

**DISABILITIES ADVISORY COUNCIL (DAC)  
MEETING  
Final Minutes  
December 11, 2008**

- Members Present:** Betty Friedrichsen, Larry Friedrichsen (Vice Chair), Shirley McInnis (Chair), Melissa Meade, Melanie Paul, Arva Priola, Lisa Ritchie, Linda VanAken
- Members Absent:** Mary Jane Sufficool, Monica Wiley
- Guests Present:** Charles Cooper (VOPA Board member), Preston Walters
- Staff Present:** Sherry Confer (Deputy Director), Kim Mendella (Executive Assistant),  
  
*For portions:* Eric Berthiaume, LaToya Blizzard, Paul Buckley
- Call to Order/  
Welcome/Introductions:** Shirley McInnis called the meeting of the Disabilities Advisory Council to order at 10:00 a.m. and asked everybody present to introduce themselves.
- Public Comment:** No public comment was offered.
- September 2008 Minutes:** Ms. McInnis referred the Council to the September 2008 minutes in the packet and asked if there were any questions or changes. Melissa Meade said that she was a guest at the last meeting and her first name was incorrect, the minutes had "Melanie Meade" instead of "Melissa Meade." Ms. McInnis asked if there were any further changes required and with no comment offered, Ms. McInnis asked if there was a motion to accept the minutes as amended. Lisa Ritchie made a MOTION to accept the minutes as amended. Betty Freidrichsen SECONDED the MOTION to accept the minutes as amended. The MOTION carried unanimously.
- Staff Presentation  
Overview of State  
Operated Mental  
Retardation Facilities in  
Virginia** Sherry Confer gave a brief summary of the history of the DAC. The DAC is a partner to the PAIMI Advisory Council. VOPA is required by the federal funding agency to have a Protection and Advocacy for Individuals with Mental Illness (PAIMI) Advisory Council. For the longest time, VOPA had a PAIMI and DD Advisory Council. The DD Advisory Council only addressed the Developmental Disabilities (DD) Grant. When VOPA became an independent agency, the Governing Board decided that other

grants were not being monitored or having any advisory representation. The DD Advisory Council encompassed all other disabilities and became the Disabilities Advisory Council. The DAC membership had heavy representation from the DD community during the initial years, in particular the Intellectual Disability (ID) community. VOPA has succeeded in recruiting a more diverse Council in recent years. However, the DD grant is one of VOPA's largest operating grants and prioritizes working in State operated ID facilities in Virginia.

Ms. Confer introduced Paul Buckley who is the Managing Attorney for the Institutions Unit that deals with State operated facilities. Mr. Buckley stated that he would be talking specifically about the facilities operated by the Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS). Training Center is just another word to refer to State operated ICF/MR (Immediate Care Facility for persons with mental retardation). ICF/MRs are governed by the Centers for Medicare and Medicaid Services. Two required components of an ICF/MR include that 1) they are supposed to be providing active treatment, and 2) it is in a home-like environment. Active treatment is supposed to be an aggressive program for a specific individual, not a generic group program of training and rehabilitation. The individualized program plan is made for the specific individual based on their own needs on what they need to maintain their skills and develop new skills so that the person could move into a less restrictive environment. ICF/MRs are not intended to be the end of the road for people with ID, ICF/MRs are intended to help individuals develop skills to allow them to move into a less restrictive environment.

There are two ways this level of care is provided in Virginia; the community ICF/MR and the State operated ICF/MR. The community ICF/MR is somewhat misleading as some of them are quite large institutions, a total of 32 with approximately 360 certified beds. There are five State operated ICF/MRs called training centers with 1,636 certified beds. In many other states there is a trend to closing State operated ICF/MRs and integrating individuals into the community and providing services in the community.

Mr. Buckley turned the presentation to discuss funding of the State operated ICF/MRs. Money is budgeted from the

General Assembly every year to operate these facilities. When the facilities receive their funding, they only receive what has been allocated by the General Assembly. The facilities do not receive all of the Medicaid dollars that they actually bill for. Mr. Buckley stated for example, that Southeastern Virginia Training Center (SEVTC) bills Medicaid for services for individuals. However, SEVTC is not receiving all those dollars, DMHMRSAS Central Office only sends SEVTC what the state legislature allocated. The DAC members had many questions about why this is happening.

Mr. Buckley showed the DAC a number of pictures of the State operated ICF/MRs in Virginia. Central Virginia Training Center (CVTC) was established in 1910 and has a total of 97 buildings, many of which are no longer used due to structural concerns. Currently only one building meets life safety code standards. Medicaid surveys all the facilities to see if the facilities are providing active treatment and if the buildings meet life safety codes. The 2008 General Assembly allotted \$43 million dollars to fix buildings that provide services to 500 people. Arva Priola asked Mr. Buckley why the money is not being used to allow the residents to move back to the community. Mr. Buckley said the money was given to CVTC to replace, rebuild or repair the facilities.

Mr. Buckley discussed that in all five State operated ICF/MRs, the average length of stay was 25 years. Charles Cooper asked about the life expectancy of ICF/MR residents. Mr. Buckley quoted research by the Dr. Everett, the previous Inspector General of Virginia, that found that people who live in ICF/MRs die sooner than individuals who live in the community. Mr. Cooper announced that when his son was born in 1958 with Down Syndrome, the life expectancy in the institutions at the time was only 19 years of age. Mr. Cooper was pleased to announce that his family just celebrated his son's 50<sup>th</sup> birthday at home recently.

Mr. Buckley stated that there is more oversight in community providers. First thing is that the DMHMRSAS provides licensing oversight. The fact that people are in the community means that there are more eyes on that individual. For example, if an individual requires transportation to a day program, there are different entities providing transportation and day program services. Ms.

Confer said in addition, in smaller settings staff can be more person-centered and develop real individualized plans. This is very different than what happens at State operated ICF/MRs where there can be up to 30 individuals with only two staff trying to teach a skill to the entire group. Ms. Priola asked why state staff could not provide services in smaller community settings where services can be more individualized and therefore more effective. VOPA staff are currently working on this issue. Mr. Buckley noted that there is a misconception that large facilities means safe. However, State operated ICF/MRs are understaffed and residents are left alone with people who should be supervised. Mr. Buckley based this opinion on the number of Critical Incident Reports received by VOPA with people injured at the State operated ICF/MRs.

Sherry Confer talked about one of her visits to SEVTC where there are many people who are nonverbal for a number of reasons. Often the facilities do not have or use certified interpreters or assistive technology devices. If people are not able to communicate, integration cannot happen, even with your housemates. Ms. Priola really wants more money set aside for communication access, in both the facilities and community.

### **Governing Board Report**

Charles Cooper introduced himself to the DAC as a member of VOPA's Governing Board. Mr. Cooper talked briefly of his 50 years of experience in the disability field starting with the birth of his son.

Mr. Cooper stated that at the last meeting in September, there was a presentation by VOPA Staff Attorney, Dana Traynham, on Fair Housing. Mr. Cooper shared that Colleen Miller received a alarming e-mail about restraint and seclusion in public schools. Mr. Cooper was shocked to hear about this stating that he did not realize that this went on today, although he has heard about instances occurring in State operated facilities.

Mr. Cooper went on to discuss the Governing Board Committee reports. At the Finance Committee the mileage and reimbursements rates were increased. The Public Awareness and Goals Committee brought forward to the Board the recommended FY 09 Goals and Objectives which the Board approved.

**Governing Board  
Committee Reports**

Ms. Confer discussed more in detail about the Finance Committee's directive. Finance Committee receives quarterly financial reports with all the expenditures. Because VOPA is federally funded through grants, there are certain limitations, such as VOPA cannot lobby. The Finance Committee has recently been asked about finding other methods or other funding streams that are permanent to overcome some of the limitations. The Board and Advisory Councils have asked about the application process to the Advisory Councils and to overcome a potential barrier of membership. Before a person is appointed to the Advisory Council, that person is invited as a guest to see if membership to the Advisory Council is a good fit for all. However, the initial visit guests are not reimbursed for travel or hotel rooms if required. This can be very burdensome for people on fixed incomes or who have to take a day off work without pay. The Finance Committee is now looking into fundraising so we can address that barrier for potential Advisory Council members. VOPA staff are not allowed to use federal money to fundraise so it may be up to the Governing Board and Advisory Councils members.

**Work Session – DAC Annual  
Report**

Kim Mendella distributed draft copies of the DAC Annual Report to members. Ms. Mendella asked the DAC to remember back to the September meeting when staff asked the DAC to comment on the progress on the FY08 Goals and Objectives. Those comments were then compiled to draft the DAC Annual Report.

Linda VanAken asked about feedback about voting location accessibility. Ms. Confer discussed about one test of accessibility during the November election and there was no problem at that particular site. However, it one only one location and does not represent Virginia as a whole. Ms. VanAken talked about a disability awareness fair in October where a new voting machine to help those with vision impairments to vote unassisted was demonstrated. Ms. VanAken expected to see these machines at the November election but did not. Betty Friedrichsen said that she heard and saw a lot of advertisements about getting access to polling sites and how to contact your local voting registration office for help. She also mentioned that these ads were sponsored by VOPA. Ms. Confer was pleased to hear that the VOPA Public Service Announcements were received.

**Other Business**

**New Members**

Ms. Confer introduced three new members of the DAC: Lisa Ritchie, Arva Priola, and Melissa Meade.

**New Applicant**

Ms. Confer introduced Preston Walters as a guest and asked him to talk about why he wants to become a member.

**Meeting Dates**

The Council discussed potential meetings dates and unanimously decided on the following:

March 12  
June 12  
September 11  
December 11

**Working Lunch**

Networking lunch between VOPA staff and DAC members.

**Executive Director's Report**

Colleen Miller gave a brief introduction about the federal funding sources for VOPA. There are eight different federal grants also called programs.

Developmental Disabilities (DD) is the largest of VOPA's grants and is the Protection and Advocacy for People with Developmental Disabilities.

PAIMI is the second largest grant and is the Protection and Advocacy for Individuals with Mental Illness

The Client Assistance Program (CAP) and it is used to work with people in Vocational Rehabilitation and Independent Living Centers.

Protection and Advocacy of Individual Rights (PAIR) basic intention was to create an agency other than the Federal Government to help enforce the Americans with Disabilities Act (ADA). PAIR allows VOPA to serve anybody with any disability who cannot be served under one of these other programs. PAIR has a huge mandate but not a lot of money, about \$200,000.

AT – to help people with disabilities obtain Assistive Technology, and provide services and training to be able to use that technology.

TBI – Traumatic Brian Injury; both AT and TBI are very

small grants for VOPA.

PABSS – Protection and Advocacy for Beneficiaries of Social Security. About seven years ago, Congress created the Ticket to Work program as part of its return to work effort.

HAVA – Help America Vote Act passed in 2000 to help states update their electoral process.

Each one of the above programs have a dollar amount that goes with it every single year and each one has strings attached to it.

The DAC does not need to know anything about PAIMI as the Federal Government mandates PAIMI to have its own separate Advisory Council and the DAC is not it.

VOPA's DD grant has about \$735,000 to serve people with developmental disabilities. The disability has be onset before age 22, likely to be lifelong. A person with DD does not necessarily have to be born with it, for example a brain injury at age 5. Virginia defines DD somewhat differently than the Federal Government. In Virginia, DD does not include mental retardation but does refer to autism. The Federal definition and the other 49 States define DD to include mental retardation and other intellectual disabilities. The Federal DD definition also requires three functional limitations and there is a list of seven, for example independent living, leaning, mobility, communication, just to name a few.

Although, \$735,000 sounds like a lot of money, Ms. Miller noted there are 1,398 people living in State operated ICF/MRs according to the 2007 census; 4,000 in congregate settings; 7,500 people with MR Waiver services; 419,000 children under the age of 21 who qualify for Medicaid who qualify for certain programs under Medicaid and very probably meet the definition of DD; 134 school divisions; 169,538 children in special education; 40 Community Service Boards providing services to people with DD; 4,000 people on waiting lists for the MR waiver. Ms. Miller stated that VOPA cannot come even close to doing everything needed so the plan is to be very strategic as to where we spend out DD monies. VOPA looks for work that will have the biggest impact statewide.

One of the ways VOPA is focused on looking at the five State operated ICF/MRs. VOPA does abuse and neglect investigations, promote individual rights and pushes for full inclusion. Currently, VOPA is focusing efforts on two ICF/MRs: SEVTC and CVTC. At SEVTC and CVTC there are school-aged children who do not go to school. Every child under the age of 22 is entitled to go to school, it is mandated in Virginia. However, it is not enforced if a child has a severe disability. People with disabilities are also entitled to vocational or job training. Other problems are communication and assistive technology. Currently there are individuals in facilities with borrowed wheelchairs because some staff erroneously believe that Medicaid will only provide a new wheelchair every five years.

Ms. Miller told the DAC that community inclusion is a very large issue in State operated ICF/MRs. In order for one person to go into the community, usually the entire cottage will have to go into the community. That means 16 to 20 people have to come to a consensus to decide where they all want to go. Then transportation into the community becomes an issue as you have to make sure you are properly staffed. Even if you want to take a walk around the campus to stretch, you have to be accompanied by a staff person. With each cottage having only 3-4 staff persons, this can be an issue.

Ms. Miller discussed the fact that many of the State operated facilities were built in the 1960's, pre-ADA. Therefore there are a lot of concerns about fire safety codes and rescue assistance.

Ms. Miller believes that VOPA can make a positive difference in the areas around Assistive Technology such as communication and mobility devices. VOPA receives reports from State operated ICF/MRs where the resident is described as nonverbal. There is no indication that they think they can communicate with that individual. There are other ways to communicate besides speaking. Assistive technology is supposed to be funded by Medicaid but is not being provided. VOPA believes that State operated ICF/MRs have a limited vision of how people can communicate and therefore do not fully explore the options.

Ms. Miller explained to the DAC that VOPA is entitled to

have surprise visits at the State operated ICF/MRs. VOPA has 24 hour, 7 days a week unannounced access to the sites.

At CVTC, VOPA is using a different strategy. At the 2008 General Assembly passed a budget to allow the State to raise \$43 million in capital bonds to replace, rebuild, or repair CVTC. Even the Federal Government has told Virginia that if you rebuild that facility, you will be in violation of the Americans with Disabilities Act. VOPA's is part of an alliance with the DD Network (Virginia Board for People with Disabilities and the Partnership for People with Disabilities) and Arc called Virginia Alliance for Community (The Alliance). The Alliance is negotiating with the State to consider another option for the \$43 million dollars. What The Alliance wants is for the State to use that money to buy several houses in the area and renovate those houses for the CVTC residents to live in. You can still fund the houses with ICF/MR dollars and employ the same staff. In essence, The Alliance wants CVTC to have a different footprint, instead of having one large facility far removed from the community to having one that is a series of homes in the community. There is a lot of opposition from the some parents of CVTC residents.

Ms. VanAken asked if VOPA has an idea of what the financial differences of having a huge facility compared to staffing several homes. Ms. Miller said that the \$43 million is for capital dollars, not operation. Currently the State is paying somewhere between \$190,000 to \$230,000 per person at the State operated ICF/MRs. The average cost of serving someone in the community is \$70,000. That ranges from people who are living pretty independently to people who are living in congregate settings. The average cost of care in a congregate setting is about \$95,000. So every capital dollar you are investing in the institution you can get twice as much if you put the money in the community. Preston Walters stressed that it should be a choice for where the resident wants to live, the decision should not be based on what is cheaper or more convenient for the State.

Ms. Miller turned the conversation to talk about the Progress on Objectives Report for FY08. There has been a lot of work completed in special education concerning the regulations. A few years ago, Congress changed the Individuals with Disabilities Education Act (IDEA) and took out some provisions that VOPA believes to be important protections

for students. It made it easier for schools to suspend children with disabilities, put less demands on them and tracking benchmarks in their Individualized Education Plans (IEPs). After the Federal Government passes a law, they issue regulations and it is up to the State to issue its own regulations. The State has the option to be more generous than the Federal Government if it wants to. In the last six months, VOPA has been working with the Coalition for Students with Disabilities trying to have the State regulations enforcing the IDEA to be as protective for students as possible. There has been a few modifications and it is up to the Governor to decide to sign or not. VOPA will continue to work with the Coalition and note what is wrong with the current version of the regulations.

Ms. Miller called attention to the work VOPA is doing with helping people with disabilities access their right to vote. In the past several years, VOPA received complaints about obtaining absentee ballots. One example is that you can only obtain an absentee ballot because of a physical disability, so you are out if you have a mental disability. VOPA worked closely with the legislature and pretty much threatened to sue if the legislature did not fix it. Last March, the legislature changed the law so you can obtain an absentee ballot if the reason why you cannot go to the polling place is due to a disability. After that, VOPA has been presenting at nursing facilities, mental health facilities and private facilities to make sure that people know they can apply for an absentee ballot if they need one. VOPA has helped about 300-400 people to register to vote at these presentations.

Ms. Miller then talked about the work VOPA was doing in the Roanoke area. Litigation resulted from a multi-stage campaign where VOPA initially surveyed all the businesses in the "Market" area of downtown Roanoke. If the business was not up to code based on accessibility, that business received a technical assistance letter that talked about how to improve access. The majority of the businesses complied and improved access, however five did not. VOPA then drafted litigation to be filed in court and sent it to the five businesses. Two businesses fixed the access problem and VOPA sued the other three. Currently, there is only one on-going litigation case. VOPA can solve the vast majority of cases at the first call or letter. People are not actually mean, they may not know what they are doing is illegal or discriminatory and are grateful to learn of ways to fix the

problem.

**Other business**

Melanie Paul informed the Council of that the Department of Professional and Occupational Regulation is looking into Regulating the educational standards for Interpreters. The deadline to make comments is December 12, 2008.

**Adjournment**

With no further business, Ms. McInnis asked if there was a MOTION to adjourn the meeting. Ms. McInnis made a MOTION to adjourn the meeting and Ms. VanAken SECONDED the MOTION to adjourn the meeting. The MOTION carried unanimously.

Final Minutes

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December 11, 2008

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Date

**Virginia Office for Protection and Advocacy  
Mission Statement**

Through zealous and effective advocacy and legal representation, to: protect and advance legal, human, and civil rights of persons with disabilities; combat and prevent abuse, neglect, and discrimination; and promote independence, choice, and self determination by persons with disabilities