Points for discussion – CQC 17th November 2021 12noon – 1pm

Amy Jupp and Patrick Wilkinson by Teams

Contact campaigns@rescare.org.uk for link to meeting

It seems reasonable to use this opportunity to explore Amy's and her team's perceptions of some key concepts which are important to Rescare and its friends. Our aim is to facilitate dialogue and understanding so that we can work together to serve those with learning disabilities and their families.

In particular:

- Clarify how the role of CQC has evolved now it takes in places like GP surgeries. Is it to do with registration or inspection?
- What is the relationship now between implementing policy and influencing its development?
- If her office does inform policy, how can we with our joint grass roots experience help?
- Definitions can be confusing. Do we talk about intentional communities, legacy facilities, campus sites?
- A member says about the use of words *I* wish that people in authority would stop parroting phrases about "Independent Living". For many learning-disabled people "Independent Living" is simply impossible; and for many others, the phrase "Independent Living" has to be qualified by words such as "to the extent that this is possible given the nature and the extent of their learning-disability".

Items we would like to talk about:

- 1. We have found the Covid crisis has exposed less vulnerability for residents in residential facilities where the staff is stable with well managed staff (often larger places).
- 2. We all agree that positive care outcomes for residents, good communication with families where possible and involvement with locality are more important than size per se. A micro-culture with these elements we feel is conducive to an open organisation, well managed and able to respond effectively when problems arise. (See quote below)
- 3. We therefore feel the guidance that: residential care "should usually be provided in small, local community-based units (of no more than six people and with well-supported single person accommodation)" <u>NICE guidance (CG142)</u>: the definition of 'small' services for <u>autistic people with mental health conditions and/or behaviour that challenges</u>, is unduly restrictive and does not reflect the care which can be delivered to a high standard in places of various size. Sensitive commissioning and adequate funding we feel are far more important than number of beds.

4. From our point of view CQC should be aware that its policies are being suborned for use by providers/ site owners as an excuse to close down and relocate. The fact that these closures have been announced without consultation These decisions seem to have been taken without any sense of responsibility for where the people who are being effectively turned out of their homes are to go. Thrown onto the mercy of the local authorities whose statutory duty it is to support them but who in so many cases do not have suitable alternative provision for them. How should families react when these issues arise?).

On a different point about tenancies one of our members **says** *I* have seen numerous examples of people in Supported Living who require a huge amount of care, would have no clue that they have a tenancy, which someone has signed on their behalf etc and quite clearly should be in a care home. Is the issue of signing leases and security of that tenure something the CQC can influence?

Where a provider seeks to close down or leave a site or customer would the customer's interests be better served if CQC had to be notified of such intention and provide a regulatory framework which would give the customer much greater agency in that process? We do not find it acceptable that a provider can simply abandon a customer at a moment's notice and that the customer's only way of challenging such a decision is through Judicial Review. However, Judicial Review is expensive and seems very heavy handed. What could be done?

- 5. In Rescare's submission to the parliamentary (Joint Committee)'s inquiry, *protecting human rights in care settings* reported on the deep dissatisfaction can result when family members of people with learning disability complain to the proper authorities We talked about **complaints which do not seem answered in a clear and timely manner, or fail to address the problem at the core of the complaint.**
- 6. We want to discuss CQC and its stance about transitioning of sites from residential care to Supported Living or Specialised supported housing in terms of registration, and where a new provider is taking over on a legacy site? Also, what is CQC's attitude/approach to Core and Cluster models of the above, particularly where there might be a variety of provision (residential care and learning disability dementia care unit) within the site?
- 7. We would like to think about the concept of choice. Guidance, specifically as it relates to placements in intentional communities because those individuals who have chosen to live there in many cases for many happy years surely could be supported to remain there for as long as they wish. Choice will be eroded for all if vibrant communities for people with learning disability are systematically destroyed.

We would also like to think that if the elderly choose to live in residential care (perhaps in rural settings), or with more than six places why is the ability to live in this type of community denied to people with learning disability because new sites above a certain size seem to be discouraged? . **Surely choice should be equitable.**

Very little happened in the bungalow, partly because Social Services declined to finance people to come in and put on activities (eg making jewellery, drawing etc), so the residents tended to keep themselves to themselves (by -eg - watching TV all day) Our daughter's spirit would have been completely crushed by this placement. Fortunately NHS Continuing Health Care came to the rescue and approved the funding for her placement at xxxxx's.

She now lives in a thriving community - 60 acres, 200 children and adults with SEN and epilepsy, and 700 staff. She has a number of activities including propagating plants (a huge veg garden and chickens), drawing etc, which will be expanded back to pre pandemic levels in January. Every time she goes out of her bungalow she waves to and talks to lots of people, most of whom know her by name. The residents do of course go outside their own community to shop in xxxxxx, go for a ramble in a local park and so on., but their real "community" is what they have on site