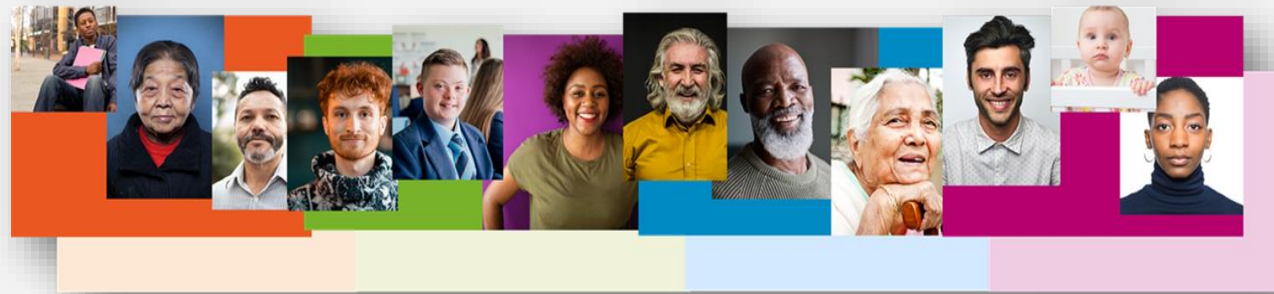


# Driving improvement in services for people with a learning disability and autistic people



**Jeanette Blackburn, Policy Manager, Care Quality Commission**

*Thursday, 20 April 2023*

# Our role and purpose

The Care Quality Commission is the independent regulator of health and adult social care in England.

We make sure health and social care services provide people with safe, effective, compassionate, high-quality care and we encourage care services to improve.



# Unique oversight of care



**Is it safe?**  
**Is it effective?**  
**Is it caring?**  
**Is it responsive?**  
**Is it well-led?**

23,982 adult social care services  
136 NHS acute hospital trusts  
385 independent acute hospitals  
141 NHS or independent community health providers or locations  
10 NHS ambulance trusts  
141 Independent ambulance services  
205 hospices  
49 NHS mental health trusts  
239 independent mental health locations  
11,164 dental practices  
6,331 GP practices  
184 Urgent care and out of hours

# An outrage and a call to action

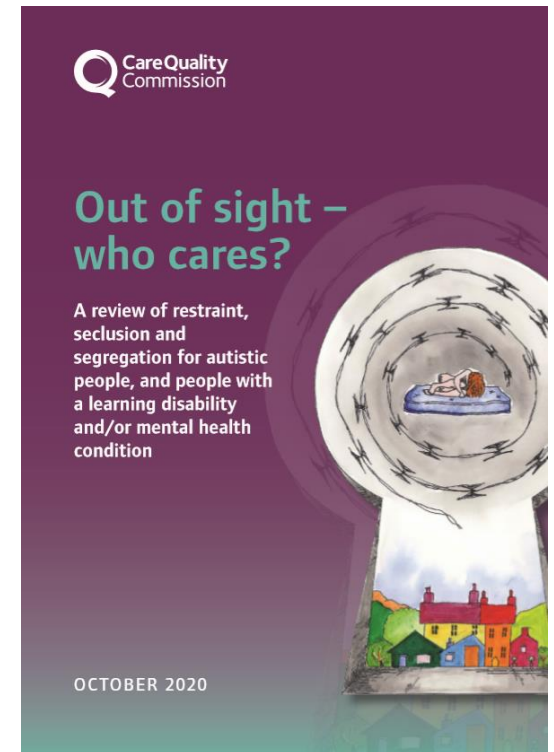
## Wharlton Hall: Professor Glynis Murphy reports, 2019

- independent hospital for people with learning disabilities and autistic people.
- 2019 media exposure of appalling abusive behaviour and restraint long periods of restraint. Independent review.




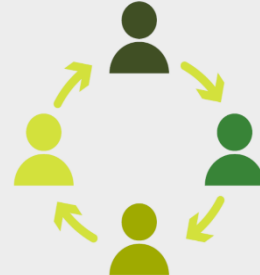




## Out of sight who cares?, 2020

- Independent review in the context of serious concerns about the human rights of a young woman who had been held in seclusion for 22 months.
- Focused on the use of restrictive practices such as restraint, seclusion and segregation.

Exposed serious abuses of people's human rights. Made system wide recommendations, including about how CQC needed to improve regulation of these services.



# Who has an influence on quality of care?

<p><b>Anticipatory impact</b> Changes are made before the inspectors arrive</p>		<p><b>Directive impact</b> Regulators tell providers to do things</p>	
<p><b>Informational impact</b> Published information provokes action</p>		<p><b>Lateral impact</b> Providers work with peers to learn and improve</p>	
<p><b>Organisational impact</b> Organisations make changes beyond those directed</p>		<p><b>Relational impact</b> Ongoing relationships have an impact</p>	
<p><b>Stakeholder impact</b> Stakeholders work with providers to bring about change</p>		<p><b>Systemic impact</b> Aggregated findings provoke wider change</p>	

**The public** – people who use services, families and carers

**Providers** – culture, organisation, workforce

**National and local government** – policy and funding

**Regulators** – register, assess, rate, take action, celebrate

**National partners** – standards and guidance for professionals and staff



# Recognise, respect, respond

Appointed a Director to lead a programme of work, putting people at the front and centre, focusing on their experiences, outcomes and the culture of services.

- I use services that support me in the way I want to live and where I want to live.
- I will not be asked to move to a service that isn't safe
- I won't be expected to continue to live in a service that doesn't meet my needs

This means:

- Only registering the right services
- Having the right tools and methods
- Supporting services to improve and take the right action where they don't
- Working with partners and across systems



# Right Support, right care, right culture

- **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

*Right Support, Right care, Right culture* is....

- ✓ Used across all our regulation
- ✓ Used to assess applications and talked about **before** a service is set up
- ✓ Clear in Statement of Purpose
- ✓ properly understood by planners and commissioners.



# Tools and methods

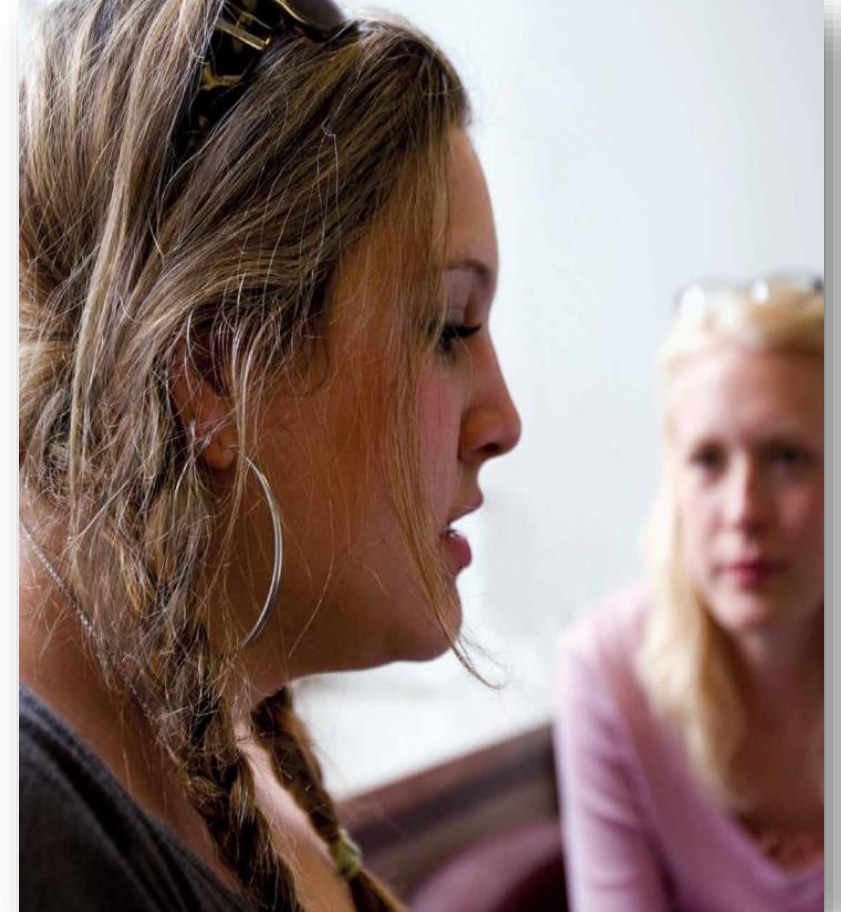
- Registration - new specialist team
  - Pre-application discussions
  - Detailed assessment against RSRCRC
  - Using legal conditions
  - Engage with commissioners, planners etc
- Training – hearts and minds
  - Closed cultures
  - Language
  - Learning from people's lived experience
  - Focusing on quality of life, people's experience outcomes





# Focus on people

- Increased time observing what happens in the service and how people are supported
- Speaking to more people and their families or carers and more people who have contact with the service
- Increased range of tools and guidance: **Quality of Life Tool, Talking Mats**
- Cross-sector inspection teams and experts by experience
- Unannounced and out of hours
- Always reviewing restrictive practices
- Looking for signs and risks of closed cultures.
- Reporting on people's experiences of the service
- Supporting improvement and taking enforcement action.



# Impact

- New condition for non-specialist services – greater scrutiny of applications; screening out pre-application
- Increased levels of confidence amongst CQC staff when doing assessments – increased awareness of risks, good practice, able to challenge practice
- More time to focus on people's experiences and gain better understanding and insight into the culture of the service
- Better evidence. Refused more applications / issued more notices to refuse
- Increased confidence in our inspections and judgements. Getting more feedback from people.
- Reports reflect people's experiences and outcomes
- Increased engagement with commissioners – greater awareness of RSRCRC and use in commissioning activity and quality monitoring



# Supported Living Improvement Coalition

- Convening role to bring partners together with a shared focus and aim on a system wide issue: variable quality in supported living services.
- Brought together all relevant agencies to listen, share and learn from each other.
- People with lived experience co-produced the work.
- Met several times as a main group throughout the year to identify the key areas of focus.
- Smaller learning and action groups to work on key issues and actions.



# Areas of focus

- What is supported living and what does good supported living look like
- Citizenship and community; protecting people's human rights and ensuring they are respected as equals with real ambition for their lives
- Ensuring and protecting people's rights to person-centred choice and control
- Good partnership working to create a supportive system
- Regulation



# Impact

- Understanding people's lived experiences and hearing people's stories – what matters, what makes a difference. Making it personal.
- Better understanding of what good looks like and how to achieve it; what this means from different perspectives.
- Ongoing platform to share examples of good practice and ways to overcome issues and challenges.
- Better understanding of roles and responsibilities.
- Created lasting alliances and networks with strong relationships, with people invested in finding solutions, overcoming barriers and making improvements – at individual person, service, agency and system levels.





# Moving forward




- We have concluded our convening and organising role; Coalition has become a lasting Supported Living Improvement Network.
- Two of the three main groups, Housing Matters (focuses on where people live, their homes and their community) and Supporting People Well have grown out of the Coalition and will be led and taken forward independently from CQC.
- Informed content of CQC's new single assessment framework and how we register, assess and report on supported living services.
- Increased our insight of the operating environment supported living services and impact of various agencies - informed our assessment model for health and social care systems.

# Who I am Matters - What have we found?

## Who I am Matters (Nov 2022)

We found pockets of good practice but:

- Nearly 6 years after Oliver McGowan's death, change and improvement for people with a learning disability and autistic people is still too slow.
- People are still not being given the quality of care and treatment they have a right to expect.
- People are not being fully involved in their care and treatment. There is not enough listening, communication and involvement.




Hospital

### Who I am matters

Experiences of being in hospital for people with a learning disability and autistic people

November 2022



# How You See Me Matters – What have we found

## How you see me matters: perspectives of autistic people using primary care services (Mar 2023)

We were able to identify three groups of contributing factors to the quality of primary care for autistic people:

- **Person factors** – fear and anxiety, sensory differences, stress-related factors, person-centred approach
- **Provider factors** – understanding and awareness of autism, communication, the physical environment, time factors
- **System factors** – diagnosing autism and providing support



### How you see me matters: perspectives of autistic people using primary care services

How you see me matters: perspectives of autistic people using primary care services

#### Introduction

CQC is committed to encouraging health and care services to provide the same good quality of care for everybody. To do this, it's vital to listen to what people say about services and learn from their experiences.

This is particularly important for us as we develop our new methods and approach to regulating. Knowing what people feel about their care services enables us to focus on the right areas and ask the right questions when we assess the quality of care.

One of our strategic ambitions is on tackling inequalities in care. This is specifically pushing for equality of access, experiences and outcomes from health and social care services.

# What's next?

Three priority areas:

1. Health and well-being - *how can CQC, with its regulation of both health and care services play a part in improving health and well being?*
2. Community support - *how can CQC lever the development of high-quality community support?*
3. Reducing restrictive practices - *how can CQC do more to reduce the use of restrictive practice?*

Beyond assessment of individual services, to how well the system operates as a whole:

- How do local areas understand need, demand, supply, quality, capacity and capability?
- How well do partners work strategically and to address shared objectives?





## Provider Bulletin

<https://www.cqc.org.uk/news/newsletters-alerts/email-newsletters-cqc> or Search: CQC bulletin



## Social

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