Shared learning bulletin

An independent care pathway review of a young person

Introduction

This document provides an overview of the findings from an independent review to identify learning from a young person's care pathway. Agencies and teams who might benefit from this bulletin include: NHS England; Integrated Care Boards (ICBs); child and adolescent mental health services (CAMHS); adult mental health services; local authorities and education partners.

Case background

Our care pathway review focussed on interventions over a seven-year period, a time when the young person was adolescent. During the period we reviewed, they had various working and confirmed diagnoses, including severe obsessive-compulsive disorder (OCD) and autistic spectrum disorder (ASD) with depressed mood and history of tic disorder.

The young person's behavioural difficulties were noticed age 10.

The young person was first referred to CAMHS by her primary school. They were assessed and offered follow up appointments for further assessments. These were cancelled by the parents who reported that the young person was seeing a privately funded psychologist. The young person was discharged.

A year later the young person's GP made a second referral to CAMHS. Following assessment, it was planned for them to be put on the waiting list for a full ASD assessment. Further appointments were cancelled by the parents who reported that the young person had been admitted to hospital abroad.

A year later a third referral was made to CAMHS by the young person's school. The case had remained open to the service, and they were offered further appointments. An ASD assessment was planned.

The young person was also referred to an adolescent outreach team who undertook some psychoeducation work about ASD with her and her family.

The following year the young person was referred to a specialist CAMHS OCD clinic. At this time, the parents provided an assessment report from a psychiatrist abroad which concluded that her presentation was not consistent with a diagnosis of ASD and that her presenting problems over the previous two years were due to severe OCD and tics.

The young person was diagnosed by the specialist CAMHS OCD clinic as having severe OCD, a tic disorder and probable speech and language difficulties. She received cognitive behavioural therapy. At this time, she was provided with a Statement of Special Educational Needs.

The young person experienced a relapse in her condition the following year and was seen by the adolescent outreach team. She was referred to an adolescent unit and was informally admitted but struggled with the environment, so she was discharged back to the adolescent outreach team. Her behaviour escalated in the community, and she was admitted to a low secure adolescent unit.

Due to a sustained increase in aggressive behaviour, the young person was transferred to a medium secure adolescent unit; she had been nursed in long-term segregation since admission.

The young person was transferred to a medium secure adult unit three years later (seven years after first presenting). She remained in long-term segregation, detained under Section 3 of the Mental Health Act 1983 (MHA), in a bespoke package of care in a dedicated ward. It was considered that her needs were exceptional; she frequently assaulted staff or self-injured and required frequent restraint.

Key learning points

Patient care

- Engagement with international medical teams who have been involved in care is important, particularly when there is a lack of consensus about the patient's diagnosis. Successful engagement, which is heavily dependent on facilitation by the patient and/or their family, was not always achieved in this case.
- Positive therapeutic relationships developed with the adolescent outreach team was lost when the young person moved into secure services. The presence of a whole care pathway clinician providing family liaison could provide a bridge between the family and new services and help families navigate complex care pathways.
- It is not clear whether this included a sensory assessment took place prior to the sensory integration assessment being requested. Teams should have a directory of those trained in sensory integration assessments, and the ability to commission such an assessment in circumstances where sensory function is being considered.
- The lack of clear formulation led to the use of mental health secure placements instead of placements better suited to someone with ASD. It is possible that an ASD focussed placement may have prevented some of the young person's behaviours that became entrenched and challenging.
- Support to young people and their families following a diagnosis of ASD should be an integral part of the service offer. When there is a lack of support by families for a diagnosis, it can be helpful to spend time with them to understand their reasoning and to explain what the diagnosis means.
- Positive behavioural support should have been considered in the holistic understanding of the young person's behaviours. Its scope of practice could have been discussed and explored to identify how it could be expanded to work with the formulations which were available to the care team.

Staff caring for complex patients

- Reflective practice as a team should be an essential part of team development. It should be protected particularly when services are understaffed or overwhelmed because at these times the function and purpose of reflective practice groups is even more vital to maintain high quality care and staff well-being.
- Teams should have access to external debriefing following some incidents. Debriefing was provided by psychologists who were part of the multidisciplinary team caring for the young person; this meant that they were less able to provide an external perspective of her behaviours, consequences and impact on staff.
- While at the medium secure adult unit the relationship between staff and the young person's family was considered as important as the relationship between her and the staff. There was a structured approach to communication with regular and frequent opportunities for the parents to express their opinions and engage with the care team. Concerns raised were taken seriously.
- In cases of considerable complexity and multi-faceted issues it is important for staff to focus on the patient and their needs as a whole, rather than trying to address individual aspects of a patient's overall presentation. This is particularly relevant in cases where thresholds for services may preclude a patient for an arbitrary reason, such as the patient being/not being in the community.

Commissioning

- It is possible that the clinical pathway, and consequently the clinical outcomes, might have been different had the young person been placed in an adapted learning disability or ASD placement. In particularly complex patients, care should be taken to identify their individual needs and consider whether those needs should be met in a bespoke package of care at an earlier stage in the care pathway, thereby significantly reducing the exposure to negative experiences and potential harm.
- Commissioner understanding of the complexity of the young person's needs improved significantly after there was appropriate oversight by the NHS England case manager.

Key learning points (cont.)

- The medium secure adolescent unit continued to provide care and treatment to the young person in an environment that was identified as inappropriate. The consequence of this was a highly restrictive approach to managing risks resulting in assaults on staff, reduced staff capacity and difficulties recruiting to the service. It also had a significant impact on the service the unit was able to offer other young people whose needs may have been more appropriate for the environment.

Recommendations

The independent review made a total of eight recommendations.

National recommendations

Recommendation 1: Management of highly complex cases

Commissioning the bespoke package of care for the young person took a very long time resulting in her remaining in an inappropriate inpatient environment for too long.

Provider Collaboratives were introduced after the young person was admitted to the secure estate. One of their purposes is to enable specialist care to be provided in the community; this aims to prevent unnecessary hospital admissions and enables people to leave hospital when they are ready. When admission to hospital is needed and specialist secure provision is required, not all Provider Collaboratives have access to local provision appropriate for the most complex patients.

We have observed from evidence in this case that there is a possible risk to financial resilience in the current arrangements for ringfencing funding at provider collaborative level. There may be a case for financial risk to be shared between national and provider collaborative level for a small number of highly complex patients.

Patients with highly complex needs (and their families) sometimes lose the benefit of a clinical care coordinator who understands them, the healthcare system and pathways. The young person and her family did not have access to a consistent member of staff who was independent of the treating care team but who understood their needs, the commissioning thresholds and processes.

NHS England should introduce a framework (perhaps linked to the CETR process where appropriate) which enables early identification of highly complex adolescent patients in order to facilitate the development of bespoke packages of care in a timely and patient centred fashion. The framework should also allow issues to escalated to a sufficiently senior manager to enable problem resolution across health, children's social care, and education.

The framework should include commissioning arrangements to assist with the continuity of care across care providers and geographical areas for these cases where relationships are paramount to recovery.

NHS England should ensure that resources are available nationally to help in the most complex of cases, rather than ringfenced for Provider Collaboratives.

NHS England should review the learning from this case to inform decisions on refining the role of a complex care coordinator/case manager/specialist intervener. Given that these are long-term placements, continuity of case management may also be boosted by a team approach. These teams would develop in-depth knowledge of complex cases and would enable clinicians to form relationships with commissioners and to familiarise themselves with the different commissioning thresholds and processes; they would also facilitate applications for specialist funding. The team would be a point of contact for patients, families and treating teams, keeping them up to date with progress, and providing a single point of contact for commissioners. It is also important for the degree of complexity to be identified at an early age so that appropriate resources can be directed accordingly.

ICBs should ensure that they are engaging with local social care and education partners to enable timely identification of young people with complex presentations.

Recommendations (cont.)

Recommendation 2: Working with international medical teams

Engagement with the young person’s [overseas] medical team was not evident; there was a lack of consensus about her diagnosis and a failure to approach [the overseas] services to understand their assessment.

Best practice guidance should be developed to support staff in navigating approaches to international medical teams or opinions.

Recommendation 3: Commissioning post ASD diagnostic support

We identified a lack of support after ASD was diagnosed. Literature suggests that if families are not offered adequate support following a diagnosis, this impacts negatively on parental mental health and family functioning and can lead to an over representation of families with an autistic family member being referred to receive family therapy. This is especially the case for families where ASD is diagnosed alongside co-occurring disorders and there is increased pressure in the family home.

The Autistica ASD Support Plan makes recommendations for how ASD support should be developed and delivered by 2030. Their report focuses on three areas:

- Support understanding ASD.
- Support preparing for the future.
- Lifelong support

NHS England and Specialised Commissioning should establish if a wider introduction of the Autistica guidance in supporting families with autism diagnoses is required across services.

Recommendation 4: Sharing learning

NHS England is keen to share the learning from this case across all regions.

NHS England Specialised Commissioning must share the learning from this case across all regions to ensure a multi-agency systemic approach to complex cases sufficiently early in the patient’s pathway.

Provider recommendations

Recommendation 5: Access to sensory integration assessments

Access to a sensory integration assessment helps inform restrictive practice, de-escalation and distraction, and other activities; however, there was a lack of opportunity for staff at the medium secure adolescent unit to access a sensory assessment.

Trusts and their commissioners should ensure that inpatient teams have a directory of staff, services, or organisations where staff are trained in sensory integration assessments. The commissioning of such sensory integration assessments should be at the discretion of the treatment team where sensory function is being considered.

Recommendation 6: Contested diagnoses

Throughout this young person's pathway there was consistent disagreement between her family and various clinical teams in respect of a professional opinion that she was autistic. This resulted in an inadequate diagnostic formulation of her autism and subsequent adjustments and care planning. This was partly responsible for delays in seeking a bespoke placement.

Trusts should set out guidance for staff to take when there is a contested diagnosis. This should include best practice in respect of best interest decisions and options for seeking independent views.

The guidance should include:

- mediation approaches;
- legal options; and
- when to seek independent advice.

Recommendation 7: Post diagnostic support

The young person's family was not offered the right support after ASD was diagnosed. Literature suggests that if families are not offered adequate support following a diagnosis, this impacts negatively on parental mental health and family functioning and can lead to an over representation of families with an autistic family member being referred to receive family therapy. This is especially the case for families where ASD is diagnosed alongside co-occurring disorders and there is increased pressure in the family home.

The Autistica ASD Support Plan makes recommendations for how ASD support should be developed and delivered by 2030. Their report focuses on three areas:

- Support understanding ASD.
- Support preparing for the future.
- Lifelong support

All services should introduce the Autistica guidance in supporting families with autism diagnoses. This should be embedded in protocols for organisations.

The application of support to families with a newly diagnosed family member with autism should be the subject of a thematic review.

Recommendation 8: Reflective practice

Reflective practice was sometimes difficult to access or provide when the service was understaffed or overwhelmed by the volume of incidents. Reflective practice allows teams to have a safe space in which to share concerns, communicate and connect with each other and to promote team and individual well-being. In addition, this space allows teams to consider issues broader than individual care; for example, how events influence care delivery or patient pathways. There can be challenges of maintaining this space when services are understaffed or overwhelmed but at these times the function and purpose of reflective practice groups is even more vital to maintain high quality care and staff well-being.

Trusts must ensure that group and individual reflective practice are essential parts of team development and must be facilitated when dealing with particularly challenging and complex patients.

Learning Quadrant

Individual/team practice

- Have I/we considered if a bespoke package of care would be appropriate for a complex patient?
- Have I/we considered if a patient's pathway and/or placement is appropriate? Is this clearly documented and reviewed regularly?
- Have I/we engaged the patient and their families in care planning?
- Have I/we explored if positive behavioural support can be used to gain a holistic understanding of a patient’s behaviours?
- Have I/we considered if a sensory integration assessment is appropriate?
- Do I/we have a clear and shared understanding of a patient’s diagnosis?
- Have I/we taken the time to understand a patient’s and their families views, particularly when there is a lack of consensus?
- Have I/we offered support to patients and their families following a diagnosis?
- When international medical teams are involved, have I/we engaged with them to gain collateral information?
- Is there an opportunity for us to reflect as a team or individually?

Board assurance

- Has a framework been developed to identify highly complex adolescent patients to facilitate the development of patient centred bespoke packages of care?
- Is there an escalation process to enable patient specific problem resolutions across health, social care and education?
- Do commissioning arrangements enable continuity of care across providers and geographical areas?
- Do we have sufficient monitoring and quality processes for complex pathways and placements?
- How are we assured collateral information from families and other professionals is proactively sought by staff?
- Do we have sufficient oversight for commissioned sensory integration assessments?

Governance focused learning

- How are we assured that complex patients are on the appropriate care pathway and placed in appropriate settings? Is this reviewed regularly?
- How are we assured that staff focus on patients’ needs particularly when addressing complex multifaceted issues?
- Are thresholds for services clear and do reasons for not accepting patients focus on the individual and their needs as a whole?
- How are we assured families are involved in a complex patient’s care and treatment and is there a whole care pathway clinician available to help families navigate complex care pathways?
- How are we assured of the safety of staff and other patients’ when managing complex patients?
- Are we assured staff are trained in positive behavioural support?
- Is there clear guidance for staff for follow when there is a contested diagnoses?
- Is the Autistica guidance used by staff when supporting families with autism diagnoses?
- How are we assured that sensory and sensory integration assessments take place at the appropriate time?
- Are we assured reflective team practice takes place and that staff can access external debriefs?

System learning points

- As an ICB, do we engage with local social care and education partners to enable timely identification of young people with complex presentations?
- Is there a clear system/pathway in place to ensure patients' have access to services that consider and help with complex and multifaceted issues?
- Is there an agreed approach in place for communicating with international medical teams?
- Do we have a structured approach in place for communicating with families?
- Is there a directory of staff trained in sensory integration assessments?