

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

Wednesday, February 5, 2014
12:15 p.m. – 2:20 p.m.
Continuing Education and Conference Center
University of Minnesota St. Paul Campus
1890 Buford Avenue, St. Paul, Minnesota 55108

MINUTES

MEMBERS PRESENT

Dan Reed, Chair
Dawn Bly
Peg Booth
Jennifer Giesen
Tom Holtgrewe
Eric Kloos
Steve Kuntz
Louis Lenzmeier
Barb Lundeen for Shawn Holmes
Lynne Megan
Stevie K. Nelson
Scott Price
David Quilleash
Mary Raasch
Robbie Reedy
Bryan Schmidt
Bonnie Jean Smith
Mike Stern
Joe Timmons
Wendy Velzke
Katheryn Ware

STAFF PRESENT

Colleen Wieck
Mary Jo Nichols

MEMBERS EXCUSED

Mary Hauff
Matt Kramer
Carolyn Perron

MEMBER ABSENT

Melissa Winger

GUESTS

Julie Anderson, The Arc Minnesota
Sarah Cox, Department of Health
Pamela Hoopes, Minnesota Disability Law
Center
Kirstin Jorenby, Olmstead Implementation
Office
Steve Larson, The Arc Minnesota
Shelley Madore
Nancy Miller, Metropolitan State University
Roberta Opheim, Ombudsman for Mental
Health and Developmental Disabilities
David Sherwood-Gabrielson, Olmstead
Implementation Office
Dan Stewart, Minnesota Disability Law Center
Mike Tessneer, Department of Human
Services

GUESTS, cont'd.

David Thompson, Department of Human
Services
Jerrod Vincent, staff support for Robbie
Reedy
Jonah Weinberg, Autism Society of Minnesota

COUNCIL PROGRAM

Colleen Wieck introduced Rud Turnbull, Distinguished Professor in Special Education and Courtesy Professor of Law, his titles at the University of Kansas where he is the Co-founder and Co-director of the Beach Center on Disability. He has authored more than 300 peer reviewed books, articles, chapters, and monographs. He has served as an officer of nearly all major national disability organizations, including AIDD, The Arc, and TASH; chair of the American Bar Association Commission on Disability Law, and Trustee and Chair of the Board of Trustees for the Judge David L. Bazelon Center for Mental Health Law.

When the past is confronted, Rud Turnbull has been there. When Baby Doe was discussed, Rud Turnbull was there. He worked with the EEOC on a major monograph and, with Ann Turnbull, wrote the national family support legislation. Everything he touches has the values and principles that our Council abides by.

He spoke about his family. His father was a recovering alcoholic and senior vice president of Hamm's Brewery in St. Paul. Turnbull was invited to be here with his dad in 1958 and given a key to the tap room at the Brewery. Much of Turnbull's time during one summer, he said he learned about banking from that experience, sitting on the banks of the Mississippi River and enjoying the Brewery beer. He has many fond memories of the Minneapolis/St. Paul area.

Turnbull's son Jay had multiple and significant disabilities and three years of his young life were spent at residential facilities on the east coast. When Turnbull met his now wife, Ann, one of the marriage conditions was to bring Jay home.

While working at the University of Chapel Hill in North Carolina, he met with the Governor of North Carolina who wanted Turnbull to find out about "aversive therapy" that was going on at one of the state institutions. It was there that he was introduced,

very reluctantly, to “aversive interventions” and baselines on the “learning to be better box,” a new method for teaching people how to behave. The box was a 4” cube with a copper wire attached to batteries and a switch. If a resident misbehaved, the box was placed on his/her abdomen, the switch turned on, and a shock produced.

Turnbull asked for a demonstration on himself and found this method very shocking and disturbing. He immediately believed this approach was not right but also wondered, if this is what was happening in North Carolina, then maybe something else was really wrong. It was that experience that triggered his search into disability law in North Carolina. He became a student of disability in the policy context. He then referenced the METO lawsuit and noted that it's the power of advocacy and the law that still plagues us.

From a historical perspective, Turnbull then went back to 1946 where, he said, the story began with the Nuremberg war crime trials, the crimes against humanity. Following these trials, in 1948, the United Nations General Assembly adopted the Universal Declaration of Human Rights; the first section contains a list of human rights and dignity is included. In 1971, the Declaration on the Rights of Mentally Retarded Persons was adopted by the General Assembly. In 2010, the United Nations Convention on the Rights of Persons with Disabilities was created. There is an international declaration of rights, and rights and dignity go together.

In the United States, dignity has been addressed by the United States Supreme Court in several cases. In each case, dignity is expressed as an important concept.

Regarding the internment of Japanese Americans at the start of World War II, the Court said it was not dignified to segregate persons simply by reason of race. A series of cases in the criminal justice system have addressed dignity, including the failed execution of a man in Louisiana and the execution of minors where dignity is part of the discussion regarding the Eighth Amendment ban on cruel and unusual punishment. However, dignity and disability were never discussed together.

In Atkins v. Virginia, a case involving young man with developmental disabilities who was convicted of capital murder and sentenced to death, the Court ruled that the execution of a person with developmental disabilities is a violation of the Eighth Amendment and institutional norms, and is not dignified.

That notion of dignity, however, is still illusive. Turnbull talked about 18 core concepts that provide a framework for proper legislation, concepts that include anti-discrimination, individual services, and autonomy. Then, he noted, there are the three principles

contained in our Declaration of Independence – life, liberty, equality (that all are created equal), but they don't capture what people are ready and wanting to talk about.

Turnbull then offered his "CIA Framework" – Capacity in the System, Individualization, and Accountability - that is based on three ethical principles: 1) Family is the core of society, 2) Dignity, and 3) Being in and of community. Much is written around family support. Family support is instrumental in the developmental and nurturing of a person with a disability but it's "beyond mechanics, interventions, and techniques."

Family support, or better, supporting families, is about personhood (a concept that can be bestowed or withdrawn), empathy (the ability to place yourself in another person's shoes), compassion (an outgrowth or result of empathy), and dignity (being valued, worthwhile, an essential component of quality of life, inherent in being a person). These concepts, taken together, create an ethical community.

Turnbull talked about his son, Jay. Jay knew how to make friends. They saw him as a person, and they treated him with respect and dignity. Jay's family took the risk of giving Jay away to the community. They trusted the community to do right by him. An ethical community helps to keep its members safe.

Thinking about the concept of dignity and disability can be challenging. Being less able does not make a person less worthy. There is dignity in simply being.

As Turnbull scanned state statutes and court decisions, he was seeking how those 18 core concepts were being advanced, whether they conform with the United Nations Convention on the Rights of Persons with Disabilities; are they sufficiently expressive about rights and dignity, concepts that are separate but go together; and how do the resulting practices treat people with disabilities.

Turnbull talked about starting a dignity project in Minnesota. Scan court cases, statutes, regulations, and practices; and ask if we're doing the right thing. Collect stories, and look for the presence or absence of dignity in those stories. Mobilize across disability groups and recommend reforms. Dignity is a universal approach; don't frame dignity as a political issue.

Wieck asked Turnbull to speak about seclusion and restraint, including prone restraint.

He said he wrote an article about this 25 years ago. Seclusion and restraint are morally indefensible. Such practices are dangerous and they don't dignify a person. Research suggests a far better way, positive behavioral supports, that works for everyone.

There's exposure to liability that doesn't have to be there when anyone is hurt or killed. There are professional standards regarding positive interventions. Minnesota should be looking at what other states are doing and come to terms with why positive interventions are not in place here.

In terms of education, are teachers highly qualified; are they using standards or practices that could be provoking behavior problems; who is trained, where and how are they trained, and by whom. Begin with the public schools, ask higher education institutions what curriculum they're using.

In response to Reed's question about what is happening at the higher education level, especially now with federal accreditation of higher education institutions, Turnbull suggested getting on the agenda of the Council of Deans to address a positive behavior supports curriculum. He added that there is a Positive Behavior Training Institute in Kansas and mental health providers are receptive to the concept.

Bly asked about early childhood programs. Turnbull suggested inviting the Minnesota Academy of Pediatrics, Internal Medicine group, to talk about positive behavior supports in the medical field, both the educational model (all people can learn) and the psychological model (fight or flight response).

Dan Stewart talked about dignity and employment. Personhood is defined by whether a person is working or not. Dignity attaches to working, being productive, contributing in some way to the community. Employment attacks the idea of dependency.

Kloos noted that in teacher education programs, the core skills include both knowledge and demonstration of restrictive procedures.

Everyone thanked Rud Turnbull for his presentation.

I. CALL TO ORDER

Dan Reed, Council Chair, called the meeting to order at 1:50 p.m.

II INTRODUCTIONS

Everyone present introduced him/herself.

III. APPROVAL OF AGENDA

Reed asked for approval of the Agenda.

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

IV. APPROVAL OF MINUTES FOR DECEMBER 4, 2013

Reed asked for approval of the Minutes as written for December 4, 2013.

MOTION: Smith moved, seconded by Reedy to approve the Minutes as written for December 4, 2013. Motion carried; there were no dissenting votes.

Reed asked for the Grant Review Committee report next because of motions that needed to be taken care of.

V GRANT REVIEW COMMITTEE

Holtgrewe reported on the evaluation results and funding recommendations for cosponsorship funds for training conferences. Eleven applications were approved for funding; a total of \$20,000 is available but only \$18,545 was requested so no funding reductions needed to be made.

Members were reminded about the Conflict of Interest Policy and Conflict of Interest Form. The Form must be signed if a member does not have a conflict of interest with the applicant organization. Holtgrewe said that each of the funding recommendations will be presented separately so abstentions can be recorded.

Holtgrewe asked for a motion to approve the application from Arc Kandiyohi County for \$ 475.00.

MOTION: Reedy moved, seconded by Lenzmeier to approve the application submitted by **Arc Kandiyohi County** for **\$ 475.00**. Motion carried; there were no dissenting votes or abstentions.

Holtgrewe asked for a motion to approve the application from Arc Southeastern Minnesota for \$ 1,990.00

MOTION: Reed moved, seconded by Schmidt to approve the application submitted by **Arc Southeastern Minnesota** for **\$ 1,990.00**. Motion carried; there were no dissenting votes or abstentions.

MOTION: Holtgrewe moved on behalf of the Committee to approve the application submitted by **Arc United** for **\$ 1,500.00**. Reed seconded. Motion carried; there were no dissenting votes. Bly and Timmons abstained.

MOTION: Holtgrewe moved on behalf of the Committee to approve the application submitted by the **Autism Society of Minnesota** for **\$ 2,000.00**. Reed seconded. Motion carried; there were no dissenting votes. Stern abstained.

MOTION: Holtgrewe moved on behalf of the Committee to approve the application submitted by the **Center for Inclusive Child Care** for **\$ 1,500.00**. Schmidt seconded. Motion carried; there were no dissenting votes or abstentions.

MOTION: Stern moved on behalf of the Committee to approve the application submitted by the **Down Syndrome Association of Minnesota** for **\$ 1,900.00**; Schmidt seconded. Motion carried; there were no dissenting votes. Holtgrewe and Timmons abstained.

MOTION: Holtgrewe moved on behalf of the Committee to approve the application submitted by the **Epilepsy Foundation of Minnesota** for **\$ 1,980.00**; Schmidt seconded. Motion carried; there were no dissenting votes or abstentions.

MOTION: Holtgrewe moved on behalf of the Committee to approve the application submitted by **Fraser** for **\$ 1,200.00**; Bly seconded. Motion carried; there were no dissenting votes. Stern and Timmons abstained.

MOTION: Holtgrewe moved on behalf of the Committee to approve the application submitted by the **Lutheran Home Association of Minnesota** for **\$ 2,000.00**; Schmidt seconded. Motion carried. Smith and Veltzke dissented; Bly and Timmons abstained.

MOTION: Holtgrewe moved on behalf of the Committee to approve the application submitted by the **MnDACA** for **\$ 2,000.00**; Veltzke seconded. Motion carried; there were no dissenting votes or abstentions.

MOTION: Holtgrewe moved on behalf of the Committee to approve the application submitted by **Reach for Resources, Inc.** for **\$ 2,000.00**; Lenzmeier seconded. Motion carried; there were no dissenting votes or abstentions.

VI CHAIR'S REPORT

Reed reported that the TwinsFest invited Partnership Resources to participate this year. This is a community fundraising event, very successful, and the first time it was held at Target Field.

Reed said that he has talked with Pamela Hoopes, Minnesota Disability Law Center, regarding 245D. Day programs are very concerned about revenue issues. There is a huge backlog with setting up service agreements so providers are continuing to serve people but with no agreements in place.

Smith said that service plans are not being signed and that's a statewide problem.

Megan noted that the primary problem is that counties don't know how to complete the service agreements. There has been no clear communication or direction; CMS has said there has to be uniformity across the state.

VII. PUBLIC POLICY COMMITTEE

Reedy reported that the Committee talked about the Olmstead Plan. Members provided comments and feedback on what they thought should and shouldn't be in the Plan. By Court Order, input needs to be submitted to the Court by February 22, 2014.

VIII. EXECUTIVE DIRECTOR'S REPORT

Wieck provided the following updates and highlights from monthly reports:

1. Congress has passed a two year budget so we are expecting two years of level funding.
2. The past two days have been spent working on Rule 40. An implementation plan will be reviewed by the Court. Work needs to be completed by July 2015.

3. The Olmstead Plan was accepted by the Court on January 22, 2014; comments are due within 30 days. The Subcabinet is scheduled to meet on February 20, 2014. A search is underway for an Executive Director for the Olmstead Implementation Office. Smith is serving on a committee to review applications; 30 applications have been received to date.
4. Regarding the ADA Legacy Project feature: The January "Moment in Disability History" was dedicated to Lowell Weicker. Ed Roberts Day was January 23rd and the film *We Won't Go Away* about the 504 demonstrations in San Francisco was posted.
5. Governor appointments are proceeding.
6. The annual Program Performance Report was submitted two weeks early.
7. The Council's disaster recovery plan was updated.

IX ADJOURNMENT

Reed asked that the meeting be adjourned.

MOTION: Ware moved, seconded by Bly to adjourn the meeting.

The meeting was adjourned at 2:20 p.m.

Respectfully submitted,

Colleen Wieck
Executive Director