

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

Wednesday, December 4, 2019
9:30 a.m. to 11:30 a.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
Michelle Albeck
Alex Bartolic, Vice Chair
Wendy Berghorst
Lisa Emmert
Eric Kloos
Mary Martin
Noah McCourt
Jillian Nelson
Stacey Nelson
Kate Onyeneho
Dan Reed
Jacki Rightler
Reid Scheller
Lee Shervheim
Bonnie Jean Smith

STAFF PRESENT

Colleen Wieck
Mary Jo Nichols

MEMBER EXCUSED

Hanna Barr
Jim Lovold
Randy Miller
Heather Tidd
Alan Wilensky

GUESTS

Ann Turnbull, Beach Distinguished Professor
Emerita, Department of Education,
University of Kansas
Laurie Beyer-Kropuenske, Department of
Administration
William Kowalski, FEIS Systems,
Columbia, Maryland
Lana Mattonen, Support Person
Donnally Moua, Merrick, Inc.
Southside Services
Stephanie Nelson
Valeri Smirnov
Jahna Sundquist

I. CALL TO ORDER

Senator John Hoffman, Council Chair, called the meeting to order at 9:30 a.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 Jillian Nelson, to approve the Agenda Motion carried; there were no dissenting votes.

IV. APPROVAL OF MINUTES FOR OCTOBER 2, 2019

Senator Hoffman asked for approval of the Minutes as written for October 2, 2019.

MOTION: McCourt moved, seconded by Jillian Nelson, to approve the Minutes as written for October 2, 2019. Motion carried; there were no dissenting votes.

COUNCIL PROGRAM

Colleen Wieck introduced Ann Turnbull, co-founder of the Beach Center on Disability and Professor Emerita at the University of Kansas. Professor Turnbull has served as Principal Investigator for more than 25 federally funded research projects, authored 34 books and more than 340 articles, and held leadership positions on more than 50 boards of national organizations. She is a leading family researcher on the topics of family quality of life, community inclusion, and professional partnerships.

Professor Turnbull said she was delighted to be here and thankful for the warm hospitality she has received. She noted that she and her husband, Rudd, always think of our Council as the lead Council in the country, particularly because of the life changing Partners in Policymaking® program. She speaks today about family quality of life across the lifespan from both a personal and professional perspective, and a desire to leave seeds of ideas with everyone that may come to fruition in thinking about families.

Turnbull began her presentation with son Jay's birth in 1967. He was diagnosed with multiple intellectual disabilities at six months and then autism, and schizophrenia later in life. There were no respite care or early intervention services in those days so Jay spent the first year of his life in the hospital, and didn't leave until an out of home placement was found for him. Jay's "temporary home" was in Connecticut.

Jay was seven when Ann and Rudd Turnbull were married, but a condition placed on the marriage was that Jay would come home to live with them. There were no public school programs for children with disabilities but the Turnbolls were determined that Jay would have and experience what children without disabilities did. He attended school, not in a classroom with his peers but in a cleared out custodial area. Even though IDEA requires research based interventions to address behavior issues, the consequence for some of Jay's behavior issues was a "turnaround room."

In 1988, Professor Turnbull began her research on family quality of life with a focus on maternal characteristics. The initial research study included 33 focus groups of families with children and without disabilities, and 34 interviews with non-English speaking families. The national survey was then designed and conducted in seven states with 500 families of children with disabilities.

From that survey, a definition of family quality of life was created along with a Family Quality of Life Framework consisting of five domains and 25 indicators.

As Turnbull explained each of the domains, it was always in the context of their family's life. In large part, what the Turnbull family learned from and about Jay influenced the research that continues today and has withstood the test of time. Through trial and error, and taking advantage of multiple grant opportunities and other research studies, Jay had what they most wanted him to have – a dignified life.

Along the way, there were both very positive and unexpected surprises, as well as regrettable mistakes. Turnbull shared some examples.

Jay had behavior issues. While some of his behaviors were not appropriate in all environments, they were totally appropriate in a frat house on a college campus. When it came time for Jay to move out of the family home into his own living situation, and the Turnbolls wondered how that might ever happen, his fraternity stepped up to the plate and announced that "we want to be his roommates."

There were also the less than positive realities of life when a family member has a disability. The physical impact is one stressor but the emotional impact is far greater, especially when physical aggression is an issue. An ongoing worry was

always about Jay's meltdowns and outbursts. The consequences of those behaviors were not fully recognized until Jay's adult years when his younger sister talked about dreams she would have of a boogey man coming to hunt her down.

Family travels were not enjoyable for Jay. But in terms of family interactions and relationships with family members, spending time together doesn't mean that everyone always has to do the same thing at the same time.

Grant funds were sought out not only as an opportunity to test out new ideas but also to open the door for Jay to experience aspects of life that individuals without disabilities enjoy. In the 1990s, students with disabilities went from school to sheltered work. When Turnbull learned about research in Oregon that was shifting from sheltered work to supported employment, and wanted Jay to participate, she was told he was "too disabled."

So the Turnbuls planned for Jay to transfer to another high school class to a program that was also being transformed. The transfer was not to Jay's liking. He hated the program and demonstrated how much he disliked it by using his self determination skills by way of aggressive outbursts. He spent so much time in seclusion and timeout, and became more depressed with each incident. Knowing that Jay would be expelled, they decided to meet with the program director and simply announce that they were withdrawing Jay and look into other options. The director's response, "And what are you going to do when you fail?" did nothing to dissuade them differently. To be free of the only program in town was a relief.

When person centered planning was born, the concept was very much in keeping with Turnbull's perspective on the role of support people in relation to an individual with a disability and his/her life. She believed, however that it had to be more than planning; it had to be action oriented. The funding and the people were there to turn this into reality.

The process came to be known as Group Action Planning - when family, friends, professionals and others are supporting an individual and his/her decision making, assuring that the individual's needs, preferences, strength, and interests are respected. The planning process, the Road to Success, is divided into five parts, each with concrete, practical suggestions to get to the desired action.

Turnbull concluded her presentation by sharing what Jay accomplished in his life. After being kicked out of the one program, he went on to complete a Public Policy Fellowship in Washington, DC. He was working 20 hours a week and living with fabulous

roommates. He loved music and played four nights a week. He had the dignified life that the Turnbolls always wanted for him, an enviable and exceptional life, a wonderful life after very tough years. In 2009, he died quickly and unexpectedly. No one saw anything coming on. It just happened.

Turnbull emphasized the importance of relationship and partnerships, one of four characteristics that are associated with a higher quality of life. Then she gave everyone an assignment – to reach out to someone and, on a one-to-one basis, develop a trusting partnership.

Everyone thanked Professor Turnbull for her presentation. Her PowerPoint and Group Acton Planning, the Road to Success are attached to the Minutes.

VI. CHAIR'S REPORT

There was no Chair's report.

VII. EXECUTIVE DIRECTOR'S REPORT

A. FFY 2019 Business Results

Colleen Wieck presented the FFY 2019 Business Results. The Results are aligned with the Baldrige Criteria and include Customer Focus, Financial and Market Results, Human Resources, and Supplier/Partner Results. Data represented in the graphs cover a five to 10 year time period.

Copies of the Business Results were handed out to Council members. They are also posted on the Council website at

<http://mn.gov/mnddc/council/documents/2019-Business-Results.pdf>

VIII. ADJOURNMENT

Hoffman asked that the meeting be adjourned.

The meeting was adjourned by consensus at 11:30 a.m.

Respectfully submitted,

Colleen Wieck
Executive Director