

**GOVERNOR'S COUNCIL ON DISABILITIES
AND SPECIAL EDUCATION**

**Combined Self-Advocacy & Leadership (SAL) and
Legislative Committee Meeting**

MINUTES

Videoconference Host

Governor's Council
550 W. 7th Avenue, Suite 1220
Anchorage, Alaska

Meeting Date

January 18, 2023
10:00 a.m. – 11:30 a.m.

Committee Members:

Jena Crafton, SAL Chair
Art Delaune, Legislative Committee Chair
Margaret Evans
Nona Safra
Shelly Vendetti-Vuckovich
Heidi-Lieb Williams
Director Duane Mayes

Guests:

Dave Fleurant
Lesley Thompson
Courtney Westmann
Myranda Walso

Staff:

Patrick Reinhart
Jamie Kokoszka
Lanny Mommsen
Rich Saville
Michael Stevenson

Prepared by: Sheila Garrant, Peninsula Reporting

CALL TO ORDER – 10:05 a.m.
ROLL CALL – Quorum established

WELCOME FROM THE CHAIR

Mindfulness

Jena Crafton welcomed the attendees to the meeting and led the committees in a mindful moment.

Announcements

Jamie Kokoszka announced that the Council is seeking applications from the DD community for the Micro-Enterprise Grant, which helps to support individuals with developmental disabilities in self-employment. The deadline for applications is March 1st, 2023. More information is available at the Council.

Jamie Kokoszka shared that Empower Hour is scheduled for January 19, 2024 from 7:00 – 8:00 p.m.

Patrick Reinhart reported that the Council held a special meeting to address the executive director position. The Council went through an executive search that did not yield a qualified candidate. They ultimately chose to offer the position to Patrick, who is currently the acting executive director. Patrick agreed to continue as executive director for the foreseeable future.

Declarations of Conflict

No conflicts of interest were declared.

APPROVAL OF THE PREVIOUS MEETING MINUTES AND AGENDA

Tabled due to a lack of quorum.

REPORTS

Chair Jena Crafton

Jena Crafton reported that she has been enjoying her volunteer work at the Council.

Chair Art Delaune

Art Delaune had no news to report.

GCDSE Staff Report

Patrick Reinhart reported that the Council is close to hiring a planner. He also shared that the Council has three volunteers in the Council office: Jena Crafton, one individual supported by DVR, and a MASST volunteer.

Patrick Reinhart announced that Chair Heidi Lieb-Williams will be honored by Governor Dunleavy at the State of the State address.

BUSINESS

Discussion on Potential Legislative Priorities

Art Delaune opened the floor for a discussion on legislative priorities.

Deaf and Hard of Hearing Child's Bill of Rights

Courtney Westmann joined the meeting to share information on the Deaf and Hard of Hearing Child's Bill of Rights. She explained that the Deaf and Hard of Hearing Child's Bill of Rights was established through the Alaska Deaf Council in 2014 and was sponsored by Representative LeDoux. The Bill of Rights aims to strive for equal access to communication and language acquisition for deaf children. Deaf and hard-of-hearing children have unique language use and needs, especially if their primary language is American Sign Language (ASL). The Bill of Rights has six main points:

1. Having the ability to communicate as a priority.
2. Having qualified personnel who can communicate directly with deaf and hard-of-hearing children.
3. Having a sufficient number of deaf peers of the same language mode, level, and age.
4. Having opportunities to interact with deaf adult role models and have that community in their primary mode and language.

5. Having benefits from all services and programs at their schools.
6. Having appropriate assessments and being assessed appropriately through their primary mode of communication or language.

Courtney Westmann stated that the hope is that through this Bill of Rights, the rights of the deaf and hard-of-hearing children are honored, and the resources are present to support deaf children statewide. The Bill of Rights strives to ensure that IEP teams and families statewide have access to early intervention services and that children can be referred to appropriate resources. Courtney noted that the Individuals with Disabilities Education Act (IDEA) does not explicitly address language and communication. The Bill of Rights essentially enforces that communication has to be prioritized and enshrines the rights of deaf children to have access to options from the start.

Courtney Westmann stated that the proposed bill does not have a sponsor, and she was looking for Council support as well as assistance from the Council to identify sponsors. She stated that she is not aware of a fiscal note attached to the proposed bill. Courtney noted that approximately 20 states have passed a similar bill of rights, and most of those states have a rural deaf population.

Heidi Lieb-Williams **MOVED** to adopt the Deaf and Hard of Hearing Child's Bill of Rights as a legislative priority, **SECONDED** by Director Duane Mayes and Margaret Evans. Hearing no objection, the motion **PASSED**.

The committee members agreed to adopt the Deaf and Hard of Hearing Child's Bill of Rights as a legislative priority and take the lead from the language provided by the bill drafters to create a support document and work to find legislative sponsors utilizing the connections of the deaf community.

Participant-Directed Care HCBS Option

Patrick Reinhart reported that a subject matter expert was unavailable to present information on the participant-directed care HCBS option. He shared that the Council is invited to a meeting on January 27th, 2023 to get an update on the option. Patrick remarked that given the historical interest in self-directed options for people with disabilities, this could be a high-level priority for the Council.

Current or Potential Letters of Support

Art Delaune opened the floor for members to voice current or potential letters of support.

Patrick Reinhart reported that the Council has yet to be approached for other letters of support. He noted that the Council and other Trust beneficiary advisory boards have developed a generic package of position papers for issues such as flexible services, prevention services, and other policy issues.

Patrick Reinhart called attention to the Alaska Work Matters Task Force's recommendation for creating a centralized accommodation fund in state government for employees who experience a disability. He said the Council could consider supporting the recommendation and put it forward as a proposed bill. He remarked that the development of the bill language would be straightforward. Patrick noted there is a fiscal note, which has been approximated between \$200,000 and \$300,000.

Patrick Reinhart reported that the Department of Justice's report on the unnecessary institutionalization of children with disabilities in Alaska has not spurred any legislative action yet. The Council will keep abreast of movement regarding the information. Jamie Kokoszka noted that the issue relates to the lack of home and community-based services available on the mental health side as opposed to direct care services. Patrick Reinhart suggested referencing the HCBS issues in a white paper created by the Council related to supporting flexible services and modifications of existing waiver services.

Patrick Reinhart remarked that the HCBS system is in crisis because of workforce issues. Over and over, service providers are dropping out of the industry. Based on information from agencies, they are losing care coordinators at an alarming rate. He stated that care coordinators are the gatekeepers for developing plans of service. If a person is lucky enough to have a care coordinator, the likelihood of being able to find a direct service provider is bleak. Patrick commented that some of the biggest agencies are on the verge of collapse in the next few years if the state doesn't figure out a rate methodology that will keep agencies in business and reform

waivers to include flexibilities. He warned of an inevitable drift back towards institutional care.

Shelly Vendetti-Vuckovich suggested the formation of a task force with wide-based representation that would identify the issues facing the HCBS/waiver system and develop recommendations that could be taken to the administration for consideration. Patrick Reinhart remarked that a process similar to that was implemented through the legislature to address personal care assistance services in the state. The legislature put together a legislative task force comprised of senators, representatives, subject matter experts, and beneficiary boards who spent a year identifying the issues and finding solutions for the administration and legislature to develop.

Patrick Reinhart noted that staff will be working in the upcoming week on developing draft white papers for the committees to review.

Self-Advocacy Training for Upcoming Juneau Visits/Council Meeting

Patrick Reinhart reported that the Council staff will update the legislative advocacy PowerPoint to include the current priorities and present it at the Council meeting as a training component.

Other Topics Open for Discussion

Due to time constraints, no other topics were brought forward for discussion.

UPCOMING MEETINGS

Alaska Participant-Directed Care HCBS Option
January 27, 2023, 9:00 – 10:00 a.m. – Zoom Meeting

GOOD OF THE ORDER AND ADJOURNMENT

Director Duane Mayes **MOVED** to adjourn, **SECONDED** by Heidi Lieb-Williams. Hearing no objection, the motion **PASSED**, and the meeting adjourned at 11:30 a.m.