North East and North Cumbria Advocacy Network

FINAL REPORT

What was the North East and North Cumbria Advocacy Network?

The Network was established in July 2022 and ran until December 2025. It followed an in-depth development programme for advocacy workers supporting learning disabled and autistic people detained in hospital in the region.

It became apparent during the programme, advocates working with this group were themselves feeling isolated and under supported. The Network was developed to try to assist with that. It was funded with a small amount of money left over from the development programme, itself funded by NHS England, and by the North East and North Cumbria ICS.

Membership of the Network was available to all advocacy providers, and advocates working for them, who were:

1) working in the region
2) working with learning disabled and/or autistic people (adults or children).

The Network had an online presence. Firstly, on the NHS Networks service and latterly on NHS Futures. We received feedback that the first platform was not easy to use, and was putting advocates off, so we switched to a different online space.

Membership numbers varied over time, as anticipated given the turnover in the advocacy workforce. At November 2025 there were 104 advocates registered on the online Network community.

What did the Network do?

Network activity was organised around four strands of focus:

1) Connection – supporting advocates to network with other advocates also working with learning disabled and autistic people
2) Learning – provision of online training and learning opportunities designed for, and with, network members
3) Research and policy – opportunities to keep on top of latest developments in research and policy
4) Reflect and grow – prompts and reminders to support advocates to reflect on their practice and professional development.

Lunchtime learning sessions were offered on a range of topics including communication, HOPES model, the national advocacy review, and learning from Whorlton Hall: Closed Cultures; Working with Patients; Working with Professionals; the Illusion of Advocacy; Commissioning Containment and Restraint.

There was also an online book group, an online discussion forum and new research and policy developments summarised for members.

In 2023, following the conviction of four former support workers at Whorlton Hall, Network members came together to reflect on what happened, including advocacy's role, and what needed to change.

We wrote Breaking the Silence: Statement of the North East and North Cumbria Advocacy Network's ongoing concerns relating to Whorlton Hall. This was distributed to key stakeholders in the region, and nationally. We had a number of follow up meetings and discussions about how advocacy organisations could work with these organisations to improve things for learning disabled and autistic people.

In 2024/25, we held a Deep Dive exercise to understand what stops learning disabled and autistic people who are inpatients in hospitals in our region, leaving hospital. It also sought to understand the role of advocacy in supporting people to stay in the community and to leave hospital.

In 2025, we conducted a follow up piece of work for advocates who were supporting learning disabled and autistic people in hospital who are held in, or at risk of seclusion and segregation. This reflective peer network supported advocates to consider and develop their practice to enable them to best support people in seclusion and segregation.

This report discusses these last two focused pieces of work and introduces the learning and resources developed as a result of them.

2024/25 Advocacy Deep Dive

Why was it important?

A number of reports nationally, and locally, have criticised the role of advocacy in supporting learning disabled and autistic people in hospital. As a Network we responded to the Safeguarding Adults Review conducted into Whorlton Hall and committed to understanding better the role of advocacy in our region. This work was a response to that commitment.

What did it focus on?

The work focused on:

- people with a learning disability and autistic people who are inpatients in hospitals in part of our region
- understanding what stops people leaving hospital
- understanding what stops people staying in the community
- understanding how advocacy is involved in these processes
- understanding whether advocacy services adapt their practices to support this group of people flexibly
- understanding what role advocacy took (in a sample of cases), and what it could have done differently if we changed our approaches
- knowing where the gaps are and who we are likely to be missing
- understanding how advocacy can adjust and adapt to support this group best in our region.

The work started by interrogating publicly available NHS England data from the Assuring Transformation and Mental Health Services datasets to understand the current state of play.

From there a snapshot of the hospital services that the participating advocacy services were working into was undertaken. We had intended to interrogate historic advocacy data next but this proved impossible due to the way in which data was collected and stored by advocacy organisations.

Instead, we moved to a deep dive case audit, with participating advocacy providers looking at historic cases and the role of advocacy in supporting learning disabled and/or autistic inpatients. This was followed by a peer review process where all participants presented their cases and their peers asked questions and challenged some of their decision making.

Work took place between May 2024 and January 2025. Whilst the Network was able to offer some payment to participating organisations to resource the work, there were still challenges in identifying staff with capacity to undertake the work.

Initially we hoped to involve 4 organisations who were all working in one geographical part of our region, however one of the four were unable to participate due to staff turnover and other demands.

Resource challenges led to the timescales for the work being extended. We took a pragmatic approach to the work, adapting our focus once we had started.

Most of the sessions were held online. The final peer review session, a two day in person meeting was held in January 2025.

Who was involved?

Three local advocacy organisations participated in the work, People First and two others.

What did we find and learn?

1. We are failing learning disabled and autistic people in our region

Our region does not have an exceptional population of people living in it, but we have a much higher number of learning disabled and autistic people held in hospitals than elsewhere in the country.

In December 2023, nationally adult inpatient rates were 43 inpatients per million people, our ICB (North East and North Cumbria) had the highest rate in the country, at 74 inpatients per million. By December 2024 the national rate remained the same, 43 inpatients per million people, and locally we had 69 inpatients per million.

The Assuring Transformation dataset reports patients by provider organisation. In December 2023 there were 100 inpatients in CNTW and 80 in TEWV, which equated to 9% of all inpatients of this group in the country. By December 2024, CNTW still had 100 inpatients and TEWV 65, which accounts for 8% of the national population of inpatients.

Question: Given almost 1 in 10 learning disabled and/or autistic people held in hospitals are in our local area, should there be additional investment in advocacy to support people to leave and to safeguard their human rights whilst there?

2. It is not true that people are stuck in hospital because they are legally not allowed to leave because they are in hospital as alternatives to prison

When discussing people stuck in hospital there is often a suggestion that people are held in hospital due to legal restrictions. Assuring Transformation data from December 2023 showed there were only 45 people who were unable to be discharged for legal reasons. By February 2025 (most recently available data at the time of writing) this had reduced to 30 patients.

3. The patient population is changing over time, but learning disabled people are really stuck

The Assuring Transformation data suggests that there is an increasing number of autistic people getting admitted to hospital and getting stuck there, but there are numbers of learning disabled people who appear to be really stuck.

December 2023 data was provided about the breakdown of people by length of stay and whether they have a learning disability, autism or both. This allows us to focus on those who have been in hospital for long periods of time and chart the change in population over time.

345 people in hospital more than 10 years, of which:		
205	60%	Learning disability
65	19%	Learning disability and autism
75	21%	Autism

290 people in hospital 5–10 years, of which:		
115	39%	Learning disability
85	29%	Learning disability and autism
95	32%	Autism

435 people in hospital more than 2–5 years, of which:		
145	33%	Learning disability
110	25%	Learning disability and autism
180	41%	Autism

280 people in hospital more than 1–2 years, of which:		
65	23%	Learning disability
60	21%	Learning disability and autism
155	55%	Autism

This data was 'temporarily removed due to data processing issues' in the April 2024 dataset and had not returned over a year later. This meant it was no longer possible to identify how long people who are learning disabled and/or autistic were staying in hospital. However, we can see the change in population over time in the earlier data and there is no reason to suspect that will have changed significantly.

4. We are failing to discharge people, with growing numbers of people held for long periods of time

The Mental Health Services Dataset is also useful in this regard. It reports inpatient length of stay by provider organisation. It is clear from this data set that there are a cohort of patients who have been in hospital for over two years, that are not being discharged.

* Less than 5	Dec 2023		Dec 2024	
	CNTW	TEWV	CNTW	TEWV
10 years or more	**5**	**20**	**10**	**25**
5-10 years	**25**	**15**	**25**	**25**
2-5 years	**30**	**25**	**35**	**20**
1-2 years	**25**	**5**	**15**	**10**
6-12 months	**20**	*	**20**	**15**
3-6 months	**15**	**15**	**15**	**10**
1-3 months	**10**	**10**	**20**	**10**
2-4 weeks	**5**	**10**	**5**	**5**
1-2 weeks	*	**5**	*	*
4-7 days	*	*	*	*
0-3 days	*	*	*	**15**

5. Advocacy provision nationally is under pressure and consequently failing to provide adequate support to learning disabled and autistic people in hospital

Assuring Transformation data reports on advocacy provision for learning disabled and autistic people in hospital. Advocacy data includes the number of inpatients with an advocate (IMHA, IMCA, other) and reasons why patients do not have one. The data set also asks a question about whether the advocacy provider holds the QPM.

Comparing data available since December 2023 shows a deteriorating picture of advocacy provision. In December 2023 nationally there were 35 patients reported as being on a waiting list for an IMHA, a year later 110 patients were on a waiting list for an IMHA and additionally 20 recorded not having one as “none available”. At the time of finalising this report (November 2025) the picture has declined further. August 2025 data recorded 145 patients on a waiting list for an IMHA and 35 recorded “none available”. In December 2023 30 patients were on a waiting list for an IMCA and 10 were reported as wanting an IMCA but there was not one available. Just twelve months later that had increased to 155 inpatients on a waiting list, and an additional 55 patients recorded “none available”. By August 2025 that number had increased further still, with 225 patients nationally on a waiting list for an IMCA and 60 recording there was “none available”.

6. Advocacy is provided flexibly depending on the needs of people we support with reasonable adjustments being made routinely by advocates, but not always by hospital staff

One provider changed the model of IMHA delivery to ensure they had the same two consistent advocates assigned to the ward. Advocates visited at least once a week for a morning or afternoon session. During those periods they would work with assigned clients and also provide support to anyone seeking out advocacy from them. They report that this helps where people might struggle to keep appointments at set times, or when they are only able to engage for short periods of time.

Advocates reported that whilst Easy Read information on someone's rights under the Mental Health Act are given out as standard, Easy Read is not routinely incorporated to other communication on the wards. Easy Read information on medication or psychology reports were not used.

> *"On one occasion, the person we were working with who has a learning disability, when asked by his psychologist, told them he did understand the report. His IMHA spoke with him afterwards and found this wasn't true. He said he was dyslexic and really struggled but just found it easier to say he understood. The lack of easy read options, or even just less clinical versions of reports is evident in tribunals and hospital managers reports too".*

Advocates use many techniques to make sure they are adjusting their practices to an individual's needs. This includes offering Easy Read versions of consent forms and advocacy packs, communicating in a way that suits the individual whether this be calls, the use of visual aids or meeting face to face, meeting in a location and at a time that suits the individual, and summarising the main points of a meeting in writing so they can refer back to it.

Many of the advocates have attended training, including that organised by the Advocacy Network, to build their confidence in supporting people who do not use words to communicate through the use of Talking Mats, social stories and other communication strategies.

On discharge, if someone lives locally, one advocacy provider automatically continued providing advocacy support as long as the person wanted an advocate. Once that ended people could return for support and request the same, or a different advocate. This was not always possible for all providers due to the way advocacy is commissioned, and it is not possible when a patient is from another local authority area to where providers are based.

7. Access to advocacy often requires staff on the wards to make referrals, yet high staff turnover and reliance on agency staff affects timeliness of referrals

Advocacy providers report they are not always informed of new admissions, or when a patient wishes to speak with advocacy. All providers reported that there have been high levels of staff turnover and high reliance on agency staff in the hospital wards included in this work.

Some providers reported that new members of staff and/or agency staff can often lack confidence, and lack knowledge of patients, and sometimes appear scared of patients. As advocacy providers we have the opportunity to make reports to CQC or raise safeguarding alerts if we feel staffing is impacting on patient care, but we were not confident that these options were used regularly enough.

Advocates are frequently supporting patients subject to restrictive practices and held in seclusion and segregation, yet they may not be alerted to someone moving to seclusion or segregation until they next visit.

8. Advocates report there is little understanding of their role or respect shown to them by staff teams

We questioned whether advocates were advocating strongly enough to be included as key partners in people's care, or whether they had become resigned to being treated poorly.

Advocates reported feeling they were often at the bottom of the pecking order.

Their availability is rarely considered when meetings were scheduled, they are routinely not copied into notes and do not have minutes of meetings they attended shared with them.

9. Advocates report ward and hospital environments are still not fit for providing care and support to ill people

All the advocates raised concerns about the suitability of the hospital environment for distressed learning disabled and autistic people. Environments were reported to be noisy and echoey, with constant banging, music and alarms going off. Lighting is harsh and spaces to decompress are limited.

Some advocates reported individuals they support removing themselves to the seclusion suite because they were distressed and aware that they would not cope in the general ward environment. Whilst this is a sophisticated coping mechanism for patients to demonstrate, it is also an indicator that the ward environments are inappropriate and not suitable for helping with recovery.

Many advocates reported the people they support often face frequent moves between services and wards. One provider was described as "managing risk through movement" as they have lots of ability to move people.

Conversely other advocates reported autistic people's distress at change and moves were being used as rationale to stop people moving, or leaving, at all. It seems that there is no problem moving people to other wards in the hospital estate, but there is a reluctance to move people to step down services to enable them to return to the community.

10. Why are people stuck in hospital?

These inappropriate hospital environments are impeding people's recovery and in turn reducing the likelihood that they will be discharged.

Advocates reported staffing difficulties contributing to delays in people being discharged, for example when there are insufficient experienced staff who know patients well available, Section 17 leave is restricted. The consequence of this is that people's recovery is impacted, and their hospital stay lengthened.

Other factors mentioned by advocates were a lack of suitable accommodation, or people having no fixed abode to return to. Long waits for suitable housing were reported, alongside delays in securing support providers for learning disabled and autistic people.

Related to the delays, were concerns commissioners were getting involved too late in discussions and therefore discharge options are not being explored soon enough. This is not a cost neutral situation, as for every day someone is detained in an inappropriate environment, which is escalating their anxiety and frustration, the risk of their behaviours deteriorating and in turn then being deemed 'unsafe' to live in the community, increases.

Another concern raised by advocates is whether transitions from a hospital environment to the community were planned well enough, or whether we were "setting people up to fail" without sufficient appropriate preparation. There are questions for advocacy about its role and how best advocates can support in the community if there are no non-statutory services available.

11. Our data quality in advocacy is not as robust or detailed as we would like

The organisations involved in this work have made changes to their record keeping since starting the Deep Dive exercise. We had hoped to interrogate historic advocacy data to learn more about how learning disabled and autistic people had been supported over the three previous years, but the reporting mechanisms in use did not enable us to do this in the detail we had hoped for.

For example, when asked where people were discharged to when leaving hospital, providers did not log or store that information. While it might have been possible to find it within case notes, there was no way of drawing down just that aspect to consider as a group. Instead, it would have been necessary to check each advocate's notes per patient, too considerable a task within the time and resource available.

12. Contingency planning for sick/ annual leave to ensure people aren't stranded without access to advocacy

One of the criticisms of advocacy in the Whorlton Hall Safeguarding Review was around the poor contingency planning that led to no statutory advocacy being provided to people once the advocate covering Whorlton Hall was unavailable for a prolonged period.

All providers reported processes in place to ensure cover was provided in the absence of a named advocate.

13. Supervisory support for advocates and oversight from advocacy providers

All advocates reported that they receive 6 weekly formal supervision. Additionally, managers reported that advocates can, and do, reach out on an ad hoc basis for support as needed. One provider insists on advocates being present in the office at least once a week and noted that often this created opportunities for advocates to access extra supervision if needed, and to have day to day conversations which often help in reflecting and findings solutions.

A number of structured team meetings were also held, including one dedicated for advocates working into a hospital setting.

All providers mentioned that patient's cases were formally reviewed at least every 6 weeks. Often there were more regular discussions in people's supervision meetings.

14. Raising concerns with other stakeholders

Another area where advocacy failed in Whorlton Hall was around raising concerns, and applying scrutiny when complaints were made. This went hand in hand with accepting Whorlton Hall staff members justifications for restraint and uncritical acceptance of their risk assessment about access to individuals.

The Deep Dive process identified that this is likely an area where further work needs to be done [which led in part to the later Seclusion and Segregation work].

Only one of the three providers had raised complaints with commissioners using the services, and even that provider recognised it was an area where further work was required to support advocates to do so when commissioners were out of area and less present.

Only one of the three providers had raised complaints with CQC about the services they were working into. Another said they had raised concerns and advocates spoke with CQC inspectors when visiting.

15. Advocacy is not commissioned to appropriately support people with learning disabilities and autism to stay out of hospital, to support them flexibly when in hospital, or to provide long term support after hospital

No-one was commissioned to provide support to people before their admission to hospital, other than through general advocacy services. There is no requirement to trigger advocacy involvement in Community CETRs, when people are at risk of admission to hospital, there is therefore no-one professionally acting to protect people's human rights at this critical time.

Once people are admitted to hospital, advocacy is rarely informed in a timely manner so they are not likely to be present at the formulation meeting (as it is not yet known whether advocacy will be required). This led us to believe that advocacy is being provided too late and missing key opportunities to protect people's human rights.

16. In addition to advocacy provided for people in hospital, there are excellent examples of advocacy working to support people to stay out of hospital

One provider was using flexible charitable funding given to provide general mental health advocacy, to work with a person who had previously been in hospital and was struggling in the community

Advocates were persistent, compassionate and creative in the support provided to this person, and the advocacy provider was working hard to make internal arrangements to ensure advocates did not burn out with the level and nature of support they were required to give.

This exceptional support ensured the person did not fall through the gaps in support and was not immediately returned to hospital, due to a lack of community support.

Conclusion

The Advocacy Network did a further piece of work to look at how to support advocates working with learning disabled and autistic people in hospital, with a particular focus on people at greatest risk of having their human rights infringed, those in seclusion and segregation.

2025 Seclusion and Segregation Reflective Peer Network

This 8 week peer reflective network enabled a small group of advocates to consider their practice, and how they could best support people held in, or at risk of, seclusion and segregation.

The advocates heard from 5 guest speakers with lived experience of, and family members of relatives in seclusion and segregation.

The work focused on:

- Scene setting on what is seclusion and segregation
- How advocates support people in seclusion and segregation? What does good look like? What is challenging?
- People's lived experience of seclusion and segregation
- Advocating in the moment for day to day human rights
- Families experience when a loved one is in seclusion and segregation
- Advocating to change the status quo
- Non-instructed advocacy when communication is complex
- Tools, resources and self-care

It became apparent that there was not always a shared understanding of what advocacy provided to people in seclusion and segregation, or hospital more generally. So, three tools were designed to help make clear to people the ways in which advocates work, in keeping with the Advocacy Charter:

- Expectations document for learning disabled and autistic people
- Expectations document for family members
- Expectations document for staff

Additionally, discussions identified pinch points or places where people get stuck in their journey through services. These can contribute to people being held in seclusion and segregation for longer than necessary or not being discharged from hospital.

Two checklists were developed for use by advocates to reflect on their own practice, or with a supervisor or manager:

- Checklist for advocates
- Checklist for managers and supervisors

They are both designed to help advocates consider how they are working with learning disabled and/or autistic people subject to seclusion and segregation or resident on mental health wards. Advocates and their supervisors can pick and mix items from both checklists to discuss together to provide critical challenge over advocacy practice.

Conclusion

This work was focused on developing people's individual practice. It was acknowledged that being stuck in seclusion and segregation in hospital is one of the most isolating situations, for people in hospital, their family members and the advocates working with them.