***Breaking the Silence: Statement of the North East and North Cumbria Advocacy Network's ongoing concerns relating to Whorlton Hall***

Following the conviction of four former support workers at Whorlton Hall for mistreatment of a person in their care, we, as a regional network of advocacy organisations have done much thinking about what happened, and what needs to change.

The North East and North Cumbria Advocacy Network is a collaboration of advocacy providers working in the region, who provide statutory and non-statutory advocacy. Funded by NHS England and North East and North Cumbria ICS, and facilitated by Inclusion North, we exist to bring together and strengthen the offer of representational advocacy in the region, with a focus on advocates working with learning disabled and/or autistic people.

Since the criminal case has concluded, we've held six Lunchtime Learning sessions for advocates, to discuss and debate a number of aspects of what went wrong at Whorlton Hall. These build on the content of the Safeguarding Adults Review and have focused on Closed Cultures; Patients; Professionals; the Illusion of Advocacy; Commissioning Containment; and Restraint.

So many people failed those patients detained in Whorlton Hall, including the care provider, the commissioners, the advocacy provision, the safeguarding systems and the regulator. We have no doubt that without drastic change, there will be another Whorlton Hall.

In fact, given the high levels of restraint, seclusion and segregation documented regularly in the Mental Health Services Dataset, within our region, we consider there is a very real risk that people are not sufficiently safe as we write, and you read, this.

As long as high risk settings continue to be commissioned to detain learning disabled and autistic people, there will be a need to provide safeguarding and advocacy to those within them.

We are determined to do what we can to improve things and we seek your cooperation in doing so. As a first step we would welcome a regional conversation between advocacy providers, commissioners and those in the wider system. At the end of this document are a list of questions that we are seeking the answers to.

**We condemn the abuse and mistreatment of learning disabled and autistic people, whether that is found to a criminal standard or not**.

We, as a network, strongly condemn the horrifying abuse that took place at Whorlton Hall in County Durham. It is disheartening to witness how the voice of the people contained within the hospital, was completely absent throughout the entire scrutiny process, including the safeguarding adults review, criminal investigations, and subsequent actions.

## *The illusion of advocacy*

We cannot overlook the disturbing reality that advocacy, which should serve as a vital safeguard for individuals in vulnerable situations, has seemingly become an illusion within the context of Whorlton Hall and similar settings.

The absence of a genuine, independent voice advocating for the rights and well-being of individuals raises serious concerns about the effectiveness of existing advocacy mechanisms, and the oversight of them from commissioners, local and national.

The Whorlton Hall Safeguarding Adults Review highlighted that advocacy was lacking, and contributed to the circumstances that led to the abuse happening. It is crucial that the failings identified drive future improvement of advocacy rapidly in restrictive settings.

One of the key issues highlighted by the investigation was the failure of some independent advocates to protect vulnerable people, by providing them with support and representing their interests.

Advocates were found to be too accepting of the explanations offered by staff for restricted access to individuals, and also for excessive use of restraint. Advocacy was in place for all the people affected, and it failed them. This is not good enough and as a collection of advocacy organisations, we want to own and acknowledge this failure.

We have been considering what needs to change in order that regionally we are assured of the quality of local advocacy provision, and how we as a network can hold each other to account. We are committed as a collective to drive quality locally and nationally, but we also need to acknowledge that some of the factors that impact the quality of advocacy provision can’t be addressed by providers alone. We would welcome a discussion with commissioners and other key stakeholders across the region to tackle issues around funding, procurement and how independent advocacy is valued and empowered by the broader system.

As a network we are committed to addressing the underlying factors that contributed to the illusion of advocacy at Whorlton Hall, but as individual organisations our role is to amplify the voices of the people and families who find themselves in similar circumstances. As such we have a responsibility to highlight the broader issues that need to be addressed by the system as a whole, to stop the mistreatment and abuse of learning disabled and autistic people.

### *The voices of people and their families*

The voices of learning disabled and autistic people, and their families have not featured in the investigations into Whorlton Hall. It is crucial that the voices and well-being of individuals are prioritised in all support settings. We hear time and time again that people and families are not listened to, and this was demonstrated in this case, in part due to the fact that the prosecution had no-one to call on who knew people well enough to support their case.

### *The failure of commissioning*

It is over 12 years since the BBC Panorama investigation into Winterbourne View was broadcast. In its wake, the Transforming Care programme promised to transform the lives of learning disabled and autistic people in this country, and release people contained in hospitals, and support them to live in the community instead.

This has been an abject failure. There are still over two thousand people detained inappropriately in hospitals, and large numbers of those are in the North East and North Cumbria.

We cannot ignore the exorbitant sums of money being paid by the State to contain individuals within facilities like Whorlton Hall. It is alarming to consider that such vast financial resources were allocated to confining people, rather than investing in comprehensive, community based support that prioritises their well-being and independence.

We continue to be deeply concerned that individuals who receive this type of “support”, in these types of services are somehow lost in the system, miles away from home, with few or no meaningful relationships with anyone who is not paid to support them.

### *The failure of safeguarding systems*

We think there needs to be a commitment from Safeguarding Partnerships and Boards to understand the advocacy role in relation to safeguarding.

We would welcome clear processes that detail how advocates will be supported to challenge safeguarding decisions.

We think advocacy organisations need more robust procedures to support advocates in these situations, but at the same time there should be clear lines of local responsibility when this happens.

We believe that there should be a clear pathway for advocates to highlight concerns of culture or practice, where these may not meet the safeguarding threshold. This is particularly important for people who are placed out of area.

### *The failure of the regulator, the Care Quality Commission*

Alongside failings in advocacy, commissioning, and safeguarding, there were a number of failings identified within the regulator. We are aware of the investigations that the CQC commissioned to look at its own practice following the discovery of abuse at Whorlton Hall.

### *Excessive focus on restraint and MAYBO techniques, at the cost of seeing people as fully human*

The legal case has highlighted that staff at Whorlton Hall received more introductory training on MAYBO and restraint, before commencing work, than anything else. Seven days induction training covered first aid, manual handling, local policies and practices, and restraint (3 days).

Staff received no meaningful introduction to learning disability, or autism, or communication methods that patients relied on.

We believe that this placed a disproportionate focus on control and restraint, and created a culture where staff considered patients as not fully human, before even setting foot in the hospital.

Whilst we encourage the need for training of this type in order to keep people safe, we believe that values training should come first, followed by extensive communication training to support staff to really understand and properly build relationships with the people they support.

### *What needs to happen?*

The abuse and neglect of people at Whorlton Hall, and the findings within the Safeguarding Adults Review, in many extents read like a carbon copy of what happened a decade earlier at Winterbourne View. We believe that there need to be a number of changes to ensure that we do not find ourselves repeating these failings again.

## 1) Seeing people as fully human

We believe that all staff need to be supported to see the whole person, their strengths and assets, rather than the focus being placed on control and restraint.

## 2) Knowing where people are

Commissioners should have systems in place to flag where and when new learning disabled and autistic people are moving into settings within their local area. This in turn should lead to them automatically considering the individual's advocacy needs.

We believe systems should be put in place to enable advocacy providers to collaborate where there is cross boundary movements of individuals from one Provider to another, and track those movements until suitable support is provided and a handover has happened.

Advocacy providers, in open discussion with other interested parties, possibly commissioners and/or mental health providers need to understand where all settings are and the people needing advocacy.

## 3) Supported decision making, inclusion and active participation

We must promote a culture of inclusion and active participation, where individuals are not only listened to but actively involved in decision-making processes that affect their lives.

This requires a fundamental shift in how we support people and how we implement advocacy. Advocacy needs to be a genuine partnership between the advocate and the person they represent, time needs to be given to build a trusting relationship and to support people over much longer periods of time.

We will be supporting our advocates and reminding and encouraging them to routinely check records and notes, to identify any incidents and issues. The advocate must get to know their advocacy partner to understand their wishes, communication and work in the most person centred way possible.

Advocates in such settings should have increased experience and skills, in addition to enhanced supervision and support. In order to secure the best outcomes, we believe advocates should be invited to all meetings, and be part of any arrangements or planning of meetings to ensure that they are available.

Advocates in our region will always be supported to use a human rights approach in their advocacy, at all times.

## 4) Respecting the independence of advocates

Advocates must be allowed to work independently, and access people detained in these settings when they choose. This includes at varied times, out of hours, without prior arrangement, to enable them to observe and reflect on whether there are any concerns, or untoward activity happening.

The Whorlton Hall Safeguarding Adults Review references internal reviews that identify advocates from both the internally and externally commissioned advocacy providers, were too willing and accepting of staff reasoning for why they could not see patients, and why excessive restraint was being used.

We have worked, and will continue to work, to support advocates in our region to question, challenge and reflect on their own practice and the support that they are able to provide. Considerable focus will be given to empowering them, when required, to challenge the status quo and secure access to people who are detained, especially those subject to restraint, seclusion and segregation.

## 5) Education and awareness raising of the role of advocacy

All too often we still meet staff working in care and support who do not understand the role of advocacy, and who consequently fail to secure advocacy, or limit access to patients.

As a network, we will work to develop case studies to demonstrate where advocacy has made positive change, to help raise awareness, educate and negate some of the perceptions around advocacy.

We consider that it would be useful if there were education programmes within all mental health providers to ensure there is a professional respect for advocates, with clear guidance on an advocate's rights and responsibilities when supporting individuals, in the hope that this will ensure a level playing field in relation to professional boundaries.

We will also continue to raise awareness of advocacy, to ensure people know what advocacy is and how to access it, their rights and entitlements and how to complain about advocacy that is not good enough. We commit to work to increase this understanding for family members, carers and those who support people.

We are committed to continuing to build on and strengthen our approaches of working with healthcare providers so people who would benefit from and have a right to advocacy support, are identified and supported

## 6) Commissioning and funding of advocacy

Advocacy for learning disabled and autistic adults should be commissioned with adequate funding, which allows the advocacy relationship to develop, and that ensures the advocate has sufficient time and space to support individuals to build relationships and ensure that they are properly supported.

It is important that we recognise the importance of a robust advocacy system that works hand in hand with individuals, placing their needs and desires at the forefront. We must collectively work towards reforming and adequately funding advocacy services to ensure their role is truly aligned with the person they represent.

We know that County Durham have recently recommissioned their advocacy service, and having read the specification it raised questions for us about whether it would sufficiently address the concerns within the Safeguarding Adults Review.

Commissioners of advocacy need to have an enhanced understanding and commitment to the role of advocates and advocacy, including the need to challenge freely and independently.

Advocacy Providers are willing to upskill commissioners on the needs for delivery, and in turn commit to have highly qualified specialised advocates and demonstrate they have the capacity to meet demands and can respond quickly.

Whilst the review of the Mental Health Act is still taking place, we have concerns about how these gaps in provision get filled, to ensure that all people in hospital have access to independent advocacy e.g. patients who are informal but out of area.

The commissioning of advocacy should ensure that every person in such settings has a named and consistent advocate who has regular and sustained contact with their advocacy partners.

We also have concerns that advocacy commissioned by care providers is not able to provide truly independent scrutiny, and we consider that it would be preferable for a body other than the setting to commission provision e.g. the local authority.

Where an advocate needs to challenge clinicians or a setting then it should be accepted by commissioners that the support of a second advocate may be needed to help address the power imbalances that occur in such settings. We are also committed to taking pressure off advocates when they are dealing with complex caseloads, and ensuring that advocacy remains holistic and does not simply become a tick box exercise.

We consider that there is still much to learn from elsewhere, for example the practice in Wales where there is a fixed price for contracts and tenders are scored wholly on quality, and that there is still much that needs improvement to ensure that advocacy is commissioned in line with the NICE guidelines published last year.

Whilst our concerns mostly relate to provision for learning disabled and autistic people who are detained in hospital, we acknowledge that since the Cheshire West ruling the need for statutory advocacy has grown exponentially, and budgets and resourcing have not matched this increase in demand. In real terms, when considering inflation, reductions in contract budgets, and competitive tendering that prioritises price over quality, advocacy budgets have reduced.

Advocacy providers have been left to manage the tension between their responsibilities to the individuals their service supports, and their responsibilities to the broader population of people entitled to an advocacy service. This is a significant challenge for advocacy providers, many of whom are smaller voluntary sector organisations.

There is an ongoing risk that this has resulted in an almost transactional form of advocacy, with advocates being forced to prioritise meeting the needs of the population, over the quality of the service provided to the individual. On a related note, we think that one way to improve support for communities without compromising that available for individuals, is to build in a requirement to contracts to strengthen self-advocacy for people and families, through provision of training, networks, resources and support.

We hope that by raising these concerns, we can start a regional conversation with commissioners about commissioning approaches. Within that conversation we would also like to consider other roles that advocacy could help strengthen, such as the support provided in the CETR process, where we consider advocates must have a more central and clearly defined role.

## 7) Ongoing evaluation and development

We believe that through ongoing evaluation of advocacy services, increased funding, and professional development for staff, we can foster an environment where individuals receive the necessary support to exercise their rights, voice their concerns, and actively shape the services and support systems that impact their lives. We would welcome a conversation with commissioners where we could explore this further.

We consider that an ongoing education programme is required to ensure that the quality of professional development of advocates is supported, alongside work associated with the Quality Performance Mark (QPM).

We are ambitious about raising standards in our region. We would welcome a conversation to explore the role that the QPM plays in assuring quality, and to discussing whether, or how, our Advocacy Network might develop and sign up to an advanced set of standards to drive up quality further.

We believe that we have the potential for creativity and innovation, to work in partnership with commissioners in our region, to improve standards for all. It is unclear what form that might take, but one option we would be interested in exploring is the potential role of Quality Checking, where independent self-advocacy organisations and/or people with lived experience spot-check the quality of advocacy services.

We consider that there is a need for ongoing work in this area. We would like to explore whether we can secure additional funding to look at how advocacy might need to be delivered differently for some people in certain settings or circumstances. If commissioners are interested, this might be something that we can use our network to explore further, including to potentially pilot different approaches, measure impact and cascade this learning to inform future contract specifications.

### *Our offer and invite to the system*

We feel the system has gone silent and we do not understand what actions have been taken following the Whorlton Hall Safeguarding Adults Review.

We have grave concerns that our region is home to two of the largest NHS Trusts providing services to this population in the country. Both have recently been inspected by CQC and one is graded as requires improvement and the other inadequate. We are also aware one is currently subject to criminal investigations.

We stand committed to advocating for change and pushing for reforms in the support and care provided to learning disabled and autistic people.

We believe that there needs to be a fundamental shift away from detained services, towards care and support that emphasises community inclusion, choice, and dignity for all.

We consider many of the issues highlighted above are relevant, not just to hospital settings, but also to other settings where people are subject to a high level of restriction.

We acknowledge that we are not yet at a place nationally where there is anywhere near enough collaboration within advocacy itself. The competitive nature of tendering and restrictive quotations can impede the delivery of excellent services to people, whilst commissioners are driven to reduce funding. We wish to address this in our region.

As a first step we would welcome a regional conversation between advocacy providers, commissioners and those in the wider system. We are keen to work together to address these urgent matters.

We know you will share our concerns and we hope that you will take up this opportunity to connect with us.

**Durham Safeguarding Adults Partnership / All Safeguarding Adults Boards in our region**

1) You promised that you would "engage with everyone in a meaningful way once the criminal process concludes" [Para 1.4.7]. We would like to know what form that engagement will take?

2) How are you ensuring that your work is compliant with the 2022 NICE Guidance on Advocacy, and what changes have been made to your Safeguarding Policy and Protocols as a response?

3) Where advocates or other visiting professionals identify factors that indicate a toxic culture, but do not amount to a safeguarding issue as such in isolation, how do local safeguarding systems wish to collect this information in order to identify patterns and systemic concerns?

4) We understand local Safeguarding Partnerships and Boards have oversight responsibility of settings within their local authority area. How is this carried out in practice? How could advocacy play a role in supporting this to happen.

5) What can advocacy do to help you?

**Durham Local Authority / All Local Authorities in our region**

1) Whorlton Hall was not used by Durham for local residents. It is not clear from our reading of the Whorlton Hall Safeguarding Adults Review why that was? Can you tell us?

2) What steps were taken to alert commissioners from other local authorities to the concerns you held about Whorlton Hall?

3) We are keen to understand how the advocacy service you have newly recommissioned will meet the needs of learning disabled and autistic people who are detained in services, and address the concerns raised within the Safeguarding Adults Review?

4) What can advocacy do to help you?

**North East and North Cumbria ICB**

1) Do you know how the patients subject to abuse and mistreatment at Whorlton Hall have been supported?

2) Can you give assurances that they are no longer detained in inappropriate settings?

3) How are you supporting patients placed out of area? Are you confident that they are receiving appropriate advocacy support?

4) What can advocacy do to help you?

**NHS England and Improvement**

1) Why are you not insisting that people are removed from settings rated as Inadequate by the regulator?

2) What steps are you taking to provide oversight, and to reassure yourselves of the safety of patients when multiple ICBs are commissioning spaces out of their local area?

3) What can advocacy do to help you?

**Care Quality Commission**

1) What steps have you taken to ensure that you are no longer at risk of ignoring concerns like those raised about Whorlton Hall?

2) Are you confident that the same failures made by your organisation, would not, and are not, reoccurring in other settings?

3) What can advocacy do to help you?

**Everyone**

1) What steps are now in place to ensure when local commissioners hold concerns about a service that it does not become an island for people from out of area?

2) What can advocacy do to help you?