

**MINNESOTA GOVERNOR'S COUNCIL  
ON DEVELOPMENTAL DISABILITIES**

Wednesday, June 6, 2018  
12:15 p.m. to 2:30 p.m.  
Continuing Education and Conference Center  
University of Minnesota St. Paul Campus  
1890 Buford Avenue, St. Paul, Minnesota 55108

**MINUTES**

**MEMBERS PRESENT**

Senator John Hoffman, Chair  
Ashley Bailey, Vice Chair  
Hanna Barr  
Lisa Emmert  
David R. Johnson  
Eric Kloos  
Mary Martin  
Noah McCourt  
Jillian Nelson  
Kate Onyeneho  
Carolyn Perron  
David Quilleash  
Dan Reed  
Jacki Rightler  
Reid Scheller  
Heather Tidd

**STAFF PRESENT**

Colleen Wieck  
Mary Jo Nichols

**MEMBERS EXCUSED**

Michelle Albeck  
Alex Bartolic  
Pamela Hoopes  
Jim Lovold  
Randy Miller  
Lee Shervheim  
Alan Wilensky

**MEMBER ABSENT**

Emilie Breit

**GUESTS**

Susan B. Foote, author  
Wendy Berghorst, Department of  
Health  
Phyl Burger  
Mary Duplessia-Tschida  
Lauren Foster, Department of Human  
Services  
Lauren Girmscheid, Department of  
Human Services  
Annmarie Gibbs

**GUESTS**, cont'd.

Maureen Jovanovich  
Dennis Kalow  
Maura McNellis-Kubat, Ombudsman Office for  
Mental Health and Developmental  
Disabilities (OMHDD)  
Chris Michel, OMHDD  
Kim Moccia, STAR Program  
Roberta Opheim, OMHDD  
Amy Perron, STAR Program  
Karen Rieck  
Bonnie Jean Smith

**I. CALL TO ORDER**

Senator John Hoffman, Council Chair, called the meeting to order at 12:20 p.m.

**II. INTRODUCTIONS**

Everyone present introduced him/herself.

**III. APPROVAL OF AGENDA**

Senator Hoffman asked for approval of the Agenda.

**MOTION:** McCourt seconded by Emmert to approve to approve the Agenda.  
Motion carried; there we no dissenting votes.

**IV. APPROVAL OF MINUTES FOR APRIL 4, 2018**

Senator Hoffman asked for approval of the Minutes as written for April 4, 2018.

Onyeneho pointed out typos in the Council Program section on pages 4 and 5 to be corrected

On page 4, the first part of the paragraph, gtoup will be corrected to read group.

On page 5, the second sentence, this this will be corrected to read this only.

On page 8, the Motion for Approval of the Agenda, we will be corrected to read were.

**MOTION:** Reed moved, seconded by McCourt to approve the Minutes for April 4, 2018 with the typos corrected as noted above. Motion carried; there were no dissenting votes.

### **COUNCIL PROGRAM**

Colleen Wieck introduced Susan Foote. Wieck attended Foote's first reading of her book at the University of Minnesota. The history that is portrayed in The Crusade for Forgotten Souls, and efforts to reform Minnesota's mental institutions during the 1946-1954 time period, parallel the history of people with developmental disabilities. The overuse of restraints and the use of restraints when other more effective approaches, ones more respectful of the individuals, are known are so much a part of these histories.

Wieck mentioned Dr. Ralph Rossen, whom Governor Youngdahl appointed as Commissioner of Mental Health, and his patient centered treatment program, the concept of "one person at a time," that characterized Minnesota's reform efforts. However, we were always at the mercy of the legislature and not successful in getting the funds to initiate any of these reforms.

Susan Foote began her presentation by saying that her book is a story of courage and accomplishment that took place 70 years ago, a story that should not be forgotten.

She recounted that the beginning of The Crusade for Forgotten Souls actually fell on her head. In 2013, she happened to be helping her adult son clean out a closet when a large bag of papers fell off a high shelf. The bag was filled with clippings, speeches, photos, and personal papers that had belonged to her former father-in-law, Arthur Foote, and were given to her son.

Her background as a health policy and history professor suggested that maybe there was a story in this collection of papers.

Foote talked briefly about her writing style and why would anyone want to read a history book with footnotes. But it was important to her to come to know the people in her book. They are the characters, and we need to hear their stories and search for their words. Many people led her to new places and discoveries to help shape her book.

The story of mental health treatment that unfolded involved politics and culture, and crossed many barriers. Ordinary people who wanted to leave the world a better place persuaded Governor Youngdahl to take action. One of these individuals was Engla Schey, a hospital attendant, who was mentioned frequently in Foote's presentation and referenced at length in the book as a mental health reform crusader. She wrote letters about conditions in the mental health hospitals and the people there, and found her way on boards and committees to speak about policy measures.

In the 1940s, there were seven mental hospitals. Rochester, St. Peter, Fergus Falls, Anoka, Willmar, and Hastings. Faribault opened in 1879 with 14 children with developmental disabilities transferred from St. Peter.

Foote showed photos of the hospital conditions in the early 19<sup>th</sup> Century. It was believed that the design of the institutions could influence behaviors so people lived in highly structured and controlled environments, and isolated from society. "Cures" included drugs. There weren't enough resources to adequately care for the increasing number of individuals who were housed in the institutions, and overcrowding gave way to hopelessness. Conditions were at an all time low.

A United States Public Health Survey in 1940 found that institutions in Minnesota were some of the worst in terms of per capita spending. There was excessive use of restraints, diets were unpalatable, and staff were grossly underpaid. The problem was a system problem; superintendents had absolute power. They noted that some restraints belonged in museums.

In the 1940s, about 15,000 individuals lived in the institutions: 80% were there involuntarily, about 30% were elderly; women with postpartum depression or grieving widows. Many individuals who were diagnosed with some form of mental illness were living in the state's institutions. About 2,500 people with developmental disabilities were in Faribault; infants could be there for their lifetime.

The institutions touched more than the individuals who were living there. Families were affected, too. There was shame about having a family member in an institution and employees were ashamed to admit that they worked there.

Foote shared some stories from Engla Schey's journal writing and a letter to Governor Youngdahl from a resident at Faribault. He said he had been there for 19 years and "that's too long for anyone." He went on to say how people were treated, hit with broom handles and coat hangers and keys. He said that he had "always been good and would like to get work at a farm."

During World War II, as mental hospital staff were drafted, labor shortages resulted in disruptions in the delivery of services to an increasing number of individuals in the institutions. Conscientious objectors were assigned to serve in that capacity but they came from a different segment of the population than the male attendants who preceded them. They were better educated and raised to be compassionate to all, and horrified by what they saw. They began documenting the abuses and organized among themselves, and provided the information that became the "Bedlam 1946" exposé that was published in *Life* magazine.

*The St. Paul Pioneer Press* then published its own version of conditions in Minnesota's state institutions. In an article entitled, "No Snake Pits in Minnesota Asylums," conditions were represented in a very different light - the food was good, people were well cared for, and restraints were never used. The myth was created that everything was fine.

Foote then talked about Engla Schey and who she was; she appeared briefly in Governor Youngdahl's biography but is not mentioned anywhere else. She was born to a farm family. She never married, had a brother and sister, worked for relatives, and had a deep respect for the Salvation Army where she spent 14 years. She wanted to be a writer, and a descendant had an incredible cache of her diaries and papers. Through this collection, much was learned about the life of Engla.

Her childhood was shaped by a controlling and perfectionist mother, and a father who was a free thinker. Engla identified with her father. She always wrote in the third person and "wanted to do something worth living for."

When she came back to Minnesota, Engla was hired at Anoka State Hospital in a custodial position, the lowest level attendant. She was outspoken and objected to how the individuals there were treated. She refused to place them in "camisoles" (straitjackets), was rebuffed by the doctors and ridiculed by the nurses. She worked there for six years, 48 hours a week, and took classes at the University. All of her efforts to change the way people were treated were to no avail. She pursued transfers to other hospitals while being blocked from promotions, and herself treated so poorly at Anoka. She also discovered the Unitarian Society and joined in 1943.

She was finally successful in getting an interview at Rochester State Hospital and began working there in 1945, "spreading the gospel of mental health reform." She received a poor reception from the doctors there but went forward regardless of the barriers.

In October 1946, Engla was invited to the Minnesota Unitarian Society Conference. Conferences usually focused on church matters but that year, the focus was on social action and mental health reform. She disputed the *Pioneer Press* article stating that those in authority had no idea about what was actually occurring in the institutions with the people who were living there. She urged people to "...dance with the patients, then you will get an idea about what needs to be done in mental hospitals."

Arthur Foote was among those who attended the Conference and took a year to study the issues. He believed that one can't just protest, you have to listen, learn, and understand the problems to get the answers.

At this same time, Genevieve Steefel, another social activist and member of the Unitarian church, and Engla became connected. Engla wrote many letters to Genevieve and let her know how the state manipulated the social service system. Genevieve was an expert communicator. This was the beginning of mental health reform movement.

A team of Unitarians was built. They could have gone to the Legislature in 1947, it would not have been difficult, but they never would have been successful.

In 1946, Luther Youngdahl was approached and asked to consider running as the Republican candidate for Governor; he agreed and was successful. During the campaign, he was challenged by a candidate who had switched parties, Hjalmar Petersen, who spoke out about conditions at the Faribault School, the mistreatment and abuses of residents, including children; and called for a grand jury investigation. The Republican leadership accused Petersen of lying. The investigation closed down the controversy. A study was conducted but forgotten.

Engla wrote to Petersen following the election, expressing that "the outcome of the Faribault investigation grieved me."

Youngdahl's priorities and initiatives were always about people; he wanted to serve everyone. A group of people, mainstream citizens and committed activists, were willing and able to take a stand and support him. The Faribault issues resurfaced as did Arthur Foote, who contacted Geri Hoffner and suggested that the *Minneapolis Tribune* might want to do a story about the state's mental hospitals. The result was the 11 part "Minnesota Bedlam" series.

The 1948 elections and the 1949 Legislative Session saw a statewide movement of people and county citizen committees, all of whom were pressing for reforms. The

results were immediate in terms of the beginnings of change. Youngdahl was honored by the Menninger Clinic, reform legislation was passed, and his burning of straitjackets was seen as the beginning of a new era in the care and treatment of people living in the state's institutions.

Two core principles emerged from these changes – in terms of legislative language, the fundamental human guarantees to which every patient is entitled; in terms of systems change, the process is from the top down.

In the summer of 1951, Youngdahl resigned the governorship and was appointed to serve as a federal judge in Washington, D.C. In 1954, he returned to Minnesota, giving a speech that honored Dr. Ralph Rossen, and stating that constant vigilance is required regarding these reforms. When Rossen was appointed Commissioner of Mental Health, he said that he needed 10 years but he only had two years.

Susan Foote concluded her book reading and presentation by saying that citizens who do care can act and can make change. She was thanked for her work in writing this history and sharing some of the memorable stories.

A book signing followed her presentation.

## **V. CHAIR'S REPORT**

There was no Chair's report today.

## **VI. GRANT REVIEW COMMITTEE**

Quilleash reported for the Committee.

Abdi Matan, HAARAN, presented a summary of the results of this first year's Cultural Outreach Program in the Somali Community in the St. Peter area. He talked about the many benefits for participants who came from countries where there were no services, from refugee camps, and their first experiences with learning about programs, how to access services, and navigate delivery systems. Much individual assistance was provided, resource materials were translated, and participants gained a great deal of new knowledge that they could share with other families in the community.

This as a bridge year for the Ambassadors for Respect/Anti-Bullying Program PeaceMaker Minnesota developed a replication plan for continuing the program

using the Ambassadors for Respect Handbook. An informal solicitation will be issued for proposals to begin the replication process.

A Pre-Allocations memo was presented to the Committee with highlights of the results of this year's grant projects and activities to date, and suggested allocations for FFY 2019.

## **VII. PUBLIC POLICY COMMITTEE**

Kloos reported for the Committee

Alicia Munson, The Arc Minnesota, presented a summary of the 2018 Legislative Session. There was a lot of unfinished business. Many of the policy issues on The Arc Minnesota's agenda, important for individuals with developmental disabilities and families, were contained in the Omnibus Bill that was vetoed.

Elyse Bailey and Colin Stemper, Department of Human Services, Disability Services Division, presented about the Waiver Reimagine Project, thinking about person centered approaches in developing waiver services. Concerns were raised about this effort being similar to other projects in the past. Operational definitions are needed. Some things could be done administratively and that would be easier. Studies are underway and options will be presented to the legislature.

## **VIII. EXECUTIVE DIRECTOR'S REPORT**

Colleen Wieck presented an overview of the Legacy Grant project, "With An Eye to the Future," that is being launched today. We delivered much more than what we included in our proposal to the Minnesota Humanities Center, which was 750 documents and 20 video interviews.

"With An Eye to the Future" covers the 2000 to 2018 time period with highlights for each year.

- Total of 25 video interviews with Partners graduates, self advocates and parents, speaking about what they see for the future of disability rights in Minnesota.



- The State Capitol Grand Opening in August 2017 with images and videos of Justin Smith and former United States Senator David Durenberger.
- Total of 120 story segments with links to videos; media events; surveys, studies, and reports; presentations by subject matter experts; publications; public policy actions; and public television projects.
- Regarding the Jensen Settlement Agreement and Olmstead Plan –  
  
The Jensen Settlement Agreement docket contains 670 documents; 228 of the most critical documents were selected  
  
Links to Olmstead Plan documents that are housed at the Department of Human Services.  
  
Assorted document created in developing Minnesota's Olmstead Plan.
- Legislative Reference Library – mandated reports.
- Legislative summaries from the Minnesota Disability Law Center.

After July 1, 2018, the following will be added:

Additional documents from the Minnesota Historical Society.

The STAR Program's Assistive Technology archive.

Employment videos.

Customer research summaries.

Additional Jensen Court documents.

The following updates and highlights are from monthly activity reports:

1. No action has been taken on Council appointments.

2. Our final award letter was received on May 21, 2018 for a total of \$ 1,028,414; this represents \$ 3,000 more than we received for FFY 2017. The encumbrance/liquidation time period is now an issue with a new interpretation by the federal government.

We are still awaiting direction on submitting the 2017 Program Performance Report.

3. The Olmstead Plan quarterly report was submitted in May.
4. An Olmstead Plan milestones document was prepared.
5. An Olmstead Plan chronology was prepared.
6. The 8<sup>th</sup> Circuit Court of Appeals hearing is scheduled for June 13, 2018 regarding the Court's continuing jurisdiction in the Jensen case.
7. Work continues in cooperation with the Department of Health on the Bill of Rights project for Supervised Living Facilities.

**IX. ADJOURNMENT**

Hoffman asked that the meeting be adjourned.

The meeting was adjourned by consensus at 2:30 p.m.

Respectfully submitted,

Colleen Wieck  
Executive Director