

24 May 2019

North West National Campaign Group response to LeDeR and Panorama:

It has been a terrible week for people with learning disabilities, autism, or both and their families. This week we have seen even more evidence that we are not thought of as equals and we are still denied our rights.

The annual LeDeR report was published. It shows that people with a learning disability are still dying too young. We are frightened and angry (but not surprised) that the report shows some people had Do Not Resuscitate orders which said the person's learning disability was the reason they should not be resuscitated. We know these things mean our lives are still seen as not being worth living by too many people. We urgently need to work together to challenge this view: our lives are just as important as those of non disabled people. We need to continue to challenge a system where accidental or wilful neglect of people with learning disabilities is allowed to cause avoidable deaths. We want to see that people's records are checked in case these orders are there when they shouldn't be. Having a learning disability is never a reason to allow someone to die.

The national campaigns group are disgusted by the degrading, inhumane treatment of our peers at a secure hospital run by Cygnet. It has been 8 years since the abuse at Winterbourne View was exposed. We have still not managed to change the culture in services so people with learning disabilities, autism, or both and their families can be assured they will be treated with respect when they need support most. Experts by experience: people with learning disabilities, autism and family members are often accused of not having skills to understand what people need, or of 'only challenging' NHS commissioners and providers. We hope that this latest in a series of evidence of the disregard for people's human rights, shows that health and social care professionals can not yet be trusted to have the skills to commission or deliver safe, quality support. We make absolutely no apologies for continuing to challenge a system which continues to fail in upholding the human rights of our community members.

We strongly disagree with the action taken by NHS England to hastily close this service and move people on. We know that people need change to happen in a supported, planned way. We know that when this same approach was taken with the people at Winterbourne View things became much worse for some people before it got better. We now hope each person receives a Care Treatment Review, all the support they need to feel secure again and the patience and respectful care they need to deal with this. We want everyone involved to get support to deal with the trauma they have experienced.

People with learning disabilities or autism, or both and their families have long been challenging the closure of NHS provision, because we do not want to see private providers developed to make money from us instead. We want to see the owners of private companies who abuse people held properly to account, not just the staff paid minimum wages who are badly supported. We want the way staff are recruited, trained,

paid and supported to be looked at, so we don't just have anyone who will do the work being paid to support people. We want the right people for this vital work.

We think secure hospitals and assessment units urgently need strong links with communities, so more independent people visit and people living and working there know they are valued members of our community. We think there must be more unplanned visits as well as Care and Treatment Reviews to ensure care is safe and respectful.

#OurLivesMatter