

Human Services Committee
Workforce Issues Related To Care for People Who Have Disabilities
December 6, 2017

Written Statement from M.J. Bartelmay, Jr.
Parent and Past President of The Arc of Pennsylvania

Good morning Chairman DiGirolamo, Chairman Cruz, committee members and guests. I'm here to share how Direct Support Professionals (DSP) have had an impact on my family and in particular my son. I'm a single father of two children ages 23 and 25. The oldest child, MJ III, I call him M or M'er, has the diagnoses of Down syndrome and is on the Autism Spectrum. My ex-wife, Theresa, and I share joint guardianship and co-parent M. His disability creates significant challenges and barriers to living the normal independent life of a 25 year old man. He is nonverbal, has virtually no self-help skills and no self-preservation or safety skills. He requires 24/7 care and support. Standardized testing categorizes him as having no measurable IQ. In reality, he is a bright, engaging young man that requires specific and different interactions to develop a relationship than most are used to.

That said, he is a happy, healthy member of our society and active in his community. He attends church with his family, shops for groceries and household items, practices pre-vocational skills, and continues to develop life skills that will allow him to be as independent as possible. He has friends and enjoys bowling and swimming with them. None of this would be possible without the support of his family and DSP's.

We have been the beneficiaries of various DSP's throughout his life. The services began with early intervention as an infant and continue today with habilitation aide and companion services through a local provider of Medicaid Waiver services in Mercer County. Unquestionably, M would not be where he is today without the involvement of DSP's in his life.

Over the course of the past 25 years M has had in excess of 20 DSP's working with him. This does not include school personnel such as teachers and teacher's aides. Much of the reason for the large number of staff has been related to the high turnover rate. By far, the vast majority of these folks have been outstanding in their ability to work with M. They all have been minimum wage or slightly above minimum wage employees. Fortunately, we have been able to find great people to work at this wage. Unfortunately, we have been unable to keep these folks on board for any length of time. The impact of staff turnover cannot be overstated. Because of my son's lack of communication skills, a great deal of time is required to build a relationship and establish the trust that allows progress to occur. High turnover is the enemy of this process. Each time a new person begins a relationship with my son the long process of developing trust starts over. Initially, M will resist being left in a one-on-one situation with new staff. Like many individuals with autism, trust is something that comes with great difficulty.

We are currently experiencing this struggle. Over the course of a couple years, M had developed a great relationship with a young woman named Heather at Professional Habilitation Services, a local provider agency. We watched our son grow and thrive in this relationship. We saw it reflected in his behavior at

home and in community situations. He was as happy as we had seen him since he left the Hickory School system 4 years ago. This was also the longest continual relationship with the staff person that he had enjoyed. Unfortunately, she felt it necessary to find other employment to allow her to provide for her family. While employed at PHS, Heather was paid slightly more than minimum wage. PHS is an outstanding organization that we could not speak more highly of. We understand that the salary rates are constrained by the rate that a provider can bill for Medicaid Waiver services.

M.J.'s normal week consists of approximately 7 hours per day of pre-vocational training with his Hab Aid. These activities occur Monday through Friday. Additionally, he works on life skills such as shopping, toileting, laundry, and other personal care skills. All of these are done in conjunction with my ex-wife and me. It is critical that we are consistent in the care and training our son receives. We have worked closely over the years in developing his Individualized Service Plan (ISP) to ensure that all parties involved in his life are on the same page. Again, for the most part this has been very successful. But problems occur with staff turnover as we start over each time a new staff member comes on board.

It is very difficult, if not impossible to get M.J. to understand why turnover occurs. He doesn't just experience a new staff member; he experiences the breaking of a bond of trust that has taken time to develop. The impact that this has on his development has been enormous. It is not unusual for us to see him regress in some of his skill development. Additionally, we can see changes in behavior. He will not leave the home or work with new staff until the relationship is developed. This is a time-consuming process for M, as it is for all of us. Trust does not come overnight.

On a more positive note, relationships such as the one he has had with Heather have been a blessing to my family in more ways than I can begin to share in our limited amount of time. M has had the opportunity to experience life in the community to the fullest possible extent because of these relationships. He has had the opportunity to develop friendships, not only with peers from the agency but with community members at large. The impact on him directly, and on my family indirectly, cannot be adequately conveyed. Had we not had quality DSP staff to work with our son, we would not have been able to experience everyday activities as a family.

I want to take a moment and share some of the positive aspects and results of DSP's in the life of my family. As I mentioned, Theresa and I are divorced. We would both not be able to work or manage our homes if not for direct care support. It is during these hours that support is provided, that we are able to work, see health care providers, and take care of other necessities of life.

Furthermore, we would have missed out on activities involving our other son Charley. DSP support and care has allowed us to attend events and activities that would have been virtually impossible for us with M.J.'s limited mobility and self-help skills.

Additionally, DSP's have been invaluable and helping us to create the skills necessary for our son to thrive in the community. Social skills and appropriate behavior are just one of the many benefits we have received.

I would like to close with the statements from the Office of Developmental Programs document entitled "Everyday Lives: Values In Action".

1. We value what is important to people with disabilities and their families, who are striving for an everyday life. An everyday life is about opportunities, relationships, rights, and responsibilities. It is about being a member of the community, having a valued role, making a contribution to society, and having one's rights as a citizen fully respected. It is a vision that we should all be working toward together.

2. People with disabilities have a right to an everyday life; a life that is no different than that of all other citizens. This continues to be the truest statement on which we can build our work.

These statements are the embodiments of everything we hoped for and desire for our son. Quality direct service professionals have allowed us to work towards an *Everyday Life* for M.J. Thank you for your time and consideration as you weigh the impact of salary on Direct Service Professionals and more importantly the people that are served like my son M.J.