



Delaware Partners in Policymaking 20th Anniversary Celebration Retreat Final Report

On Saturday, October 19, 2013, the Delaware Developmental Disabilities Council held a 20 year celebration retreat for its Partners in Policymaking and Junior Partners in Policymaking graduates. The retreat was held in the Duncan Center in Dover, Delaware. Invitations were sent out to all graduates starting with the first class in 1993. The purpose of the day was twofold. One was to celebrate the accomplishments of the Partners in Policymaking and Junior Partners in Policymaking graduates over the last twenty years and the second was for the graduates to develop an action plan to continue their important work in the future. A total of 42 graduates attended the retreat. Every Partners and Junior Partners in Policymaking class through those twenty years had at least one representative attend.

The day began with registration and a continental breakfast. That was followed by welcoming remarks from Diann Jones, the Chair of the Developmental Disabilities Council, and Pat Maichle,



the Council's Executive Director. Diann is a graduate of the Partners in Policymaking and she

talked about how the program changed her life. As a result of attending the program, she has become a staunch advocate for all people with disabilities. Pat



talked about the many leaders in the state’s disabilities community who are graduates of the program and who credit the program for their advocacy. The Developmental Disabilities Council is just one of the state’s disabilities councils that has benefited by the leadership and hard work provided by Partners in Policymaking graduates.

Next Jane Gallivan, the state’s Director of the Division of Developmental Disabilities Services, provided a presentation on the services the division is currently providing Delawareans with developmental disabilities and their families. Additionally, she asked the attendees to tell her the services they feel are needed when the state implements its new Home and Community Based Waiver. Many excellent suggestions were provided by the attendees. Director Gallivan thanked the attendees for their input and promised to take their suggestions into consideration when implementing the waiver. However, she did point out that the extent to which her Division could implement these suggestions will depend on available funding.



Director Gallivan’s presentation was followed by a segment entitled, “Tell us about your accomplishments”. During this segment, several Partners’ graduates discussed what they had



been involved since their graduation. A number of graduates spoke of important advocacy issues they worked on and the results they achieved. They talked about issues of importance to them and people with disabilities in general such as transportation, employment, healthcare and housing. Also a few talked about



their experiences working with their legislators and making presentations in front of legislative committees on their issues. It

was gratifying to not only hear about the accomplishments of the Senior Partners in Policymaking graduates, but also what a number of the Junior Partners in Policymaking graduates have already accomplished.

After the presentations, the next phase of the day was entitled, "Lets Join Generations". Here



graduates of the Senior Partners in Policymaking classes discussed their past, current and potential projects with graduates of the Junior Partners in Policymaking classes.



This exercise proved to be very beneficial for all involved. The graduates of both programs broke into small discussion groups. The Junior Partner graduates benefited from learning about the experiences of the Senior Partner graduates and the Senior Partner graduates benefited from new ideas and fresh perspectives from the Junior Partner graduates.

Those remarks were followed by remarks from the founder of Partners in Policymaking, Dr.



Colleen Wieck who is the Executive Director of the Minnesota Governor's Council on Developmental Disabilities. We were fortunate that she was willing to travel from Minneapolis to attend our event. She discussed the importance of the program over the years to improve the lives of people with disabilities. She started the program in Minnesota in 1987 as a leadership training program for adults with disabilities and

the parents of young children with developmental disabilities. The program has been replicated nationwide and in several locations in the United Kingdom, the Netherlands and New Zealand. Approximately 23,000 people have graduated from Partners in Policymaking, both

nationally and internationally. The outcomes of Partners in Policymaking have been documented with quantitative results of increased citizenship activities as well as qualitative reports of significant life changes. Equipped with new skills, several graduates have changed their careers and become attorneys, social workers and special education directors while others have successfully been elected as mayors, school board members, county commissioners and state legislators.

Following, Dr. Wieck's presentation another highlight of the day was a presentation by Clement Coulston, a Junior Partners in Policymaking graduate. Junior Partners in Policymaking is an intensive one-week program modeled after the Senior Partners in Policymaking Program. The first class was in 2005 and,

classes graduate, one every the campus of the The students live in a hall and attend classes on culminates with a visit to where they learn first-hand



to date there has been five two years. It takes place on University of Delaware. dormitory, eat in a dining campus. Their week Delaware's Legislative Hall from several legislators the

most effective way to give testimony and to get their point across. The Delaware Developmental Disabilities Council developed the program in-conjunction-with the Center for Disabilities Studies at the University of Delaware. Clement is a leader driven by passion ensuring all youth are authentically engaged as valuable assets in co-creating positive social change for today and tomorrow. He has spoken about his passion both nationally and internationally and attributes his fervor to his training in Junior Partners in Policymaking.



Next, the attendees were asked to provide their ideas on, "Where should we go from here?" which was an effort to get all graduates to think about how they can collaboratively continue to work to improve the lives of

all Delawareans with disabilities. During this phase, they worked diligently in developing an Action plan for the future. To do this, the attendees broke into small groups and discussed their ideas and wrote them down. Many good ideas were presented and captured. All the ideas were collected and an action plan will be developed from them. The ideas presented are found in Attachment A.



The last event of the day was entitled ‘Generation Mentoring’. During this exercise, senior Partners in Policymaking graduates discussed their experiences and provided advice to the Junior Partners in Policymaking graduates. Information on how to best access the state’s services was provided along with the best ways to express your needs to legislators. The senior Partners in Policymaking graduates told of their struggles to obtain their rights and what they learned along the way that helped them in that endeavor. The Junior Partners in Policymaking graduates listened intently and eagerly took in the advice provided.

On a sad note, the graduates paid tribute to their classmates who have passed away over the years. Graduates from both the Senior and Junior Partners in Policymaking classes who died were listed in the retreat’s program and are again listed in this report’s Appendix B. They were staunch advocates and many of the improvements Delawareans with disabilities are enjoying today are directly attributable to their efforts.

The day was exciting and it was filled with energy and good ideas. It was gratifying to have Dr. Coleen Wieck in attendance and hear from her about how the Partners in Policymaking program got started and how it has expanded, both nationally and internationally, over the years. Our graduates are proud to be included in that select group of advocates dedicated to improving not only their lives or the lives of their children, but also the lives of all people with disabilities. It was gratifying to hear some of the older graduates say the day has caused them

to become reenergized to continue with their advocacy. The intent of the retreat was accomplished. Both sets of graduates learned from each other's accomplishments over the years. The Junior Partners in Policymaking graduates benefited from learning how the Senior Partners graduates overcame obstacles in fighting to obtain their rights or their children's rights. The Senior Partners graduates were infused with fresh new ideas from the Junior Partners graduates. As a result of their combined efforts, an action plan will be developed to guide all the graduates in their future advocacy.



Appendix A

Action Plan Ideas

1. Develop an Advocates Website.
2. Develop a “Connect to Families” Website.
3. Be more visible and participate in non-disability related events.
4. Work with legislators, educators, agencies and other interested groups to stop all forms of bullying, including cyber bullying. Also work with these groups to stamp out the uses of the “R” word.
5. Encourage each Partners graduate to join another advocacy group outside of strictly disabilities groups (AARP, League of Women Voters, Chamber of Commerce, Lions Clubs, Business Groups, etc.)
6. Encourage older Partners in Policymaking graduates to be a mentor to younger graduates; adopt a project or issue to work on and report back to all the graduates on the outcomes.
7. Have Partners in Policymaking graduates help train and be mentors to each person in a new class.
8. Have the Developmental Disabilities Council write a “Story Book” of Partners in Policymaking graduates’ stories about life, advocacy and the impact it had.
9. Host a Disabilities Advocates Summit involving all of Delaware.
10. Offer Junior Partners in Policymaking graduates a “retraining” periodically to keep improving and energizing advocacy efforts.
11. Work with legislators to improve transition services and supports for people with disabilities.
12. Work with legislators to require community support providers to be required to offer “emergency back-ups”.
13. Offer “Transition Training”. Partners’ voices need to be heard and schools need more extra-curricular activities.
14. Develop a communication method, (ListServ, Google Group, website, etc.) to allow all Delaware Partners in Policymaking graduates, both Senior and Junior, to communicate with each other. Have each member create a profile with personal details, including current advocacy efforts, areas of interest, specialties, contact information, etc.
15. Do a study about biases in hiring people with disabilities for competitive employment. Identify the obstacles to hiring people with disabilities for competitive employment and

how to overcome them. Also study how to change the cultural mind set concerning hiring people with disabilities for competitive employment.

- 16.** Work with legislators to modify policies on how to accommodate people with disabilities who need access to transportation no matter where they live in Delaware.
- 17.** Work with legislators to reduce auto insurance costs for accessible vehicles as current costs are too high.
- 18.** Provide initial and ongoing education to employers concerning the benefits of hiring people with disabilities. This education should include government initiatives, money incentives, free publicity that will occur, goodwill and Better Business Bureau recommendations.
- 19.** Work with legislators on ending the “institutional bias”. Encourage the funding “Money Follows the Person” past 2016 so more people can move from institutions into the community. Continue to press for the “Community First” option when evaluating people with disabilities.
- 20.** Encourage the Division of Substance Abuse and Mental Health to apply for 1915 (i) waiver that is flexible and could serve people with serious persistent mental illness.
- 21.** Work with the Department of Education and the school districts to train Early Childhood Educators on Sensory Integration Disorders.
- 22.** Work with legislators to have Medicaid pay for Hearing Aids for people over 21 and also pay for two cochlear implants.
- 23.** Develop a “Delaware Loop Project” for people with hearing loss.
- 24.** Increase the awareness of captioning technology by businesses and organizations.
- 25.** Encourage agencies to offer more inclusive social events for people with and without disabilities.

Appendix B

• *Remembering Partners Graduate* •

Len Frescoln
1947-2012



Len was active in high school sports and received a Bachelor of Arts Degree in English from Kenyon College in 1970. Len held various positions in the business sector after graduation. In 1982, he was Interim Acting Manager for Combustion Engineering Corporation when he became disabled due to a severe chemical accident at work. As a result, he had extensive rehabilitation and gradually became partially sighted. He was not able to return to work as a result. In 1985 he received a Master's in Business Administration with a 3.8 average and had to write all his assignments and read his texts and class materials using low vision technology available only at the University of Delaware Library.

After completing rehabilitation and his Master's degree he soon became actively involved in the disability community. He became an active advocate for the National Federation of the Blind on legislative and policy initiatives to help the blind. He became an active member of the Statewide Elderly and Disabled Transit Advisory Committee for the Delaware Transit Corporation. His participation resulted in more consumer oriented procedures, including radical changes in the "No-Show" policy. He was on the New Castle County Board of the Delaware Assistive Technology Initiative (1993-1999). In 1995 he was a graduate of the Delaware Partners in Policymaking Program and thereafter, worked on many legislative and policy initiatives. He was appointed and became a valuable member of the Policy and Law Committee of the Developmental Disabilities Council.

Len has the respect of colleagues and Delawareans because he reflects the best in each of us. He loves to do research, is very knowledgeable and thoughtful about issues. His special interest has been in transportation and helping to give more opportunities for people with disabilities to have accessible transportation. In spite of his physical disability and gradual blindness, he pursued a Master's Degree and completed it Cum Laude. Len has a keen intellect and can remember hundreds of telephone numbers. He is a music enthusiast and was knowledgeable about several genres, especially classical music. Len loves mentoring others and was a model positive advocate, a consummate gentleman, kind, compassionate, humble and a wonderful listener. While he influenced many decisions to help people with disabilities in Delaware, he never expected or sought any credit for his achievements. He was very appreciative of any help he received and was always willing to lend a hand to others. Len is a model advocate and human being to people with and without disabilities.

• **Remembering Partners Graduate** •

Virgil Horne
1964-2004

Virgil Horne was a member of the State Council for Persons with Disabilities (SCPD) from 1996 until he passed in 2004. Virgil was a man of integrity, had a great sense of humor and a passion for improving the lives of people with disabilities. He had a particular interest in accessibility and, along with then Chief Administrator of the Architectural Accessibility Board (AAB), drafted legislation known as the Architectural Accessibility Act which expanded and strengthened the purview of the AAB. It was introduced in the 139th and 140th General Assemblies. Although the bill did not pass, the legislation and Virgil's efforts were ground-breaking in that it inspired SCPD to collaborate more with the legislature and learn the legislative process so we could pass laws which positively impact people with disabilities. His work set a precedent for our Council in the legislative area which led SCPD to introduce and pass HB 30 (Personal Attendant Services Act) and eventually the many pieces of legislation that the entire disability community has worked on since. His work and advocacy will always be remembered.

Bofotola Akemba
1952-2012

Bofotola Bangelankoy Akemba, 60, was born in Mbandaka, Zaire (the Democratic Republic of Congo) Jan. 1, 1952. He departed this life Tuesday, Sept. 25, at home, after a short illness. He was an officer in the Zairean Army, receiving several years of training with the U.S. military armed forces. Bofotola was currently employed as an Electrolux salesman. He enjoyed fishing, traveling around the world, and was truly a people person, engaging in conversations with persons he did not even know. He enjoyed his time spent preaching the Good News. He was a devoted Jehovah's Witness. He was married to Namuliza Sept. 25, 1992, in South Africa - ironically, the same date that he passed away. They have one son together, Esha. He is survived by his loving wife, Namuliza; and seven children: Papy, Georgina, Etafe, Bompuku, Ngolo, Bilamandi and Esha. Bofotola had six sisters and six brothers and many cousins and family members, with whom he had a very special relationship.



"It was a wonderful experience for our family. Partners in Policymaking has been very supportive to our family in so many ways; from assistance with school issues to problems after Bo died, such as respite..."
- Namu Akemba

• **Remembering Partners Graduate** •

Chauncey Bailey
1952-2012

Chauncey Bailey was an advocate for people with disabilities. He had the courage to give his voice to the important issues that he and others faced while a resident of a state institution. The courage was all the more impressive as he stood up for those around him, while often times standing up in opposition to the very people who provided him care, such as bathing, getting him dressed and helping him getting in and out of bed. He was given the title of Mayor of the Delaware Hospital for the Chronically Ill. He was more like an Ambassador to independence from DHCI. Chauncey made it his goal to educate and inform new residents of DHCI about community based services and leading them to Centers for Independent Living.

Chauncey was a member of ADAPT and participated in ADAPT actions to promote the rights of all people to have choice in their lives. He participated in local ADAPT actions and traveled to Washing DC to assist National ADAPT. He was passionate about the cause of deinstitutionalization. As a person who spent over 30 years in an institutional setting, he spent the latter years of his life doing everything that he could to educate legislators and policy makers about the importance for all people to have the right to live independently in the community.

One of Chauncey's proudest achievements was becoming a graduate of Partner's in Policymaking. He loved the idea of participating in a program that allowed him to learn new ways to educate policy makers and help his peer's better understand the how easy it is to get "stuck" in a nursing home, simply due to a life altering event that could happen to anyone at any time.

I will always think of Chauncey as one of the most persuasive advocates that I have ever met. But to me he will always be defined as a friend. I spent many days with Chauncey both at DHCI and in social settings. While Chauncey slept and ate at DHCI, I could never think of him as being institutionalized. He was as free inside the facility grounds as he was at the local pub. Chauncey used his experience to help people better understand how it was so easy and unfair to get confined to that setting. However, Chauncey had a secret, which I only discovered after reflecting back on his life for this story. Chauncey's secret was that he was never institutionalized. It's a secret that he gave away while providing testimony to the Delaware Nursing Home Quality Assurance Commission hearing in 2005. Chauncey stated, "freedom and making choices was a mindset." Chauncey's mindset was to live free wherever he was and he did it well.

Submitted by: John McNeal

• **Remembering Partners Graduate** •

John Jefferson
Partners in Policymaking Graduate
Class of 1996

“John Jefferson was the bravest man I have ever met. He was totally blind and, because of juvenile arthritis, had to lay prone in his wheel chair. John would travel by himself from Sussex County to meetings in New Castle County on paratransit, making a transfer in Milford and Smyrna. He would be dropped off at the transfer sites and left until the next driver put him on the van. On several occasions, I know he was dropped off at his final destination and left in front of the building relying on someone going to the meeting to bring him in. Also, he had a tracheotomy and, on several occasions, the trach tube would get clogged and he would ask someone at the meeting to take it out and clean it and reinsert it. I did it several times. He did all this and I never once heard him refer to or complain about his disabilities. He was always in good spirits, telling jokes and making valuable contributions to the meetings.

To do all that, took a tremendous amount of courage. He set a wonderful example for people with disabilities and I consider that a tremendous accomplishment.”

Submitted by: Al Rose

James Allen Tapert
1969-2012

James Allan Tapert, of Dover, passed away Friday, April 13, 2012, in his home. He was 42. He was born, September 29, 1969, in Madison, Wisconsin. He was a graduate of Caesar Rodney High School.



James enjoyed fishing, hunting, cooking, gardening, and woodworking. He also had a love for animals. He was a member of the Developmental Disabilities Council, Narcotics Anonymous & the National Alliance on Mental Illness (N.A.M.I.)

James is survived by his parents, Allan & Mary Ann Tapert, of Dover, sisters, Christine Tapert of Dover; and Sally Forrest and her husband Fran of Wilmington; a niece, Meridan Tapert; a nephew, Sean Forrest; two aunts, and seven cousins, living out of state.

• **Remembering Partners Graduate** •

Nancy Martin
1940-2008

"I learned a lot in Partners in Policymaking. So did my roommate, who also attended Partners, Patricia Desmond. We both learned how school children with learning disabilities or special children can learn. We also learned how parents can learn and teach. We met others who are mentally ill and others who were interested in learning about us. There were a number of different Partner members we got to know. Also we really learned from the many speakers. They taught us what we needed to know about the disabled and how the disabled can advocate. Then we learned about taking things we need and believe in to the legislature. We learned about presenting to lawmakers and also doing this for other disabled. We are happy we graduated from Partners in Policymaking and would like to continue learning and advocating with them." -Nancy Martin, Partners in Policymaking Class of 2004

Samantha Tulenko
Junior Partner in Policymaking Graduate
Class of 2005



Samantha J. Tulenko, 26 of Newark, DE, peacefully passed away on Tuesday, February 26, 2013. A graduate of Delcastle High School, Sam was a seasonal employee with the State of Delaware. She was also a dedicated and active volunteer at Resurrection Parish. She was a true "people person" and enjoyed being with her family and many friends.

Sam will be lovingly remembered by her parents, Kenneth and Christine (Sabo) Tulenko; her sister and brother-in-law, Julan and Ryan Moseley, and their children, Cole and Kendall; her brothers, Nicholas Tulenko and Ezekiel "Zeke" Tulenko; and her grandmother, Christine M. Sabo. She is also survived by a host of other family members and friends.

Bill Pickard
Partners in Policymaking
Class of 1996

"I remember Bill Pickard. Sign language instructor and extraordinary lip reader (I took 3 of his classes). He used to say some people thought he was French because of his "accent" (-; He, Carol Barnett and I used to go to some local schools and colleges to talk to kids or young folks about people with disabilities." Submitted by: Daniese McMullin-Powell