THE ROLE OF THE CQC IN REGULATION AND IMPLEMENTATION

Development of the current approach to learning disability services

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INTRODUCTION

- Consider the role of the CQC in regulation and in policy implementation
- Consider the role of human rights in policy development and implementation
- Consider the development of the policy of developing smaller scale services in community settings
- Consider the research evidence in relation to outcomes for people with learning disabilities in different types of service settings

ROLE OF THE CQC

- “We make sure health and social care services provide people with safe, effective, compassionate, high-quality care and we encourage care services to improve.”
- The CQC registers, inspects and monitors services and has a safeguarding function
- The CQC takes enforcement action if standards not met
- It also reports publicly on the state of care services.
- Registration: CQC registers health and adult social care services that meet the ‘fundamental standards’ of quality and safety.
- Registration: “Before a care provider can carry out any of the activities that we regulate, they must register with us and satisfy us that they will be able to meet a number of legal requirements.”
- Registration: CQC will look to see if the conditions are in place that will make it likely that the standards will be met.

THE CQC APPROACH

- CQC is an arms length body, accountable to DHSC
- Does not determine government policy, responsible for following and implementing it
- RSRCRC (2022) has status of statutory guidance – should be followed unless there is a compelling reason not to. Applications to register should show:
  - There is a clear need for the service and it has been agreed by commissioners
  - The size, setting and design of the service meet people's expectations and align with current best practice
  - People have access to the community
  - The model of care, policies and procedures are in line with current best practice
- Allows for shared lives schemes but the provider must still meet standards and demonstrate that they can achieve the above

THE CQC APPROACH

- Applications to register a new service are considered in the light of current policy, which has developed from previous policy, human rights values and law, and from available research evidence
- Small services are unlikely to be approved if they have not been agreed by local commissioners, are poorly designed (e.g., is there enough space?), have poor access to the community and cannot demonstrate that they are truly person-centred (e.g., will not be able to provide for individual wishes and needs)
- Larger services have been approved if they can demonstrate a local need, are well designed and located (e.g., good personal space, easy access to a range of community activities) and that they will be truly person-centred.

Article 19 of the UN Convention on the Rights of People with Disabilities (signed by UK in 2007) states:

‘States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

- Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community

- Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.’

HUMAN RIGHTS – LAW AND POLICY

- Human Rights Act 1998
- Disability Discrimination Act 2009
- Equality Act 2010
- Mental Capacity Act 2005
- Death by Indifference (Mencap 2007)
- Healthcare for All (2008)
- ’A life like any other’ (JCHR 2008)
- ‘The detention of young people with learning disabilities and/or autism’ (JCHR 2019)

TIMELINE OF DEVELOPMENT OF GOVERNMENT POLICY

- 1920s: people lived in asylums/colonies (if they weren't with their family), and there was a program to build more
- 1940/50s: more involvement of parents and the beginning of a focus on education. And the first Camphill community in 1940 in Aberdeen.
- 1948: NHS was founded and asylums/colonies became hospitals. People became patients.
- 1951 NCCL highlighted the lack of civil liberties for people with learning disabilities,
- 1962 Ministry of Health outlined plans to develop hostels instead of hospitals
- 1960/70s Hospital scandals (Ely, Normansfield, South Ockendon)
- 1971 White Paper "Better Services for the Mentally Handicapped" focus on moving care into the community and developing homes for people to live in.
- 1980 "An Ordinary Life" (Kings Fund) published

GOVERNMENT POLICY

- 2001 "Valuing People" published – emphasized consulting with parents. A focus on the principles of rights, inclusion, independence and choice for all people with learning disabilities. Included village communities as an option
- 2007 UN Convention on the Rights of People with Disabilities (UNCRPD) signed by UK
- 2009 "Valuing People Now" published – reiterated principles of Valuing People. Village communities not mentioned. States "possibilities include people with learning disabilities being supported to live in their own home as owners or tenants; being supported to share with a group of friends; or living in residential care."
- 2011 Winterbourne View scandal
- 2012 Transforming Care: A national response to Winterbourne View Hospital
- 2015 "Building the Right Support" published
- 2017 "Registering the Right Support" published
- 2019 Whorlton Hall scandal and review into Atlas Care Homes published
- 2022 "Right support, right care, right culture" published

GOVERNMENT POLICY

- Clear direction of travel over time
- Awareness of the difficulties of providing good support and care in large scale isolated settings, awareness of the risk of abuse and of institutional practices
  - Rigidity of routine
  - Block treatment
  - Social distance
  - Depersonalisation
- Government policy aimed to provide services where people lived and were supported in the same places as everyone else
  - Participation in activities alongside other people in the local community
  - Learning skills to enhance as much independence as possible
  - Human rights
  - Making choices as much as possible

DEFINITIONS OF SERVICE SETTINGS

There is a range of service settings:

- Intentional community: services operated by independent sector organisation comprising houses and some shared facilities on one or more sites and based on philosophical or religious belief (Valuing People). An intentional community is a group of people who have chosen to live together or share resources on the basis of common values *(FIC - retrieved March 2025)*. Can be urban or rural
- Village community: service operated by independent sector organisation comprising houses clustered on one site together with some shared central facilities. (Sometimes used interchangeably with intentional community, although may not include the shared lives component)
- Campus: Often old hospital sites, where people moved out of the hospital ward into smaller living accommodation,
- Congregate: A setting where a large number of unrelated people live together. Can be one building (large group home) or a cluster of houses on the same site/same street. Has been defined as 10 or more (unrelated) people living together
- Cluster housing – a relatively small number of houses on the same site or in the same street
- Ordinary (dispersed) housing: small scale, similar to other houses in the area, can be urban or rural. Small scale can be 1-6 (or more)

RESEARCH

- Large number of studies and papers. Viewed from a social science perspective there should be a good sample, good data, good analysis and reasonable conclusions based on the findings. This is not the case for many papers.
- Kozma et al, 2009. Different types of community setting. Meta-analysis compared residential arrangements for adults with learning disabilities and showed that community-based services were better than congregate settings. Dispersed better than cluster. Participants had a range of needs. Intentional communities had some some advantages
- Emerson 2004. People in cluster housing more likely to live in larger settings, be supported by fewer staff, have greater inconsistencies in living arrangements, be exposed to more restrictive practices, lead more sedentary lives, be underweight and participate in fewer, and more restricted range of, activities than in dispersed housing

RESEARCH

- McCarron et al 2018. Meta analysis. People who moved from institution to dispersed community settings and to another congregate setting (clustered housing) both showed increases in measured QOL. Greater increase for those who moved to dispersed housing.
- Emerson et al 1999. There are small numbers of intentional communities, which may provide some explanation as to why they are often not present in studies. When they are, the research show some benefits, although they often support people with less complex needs.
- Cumella & Lyons 2018. Reviewed evidence from studies that included intentional communities. Dispersed housing and intentional communities showed better outcomes than congregate housing. Intentional communities had benefits in meaningful employment, opportunities for friendship and long-term relationships with co-workers/assistants.

RESEARCH

Hatton et al (2022). '200 Lives'.

Showed a complex picture. Looked at residential care (5-12 people) and supported living (1-7).

Findings: similar outcomes on many domains.

Also:

- Residential care – more likely to provide for specialist needs and have greater support needs, have areas in the home where residents weren't allowed to go, have block treatment. More likely to not get on with someone they lived with (probably due to larger setting, and more people in supported living were single occupancy). People in residential care were more likely to report travelling in a minibus with people with learning disabilities, compared to people in supported living.
- Supported living - more likely to live close to family and friends, more likely to have had a choice about who they lived with. More likely to get support from staff at home when they want it, have a key to the front door. More likely that other people did not have access to their bedrooms without asking. They were more likely to like their neighbours.
- Both settings reported feeling safe at home, both had experienced verbal abuse from others.

RESEARCH: WHAT DOES IT TELL US?

- Research suggests there are many positive consequences for people who live in small-scale, more dispersed services. And some negative e.g., in terms of loneliness for people living alone
- Research also suggests that intentional communities can offer benefits to those who live in them. (There is an important question as to whether they would be beneficial for people with more complex needs)
- Based on current research evidence, it seems that large scale and segregated services produce worse outcomes in comparison to smaller scale community services.
- In addition to size, there are a number of factors that are implicated in outcomes, including
  - Opportunities to develop skills, make choices and be person-centred
  - Staff training and skills
  - Management and governance

INSPECTION AND MONITORING: CONCERNS ABOUT ABUSE

- After Whorlton Hall, the CQC developed methods of assessing “closed cultures”, where it is recognized that abusive practices can develop
- Closed cultures are more likely to develop in services where:
  - people are removed from their communities
  - people stay for months or years at a time
  - there is weak leadership
  - staff lack the right skills, training or experience to support people
  - there is a lack of positive and open engagement between staff and people using services and their families
- Indicators of a closed culture
  - People may experience poor care, including unlawful restrictions
  - Weak leadership and management
  - Poor skills, training and supervision of staff providing care
  - Lack of external oversight

MONITORING AND INSPECTION:
ASKING ABOUT QUALITY OF LIFE

- CQC developed Quality of Life Tool to address recommendations in relation to Whorlton Hall and Restrictive Practices review.
- Asks
  - Is there a planned programme for each person that focuses on their quality of life? (includes physical environment, activities, choice, staff support, commitment to reducing restrictive practices)
  - Are the planned programmes relevant to each person's needs? (plans for future as well as current needs and aspirations, are they monitored and reviewed)
  - Is each person's support programme being delivered at the right level of intensity? (is it intensive enough to enable the person to learn skills, do staff know how to deliver the detail)
  - Is there a balance of the programmes and support plans for each individual with coherence across settings and over time? (working across settings, providing for continuity)

SUMMARY

- The CQC undertakes its regulatory function in the context of government policy which is based on human rights (including legal requirements) and on research evidence.
- The existing body of research generally shows better outcomes in smaller dispersed settings than in large and segregated services.
- There is a need for awareness and scrutiny of risk factors in services in order to protect people with learning disabilities from abuse
- The CQC accepts shared lives provision
- Shared lives providers have to meet the regulatory standards set by the CQC