

## 150,000 Stories

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**A**s a CDPAANYS member once said, there is not a CDPA program in New York, there are 150,000, because every single consumer runs their program slightly differently, which is the beauty of self-direction. Each person runs their program based on their needs.



Our struggle has often been telling those stories. How do we, as an organization with a voice both in Albany and across the state, lift up the voices of consumers to tell their stories? They are complex stories – stories full of heart, compassion, bonds and the strong sense of independence that is the story of CDPA and the story of a consumer and their personal assistant (PA).

Last year, we started by giving recognition to PAs through our sister organization's, Consumer Directed Action of New York, Fausto Romero Personal Assistance Excellence Award. The first award went posthumously to Fausto, a PA whose commitment to his consumer ultimately resulted in him contracting COVID-19 early in the pandemic and passing. We just marked the three year anniversary of his passing, and it continues to be felt today by family – including the consumer he worked for.

But that relationship and the program is too big to be captured by just an award. It is a start, but it can't tell the whole story.

Well, when a story is too long – use pictures. And if a picture is only worth a thousand words, then use video.

That is just what CDPAANYS is doing. We are talking with consumers and their PAs across the state to lift their voices up to talk about the relationship between a consumer and their PA to tell the story of CDPA and why this program is so necessary. And we are turning these conversations into videos on our YouTube channel.

As of mid-April, we have heard from Joe Slomba, who talks about his relationship with his brother and PA, Ben. Joe tells us Ben “has given him the freedom to be a man, not a child.” When asked what his life would be without CDPA, Joe laid it out. “Picture a TV screen and you're waiting for a movie. And the movie doesn't come on, and it's all black. That's what my life would be like.”

We heard from Jose Hernandez and Marcus Johnson, who had an in-depth conversation with each other about what their PAs and the program have meant to them. I can't begin to do this conversation justice – it is just one you have to go see. Oddly, the piece that most stood out to me was this exchange, where Marcus talked to Jose about the fact that he and his PA, as close as they were, would “go at it” with each other. And Jose recounted but that is what would happen, they would “go at it” and then make it right – because that is what you do with family, and that is what their PAs were to them. Family.

In our most recent video, we have Zack Hilty, “a professional quadriplegic” and Lolli Edinger, his PA. Zack talks about how Lolli helped him as he went through an abusive relationship and once again noted she is “family” without whom he would be “completely lost.”

Zack, Marcus, Jose, and Joe each told their story in a compelling way that tells the story of CDPA. They talk about their relationship with their PA in a way that is so much more than what anyone else could - because it is their story they are telling. And they are stories that need to be told. If I had my way, we'd tell all 150,000 of them.

Not every story is about a relationship with a PA. Sometimes it is a story about the value of the program overall. What has the program meant? What struggles did you face? What did the ability to overcome those struggles on your own, rather than having a doctor or an agency do it for you, mean to you? All of this is the reality of CDPA. And we want to hear it all – from you.

You can share your CDPA story by emailing [Stories@cdpaanys.org](mailto:Stories@cdpaanys.org) to schedule an online interview. To witness the experiences of others visit the CDPAANYS YouTube channel.