

CHOICE

Valuing People 2001*

A white paper that cited 4 main principles; Rights, Independence, Choice, and Inclusion and had as one of its 11 main objectives;

‘To enable people with learning disabilities and their families to have greater choice and control over where, and how they live.’

Choice must include;

‘Supported living
Small scale ordinary housing
Village and intentional communities’

Page 73; Village and intentional communities:

3,000 people living in 73 village and intentional communities.

associated with better activity planning, more routine day activities and better access to health checks.

local authorities are reluctant to support people with learning disabilities who wish to live in a village or intentional community.

‘The Government will issue statutory guidance to local councils to ensure they do not rule out any of these options

Valuing People Now 2009
new three-year strategy for people
with learning disabilities
'Making it happen for everyone'

Overall policy objective: all people with learning disabilities and their families have the opportunity to make an informed choice about where, and with whom, they live.

Identifies a specific group of people who have a learning disability and challenging behaviour (comprising 19,000 - 32,000 of the 190,000 adults with a learning disability accessing disability services).

This group require special consideration in the choice of residential care provision -referencing the Mansell report 2007*

Challenging behaviour: behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy

Valuing People 2001*



Valuing People now 2009



Valuing People 2001*

Mansell Report 2007*

Services for people with learning disabilities and **challenging behaviour** or mental health need

Is a revision of an original report from 1993 that provides recommendations to facilitate the continued closure of NHS 'campus' style in-patient hospital settings

Focuses on the lack of appropriate residential service provision for this specific group of people not for all people with learning disabilities

Deinstitutionalisation and community living - outcomes and costs: report of a European Study. Volume 2: main report - Mansell et al 2007*

Focuses on people with a learning disability living in institutional care in 28 European Countries. Most of these people would display **challenging behaviour**

Concludes that smaller community based residential settings are best for people with a learning disability who also display behaviour that challenges.

Specifically excludes intentional and village communities from its recommendations

Valuing People now 2009



Health and Social Care Act 2008*

Establishes a new commission, the Care Quality Commission (CQC) with the aim of improving health and social care services in a way that focuses on the needs and experiences of people who use those services

Valuing People 2001*

Transforming care: A National response to Winterbourne View Hospital 2012*

...a programme of action to transform services for people with learning disabilities or autism and mental health conditions or **behaviours described as challenging**.

Focuses entirely on the group of people in NHS funded and private in-patient hospitals and assessment units (approx. 3,400).

This group invariably had behaviours that were considered challenging

Cites the Mansell report 5 times but there is no mention of either Valuing People, Valuing People Now or any mention of village communities.

Introduces the concept that people with challenging behaviour should live in accommodation of 6 or less people, referencing NICE guidelines that actually relate specifically to people with Autism*.

Winterbourne view Exposé 31 May 2011*

A private in-patient hospital assessment and treatment service for people with a learning disability and / or Autism who had **behaviours that challenge**.

Valuing People now 2009



Valuing People 2001*

Building the right support 2015 - National plan*

A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display **behaviour that challenges**, including those with a mental health condition

Service Model - 2015*

Supporting people with a learning disability and/or autism who display **behaviour that challenges**, including those with a mental health condition

Service Model - supplementary information - 2015*

Supporting people with a learning disability and/or autism who display **behaviour that challenges**, including those with a mental health condition

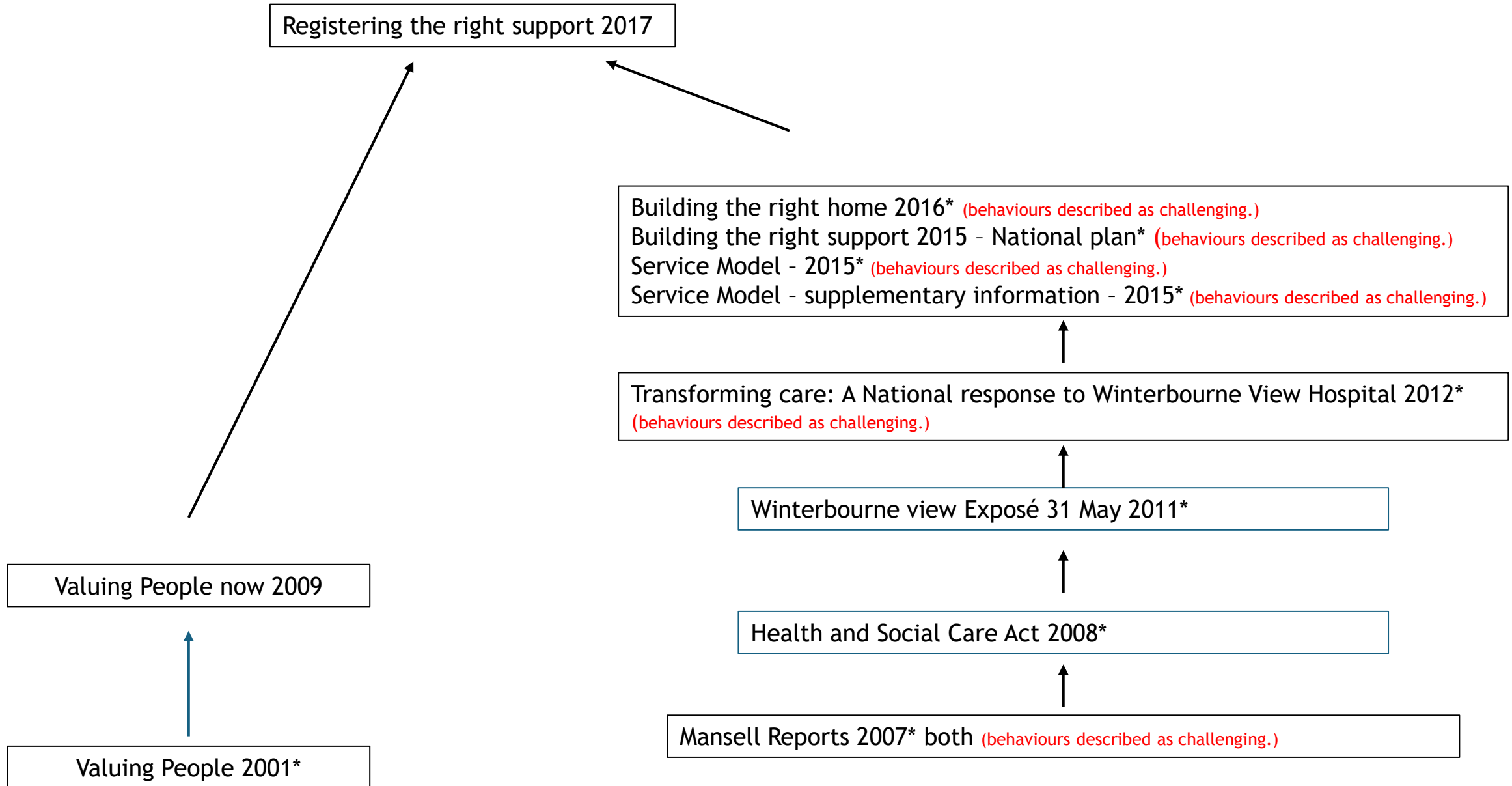
Building the right home 2016*

Guidance for commissioners of health and care services for children, young people and adults with learning disabilities and/or autism who display **behaviour that challenges**

All of these documents form a national plan and service model to inform all health and social care commissioners with respect to the provision of social care services specifically for people with a learning disability and challenging behaviour. They form the core of the Best Practice guidance

They all state in a footnote at the beginning that people with LD and / or autism and behaviour that challenges will 'hereafter be people with a learning disability and/or autism'

These are the first mainstream guidance documents that refer to the concept that more than six people in a care setting represents a campus or congregate setting



Registering the right support 2017

CQC's policy on registration and variations to registration for providers supporting people with a learning disability and/or autism

Guidelines and regulations that service providers must follow in order to register new residential care provision for all people with a learning disability and / or Autism.

The principles of 'valuing people' and 'Valuing people now' for all people with a learning disability and / or autism are supplanted by those in 'the national plan' and its associated guidance.

The introduction starts with Winterbourne View and immediately cites 'valuing people' and the Mansell report. It then goes on to cite 'building the right support' and 'building the right home' with its accompanying 'service model'. Over 3 pages this background summarises the guidance from these documents mixing terminology between 'people with a learning disability and / or autism' with 'people with a learning disability and / or autism who display behaviour that challenges

Registering the right support 2017

CQC's policy on registration and variations to registration for providers supporting people with a learning disability and/or autism

A single paragraph on page 6 of the document cements the conflation of the guidance between these different groups of individuals;

Page 6.

The service model within Building the Right Support refers specifically to “people with a learning disability and/or autism who display behaviour that challenges, including those with a mental health condition”. We do, however, believe that the underpinning principles of choice, promotion of independence and inclusion for individuals are fundamental to what a good service looks like for every person with a learning disability.

Registering the right support 2017

CQC's policy on registration and variations to registration for providers supporting people with a learning disability and/or autism

So, without reference to any qualitative research this CQC guidance determines that all people with a learning disability and / or autism should be treated as also having behaviour that challenges.

Providers of registered care for any person with a learning disability and / or autism must now adhere to the service model, national plan and other guidance which was developed specifically for people with a learning disability and / or autism who display behaviour that challenges;

Right Support, Right Care, Right Culture - 2020 revised 2022
How CQC regulates providers supporting autistic people and people with a learning disability

Registering the right support 2017
CQC's policy on registration and variations to registration for providers supporting people with a learning disability and/or autism



Building the right support 2015 - National plan*
A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display **behaviour that challenges**, including those with a mental health condition
Service Model - 2015*
Service Model - supplementary information - 2015*
Building the right home 2016*

Transforming care: A National response to Winterbourne View Hospital 2012*
....a programme of action to transform services for people with learning disabilities or autism and mental health conditions or **behaviours described as challenging**.

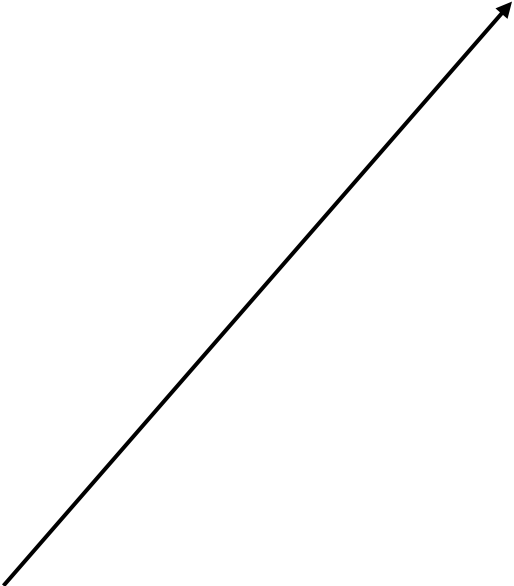
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Mansell Report 2007*
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Valuing People now 2009



Valuing People 2001*



Right Support, Right Care, Right Culture - 2020 revised 2022

How CQC regulates providers supporting autistic people and people with a learning disability

Registering the Right Support (RRS) and Right Support, Right Care, Right Culture (RSRCRC) makes the position of the CQC very clear on the size of residential services

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)'

'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.'

'.....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.'

SUMMARY:

Valuing People and Valuing People now created a wide range of choice of residential accommodation for all people with a learning disability and / or autism from individual housing up to and including village intentional and congregate communities.

Separate to this, for the small group of people with a learning disability and / or autism who display behaviour that challenges a national plan and service model was developed. Fewer choices of residential accommodation for this group were deemed appropriate, ideally individual accommodation up to shared housing comprising no more than 6 people.

The CQC develop regulations for registration for providers of new residential accommodation (RRS and RSRCRC) based on 'best practice, which applies the restricted choices for people with challenging behaviour to all people with a learning disability and / or autism yet no evidence is provided to support this ideology.

Congregate settings

Right Support, Right Care, Right Culture (RSRCRC) and Registering the Right Support (RRS) states 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.’

This description is taken from the Chairmans foreword of a 2011 working group report that focussed on moving people from congregated settings to the community in Ireland

A congregate setting is defined as settings where ten or more people with disabilities live.

The study specifically states that; *‘residential services for people with autism were not included. Intentional communities were not included.’*

Campus settings

Right Support, Right Care, Right Culture (RSRCRC) and Registering the Right Support (RRS) states that;

‘Campuses: group homes clustered together on the same site and usually sharing staff and some facilities. Staff are available 24 hours a day’.

This description of a campus is taken from Mansell et al 2007 Deinstitutionalisation and community living – outcomes and costs.

In this paper there is a clear distinction between ‘campus settings’ and ‘village communities’ where a campus refers to clusters of care homes in the grounds of in-patient mental hospitals and assessment centres

Mansell acknowledges that 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.

WHY DOES THIS MATTER?

Over the last 20 years approximately 40 intentional congregate / village communities have closed

FOI reveals Local authority commissioners cite wording in RRS and RSRCRC as the reason they will not use such provision even if they thought these settings would be appropriate

The CQC have started inspecting and rating local authorities. This will inevitably influence decisions on residential placements.

Providers state that CQC policy on size and location forces them to reconsider their provision

The CQC will not consider registration of new congregate or village communities

People who CHOOSE to live in these larger settings are forced to relocate away from their social group and preferred environment and other people are deprived of the CHOICE to live in these communities.

CQC inspection reports (at end 2023)

Over 166,000 reports covering all social care regulated services available to view on the CQC website

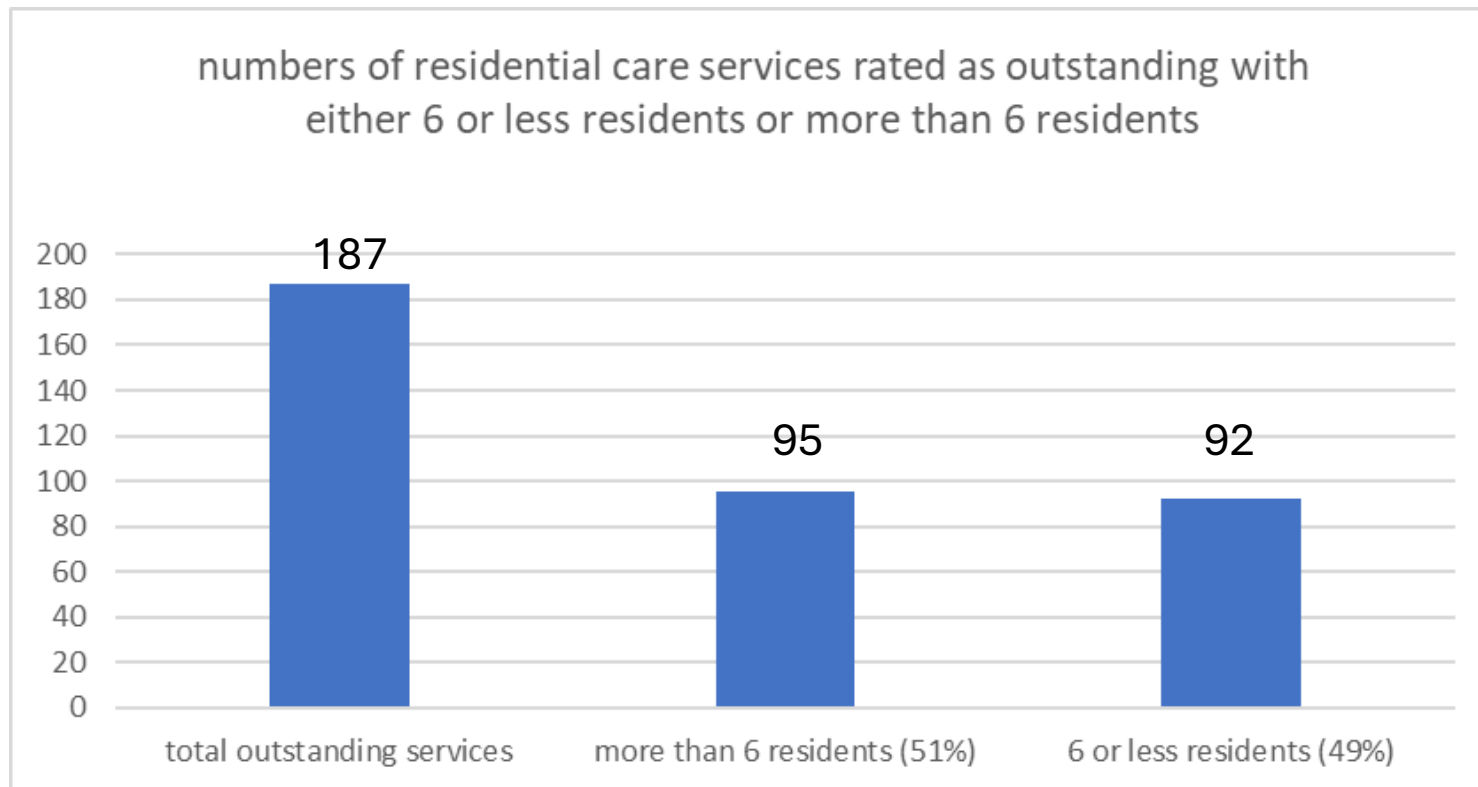
Filtering these reports for 'care homes (active)' / 'residential homes' / 'learning disability' produces 5,000 services

Further filtering for those services rated as outstanding gives a list of 187 regulated residential care homes for people with a learning disability and / or autism.

It would be expected that for a service to attain an outstanding rating from the CQC it would need to fully comply with national best practice and the fundamental guidance and principles in RRS and RSRCRC.

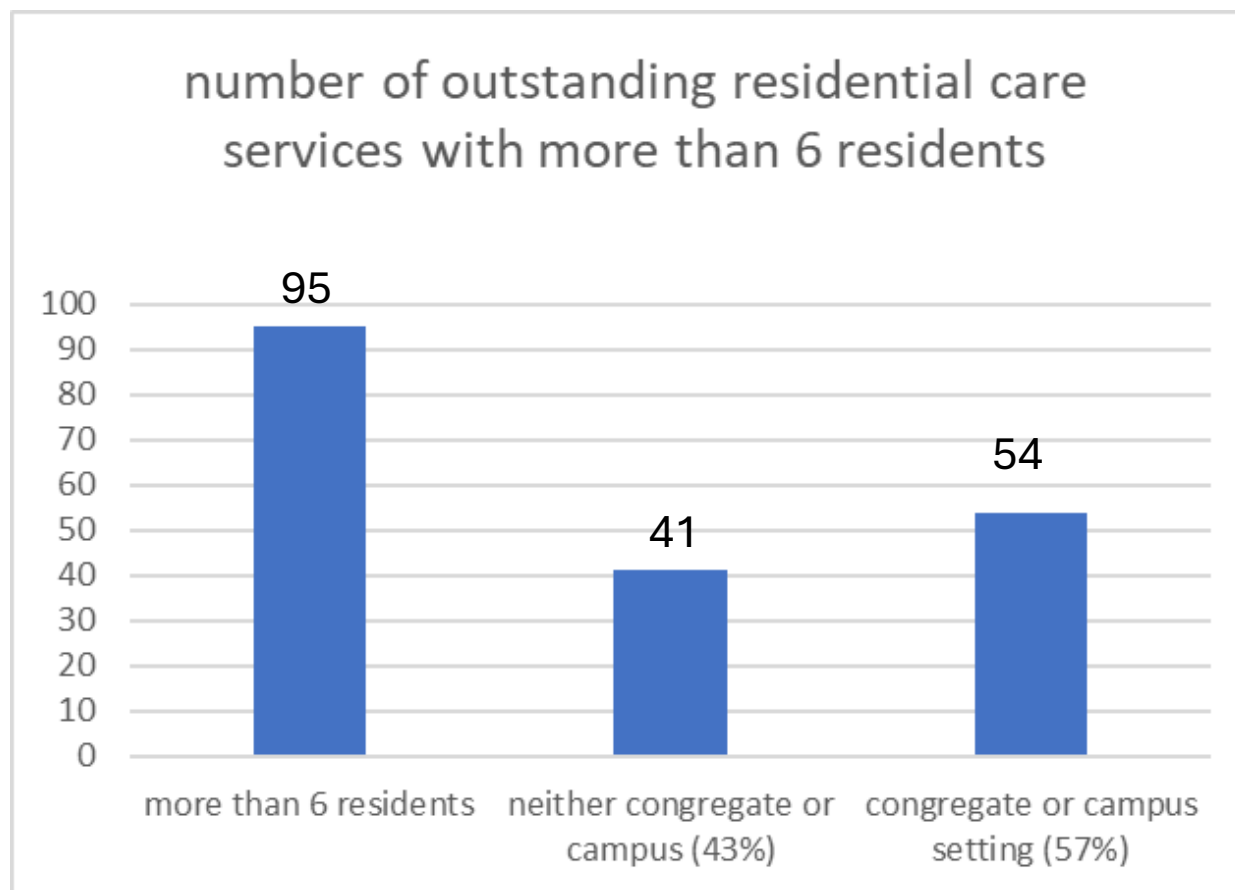
CQC inspection reports (at end 2023)

Looking specifically at the size of the residential service where RSRCRC states residential care “should usually be provided in small, local community-based units of no more than six people...”



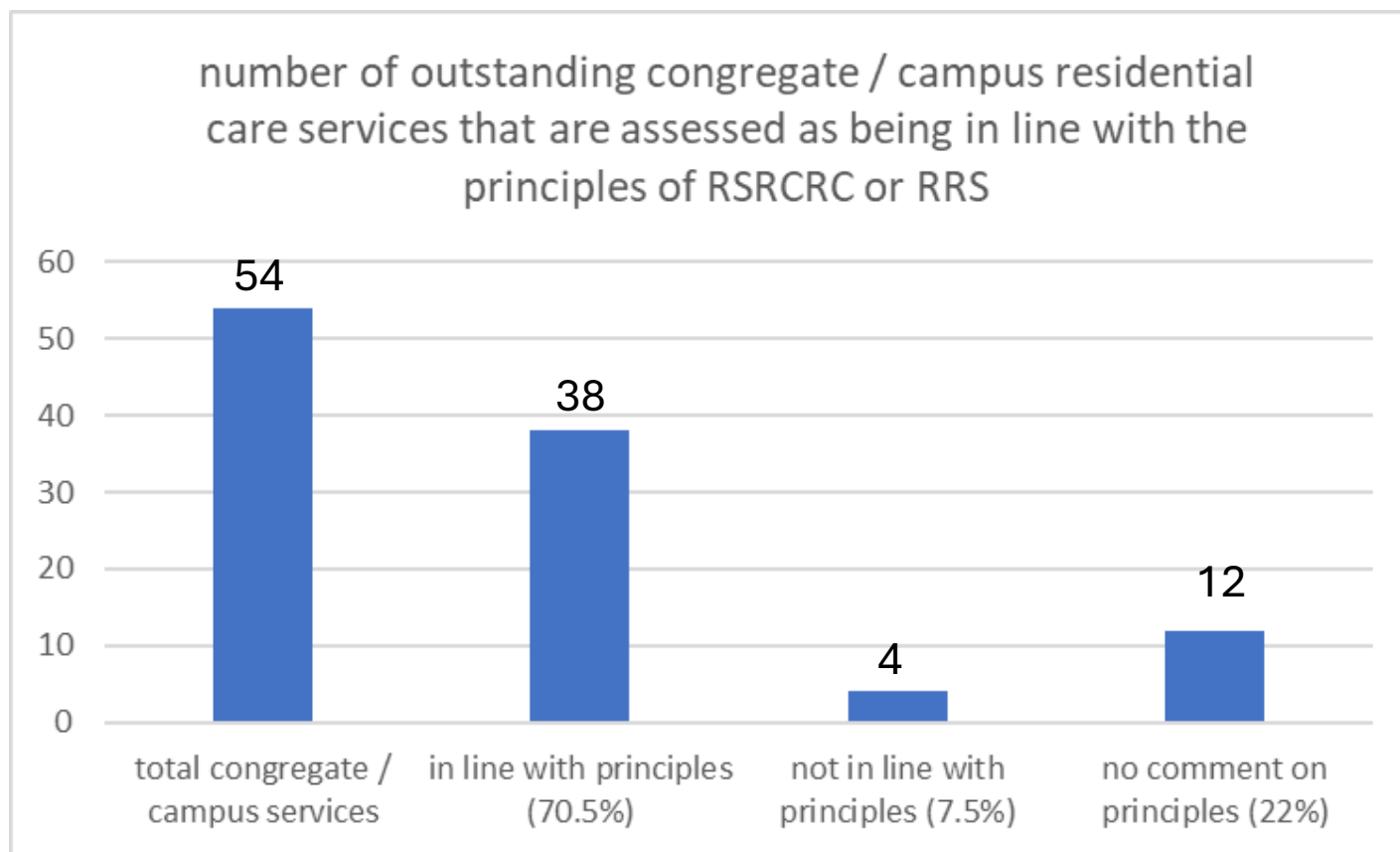
CQC inspection reports (at end 2023)

Looking specifically at what Our Life Our Choice has deduced the CQC means by ‘congregate settings’ (10 or more residents) and ‘Campus settings’ (clusters of 3 or more units on the same site)



CQC inspection reports (at end 2023)

Often the CQC reports indicate whether the service meets the principles of Registering the Right Support(RRS) and / or Right Support, Right Care, Right Culture (RSRCRC)



RSRCRC Principles

Right support:

- Model of care and setting maximises people's choice, control and independence

Right care:

- Care is person-centred and promotes people's dignity, privacy and human rights

Right culture:

- Ethos, values, attitudes and behaviours of leaders and care staff ensure people using services lead confident, inclusive and empowered lives

Summary

Over 50% of outstanding regulated care homes accommodate more than 6 people

Of those more than 50% are congregate or campus settings as defined by the CQC

Of these congregate or campus settings over 70% meet the principles in RRS and / or RSRCRC according to the CQC inspectors.

This is a clear real-world demonstration that the size and location of residential care provision in a well managed and regulated service has no negative impact on the quality of life of the residents.

There is no good evidence in either RRS or RSRCRC to support the CQC stance that congregate and campus settings cannot provide access to the options, choices, dignity and independence that most people take for granted in their lives. CQC inspectors have determined that in many cases congregate and campus settings offer an outstanding provision

Therefore;

Our Life Our Choice is campaigning for a full range of CHOICE of residential care provision for all people with a learning disability and / or autism. The CQC's role should be to enable better care, not restrict it and so must ensure that CHOICE includes village / intentional / congregate communities.

Judge Ian Roberston 2018 appeal hearing

‘choice. This is a fundamental principle of the guidance. Some people choose to live in city’s, some in towns, some in villages and some in the country. If they are economically able that is their choice. If the CQC argument is followed this choice is denied to this group of service users’.

Rural communities

Eco communities

Religious communities

Retirement communities

Dementia communities

Nudist communities

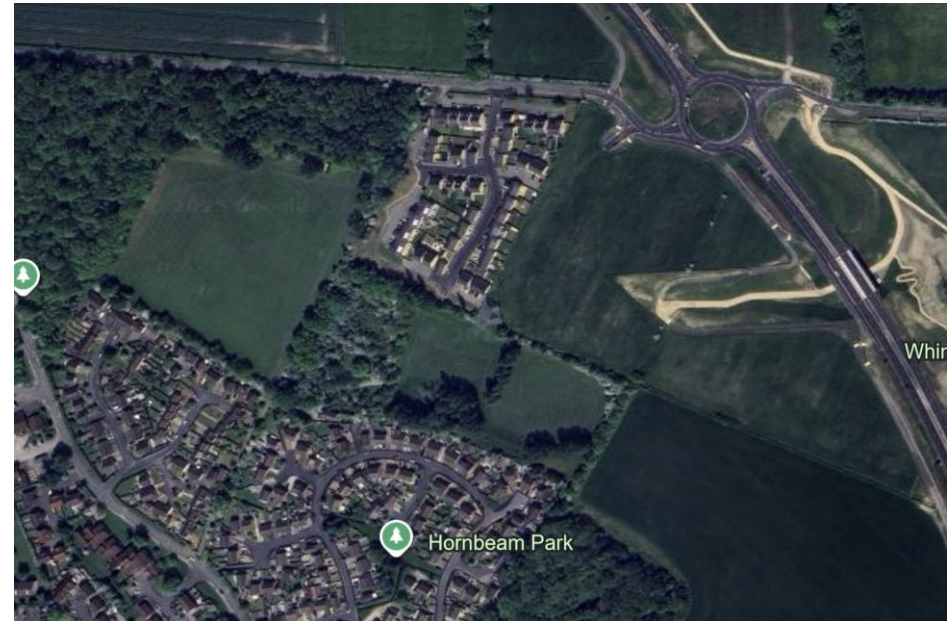
Survivalist communities

Gated communities

HFT village community for 41 people closed in 2016



Developed to provide private housing completed 2021



Registering the right support 2017

CQC's policy on registration and variations to registration for providers supporting people with a learning disability and/or autism

A small window is left open to providers if they have 'compelling reasons' to depart from the best practice guidance, but with respect to village, or intentional communities this is firmly closed later in the CQC guidance.

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We do not wish to be overly prescriptive, and it is not our intention to create a 'one size fits all' approach. We will support genuine innovation where providers are able to demonstrate that their model aligns with the national model and is underpinned by evidenced-based best practice.

Right Support, Right Care, Right Culture, 2020 – updated 2022

How CQC regulates providers supporting autistic people and people with a learning disability

Autistic people and people with a learning disability are as entitled to live an ordinary life as any other citizen. We expect health and social care providers to guarantee autistic people and people with a learning disability the choices, dignity, independence and good access to local communities that most people take for granted.

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Valuing People - 2001

A New Strategy for Learning Disability for the 21st Century

4 key principles - Rights, Independence, Choice and Inclusion

Valuing People, 2001

Choice must include;

Supported living

Small scale ordinary housing

Village and intentional communities

Valuing People, 2001

Choice must include;

Supported living
Small scale ordinary housing
Village and intentional communities

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Registering the right support, 2017

New services should not be developed as part of a campus style development or
congregate setting

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)”

Building the right home 2016*

Guidance for commissioners of health and care services for children, young people and adults with learning disabilities and/or autism who display **behaviour that challenges**

Supplementary guidance to Building the Right Support (National Plan) both are designed to inform all health and social care commissioners with respect to the provision of social care services specifically for people with a learning disability and / or autism who display challenging behaviour.

Like the National Plan it states in a footnote at the beginning that people with LD and / or autism and behaviour that challenges will 'hereafter be people with a learning disability and/or autism'

Repeats the statement that equates housing of more than 6 people with 'institutional', 'campus' and 'congregate'.

Building the right support 2015 - National plan*

A national plan to develop community services and close inpatient facilities for people with a learning disability and/or autism who display **behaviour that challenges**, including those with a mental health condition

Sets out the range of support that should be put in place for people with LD and challenging behaviour with the aim of further reducing the need for in-patient hospital facilities

No mention of the larger general group of people with LD and / or Autism who do not present with challenging behaviour

In fact, the document introduces confusion by stating in a footnote at the beginning that people with LD and / or autism and behaviour that challenges will 'hereafter be people with a learning disability and/or autism'

Building the right home 2016*

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Valuing People now 2009

Valuing People 2001*



Registering the right support 2017

CQC's policy on registration and variations to registration for providers supporting people with a learning disability and/or autism

Registration of new residential care provision

Page 12

New services should not be developed as part of a campus ^c style development or congregate setting ^d.

c Campuses: group homes clustered together on the same site and usually sharing staff and some facilities. Staff are available 24 hours a day.

d 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.