My Views Matter

Residential and in-patient care for people with learning disabilities and autism in Norfolk

healthwatch Norfolk

Summary

Between April 2018 and July 2020, three patients, Joanna, "Jon" and Ben, died at Cawston Park Hospital in North Norfolk, having suffered neglect and abuse. They were all in their 30s, and they all had learning disabilities. An important finding of reports into the tragedy was that the views of patients and their families were systematically ignored by the hospital. As part of the system response to these events, the Healthwatch Norfolk board agreed to undertake a review of the residential and in-patient sector caring for people with learning disabilities and autistic people.

In line with Healthwatch's mandate this review has looked at three main questions:

1. How have the residential care and secure-inpatient sectors caring for people with learning disabilities and autistic people in Norfolk changed in recent years, and what plans are in place for the future?
2. What mechanisms are in place in the sector to make sure people's voices are heard and acted upon?
3. What do people using these residential and in-patient services, and their families, think about the care they receive?

To answer the first question, we interviewed 25 professionals working in the sector, and reviewed literature on recent developments in the sector in Norfolk. To answer the second and third questions, we carried out Enter and View visits to 21 residential homes and 4 secure in-patient units, talking to 94 service users. We also interviewed 58 family members, and commissioned a user-led advocacy organisation for people with learning disabilities and autism, Opening Doors, to run focus groups with their members about their experiences of residential care. These were attended by 42 people.

Views from professionals

Most professionals we spoke to expressed concern about the overall state of the residential care sector in Norfolk. People we spoke to in Norfolk County Council (NCC) identified a number of key difficulties. The quality of Norfolk's social care services is rated by the CQC as

being lower than in most parts of England, and includes services that are not compliant with current standards, and which would not be commissioned under current frameworks.

The sector in Norfolk was said to face several geographical and historical issues that affect its residential care, some of which make it difficult to recruit care staff. These include having a long coastline, and so fewer neighbouring areas to recruit from, and homes based in rural areas which are less attractive for people to live in and can be expensive to travel to. Norfolk also has a relatively elderly population, with a low proportion of working-age adults, compared to other areas.

In addition, over time, Norfolk has developed a higher proportion of residential care compared to other areas, with a lower proportion of supported living, which, we were told, results in some people becoming de-skilled.

NCC's Integrated Quality Service is giving support to providers to improve the quality of their services, whilst also taking enforcement action against providers who persistently breach their contracts, including closing some services down. They envisage closures of a significant proportion of homes in Norfolk. NCC's learning disabilities commissioners undertook a consultation exercise in 2020 and 2021 to try to understand what people's families want from the housing for their relatives in care. In response to this consultation and shortfalls that NCC have identified in the sector, NCC has developed a strategy to increase provision of supported living settings, including increased places for people with complex needs. £18 million has been made available to meet the capital costs to start to meet the projected demand.

The council is also seeking to improve the skills based in residential homes by providing free Positive Behaviour Support (PBS) training to all providers free of charge.

We spoke to a senior nurse for learning disability quality at Norfolk and Waveney ICS about the physical health of care home residents. She told us that, while there is more oversight of residents' health than there used to be, several problems remain. One is that care staff do not always explain to people the consequences of unhealthy choices, but accept a refusal to eat well and look after their health properly at face value. After a dip during the pandemic, the numbers of people participating in Annual Health Checks has increased to attain the

national target. Work is underway to improve the quality of health checks through a network of LD champions in GP surgeries.

We also sought the views of clinicians from the Hertfordshire Partnership NHS Trust Learning Disability and Forensic Services Team about work to prevent admission of people to secure units. They told us that there had been progress in this regard in the past ten years, but that people can still be discharged into settings where staff do not have the expertise to cope with their behaviour. This team includes services to provide a bridge between in-patient units and the community, providing support for people and their community placement staff, before and after they are discharged from secure services, to reduce the risk of (re-)admission.

We also spoke to the Norfolk Care Association, a membership body representing provider organisations in social care, to try to understand the perspective of care home providers. We were told that providers were keen to see the cost implications of NCC's new proposals for residential care, with some being sceptical that funding would be provided to match the increased demands of the new model. Providers were also said to be worried about the difficulty of recruiting care staff, which they consider to be more difficult now than at any other time anyone can remember. This is partly about pay levels that compare poorly to other, less demanding jobs, and is also related to the superior respect, terms and conditions, career progression and salary that workers in the health sector enjoy.

Finally, we spoke to three third-sector organisations who work with people with learning disabilities and advocate with and for them. They had a critical view of the sector, and spoke of people who used their services who had been given inappropriate placements, and who found it very difficult to move to a placement that was appropriate for their level of need, for their preferences and that was close to their friends and family. Problems with the annual review process were also raised, with annual reviews said to be delayed in some cases, being carried out by less-experienced assistant practitioners, rather than social workers, and being carried out by a different person at each review.

Feedback about residential homes

We received most feedback on the following topics, with the following findings:

Shortages of suitable placements

Some relatives reported having been unable to find care placements, particularly for young people transitioning from children's services to adult services.

- Despite the improved support of NCC's preparing for adult life team, many families have been waiting for years for a suitable placement.
- This is putting considerable strain on the mental health of family carers, and preventing young people from living where they want to.
- Some parents had made the difficult decision to send their young people out of county, or people had spent years in an unsuitable placement before a more suitable one became available.

Norfolk urgently needs to develop more specialist residential and supported living placements, and there needs to be better forward planning and resourcing to provide places for young people when they become adults.

Listening practices

Homes used a variety of methods to listen to people. These would often include monthly or weekly residents' meetings, and/or more personalised ways of consulting them. Most people we spoke to were happy that they were listened to by staff in the homes, and gave us examples of when this had happened. When people in homes complained that they were not being listened to, it was often because of a negotiation around a person's preferences and their best interests. A minority of residents identified some other problems. Three relatives of people in the homes and five people in the focus groups identified communication and listening problems. Five relatives reported problems with listening and responsiveness in the homes due to staff shortages.

People's relations with care staff

People living in homes were generally very positive about their relations with staff, and did not want to change anything about their staff support. This positive picture was supported by our observations in the homes. Feedback from relatives was also mostly positive, as was feedback from the focus groups.

What mattered most to people about their staff was:

- Reciprocal and non-hierarchical relationships
- Long-term relationships, particularly for people with communication difficulties or complex needs
- Family-like, affectionate relationships with staff
- Staff who know residents well, and know what makes them tick

People's main concern in this area was high levels of turnover of care staff, since many people find it difficult to adjust emotionally and mentally to the loss of a significant person in their life, and people with communication difficulties often struggle to communicate with new staff.

Managers

Again, most feedback about managers was positive. What mattered most to service users' families in their interactions with managers was:

- Managers who were engaged in the everyday life of the home
- Managers who knew and understood residents well
- An approach to disagreements based on open communication, being receptive to suggestions, and clearly prioritising the best interests of the resident over other considerations

Some relatives and staff spoke to us of the disruption that could ensue when there was a high turnover of managers and were very keen to avoid this.

Premises

The physical aspect of homes could both reflect and facilitate people's control over their homes and their everyday lives within them. We saw a range of different levels of personalisation in homes:

- Most people's bedrooms were well-personalised, but only in a minority of homes were people able to choose how they were decorated.
- Even fewer homes allowed people to have extensive control over the decoration of communal spaces. We also found that more homes could make use of accessible and well-organised information displays, to help people navigate their homes and gain new skills.
- It was comparatively rare to find a culture of ownership and participation where people moved around their home freely and participated in its upkeep on a regular basis.

Activities

What mattered most to people about their activities:

- People with high support needs valued attentive activities support, which combined day-to-day individualised responsiveness and the chance to develop their interests
- Some people needed encouragement to try new things, and were grateful for this despite their initial reluctance
- People with lower support needs appreciated support with developing the independence and confidence to be able to go out and participate in activities by themselves
- Most people were happy with their day services, and many particularly liked the work or work-like activities that they undertook there.

Friendships and relationships

Most people were happy with the support staff provided for maintaining relationships. However:

- Few people managed to maintain friendships established before they moved into their home.
- People's social networks were mostly limited to other disabled people, staff and their families, perhaps suggesting shallow community integration.
- Only one person was engaged in a romantic relationship, suggesting a lack of support in this area.

Homes' interactions with families

Most people were happy with homes' communications with them, and how they supported relatives to visit homes. However:

- More support could be given to help people visit their elderly parents at home, as they become less able to travel.
- A significant minority of relatives reported being under considerable strain, because they kept having to check that homes were maintaining appropriate levels of care for their family member.
- Some of these relatives were worried about the adv erse consequences for their family member, and for their continued access to their family member, if they kept complaining. More

reassurance and safeguards may be needed to ensure that relatives can express themselves freely without negative consequences.

Feedback about secure units

- Patient satisfaction: Many patients did not want to be living in secure units, but most felt that staff did a good job, and that they were treated fairly. A relatively small minority of people disagreed.
- All the units seemed to have thorough mechanisms for gathering feedback and allowing patients to participate in the governance of the units. These included regular Care Programme Approach (CPA) review meetings and Care and Treatment Review (CTR) meetings, ward meetings, inclusion on governance committees, individual meetings with staff and well-understood complaints procedures.
- Our observations suggested that the units had cultures which were open to external scrutiny, and they actively elicited negative feedback from patients.
- There are blockages preventing timely discharge, including some legal delays, particularly delays in the processing of Deprivation of Liberty requests by the Court of Protection. The biggest and most difficult problem, however, is the lack of suitable community placements for people to be discharged into.
    - These delays are worrying, and some patients are still facing unacceptably long delays to discharge, particularly from the Assessment and Treatment Unit.
    - NCC's new housing programme seems to be helping to clear some of this backlog, but it remains to be seen whether it will be sufficient to cope with all of current or future demand.

Feedback on the broader health and social care system in Norfolk

Some of the feedback that we received was not only about residential and in-patient service providers, but related to how they were supported by the broader health and social care system in Norfolk. Relatives spoke to us most about their family members' experiences with social workers and GPs. Most people we spoke to were happy with their experience of annual reviews with social workers, but five people mentioned that they found relations with

social workers more difficult now that they did not have the same social worker for each annual review. This was particularly difficult for some people with learning disabilities, because it could take a long time to understand properly they like to communicate and what their personality is like. Four people also told us that they found it hard to get a response from social services when they contacted them between reviews.

In all of the homes that we visited, all of the residents were up to date with their annual health checks with their GPs, and almost all of the feedback that we received about GP surgeries was positive, with a few isolated exceptions.

Conclusion

The feedback that we gathered during this project has yielded substantial positive feedback and useful examples of best practice. In our attempt to gain an overview of how people are being listened to in the sector, we have not found that the problems present at Cawston Park are widespread in the sector. In most cases people have avenues for having their voices heard, and most relatives felt that they were being listened to well.

However, the people we spoke to also identified several important areas for improvement, we which summarise below.

Recommendations for providers

Staff:

- The people we spoke to most valued reciprocal, non-hierarchical, family-like relationships with staff. This suggests that providers should find ways to encourage staff to develop relationships with residents based on shared interests, a balanced sharing of personal communication, and the empowerment of residents. This means supporting, wherever possible, keyworker stability for residents, to allow for longer-term, deeper relationships.

Managers:

- Families particularly valued managers who were well-informed and engaged in the everyday life of the home and the people who live there. Managers should therefore ensure a regular presence in the everyday life of the home, and avoid delegating this to deputy managers or other senior staff.

- Clear and honest communication was particularly valued by families. Particularly when problems or disagreements arise, transparency, regular communication and an open-ness to compromise and accepting the suggestions of family members can avoid damaging conflicts.

Premises

While most homes made some efforts towards personalisation, more could be done to consult people more fully about the decoration of both bedrooms and communal spaces, to allow people to influence the overall look and feel of the home.

If it fits the ethos of homeliness that a home is seeking, more use could be made of well-organised and accessible information displays. Greater use of these could be made to share more information about staff with residents, and to use as education and enablement guides.

Providers should take care to ensure that people are participating in the upkeep of the home to the extent that they are capable, as this was not always the case in the homes that we visited. People who were participating in this way were particularly proud of it.

Homes should seek to establish everyday habits that show people that they can move around homes at will and make suggestions about upkeep or changes at any time. While this is technically allowed in many of the homes we visited, this did not always seem to have filtered through to the expectations and habits of residents.

Activities

Providers should take care to constantly encourage people to try new activities, rather than take a refusal at face value. The people who had broadened their horizons and tried new things generally reported being most happy.

Where people have substantial one-to-one support, attentive support should be given to people's daily activities, using creativity to allow them to follow their interests both in the moment, and to invest in longer-term interests over time.

Where people have more capacity for independence, homes should not rely on communal activities to keep them happy, but invest in developing their independence skills and confidence, so that they can follow their own interests with minimal staff support.

Friendships and relationships

Relatively few people that we spoke to had managed to maintain friendships that they had established at the previous places they lived. This suggests that homes could do more to support people to keep in touch with older friends.

Only one person we met was in a romantic relationship. This suggests that people living in homes are not given the support that they need to develop romantic relationships. Homes may need to invest in training in how to support these relationships, as this was an issue that did not seem to be on the agenda for most of the homes that we visited.

Providers should seek more opportunities for residents to form friendships with non-disabled people outside the home, since meaningful community participation will not be achieved with this. Although this is partly a problem of ableism in wider society, more thought could be given as to how to develop programmes similar to gig buddies, to provide more opportunities for barriers between disabled and non-disabled people to be broken down.

Homes' interactions with families

More support could be given, as relatives age, to help people to visit their elderly relatives, when they are no longer able to visit their family member in the home.

Homes should ensure that, especially when relatives have requested changes to someone's care, that these are followed up consistently, and that relatives are given regular updates as to progress on making the changes.

Providers should also take steps to reassure relatives that, if they complain, that no adverse consequences will ensue, for their family members, or for their access to their family members.

Recommendations for the Health and Social Care system in Norfolk

As discussed in the section on 'Views from Professionals' above, many of the issues raised for the broader health and social care system in Norfolk are already being addressed, or there are plans to address them. These include the central problems of the availability of sufficient care for people with complex needs, and more enabling forms of accommodation for those who will benefit from that; and the central issue of the shortage of care workers and its knock-on effects for people in care homes and secure units. The latter is partly a national issue, as is the shortage of social workers which makes maintaining a regular social worker at annual reviews so difficult.

However, some issues did come up in people's feedback, that could be addressed:

- Some relatives were paying for some types of day service that NCC had declined to pay for, but which service users and their families found very beneficial. It might be worth investigating whether funding could be found for a broader set of day services might be funded. When considering funding decisions on day services, feedback suggests that people's social lives and long-standing relationships should also be considered, and not just participation in activities.
- Some thought could be given to the fear of some relatives of being labelled 'problem parents' or similar, and how these fears could be allayed, and safeguards put in place to make sure that these labels are not used inappropriately.
- Given that some people living in residential care value relationships with non-disabled people, some consideration could be given as to how to support homes to support people to form these relationships, or even to re-establish a gig buddies scheme, or similar, in Norfolk.
- Our findings suggest that people living in residential care are being denied the opportunity to form romantic relationships. More support could perhaps be given to homes to help them to

build the capacity to support people to establish these relationships, where this is an aspiration