

## **TRANSCRIPT: What's wrong with the system?**

Simon, Harvey's father

The system could always do with more money. Harvey could have three or four people work with him every single day on mobility, massages, physio, speech and language therapy, teacher of the deaf. So what's wrong with the system – it needs resourcing. The resources came right at the beginning of his life. They spent, I don't know what the equivalent today would be, £1,500 a day keeping him alive. You saw cutting edge technology, the best doctors in the world keeping him alive and then, gradually, as he gets older and older and older, the resources drift away.

We fought the local council for about nine months to get Harvey, at the age of six, into a Peto Institute School that believes in getting children moving, in standing frames, walking, moving around. And, at the time, that was really good for Harvey but it was approaching £7,000 a term and the local authority were unwilling to fund it. And we were very good at fighting the council and we won. But you have to appreciate that it's a game of business. It's not an emotional game. It's a game of limited resources and you have to employ business skills, rather than personal skills, in order to win. We employed a lawyer and we didn't get emotional or upset about it, but not all families are in our position and the problem is that local authorities are looking at a number with a pound sign. At the end of the day, they may have four or five thousand, locally, who require special needs, wheelchairs, therapy, hearing aids and they can't get involved in every sob story. But to the families involved, it's intensely personal. So, at one end you've got extreme emotion, at the other end you've got an accountant and somewhere in the middle the two have to communicate and make it work, and it's difficult.