

Mental Hygiene 2/6
ELLY Sheller Rufer
Parent

Elly Sheller Rufer

201 East 17th Street

New York, NY 10003

212-477-1225, 917-833-4738, elly.rufer@gmail.com

Thank you for the opportunity to submit written testimony to the Joint Hearing of the Senate and Assembly Ways and Means Committees concerning the 2017-18 Executive Budget for Mental Health as it concerns Developmental Disabilities.

My name is Elly Rufer. I am the parent of two children, one of whom is intellectually compromised with a very involved seizure disorder and recently "behavior" issues. Kate lives in a residence and the Direct Care Professionals help her with everything – including taking her numerous medications, getting up and out for the day, recreation activities, everything that makes a life.

If you have children you can remember what it was like to leave your child alone for the first time - It was frightening: it was necessary: it was a natural part of growing up but hard to trust that the caregiver was up to the job.

You may have called 17 times checking in, worrying about how things were going.

Now imagine that for parents like us this feeling goes on forever.

Our lives are manageable because we have wonderful, caring, devoted Direct Support Professionals to be there when we cannot, when we are working, as we age and when we are no longer here. They are there to watch over our kids, assure them when they are worried, help them master new skills, step in when something goes wrong. These are the people I entrust Katie's life to – Is there any more important job?

The DSP's job does not begin & end with the IDD person. **They are an integral part of how well the family function.**

WE, families, CANNOT survive without the help of DSPs. Other families have economic pressures, work problems – all sorts of stuff happening. At times like this, we need DSPs more than ever to make sure all is in order so that life can go on.

I rely on, and need to know that a kind, thoughtful, careful person is with Katie- that they are patient with her and understand her ways. This is not a job for just anyone – the demands are huge, there are physical and emotional pressures and mistakes can have terrible consequences. How can we expect people with these qualities to work for so little, who here would?

These are people who have chosen to work with my child and others like her – if they can't make a living they will leave and we have to help Katie understand that they aren't coming back and help her not resent the new people who take her "friends" place. Every staff turnover is a loss to Kate. Every disappearance is like the death of a family member. I'm not exaggerating.

No one, no one should have to live with the anxiety that comes from the uncertainty that their child will not be cared for properly and when we are gone – hopefully cared for her as we do.

How can we pay the DSPs so little when what they do is keep people healthy, happy, living as full a life as they can? The responsibility is endless, the stress huge – it takes, judgement, understanding and endless, endless patience. **I challenge everyone here to work as they do – day after day after day. It's scandalous that their hard work is not valued.**