

MINNESOTA GOVERNOR'S COUNCIL ON DEVELOPMENTAL DISABILITIES

December 4, 2024

Masonic Institute for the Developing Brain
2025 East River Parkway
Minneapolis, MN 55414

MEETING MINUTES

MEMBERS PRESENT

Lee Shervheim, Chair
Dupree Edwards
Lisa Gemlo
Lisa Jemtrud
Heather Kainz
Lesli Kerkhoff
Joel Liestman
Elizabeth Marsh
Katie McDermott
Chris McVey (virtual)
Alan Morrison
Mike Nichols
Garrett Petrie (virtual)
Jenn Purrington
Connie Rabideaux (virtual)
Jenny Santema (virtual)
Bonnie Jean Smith
Sumukha Terakanambi

MEMBERS EXCUSED

Jenny Arndt
Jason Blomquist
Amy Hewitt
Abdi Matan
Christine Mueller
Mary Raasch
Erin Schwab

STAFF PRESENT

Stephanie Nelson
Colleen Wieck

GUESTS

Dan Reed
Heather Stillwell

I. MEETING CALLED TO ORDER

The meeting was called to order by Chair Lee Shervheim at 12:15 pm.

II. INTRODUCTIONS

Shervheim invited everyone present in person and online to introduce themselves.

III. APPROVAL OF AGENDA

Shervheim called for approval of the agenda.

MOTION: Smith moved, McDermott seconded a motion to approve the agenda. **Motion carried.**

IV. APPROVAL OF COUNCIL MINUTES (October 2, 2024)

Shervheim called for approval of the October 2, 2024 Council Minutes.

MOTION: Morrison moved, Edwards seconded a motion to approve the Minutes.
Motion carried.

V. AFTER ACTION REPORT FROM THE MINNESOTA DEPARTMENT OF HEALTH ABOUT COVID

Lisa Gemlo, Program Coordinator, Children and Youth with Special Health Needs and Disabilities Section, Minnesota Department of Health presented on the department's efforts during the pandemic. She wanted to share the challenges, the activities, the lessons learned, and how the Department of Health is moving forward.

Gemlo served as the lead person during the pandemic, and the challenges included: transportation, housing, employment, technology, education, data, masking, testing, vaccines, caregivers, community services, staffing, mental health, isolation, and guidance. COVID disproportionality affected people with disabilities and in turn experienced a higher risk of dying. Individuals also suffered from psychological distress because of restrictions.

Telehealth worked for some and not others. Caregiver stress increased and many programs were not implemented. During the first months of the pandemic, nearly one million workers with disabilities lost their jobs in the United States. The pandemic affected access to medications, food, and basic necessities. HCBS providers did not receive the federal assistance that other providers received.

Lisa created a disability unit inside MDH, and it included 1 to 4 people. The Disabilities Unit responded through several strategic actions including assessment, informing, engagement, guidance, accessibility, and empowerment.

Assessment included survey data, Let's Talk forums, ongoing data scanning, and creation of situation briefs.

Informing was both external and internal communication.

Engagement occurred through an advisory group, the Let's Talk Forums, an Accessibility Workgroup, and Topical engagement.

Guidance was developed or modified in the areas of masking, hospital visits, medical rationing, elective medical procedures, accessibility, schools, congregate settings, allocation of vaccines, and vaccinations for children with disabilities.

Accessibility included physical, technological, cognitive, and sensory issues.

Empowerment was carried out by COVID Community Coordinators (CCCs) which involved several contracts with local organizations. These contracts helped with increasing access to PPE, vaccination support, and real time information.

Barriers included lack of data, the balancing of rights of people with the risks posed by COVID, lack of prior engagement, accessibility issues, and lack of clarity or slow response to the pandemic.

Lesson learned-- disability is a health equity issue. There must be intentional outreach to the disability community. The CCC efforts were instrumental in reaching the disability community,

Recommendations—Create a long-term plan to engage the disability community; complete an ethics review of the pandemic response; use the State Fair Vaccination Site as a model; convene state-to-state communities of practice, improve lines of communication across state agencies, review and reflect on disaster planning, assign a coordinator to the Office of Emergency Management focused on access and functional needs.

Things have changed at MDH with a disability health equity collaborative working internally, adoption of data standards for disability issues, a new disability portal for data, and more resources focused on disability.

A new strategic planning process will focus on disability equity, what MDH can do, creation of an actionable plan, and messaging about MDH's role in disability equity.

Gemlo has shared her 140-page after-action report internally, but this report has not been officially released. MDH did not have a disability unit when the pandemic began. As a result, MDH lacked understanding about the people, the services, and the hesitancy of MDH which believes DHS is responsible for all disability issues. Gemlo heard the stories of individuals being locked in their rooms in group homes. Systems had to be put in place and so disability issues ended up being addressed last. Rationing was occurring because health professionals did not understand that some procedures for people with disabilities weren't elective, they were critical. Another problem was the overlay of the CDC guidance which seemed to lag for people with disabilities.

The discussion included the policy of vaccinating caregivers before people with disabilities. Part of the issue was the lack of data about people with disabilities which affected vaccination priorities. Then the Governor's Office took over and the vaccination priorities became political.

Another point was the vulnerability of several systems to future disasters including the infrastructure as well as another potential pandemic. Another question was whether guidelines exist now. The pandemic worsened the workforce issues and so is MDH doing anything to look at the workforce crisis. MDH has created a new Council on the Workforce and Gemlo is trying to make sure existing workforce initiatives are connected and groups know about each other.

VI. UPDATE ON THE MURPHY LAWSUIT

Jenn Purrington, Minnesota Disability Law Center, gave an overview of the status of the *Murphy* Lawsuit. The *Murphy* case began seven years ago and will conclude in 2026.

DHS has been complying with the provisions of the settlement agreement by updating their policy manual, adding a new section to the MnCHOICES assessment, training case managers, etc. They are creating a list of individuals who indicate they want to move and there is follow-up by lead agencies. Purrington asked members to contact MDLC if they know of any problems with the lawsuit implementation.

The discussion topics included: guardianship issues, people being moved from integrated settings to segregated settings, the lack of housing, the lack of supported living services in MN compared to other states, the background of the lawsuit, the difficulty in getting the data out of the previous version of MnCHOICES, individuals with disabilities not being consulted, the lack of education for individuals and families, and the turnover rate of case managers, etc. For example, Ramsey County has 23 different contracted case management agencies.

Kerkhoff urged members to use several resources available at Disability Hub.

VII. NEW E1MN POLICY (Increasing paid work experiences for students with disabilities)

Chris McVey, Deputy Director, Disability Employment Services, Vocational Rehabilitation Services, Department of Employment and Economic Development

Directly quoting from the new E1MN policy memo:

“ One outcome of Minnesota’s Youth in Transition Framework is that youth with disabilities “find competitive integrated work they enjoy”. Research shows that early paid work experience is a primary predictor of post-school employment success for youth with disabilities (Mazzotti et al., 2016; Wehman et al., 2015). The Work-Based Learning section of the Framework emphasizes that we want all students to receive a full range of work-based learning experiences throughout high school and 18-22 transition programming which ultimately leads to competitive integrated work experience before graduation.

Thus, E1MN leaders at Department of Employment and Economic Development (DEED), Minnesota Department of Education (MDE), and Department of Human Services (DHS) have a vision that:

All students with disabilities have paid competitive integrated employment (CIE) work experience prior to earning their high school diploma.”

The remainder of the memo then provided key resources for the field on how to implement this new directive. McVey emphasized that it is the responsibility of several groups to make this new policy work. VRS currently works with 10k students, and this has been an enormous effort. Two of the three top categories of individuals served are individuals on the autism spectrum and developmental disabilities.

Discussion topics included the need for affordable transportation. Dental coverage through MAEPD does not include expensive procedures and people cannot pay these expenses. There is also a lack of dentists who will take Medical Assistance. Another topic was individuals who are removed from social security, overpayments, and penalties. McVey and Kerkhoff urged people to use benefit counselors and online disability benefits estimators.

VIII. GRANT REVIEW COMMITTEE REPORT

Shervheim shared that the major task was to review the application form for training conferences. The Committee reviewed the application form and proposed a few changes. The proposals will be due in January and the Committee will review the proposals at the February meeting.

IX. PUBLIC POLICY COMMITTEE REPORT

Terakanambi summarized Kevin Parker’s presentation about Project 2025 and other proposals that could potentially harm individuals with disabilities. The November budget forecast was released this morning and so Kevin cautioned that 2025 could be a policy year more than a budget year, but individuals and advocates should continue to push for hearings. The second part of the meeting focused on the greatly expanded services for crime victims by the Department of Public Safety as presented by Becky Rabb. Her PowerPoint will be forwarded to all members.

X. EXECUTIVE DIRECTOR REPORT

Wieck shared the following highlights:

- A. Congress voted on a Continuing Resolution (CR) in September for FFY 2025 and the CR ends on December 20, 2024. The amount received to date is \$255,794.00. The Council is currently using FFY 2024 funding for the grants and the administrative costs.
- B. The Treat People Like People funding from Moving Home Minnesota ended on September 30, 2024, and all reports have been submitted. The campaign is currently being funded by the Department of Health, the Minnesota Council on Disability, and the Institute on Community Integration. The Ombudsman for MH-DD has also pledged funding.
- C. The Olmstead Implementation Office has received three reports that will be summarized and presented to the Council as part of our public input for our next Five-Year Plan.
- D. The traveling exhibit is currently being hosted by the University of Wisconsin, Stout during part of November and December. It will be hosted by the Department of Transportation next.
- E. Partners in Policymaking—Class 42 has now completed three weekends of training. A graduate workshop about civil conversations was held in October. The schedule for Class 43 of Partners in Policymaking has been set for September 2025-May 2026.
- F. Publications—The Council released the 9th edition of the Partners in Policymaking Coordinator's Handbook and two Easy to Read Workbooks to supplement the 245D Bill of Rights video series.
- G. The 2024 Program Performance Report is completed. The Annual Report is in the packet and will be posted early next week. If anyone has any editing suggestions, please contact the staff.
- H. The rest of the report was a review of the Business Results. This document will be posted along with the Annual Report.

XI. PUBLIC COMMENT PERIOD

Shervheim invited members to share any updates.

Nichols shared that the video of Hannah taped as part of the Treat People Like People campaign has over 86k video views.

Liestman announced that Taki Taimani, Minnesota Vikings player, has chosen the Williams Syndrome Association for "Cleats for a Cause" that will be celebrated at the December 8, 2024 Vikings game. Cleats for a Cause is an initiative of the NFL where players choose a charity and wear specially designed cleats during the game. The cleats are then auctioned off and 100% of the proceeds are donated to the player's chosen cause.

XII. ADJOURNMENT

Meeting adjourned at 2:32pm.

Respectfully submitted,
Colleen Wieck, Executive Director