

STATEMENT FOR THE RECORD BY LISA COHEN

IN SUPPORT OF (FAVORABLE)

HB 1020 – THE SELF DIRECTION ACT

My name is Lisa Cohen and I am writing in support of The Self Direction Act - HB1020 & SB868. I am requesting favorable consideration of this legislation.

By way of introduction, I am the mother of three children and currently reside with my husband in Montgomery County. I am a lifelong Marylander and my family on both sides has lived in Maryland for generations. I am writing on behalf of my 24-year-old son Michael.

Michael is severely handicapped. His diagnosis is very complex and includes: intellectual disability, chromosomal anomaly, seizure disorder, sleep disorder, cerebral cortical dysgenesis, spastic quadriplegic cerebral palsy and speech/language impairment. Put simply, Michael's is unable to walk, talk or provide for himself in any way. He is 100% dependent on support from a caregiver in order to eat, bath, move, and toilet. He experiences seizures and currently takes 4 anti-seizure medications twice daily. Over the past few years, Michael's overall seizure activity has increased. His grand mal seizures can occur with little or no warning through-out the day as well as during overnight hours while sleeping. During seizures Michael's breathing often becomes interrupted causing cyanosis and requiring airway maintenance. Michael has a fifth emergency medication to use when he has more than three seizures in a day or when he stops breathing and becomes cyanotic

Early on, my husband and I decided that Michael would remain at home with us. We have committed our lives to providing him a loving and caring home so that despite the pain and difficulty he experiences each day he knows that he is in a safe place with people who love him. While we are convinced, we made the right decision, it has been a difficult journey for our entire family. There is no part of our lives that hasn't been impacted - we haven't been able to take family vacations, we have lived with medical emergencies and we have made professional sacrifices.

We are lucky to live in Montgomery County. Until his 21st birthday, Michael spent his weekdays in a school-based program managed by the Montgomery County Public School System. Notwithstanding the love and care he received daily from the teachers and aides during those weekdays, it was up to us to either pay out of pocket for or provide in home care when he was not in school. After he turned 21, we selected the self-directed program through Maryland Developmental Disabilities Administration (DDA). We choose this route because as we considered facility-based day programs I found my visits to those programs usually resulted in my crying after the visit. Seeing the conditions of many of these facilities - places where the most vulnerable of our society spend their days reduced me to tears and strengthened my resolve that we would find a way to keep Michael at home and create opportunities that enable him to experience community learning. We know that there are many other families in Maryland taking a similar journey - families that are willing to sacrifice much to experience a brief smile or a hug from a child who didn't ask to be born with disabilities or life altering medical conditions. I hope that as you consider and debate this Bill, you do so thinking about these families, who despite the tremendous support of the wonderful people at DDA, struggle each day simply just to keep their heads above water.

One provision of this Bill that I ask for you to support is that pertaining to overnight personal support. For years we have tried to get respite care and overnight support so we could get a night's sleep or take a few days of vacation with our other children. It simply hasn't been available. For years we took Michael with us on vacation. But now - his medical situation does not allow for that. Currently, we care for Michael overnight. My husband John and I have slept with a baby monitor for twenty-four years. Most nights, Michael will make noises, awaken, need to be re-positioned or he can even have seizures. Some nights he wakes up hungry and needs to be fed and other nights he will require toileting or he will urinate in his bed. There have been occasions where we are awakened by him having a seizure and in those instances, we need to run to his room to care for him. I can't begin to explain the level of exhaustion that we feel. We have had to raise our other children and work while never getting a good night's sleep. Michael has always had erratic sleep patterns. Having night-time personal support would change our lives particularly as we age. My husband turned 60 and I just turned 57.

Facilitating family as staff is another important aspect of this Bill. Michael receives Community Learning and Personal Support services from the Maryland Developmental Disabilities Administration as part of the Self-Directed Program. And while we are grateful for the support provided by the program, it still falls on my husband and I to provide considerable care for Michael during parts of the day and all nighttime hours. My husband works full-time and also provides care to Michael. So in addition to being his loving parents, we are also his staff. Currently, there is ambiguity regarding whether family members can serve as staff. The ambiguity has resulted in inconsistent guidance from support brokers and even DDA. The section of this Bill that clearly states that family members can serve as staff, would end confusion, simplify the process and allow families who are doing the work for their adult children to be compensated.

Being the parents of a severely disabled child has been a long and difficult road for our family and we have worked very hard to keep our family intact. We realize there will be those who say that these are simply the cards that have been dealt and it is our responsibility to care for our child - or that this isn't an issue that impacts a majority of Marylanders. To those people I say this. While I may just be a Mom living in this great state, I have always been taught and have always believed that the role of government is to protect all of society - and that includes our most vulnerable who didn't choose or ask to be born with their disability or medical condition. There are too many families in this state that are struggling on this journey alone. The provisions of this Bill may seem to some unnecessary or insignificant, but to Michael and others like him, they can be life changing.

We love Michael very much and want him to remain in the self-directed program so that we can ensure he lives his best life. We are asking for your support of this Bill which will help make that a reality.

Thank you for your consideration,

Lisa Cohen