Our Life Our Choice is campaigning for a change in the CQC guidelines to reinstate village communities and intentional communities as a choice of residential provision for people with a learning disability and / or Autism. This choice was explicitly included as a choice in **Valuing People 2001**[1].

In this paper we have examined in detail how CQC guidance to care providers and commissioners of residential care and other national guidelines and policy (based on inappropriate evidence) have forced the closure of over 40 such communities and continues to prevent new communities being developed.

What are village communities and intentional communities?

The population of people with a learning disability and / or autism have a full range of needs. Many can lead independent lives with minimal support from families and care professionals. At the other end of the range are people who have such severe difficulties that they require 24 hour care in controlled settings to protect their well-being and safety.

Another small (approximately 2%)[2] group are represented by people who have complex learning disabilities and / or autism and it is in the context of this minority that communities variously described as village communities, intentional communities, or 'shared -life' communities came into being. These environments enable their residents to live as full and as independent a life as possible by providing light but constant supervision and care, to ensure their safety and wellbeing. These communities have specifically developed a model of care that enables their residents to have a quality of life that no other choice of care and support can offer.

Communities will vary in size. Typically, residents live in small scale housing including bungalows, flats and shared houses clustered together either in urban settings or in rural or semi-rural environments. Residents in some can get the physical and mental health benefits of green open spaces, gardening, vegetable and fruit growing and tending farm animals. Other facilities offered within these communities can include craft, music, computer and other workshops as well as swimming pools, and horse and bike riding. Some have a community hall, which is used for parties, films, discos and events throughout the year both for the residents and for people who live in the vicinity.

Probably though the most important aspect of these communities is their ability to provide their residents with an environment where people can enjoy the freedom of a safe home among like-minded people with a rich set of personal interactions and relationships – all within a sheltered environment. Residents can wander safely from their home into one of their friends' homes and have a coffee. Every day, they can dip in and out of a variety of activities taking place on site. Every day, they can talk and engage with the many staff who work in such communities – thereby having meaningful and enriching relationships with many different people. It is also an environment that is fully integrated with its neighbourhood, drawing on and adding to the local facilities. Residents, enjoy a wide and enriching variety of activities off site as well. They go to the pubs, nearby community centres, sports events, discos, shopping, walking and cycling in local parks and the countryside. They are accepted and are well-known and loved parts of the neighbouring communities.

If this sounds like a familiar caring environment, simply replace the words that describe who may want to live in such communities from learning disability and / or autism to 'old-age' or 'dementia' or 'Alzheimer'. These would then be considered desirable settings (most also being regulated by the CQC). Similarly groups of people who follow the same ideals such as 'religious faith', 'environmental protection', or 'co-housing' amongst others have an absolute right to choose to live in e.g. kibbutz's

(https://archive.jewishagency.org/) or eco-villages (https://ecovillage.org/ecovillages/?gen_country=united-kingdom) or co-housing communities (https://cohousing.org.uk/about-cohousing-2/)

So why is the small group of people with a learning disability and / or autism who choose to want to live in similar village or intentional environments discriminated against by national guidelines and policy?

The history of the development of the current CQC guidelines that discriminate against village communities and intentional communities.

The CQC was established in 2009 and is now the independent regulator of health and social care in England. Its primary roles are to register care providers and to monitor, inspect and rate services.

Registering the Right Support (RRS)[3], published in 2017 was the CQC's policy on registration and variations to registration for providers supporting people with a learning disability and/or autism. This policy was revised and retitled in 2022 as **Right support, right care, right culture (RSRCRC): - How CQC regulates providers supporting autistic people and people with a learning disability[4].**

Residential care providers must register with the CQC and must comply with the guidelines in RRS and RSRCRC. Local authority commissioning groups are expected to follow a framework to help them make decisions about provision for people with a learning disability and / or Autism[5]. This framework references national guidance and other documentation mostly listed in RRS and RSRCRC.

RRS relies heavily on **Building the Right Support 2015 – The National Plan[6]** and the **Service Model 2015[7].**

The most important and relevant observation to make about these plans and models are;

They were developed specifically for a small proportion of people who have a learning disability and / or autism with behaviour that challenges (these people represent between 5 – 15% of people with a learning disability and / or autism who access health or social care services[8,9]). They were never intended to be used as guidelines and statutory regulations for the other 85 -95% of people with a learning disability and /or autism.

These guidelines and RRS and RSRCRC all rely heavily on research and other documentation that looks specifically at this small group of people with challenging behaviour. These guidelines were developed with the laudable objective of closing outmoded NHS inpatient institutions as a result primarily of the Winterbourne View expose. In fact, the entire introduction to the National Plan talks exclusively about the closure of Hospitals and NHS inpatient facilities. Nowhere does it suggest or conclude that the contents should be applicable to the wider population of people with a learning disability and / or autism. Similarly, the introduction to the Service Model states on several occasions that the guidance is specific to the small group of people with a learning disability and / or autism with behaviour that challenges and does not seek to apply the guidance to the wider population of people with a learning disability and / or autism.

RRS clearly recognises this at the beginning of the first page that describes the scope of the guidance (page 6) but simply applies the principles developed for a small group to all people with a learning disability and / or autism. No reference to any documentation or studies to support this generalisation are provided.

Why does this matter when it comes to the choices of residential care and specifically village communities and intentional communities that are available to people with a severe learning disability and / or autism?

RSRCRC starts with an entire page titled '**Our position on the size of residential services'**

It references two NICE guidelines[10,11] to support 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)". The original source of this statement appears to be in **Supporting people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition Service model for commissioners of health and social care services Supplementary information for commissioners October 2015[12]** where it states on page 16 'People should be supported to live as independently as possible, rather than living in institutionalised settings (which, for instance, housing with occupancy of six or more can quickly become)'. However, there is no reference to any research that demonstrates that occupancy of 6 or more creates an institution. These NICE documents focus either on people with autism[10] or people with a learning disability and / or autism with behaviour that challenges[11]. Neither of these groups are representative of people with a severe learning disability and / or Autism or most people with a learning disability and or autism.

Neither of these NICE documents refer to 'congregate' or 'campus' settings yet RSRCRC states;

"We will only register, and favourably rate, services that allow people's dignity and privacy to be maintained and that facilitate person-centred care. This must be in line with current best practice guidance and not be developed as new campus or congregate settings."

RSRCRC defines 'campus' and 'congregate' settings as;

'Campuses' are group homes clustered together on the same site and usually sharing 24-hour staff and some facilities. 'Congregate' settings are separate from communities and without access to the options, choices, dignity and independence that most people take for granted in their lives.

Whilst a reference to this definition of 'campus' is not provided it is taken from RRS that does provide a reference to **Mansell et al 2007[13]**. This compares different residential settings across Europe but where it focusses on the UK it actually distinguishes 'campus' settings from Village communities as follows;

'Comparison of residential campuses, village communities and dispersed housing schemes found that the campuses were less expensive but also of lower quality. Both village communities and dispersed housing were associated with particular benefits, with different settings appropriate for people with different needs and preferences.'

and;

'The study supported the development of a range of models, as acknowledged in the UK Government's 2001 White Paper ***Valuing People***, provided that residents were given genuine and informed choices about their accommodation.'

Valuing People[1] clearly includes village communities in the range of models that should be a choice.

Moving on to 'congregate' settings again there is no reference to the definition in RSRCRC however it too is taken from RRS where there is a reference **(health service executive of Ireland 2011)**[14]. This study looks specifically at congregated settings in Ireland stating as in RSRCRC that 'Congregate settings are separate from communities and without access to the options, choices, dignity and independence that most people take for granted in their lives' however does not offer any research to support this description. Furthermore, the research explicitly excludes from the study intentional communities (page 25) that it describes as;

'a planned residential community designed to promote a much higher degree of social interaction than other communities. The members of an intentional community typically hold a common social, cultural, political or spiritual vision. They also share responsibility and resources. Intentional communities include co-housing, residential land trusts, communes, eco-villages and housing co-operatives.'(www.wikipedia.org). In the Irish context, intentional communities include Camphill Community and L'Arche Community.'

So, since the inception of the CQC there has been conflation of academic and other statutory guidance developed for a small group of people with a learning disability and / or autism with behaviour that challenges such that it now applies to the wider population of people with a learning disability and / or autism without any research to support this. In this context the definitions of campus and congregate settings places village communities and intentional communities outside what the CQC considers best practice, again without any research to support this.

The CQC continues to inspect and rate existing village communities and intentional communities although in some inspection reports (e.g. Stallcombe House 2019, Stanley Grange 2020) it is made clear that the provision does not align with 'the values that underpin the Registering the Right Support and other best practice guidance' and 'It would be unlikely that we would register this model of services now when considering applications for services for people with a learning disability and/or autism'.

It is clear from RSRCRC (page 4 and page 8) that no new communities will be considered and there is evidence that expansion of existing residential care facilities that exceeds the arbitrary limit of 6 people or leads to the creation of a congregate setting (using the CQC definition) will also not be considered[15].

What specific research and other evidence has the CQC relied on to develop its regulations on the size and location of residential services that must be applied to ALL people with a learning disability and / or autism

Our Life Our Choice has made repeated requests to the CQC to provide the documentation, guidance and academic research used to develop RSRCRC. The CQC has now confirmed to us that the guidance in RSRCRC is based on the references listed at the end of the guidance. We have analysed all these references in an attempt to establish what evidence is used to support the argument that congregate / campus settings (and by definition village communities and intentional communities) are not best practice. Of the 17 references, 7 relate specifically to people who have a learning disability and / or autism with behaviour that challenges and another 4 relate specifically to hospital settings. Only 2 references actually mention congregate settings, and both of these do so in the context of Winterbourne view and refer to the NICE guidelines we have already discussed and which have no evidence base. Only 6 references mention campus settings. Of these 4 relate specifically to NHS campus institutions which we have already demonstrated are completely different to village communities and intentional communities. The other 2 references refer to campus settings as defined

by the National service model which we have already indicated deals solely with people who have a learning disability and / or autism with behaviour that challenges and not the wider population of people with a learning disability and / or autism. In contrast all 17 references mention inpatient or hospital wards in the context of that guidance / research. No references look at village communities and intentional communities.

As mentioned at the beginning of this paper RSRCRC has been developed from RRS and so we have looked at the references listed in this guidance. The only academic references that mention intentional / congregate communities are **Mansell et al 2007[13]** and the **Health Service Executive 2011[14]**. We have already indicated that these academic studies explicitly separate village communities and intentional communities from the campus / congregate settings that they are studying. **Valuing people 2001[1]** is referenced and this guidance states that villages and intentional communities should be a choice. 13 of the 27 references relate specifically to the small group of people who have a learning disability and / or autism with behaviour that challenges.

The arbitrary definitions of campus and congregate settings used by the CQC and the application of these definitions to any people with a learning disability and / or autism without consideration of an individuals needs has been successfully challenged in the UK court[15] where the Judge clearly concludes that the CQC guidelines do not offer a full CHOICE of residential provision to all people with a learning disability and / or autism. The Judge also highlights the lack of evidence to support the CQC definition 'congregate'.

The Centre for Social Justice[16] has also questioned the lack of evidence to support the ideology of the CQC guidelines, stating;

'It is important that care commissioning decisions are based on evidence-led research and assessment of need not on ideological considerations. The answer to care for those with learning disabilities lies neither solely in supported living nor in residential care. We need a care system which offers the option of care delivered in either an independent or communal setting. When making commissioning decisions we should place the individual's needs and preferences at the heart of process; not the form of care in which these needs are met.'

<u>What academic research has examined the role of village communities and intentional communities as a choice of residential provision for people with a learning disability and / or autism.</u>

There are several academic papers that have looked at village communities and intentional communities. Some of this research is reviewed by **Stuart Camella[17]** in which he coins the phrase 'shared life communities to encompass the various congregate settings that include village communities, intentional communities and smaller but congregated care provision. It is concluded from this review of literature that;

'shared-life communities can provide as good a quality of life as dispersed communities, but in some cases at lower cost. As noted by Professor Emerson and his colleagues[18], shared-life communities and dispersed housing schemes each have a distinctive profile of benefits, thereby providing an element of choice for people with a learning disability and their families. A further implication of the research is that the quality of life experienced by people with a learning disability is a product of the ethos and day-to-day organisation of a residential setting rather than its size or location . Shared-life communities usually have strong religious and ethical foundations that have resulted in the

recruitment of committed volunteers with a personal commitment to sharing their lives with disabled people.

One study in Australia[19] highlighted the need for 'group homes' for people with an intellectual disability (ID) as they age, reporting that;

'Participants with an ID and their carers want housing and support that enable people with an ID to maintain and enhance their social networks with their peers as they grow older and require transition to formal housing and support services, and to be able to 'age in place'. A preference was expressed for models of housing that provide the opportunity for people with an ID to live in close proximity to their peers and in large groups in the community rather than in small, dispersed community housing'.

Another study authored by Dr Cumella[20] that explored the perceptions of people with an intellectual disability (ID) living in an intentional community and the meaning of their community to them reported;

'Results confirm those from earlier studies of intentional communities and suggest that positive outcomes derive from the absence of the overt subordination of residents to staff, the facilitation of friendship with other people with an ID, high levels of meaningful employment and a sense of community. These factors contrast with the experience of living in small homes funded on a contractual basis by public authorities, in which cost pressures reduce wage levels for staff resulting in difficulties in retaining suitable staff and a consequent high staff turnover'.

The CQC does not preclude 'village community' type services!

After the online 'Teams' meeting on 05 September 2023 attended by representatives of the CQC and representatives of 'Our Life Our Choice' the CQC sent us an email (08-09-23)[21]. This confirmed that the evidence relied on to develop the policies in RSRCRC was taken from the references on page 47 of RSRCRC. In this paper we have demonstrated that none of this evidence or any other evidence that follows on from this concludes that the CHOICE of village communities and intentional communities should be denied to people with a learning disability and / or autism. We have clearly shown that the definitions of campus and congregate settings used by the CQC are arbitrary, taken from academic studies examining specific situations and which explicitly exclude village communities and intentional communities from those definitions. Furthermore, we have clearly shown how research and guidelines developed for a specific and minority group of people, those with a learning disability and / or autism with behaviour that challenges has been conflated in RSS and RSRCRC such that it now applies to all people with a learning disability and / or autism.

The same email from the CQC confirmed that RSRCRC does not preclude a 'village community' type service although it is clear from this same email and in RSRCRC that such services are not considered best practice due to their congregate and campus settings (the CQC definition of 'best practice' relies again on the same evidence we have already referred to above that looks at the minority group of people with a learning disability and / or autism with behaviour that challenges). Indeed, there are many CQC inspection reports freely available from the CQC website that rate residential care homes in village communities and intentional communities using the same metrics as other forms of residential care. Some of these reports do state that the provision being inspected does not meet best practice guidelines due to its congregate or campus setting but nevertheless gives 'good' or 'outstanding' ratings, finding no detrimental outcomes from the setting. The CQC therefore clearly has its own evidence from these detailed reports that village communities and intentional communities can provide 'truly person centred care and supports people to live their best lives including ensuring people have choice and independence as well as opportunities to broaden their horizons, develop

their skills and knowledge and integrate into community life'[21]. So why don't the CQC recognise the human rights of people with a learning disability and / or autism to choose where they live by offering well regulated village communities and intentional communities as a CHOICE?

One of the major problems resulting from the CQC stance on village communities and intentional communities is that local authority commissioners of residential care will not consider such provision[16] (this is acknowledged in the email we received from the CQC[21]). We have obtained Freedom of Information responses from a significant number of local authorities in which they explicitly state that CQC guidelines have led them to ignore such provision (31% of 16 respondents). The consequence of this is that these communities have struggled to fill vacancies, resulting over time in a downward spiral of financial difficulties ending in the closure of the community and the forced move of people with a learning disability and / or autism from their long term homes and away from their friends and local community into supported living environments that are unsuitable for them and which do not meet their needs. We have evidence from providers of struggling village communities and intentional communities that the CQC stance is the direct cause of the problems they face in continuing to provide residential care to those in these communities and why they are considering or going ahead with closure.

Moving on, there is a clear statement in RSRCRC;

'We will only register, and favourably rate, services that allow people's dignity and privacy to be maintained and that facilitate person-centred care. This must be in line with current best practice guidance and not be developed as new campus or congregate settings.'

When we raised this in our online meeting with the CQC on 05 September 2023 we were told that the CQC would consider any request for registration of a regulated residential care provision, and this was indicated in the CQC email response. We therefore asked for examples of either applications for new village communities and intentional communities or registration of such communities. Understandably it was not possible for the CQC representatives to give examples there and then and they agreed to send us some. What we received which was attached to the CQC response were several examples, none of which demonstrated their support of either existing or new village communities and intentional communities. One example was where an existing 'campus style' community (CQC terminology) was being re-registered to provide supported living in a new housing development (in other words de-assembling the community). Another example was where the CQC registered multiple supported living houses on 'an ordinary street' (how many supported living units on an ordinary street no longer make it an ordinary street is not mentioned!).

In conclusion, Our Life Our Choice is asking that the CQC simply offer a full CHOICE of long term regulated residential care provision that includes village communities and intentional communities. This CHOICE is a fundamental human right and should be offered to all people rather than discriminating against people with a learning disability and / or autism. Such settings would be subject to the same metrics of care used by the CQC to inspect all regulated residential care provision but would not be subject to the arbitrary and inappropriate CQC guidelines on what constitutes campus / congregate settings.

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