

Sue Bott interview transcript

My name is Sue Bott and I'm the Director of The National Centre for Independent Living, which as its name suggests, is all things independent living. Our membership is made up of a network of centres for independent living and other local disabled people's organisations.

User led organisations, as a term, can be very confusing and quite controversial because some people would like them to be termed as disabled people's organisations but essentially anyway, what they're about is they are organisations that are run and controlled by people who need support to lead their everyday lives.

The first thing a commissioner would do is look at who is running the organisation. Now, that's not always easy to determine. You can look at a management committee or board of an organisation and it might appear that the majority of people on that board are people using services so therefore you might conclude, well that's a user led organisation. That has to be a starting point and then you look at what else the organisation is doing. How's it representing its constituency? To what extent are people who use services, genuinely involved in determining the policy of that organisation and how it's run? If the organisation employs staff, are some of the staff people who need support services? These sorts of questions.

I'm a member of the Department of Health's User Led Organisations Project Board, representing user led organisations and it was our task to put together these 21 design criteria.

Some of them are pretty basic, so to be a user led organisation then the majority of the management board and preferably 75 per cent of the management board, are drawn from people who use support services. So, that's a pretty basic criteria but there are other criteria that are more aspirational. For example, delivering services to support people with independent living. Some organisations deliver those services, some don't but we wanted that in there really to help explain what a user led organisation could potentially do and how it could support the people that make up the membership.