

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

Wednesday, April 4, 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
Alex Bartolic, Vice Chair
Michelle Albeck
Pamela Hoopes
David R. Johnson
Eric Kloos
Mary Martin
Noah McCourt
Randy Miller
Jillian Nelson
Kate Onyeneho
David Quilleash
Dan Reed
Reid Scheller

STAFF PRESENT

Colleen Wieck
Mary Jo Nichols

MEMBERS EXCUSED

Emily Breit
Lisa Emmert
Carolyn Perron
Jacki Rightler
Lee Shervheim
Heather Tidd

MEMBERS ABSENT

Hanna Barr
Jim Lovold
Alan Wilensky

GUESTS

Dr. James Conroy
Center for Outcome Analysis, Inc.
MarketResponse International
Susan McCollough
Derek Pearson
Lynne Schreifels
Tom Pearson
Wendy Berghorst, Department of Health

GUESTS, cont'd.

Laurie Beyer-Kropuenske, Department of
Administration
Bonnie Jean Smith
Ellie Wilson, Autism Society of Minnesota

COUNCIL PROGRAM

A. General Population Health Care Survey Results

The Council's partnership with MarketResomse International (MRI) began 18 years ago with the first Quality of Life survey. Individuals with developmental disabilities were asked about the quality of services they are receiving and their levels of independence, productivity, integration and inclusion; self determination was added soon after. Customer research studies are now a priority area and a specific goal in the Council's Five Year State Plan.

In 2004, MRI conducted the first Minnesota Health Care Opinion Poll. Given that health care has become such a critical issue across all segments of the population, particularly for individuals with developmental disabilities and families who rely on Medicaid and Medicaid funded programs and services, the decision was made to repeat and update the 2014 study.

The qualitative phase of this year's study included two panels of individuals to learn about their perspectives and insights about health care costs, quality of services, and satisfaction with the health care they received. A literature review was done, and recent surveys on health care issues were reviewed to see what identical questions were asked.

A welcome was extended to Tom Pearson and Derek Pearson, and their staff to present the results of this year's Health Care study.

Tom Pearson then introduced the other members of the MRI team, Susan McCollough and Lynn Schreifels.

Tom Pearson said that the final survey was a 20 minute questionnaire. The report is divided into two sections – how people with different types of health care insurance evaluate their satisfaction with health care coverage and care, their

outlook about health care and concerns; and then their personal beliefs and opinions about the health care system as a whole and what government should be doing in terms of health care policies.

A Bulletin Board focus group method was used for the qualitative phase. A total of 30 individuals were recruited, 15 for two groups, that included three day sessions to learn about their experiences with health care services, their outlook about health care, and the extent of the government's role. Their insights were used to compare and update the 2004 survey questions with changes and additions relevant to today's health care systems.

Survey highlights included the following:

A total of 1,009 respondents completed the survey.

MRI worked with a sampling provider to assure that the age, gender, and race/ethnicity of respondents was a good match with the state's general population.

Part One included questions that were asked in the 2004 survey about the kind of insurance coverage respondents had; for those with private insurance, their employer's share if any; and increases in premiums or additional costs.

For respondents who said they delayed treatment due to costs, or delayed treatment for a "serious" condition, Nelson asked how "treatment" was defined in those instances. Pearson said it was up to respondents to determine what serious meant to them.

A total of 39% of respondents gave their health care coverage and care a less than good rating.

Senator Hoffman asked whether health care coordination was addressed. Pearson said that various health care experiences were evaluated in terms of levels of satisfaction. A new item was also added regarding the process of pricing, billing and reimbursement for services provided.

The level of satisfaction with health care experiences determined the overall quality of health care.

Seven predictors were identified as having the most impact on improving overall health care quality – processes for pricing, billing, and reimbursement; and finding a plan to best meet individual/family needs; out of pocket costs; choice of doctors and specialists; and prescription drug costs.

Regarding a correlation between types of insurance and levels of satisfaction, respondents with Medicare coverage were more satisfied than respondents with private insurance coverage in all aspects of health care experiences.

Senator Hoffman added that there are fewer barriers to choosing doctors and fewer prior authorization issues in Medicare.

Nelson noted that she's worked for a small pharmaceutical benefits group that wanted to take care of people; much of what people pay for and receive depends on what their employer decides to offer.

Quilleash said that he's incredibly satisfied with the care he receives (he's covered under both Medicaid and Medicare) but his specialists don't accept Medicaid.

Tom Pearson said that households with a person with a developmental disability are most concerned about rising costs – for premiums, co-pays and deductibles, and prescription drugs.

Part Two included 24 survey questions about attitudes related to health care services, costs, access, and personal responsibilities. Respondents rated their agreement or disagreement with those statements resulting in four segments of fairly like minded people and their respective positions.

Even with strong opinions and attitudes about some aspects of health care, the majority of Minnesotans agreed on four basic issues –

Health care should be available to all.

No one should be turned away from necessary medical treatment.

Everyone should pay something.

People who need more services should receive them without having to pay more.

Tom Pearson added that MRI will be oversampling racial and ethnic communities to make sure that their experiences and insights are represented.

The MRI team was thanked for conducting this this year's General Population Health Care Survey and presenting the results.

Jim Conroy commented that this is the first time in 50 years that he's seen a lower rate of increase in health care costs compared with previous years.

Senator Hoffman referred to the recently released Department of Human Services Medicaid Matters report. The Department of Human Services has released a report entitled. Senator Hoffman asked Alex Bartolic to speak about the report.

Bartolic said that this is the first report that will be published annually. The report presents a brief history of Medicaid, the history of the Medicaid program in Minnesota, how the program has been used to cover both medical care as well as long term care services, innovations, and a breakout of services provided.

Copies of the Medicaid Matters report were given to Council members.

B. Quality of Life Survey: Its Relationship to Minnesota's Olmstead Plan, Its Purpose, and Results

Dr. Jim Conroy, Center for Outcome Analysis, Inc., began his presentation by sharing some background about how he started in the field. It wasn't in the usual way that families become acquainted with programs and services and delivery systems because of a family member with a developmental disability. He landed a job with a consulting firm, visited Pennhurst, and designed a survey to try to understand what happens to people when they leave an institutional setting and are they better off when they do.

Until the Pennhurst study, people who had lived in institutions and then moved to community settings were never directly asked how they felt, or if their life was better as a result of moving into the community. The Quality of Life Survey is asking the same kinds of questions – are people better off as a result of the Jensen Settlement Agreement and Minnesota's Olmstead Plan.

A total of 2,005 people, who were receiving day services or center based employment services or residential services, participated in the Quality of Life Survey. They were asked directly about work, where they worked and the number of hours per week, and earnings; opportunities to go places and do things in the community, how often, and their interactions with others in the community; personal choices in a broad range of daily living activities; how much control they have over their own lives; and their perceptions about qualities of life.

Conroy noted that this is a baseline survey and provided some background on the Quality of Life Survey.

Minnesota's Olmstead is in response to two court cases –

The 1999 Olmstead decision and the US Supreme Court's ruling that services must be offered in the most integrated setting; and Justice Ruth Bader Ginsburg's statement that "people should not be deprived of the opportunity to live in community unless they object;" and

The Jensen Settlement Agreement that required the development and implementation of an Olmstead Plan. The Olmstead Plan also requires a longitudinal study.

Conroy highlighted the origins of METO, the Cambridge facility that opened in 1999, was licensed for 48 beds and, over a 20 year period, raised continuing concerns about aversive programming and widespread use of restraints. Investigations by the Ombudsman Office for Mental Health and Developmental Disabilities in 2007 led to their "Just Plain Wrong" report in 2008. The Jensen lawsuit that was filed in July 2009.

The Settlement Agreement was approved by the Federal District Court in December 2011, and the provisions that are critical to where we are today are the Positive Support Rule (Rule 40) and the Olmstead Plan. US District Court Judge Donovan Frank has asked repeatedly if people are better off as a result.

Conroy highlighted some of the history of the Olmstead Plan, including its final acceptance by the Court in 2015 with up to 40 measurable goals. The Quality of Life Survey was discussed four years ago in terms of which assessment to use.

Conroy's work and experience in this area were eventually brought here to Minnesota.

As a result of the Settlement Agreement, people with disabilities should gradually become more integrated in the community and better off outside of an institutional setting.

The Survey looks at Community Integration and Engagement, and is divided into two parts. **Part One** asks what people do all day, are they earning any money (from subminimum wages in a workshop setting to regular competitive employment), and how integrated are they.

The baseline survey is testing the temperature of the system. When we come back three years from now, will we find that people are better off than they are today?

Nelson asked about integration and the extent to which people with disabilities are working with people without disabilities. She has a good job but she's working in the autism community.

Conroy said that these questions are getting at whether people are making independent choices about where they work, if they really have a choice about working with and/or without people with disabilities. If integration is not desired, that's a choice the person is making and hopefully it's an informed choice.

Part Two asks the number of times each week that people are getting out in the community, in what kinds of daily life activities, the size of the group, and the extent of their interactions with other people in the community that are also involved in that same type of activity. Conroy noted that this is a measure of integration.

The opportunity to make choices about different aspects of those daily life experiences, who may be making or controlling those decisions, is getting at how much autonomy people actually have over daily life activities.

Conroy said that in 15 studies over 25 years, people with about in the middle – decisionmaking was shared. Nineteen states did before and after scales regarding services and increases were seen across all states. We know that we can spend less, and people are better off and have a better quality of life.

How questions are asked can result in a better assessment of what people are actually experiencing. Regarding health care, for example, and asking people about their health, an "either or" question alone - is your health good or bad - is terrible. Asking two either – or questions gives a more accurate response.

Conroy then talked about weighting scales, characteristics that help to assure that the survey sample represents that population. He noted that Minnesota's weighting scales are remarkably high compared with other states.

In Michigan, for people living in six bed group homes, the weighting scales are the lowest with no changes noted over time.

Reed said that we're now experiencing chronic understaffing and that can affect survey results. People who may want to move out are not able to do so. We're in danger of creating institutions again.

Conroy cautioned against applying a quality of life survey to a "three shift model," saying that you won't get quality. Continue to advocate for the long term as it may take years to see people's lives improving.

Dr. Conroy was thanked for his presentation. Senator Hoffman said it's our responsibility to share and disseminate the information contained in the survey results.

I. MEETING CALLED TO ORDER

Senator John Hoffman, Council Chair, called the meeting to order at 12:30 p.m.

II. INTRODUCTIONS

Everyone present introduced him/herself.

III. APPROVAL OF AGENDA

Senator Hoffman asked for approval of the Agenda.

MOTION: McCourt moved, seconded by Nelson to approve the Agenda. Motion carried; there were no dissenting votes.

IV. APPROVAL OF MINUTES FOR FEBRUARY 7, 2018

Senator Hoffman asked for approval of the Minutes as written for February 7, 2018

MOTION: McCourt moved, seconded by Nelson to approve the Minutes as written for February 7, 2018. Motion carried; there were no dissenting votes.

V. CHAIR'S REPORT

There was no Chair's report today.

VI. GRANT REVIEW COMMITTEE

Quilleash reported for the Committee

- A Results of Review and Evaluation of Proposals Received in Response to the Request for Proposal for Leadership Development (Replication of the Partners in Policymaking Program and All Related Activities).

Two proposals were received. The proposal submitted by The Odyssey Group was recommended for funding.

Quilleash reminded members about the Conflict of Interest Policy and Conflict of Interest Form. Members who do not have a conflict with the applicant organizations are to sign the Form.

MOTION: Quilleash moved on behalf of the Committee to approve the proposal submitted by The Odyssey Group; McCourt seconded. Motion carried. There were no dissenting votes or abstentions.

- B Evaluation Results for Application for Cosponsorship Funds for a Training Conference.

Quilleash said that an application for cosponsorship funds was submitted by the Minnesota Association for Children's Mental Health at the February meeting but not approved because there was not a strong enough connection with individuals with developmental disabilities. This second

application was aligned more closely with developmental disabilities and approved for funding by the Committee.

MOTION: Quilleash moved on behalf of the Committee to approve the application submitted by the **Minnesota Association for Children's Mental Health** for **\$ 2,000** for their "Child and Adolescent Mental Health Conference;" seconded by Nelson. Motion carried; there were no dissenting vote. McCourt abstained.

C. Reallocation of Cosponsorship Funds for Training Conferences

Quilleash also reported that a total of \$2,500 remained for cosponsorship funds for training conferences. The Committee decided to reallocate those dollars to Publications, Websites, and Online Learning.

VII. PUBLIC POLICY COMMITTEE

Kloos reported that Dr. Jim Conroy, Center for Outcome Analysis, Inc., discussed the Quality of Life Survey results and the different aspects of life that were measured. Members received three handouts that included the assessment tool that was used and what was considered and weighted for each of the measures.

VIII. EXECUTIVE DIRECTOR'S REPORT

Colleen Wieck provided the following updates and highlights from monthly reports:

1. No action has been taken on Council appointments.
2. A \$3 million increase is expected for DD Councils for FFY 2018.
3. The Ambassadors for Respect Anti-Bullying Program was selected as a finalist for a Better Government Award.
4. The Program Performance Report for FFY 2017 has been drafted; a submission date is still pending.

5. Regarding Medicaid:
 - a. Talking points were created from the February Partners graduate workshop;
 - b. Copies of *Why Medicaid Matters* have been given to Council members;
 - c. Video interview were conducted with 20 individuals, self advocates and parents, about the importance of Medicaid in their lives;
 - d. The health care opinion poll, the General Population Survey of Attitudes and Outlook Regarding Healthcare Services and Costs, was conducted; the Survey addresses the role of government in Medicaid funding.

6. Regarding Olmstead:
 - a. Olmstead Plan amendments were submitted to the Court on March 30, 2018; a quarterly report was submitted in February; the Quality of Life survey results were submitted on March 26, 2018;
 - b. A direct support staff report was provisionally accepted on March 26, 2018; fiscal estimates need to be added;
 - c. A status conference is scheduled for July 12, 2018.

7. Regarding the Jensen Settlement Agreement:
 - a. Semi-annual and Annual Reports were submitted to the Olmstead Subcabinet;
 - b. Prevention of Abuse project with the Department of Health - video segments will be created, in an easy to understand format, about four specific rights contained in the Bill of Rights for individuals living in a Supervised Living Facility.

8. The Minnesota Management and Budget Affirmative Action Report was reviewed and comments provided;

9. Minnesota Management and Budget's proposed policy entitled, "Protected Class Harassment Prohibited," was reviewed and comments provided.
10. Minnesota Management and Budget's proposed policy, Americans with Disabilities Act Title II regarding Accessible Meetings and Communications, was reviewed and edits provided.
11. Joe Shapiro, NPR Investigative Reporter, will be attending the Class 35 Partners graduation.

IX. ADJOURNMENT

Hoffman asked that the meeting be adjourned.

The meeting was adjourned by consensus at 2:25 p.m.

Respectfully submitted,

Colleen Wieck
Executive Director