

Stop people with a learning disability dying too young. Confirm and Challenge Group



Notes from our meeting in July 2019





Update from our meeting in June

We looked at the Leder annual report and wrote our response.

We agreed to send this out to as many people as possible.

We were really proud of it.

Phil made a video reading out our response.

You can see that [here](#)

<https://vimeo.com/346183517/7e7419e56d>



At our meeting in July

Aaron Oxford and Lesley Savage attended from NHS England.

Aaron wants to set up a national steering group for Leder, with around 10 self advocates and family carers on.

He wanted to see how our group works and to learn from us.

Aaron was also interested in us wanting to be Leder Reviewers.

We had a long discussion about it.

What else we talked to Aaron about

Aaron told us about the Learning into Action group. They try to change things based on what Bristol are learning.

It sounds like a useful thing to be involved in.

We asked if their work is shared with Leder Steering Groups. Aaron didn't know but will find out.

We asked if there are any self advocates or family carers on the group who do not work for NHSE.

No, but membership is being reviewed.

Aaron asked if we were interested in being on it. We said yes. He will look into this for us.

We shared our experience of asking Bristol to make their briefings for carers in easy read.

Aaron is going to look into it for us.



What else we talked to Aaron about



We looked at the video Pauline Heslop made for Learning Disability week.

We came up with our own questions about the Leder programme for 2019-20.

We are going to make our own video.



We talked a bit about Whorlton Hall, and what happened after.

We felt NHSE could have made a values based statement to show they cared without affecting the police investigation..

Aaron will feed this back.



We talked about a carer from Newbus Grange (another local Cygnet hospital) going to court this week for abuse..