

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

Wednesday, October 5, 2016
9:30 a.m. – 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

Ashley Bailey, Vice Chair
Alex Bartolic, Vice Chair
Michelle Albeck
Marrie Bottelson
Emilie Breit
Mary Hauff
Pamela Hoopes
David R. Johnson
Eric Kloos
Jim Lovold
Lynne Megan
Kate Onyeneho
David Quilleash
Mary Raasch
Robbie Reedy
Jacqueline Rightler
Bonnie Jean Smith
Michael Stern

STAFF PRESENT

Colleen Wieck
Melody Johnson
Mary Jo Nichols

MEMBERS EXCUSED

Senator John Hoffman
Carolyn Perron
Linda Simenstad
Kathy Ware

MEMBER ABSENT

Alan Wilensky

GUESTS

The Honorable Donovan Frank
Becky Baertsch, Judicial Assistant
Allan Bergman, HIGH IMPACT Consulting
Laurie Beyer Kropuenske, Department of
Administration
Sara Engelby, MENTOR
Steve Larson, The Arc Minnesota
Shelley Madore
Liam Monahan, Senate Legislative Analyst
Julie Nelsen, Department of administration
Chris Paul, support staff for Robbie Reedy
Carolyn Sampson, Metropolitan Center for
Independent Living

GUESTS, cont'd.

Joan Willshire, Minnesota State Council on
Disability
Wendy Zaun-Herbers, MENTOR

I. CALL TO ORDER

Ashley Bailey, Council Vice-Chair, called the meeting to order at 9:30 a.m.

II. INTRODUCTIONS

Everyone present introduced him/herself.

Steve Larson recognized Robbie Reedy. Robbie received the Bill Sackter
Citizenship Award at The Arc Minnesota Awards Banquet.

III. RELEASE OF TWO NEW PRODUCTS

In celebration of the Council's 45th Anniversary, Colleen Wieck announced the
release of an updated version of Parallels in Time, and an updated and revised
edition of the Partners in Policymaking® Coordinator's Handbook.

The original Parallels in Time was designed using CD technology and released
on the Council's 25th Anniversary in 1996. Parallels in Time Part 2 was created
for the Council's 35th Anniversary in 2006. This latest version combines both
Parallels in Time products as a single product that has been also been updated
to a responsive design format for accessibility on mobile devices.

Wieck noted that October is also National Disability Employment Awareness
month. A feature was created on the Council home page with links to many
employment related educational materials and resources that are available at the
Council website.

IV. PROCLAMATION FROM GOVERNOR MARK DAYTON

Laurie Beyer-Kropuenske, Department of Administration, said it was an honor for
her to share the Proclamation from Governor Dayton with the Council as
Commissioner Massman was not able to attend today.

The Council's actual anniversary date is October 28th.

The Proclamation recognizes the Council's 45 year history and its impact in Minnesota, across the United States and worldwide; the number of Partners graduates in Minnesota as well as nationally and internationally; and the more than \$20 million the Council has received in innovative grants with specific mention of the attitudinal research studies and international archive of disability history.

V. INTRODUCTION OF ALLAN BERGMAN

Bailey introduced Allan Bergman. Bergman is a nationally recognized leader who has influenced many federal and state policies related to best practices in the field of developmental disabilities. He has held leadership positions with local, state, and national non-profit organizations; served as President and CEO of the Brain Injury Association of America; and held several positions with United Cerebral Palsy Associations.

VI. LOOKING TO THE FUTURE, THE AGENDA AHEAD

Allan Bergman extended good wishes and congratulations to the Council on its 45th Anniversary. He said that the Council is well known nationally and internationally. His relationship with the Council goes back to the beginning of the Partners program and other policy work. We were connected with Allan in the early 1980s

Today, Bergman said he will talk about where we've been, where we are today, and where we need to be. There are lots of opportunities and massive challenges. Key points he will address today include the following -

1. Keep your eye on the person, not the model or the program. Life is not a program. The hardest lesson to learn is to let go of the old model;
2. It's not about the dollars but how we spend what we have; and
3. Where the Council is in all of this.

Bergman then shared quotes from two individuals, each a recognized leader –

"Alone we can do so little; together we can do so much." Helen Keller

"Authenticity has become the gold standard of leadership." Authentic leaders are "people of the highest integrity, committed to building enduring organizations...who have a deep sense of purpose and are true to their core values, who have the courage to build their companies to meet the needs of all of their stakeholders, and who recognize the importance of their service to society." Bill George, former Chair and CEO, Medtronic

He added that the Council has a deep sense of purpose and core values, and the courage to challenge the status quo.

Bergman then presented an abbreviated history of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) with a focus on the Developmental Disabilities Councils.

Grant funds started construction of University Affiliated Facilities (UAF) in the 1960s; the UAFs eventually became the University Centers for Excellence in Developmental Disabilities. The Protection and Advocacy System (P&As) was added with the 1975 DD Act Amendments.

A line of court cases in the 1970s, including Wyatt v Stickney and Welsch v Likens, established the right to treatment "in the least restrictive environment." The Willowbrook exposé in 1975 and subsequent closure spoke about the "most normal conditions possible" with opportunities for residents to interact with the community.

A functional definition of "developmental disability" was added in 1978.

Independence, Productivity, and Integration in the community were added and defined as measurable goals along with employment related activities and paid work in 1984. This was all 32 years ago and considered "bell weather" legislation.

The 1990 Amendments added a purpose statement that individuals with "severe disabilities" can live and work and contribute to society.

Respect for the individual's dignity, individual wants and preferences, and consideration of the person's culture when planning and providing services were included in 1994.

The reauthorization of the DD Act in 2000 required Councils to report on advocacy, capacity building, and systemic change activities; and at least 70% of federal funds received had to be set aside for goal activities.

In the words of Heraclitus, "The only thing that is constant is change." Best practice today is focusing on the person, not the model or the program.

Bergman then talked about a convergence of forces at play at the present time, including the four civil rights goals under the Americans with Disabilities Act; the subminimum wage issue; runaway costs of SSI, SSDI, Medicare and Medicaid; the ABLE Act; and National Core Indicators that focus on outcomes.

Regarding education and the inclusion of students with disabilities in a regular classroom, only 17% of students with disabilities spend more than 80% of their day in a regular classroom; 26.6% are included between 40 and 79% of their day; and 48.8% are included less than 40% of their day. There are still 6.5% of students with disabilities who are in separate schools or residential facilities.

Attitudes and values are learned. Kids learn what's in their environment

National Core Indicators data show that, although 47% of youth with disabilities want a job, only 16% of youth with disabilities have a paid job and 70% have nothing in their written plans about employment.

Employment participation data from 2011 show that only 32.4% of working age adults with disabilities were actually working compared with 70.5% of working age adults without disabilities.

Medicaid data from the Congressional Budget Office (2012) and 2014 SSI beneficiary data show that only 4.7% of SSI beneficiaries of working age reported earned income, the average being between \$300 and \$460/year. Current Social Security data are showing upward trends in the projected number of SSDI and Medicare beneficiaries in 2020.

By all counts, current fiscal policies are not sustainable. We need to rethink our values and look for valued outcomes. In the words of William Shakespeare, we have to "suit the actions to the words."

The DD Act is the bell weather of values, principles, and outcomes. It focuses on the unique strengths, abilities and capabilities of the individual, resources,

priorities and concerns. Inclusion is defined as the “acceptance and encouragement of the presence and participation of individuals with developmental disabilities in school, work, and community activities.

The Assistive Technology Act looks at equipment and systems used to “increase, maintain, or improve the functional capabilities of individuals with disabilities.”

The Individuals with Disabilities Education Act seeks “to ensure that all children with disabilities have available to them...special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.” The 2004 Amendments contain language about transition services as a “coordinated set of activities...designed to be within a results oriented process...improving the academic and functional achievements of the child.”

Erik Carter, Vanderbilt University, said, “Expectations matter a lot.” Both parents and teachers have to raise expectations, changing from deficits and what can't be done to strengths, preferences, interests, gifts, and contributions – what can be done. That includes real work experience during the school years. Paid work is the number one factor in predicting post school career success.

The new accountability framework raises the bar for state special education programs, improving both educational outcomes for children and youth with disabilities, and the effectiveness of those programs.

The 1992 amendments to the Rehabilitation Act shifted the focus and policy regarding vocational rehabilitation services to a presumption of eligibility for all individuals with disabilities. Everyone can work and everyone must be provided the opportunity to obtain employment in the most integrated setting, consistent with the individual's strengths, resources, priorities, concerns, abilities and capabilities, interests, and informed choice.

The Workforce Innovation and Opportunity Act (WIOA) was in development for 10 years. There was massive bipartisan support for a bill that creates massive change. The emphasis is on transition and youth with the most significant disabilities, and pre-employment transition services. A total of 15% of funds received must be used for job exploration counseling and support, work based learning experiences, counseling on post secondary education opportunities, workplace readiness training, and self advocacy training. Rich Luecking would like WIOA to include only evidence based practices.

Supported employment is defined as integrated competitive employment; 50% of funds for supported employment must be used to support youth with significant disabilities (up to age 24) with supports for up to four years.

Bergman reviewed supported employment costs compared with "sheltered" employment costs, showing that for all factors from hours worked and dollars earned to efficiency/return on investment factors and cumulative costs, supported employment is more cost effective.

Regarding customized employment, Bergman noted there are no readiness criteria but a requirement to build a "positive personal profile."

The impact of employment on total Medicaid claims savings is \$20,828,409.

Bergman then discussed the ADA's integration mandate and the four goals of this civil rights statute – equal opportunity, full participation, independent living, and economic self sufficiency. As the Rehab Act now carries a presumption that everyone can work, the ADA carries a presumption that everyone can live in their own home.

The final CMS rules on Home and Community Based Services include a definition of "community" and extensive criteria for person centered plans. Emphasis is on full access in community life, employment in integrated settings, and engagement in the community.

Bergman reviewed what we can expect for the remainder of 2016. Congress is on recess until after the election. Most federal agency appropriations for FFY 2017 have not been made; a Continuing Resolution expires on December 9, 2016. In terms of disability issues, the next Congressional Session will be addressing the reauthorization of IDEA and the Higher Education Act, Keeping All Students Safe Act, ADA Notification, Medicaid Reforms/block grant, and the Transition to Independence Act.

Allen Bergman was thanked for his very comprehensive presentation and insights into the next session of Congress.

VII. INTRODUCTION OF UNITED STATES DISTRICT COURT JUDGE DONOVAN W. FRANK

Robbie Reedy introduced US District Court Judge Donovan Frank. Reedy gave a warm welcome to Judge Frank, noting that he has been a friend to people with disabilities for many years. He has been on the federal bench since 1998. Reedy said that it's a pleasure to be part of this history.

VIII. THE VIEW FROM THE FEDERAL BENCH

Judge Frank thanked the Council for the invitation to present today and extended congratulations for its many accomplishments over the years.

He noted that he's talked with the Council previously and begins his remarks with asking the question – "Why would a Federal Judge appear here?" He said it's not because anyone considers him to be an expert on developmental disabilities. For a judge to discuss issues is in keeping with the notion of equal justice for all as Allan Bergman said in ending his presentation. This is the constitutional promise that each judge and each attorney takes.

Judge Frank said that many others have taught him the way, so many self advocates have contributed to his learning. He acknowledged Colleen Wieck who asked him to please not talk about diversity without including people with disabilities.

Over the past seven years, 1,000 judges and lawyers have attended CLEs on disability justice issues. Law firms, and conferences sponsored by city and county attorneys have addressed these issues and each program has been approved for Elimination of Bias credit by the Minnesota State Bar Association.

An annual seminar sponsored by The Federal Bar Association and Interact Theatre have included disability justice topics. CLEs have been offered on website accessibility. Robins Kaplan began featuring a self advocate on panel discussions.

Judge Frank then spoke about voting issues and specifically the August 2012 decision in Minnesota Voters Alliance v Ritchie. In part, that case challenged the Minnesota State's Constitution categorical denial of voting rights to persons under guardianship when other state laws protect those very same voting rights. Judge Frank's decision in that case said that the Minnesota State Constitution,

which doesn't define "person under guardianship," and other state statutes can work together so as not to violate due process. Persons under guardianship are presumed to have the right to vote unless prohibited by an individual judge's order and specific finding of "incapacity" to vote.

Stern said that judges in Hennepin County are routinely denying the right to vote. The Secretary of State's Office identified 21 restricted votes out of 17,000 ballots cast by persons under guardianship.

The question was raised about whether guardians should be allowed to respond to voting restrictions as they are supposed to be acting in the person's best interest. Judge Frank emphasized again that, in Minnesota, an individual can't be restricted in their right to vote unless an individual exam is conducted and a finding of incapacity is made by a judge.

Judge Frank recognized the Ambassadors for Respect and the impact they have had with their anti-bullying program and the trainings they are doing with students, the focus on people first language, and helping students learn how to stand up for others.

He then recognized and thanked Magistrate Judge Becky Thorson for her role in dedicating the December 2012 issue of *The Federal Lawyer* to disability issues.

In 2013, in collaboration with many other organizations, TPT produced the *Independence to Inclusion* documentary. The documentary was funded through a *cy pres* fund and nominated for an Upper Midwest Emmy award.

The Disability Justice Resource Center contains resources and content for continuing education courses. Wieck noted that Professor Elizabeth Schiltz, University of St. Thomas School of Law, wrote a letter about the Resource Center and sent it to colleagues across the country. As a result, we learned about the Human Trafficking Pro Bono Legal Center and its founder, Martina Vandenberg. This resource has been added to the website.

In 2014, the US District Court held an In-Court Seminar and Retreat that focused on disability justice issues. The Seminar included an overview of the history of developmental disabilities, the Disability Justice Resource Center, the Men of Atalissa case (EEOC vs Henry's Turkey), and Tom Nelson's discussion of "10 Things I Didn't Know."

The Attorney General's Office sponsored a CLE and the Minnesota CLE Center sponsored a webinar on disability justice issues.

The Ambassadors for Respect received The Arc Minnesota Community Innovator Award for their anti-bullying program and training sessions they offered to fourth grade elementary school students in North St. Paul and White Bear Lake school districts.

Chip Scoggins, *Star Tribune* reporter, received The Arc Minnesota Community Media Excellence Award for an article he wrote that demonstrated the best in sportsmanship. A young man with Down Syndrome, the senior manager for his high school team, was excited and graciously received his medal, even though team members did not respond in like manner with the loss of a state basketball title.

In 2015, the Minnesota Chapter of the Federal Bar Association sponsored a webinar, "25 Years of the Americans with Disabilities Act: Reflections on the Past and Hopes for the Future" to educate attorneys about the ADA. An article about the webinar was also published in *Bar Talk*, the Chapter's newsletter.

The University of St. Thomas School of Law sponsored a CLE, "The ADA at 25: Continued Inequality of Americans with Disabilities."

Self-advocates who completed a 12 month Olmstead Academy training program celebrated their successful pilot year with Judge Frank at the Warren E. Burger Federal Building in St. Paul.

On September 29, 2015, Minnesota's Olmstead Plan was approved.

In November, 2015, the five part *Star Tribune* series by Chris Serres, was published; the series examined state programs and policies about services for individuals with disabilities.

In 2016, a Public Media Forum was held that brought together representatives from the local media to discuss how disability issues are covered or not covered in the press.

Several individuals received Public Policy Awards from The Arc Minnesota for their work on disability justice issues – Jim Backstrom, Dakota County attorney received the Andrew R. Richardson Award for his work in assuring justice for all

crime victims, including individuals with disabilities; and Judge Frank, Magistrate Judge Becky Thorson, and Commissioner Mary Tingerthal, Minnesota Housing Finance received the Luther Granquist System Change Award for their work on Minnesota's Olmstead Plan.

Judge Frank stated the importance of continuing to confront stereotypes and work to assure equal justice under the law. When he asks self advocates what are the most important rights to them, their answers are probably no different than how anyone would respond –

- The right to be independent
- The right to be believed
- The right to live in the community
- The right to have a job, to use my brain
- The right to a fair wage.

Judge Frank was thanked for his presentation, and all that he has done and continues to do in the interest of disability justice

IX. STATEMENTS BY COUNCIL MEMBERS

Council members were then invited to share statements about the Council on this 45th Anniversary –

I'm proud to be a self advocate member. I love to keep on going. I feel badly when I have to miss a meeting. I'm on the Public Policy Committee now but I've been on both sides (Mary Raasch).

It's an honor to be able to serve on the Council. I'm always challenged by the information we received. I'm proud of services that are available where I can serve people with disabilities. I'm encouraged to be a strong advocate for family members and serve on several advisory groups (Lynne Megan).

The Council gave me a voice. I don't know what I would do without it (Marrie Bottelson).

There are no words to describe how thrilled I am to be part of this group. I'm very proud to be here. I need to be part of the Council because of the impact on my community (Kate Onyeneho).

Thanks for a fabulous Council over many years with Minnesota's Protection and Advocacy Agency. We're fortunate that all three DD Act programs share a vision and passion, and where it's possible to continue to make progress (Pamela Hoopes).

There's a stability that exists here that's not seen any place else. Bob Bruininks (former President of the University of Minnesota) always used to mention his experience here (David R. Johnson).

Bergman added that it's not common to see this level of collaboration and mutual respect among all DD Act programs. There may be five states in the United States showing real unity.

This is just my second meeting. When I get here and hear the stories, it recharges me. I'm doing this for a reason and for my children (Michelle Albeck).

It's a privilege to serve on the Council. I always leave here feeling inspired. This is a wonderful organization (Jackie Rightler).

I'm at the end of my first term but I'm coming back for another term. The Council has made me a better advocate (Jim Lovold).

In addition to this being a fabulous Council, we have fabulous Council members with profound knowledge and expertise. I have worked with other Councils for many years but the work here is fantastic.

I'm reminded of a conversation with my father many years ago about getting a chance to help other people with disabilities, never knowing where your life will take you or when you might be in a position to help a lot of people.

I'm also reminded about how far we've come and the many people who have helped me to be who I am today. I want to continue helping to move us forward the causes that we care about (David Quilleash).

I never expected to even be in this room. I've been on an amazing journey the past six years with an amazing and awesome group of people. I'll never forget who you all are. I want to keep on going as long as I possibly can. Thank you for letting me be a part of this (Robbie Reedy).

Thank you. I'm honored to be on the Council. Partners really got me going (Ashley Bailey).

X. REFRESHMENTS

Everyone was invited for refreshments.

XI. ADJOURNMENT

Bailey called for adjournment.

The meeting was adjourned by consensus at 1:50 p.m.

Respectfully submitted,

Colleen Wieck
Executive Director