

Opening Statement by Fionn Crombie Angus to the Committee on Disability Matters

I'm grateful to be given the opportunity to speak to you today. This shows us that you are keeping in mind the fact that Disability comes in many forms.

The kind of support I need is time to think things through, sometimes with the help of someone else. I'm happy that my dad gave up his work as a primary teacher to be my paid assistant. But don't let that fool you – I am in charge, making my own decisions. I am Ireland's first person with a learning disability to manage my own HSE pilot, having begun nearly six years ago. I have informed those running the HSE pilot that I am available for consultation.

Supported independence is actually what every member of society needs. After all, we all are disabled without the right supports and accommodations. And, with them, disability disappears.

Personal Assistance needs to be personal, and flexible. Currently, my employees are required to take a course in manual handling, even though I am not physical impaired. I would welcome social care students from colleges where I lecture to apply for a job as my assistant, but I'd more likely benefit from someone with experience performing music or making films, regardless of what's on their CV.

The ideal personal assistant isn't always found within the family, but sometimes she or he is. Think of those disabled with dementia, or those who don't use words. Paid family support must be allowed.

Who has choice and control in disabled people's lives? Service Providers sometimes use bundling of funds as an excuse to keep our money. It only belongs to them if we want their service, and we have the right to end the contract at any time.

Other individuals in Ireland with similar impairments to mine receive an HSE budget nearly three times what I get. Neither they, nor I, understand the discrepancy – call it the HSE lottery. We ask for transparency with the allocation spent in our name, whether we manage those funds or not.

The HSE required us to set up company to run my PA programme. We turned it into a social enterprise, Fionnathan Productions, which then hired me, as well. I teach in primary school for the Heritage Council, lecture at universities, make films and play music. Earned income makes up 4/5 of our running costs, and the Wage Subsidy Scheme helps cover my salary. As a public speaker, I travel for work – having visited more than 20 countries. The HSE can't or won't tell me why they sometimes allow me to pay work expenses out of my support budget, and sometimes refuse. And the costs of management and administration of, and insurance for a Personal Assistance Service must be financed in addition to the deliverables costs.

In places like Cambridgeshire, England, people use their budgets to pay for gym membership, a conference, or lunch with a friend. Having a good life often involves a paid assistant, but there are other ways to creatively support community involvement, and I know how best to use my own resources. You need to assure that it's an Assistance Service, rather than exclusively an Assistant Service.

In summary, my key recommendations to the Committee are:

- Allow us freedom to decide how our personal budgets are spent
- Allow us freedom to hire without regard to qualifications or relationship
- Make funding transparent, and transferable away from service providers
- Fund non-programmatic costs

Thank you.