

## Statement regarding transition to PPL April 1<sup>st</sup>, 2025 – Mary Somoza

My name is Mary Somoza and I work as an aide to my twin daughters, Alba and Anastasia Somoza. Both girls have cerebral palsy, spastic quadriplegia and are full time wheelchair users. Alba is medically fragile, has a gastrostomy feeding tube, is a choking risk and needs to be turned and repositioned several times throughout the night. She is non-verbal but highly intelligent. She needs assistance in all aspects of daily living. Her twin sister Anastasia is also quadriplegic, but verbal. Both girls have been severely disabled since birth and are now 41 years old. They have always lived at home with our family, and now share their own apartment in the building where we all live.

I have been an advocate for my daughters since birth and served for 31 years as a Governor appointed member of the Advisory Council of the Office of People with Developmental Disabilities amongst many other appointments over the years. It has always been a struggle to get and keep services, but in all these years there has never been such chaos and uncertainty in the delivery of CDPAP services. My daughters were the first children to be accepted into CDPAP when they were 12 years old. Homecare services were mainly provided to the elderly, and trained for that type of work. It is not the same level of care and involvement for a young person as it is for a senior. Both of my daughters have worked on and off since graduating from college and receive 24/7 home care provided by a team of aides (8) including family members, and occasional back up workers.

As an advocate for people with disabilities for the last forty years, I have worked closely with other parents and family members and I have a listserv of hundreds of parents, people with disabilities – no agencies or professionals allowed – so parents can share information with privacy. All our families are going through extremely difficult times with the transition to PPL. The Time4Care app is very unreliable, and most days I need to restart my phone, and go through multiple steps before it allows me to clock in, sometimes five to fifteen minutes after I begin to work. This is not just my problem, but seems to be system wide. Frequently the app says there is no “internet” connection, when all other devices are running on the internet.

It is extremely difficult to get anyone on the phone, and when you do, it is a random person who does not know how to fix your problem telling you someone will call back. They don't have direct phone numbers so you can call back, or email addresses, so there is **zero accountability** and huge frustration on our part. We often have to spend days, and many hours trying to get a problem resolved. It adds enormous stress to our everyday lives, complicates recruitment by the complicated enrollment process, and it appears to me (and many families) that there are very few staff members on hand that are well trained in all the issues affecting this program. We need individual case managers, with email addresses and phones, so we can get our issues resolved.

There are also issues with holiday pay, overnight shift cut offs (so as not to pay overtime) the miserable health insurance which makes it very hard to recruit aides. Wage Parity money is being used for “Flex Card” benefits instead of going directly to hourly wages, a 56 hour limit on

earned Paid Time Off (PTO), The issues are widespread (my listserv is increasingly filled with parents who have issues and need help from other parents – PPL having failed to help them).

The reason there were 600 to 700 FI's in the state was because the state failed to implement procedures and protocols for new FI's, and so they proliferated with no control. But we pay the for the consequences of the state's mistakes. There were some highly reputable FI's and Independent Living Center's functioning in the state, but when the state failed to regulate new FI's, then the bad actors came along, and now, the good guys have been thrown out with the bad.

Something needs to be done to fix this situation.

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