youth with disabilities under the Vocational Rehabilitation program, and a shift of Statewide Independent Living Council's (SILCs) and Center for Independent Living (CILs) to the [Administration on Community Living](#) (ACL). With the Council's efforts already on youth employment, we very much supported the changes in WIOA and we welcome our partners from the independent living movement to ACL. The Council made frequent comments to Senator Murkowski on ESEA reauthorization because several provisions and amendments had to do with children with disabilities. Senator Murkowski sits on the Senate Health, Education, Labor and Pensions (HELP) committee, which has responsibility for writing the senate version of the bill.

Statewide Advocacy – The Council submitted several bill ideas and advocated for a number of issues that impact the lives of Alaskans with disabilities. One such bill that passed in 2015 is HB 161, which allows for the re-use and recycling of durable medical equipment purchased through Medicaid. This law will save the state money by allowing Medicaid to authorize the purchase of gently used or recycled wheelchairs or other durable medical equipment rather than buy new, when appropriate. A big thanks to Representative Gattis and the Key Coalition for taking on this legislation as a priority.

In addition, the Council provided a steady stream of input and advocacy on budgetary issues that impact families and people with disabilities. With budget shortfalls of billions of dollars for the State of Alaska, everyone is looking at ways to cut back and gain efficiencies, where possible. Overall, the state was able to



Alaska Governor Bill Walker with Council executive director, Patrick Reinhart, at the signing of HB 161.

reduce the budget by 8%, including a \$4.4 million dollar decrease to Medicaid Home and Community Based Services, a \$506,000 decrease in Developmental Disabilities (DD) grants, and a \$50,000 cut in Council funding, which we have been able to absorb by reducing travel and decreasing the number of Council members.

Self-Advocate Support – One of the Council's main responsibilities is to ensure we have a thriving self-advocacy network. This is the primary reason the Council supports [Peer Power Alaska](#), a statewide self-advocacy organization for individuals with disabilities. Peer Power has 7 board members, and 25 supporters. Peer Power members have been working on their presentation skills as self-advocates by presenting at the Arc of Anchorage Self-Advocacy Group meeting this past April. Peer Power is assisting members to hone their skills so that they can be speakers at similar events in the future. The Council's employment initiatives have intersected with Peer Power at six job fairs across the state, either via co-sponsorship or participation, where workplace incentive and self-advocacy resources were offered. Peer Power is also participating with 3 other states on a regional self-advocacy network, called [EPIC \(Equal Partners Interstate Congress\)](#), that will serve as a significant force to further the progress towards holding statewide conferences and advocacy awards programs.

Community Choice and Supports

The Council's [Developmental Disabilities \(DD\) Committee](#) spent this fiscal year focusing on housing for individuals with disabilities. Council staff participated in several collaborative partnerships with [Alaska Housing Finance Corporation \(AHFC\)](#), including research support for their [2015 Fair Housing Impediments Report](#). Staff also provided subject matter expertise to AHFC on the formation of their new [HUD 811 Project Rental Assistance Program](#) for permanent supportive housing, to the Division

of Behavioral Health for their Statewide Strategic Supportive Housing Plan, and began attending meetings of the [Alaska Coalition on Housing and Homelessness](#) and the [Governor's Council on the Homeless](#). The Council also embarked upon a large-scale research project, incorporating qualitative and quantitative data collection methodologies to produce a comprehensive [Housing Barriers Report](#) for Alaskans who experience intellectual and developmental disabilities. This report is being used by several local agencies to increase the availability of supportive, accessible housing in the municipality of Anchorage and throughout the state.

The Council also works with partners to administer mini-grants. In collaboration with the [Alaska Mental Health Trust Authority](#) and [Stone Soup Group](#), the Council helps to grant out up to \$2,500 per individual,

Trust
Alaska Mental Health Trust Authority

per fiscal year for people with intellectual or developmental disabilities who need services or equipment to improve their quality of life. This year, 176 individuals received grants totaling over \$232,730. The Council has continued to partner with the Trust on its Beneficiary Employment and Engagement (BEE) Initiative as well as on the [Trust Microenterprise Grant Program](#). Several presentations and open house events were held this past year for the Microenterprise grant program. This fiscal year, 15 grant awards totaling \$85,122.96 were awarded to 15 beneficiaries to start or enhance their current small business.

The Council has also embarked upon the process of creating our next 5-year state plan. The state plan provides a framework of Council priorities, and gives guidance to each committee via individual work plans for federal fiscal years 2017-2021. Council members and staff have been busy traveling throughout the state to collect public input by holding community forums in 13 urban and rural locations. These roundtable discussions with self-advocates, family members, providers, administrators, and the general public are producing a wealth of information that is being analyzed and presented to the Council at their regular meetings. The Council members are currently in the process of taking the public input and formulating it into goals, objectives, and work plan items for the next 5-year state plan.

The Council's [Workgroup on FASD](#) (fetal alcohol spectrum disorders) has been hard at work to be sure that all school districts in the state recognize FASD as a disability that qualifies students for special education services. To that effect, the Workgroup collaborated with the [Council's Education Committee](#) to propose a regulation change that would classify FASD as an "Other Health Impairment" on Individualized Education Plans (IEPs). The FASD Workgroup also took leadership of this year's [FASD Awareness Day event in Anchorage](#) on September 9. Cooperating with the Center for Human Development (CHD), [FASDx Services](#), the [Arc of Anchorage](#),

the [Anchorage School District](#), Stone Soup Group, [Volunteers of America](#), [Alaska Center for Resource Families](#), and other partners, the Council workgroup was able to organize a successful event including speakers such as First Lady Donna Walker and Mayor Ethan Berkowitz. The Workgroup was also instrumental in FASD Awareness Day events in other communities across the state, reaching from urban Fairbanks to rural Kiana.



Community Forum in Kotzebue, October 21, 2015.

Autism

In September 2014, a group of stakeholders met with Dr. Matthew Siegel, from the Maine Medical Center Research Institute, to discuss the gaps and challenges in autism diagnosis and intervention in Alaska. Another meeting of these stakeholders was convened by the Trust to follow up on his recommendations. The outcome of this meeting was a determination that the state needed to develop a "Phase II" autism plan to cover not just screening and diagnosis, but comprehensive across-the-lifespan support systems. In October, the Council worked with a [LEND fellow](#) (Leadership Education in Neurodevelopmental and related Disabilities) whose research project was to compile background and historic materials to develop a new autism 5-year plan. At the January Council meeting, The Trust made a formal request to the Council to spearhead this collaborative effort. The Council approved the formation of an [Autism Ad Hoc Committee](#). With funding for meeting costs from The Trust and from the Alaska Division of Women's, Children's, and Family Health, the Council engaged the services of a facilitator to develop a strategic plan. From this meeting came a purpose, a vision, and a promise to develop a shared plan and common set of priorities to make positive and lasting improvements to the autism continuum of care in Alaska. Five focus areas were defined and each became a workgroup that convened meetings to compile data and work on their priority areas. A second, full-day meeting was held in May. The groups reported to the committee on their activities and at the end of a full day of in-depth and engaged discussion, short and long-term strategies and priorities were agreed upon. A third meeting to finish the plan and establish measurable targets is scheduled for 2016.

Medicaid

This year, a Governor-appointed [Medicaid Reform Advisory Group](#) met several times to discuss various options to cut costs to the Alaska Medicaid program. The Governor's Council chair and staff attended these meetings

and [provided public comment](#) on October 20, 2014. In March of 2015, the Council released a [resolution in support of Medicaid expansion](#). Governor Bill Walker announced plans to expand Medicaid for more Alaskans on July 16, 2015, kicking off several other reform efforts to make the system more sustainable. Council staff have been involved as key stakeholders in the design of Medicaid expansion since it took effect on September 1, 2015. Council members and staff are also part of several committees to improve the Medicaid waiver program (1915 c) by expanding services to more Alaskans with disabilities via the 1915 (i) and (k) state plan options. In addition, the Division of Senior and Disabilities Services (SDS) released several policy changes and updates to the Medicaid waiver program this fiscal year. The Council's Medicaid Reform Ad Hoc Committee provided public comment to SDS on these changes, ranging from modifications to the Medicaid [waiver performance measures](#), to an annual reduction in the number of applicants drawn from the [Developmental Disabilities Registration & Review \(DDRR, or "waitlist"\) to receive a waiver](#).

The Governor's Council put considerable effort into the review and analysis of several products resulting from the March 2014 Center for Medicaid and Medicare Services (CMS) final rule on Home and Community-Based Services (HCBS). This final rule detailed person-centered planning, integrated settings, and conflict-free case management that must be in place in every state. The rule led to two versions of the Alaska Transition Plan on HCB Settings and a major redesign of the care coordination system in the state. The Council provided extensive comments on the [draft transition plan](#) as well as the [revised transition plan](#) on settings. Council members and staff have also been integral partners in several planning sessions on the design of conflict-free care coordination, a system that will take effect next fiscal year.

Employment

The Council has continued to support four [Project SEARCH](#) sites in Alaska, including [Providence Alaska Medical Center](#) (Anchorage), [Fairbanks Memorial Hospital](#), [Central Peninsula Hospital](#), and the [Mat-Su Regional Medical Center](#). Currently, 26 interns (high school students with disabilities) are enrolled, learning employability skills while immersed in competitive and integrated employment. The National Director of [Project SEARCH](#), Erin Riehle, visited Alaska this past year, assisting with technical assistance for the current sites as well as working towards program expansion efforts. The Council facilitated Ms. Riehle's giving several presentations, including the keynote address for the Alaska Society of Human Resource Management Conference regarding achieving meaningful employment of individuals with disabilities to over 330 of Alaska's top HR professionals from across the state.

The [Alaska Integrated Employment Initiative \(AIEI\)](#) grant was in its third year in FY15 and seeks to improve employment outcomes for youth and young

adults with intellectual and developmental disabilities over the five-year life of the grant. The AIEI Policy & Regulations Team has submitted four recommendations regarding data, including data system enhancement and identification of core employment data indicators. Through the AIEI grant, training in customized employment, self-employment, and Plan to Achieve Self-Supports (PASS) creation have continued to be offered monthly via distance delivery. AIEI has partnered with CHD at UAA and the [University of Washington Center for Continuing Education in Rehabilitation \(CCER\) program](#) to build a Certificate in Employment Services training into the Alaska training system. This will ensure increased capacity for providers who receive the training, and the Association of Community Rehabilitation Educators (ACRE) certification, enabling them to become a Vocational Rehabilitation (VR) vendor of services.

The [AK APSE Chapter](#) is now fully chartered by national APSE (Association of People Supporting EmploymentFirst) and held its first events in collaboration with the Council and the Trust this past May. Two [CinemAbility](#) showings, a documentary which focuses on the evolution of disability in the entertainment industry, included a panel of experts on employment. Council staff gave two national presentations at the [APSE Conference](#). Council member and AK APSE Co-President, Lucy Odden, won the national APSE Personal Achievement Award and was recognized at the national APSE conference in Philadelphia. Employment First legislation originator, Representative Charisse Millett, was also recognized at the national APSE conference in the Public Policy award category.



Left to Right: Patrick Reinhart (Council director), Kristin Vandagriff (Council staff), Lucy Odden (Council member), and Representative Charisse Millett (AK House majority leader & Council member).

This past year, due to the overwhelming success of interagency partnerships through job fairs and federal contractor trainings, the Business Employment Services Team (BEST) was created. BEST is an interagency collaboration between the Alaska Departments of Health and Social Services and Labor & Workforce Development as well as other state and federal agencies dedicated to meeting the workforce needs of Alaska businesses while improving hiring outcomes for individuals with disabilities and veterans. BEST holds two annual job fairs dedicated to its hiring mission for individuals with disabilities and veterans. BEST has been featured in the [September 2015 Alaska Department of Labor TRENDS](#) statewide newsletter and is partnering with the Society of Human Resource Management to give presentations on state hiring resources for employers interested in hiring and retaining veterans and individuals with disabilities.

Early Intervention

The Council has been very involved in the second year of the five-year State Systemic Improvement Plan (SSIP). The new performance indicator required by the federal Office of [Special Education Programs \(OSEP\)](#) is focusing on improving the social and emotional outcomes of infants and toddlers in Alaska's Early Intervention/Infant Learning Program (EI/ILP). This year Council members and staff participated in the leadership team developing the SSIP. Council staff and parents have also participated in OSEP-sponsored trainings and workgroups including traveling with state office staff to Atlanta and Chicago to provide stakeholder involvement on improving socio-emotional outcomes and the data collection necessary to document improvements.

The Council has also been taking an active role in facilitating a collaborative effort to expand and improve telepractice efforts in the state. This started with identifying the strengths and challenges to effective telepractice delivery in the state's ILPs. A presentation from tribal health on early intervention telehealth practices and successes in their programs led to the Council taking an active and increased role with the formation of a new Telepractice Ad Hoc Committee. This committee facilitates a collaborative effort that expands past the initial early intervention focus, to include other educational, medical, and therapeutic settings and to advocate for systems reform that will optimize workforce development, technology accessibility, and billing policies.

The Council identified a need from parents and data collected in the [Alaska EI/ILP Program 2014 Family Outcomes Survey](#), that there was a gap in understanding by both ILP providers and families on parental rights and procedural safeguards. The Council [surveyed the ILP programs](#) on their experiences and obstacles with informing parents of their rights. The programs had widely varying comfort levels with discussing these rights with parents and no consistent training or guidance on what program staff needed to make these discussions sound family-friendly. The programs specifically asked for the State ILP Office to provide professional development on best practices for informing parents of their rights and protections. The Council made recommendations to the State Office on improvements and OSEP-recommended practices. The Council provided support letters for independent grant funding for one of the Infant Learning Programs to develop this training, which they would share with the State ILP Office. The Council also presented on parent rights and procedural responsibilities, along with the State ILP Director, at a parent conference.

Education

The Council continues to work with the [Department of Education and Early Education \(DEED\)](#) to identify ways to increase the graduation rate for students with disabilities. The Council continues to participate in the 5-year SSIP for the development and implementation of a new OSEP performance indicator to narrow the gap between the graduation rates of

students with disabilities from those without disabilities. We were involved in the data analysis and review that comprised the first year and are active in the second year's improvement strategies and implementation planning.

To advocate and participate in collaborative initiatives that improve the scope, delivery, and effectiveness of post-secondary transition, the Council has been involved in several activities. One is the development of a high school transition course that will provide a person-centered employment plan for students with disabilities. This partnership between the [Division of Vocational Rehabilitation \(DVR\)](#) and school districts with funding from the AIEI grant and curriculum development from CHD has created a pilot course incorporating DVR "discovery" with pre-employment soft skills instruction. Students will then be paired with a DVR Community Rehabilitation Professional (CRP) who can assist the students with finishing their plan and help them find jobs. This pilot program will start in the 2015-16 school year with four school districts. In addition, the Council has been collaborating with CHD and LEND Family Advisory Council on an Alaska Transition Handbook.

The Council also provided comments to the State Board of Education on the new assessment guidelines for students with disabilities and for those taking alternate assessments. As part of its ESEA waiver, Alaska has not only new education standards, but new assessments. The Council was involved in the implementation of these assessments, including participating in statewide trainings on the new [Alaska Measures of Performance \(AMP\)](#). The Council also engaged the assistance of early education experts in developing comments on the importance of early literacy screenings in response to a proposed waiver from these screenings requested by a charter school.



Left to Right: Jay Brauch (paraprofessional), Margaret "Peggy" Fedoroff (Special education teacher), Tyler McCarty (special education teacher), and Christie Reinhardt (Council staff).

The Council participated in the [Alaska Statewide Special Education Conference \(ASSEC\)](#), the largest conference of its kind in the state. We presented on implementation and training on the new restraint and seclusion regulations. As we have done since 2003, we sponsored and

presented the Inclusive Practice Award at the conference. This award was established to recognize outstanding educators who work to ensure that students with disabilities have the opportunity for an inclusive education with their peers. Nominations are made by parents, students, and educators. For the first time, this year's winner was an entire school, Keet Gooshi Heen Elementary in Sitka, Alaska. Under the leadership of their principal, Casey Demert, the clear assumption at Keet is that students with disabilities will participate in the general education curriculum and the school community. The school was able to send three staff members to the conference to accept the award in front of an audience of over 200 of their peers.

Health

Collaborating with the University of Alaska Anchorage's CHD, the Council completed significant work on the [Alaska Safety Planning Empowerment Network \(ASPEN\) project](#). ASPEN is a statewide partnership invested in helping Alaska community providers serve the needs of people with disabilities who are victims of domestic violence, sexual assault, and stalking. In 2015, the ASPEN strategic plan was implemented and a satisfaction survey was administered. Positive outcomes of this project include collaboration between disability agencies, domestic violence/sexual assault shelters, independent living centers, behavioral/mental health agencies, and tribal organizations. ASPEN also facilitates the creation of a "no wrong door" model where survivors with disabilities can contact any of the above listed agencies and receive referral and wraparound care, increased cross-training between service delivery systems, long-term systemic changes that will continue after completion of the ASPEN project, and increased awareness of interpersonal violence among survivors with disabilities. Project coordinators have implemented this project in a new community this year and plan to work with another Alaskan community in FY16. Plans are underway to conduct focus groups, key informant interviews with agency staff, needs assessment, and strategic planning that will pave the way for future work on this important project.

The Council also partners with the Division of Public Health's section of Women's, Children's, and Family Health on the [Alaska Health and Disability Program \(AHDP\)](#). In 2014, AHDP created the ["Get Ready!" emergency preparedness toolkit](#) for people with disabilities as a guide that gives step-by-step instructions on how to make a plan and prepare for a disaster. A total of 4,308 copies of the Get Ready toolkit have been distributed in Alaska this fiscal year. In addition, AHDP created a starter emergency kit called a SKIP kit (Safety Kept in Place). In FY15, 2,660 of these kits have been distributed to Alaskans. Through this partnership, 14 emergency preparedness (EP) presentations were given to 10 different agencies, totaling more than 330 people trained. Staff to the Council and AHDP created an EP workgroup to address the functional and access

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needs of Alaskan with Disabilities during an emergency. This workgroup meets monthly and consists of representatives from 7 different agencies. The EP workgroup began a pilot project that will assist disability agencies in creating their own Continuity of Operations Plan (COOP). A presentation on the COOP plan was given at the [Full Lives Conference](#) with 30 attendees. Additionally, two presentations were given on each of the following health topics: abuse prevention and intervention (54 people reached), nutrition (53 people reached), mental health (41 people reached), and diabetes (49 people reached).

Council staff are also partnering with agencies statewide on the completion of [Alaska's strategic plan](#) to promote the health of people with disabilities. These activities include exhibiting at health fairs, participating in [Anchorage's ADA 25th anniversary event](#) (July 27, 2015), and collaborating with [Special Olympics Alaska](#) on a project to improve the health of aging individuals with disabilities.

Council Members

Jill Burkert – Juneau

John Cannon* – Juneau

Anthony Cravalho – Kotzebue

Art Delaune – Fairbanks

Sandra DeHart-Mayor* – Anchorage

Edna DeVries* – Palmer

Donald Enoch – Juneau

David Fleurant – Anchorage

Angie Fraize – Anchorage

Dean Gates – Anchorage

Jeanne Gerhardt-Cyrus – Kiana

Alex Gimarc – Anchorage

Taylor Gregg – Ketchikan

Heidi Haas – Fairbanks

Mallory Hamilton – Anchorage

Alexis Henning – Anchorage

Tara Horton – Anchorage

Susan Kaplan – Anchorage

Terese Kashi – Soldotna

Christine King – Eagle River

David Kohler* – Anchorage

Margaret Kossler – Anchorage

Sarah Kveum* – Juneau

Banarsi Lal – Fairbanks

Kaleen Lamb – Fairbanks

Karli Lopez – Anchorage

Charisse Millett – Anchorage

Sharon Miranda – Anchorage

Ric Nelson – Anchorage

Sean O'Brien – Juneau

Lucy Odden – Anchorage

Justine Sheehan – Barrow

Amy Simpson – Eagle River

Maggie Winston* – Kenai

* Appointed in Oct 2015

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Ric Nelson, MPA, Program Coordinator

Brittney Howell, M.A., ABD, Research Analyst

HalleliYah Yisra'el, Administrative Assistant

Ian Miner, Office Assistant



*In memoriam
Marilee Mendenhall-Rivas, Council staff*

"There was a pier filled with thousands of people, men and women, fathers and mothers and children- so many children- children from the past and the present, children who had not yet been born, side-by-side, hand-in-hand, in caps, in short pants, sitting on each other's shoulders, sitting in each other's laps. They were there, or would be there, because of the simple mundane things she had done in her life, the accidents she had prevented, the rides she had kept safe, the unnoticed turns she had affected every day. And while their lips did not move, she heard their voices, more voices than she could have imagined, and a peace came upon her that she had never known before."

Mich Albom The Five People you Meet in Heaven, 2003



ABLE (Achieving a Better Life Experience Act) (529A) Accounts:

1. What is an ABLE account?

- Tax-advantaged savings accounts for individuals with disabilities and their families
- Similar to 529 college saving accounts
- Income earned by the accounts = not taxed
- Contributions to the account = not tax deductible.

2. Why the need for ABLE accounts?

- ABLE savings accounts will not affect eligibility for SSI, Medicaid/other public benefits
- Previously, public benefit eligibility required an individual to remain poor
- Recognizes of the extra costs of living with a disability

3. Am I eligible for an ABLE account?

- Eligibility = individuals with significant disabilities with an age of onset prior to turning 26
- SSI and/or SSDI = automatically eligible to establish an ABLE account
- No SSI and/or SSDI = eligible to open an ABLE account if you meet SSI criteria
- Significant functional limitations
- Can be under 26 or over 26
- If over 26 - documentation of onset needed

4. Are there limits to how much money can be put in an ABLE account?

- Total annual contributions = \$14,000
- Amount will be adjusted annually for inflation
- Gift Tax Exclusion: \$14,000 = maximum amount individuals can give & not pay taxes
- Total limit over time = determined by state:
- SSI/Medicaid recipients = exempt from resource limit up to \$100,000
- Exceeding \$100,000 = loss of SSI eligibility/benefits, Medicaid eligibility continues

ABLE Act Implementation U.S. & Alaska

- HB 188/SB104: Disability Savings Accounts (ABLE ACT)
 - Introduced last session - Representative Saddler is sponsor in the House and Senator Giessel in the Senate
 - "An Act relating to financial accounts for persons with disabilities; relating to financial institutions; relating to property exemptions; relating to securities; and providing for an effective date."
 - To read more about the bill, visit:
http://www.legis.state.ak.us/basis/get_bill.asp?bill=HB%20188&session=29
- Internal Revenue Service Proposes Regulations for New State-Sponsored ABLE Accounts
 - To help states implement these accounts, the Internal Revenue Service (IRS) has issued proposed regulations that are now available for public comment until September 21.
 - Proposed regulations link:
<https://www.federalregister.gov/articles/2015/06/22/2015-15280/guidance-under-section-529a-qualified-able-programs>



Please join the Council in supporting HB188/SB104: The Achieving Better Life Experience (ABLE) Act

WHAT IS IT?

This bill would direct the Department of Commerce, Community and Economic Development (CCED) to set up a new federally authorized program with Alaska-based financial institutions that allow certain eligible persons with significant disabilities to have a non-taxed savings account to help pay for qualified disability-related expenses.

WHY IS IT NEEDED?

In passing federal authorizing legislation in 2014, Congress recognized that people with disabilities often have higher living expenses because of their disability. Additionally, people with disabilities who receive federal and state benefits are not able to save over \$2,000 without losing some or all of their much needed benefits.

The ABLE Act helps remedy these problems by:

- Providing a way for recipients to fund planned and unexpected expenses related to their disability from their ABLE account that are not covered by public support programs
- Providing a way for relatives and friends to put funds into an individual's ABLE account
- Providing a place for recipients to put their own money without risking their qualification for public benefits
- Improving independence for recipients by allowing them to be in control of their own financial resources, unlike special needs trusts and supplemental needs trusts, which require a trustee to manage and disburse funds
- Enabling employment and greater self-sufficiency for people with disabilities through financial savings

HOW WILL IT WORK?

- An eligible individual is someone who becomes disabled before age 26
- If the recipient is over age 26, documentation of onset is needed to qualify
- The funds can be used only for eligible expenses for the recipient's benefit such as:
 - Education, housing, transportation, employment training and support, assistive technology and personal support services, health, prevention and wellness, financial management and administrative services, legal fees, expenses for oversight and monitoring, funeral and burial expenses, and any other expenses approved under regulations which are not eligible to be paid for by recipients benefits
- Recipients can control their account at their sole discretion if they are able to do so
- These are tax-advantaged savings accounts for individuals with disabilities and their families similar to 529 college saving accounts
- Accounts are regulated by the IRS similarly to the current 529 college saving plans
- The ABLE account can reach a value of up to \$100,000 without losing any benefits
- Income earned by the accounts is not taxable
- Contributions to the account are not tax deductible
- Can be funded annually up to maximum gift tax amount (Currently \$14,000)

RESOURCES:

http://www.legis.state.ak.us/basis/get_bill.asp?bill=HB%20188&session=29

http://www.legis.state.ak.us/basis/get_bill.asp?bill=SB%20104&session=29

<https://www.realeconomicimpact.org/public-policy/able-act>

<http://www.ndss.org/advocacy/ABLE-Act>

<https://www.autismspeaks.org/advocacy/advocacy-news/2015-year-able-momentum>

Please support HB188/SB104



Please join the Council in supporting an annual draw of 175 from the Developmental Disabilities Registration and Review DDDR (“Waitlist”)

WHAT IS IT?

The Developmental Disability Registration and Review (DDRR “waitlist”) is a program registry for qualified individuals with intellectual & developmental disabilities who meet “institutional level of care.” The registry provides an avenue for these individuals to receive the Medicaid waiver for Home and Community-Based Services when funds become available. The DDDR is managed through the Division of Seniors & Disabilities Services (SDS), and their plan is to reduce the DDDR waitlist annual draws from 200 consumers to 50 consumers per year as a way to save money in the short-term.

WHY IS THIS AN ISSUE?

- Because of the state’s commitment to draw 200 families from the DDDR for services since 2005, the number of families waiting for services has decreased from over 1200 to less than 700, currently. Reducing the draws by 75% will increase the number of consumers waiting for services and possibly triple the average wait time of 3 years.
- Families that are supporting individuals with developmental disabilities are much more likely to reduce work hours or leave the work force in order to care for their child.
- Research shows that waiver-funded supported employment services result in more job placements, higher wages, and work hours per week for individuals with disabilities. Employment ultimately has the potential to result in cost savings and better quality of life.*
- The average cost per I/DD waiver in-state is just under \$80,000 while the average cost for an out of state placement is over \$120,000.
 - Reducing the number of draws from the registry will increase pressure on state-funded grant dollars and, in some cases, result in higher-cost services if their child is placed in an out-of-state intermediate care facility.

ALTERNATIVE SAVINGS

The Council believes that we can accomplish the same level of projected savings from waiver services by implementing some of the strategies being explored now by SDS under the 1915i and 1915k state plan options beginning in 2017 as well as reviewing some current ideas, such as:

- **Streamlining the eligibility and level of care re-determination process.** Many people on the I/DD waiver have lifelong disabilities, such as Downs Syndrome, and their conditions are not going to materially improve over time. Currently, the process requires a full review and authorization every 3 years. We suggest review every 5 years and much greater use of low-cost tele-technology for reassessments vs. in-person reviews.
- **Considering implementing "soft caps" on services.** By exploring "soft caps" the division can reduce the number of hours for many services and then require justification of the need for more than a certain number of hours when needed.
- **Establishing voucher program for purchase of supplies and other personal care items.** Using a voucher card similar to the Alaska Quest card used for food stamps, allow families and/or providers to purchase some medical supplies from Walmart, Costco, or other low-cost alternatives to medical supply companies. This would also prevent continuous delivery, a common practice now, resulting in stockpiles of unneeded supplies.
- **Allowing for purchase of smart-home technology and services that reduce the need for direct staff support.** Other states and the V.A. have shown significant savings by allowing more smart-home technologies like tablets and smart phones to help a person live independently.
- **Considering a package of new services to persons who do not quite meet institutional level of care in the 1915i.** Some people and families (i.e. FASD, TBI, ADRD) need only a little bit of support, such as supervision and cuing, to help maintain community living:
 - Individuals with FASD alone cost the state nearly \$2 million over their lifetime**, through their use of the correctional system, medical treatment, residential care, and lost productivity.
 - Providing early intervention to these individuals often avoids much costlier state-funded services later in life.

Please encourage HSS/SDS to reinstate waiver draws to at least 175 individuals per year

Resources:

*Jean P. Hall, Noelle K. Kurth 2013. Employment as a Health Determinant for Working-age, Dually Eligible People with Disabilities.

<https://ku scholarworks.ku.edu/bitstream/handle/1808/11286/Hall%20Kurth%20Hunt%202013.pdf?sequence=1>

**Lupton, Chuck. 2003. The Financial Impact of Fetal Alcohol Syndrome. Fetal Alcohol Spectrum Disorders Center for Excellence. <http://fasdcenter.samhsa.gov/Products/cost.aspx>

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Please Join the Council in Supporting HB 77: **The Disability Training and Identification Bill**

WHAT IS IT?

This bill improves interactions between individuals with disabilities and law enforcement officials through three key components:

1. The institution of a training program to provide law enforcement officials with the tools to positively interact with individuals with disabilities.
2. Educating the public about their duties and expectations when interacting with law enforcement officials.
3. Providing individuals with disabilities the voluntary option to obtain a discreet mark on their driver's license or ID card to ensure law enforcement is aware of their disability when interacting with them.

WHY IS IT NEEDED?

Given the large number of Alaskans who experience disabilities, it is crucial that officers have the correct tools to interact with these individuals in the legal system. The high stress and discretionary nature of police work can result in miscommunications and unintended consequences from interactions between law enforcement personnel and persons with disabilities. For example,

- Individuals who experience disabilities that alter balance or speech can incorrectly be assumed to be intoxicated.
- Some disabilities may prevent an individual from understanding or complying with the requests of a police officer, which can lead to an officer thinking the individual is non-compliant or resisting arrest.
- Some disabilities can be mistaken as signs of aggression or imminent threat, which can lead to actions that inappropriately escalate the situation.

HOW WILL IT WORK?

- The Alaska police and corrections academies will add a disability awareness training component to their curriculum which will include:
 - ✓ Information on disabilities and how they may influence the interaction of an individual with the legal system.
 - ✓ Information on recognizing varying types of disabilities (including non-apparent disabilities) and awareness of the resources available.
- A section will be added to the Alaska Driver's License Manual to educate drivers about their responsibilities and expectations when stopped by a police officer. This information will be incorporated into the Alaska driver's license test to ensure all licensed drivers understand their responsibilities.
- Individuals with disabilities will have a voluntary option of a discreet marker if they feel that they would benefit from an additional law enforcement verification of a disability. This will be similar to an organ donor mark and will be entirely optional.
- This bill does not change or interfere with any of the established safety procedures in place to protect public officials or the responsibility of an individual for their own actions.

RESOURCES:

<http://m.ktuu.com/news/kodiak-police-release-video-of-controversial-struggle-with-autistic-man/37216474>

<http://www.npr.org/2013/09/03/218555867/are-cops-properly-trained-to-deal-with-people-with-disabilities>

Please support HB 77