Ms. Liz Kimmins
Chairperson
NI Assembly Health Committee
Room 410, Parliament Buildings
Ballymiscaw, Stormont
Belfast, BT4 3XX

New Script for Mental Health
c/o PPR
Community House
City Link Business Park
6A Albert Street
Belfast BT12 4HQ

26 April 2024

Dear Chairperson,

We are writing to the Health Committee to raise our grave concerns regarding the failures in regulatory oversight of Community Mental Health Services and to ask you to urgently scrutinise these matters. Our concerns relate both to the specific case of Gareth Waterworth, in which egregious human rights breaches continue to occur, as well as to the wider issue of RQIA's ongoing failure to regulate these services. While recognising that the Committee does not have a role in relation to individual cases, we draw your attention to Gareth Waterworth's case, as it illuminates the wider lack of regulation and accountability and should be considered in that context.

RQIA failures in Gareth Waterworth's case

The background to Gareth Waterworth's case is as follows (more information can be accessed via the links at the end of this correspondence).

Gareth is 36-year-old man who suffered catastrophic brain injuries in 2007 when he was permitted to leave Knockbracken Park, while an inpatient in its Belfast Health and Social Care Trust run mental health unit.

Following the family's move in 2015 from the Belfast Trust to the Northern Trust (NHSCT) catchment area, a 24-hour care package for Gareth was agreed by the NHSCT, only to be subsequently denied to him, with no credible explanation or alternative package offered. Since 2016 Gareth has been cared for entirely by his family, first by his mother Roberta who passed away due to illness in 2020 and then by his uncle, Mr. Paul Herbert. Mr. Herbert had supported his late sister in Gareth's care during her progressive illness. Mrs. Waterworth's only other child, her daughter Rachel, had tragically passed away in 2013. Gareth's grandfather passed away in 2019, leaving Mr. Herbert as Gareth's sole surviving relative.

Gareth is currently in 24-hour care in a care home in Co. Antrim. This short-term arrangement was put in place following a crisis that arose due to lack of support for both Gareth and Mr. Waterworth, a crisis that led to an emergency intervention by Antrim Area Hospital.

Judicial Review May 2023

In May 2023, a Judicial Review (JR) which Mr. Herbert was forced to take on behalf of Gareth due to failures in care by the NHSCT, exposed the failure of the RQIA to regulate Community Mental Health Services in their entirety for over 14 years.

In response to that JR, the RQIA conceded its failure to regulate Community Mental Health services and accepted that it does have regulatory roles in relation to Community Mental Health Services. In an FAQ issued by the RQIA, dated 20 June 2023, it set out the legislation underpinning these roles, as follows. The Health and Personal Social Servies (Quality, Improvement and Regulation) (NI) Order 2003 gives the RQIA the functions of reviewing, investigating, inspecting, and reporting on the management, provision, quality, and availability of services which HSC Trusts provide. Secondly, under the Mental Health (NI) Order 1986, RQIA has the authority and duty to make inquiry into any case, where it appears to RQIA that there may be ill-treatment or deficiency in care and treatment of a person living with a 'mental disorder' (sic).

Developments since May 2023

The High Court directed RQIA to inquire into Gareth's treatment by the NHSCT. **Yet in April 2024, almost one year since that JR ruling, Gareth Waterworth still does not have a care package.** Due to his caring responsibilities, Mr. Herbert has been unable to work since 2016. This has created significant financial pressure, added to the multiple traumas Mr. Herbert has experienced and the physical and mental toll of being a full-time carer with no respite. The RQIA has singularly failed to complete any investigation into the matter.

The NHSCT's ongoing treatment of Gareth and his uncle, Paul Herbert is nothing short of scandalous. A catalogue of documented, serious failures exits, which can be shared with the Committee. Most recently, three staff from the NHSCT's Community Mental Health Team attempted to assess Gareth, without informing Mr. Herbert and without an advocate present, causing great distress to Gareth and Mr. Herbert. They refused to tell Mr. Herbert why the needed to

assess Gareth. This was a clear breach of the Regional Care Pathway for Mental Health.

Gareth has brain damage and has previously been assessed as lacking the capacity to make decisions about his care and support. While we recognise the important principle of making the assumption of capacity in relation to a specific decision such as health and social care provision, there is documented evidence (including from Gareth's GP and the NI Public Services Ombudsman) that Gareth is not able to understand or convey his preferences and needs the support of his uncle and/or advocate to engage with the NHSCT. The Trust continues to insist on corresponding with Gareth, despite his lack of capacity.

In a letter to Paul Herbert from Mr. Peter May, Permanent Secretary, Department of Health on 22 January 2024, it was suggested he engage directly with the NHSCT, with no reference to the High Court requirement that the RQIA investigate the matter.

Section 34 of the Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003, sets out a duty of quality which requires each Trust to put in place and keep in place arrangements for the purpose of monitoring and improving the quality of a) the health and social care which it provides to individuals and b) the environment in which it provides that care.

Section 15 (subsections 1-3) of the same 2003 Order sets out the powers exercisable by the Department of Health if the RQIA fails to discharge its functions, including directing the RQIA to discharge its functions within a specified time period, discharging the functions itself or making arrangements for other any other persons to discharge those functions on its behalf.

Through their failure to provide appropriate and adequate care to Gareth Waterworth, the NHSCT are causing harm to both Gareth Waterworth and his uncle Mr. Paul Herbert. The RQIA, despite a High Court ruling in May 2023, has failed to investigate deficiencies in Gareth's care and treatment as per their legal duty. The Department of Health is failing to hold both the NHSCT and the RQIA to account for not performing their legal duties.

Aside from the serious harm being caused to Gareth Waterworth and his family by the ongoing failures of the NHSCT, the RQIA and the Department of Health, this case illuminates the wider issues relating to lack of regulation of Community Mental Health Services.

Ongoing failure by RQIA to regulate Community Mental Health Services

In a Freedom of Information response to PPR, dated 15 March 2024 (see attached), the RQIA confirmed that since May 2023 when the Judicial Review found that RQIA had failed to regulate Community Mental Health services for 14 years, **it has not undertaken any reviews or inspections of Community Mental Health Services provided by HSC Trusts.**

The RQIA has stated that inspections of Community Mental Health Services are in response to 'intelligence' received by services, stakeholders, and requests from the Department of Health. Since May 2023, a total of ten concerns were raised with the RQIA. None of these was raised by service users and only two by a relative or friend. It is entirely unrealistic and wrong to expect that service users, their relatives or friends will raise concerns, given the lack of knowledge, the vulnerability, and the fears of victimisation of service users.

The RQIA has indicated that it is developing a protocol, due to be published at the end of June 2024, to enable it to '*examine issues of concern about possible*

detriment in care and treatment for patients living in the community, in their own home or with family'. Aside from the concerningly slow pace of this work, it is critical that there is external scrutiny of any such protocol being developed.

Based on Freedom of Information responses received by PPR from all five Health Trusts, approximately 42,000 people accessed Community Mental Health services in 2023. These people are accessing a wide range of mental health services in the community, including community mental health for adults and for older people, forensics, eating disorder, addictions, and personality disorder, all of which are effectively unregulated.

All the matters above were previously raised with both the Minister for Health and the Health Committee by Mr. Paul Herbert and by Mrs. Mary Gould, a mother who lost her 21-year-old son Conall due to failures in care by the NHSCT.

Failure by RQIA to establish mechanisms for input by service users.

A document issued by the RQIA in January 2009, entitled 'Changes in the delivery of Mental Health & Learning Disability functions in Northern Ireland - Information for service users, their carers, and providers of mental health and learning disability services', contained the following information:

'To ensure a clear user and carer voice, two external reference groups will be established that will include service users, carers and advocates representing the respective interests of mental health and learning disability. These will provide a platform for users and carers to play an active part in the work of RQIA, from policymaking to providing practical advice on matters relating to inspections and reviews.'

However, in a Freedom of Information response from the RQIA to PPR, dated 16 January 2024 (available on request) the RQIA confirmed that such groups were never established.

The RQIA's response referenced ongoing work to develop an Inspection Support Volunteer Initiative, to replace Lay Assessors. These volunteers will have a role during inspections and will not provide a mechanism for services users and carers to influence overall policy and practice. Furthermore, if no inspections of Community Mental Health Services are taking place, as continues to be the case, then they can have no role.

Summary

The matters documented above are extremely serious. Despite a High Court ruling, Community Mental Health Services, accessed by approximately 42,000 people, continue to effectively be unregulated, as RQIA has not conducted any inspections or reviews of these services in the past year. It is entirely unacceptable for service users and their families to be expected to carry responsibility for triggering any intervention by the RQIA. The appalling treatment by Gareth Waterworth and his family by the NHSCT, and the absolute failure of the RQIA to investigate that treatment, must be a matter of utmost concern for the Health Committee. The failure of the Department of Health in turn to implement its powers in this respect is also of the utmost concern.

Recent media coverage of NHS England figures, which revealed that more than 15,000 people had died in one year while in the care of Community Mental Health Teams, underscores the vulnerability of this population and the imperative of ensuring that services meet the required standards and that the rights of service users are fully protected at all times.

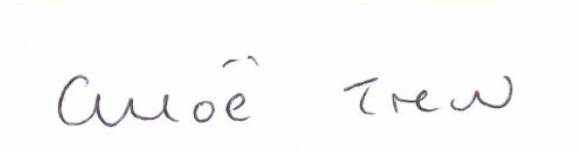
We are asking the Health Committee to urgently scrutinise the matters documented above, specifically the following:

1. The failure of NHSCT in its duty of quality under s34 of the Order in relation to Mr Waterworth
2. The failure of RQIA to investigate Mr Waterworth's specific case.
3. The failure of the RQIA to monitor/inspect community mental health services after the judgment.
4. The failure of the DOH to implement its powers under Schedule 1 s 15 The Health and Personal Social Services (Quality, Improvement and Regulation) (Northern Ireland) Order 2003

We can provide further documentation as required and are more than happy to provide oral evidence should that be required. We have included links to several media pieces on Gareth Waterworth's case.

Finally, please note that in the interests of transparency and accountability, we will be making this letter available publicly.

Yours sincerely



Chloë Trew

Director, Participation and the Practice of Rights on behalf of the New Script campaign.

Links to Media Coverage of Gareth Waterworth's Case

https://www.bbc.co.uk/news/uk-northern-ireland-67554440

https://www.nlb.ie/investigations/FOI/2023-11-does-my-face-look-bovvered-department-of-health-s-attempt-to-ignore-and-minimise-rqia-judgement

https://www.belfasttelegraph.co.uk/news/courts/co-antrim-carer-wins-legal-bid-to-challenge-alleged-mental-health-failure/125111499.html

https://www.nlb.ie/video/video-2023-11-paul-herbert-on-bbc-good-morning-ulster-29-11-2023

https://www.nlb.ie/video/video-2023-05-new-script-on-bbc-evening-extra-30-5-2023

https://www.thedetail.tv/articles/calls-for-health-minister-to-look-at-failings-in-vulnerable-man-s-care