



NATIONAL OPINION PAPER

Care Cannot Be A Commodity

A frontline nurse's case for dignity, accountability and reform in learning-disability care

Response to the public intervention by Baroness Louise Casey and ITV News Investigations Editor Daniel Hewitt

THE CENTRAL ARGUMENT

Britain should not pre-empt the Casey Commission's final recommendations. But neither should it suspend action while people with learning disabilities continue to experience fragmented healthcare, weak accountability and care markets in which public money can be extracted without transparent evidence of public value.

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1 We should wait for the report but not for permission to care better

Baroness Louise Casey's decision to let cameras observe part of the Commission's public engagement is significant. ITV News reported that it was the first time cameras had been allowed to film the Commission's work. What the public saw was not an abstract policy debate. It was people with learning disabilities and their families describing what happens when a system does not see them, hear them or organise itself around their lives.

The instinct to say, "Wait for the Commission's report," is understandable. The Commission must be allowed to gather evidence, test competing proposals and reach independent conclusions. I do not claim to speak for the Commission, nor do I presume its recommendations.

But waiting for the report cannot mean withholding professional judgment. Frontline nurses, care workers, people with learning disabilities and families already know where many of the daily fractures lie. We see what happens when information does not travel with a person, when reasonable adjustments are treated as optional, when a familiar carer is excluded from a hospital ward, when staffing instability breaks continuity, and when responsibility is passed between health services, commissioners, providers and regulators.

This intervention is therefore neither a verdict nor a substitute for the Commission. It is an invitation to act on what is already visible while remaining open to what the Commission will establish.

2 The test of the system is the life experienced by the person

Learning-disability care is too often discussed through organisational labels: NHS, local authority, private provider, voluntary sector, supported living, residential care. Those labels matter for governance, but they are not how a person experiences care. A person experiences whether someone listens, whether pain is recognised, whether communication needs are understood, whether medication is reviewed, whether family knowledge is respected, whether staff return tomorrow, and whether home feels safe.

Baroness Casey's public comments described people with learning disabilities as overlooked and the system as insufficiently able to treat and look after them. Her concern about people dying much younger than the wider population must be treated as a national equality issue, not a specialist-service footnote.

A civilised care system cannot call itself successful merely because a placement remains open or a rota is technically filled. Its outcomes must include health, safety, autonomy, relationships, communication, participation and a life of meaning.

3 What the present crisis reveals

1. Fragmentation has become normalised

People with learning disabilities frequently cross boundaries between primary care, acute hospitals, community learning-disability teams, mental-health services, social care and housing. Every boundary creates a risk that information, ownership or urgency will be lost. Families become unpaid system navigators. The individual can be left carrying the consequences of institutional confusion.

2. Reasonable adjustment is still treated as an exception

Communication passports, longer appointments, quiet environments, accessible information, diagnostic curiosity and the presence of a trusted supporter are not courtesies. They are practical safeguards. When they are absent, distress can be misread as behaviour, symptoms can be missed and consent can become performative rather than meaningful.

3. The workforce is asked to carry risk without enough stability

Good care depends on relationships. High turnover, thin staffing, weak supervision and inconsistent specialist training make those relationships fragile. Mandatory learning-disability and autism training is welcome, but training alone cannot compensate for unsafe workload, poor leadership or a culture in which staff fear speaking up.

4. Regulation can become episodic while harm is continuous

The Care Quality Commission has acknowledged shortcomings in the inspection of learning-disability services following ITV News reporting. Inspection remains essential, but periodic inspection cannot be the only line of defence. Commissioners, provider boards and system leaders must monitor warning signs continuously: medication patterns, injuries, safeguarding alerts, staff churn, agency dependence, complaints, restrictive practice and failed health appointments.

4 Profit provision and the public interest

Baroness Casey's use of the word “profiteering” deserves a careful response. Independent provision is deeply embedded in adult social care. Many responsible providers reinvest, innovate and deliver compassionate support. It would be inaccurate and destabilising to imply that every private provider is exploitative, and abrupt withdrawal could itself place vulnerable people at risk.

But it is equally wrong to treat the source and destination of public money as a private matter. A reasonable operating surplus that sustains a service, improves pay, maintains buildings, trains staff and absorbs risk is not the same as extractive profit secured through opaque group structures, excessive debt, related-party charges, weak staffing or deteriorating quality.

The question is not simply whether profit exists. The question is whether financial return is demonstrably compatible with care quality, workforce stability, resilience and value for the taxpayer. Publicly funded care must carry a public-interest obligation.

A FAIR NATIONAL PRINCIPLE

No organisation should be permitted to distribute exceptional returns from publicly funded learning-disability care while failing transparent tests on safety, staffing, continuity, workforce pay, complaints, safeguarding and measurable quality of life.

5 A reform compact for learning disability care

1. A named accountable leader for every person's care

Every individual with complex needs should have a clearly identified professional responsible for coordinating health and care across organisational boundaries, with escalation rights when services fail to respond.

2. A statutory right to supported communication and trusted involvement

Reasonable adjustments, accessible communication and the involvement of a chosen family member, advocate or familiar carer should be planned in advance and departed from only for a recorded, lawful and clinically justified reason.

3. A national learning-disability care passport that works across settings

With consent and proper information governance, essential communication, health, medication, sensory and support information should be available wherever the person receives care.

4. Commission for outcomes, not occupied beds or completed hours

Contracts should measure continuity, health access, community participation, safeguarding, communication, relationships and personal goals. Payment and renewal decisions should reflect these outcomes.

5. Full financial transparency for publicly funded providers

Providers above an appropriate threshold should publish group structures, debt, related-party transactions, executive remuneration, property arrangements, profit margins, tax jurisdiction and the proportion of income reinvested in frontline care.

6. A public-interest test for ownership and major transactions

Changes of control, highly leveraged acquisitions and sale-and-leaseback arrangements should be assessed for their effect on service continuity, quality and taxpayer exposure.

7. Continuous assurance, not inspection by snapshot

Regulators and commissioners should use live risk indicators, unannounced visits where justified, direct testimony from people and families, and rapid multi-agency escalation. Enforcement outcomes should be visible and timely.

8. Professionalise and retain the workforce

Reform must include fair pay, stable contracts, protected supervision, specialist career pathways, competency assurance and leadership development. Training must be reinforced through observation, coaching and accountability in practice.

9. Make mortality and avoidable harm a board-level duty

NHS bodies, councils and provider boards should review patterns of delayed diagnosis, failed reasonable adjustments, medication risk, restrictive practice, safeguarding and premature death, with named actions and published learning.

10. Co-produce reform and its measures

People with learning disabilities and families must help design services, inspections, outcome measures and complaints processes - and must be paid fairly for that expertise.

6 What should happen before the Commission reports

Actor	Immediate action	Evidence of progress
Government	Publish interim safeguards on provider transparency, continuity risk and family involvement.	A dated implementation plan and public reporting standard.
NHS and integrated care systems	Audit acute pathways, reasonable adjustments and specialist learning-disability nursing coverage.	Board-reviewed gaps, owners and deadlines.
Local authorities and commissioners	Risk-rank services using quality, workforce and financial indicators; speak directly with people and families.	Documented interventions and contract decisions.
CQC	Set out how inspection frequency, intelligence and enforcement will improve for learning-disability services.	Published milestones and enforcement data.
Provider boards	Review staffing, agency use, complaints, safeguarding, restrictive practice, medication and reinvestment.	A public quality and stewardship statement.

7 The standard must be dignity with proof

The Casey Commission has an opportunity to reshape adult social care. Its work should be heard in full. Yet the moral and operational test before us is already plain: people with learning disabilities must not be treated as burdens, units of funding or captive sources of return.

As a frontline nurse, I have learned that quality is revealed in small, repeated acts: noticing a change, listening beyond speech, explaining again, inviting the person into the decision, calling the family, challenging an assumption and refusing to let a handover become an abandonment of responsibility. Reform must make those acts normal, supported and accountable.

As the founder and Chief Executive of Rhymacare, I also accept that future providers must be prepared to evidence their values. Compassion without governance is not enough. Growth without stewardship is not success. An organisation seeking to be entrusted with a person's life must be able to show, in its staffing, finances, leadership and outcomes, that dignity comes first.

We should give Baroness Casey the space to complete her work. But we should not use that process as an excuse for passivity. The country can listen and act at the same time. People with learning disabilities have waited long enough to be seen, heard and served as equal citizens.

About the author

Mary Ajewole is a frontline nurse and the founder and Chief Executive of Rhymacare, a specialist community healthcare company in development. Rhymacare has not yet commenced regulated care services. She writes here in a personal professional capacity, informed by frontline practice and organisational leadership. This paper does not claim to represent the Casey Commission or pre-empt its findings.

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Selected sources

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Publication note

This paper is intended for public-policy discussion and media circulation. References to reported allegations or institutional shortcomings should be read in the context of the cited sources. Rhymacare supports independent scrutiny, due process and reform grounded in the voices and rights of people with learning disabilities.

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