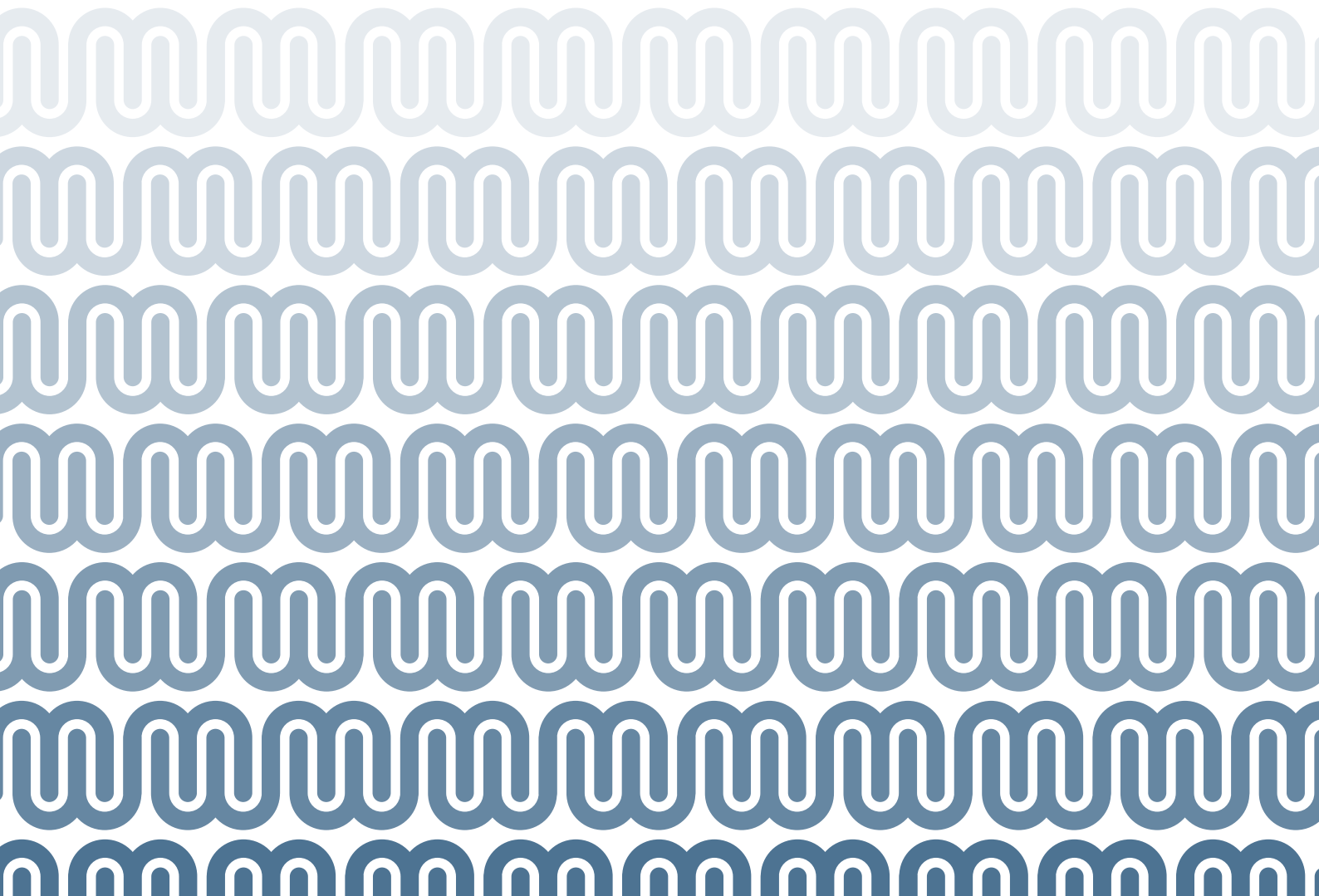




mental welfare
commission for scotland

Monitoring and visiting reports

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Our mission and purpose

Our Mission

To be a leading and independent voice in promoting a society where people with mental illness, learning disabilities, dementia and related conditions are treated fairly, have their rights respected, and have appropriate support to live the life of their choice.

Our Purpose

We protect and promote the human rights of people with mental illness, learning disabilities, dementia and related conditions.

Our Priorities

To achieve our mission and purpose over the next three years we have identified four strategic priorities.

- To challenge and to promote change
- Focus on the most vulnerable
- Increase our impact (in the work that we do)
- Improve our efficiency and effectiveness

Our Activity

- Influencing and empowering
- Visiting individuals
- Monitoring the law
- Investigations and casework
- Information and advice

Introduction

Background to visit

This is the first time that the Commission has undertaken a themed visit specifically looking at support for people with autism.

Autism Spectrum Disorder (ASD) is a term used to describe a lifelong developmental condition which affects social communication, social interaction and flexibility of behaviour, including sensory responses. Symptoms may include a range of difficulties with verbal and non-verbal communication and repetitive or very specific behaviour or interests. Within the autism community some people reject the concept of Autistic Spectrum Disorder. Some people prefer phrases such as 'autistic adult' and other prefer 'on the autism spectrum'. To reflect a range of perspectives, terms have been used interchangeably in this report, but we generally use the term 'autistic people'.

Autistic people with complex needs will often be treated and supported in hospitals or care services which are primarily designed for people with a learning disability or mental illness. We wanted to see if the particular needs relevant to autism were being adequately met in these settings, and to look at some services which specialised in support for this group.

We had concerns about people spending long periods in hospital, and about whether services were responding to challenging behaviours in a way which respected human rights.

Who we saw

Our visit focused on people who

- Have a primary diagnosis of autism
- Have significant and complex care needs
- Are aged between 18 and 65 years old, and are either:
 - inpatients in NHS Adult Acute, IPCU or Learning Disability inpatient wards and units;
 - subject to a formal civil order under the Mental Health (Care and Treatment) (Scotland) Act 2003 (MHA) or Adults with Incapacity (Scotland) Act 2000 (AWIA); or
 - in specialist autism services.

We saw 54 individuals – 28 in hospital, and 26 in a range of community settings. All were subject to at least one legal measure – 28 were subject to the Mental Health Act and 46 were subject to welfare guardianship under the Adults with Incapacity Act¹.

We also visited specialist autism services in Tayside, Renfrewshire and Northumberland, and consulted with carers and professionals.

¹ 20 were subject both to welfare guardianship and an order under the Mental Health Act

The policy background

In the last decade, autism has increasingly been seen as a policy priority. Notable initiatives include:

- The Scottish Strategy for Autism published in 2011. In 2018 the Scottish Government and COSLA issued a set of Outcomes and Priorities for the final three years of the strategy².
- SIGN Clinical Guideline 145 on Assessment, diagnosis and intervention for ASD by the Scottish Inter-collegiate guidelines network³ (SIGN 145).
- Coming Home: A Report on Out-of-area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs by Dr Anne MacDonald, which recommended the development of crisis services and flexible support responses, and the development of Positive Behavioural Support⁴.

² <https://www.gov.scot/publications/scottish-strategy-autism-outcomes-priorities-2018-2021/>

³ SIGN Clinical Guideline 145 on Assessment, diagnosis and interventions for ASD:
<https://www.sign.ac.uk/assets/sign145.pdf>

⁴ <https://www.gov.scot/publications/coming-home-complex-care-needs-out-area-placements-report-2018/pages/5/>

Assessment and diagnosis

What we expect to find

Anyone thought to have ASD should receive a full diagnostic assessment, together with a profile of the individual's strengths and needs, carried out by a multidisciplinary team which has the skills and experience to undertake the assessments. There should be post-diagnostic support, and a thorough assessment of needs for services.

What we found

Everyone we visited had had an assessment. Given our focus on complex needs, this was not surprising.

We found variations in the process of assessment, and particularly in the provision of post-diagnostic support. We heard that, in some areas, another diagnosis such as learning disability may mean that a possible diagnosis of autism may not be pursued – while in other areas a referral for ASD may be rejected *unless* the person has another disability.

We found concerns about the loss of specialist expertise because of changes in the organisation of services. There are particular problems carrying out specialised assessments in more rural and remote areas.

Where specialised services are in place, they can face significant pressures, and some respondents said there were lengthy waiting times for assessment and diagnosis – although in other areas with good multi-disciplinary teams the waiting times were low.

People described a wide range of experiences of assessment. Where there was a sense of collaboration between the individuals, families and the professionals, the experience of assessment was described positively. This included: having the opportunity to discuss the diagnosis with the team that had carried out the diagnosis, access to information (leaflets, websites) and access to peer support.

Many families we spoke to felt let down by the provision of post-diagnostic support.

Some of these assessments were done several years ago, but evidence from professionals suggested that many areas do not provide assessment and post-diagnostic support that meets the expectations of SIGN 145.

Recommendations 1 and 2

- NHS Boards should ensure that they are able to provide a comprehensive assessment and diagnosis for any person who may have autistic spectrum disorder and complex needs, which meets the standard set by SIGN 145.
- Integration Authorities should ensure that any person with a diagnosis of autism, whether or not combined with another condition such as learning disability, is given access to an appropriate range of post-diagnostic support, and that a plan for this is agreed with the adult and, where appropriate, their family.

Treatment

What we expect to find

We expect that autistic people with complex needs will receive appropriate, person centred and holistic care and support, with the involvement of a multi-disciplinary team. They will only be treated in hospital where they have specialist health needs which cannot safely be met in the community, with arrangements in place for a timely return to a community setting. All treatments will be properly authorised, with proper safeguards.

What we found

Multi-disciplinary working

Generally, we were satisfied that multi-disciplinary working was in place and operating appropriately. We were pleased to see examples of a person-centred approach, supporting the individual's strengths and with family and carers being involved.

Half of the people whose care we reviewed had had input from Speech and Language Therapy (SALT), but some carers highlighted difficulties in accessing adequate SALT support in the community.

It is estimated that 60-70% of autistic people have a sensory modulation/ processing disorder. Occupational therapists have a unique role in the assessment, diagnosis and treatment of sensory issues for individuals with ASD. We found examples of sensory assessments proving extremely helpful to staff in recognising triggers for increased anxiety and being better able to avoid or respond to these, resulting in improved communication and reduced use of 'as required' medication. Some professionals commented that this service needs greater recognition.

Psychological therapies

Positive Behaviour Support (PBS) is a set of strategies used to increase quality of life and decrease behaviours that challenge, by teaching new skills and making changes in a person's environment. The Government has committed to further investment in PBS.

We found good evidence of this model being used in hospital settings, to develop a stronger understanding of the context in which challenging behaviour occurred, and supporting the individual to be involved in support planning.

Access to the necessary support to pursue a PBS approach was less evident in some social care settings.

Medication

Psychotropic medication, such as antidepressants or antipsychotics, should not be routinely prescribed for autistic people but may be used to treat a co-morbid mental health condition.

Antipsychotic medication is also used at times to manage behaviour that challenges. Guidelines support the use of antipsychotic medication in conjunction with psychosocial

approaches to managing severe behaviour that challenges in people with ASD, but only where psychosocial approaches alone have failed.

Of the 54 people reviewed, 47 were prescribed psychotropic medications, and 26 of these cases involved psychotropic medication for challenging behaviour.

In general, we were satisfied that those given medication on an as required basis had a clearly documented care plan relating to this, and that appropriate legal authority was in place.

The individuals we reviewed have complex needs and often severe difficulties associated with their ASD. We did not undertake a clinical review of individual cases, and cannot therefore comment on the appropriateness of prescribing of medication to any one individual. Nevertheless, the figures are concerning.

In England there is an initiative to reduce over-prescribing on anti-psychotic medication amongst people with learning disabilities, and previously in Scotland there have been successful initiatives to reduce such prescribing for older people with dementia in care settings. We believe it is time for a concerted effort to do the same for autistic people in Scotland.

Recommendation 3

- The Scottish Patient Safety Programme should develop and lead an initiative to reduce the use of psychotropic medication with autistic people for the management of behaviours perceived as challenging.

Discharge planning

Coming Home and our *No Through Road* report⁵ highlighted that large numbers of people with learning disabilities, including people with ASD, experienced lengthy delays in being discharged from hospital. The same issue arose repeatedly among the people we visited.

Almost half (13/28) of the people in hospital were classified as delayed discharge. In some cases we heard that accommodation was being purpose built, and this was a positive step, albeit one that took a long time to achieve. Other causes for delay included difficulties in recruiting suitably trained staff, lack of funding, or delays in identifying a housing or care provider. In some cases, initial placement failures had been distressing and further delayed a final discharge. In one case, the fact that the council used a different restraint process was said to have caused a three month delay.

The problem of delayed discharge for this group is long-standing and pervasive, but it is not insurmountable. Sadly, the promise of integration has yet to be realised, with people spending long periods in hospital because of the complexities of funding, or different approaches by health and social care services.

This seriously compromises the human right of these adults to a life in the community, as enshrined in Article 19 of the UN Convention on the Rights of Persons with Disabilities. We

⁵ https://www.mwscot.org.uk/sites/default/files/2019-06/no_through_road.pdf

welcome the Government's recognition of the problem, but it is now time for a more systematic and time-bound commitment to addressing it.

Recommendations 4 and 5

- NHS Boards and Integration Authorities should ensure that they have arrangements to secure community provision for any autistic person with complex needs in hospital, within six months of their being assessed as able to be supported in the community. This should include discharge planning co-ordination from the point of admission.
- The Scottish Government should monitor delivery by NHS Boards and Integration Authorities of the above recommendation, and work with them to address any barriers to delivery over the next two years.

Support/Staying well

What we expect to find

People, wherever they live, should have a range of meaningful and enjoyable activities tailored to their needs. They should be able to access the community, including through accessible transport, and maintain family links. They should be supported to develop their skills and self-care. Their physical health needs will be met to the same standard as other citizens. When they need it, they should have access to independent advocacy.

What we found

We heard many positive stories, demonstrating how people with complex needs could be supported to participate in the community, and take part in volunteering, sports and creative activities. However, we were disappointed to find that one third of those we interviewed did not have structured personalised activities. Hospital timetables were described as 'limited and unimaginative', or reliant on family members taking the adult out. In the community, one professional commented

Lack of structured meaningful activities available in the community means that boredom can be a factor which negatively influences a person's presentation. Funding cuts to community support services, leisure activities and college courses is having a huge impact and increasing referrals to health teams.

We also found variable access to advocacy services.

These services should not be seen as optional extras. Under the Mental Health Act, local authorities have legal duties to secure a range of services for people covered by the Act, including people with autism. These services include care and support to give people 'the opportunity to lead lives which are as normal as possible', access to social, cultural and recreational activities, transport and advocacy.

Many autistic people have other physical health conditions, including epilepsy, gastrointestinal problems or infections. Where people have communication difficulties, diagnosis can be complex. It is important that anyone in a care setting has their health needs monitored. We were disappointed to find that only half of the people we reviewed had an easily identifiable record of an annual health check.

These services should be seen alongside the range of other treatments and supports which a person with complex needs will require. Carers we spoke to stressed the need for better, more personalised co-ordination of all aspects of care, particularly for people with complex health needs.

Recommendation 6

- Integration Authorities should ensure that autistic people with complex needs in community settings have a **dedicated co-ordinator** to oversee the full range of provision to meet their needs, which should include:
 - access to SALT, OT and psychosocial interventions, which meet the standard set by SIGN 145;
 - promotion of good health, including access to health screening, and oversight of complex health needs;
 - a tailored activity plan, which addresses needs for meaningful roles and routines including self-care, education, employment and leisure; and
 - support for family carers, including ensuring a Carer's Assessment is offered, where appropriate.

Responding to Crisis

What we expect to find

Autistic people often experience difficulties when regulating their emotions. Overwhelming and stressful situations can lead to loss of behavioural control leading to a crisis for the individual.

We expect there to be clear plans, developed with the adult and family wherever possible, setting out how to reduce the risk of a crisis occurring, and what to do to respond to the crisis. Where people may require to be restrained, this should be done safely, and lessons learned for the future.

What we found

Crisis planning

We were pleased to see that the majority of the people we spoke to had a crisis plan, and that on the whole individuals, families and staff found them helpful. We found good examples of crisis plans in both hospital and community settings.

The best of these included indicators of possible crisis, responses to divert or de-escalate crisis, information about the patient's point of view, a clear procedure for the response if the crisis occurs, follow up after the event, and regular review as needs change. Where families were involved, their experience and understanding of the adult helped greatly in preparing a good plan.

Rapid access to the multi-disciplinary team was seen as important at times of crisis. For those in the community, access to hospital was often important, although this was not always possible, particularly in rural areas, and hospital admission is not a panacea. It can be difficult for the adult to return quickly to a community setting if a placement breaks down in a crisis, so it is important to ensure that community services have the training, planning and resilience to support people through crisis wherever possible.

Restraint

Restraint was an issue in 16 of the 28 hospital patients we visited, and four people living in the community. This included arm holds, wrist straps when the adult is in public, specialised chair, and one example of prolonged restraint on the floor.

We found reasonable evidence of recording and reviewing of episodes of restraint, and appropriate decisions not to restrain because of known risks. We found a number of positive examples where the use of restraint had been successfully reduced through clear strategies and careful planning.

We were pleased to see in a number of cases where welfare guardianship was in place, that the use of restraint had been specifically considered and authorised in the powers granted.

Notwithstanding these positive findings, restraint is a distressing and potentially dangerous intervention, and it is important to continually review whether there are other better ways of keeping a person safe, particularly reducing the factors which cause behaviour expressing distress in the first place. We note the commitment following the *Coming Home* report to roll

out PBS more widely, and we are reviewing our own guidance on restraint, but would like to see more work done.

The Scottish Patient Safety Programme has focused on restraint in mental illness settings, and has been successful in reducing its use, without compromising safety. We should learn from this approach.

Recommendations 7 and 8

- The work of the Scottish Patient Safety Programme to reduce the use of restraint in mental illness settings should be extended to NHS and community services supporting autistic people with complex needs.
- NHS and community services should ensure that they have policies concerning restraint and seclusion affecting autistic people with complex needs which include consistent recording, feedback, staff training, and improvement plans to reduce their use over time.

Environmental issues

What we expect to find

A safe, welcoming and comfortable environment is particularly important for autistic people, who are often highly sensitive to sensory stimuli, including noise, light and smells.

We would expect hospitals and homes to be bright, clean and welcoming and free from excessive noise. We would also hope to see that effort has been made to make the areas “autism friendly” and that quiet areas with low stimulation and simple décor personalised to the individual where appropriate are in place.

What we found

In some cases, occupational therapists and assistant psychologists had been involved in preparing detailed environmental recommendations; but in others it appeared that professionals relied on their general awareness and even ‘common sense’.

We looked specialised services including the Mitford Unit, Northgate, England. We were impressed by the imagination and sensitivity shown in planning the environment in the Mitford Unit, which had a major and positive impact on residents.

Hospital wards we visited had single rooms and most had en-suite facilities, and quiet areas. Most had been able to make some adjustment to meet the needs of patients with ASD, for example the installation of a sensory room. Many units found creative ways to address issues of noise and light.

However, in some units there were inherent limitations of existing buildings and available space. Staff felt, and we agree, that busy admission units or assessment and treatment units were simply not appropriate for autistic people with complex needs – there was too much busyness and noise.

In a few instances, it was clear that the environment was wholly unsuitable, and led to great difficulties in nursing the particular patient.

Environment is stripped back - excessive damage, no doors, damaged floor and tiles and area generally unclean.

Community services generally had more scope to adapt the environment to suit.

Overall, hospital services had thought about how to meet the needs of patients and residents, but sometimes this felt improvised, rather than adopting a systematic approach drawing on evidence-based best practice. Services were responding to problems once they arose, but with more thorough initial assessment, these problems might have been avoided.

Recommendation 9

- NHS Boards should ensure that there is an individualised environmental and sensory assessment whenever a person with autism is admitted to a mental health or learning disability ward, using an appropriate assessment tool which is reviewed with the person regularly during their stay.

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Training

What we expect to find

All staff working with people with autism should have received autism specific training appropriate to their needs.

In 2014, NHS Education for Scotland published the Autism Training Framework: Optimising Outcomes⁶. This framework details the knowledge and skills required at different levels within the health and social care workforce to achieve key outcomes for people with an autism spectrum disorder, their families and carers.

What we found

We found that staff were aware of the Training Framework, but there was little evidence of their having used it, and there appeared to be a poor understanding about its implementation. We were also concerned to hear from a range of professional staff that clinical supervision was not consistently available.

Concerns were also raised about training in third sector and private care agencies, whose staff were often poorly paid with little prior experience with people with ASD and complex needs.

We are concerned by this. In the current state of services, it is inevitable that people with ASD will find themselves in services primarily designed for other conditions. Specialist support is highly stretched. It is therefore vital that frontline staff have the right skills and knowledge to support well people with autism and complex needs.

Recommendation 10

- NHS Boards, local authorities and Integration Authorities commissioning services should ensure that anyone who is providing services to a person with autism and complex needs is trained to the appropriate level of the NES training framework and where appropriate receives ongoing clinical supervision.

⁶ <http://www.knowledge.scot.nhs.uk/media/9595218/asd%20web%20final%20%282%29.pdf>

The needs and views of carers

All of the families we spoke to described significant, distressing and often ongoing negative effects that the diagnosis and subsequent care has had on their families.

It could be difficult to maintain a family unit, to have any life as a family, or to ensure care of siblings. For some it meant loss of marriages, careers and family life including holidays, birthdays and other celebrations. Some families expressed anxiety for the continued care of their relative once they were no longer able to contribute.

Most of the carers we spoke to had not been directed to any support for themselves and only two had had an Assessment of Needs. We saw no evidence that the new rights for carers introduced in the Carers (Scotland) Act 2016 had made a positive difference for this group of families.

We asked if there was one thing carers could identify that would make a positive difference. The ultimate aim of most was to have the individual in a well-supported community placement managing to live a full life with as much independence as possible, and a better range of activities. Co-ordination among services and streamlined care was mentioned with the suggestion of a 'care manager' type role to facilitate this. Having their own opinion and unique knowledge of the individual acknowledged and respected was important.

This perspective reinforces our view that, for this small group of people with complex needs, a more systematic co-ordination of care and support by people with appropriate expertise is required.

Conclusion

The people we met had a range of complex, individual needs, and there was a wide variation in the extent to which services were currently able to meet those needs well. Getting it right takes time and expertise, and can be expensive. But it was also clear that getting it wrong, and failing to design services around the individual, could be even more expensive, in coping with problems which might otherwise be avoided. Equally importantly, it fails the individual, and leaves professionals and care staff unable to give the high quality care and support we know they want to give.

The increased recognition of the needs of autistic people in recent years is extremely welcome. We know a lot now about what a good service should look like. The challenge is to deliver that everywhere, allowing autistic people to live fulfilled lives, and their families to be assured that they have the stability and personalised care that they deserve.



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