

Written evidence from Rescare: The Society for Children and Adults with Learning Disabilities and their Families (HCS0015)

Submitted by Dr Catherine Booth, Trustee at Rescare

Who we are;

Rescare (Charity no 1112766) was founded in 1984 by parents and friends of people affected by the closure of large NHS hospitals for people with learning disability. Run “by families for families”, Rescare is based in Stockport and has members all over the UK. Rescare campaigns for the right to choose the type of care which is most suitable, especially for people with complex medical and care needs. We consider relatives and friends with their knowledge of a person’s wishes, potential and capabilities must be consulted when decisions are made.

Rescare is the only charity which has campaigned consistently for effective choice of places of residence and for such choices to include intentional communities where appropriate. We run a helpline for families, have an online support/information forum every other month, and we are now starting up a befriending scheme. We publish Resnews our regular magazine, there is a website and we contribute to three social media platforms.

This contact with our members has meant we have always had direct feedback from families of people with learning disability and hear about their frustrations first hand. This submission intends to give a snap-shot of some of the human rights concerns our members have highlighted.

Submitting on behalf of our members and also families associated with:

Holyrood care home Haywards Heath

Furlong Close in Wiltshire

WE ARE SUBMITTING OUR COMMENTS USING YOUR 3 QUESTIONS AS OUR HEADINGS

**1 What human rights issues need to be addressed in care settings in England, beyond the immediate concerns arising from the Covid-19 pandemic?
How effective are providers at respecting the human rights of people under their care?**

One of the main issues we are aware of is the closure and threatened closure of vibrant communities by owners and care providers without adequate notice or consultation. Indeed a recent case which had generated much local publicity went to court and the litigant has been awarded costs.

In January 2021, legal proceedings were commenced seeking a judicial review of the decision by Hft to close Furlong Close. The proceedings were commenced by the litigation friend on behalf of her severely learning and physically disabled daughter, a resident at Furlong Close.

2. The proceedings sought to quash Hft’s closure decision, on the basis that Hft had violated Katie’s human rights (ECHR Article 8) because:

- a. It had failed to consult with Katie and the other residents before taking a decision which would deprive them of their long term home; and
 - b. The decision to close failed to give due regard to Katie and the other residents' right to be protected against undue interference with the peaceful enjoyment of their long-term home.
3. The proceedings were primarily defended by Hft on the technical basis that, as a private care provider, its closure decision was not amenable to judicial review. It did not pretend to have engaged in any consultation and failed to put forward a strong case to justify the decision as reasonable and proportionate.
4. In March 2021, a Judge granted permission for Katie's case to proceed to final hearing and a date was subsequently set for 22 July.
5. The proceedings have now been resolved by Hft consenting to a Court Orders in which it:
- a. Acknowledged that it has withdrawn its decision to close Furlong Close; and
 - b. Confirmed that it will continue to provide care to the residents at Furlong Close for as long as Wiltshire Council continues to commission that care.
6. In the same Order, Wiltshire Council confirmed that it had taken no decision to stop commissioning care for residents at Furlong Close.
(from summary document by M. Steele Friends and Families of Furlong Close)

Such lack of consideration and meaningful consultation by authorities is not unique. We have evidence of untold misery and worry to the families of people who have been happily settled in a community sometimes for decades when the managing authority (sometimes a charity itself) wants to close down or make radical changes to the style and content of care. One mother has informed us that a proposed closure of a residential home at short notice without a replacement being offered, could make her learning disabled son homeless. Her letter to us highlighted the need for improved security of tenure in care homes. We think that closures such as these lessen the overall availability of suitable care provision for those who are very vulnerable and have complex needs.

2 How effective are regulators in protecting residents from human rights breaches and in supporting patients and residents who make complaints about their care provider?

We have evidence which shows that deep dissatisfaction can result when family members of people with learning disability complain to the proper authorities. The complaints include poor care to an individual, or decisions by local authorities or care providers which they consider detrimental to their loved one's health and wellbeing. These complaints take a great deal of time and effort by people who are essentially lay people, not professionals in the field.

Our members have often been persistent and careful about detail, but they find systems very slow as they make heroic efforts to obtain answers from the Ombudsman, local authorities, the Charity Commission, health service providers or health authorities. In essence, irrespective of whichever body they approach, our members can find themselves facing:

- A procedure which seems complicated
- Replies which do not get to the main substance of the complaint
- An instance when a promised independent re-assessment went instead to the very person whose actions were in question
- Such delay, through appeals and correspondence, that the issue runs out of time.”
Their procedures are so complex and multi tiered that in the end, we run out of time, literally, on our complaint”. said one of our members about the Charity Commission and Parliamentary Ombudsman

3 What lessons need to be learned from the pandemic to prevent breaches of human rights legislation in future?

- We at Rescare did receive calls and emails about visiting during lockdown. The apparent lack of clear guidance meant that places of care were each having to set their rules as best they could. This issue seems now to be mostly resolved and families and facilities have found their way through. For the future clear evidence based guidance published in a timely manner would be very helpful.
- In addition meetings arranged at short notice by Zoom have been frightening and difficult for families to prepare for. Adequate time and good quality independent guidance are essential if families are to work in constructively in concert with funders and care providers.

In summary however we find as a charity that the pandemic has exacerbated problems rather than throw up new ones, which include:

- Lack of meaningful engagement with families when life changing decisions are being considered. We have found that this applies equally in NHS facilities. Families are often able to supply insight and information to ensure that Article 8 human rights are respected for very vulnerable people who cannot readily express their feelings and concerns.
- A failure by front line staff to encourage healthy habits of diet and exercise which can prevent a person becoming unable to partake in home and family life.
- Complaints which do not seem answered in a clear and timely manner, or fail to address the problem at the core of the complaint.

Summary

In essence, for the future Rescare would like to see safeguards against arbitrary decisions which impact on vulnerable people and also a commitment to upholding their rights so promoting their chance of happiness.

Finally we would like to point out that applications for Judicial Review are expensive and many families are unable to afford legal representation if they feel the need to challenge processes.

31/10/2021