mental welfare
commission for scotland

Autism and complex care needs

Visiting and monitoring reports

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30 October 2019

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

Contents

List of recommendations

1. 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 clinical guideline 145 (SIGN 145).
2. 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.
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
4. 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 6 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.
5. 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.
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:
    a. access to SALT, OT and psychosocial interventions, which meet the standard set by SIGN 145;
    b. promotion of good health, including access to health screening, and oversight of complex health needs;
    c. a tailored activity plan, which addresses needs for meaningful roles and routines including self-care, education, employment and leisure; and
    d. support for family carers, including ensuring a Carer's Assessment is offered, where appropriate.
7. 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.
8. 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.
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.
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.

Introduction – Policy background

What is Autistic Spectrum Disorder?

Autism Spectrum Disorder (ASD) is a clinical 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. The term 'spectrum disorder' is used because the degree of impairment autistic people experience varies greatly and affects people in different ways.

It is estimated that there are over 58,000 people in Scotland with ASD, although only a small proportion of them have the kind of complex needs of the people we visited.

Someone can have **complex needs** because of learning or physical disabilities, autism, mental illness, acquired brain injury or dementia, often combined with physical health needs that might include epilepsy or sensory issues. The term may also reflect behaviour that is perceived as challenging.

A note on terminology

The terms used to describe people and their needs can be controversial. The social model of disability challenges the assumption that problems associated with disability are caused by the individual's impairment, rather than societal barriers and inequalities. Similarly, there is a debate around neurodiversity – the perspective that autism and related conditions should not be seen as a problem, but as a variant on the spectrum of humanity that has strengths as well as difficulties. For these reasons, some autistic people and their families would reject the term autistic spectrum disorder, although it is still in wide clinical use.

Some people prefer phrases such as 'autistic adult' and others prefer 'on the autism spectrum'. In order to reflect a range of perspectives, terms have been used interchangeably in this report. However, we generally use the term 'autistic people'.

We refer in places to 'challenging behaviour', or behaviours perceived as challenging. Some people would use other terminology, such as behaviour that expresses distress. We have generally used the phrase used by most of the people we spoke to, and which was used in documents such as care plans. We agree, though, that such behaviour should not be viewed as an inherent fault in the person, and nor is it the case that the autistic person is intentionally challenging anyone. It should be seen as a response to distress caused by the environment and circumstances faced by the person.

The policy background and the development of ASD services

In the last decade, autism has increasingly been seen as a policy priority, although organisations representing autistic people and carers stress that there are still many gaps in services, and some gains have not been sustained.

These developments have taken place in the context of a wider shift in society's approach to disability and difference, which can be seen in the **Equality Act 2010** and the **UN Convention on the Rights of Persons with Disabilities.** Put simply, the social model of disability argues that the difficulties experienced by disabled people are not an inevitable result of their individual condition, but are a result of barriers, negative attitudes and exclusion by society. The response therefore should be to remove these barriers to allow disabled people to flourish as equal citizens.

In 2011, the Scottish Government and COSLA published the **Scottish Strategy for Autism**. It set out a ten year vision, and included 26 recommendations, and ten 'indicators for best practice', including that ASD provision should include a multi-agency pathway for assessment, diagnosis and intervention to improve the support for people with ASD and remove barriers.

As part of the Scottish Strategy, every local authority area should publish a local Autism Action Plan or Strategy[1].

In 2014, NHS Education for Scotland published the **Autism Training Framework**, which sets out the knowledge and skills required at different levels within the health and social care workforce to achieve key outcomes for autistic people, their families and carers. The Strategy Outcomes and Priorities for 2015-17 included implementation of this framework.

Also in 2014, the National Institute for Health and Care Excellence (NICE) published **Quality Standard 51 on Autism**[2]. This was designed for England and Wales, but many of its quality statements are of relevance in a Scottish context, including that people having a diagnostic assessment for autism are also assessed for coexisting physical conditions and mental health problems; that a personalised plan should be developed in partnership between them, their carers and the autism team; and that people whose behaviour challenges are assessed for possible triggers, and should not be offered antipsychotic medication for their behaviour unless psychosocial or other interventions are insufficient or cannot be delivered.

In 2015, during the passage of the Mental Health (Scotland) Act, questions were raised about the inclusion of autism and learning disability within the definition of 'mental disorder' in the MHA (which definition is also used in the AWIA). As a result, the Government commissioned an **independent review** chaired by Andrew Rome and supported by the Commission, of learning disability and autism in the MHA[3]. The review is due to report in December 2019.

In 2016, the Scottish Intercollegiate Guidelines Network (SIGN) published guidance on **Assessment, diagnosis and intervention for ASD (SIGN 145)[4]**. It recommended that people suspected of having ASD should be referred for specialist assessment, carried out by a multi-disciplinary team, and set out key features of such an assessment. It advised that all service providers should ensure that staff have up-to-date knowledge and adequate skill levels.

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[1] https://www.autismstrategyscotland.org.uk/news/local-autism-action-plans.html

[2] https://www.nice.org.uk/guidance/QS51

[3] https://www.irmha.scot/

[4] https://www.sign.ac.uk/assets/sign145.pdf

In 2018, the Scottish Government and COSLA issued a set of **Outcomes and Priorities** for the final three years of the autism strategy[5]. This included Strategic Outcomes of the highest attainable standard of living, health and family life and timely access to diagnostic assessment and integrated support services, and autistic people being able to live in community with equal access to all aspects of society; and commitments to explore alternative solutions to out of area placements for complex care needs.

In March 2018 the Government published a research report on the costs of autism – **the microsegmentation project**[6]. This included the following recommendations:

- every NHS Scotland Health Board should have, or should have access to, a multi-disciplinary team to identify and assess autistic adults;
- there should be an increased focus on personalised approaches which tailor interventions to the individual needs, strengths and personal preferences of autistic children and adults; and
- regular health checks should be made available to the whole autistic population.

In November 2018, the Scottish Government published **"Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs"**, by Dr Anne MacDonald[7]. This identified 705 people with learning disabilities placed out of area, of whom 453 were out of area not through choice, and 109 were classed priority for return. Around 50% of the priority for return group had ASD. The report's recommendations included the development of crisis services and flexible support responses, a more proactive report to planning and commissioning services, linked to local housing plans, and workforce development in Positive Behavioural Support.

In March 2019, the Scottish Government published its **Framework and Priorities 2019-21 for the Keys to Life**, its learning disability strategy[8]. That included a commitment to invest in the development of Positive Behavioural Support and provide direct support to Health and Social Care Partnerships to consider the findings of the 'Coming Home' report.

Also in March 2019, at the Scottish Strategy for Autism Seventh Annual Conference, the Minister for Mental Health announced[9] the launch of a **Scottish Government National Autism Implementation Team** (NAIT) to develop collaborative working, with speech and language therapy, occupational therapy, education, psychiatry & strategic planning. The NAIT team is happy to provide specialist advice and knowledge to NHS Boards, Integration Authorities and others to whom recommendations in this report are directed[10]. In addition, Scottish Government announced the development of a Post-Diagnostic Toolkit and the launch of a

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[5] https://www.gov.scot/publications/scottish-strategy-autism-outcomes-priorities-2018-2021/

[6] https://www.gov.scot/publications/microsegmentation-autism-spectrum/pages/4/

[7] https://www.gov.scot/publications/coming-home-complex-care-needs-out-area-placements-report-2018/pages/4/

[8] https://keystolife.info/wp-content/uploads/2019/03/Keys-To-Life-Implementation-Framework.pdf

[9] https://news.gov.scot/news/increasing-support-for-those-with-autism

[10] The NAIT team can be contacted at NAIT@qmu.ac.uk

social movement highlighting asset/strengths based model of autism in the style of the See Me campaign, designed to challenge perceptions of autism.

Why we carried out these visits

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

The Commission's strategic plan for 2017/20 commits us to prioritising people who are most vulnerable, and as part of that to develop a programme of themed visits which focuses on groups who appear to experience particular disadvantage, including borderline personality disorder and autism.

We know that autistic people have particular needs which may not always be met in settings primarily designed for people with other conditions, and that many of them will also have a learning disability or mental illness. Where they do, they will often be treated and supported in general learning disability or mental health wards or care services.

In 2016 we published our report on 'The death of Ms MN'[11]. This concerned a woman with Asperger Syndrome and complex needs, who took her own life following a period in hospital and a transfer to a care home. We commented that:

> "We believe that people diagnosed with autism or Asperger Syndrome too often fall between mental health and learning disability services, or are pushed into one or other category, when their needs are distinct."

None of the medical or nursing staff we spoke to who worked with her had any significant training in the needs of autistic people. We recommended that the Scottish Government should audit the availability of specialist services for individuals with highly complex needs who are not appropriately accommodated in learning disability or mental health settings, and identify how gaps can be filled.

This concern about the adequacy of support for autistic people in generic mental health and learning disability services was also reflected in our general programme of local visits, our casework, and discussions with stakeholders.

Where people were in specialist services, these were often a long distance from home, sometimes in England. And where people required a period of in-patient care, we were concerned about delays in arrangements for them to move on to appropriate community provision.

The nature of the care and treatment also raised human rights issues. We were aware of situations where in-patients with ASD and challenging behaviour were subject to highly restrictive regimes. In some cases, this included significant periods in seclusion and close

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[11] https://www.mwcscot.org.uk/sites/default/files/2019-06/ms_mn_investigation_summary_report.pdf

observation, where it seemed plausible that the behaviour was at least in part a response to the environment the person was living in.

In other cases, care plans involved deliberately creating a low stimulus environment with relatively little human interaction. This could be an appropriate response to the person's needs, but still raised significant legal and ethical questions.

Planning and consultation for this themed visit

In 2016 and 2017 we met with a range of organisations, including the National Autistic Society, Scottish Autism, Autism Initiatives and PASDA and attended consultation events on the National Autism Strategy. Commission practitioners attended carers' meetings in their local areas.

In March 2018 we held a consultative workshop at a meeting of the Autism Network Scotland, which included autistic people and we held a further workshop in May 2018 with a small group of professionals working in the field. During these workshops we explored our potential areas of enquiry, and sought to identify particular services which might be examples of best practice.

We grouped the issues of concern into four key themes, which we have set out in this report: Assessment and diagnosis; Treatment and support; Keeping well; and Responding to a Crisis.

We are extremely grateful to everyone who assisted us in developing our plans.

We decided to focus our visit 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 excluded people in forensic mental health services – we visited all low and medium secure forensic mental health services in 2016-17.

The focus reflected our concern that people with complex needs may not be receiving appropriate support, and allowed us to target a manageable group of people, within a wide range of services.

We found that transitions (e.g. from childhood to adult services) was a major concern for many autistic people and their families. However, a significant amount of work was already underway in relation to this issue, and we decided not to focus on the topic in this visit.

How we carried out the themed visit

In May and June 2018 we carried out four pilot visits to test our draft questionnaires.

Between June and August 2018 we visited 24 people with an ASD diagnosis whose welfare guardianship order under the AWIA had been renewed in the preceding six months. We sought to achieve as wide a range of local authorities as possible, with a balance of 80% private guardianship and 20% local authority guardianship, and with 70% male and 30% female.

Between October and December 2018 we visited individuals receiving in-patient care in adult acute, learning disability and IPCU wards and units who were subject to orders under either the MHA or AWIA. We contacted the managers for these services to ask them to flag up for us individuals in those wards who met our criteria, excluding those whom the Commission had visited in the last 6 months, or who were the subject of ongoing Commission activity.

In advance of in-patient visits we issued a questionnaire for staff, which we discussed with staff on the day. We met with patients where possible, and reviewed patient records.

We sought also to meet carers, relatives and friends, and provided a carer package for staff to distribute to them. We received 19 returns from family carers.

In total, we saw 54 individuals, from 22 local authority areas. 38 were male and 16 female.

28 were in hospital, nine were in residential care establishments, and others were in a mix of family homes, rented tenancies and supported accommodation, with one owning their own property. Care packages ranged from a few hours a week to 24 hour care.

28 people were subject to the MHA (CTO – 26, CCTO – 1, STDC – 1), and 46 were subject to welfare guardianship under the AWIA (private – 27, local authority – 19). 20 were subject to both Acts.

We obtained views of professionals working in the field via consultation and returns from hospital and residential placements visited.

In December 2018 we also sent out a short survey to professionals with an interest in ASD from a range of disciplines including psychiatry, nursing, social work, psychology, allied health professionals and the voluntary sector.

Specialist services

We also visited some specialist services, which we felt were examples of excellent practice which others could learn from.

Autism Connections, Renfrewshire

Autism Connections offers advice and support to services within Renfrewshire Health & Social Care Partnership (HSCP) to help them to become autism friendly. The small team is based at Spinners Gate Resource Centre and its aim is to increase knowledge and understanding of autism and associated disorders amongst local services.

They work with Renfrewshire HSCP services and the Renfrewshire Learning disability team. Autism Connections offers advice and direct support and training to the aforementioned services, and do not carry out direct therapeutic work. The team has a range of skills, training and experience: they understand that services will, at times, need support and guidance when supporting autistic people.

We were impressed by this team's application and understanding of the NES Autism Training Framework, and how the team had applied the framework to practice. They also demonstrated how they worked with the interface between training and the Menu of intervention. This small service has achieved much since it became operational in 2016. They have supported over 250 referrals to the service, have trained over 180 staff to the "autism informed level", and developed a library of books and resources for autism support as well as supporting front line teams to build capacity in delivering an autism informed service.

Tayside Adult Autism Consultation Team

This service became operational in January 2014. The multidisciplinary team consists of a range of professional experts in autism, psychiatry, psychology, nursing, occupational therapy and speech and language therapy. They provide a much needed diagnostic and consultancy service. Demand for the service exceeds capacity, and there is a considerable waiting list.

We were impressed by the quality of the assessment and diagnosis service and the clear policies and frameworks underpinning this model.

The team comment on the complexity of ASD individuals who are referred to their service; if they present with risk they are prioritized and assessed earlier, or the team can support the service that are already caring for the individual. The assessment and diagnosis process takes two to three sessions, and the team commented on the need for all relevant information to be presented to ensure that the assessment process is timely.

When a diagnoses is made, the individual and carer are given a verbal explanation and the opportunity to discuss the diagnosis with relevant team members. They are also given written information, and signposted to relevant websites. They also refer to the one stop shop in Perth, which offers post diagnostic support and information on local services.

We were also told about the Dundee Autism Support Hub which opened in March 2018.

The staff team are aware of the challenges of maintaining their expertise. Their knowledge and skills are maintained through training and staff supervision; this occurs through clinical meetings, peer supervision and also external expert supervision when required.

Northgate Hospital, Morpeth, Northumberland

We visited the Mitford Unit, Northgate in England because several individuals have had out of area placements there from across Scotland. The typical care pathway involves a stay of 18 months - two years during which individual stimuli and appropriate therapies are identified, before returning to the community.

Mitford is a purpose built facility providing inpatient treatment and support for adults with severely complex autistic spectrum disorders. The building provides care for up to 15 adults in single and shared flats. It claims to be the first building in the UK specifically designed for this service-user group.

Wide, organically-shaped circulation spaces encourage movement but offer a measure of privacy and 'safe' window seats. All the flats are orientated to the east for a comfortable internal environment, with direct access to private gardens.

Mitford staff told us that, after only a few months of opening, the building and clinical environment had enabled improved care provision and was having a hugely positive impact on the patients.

Happiness is ... getting everything you asked for. I never thought it would be so good. The building has been tested and it stood up to it all. The entire design of Mitford has been centred around people with autism, with slow stimulus environments and very specific features to help reduce anxiety for the people we support. This new building will provide one of the most tailored environments in the country for adults with an autism spectrum disorder.

There's one patient who used to live permanently in seclusion and crawled everywhere. Within a week of moving into Mitford he was having a coffee with staff in one of the offices.

One carer gave us an account of the excellent care received by their family member at Northgate, leading to a successful return to services in Scotland.

The staff were very professional and also friendly, understood autism and tailored his needs to his ability of understanding of what was required of him. Our son … had lost a lot of social skills when he was admitted to Northgate Hospital. When he was transferred back to [Scotland] he was a very much improved and a much better behaved person (He still has behavioural problems but I would say more manageable).

There are many ways … they helped him to improve and have a better quality of life. One example is that he would only have a cold shower or bath and refused to have it any warmer, they altered the temperature of the water by very small degrees until it was a warm and comfortable temperature. He does not like a lot of things in his room so they had an extra storage place for his belongings some were gradually introduced to his room others only used under supervision.

The new staff shadowed the other staff members so that they could see how they worked with him and then they were able to find their way of how to respond to various situations.

Assessment and Diagnosis

Scottish Strategy for Autism 2018-21, Strategic Outcome 1:
"Autistic people … have timely access to diagnostic assessment and integrated support services."

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. Carers and families should be involved in the assessment and diagnosis and intervention process, and they and the adult should have access to support during the process. Once diagnosis is confirmed there should be post-diagnostic support, and a thorough assessment of needs for services, with appropriate referrals for further assistance[12].

We asked autistic people and their families about their experience of assessment and receiving the diagnosis. We asked professionals how assessment and diagnosis was provided and how it was working in their area.

Rights

People have a right to information about their diagnosis given in a way that they understand and an opportunity to discuss this with the team providing care and access to services. This reflects Article Eight of the European Convention on Human Rights (ECHR) and the Patients' Rights (Scotland) Act 2011.

What we found

Availability and format of assessment

The returns suggested that there is still a wide variation in the format and availability of assessment and diagnosis services across the country.

Sometimes having another diagnosis, such as a learning disability, can be a barrier to proper assessment of autism.

> *I have found that some adults who have clear autistic trait but, if there is already a diagnosis of learning disability, a diagnosis is not pursued. I feel that these clients do not get a good service. (Professional).*

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[12] Sign Clinical Guideline 145 on Assessment, diagnosis and interventions for ASD: https://www.sign.ac.uk/assets/sign145.pdf

Conversely, the *lack* of a co-existing condition can in some places create a barrier to a full assessment:

Some referrals for ASD are rejected due to lack of functional disability. Assessments are often delayed/postponed due to the need to prioritise more acute/risky mental health disorders. Once diagnosed discharged from follow up. Assessment and treatment of comorbid anxiety/mood disorders. Currently referrals for ASD assessments in adults comprise approx. 20% of referral (Professional).

We found concerns about the loss of specialist expertise because of changes in the organisation of services, for example that a disaggregation of a regional service supporting those with learning disability and complex needs would lead to a loss of expertise and efficiencies of scale, and poorer outcomes in the short to medium term.

We believe that there is an important synergy between specialist and generalist services, for example in the work of organisations such as Autism Connections, where a small specialist team works alongside generalist services to increase their understanding and capacity to support autistic people.

Where specialised services are still in place, they can face significant pressures, including recruitment and retention for key staff groups.

The specialised assessment team is excellent but massively overstretched and under resourced resulting in long waiting list for assessment. (Professional).

Unsurprisingly, there are particular problems carrying out specialised assessments in more rural and island areas.

In general psychiatry services, if someone is referred to us, and autism is relevant, I can diagnose and advise, but we do not have a specialist service for ASD diagnosis (Professional)

There is no support in our area for autistic people which is difficult for mental health nurses to manage (Professional)

When complex issues or challenging behaviour arises with people with diagnosis of autism they do not have the multi-disciplinary input that they would have in an urban area. This impacts on social work and social care staff are therefore being left to manage individuals with such issues without the specialist health input that is needed. (Professional)

We were told about some services that had relatively low waiting times for ASD diagnosis, and the value of the multi-disciplinary team (MDT).

> *Relatively low waiting times for ASD diagnostic assessment. Involvement/contribution to diagnostic assessment from Multidisciplinary Team (speech and language therapist, occupational therapist, psychiatrist, psychologist and nursing). We have two sessions per week dedicated to ASD clinical development group/diagnostic service. (Professional)*

However, some respondents said there were lengthy waiting times for assessment and diagnosis.

> *There is an adult autism service but there is a very long waiting list and it appears after diagnosis the patient reverts to general adult service with little specialist input. I am a general adult psychiatrist but have a number of patients on my general adult case load who have autism and complex needs. (Professional).*

Documentation of assessment

We found information on assessment and diagnosis for most of the people we met. About half of those individuals were diagnosed when they were under ten years of age.

For six people there was no information on assessment and diagnosis. All of those were aged over 50, and had been residents in institutional care for many years.

Process, tools and formulation

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 and people said that this approach should be more widespread.

> *There was a multiagency meeting that all parties were involved in, there was good communication about what was happening and all our views taken on board. (Carer)*

Descriptions of good information being given following diagnosis included: having the opportunity to discuss the diagnosis with the team that had carried out the diagnosis, leaflets, access to websites relating to ASD, access to peer support.

> *The family felt involved in the assessment and diagnosis process, we were provided with lots of information following my son's assessment.*

One parent fondly remembered a parent training series

Yorkhill were fantastic. Went for four afternoons every fortnight. It was training for parents run by Autism Intervention - watching them and me observing their interactions when he was aged four through two way glass. Amazing experience and the support and understanding I got from that has stayed with me. Don't think they do it anymore.

We asked staff about the formal diagnostic tools used in their service. The main tools mentioned to us were; The Diagnostic Interview for Social and Communication Disorders (DISCO), Summary specialist assessment, Autism Diagnostic Observation Schedule (ADOS), Autism Diagnostic Inventory (ADiR).

Post diagnostic support

Staff highlighted the value of a clear pathway to services and post diagnostic support. These were not always available.

There is no after care for patients following diagnosis. There is a need for more specialised autism support for patients once their care has reverted back to general adult services, those services are often ill equipped to help and support adults with autism. (Professional).

Where individuals and families had access to a one stop shop, they felt that this service was helpful with post diagnostic support and information on what local support services were available. Unfortunately the future of these services is unclear. Six were established as pilots with Scottish Government seed funding, as part of the Autism Strategy. By the time of the publication of the Strategy Outcomes and Priorities for 2018-21, only four remained.[13]

In the majority of cases we found the assessment process was lengthy. Many families we spoke to felt let down by the provision of post diagnostic support.

It was a lengthy process with lots of appointments, a lot of different professionals were involved, after the diagnosis there did not appear to be a good provision of support.

Once my son was assessed and diagnosed it took a long time to find suitable services for him.

After diagnosis "it felt like we just had to get on with it".

I was involved in the assessment process but once diagnosed was offered no advice/follow-up about what this diagnosis meant for us going forward.

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[13] In Fife, Perth, Ayrshire and Highland. See p5 https://www.gov.scot/binaries/content/documents/govscot/publications/corporate-report/2018/03/scottish-strategy-autism-outcomes-priorities-2018-2021/documents/00533392-pdf/00533392-pdf/govscot%3Adocument/00533392.pdf

Information from carers suggests that there needs to be more help and support available post diagnosis for families; not only looking at what information but when and how it is given. When the diagnosis is given alongside other serious medical issues the support required for autism can be overlooked. Sensitive delivery at a time when families can take it in is also essential for any effective support.

> *We were offered a range of information at the time of diagnosis but we were so caught up in the range of physical conditions [our relative] had that we did not pay too much attention to this diagnosis of ASD.*

In some cases, these assessments were done several years ago. However, evidence from professionals suggests that many areas still lack the kind of assessment process and post-diagnostic support which SIGN guidelines recommend, and which the Autism Strategy is intended to achieve.

We are also concerned that the model of post-diagnostic support being developed as part of the Strategy (the one-stop shop) does not appear to be sustained, and it is not obvious that alternatives to a valued service are being developed.

We are not in a position to prescribe a particular model of service, but we believe autistic people and family carers are entitled to expect comprehensive assessments linked to post-diagnostic support built around their particular needs. This has already been recognised for other conditions such as dementia[14], and we believe the same should apply for ASD, particularly for people with complex needs.

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[14] Scotland's National Dementia strategy contains a commitment to a year's post-diagnostic support, with a named Link Worker: https://www.gov.scot/binaries/content/documents/govscot/publications/strategy-plan/2017/06/scotlands-national-dementia-strategy-2017-2020/documents/00521773-pdf/00521773-pdf/govscot%3Adocument/00521773.pdf

Treatment

Scottish Strategy for Autism 2018-21 Strategic Outcome 1:

"A Healthy Life: Autistic people enjoy the highest attainable standard of … health."

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, including psychology and other allied professions such as speech and language therapy. They will only be treated in hospital where they have specialist health needs which cannot safely be met in the community, and only for a limited period, with arrangements in place for a timely return to a community setting. All treatments given without consent will be properly authorised, with proper safeguards against the inappropriate use of psychotropic medication.

Rights

Everyone has the right to adequate healthcare for their physical and mental health needs, and to NHS care which is patient focussed and encourages participation. This includes access to mental health services including early intervention, good support from primary care and the local authority. This reflects Articles 2 and Article 3 of the ECHR and article 25 of the United Nations Convention on the rights of Persons with Disabilities (UNCRPD).

What we found

At consultation we heard about the value of multi-disciplinary expertise in care and treatment of the adult and of positive behavioural support plans. We were also told of the lack of psychological therapies which were adapted for autism.

We asked individuals about treatment and support for autistic people and how helpful they found it. We asked professionals about what was provided in their area, the format and tools used, and how it was working.

Multidisciplinary Team involvement.

Professionals consistently cited multi-disciplinary team working as being key to a good service for this group of people.

Of the 54 people reviewed, the majority had three to nine professionals involved with treatment and support. Just five individuals had only one or two professionals involved (GP and psychiatrist).

> *Adult seems to have had good multidisciplinary support during their admission receiving input from psychiatry, psychology nursing occupational therapy, speech and language therapy and pharmacy and advocacy.*

We found examples of the approach being person centred and asset based: supporting the individual's strengths, with family and carers involved where possible.

> *There is a full multi-disciplinary team involved in the individual's care. The day to day care is person centred. We are strongly committed to an asset based approach to supporting people with ASD and their families/carers. We look towards the individual's preferred method of communication, their skills and strengths and individual interests. We also give consideration to relapse indicators, management of behaviours that challenge and risk assessment. This portfolio of information will provide a good basis for any future transitions to care out with the hospital setting.*

Generally we were satisfied that multi-disciplinary working is in place and operating appropriately, although one professional commented to us that in their area there was:

> *No joint working between general adult and specialist adult autism service.*

Speech and language and occupational therapy involvement

Speech & language therapy (SALT) has a unique role in identifying the social and communication characteristics of the autistic person, contributing to a diagnosis, identifying if any other conditions may be present, and training others involved in the support and education of autistic people.

Half of the autistic people we reviewed had input from SALT across the different stages of the pathway. A range of assessment tools were cited including: Mount Wilgna High Level Language test, CELF 4/5 (clinical evaluation of language fundamentals),TROG (test for receptive grammar), RAPT (Renfrew action pictorial test),CCC (clinical communication checklist), and CASP (communication assessment profile).

Professionals supporting autistic people in hospital commented:

> *SALT interventions have been vital to nursing staff, ensuring they are aware of the adult's limitations in understanding language which appears to have resulted in heightened anxiety and behaviours which challenge. Guidance relates to language to use, ensure processing time for the person. Use of the 'Now and Next' method[15] for transitioning from one activity to the next. Those interventions have assisted and reduced his anxiety for the autistic person, and also he now requires less medication and restraint when in crisis.*

The importance of SALT was also highlighted by staff in the community:

> *The adult's verbal communication is more developed than his receptive language- he has very little understanding of the spoken word which has not been appreciated prior to this placement. Staff are encouraged to communicate clearly using short sentences and the communication is augmented with pictorial explanations.*
>
> *Talking mats[16] have been very helpful in assisting the adult identify and manage negative feelings.*

However, some family carers highlighted difficulties in accessing adequate SALT support in the community:

> *A referral to Speech and Language therapist has just been made, they come and go in adult's life but can't do very much so we have a bit of input for a while, they then close the case. Sometimes we find we have a lot of support, then it shrinks away and we have very few people involved now.*
>
> *He has little/no communication and we had asked for a SALT to become involved who could assess his needs and advise new providers how best to communicate with him. They did visit but did a swallow assessment only and advised about diet - they did not assess needs for augmentative or alternative communication (AAC) and we have sought this privately on an assessment only basis.*

Sensory assessment and treatment

It is estimated that sixty to seventy percent of autistic people have a sensory modulation/ processing disorder[17]. Occupational therapists have a unique role in the assessment, diagnosis and treatment of sensory issues for individuals with ASD.

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[15] Now and Next boards are resources used to show what activity the adult is doing and what they will be doing next, once the first activity is complete. They can be useful tools to help maintain focus on the current task and assist with motivation.

[16] www.talkingmats.com

[17] Adamson et al, 2006 – Impairments in sensory modulation in children with autism spectrum disorders. British Journal of Occupational Therapy. 69. pp.357-364.

Professionals told us that there was access to a sensory assessment if required for this group with complex needs.

> *The adult had a sensory assessment to help him and others understand his sensory needs which are often the driver for more challenging presentations. Staff now have a good understanding of and can recognise heightened anxiety and defuse/deescalate this before behaviours become problematic. "As required" medication is prescribed but its use has significantly reduced as the adult has settled, and communication with him has improved.*
>
> *Following a sensory assessment from our occupational therapist the adult is now wearing noise cancelling headphones to minimize noise when she is out and about in the community. The individual is very sensitive to noise and this is really helpful.*

In some places professionals felt that this service needs greater recognition and support.

> *[Would like to see] More recognition of occupational therapist and speech and language therapist as essential roles within the care and treatment of autistic people.*

Psychological therapies

Positive Behaviour Support/Care plans

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. PBS combines valued outcomes, behavioural and biomedical science, validated procedures and systems change.

The Coming Home report[18] encouraged greater use of PBS for people with learning disabilities and/or ASD and complex needs. The Implementation Framework 2019-21 for the Keys to Life, the Government's learning disability strategy, commits to further investment in PBS.

We found good evidence of this model being used in hospital settings. There was less evidence in social care settings, and access to support to formulate a PBS plan seemed to be more complicated than it was within in-patient settings, where access to psychology input was more readily available.

The PBS plans we saw evidenced a developing understanding of an individual's behaviours that challenged, based on the assessment of the social and physical environment and the broader context in which the behaviour occurred.

Sensory modulation is a neurological function and is the organization of **sensory** information for on-going use. Efficient **sensory modulation** is the ability to effectively regulate the degree to which one is influenced by various **sensory** inputs.

[18] https://www.gov.scot/publications/coming-home-complex-care-needs-out-area-placements-report-2018/pages/5/

Where possible the individual was actively involved in some processes of PBS planning.

Very detailed care plans using the PBS model; those support plans are person centred and the individual is kept at the centre of the decision making process.

We saw evidence of all the staff supporting the individual being involved, using this understanding to develop, implement and evaluate the effectiveness of a personalised and enduring system of support that enhances the quality of life outcomes for the person and others.

Excellent PBS plans in place - formulated with psychology, included: identifying information and plan development, pen portrait, behavioural summary statements, health needs, primary prevention, secondary prevention, reactive strategies, PBS Plan review.

We have been using the PBS model, and have support from a PBS advisor. We have seen improvements in the autistic adult's presentation, both his levels of anxiety and behaviour. We are able to build in more choice and flexibility to his routine. He is now participating in more activities and managing to participate in some choices relating to his day to day care. This has impacted positively on his self-esteem and confidence.

Although the PBS model is being encouraged in Scotland, and appeared to have positive outcomes for the individuals we visited, it is not the only approach. We know that other services use different models, such as the low-arousal approach[19] or the SCERTS model.[20]

SIGN 145[21] points out that the evidence base for particular behavioural interventions is still limited. The Commission is not in a position to advocate particular techniques, but we believe that it is very important that services supporting people with complex needs have a clear, proactive approach to managing challenging behaviour[22], which is user-centred and rights-based, and reduces the need for reactive or coercive interventions such as restraint, seclusion and medication.

Commission observations

We were impressed with the quality of multi-disciplinary input to the care and treatment of many people we saw, but it was striking that the experience of this in the community and with families was sometimes less evident. It is better for the adults, and better for services, if people can be fully supported in the community by the full range of professionals. SALT, OT and psychosocial interventions can all help to avoid problems escalating to the point that more restrictive care or medication is required.

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[19] http://www.open-access.bcu.ac.uk/6544/1/the-low-arousal-approach.pdf

[20] http://scerts.com/

[21] SIGN 145 para 7.4, which refers for further guidance to NICE 11 – Challenging behaviour and learning disabilities

[22] See *Note on terminology* at page 7 for discussion of this term

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, 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.

Medication

Background & what we looked at

Psychotropic medication, such as antidepressants or antipsychotics, should not be routinely prescribed for autistic people, but may be appropriate under certain circumstances[23] [24]. Most obviously, it may be used to treat a co-morbid mental health condition such as affective disorder, anxiety or psychosis, following appropriate assessment, and with ongoing review.

Psychotropic medication is also used at times to manage behaviour that is perceived as challenging, for example aggression and self-harm. Antipsychotic medications in particular are commonly used for this purpose, and there are significant concerns about inappropriate prescribing of these.

The Coming Home report on individuals with complex needs resulting from learning disabilities and/or ASD found that antipsychotics were used to manage behaviours perceived as challenging in 44% of the cases they reviewed[25]. The report also commented that "The current use of anti-psychotic medication is particularly concerning since a range of research, including a randomised control trial, has found that these were no more effective than placebo in reducing challenging behaviours (Tyrer et al, 2008)".

Clinical guidelines recommend that psychosocial interventions be attempted first and co-morbid mental illness be treated, before use is made of antipsychotic medication for managing behaviour perceived as challenging in this patient group [26, 27].

We therefore looked at whether people had been prescribed medication for their mental health, and whether this was on a regular basis, as required, or both. We recorded the prescribing of antipsychotic medication specifically, the indication for this medication, when it had last been reviewed and by whom.

We also recorded the prescribing of melatonin, which may be considered for sleep difficulties where sleep hygiene approaches have been unsuccessful[28].

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[23] SIGN 145: Assessment, diagnosis and interventions for autism spectrum disorders. SIGN, 2016. https://www.sign.ac.uk/assets/sign145.pdf

[24] NICE Clinical Guidance 142: Autism spectrum disorder in adults: diagnosis and management. NICE, 2012. https://www.nice.org.uk/guidance/cg142

[25] Dr Anne Macdonald, Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs. Scottish Government, 2018. https://www.gov.scot/publications/coming-home-complex-care-needs-out-area-placements-report-2018/pages/8/

[26] SIGN 145

[27] NICE 2012

[28] SIGN 145

What we expect to find

Where medication is prescribed on an as required basis, there should be a care plan detailing when and how it should be used and, after medication has been given, the effects should be recorded.

Where an individual does not have the capacity to make their own decisions regarding medical treatment, a certificate under section 47 of the Adults with Incapacity (Scotland) Act 2000 should be completed by a doctor[29].

In cases where an individual has been detained under the Mental Health (Care and Treatment) (Scotland) Act 2003, and given medication for their mental health for longer than two months, medication requires authorisation under a T2 or T3 certificate[30].

Care plans should include regular review of the need for medication. Psychotropic medication can have significant side effects, and can increase the risk of long-term conditions, including diabetes and cardiovascular disease. In all cases, but particularly where it is being prescribed for challenging behaviour, it is important that the benefits of medication are monitored, and that there is serious and ongoing consideration of possible alternatives, or reductions in dosage.

Particularly where the individual is in hospital, we expect to find regular reviews of the continuing need for any psychotropic medication, undertaken by a psychiatrist.

What we found

Medication Prescribing and Review

Of the 54 people reviewed, 46 were prescribed psychotropic medications for mental health conditions or for challenging behaviour. All but one of these were prescribed psychotropic medication on a regular basis. Of the 46, 26 were patients in hospital, and 20 were being treated in a community setting.

In almost all cases where psychotropic medication was prescribed, this was on the advice of a psychiatrist, and a psychiatrist was reviewing the medication on an ongoing basis.

Of the 45 individuals being prescribed regular psychotropic medication, 40 were being prescribed regular antipsychotic medication. Of that 40, 30 were also prescribed other psychotropic medication.

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[29] Mental Welfare Commission for Scotland Good Practice Guide: The Adults with Incapacity Act in general hospitals and care homes. 2017.
https://www.mwcscot.org.uk/media/339351/awi_in_general_hospitals_and_care_homes.pdf

[30] The patient's Responsible Medical Officer can issue a T2 certificate where the patient is capable of giving informed consent to the treatment and does consent. If the patient is incapable of consenting to the treatment, or refuses, a T3 certificate by a Designated Medical Practitioner is required.

Twenty-six were being prescribed antipsychotic medication for behaviour perceived as challenging (18 in hospital and eight in the community). All of the 26 were having reviews of their medication by a psychiatrist.

In a majority of cases, people being prescribed antipsychotic medication had been receiving this for more than six months.

19 of the 45 who were prescribed regular psychotropic medication were in the community. 18 of those were being reviewed by a psychiatrist. We were able to determine when the last review took place in 15 cases. Eleven had been reviewed in the previous two months. Four were last reviewed four to five months previously. This can be an appropriate timescale for those who are well established on medication.

We saw some good examples of people being closely reviewed in the community by their psychiatrist and other members of the mental health team

Psychiatrist sees Mr X every two months. Has a community LD nurse who visits every two weeks and monitors physical health/mental health. Advises on behavioural issues - liaises with psychologist for team.

Psychiatrist is part of CLDT who have regular contact with him and can feedback/take advice from psychiatrist as required. It is as a result of this feedback that full review of care is scheduled for next week.

Care planning and medication

We found that most of those who were given medication on an as required basis had a clearly documented care plan regarding how and when it should be used. These often suggested it was being used for anxiety or agitation. For example:

Diazepam PRN to support attendance at health care/dental appointments.

When as required medication was given, in most cases the effects of the medication had been recorded.

Six of the 54 individuals we reviewed were being prescribed melatonin. Four had been being prescribed melatonin for more than six months and for two, the duration was unclear. Five of the six individuals who were prescribed melatonin were being regularly reviewed by a psychiatrist (it was unclear whether this was the case for the final person)[31].

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[31] SIGN 145 para 9.11 states that ‘use of melatonin should follow consultation with a psychiatrist with expertise in the management of sleep medicine and/or ASD, and be in conjunction with behavioural interventions.

Authority to Treat

We found that s47 certificates were required to authorise medical treatment in forty cases[32], and were in place for thirty-seven of those.

Conditions being treated need to be individually specified, unless they are covered by an entry for “Fundamental healthcare procedures”. Guidance on this is contained in the Code of Practice[33] and MWC guidance[34].

We found three certificates that covered some but not all of the medications that required authorised, and four certificates which included general wording that did not properly cover medications that required authorised.

21 of the 54 individuals we reviewed had been receiving psychotropic medication under the Mental Health Act 2003 for longer than two months, and thus required a T2 or T3 certificate to authorise their medication. We looked to see if these certificates were in place.

One person was able to give informed consent to their treatment and had a T2 certificate in place to cover this. All 20 people who were either incapable of consenting, or not consenting, to their treatment had a T3 certificate in place. However, in three of these cases the individual was prescribed some medication that was not covered by the T3 form.

Commission observations

Our key finding is the widespread use of regular antipsychotic medication for challenging behaviour, rather than for an identified mental illness. This was the case for almost half of the people we saw.

It is important to bear in mind that the individuals we reviewed had complex needs and often severe difficulties associated with their ASD. It is likely that there will have been a higher rate of appropriate use of antipsychotics for behaviour perceived as challenging amongst this group than amongst people with less severe ASD.

We did not undertake a clinical review of individual cases, and cannot comment on the appropriateness of prescribing of medication to any one individual. We did find good evidence

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[32] This figure is probably an under-estimate, as we do not have the information for 6 cases

[33] Adults With Incapacity (Scotland) Act 2000: Code of Practice For Practitioners Authorised to Carry Out Medical Treatment Under Part 5 of the Act. 2010.

https://www.gov.scot/binaries/content/documents/govscot/publications/advice-and-guidance/2010/10/adults-incapacity-scotland-act-2000-code-practice-third-edition-practitioners-authorised-carry-out-medical-treatment-research-under-part-5-act/documents/0105906-pdf/0105906-pdf/govscot%3Adocument/0105906.pdf

[34] Mental Welfare Commission for Scotland Good Practice Guide: The Adults with Incapacity Act in general hospitals and care homes. 2017. https://www.mwcscot.org.uk/sites/default/files/2019-06/awi_in_general_hospitals_and_care_homes.pdf

of reviews, but we were not able to assess how much active consideration had been given to reducing the dosage or attempting alternative approaches.

Although, therefore, we cannot say that the use of psychotropic medication in individual cases was unjustified, nevertheless we are very concerned by the scale of its use. We support the view of the Coming Home report[35] and the SIGN and NICE Guidelines[36,37] that medication should only be resorted to when other approaches to managing behaviour that is perceived as challenging have demonstrably failed.

We are not confident that this approach is universally the case, and believe there now needs to be a systematic and focused effort to reduce the prescription of antipsychotics to autistic people for the management of behaviour perceived as challenging.

This could draw on other initiatives, including the STOMP programme developed by NHS England and endorsed by many professional organisations including the Royal College of Psychiatrists, to reduce unnecessary prescribing of antipsychotics for the management of challenging behaviour perceived as challenging in learning disability and autism[38]. In Scotland, we have had considerable success in reducing the use of psychotropic medication for people with dementia in care settings.

We suggest that an appropriate lead for this could be the Scottish Patient Safety Programme, which has been established to improve the safety of healthcare and reduce the level of harm experienced by people using healthcare services.

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.

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[35] Coming Home

[36] SIGN 145

[37] NICE 142

[38] Stopping Over-Prescribing of Medication for People with Learning Disabilities, Autism or Both https://www.england.nhs.uk/learning-disabilities/improving-health/stomp/ https://www.england.nhs.uk/wp-content/uploads/2017/07/stomp-gp-prescribing-v17.pdf

Discharge planning

Background

In 2016, our *No Through Road* report[39] highlighted our concerns about delayed discharge from hospital for people with learning disabilities (including people with ASD). We have continued to monitor this, and there are still significant numbers of people whose discharge has been delayed for a long period.

Our concerns were reinforced by the Coming Home report on Out-of-Area Placements and Delayed Discharge by Dr Anne MacDonald[40]. This identified 705 people with learning disabilities placed out of area, of whom 453 were out of area not through choice, and 109 were classed priority for return. Around 50% of the priority for return group had ASD.

Apart from the difficulties for the individuals whose discharge is delayed, the consequences for those urgently requiring admission to hospital units should not be underestimated.

What we expect to find

We hoped to find well established discharge planning processes which:

- supported a multidisciplinary approach;
- recognised the particular needs of the autistic person;
- identified and commissioned community services which were trained and equipped to understand and support autistic adults; and
- ensured that autistic people did not spend long periods in hospital when their needs could be met in the community.

What we found

Almost half (13/28) of the people in hospital whose care we reviewed were classified as delayed discharge, often pending suitable housing or a care provider in the community.

In some instances we heard that suitable accommodation was being purpose built, and whilst this was a positive step, it necessitated lengthy further inpatient stays while this process was underway.

Commissioning suitable support in the community was at times problematic. We saw several people who had experienced initial placement failures which had been distressing and further delayed discharge. Often this was a result of inconsistent community service provision, and staff turnover was an issue. There was a lack of professional education on environmental issues and lack of skilled community based staff.

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[39] https://www.mwcscot.org.uk/sites/default/files/2019-06/no_through_road.pdf

[40] https://www.gov.scot/publications/coming-home-complex-care-needs-out-area-placements-report-2018/pages/4/

The needs of autistic people do not fit easily into services designed for adults with either learning disability or mental illness and the lack of the right support packages can lead to delayed discharge from hospital and the individual continuing at a higher level of dependency. Commissioners require to satisfy themselves that services are appropriately skilled, trained, experienced and supported within their organisations to ensure a successful discharge to the community.

Staff highlighted a number of reasons why it could be difficult to successfully move people on from hospital, including the complexity of the individual's care needs, lack of funding, accommodation, or an appropriate care provider or a combination of those issues.

Social care funding withdrawn when people are admitted to hospital.

Large staff teams with frequent turnover and lack of communication delayed discharges - lack of suitable placements and skilled staff within the community

Similar issues were reported in *No Through Road.*

Families raised similar concerns to those of staff:

A placement is being arranged through the Council for him to be discharged to …. They have been recruiting care staff for adult's care package since Oct/Nov 2017. There have been problems with discharge planning as the Council have a different restraint process and it has taken a long time to determine that this should be satisfactory to care for him.

[Carer] wonders whether there is unwillingness or difficulty with the HSCP working as one. She commented "If integrated working worked as we are told it should, transitions should be easier and less lengthy." "The wage for staff is less than working at the supermarket checkout, to care for my son who can be very challenging at times. That doesn't seem right."

Of the adults in hospital who had discharge plans in place, there were few with agreed dates for this to proceed. Four had no discharge plans in place, on the basis that they were not ready for discharge and needed a further period of assessment and treatment.

Two people had previously been placed outwith Scotland. Following assessment and treatment those individuals had returned to Scotland. Both families reported excellent experiences of care and treatment for their family member in the Mitford Unit at Northgate Hospital.

Commission observations

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[41].

The Scottish Government has recognised the need to make progress, and the Implementation Framework and Priorities 2019–21 for the Keys to Life (Scotland's learning disability strategy) states it will:

> "provide direct support to Health and Social Care Partnerships to consider the findings of the 'Coming home: complex care needs and out of area placements' report, including the need for different models of care to bring home people identified as priority to return." [42]

We welcome this, but do not believe it is enough simply to 'consider' these findings. It is time for a more systematic, targeted and time-bound commitment to addressing the problem, commissioning bespoke services for autistic adults and ensuring robust training plans are in place so that community services have the right skills to support people with complex needs.

Integration Authorities have the primary responsibility for this in their local areas, but we believe it also needs clear leadership and oversight from Scottish Government.

Funding is certainly an issue, but at the moment large amounts of money are being spent by the NHS on accommodating people who could be supported in the community. There appear to be disincentives within current structures which may inhibit funding going to the right kind of care. Ways have been found in the past to overcome this, for example in the large scale closure of learning disability hospitals in the 1990s.

For some people this may require a higher investment at the outset, but it will produce better outcomes, and may reduce long term costs, including for continued admission or readmission to hospital.

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 6 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.

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[41] "States Parties … recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community" https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

[42] https://keystolife.info/wp-content/uploads/2019/03/Keys-To-Life-Implementation-Framework.pdf

Support/Staying well

Scottish Strategy for Autism 2018-21 Strategic Outcome 3:

"Autistic people are able to live independently in the community with equal access to all aspects of society."

What we expect to find

We expect that 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 roles and responsibilities. They should be supported to develop their self-care, education, employment and leisure options. When they need it, they should have access to independent advocacy.

Their physical health needs will be met to the same standard as other citizens. Where they have other disabilities and/or health conditions which require intensive and co-ordinated care and support, this will be available[43].

Autistic people have the same basic needs as everyone else, but may need these to be met in particular ways. As part of the Scottish Strategy for Autism, a Menu of Interventions was published in 2013[44], which can help guide services in how to do this.

Rights

People with autism have the right to services to support their well-being and social development through the local authority, to have a community care needs assessment and assessed needs met. They also have a right to independent advocacy[45]. As set out at page 20, they also have a right to health, and any necessary adjustments should be made to ensure they have at least the same access to support to maintain good health as others in the community.

What we found

Physical health

Most of the individuals we reviewed were registered with a GP (45/54). One third had chronic gastrointestinal problems and one third had epilepsy.

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[43] Conditions associated with autism include epilepsy, atopies (allergic hyper-sensitivity), gastrointestinal problems or infections. People may also have other conditions which might be overshadowed by the presence of autism (obesity, cancer and dementia), or less easily diagnosed because of communication issues. Long term use of psychotropic medication also can have significant health consequences.

[44] https://www2.gov.scot/Resource/0043/00438221.pdf

[45] These rights reflect the Social Work (Scotland) Act 1968, Article 26 of the UNCRPD, (right to habilitation and rehabilitation), and sections 25-26 and 259 of the Mental Health Act.

We heard from carers and families about a lack of co-ordination, and the challenges relating to the individuals complex healthcare needs.

> *We are unhappy with the lack of involvement from Community Learning Disability Team, who we feel could co-ordinate and oversee many of his healthcare needs.*
>
> *One of the main issues I have is the lack of co-ordination of support. He has a range of complex health issues bowel problems, dietary problems, epilepsy, incontinency and these in the main are managed by district nursing service, who are not familiar with learning disability or autism.*

We were disappointed to find that only half of the people we reviewed had an easily identifiable record of an annual physical health care check (28/54). Half the people of the appropriate age had accessed the bowel screening programme.

One professional commented on a general lack of health promotion in this population.

> *There is a lack of pro-active, evidence based, health promotion and primary preventions for autistic people.*

We were told by other staff that there was emphasis on health promotion within services, specifically healthy eating and providing opportunities to exercise. About a third (18/54) of the people we reviewed were considered by the clinical team to be overweight. Dietetic input was provided for a small number (9/54).

> *Comments on gaining weight when commencing on medication, patient's being overweight, difficulties with engagement in exercise, sleep issues impacting on individual, has sleep apnoea, this impacts on epilepsy.*
>
> *His care plan has introduced regular exercise which has resulted in weight loss, he is encouraged to think carefully about diet and he is beginning to be aware of healthy eating options.*

Meaningful activity

We were told that services that help with stress are important in keeping well, and people valued both therapeutic and social activities. Some commented on the need for more structure and activity within their day.

We asked autistic people what kind of support they had, and what kept them well.

Two thirds of individuals (36/54) had structured personalised activities and were participating in social activities; half of the people interviewed attended therapeutic groups. We were disappointed to see that a third of those we reviewed did not have structured personalised activities.

> *The adult is an inpatient and opportunities for activities are limited. Reliant on the family taking the individual home.*
>
> *The adult would benefit from a more tailored activity plan, this would be a significant requirement from any future community placement.*
>
> *Limited activity provision, it is difficult to engage adult in group activities as he becomes distressed if aroused.*

Staff shortages impacted on delivery of activities in some locations.

Professionals and carers commented on the lack of availability for activities for autistic people with complex care needs in the community.

> *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 (Professional).*
>
> *I feel he has been doing the same things since leaving school. The routine of this is good for him but I feel he is getting bored and his behaviour is becoming challenging as a result. Need to explore other activities. (Carer)*

We also heard more positive stories demonstrating how people can be helped to participate in the community, as well as more tailored support

> *Attends a swimming club with a personal assistant funded by direct payments. Very happy with the support adult receives but would have benefited from this before now.*
>
> *Numerous activities, gymnastics, Zumba, Yoga (all autism specific). Meets friends at resource centre once a week for social get-together. Goes for lunch one day a week with staff, Social night on a Friday.*
>
> *Attends art opportunities run by Scottish Autism, there is lots to do there, creative activities with the person who has autism, working with glass, textiles, paint and craft and musical theatre.*

Employment, Education and Volunteering

None of the individuals we reviewed had any links with, or were in employment. Five people were volunteering within the community and felt it added routine and variety to their lives, and allowed them the opportunity to help others. Four individuals were in college/further education.

Member of local rambling association volunteering at a walled garden

He volunteers in the kitchen of a day centre for older people - monitored by supported employment project. He is very sociable and is involved with a range of social activities - loves rave music! Swims to a high standard. He is happy with his routine.

Professionals and carers told us about care packages in the community that were well resourced with specialist input.

Since leaving school [the adult] attended day services three days a week, and participates in a range of activities. Cornerstone provide community based services two days a week and he also has residential respite of forty nights per year at local services. (Carer)

There is good support for his communication, communication board and now and next symbols. His care includes a "relationship circle", and clear information on what is important to him: "things that must be present to make me feel happy". Clear routines including activities both social and therapeutic, and family visits. He has a team of complex needs practitioners attached to his service, and access to a PBS Advisor on a monthly basis. (Carer)

Transport

We found a range of positive examples of people being supported to travel and access the community.

He has a bus pass and had been using transport independently - e.g. getting the bus to [social venues] or to visit his mother. Because has had been a bit stressed using transport independently he is currently escorted by staff, but it is planned to build up his independent travelling again.

The adult has his own minibus which is used daily for his care/activity scheduling.

The adult likes to be out of the house. Specialist transport is available for him and he has 3:1 staffing during the day which facilitates these outings.

Finance /management of finance

Most of the individuals we reviewed were on welfare benefits. We generally found no issues regarding the management of finances.

We found evidence of good practice in relation to the use of funds e.g. mobility car, clothing, buying media items for entertainment (videos, DVDs), annual holidays and a variety of social activities. A small proportion (6%) managed their own finance with support.

A third had a DWP appointee. For one-fifth of the people we met, finances were managed by their guardian in the community.

> *The financial guardianship powers were on file, noted that the adult needs support with budgeting, often when out shopping wants to buy CD, videos etc.*
>
> *The adult appears to have a wide variety of life experiences holidays daily activities.*
>
> *An organisation called Dosh[46] helped with budgeting.*

For some individuals in hospital arrangements under Part 4 of the Adults with Incapacity Act were used to manage some funds.

> *No concerns about my money, it is in a hospital account, I have a bank account and I can get my money from the cash machine.*

We found one example of a vulnerable individual who had been managing his own finances but had not claimed benefits for over a year prior to his admission to hospital.

Advocacy

The Mental Health Act puts a duty on local authorities and the NHS to ensure independent advocacy is available to people covered by the Act, including people with autism – whether in hospital or the community [47].

Scottish Government guidance,[48] states that independent advocacy is important 'to ensure the individual's views are heard and understood and that they receive support to ensure their rights are not infringed'.

One of the actions under the Scottish Strategy for Autism Outcomes and priorities 2018-2021 is "to explore the role of advocacy services in supporting autistic people across Scotland."

We welcome this, as we found that the availability of advocacy services varied across Scotland. We found evidence of awareness of or involvement with advocacy services for two thirds of the people we had met with.

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[46] Dosh Financial Advocacy - https://www.dosh.org/ The organisation website states that they currently work in Highlands, Midlothian and the Scottish Borders

[47] S259, Mental Health Act sets out that independent advocacy should be provided 'for the purpose of enabling the person to whom they are available to have as much control of, or capacity to influence, that person's care and welfare as is, in the circumstances, appropriate'.

[48] The Scottish Government (2013) Independent advocacy: guide for commissioners

https://www.gov.scot/publications/independent-advocacy-guide-commissioners/

Some staff commented that access to advocacy could be difficult.

> *Advocacy is provided by local services. This is not always readily available due to how advocacy services are funded, if the adult is subject to AWI or MH legislation, advocacy is available but not routine if adult is receiving support on an informal basis.*

While it is understandable that local services may prioritise advocacy for legal interventions such as detention under the Mental Health Act, the legal duty is wider than this. An autistic person who needs advocacy to help them access the support they need has a right to expect this.

Commission observations

All of the people we saw were in receipt of complex service packages, often in institutional settings. They could not be expected to manage their own health and wellbeing without support. In some cases people were given appropriate help to maintain good health, but this should be universal. Some people may need additional support and may not engage easily with interventions such as health screening and diet and exercise programmes, but that should not be discounted as a 'lifestyle choice' – it is a barrier which needs to be overcome.

Under the Mental Health Act, local authorities have legal duties to secure a range of services for people covered by the Act, including autistic people. 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.

This duty applies to autistic people who are not in hospital. People spending significant periods in hospital are also entitled to expect access to meaningful activities.

These services should not be seen as optional extras, but too many autistic people are not leading lives which are as fulfilling as they could be.

We welcome the fact that living independently in the community is a Priority Outcome in the Autism Strategy, but believe that more needs to be done to ensure that this is a meaningful aspiration for every autistic person.

Autistic people with complex needs and their families have to deal with a huge number of professionals and agencies. Family carers we spoke to stressed the difficulties this causes and the need for better, more personalised co-ordination of all aspects of care (see pages 54-55). Health and social care integration is intended to help ensure that services are joined up, but it is vital that this happens at the level of the individual service user, not just at the organisational level.

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. Unless properly managed, the consequences can be serious and long lasting. People can spend long periods in hospital or other restrictive settings, following a short term crisis which could not be managed.

Assessing and managing risk, and supporting autistic people when they are in crisis are key parts of their care and treatment.

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. The response to a crisis should not exacerbate the distress and harm to the individual.

Rights

Everyone has the right to be safe, and to participate in putting together a care plan and risk or safety plan. This reflects the principles set out in the Patients' Rights (Scotland) Act 2011, underpinned by the rights of respect for the person derived from Article 8 of the ECHR. The right to information about crisis and out-of-hours services also reflects Article Two and Three of the ECHR - duties to preserve life and prevent inhuman or degrading treatment.

What we found

Autistic people, carers and professionals spoke about the challenges with managing a crisis when it occurs and the support services that are available to assist when this happens. Some felt that the crisis plans when in place were clear and easy to follow.

We asked what could trigger a crisis in individuals and what response was most helpful.

The most commonly mentioned triggers for crisis were changes to the person's routine (67%), deterioration in mental and physical health (65%), communication issues (63%), lack of structure to the day (48%). Environmental factors can contribute to a crisis.

> *Being unable to complete rituals. Adult can become agitated and distressed without an identified trigger, for example he can become agitated by an item he sees outside his room he will try to exit the area to destroy the item. This can result in damage to himself and property.*
>
> *I can get upset and confused if people tell me too many different things, this is one of my main problems.*

We were pleased to see that the majority of the people we reviewed 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.

> *Clear details about how a crisis for the adult should be managed. Importantly it describes indicators that he may be heading into crisis and responses which could divert or de-escalate this. If crisis does occur, there is very clear means by which this should be managed, including one person taking the lead and the clear information on language and how to interact with him when he is in crisis.*
>
> *There is a detailed care plan which directs all aspects of the adults care, including crisis management. This is reviewed very regularly as X's needs change. Within current setting crisis has reduced dramatically as all staff adhere to X's PBS strategy. On admission, the adult was subject to regular and at times lengthy restraint due to risks to himself and others. The last time an incident was recorded is from the beginning of August this year and staff utilised de -escalation strategies rather than the need for physical restraint.*

One carer commented on not being listened to when she was concerned about her son's deteriorating presentation.

> *In the past she has felt that her views have not been taken seriously when she has identified an early deterioration in his presentation. Services have been too slow to respond – offering appointments weeks in advance or simply disregarding her concerns.*

Professionals identified the following as helping at time of crisis: regular support and monitoring by community nurses, easy and quick access to the multi-disciplinary team and the availability of immediate access to hospital if this is required.

> *We were able to access on-site PBS support and Speech and Language, as well as link with the local Community Learning Disability Team. I feel this multi-disciplinary approach works well in crisis and the more professionals involved and helpful support means that there is more of a chance of a positive outcome for the people we support.*

Some concerns emphasised by professionals were overreliance on admission to hospital, a lack of suitable placements to admit the person especially in rural areas, and respite facilities not being available for either the person or the carers.

> *Unfortunately there is an over reliance on hospital admission, this is where the skills to support him in crisis lie. If the Additional support team were a multidisciplinary team this would be more helpful to the autistic person in the community.*
>
> *There are limited placements as this is a small geographical area, If somebody has complex needs and they are in crisis, they may need to be admitted out of area. This is not helpful.*

Restraint

What we expect to find

‘Restraint’ is a broad term encompassing a range of measures which restrict a person’s actions or movement, usually to prevent them coming to harm or causing harm.

Any such restraint requires to respect the human rights of the patient, meaning it must be justified and proportionate. Any significant restraint on an adult requires to be legally authorised. Other than unplanned restraint in an emergency, this would normally require authorisation under the Mental Health Act or the Adults with Incapacity Act, and should respect the principles of that legislation.

From the patient’s point of view, restraint can be undignified, frightening and even dangerous. It can also be distressing for other patients.

The Commission has issued guidance on restraint[49]. This is currently under review.

We expect to see that services apply the principles we set out in *Rights, risks and limits to freedom*. These include:

- Individuals should be involved so far as possible in decisions about restraint, even where they lack capacity;
- Care planning should include assessment of risks, and plans to manage risks;
- Any necessary legal powers should be in place;
- Restraint should always be a last resort, and possible alternatives should be fully considered;
- Any restraint should be the minimum required to deal with the risk, for the minimum time;
- Episodes of restraint should be recorded, and there should be regular clinical audit, as well as review of the continued need for restraint in individual cases;
- Staff should be appropriately trained;
- After any episode of restraint, there should be an explanation to the person, in terms they can understand; and
- The person should have access to advocacy to support them if they are unhappy about the use of restraint.

What we found

We found evidence of restraint being an issue in 20 of the 54 individuals we visited (16/28 in hospital, and 4/26 in the community).

A variety of methods were described, including the use of arm holds, wrist straps when the adult is in public, ‘non-restrictive holds’ during personal care, and ‘light touch’ holding a limb

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[49] Rights, risks and limits to freedom: https://www.mwcscot.org.uk/media/125247/rights_risks_2013_edition_web_version.pdf

when the adult was hitting out at staff. There was an example of a specialised chair which is difficult to get out of, but also intended to be comforting and to reduce the number of staff required in an episode of restraint. Some methods were significantly more intrusive, including an episode of restraint lasting 30 minutes on the floor and involving five staff.

We found reasonable evidence of Datix[50] recording of episodes of restraint, and of episodes being reviewed at subsequent ward rounds. We also found situations where the person was not restrained because of known risks, e.g. asphyxia (suffocation), or restraint was modified, e.g. only in a sitting position due to a cardiac condition.

In one case, the patient was being nursed in isolation, and observed through a camera in the room. This case was an example of the difficulty some hospitals find in providing a safe and therapeutic environment for autistic people with very complex needs. The patient was in a large room with no floor coverings, and the wall and doors removed. He exhibited very high level of anxiety with stressed and distressed behaviours and as a result had destroyed much of his environment. A new space was being built which it was hoped would meet his needs better.

We noted one case where a patient experienced anxiety on seeing others becoming distressed and restrained.

> *Patient has not required restraint although during discussion it was apparent that he sees others becoming distressed and restrained. This induced anxiety for him.*

This concern was also commented on by staff in one unit:

> *There is sometimes need for restraint. As the unit is so small, it is quite visible and distressing for other residents.*

A range of training approaches were noted, including CALM[51], PROACT-SCIPr-UK[52], MAPA[53] and Positive Behavioural Support.

Most of the episodes of restraint concerned the need to manage stressed and distressed behaviour, although it was also used to administer medication.

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[50] Datix is software widely used in the NHS for recording of incident reporting

[51] Crisis, Aggression, Limitation and Management – see https://calmtraining.co.uk/

[52] Positive Range of Options to Avoid Crisis and use Therapy http://www.proact-scipr-uk.com/proact-scipr-uk/

[53] Management of Aggression or Potential Aggression https://www.crisisprevention.com/en-GB/What-We-Do/MAPA-Management-of-Actual-or-Potential-Aggression

It was striking that the need for restraint was not static for individual patients. We found a number of positive examples where the use of restraint had been successfully reduced through clear strategies and careful planning:

There is a detailed care plan which directs all aspects of the patient's care, including crisis management. This is reviewed very regularly as needs change. Within current setting crisis has reduced dramatically as all staff adhere to the PBS strategy. On admission, the adult was subject to regular and at times lengthy restraint due to risks to himself and others. The last time an incident was recorded is from the beginning of August this year and staff utilised de-escalation strategies rather than the need for physical restraint.

Info from key worker indicates that instances of restraint have reduced significantly…. Providers use a model called MAPA (management of actual and potential aggression) which clearly identified de-escalation/distraction strategies for use before any physical restraint is used. There is also a structured debrief following restraint which includes the patient.

The adult was subject to restraint on admission but this has decreased dramatically over the course of the admission and looking back over the notes has only occurred once in the past six months ....the adult himself has developed an insight into when he needs time out from the busyness of the ward and will take himself off to his room and put on headphones until he feels calmer.

SALT interventions have been vital in ensuring staff are aware of the adult's limitations in understanding language which appears to have resulted in heightened anxiety and behaviours which challenge ... This has allowed staff to communicate more effectively with him and has led to the use of the Now and Next method of transitioning between activities. This in turn appears to have reduced anxiety levels for the adult and the associated need for restraint.

46 of the 54 people we saw were subject to welfare guardianship under the Adults with Incapacity Act. Where there is a foreseeable need to use restraint from time to time, we believe that this should be specifically authorised in the powers granted by the sheriff. We were pleased to note several examples where this was done.

Commission observations

Overall, we saw reasonable evidence that restraint was being planned for, that staff were appropriately trained, and that the use of restraint was appropriately recorded and reviewed. We were also encouraged that, as staff got to know patients, the use of restraint often reduced significantly.

Nevertheless, 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, including reducing the factors which cause stressed and distressed behaviour in the first place. In the *Coming Home*[54] report, the author comments that Positive Behavioural Support 'has a role in providing less restrictive alternatives to physical restraint'.

We support measures to encourage alternatives to restraint but, as with the use of medication to manage behaviour, we believe these measures must be part of a more sustained effort to reduce the use of restraint in hospitals and community settings.

The Scottish Patient Safety Programme has undertaken a successful programme of improvement activity to reduce restraint in adult mental health wards, and we believe a similar initiative for autistic people would be appropriate, to develop and share best practice and organisational learning. This should be combined with initiatives by individual services to develop their own restraint reduction strategies.

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, and improvement plans to reduce their use over time.

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[54] https://www.gov.scot/publications/coming-home-complex-care-needs-out-area-placements-report-2018/

Environment

What we expect to find

A safe, welcoming and comfortable environment is important for anyone receiving care, but is particularly important in relation to autistic people. People with this condition are often highly sensitive to sensory stimuli, including noise, light and smells. An inappropriate setting, for example a noisy and busy ward with unpredictable changes to routines can be extremely distressing, and may cause or worsen behaviour perceived as challenging.

Although there are many common sensitivities, the way environmental factors may affect any one individual with autism is very personal.

We were conscious that many autistic people with complex needs, particularly in hospital, may be cared for in settings which are not specifically designed for autistic people, and we wanted to see how services addressed this issue.

Guidance exists to help services. For example:

- The NICE guidelines on Autism spectrum disorder in adults and Autism spectrum disorder in under 19s[55] include recommendations on the physical environment. NICE subsequently endorsed a checklist[56] produced by South West Yorkshire Partnership NHS Foundation Trust supporting these recommendations on the environment.
- SPELL[57] is The National Autistic Society's framework for understanding and responding to the needs of children and adults on the autism spectrum. It focuses on five principles that have been identified as vital elements of best practice in autism, and emphasises ways to change the environment to meet the specific needs of each person.
- The National Autistic Taskforce have published an independent guide to quality care for autistic people, which includes advice on tackling environmental and other stressors[58].

Many of the individuals we visited were living in hospitals or care homes. We would expect these facilities 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.

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[55] NICE CG170 (2014) Autism spectrum disorder in under 19s: support and management https://www.nice.org.uk/guidance/cg170

[56] https://www.southwestyorkshire.nhs.uk/wp-content/uploads/2018/08/Checklist-for-Autism-Friendly-Environments-November-2017-NAS-version.docx

[57] https://www.autism.org.uk/about/strategies/spell.aspx. SPELL stands for Structure, Positive approaches and expectations, Empathy, Low arousal, Links.

[58] https://nationalautistictaskforce.org.uk/

Where the individual is living in the community, in a family home, or in supported accommodation we would expect to find evidence of appropriate adaptation and personalisation.

In all settings, we would expect to see an individualised assessment of environmental issues as part of care planning.

What we found

We asked professionals how they identified environmental factors affecting individuals with autism and complex needs.

Professionals spoke of using a range of methods. Formal assessment processes (initial assessment, risk assessment, community care assessment) covered environmental factors; and included consultation with those closest to the individual and consideration of any existing clinical judgement. Ongoing assessment included observation, incident analysis, discussion at key meetings with MDT members; discussion at supervision, and daily or regular site analysis and risk assessment.

Some professionals said they did not use any particular form of assessment but relied on professional experience and even 'common sense'. It was necessary for example to take account of local factors and knowledge, for example in rural areas.

> *This is as part of my general assessment but I don't have specific tools. I have a checklist when it comes to home assessments (e.g. to view a possible house for someone).*

Occupational therapists were seen as key to assessing individuals' sensory sensitivities and formulating interventions.

> *Within the MDT we have specialist Occupational Therapists that can carry out assessment of environment, as well as sensory assessment for clients. Direct contextual observation. We include environmental strategies and recommendation in our ASD awareness raising training for providers. We are also often involved in viewing potential residencies and commenting on possible adaptations.*

A few specific approaches were described in response to our survey, these included:

> *We use assistant psychologists to implement tools appropriate for each individual circumstance e.g. ABC charts, video monitoring, functional analysis.*
>
> *REIS*[59]*; ASD booklet developed from Scottish OT special interest group; NAS information on line (i.e. SPELL – see above).*

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[59] Fisher G et al (2014) Residential Environment Impact Scale Version 4.0 (REIS) https://www.moho.uic.edu/productDetails.aspx?iid=5

Sensory overload and a change in routine were identified as the most common factors affecting individuals.

> *Noise in a neighbour's flat leading to distress and fear of going out.*
>
> *Noise and lighting within the unit was very challenging for one patient. Unpredictable environment (staff tidying things away in different orders) caused one patient great distress and anxiety.*

Professionals provided general examples of adjusting the clinical environment to the needs of individuals. However this was not always done.

> *Appointment arranged when no other clinics running so waiting area and corridors quiet…*
>
> *Walking along long hospital corridors post clinic, escalating behaviours until parents assaulted. No clinical staff stopped to assist.*

An appropriate living environment helped to maintain an individual's independence. A purpose built new build or fully adapted property was ideal. Smaller units were usually more suitable.

Input from specialist ASD providers and fully trained knowledgeable staff along with family and staff who know the person well contributed to a better outcome

Adaptation of existing properties or ward space could sometimes go a long way to meet an individual's needs; as could personalisation of an individual's space on a ward.

> *A client with autism and a severe LD was attending a day service. Staff found him challenging, especially during lunch time. A 'base' was adapted for him within the day centre as well as a specific room for lunch. Visual support and a very predictable routine was put in place. He is enjoying his attendance and has been developing his skills and ways of communication with staff.*

Professionals encountered barriers to improving environments for individuals with autism and complex needs. These included financial restraints and the lack of appropriate properties, (costs of new builds and adaptations, few single supported tenancies). Legacy communal living and shared common areas brought their own risks and difficulties.

> *Funding/resources and availability of suitable accommodation within the area. So clients are not required to move out of area.*
>
> *Shared living spaces mean that we are still fettered to some degree by the tolerance of peers.*

We assessed the environment at 11 hospital units and one care home. We also visited the Mitford Unit in Northgate, England (see page 13). We also heard comments about the environment from a range of individuals and carers during our visits to individuals in the community

All of the hospital units provided single rooms and most had en-suite facilities, although one unit had shared bathing facilities. Some units had two sitting rooms available and the majority had a quiet area also.

All but one of the units were found to be in good decorative order with no unpleasant odours and the majority had no problems with excessive noise. Heating control in some places was controlled out-with the unit but on the whole was satisfactory.

Most of the units were able to make some adaptations for individuals with ASD and complex needs.

A sensory room has been installed as is a known benefit to him.

Ward is bright, modern, well maintained. Staff have attempted to nurse and manage ASD patient is a very challenging environment. Good use of advice from specialist LD services - to adapt environment and PBS plans have in time reduced levels of distress for patient.

In particular changes to noise and light had been looked at and many units have formed creative ways around this.

Some minor changes have been made to the environment to take account of his particular needs e.g. dimmer switches on bedroom lights, small window removed from bedroom door, bleep associated with staff swiping in and out of the ward has been silenced as this was assessed as a trigger for agitation and fire alarm testing done in a different way.

However sometimes there were difficulties because of the inherent limitations of buildings and available space.

Difficult to do as the ward is 20 bedded, large, busy - Nursing patient in his bedroom.

Noise levels, lack of space, harsh lighting, high levels of noise and activity.

There were comments that the busy ward of an admission unit, or assessment and treatment unit were not appropriate for autistic people with complex needs. There was too much unpredictability, busyness and noise.

Sensory issues remain problematic as adult is particularly sensitive to heat and noisy environments - adult has learned strategies to manage these during this admission and will often go to their room and put on ear defenders if the ward is busy or nosier than usual.

Assessment and treatment ward with patients coming and going overwhelming him at times.

Living with others can be a major difficulty for autistic individuals. Several units had made efforts to address this:

Since other patients have come into the unit, this restricts his opportunity to watch his DVDs which he watches repeatedly and causes friction with other patients. As a result another television has been installed in the other lounge so that he has this opportunity. If he needs some quiet time he will go to his room although instances of this being required are now few and far between.

Patient mix has a major impact. Meal times are staggered to accommodate individual needs i.e. high stimulation.

We found that all individuals had their own room and residents could retire there to escape noise if necessary.

I like my room where all my things are. I sometimes get agitated by other residents but when I do I can go to my own room.

Some patients had access to other quiet spaces on wards.

Small kitchen area where he can prepare meals and eat on his own.

A few individuals commented that they were comfortable in the hospital unit, although this did not mean that a hospital should be seen as the long term option.

The environment isn't bad. It's not perfect. I would prefer to be in my own flat and not in a hospital ward.

One unit presented a concern related to difficulties with nursing one particular patient.

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

However work was underway to provide more suitable accommodation.

The majority of units had access to laundry facilities that patients could use and had private areas to see their visitors.

About half of the units had a specific activities area and a training kitchen but only two had a dedicated sensory room. Others made use of patient’s rooms or sitting rooms.

Current environment is unsuitable - too noisy and unable to offer sufficient meaningful activity.

All of the hospital and residential units had access to an outside space except one – where this was due to the nursing requirements of the individual person.

Individuals have direct access onto the garden from their rooms however they tend to go through the sitting room to access it. The individual I visited went out into the garden during the visit… Staff spoke of barbeques and taking the table outside to do crafts as well as individuals tending to the garden with support. There were photos on the living room wall of barbeques and individuals outside.

In the community there was more scope to choose or adapt the environment to best support the individual. Having more space and more rooms, where available, gave more opportunity for an individual to find quiet space.

Sheltered house in very quiet street. House is modern, clean, and spacious with two separate living areas which is helpful for adult as flatmate noise get on adult's nerves at times.

These are bed-sit flats, there is not a lot of space. I was used to a bigger place and would prefer a bigger house with separate rooms.

Minimal furniture. £20k was spent on his flat before he moved in creating safe concealed plumbing, switches and sockets as he would take these apart and be at risk of electrocution, causing flooding and fire. Clothes drawers in bedroom with his clothes separated into clothes for every day of the week.

Other features noted included: fewer stairs to climb, space to park a Motability car outside,

Likes his house, which he has lived in for three years. Suits him better than the old flat - less stairs, quieter. Likes having his Motability car at the door. Has had the car three years. It is empowering knowing he has the choice whether to go out or not. He used to be physically sick when waiting for a taxi to come. He doesn't like the wind, they have to take account of the weather. Having the car has made a big difference.

Commission observations

Overall, we found that community places were generally well designed and appropriate. In hospitals, thought had been given to how to make changes to make the environment suitable for the particular needs of the patient. However, this was simply not possible in some wards. In other cases, all that could be done was to mitigate the problems caused, rather than provide a truly person centred environment. The ability of the patient to use their room as a refuge from the busyness and noise of a ward may be vital to maintaining a degree of equilibrium, but it may be avoiding a crisis rather than providing a truly therapeutic environment.

Services had clearly 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, and use of best practice guidance, these problems might have been avoided.

The guide by the National Autistic Taskforce, which was published after our visits took place, points out that sensory audit tools can be useful in carrying out environmental assessments, but adds that these should be supplemented by input from autistic people[60]. We did not investigate the extent to which autistic people had been involved in environmental assessments but, on reflection, we agree that this is an important point.

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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[60] https://nationalautistictaskforce.org.uk/ page 23

Carers

Families and Friends

The support of families and friends provided a particular focus to staying well. More than half of the individuals interviewed had family involvement/support both in the community (18/26) and the hospital (17/28).

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. Mourning the person their relative could be was experienced by some as bereavement.

> *Our whole life revolves around his care and we often find that we operate as two separate families to ensure both he and his sister get what they need. We do not have holidays/breaks as we require to be available for his care at short notice.*
>
> *Adult's condition has restricted career opportunities for both parents, although father's employer was very considerate. Adult's sibling has been affected due to focus on Adult. There have been many positives also.*

Some families/carers raised the issue of financial stability and the impact on the family

> *I am a single parent. My life revolves around his needs and I have very little time for myself. When he goes to respite I work extra hours as I am on a zero hour contract and need to make ends meet.*

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. A smooth transition to this situation was also required. Having adequate provision of suitable units with well- trained capable staff was mentioned by several families. Communication among services involved and streamlined care was again mentioned with the suggestion of a “care manager” type role to facilitate this.

> *Ultimately I would like to see him living somewhere out with the family home with support, either a shared tenancy or small care home. This way he would have peer company, age appropriate activities and I would be in a position to continue to support him but not be solely responsible for his care.*
>
> *An autism specific residential resource. Staffed by autism specific staff within my own health board area with a day centre attached.*

More personalised care including allowing choices around things like pets would also be useful.

> *If she had a cat. She wants a cat, it is now recognised that having a pet helps people with psychiatric problems. The only thing she asks for is a cat.*

Some families, particularly ageing carers, inevitably also expressed anxiety for the continued care of their relative once they were no longer able to contribute.

> *We have to face the future of our son being out in the community. Where he lives now is excellent, but restrictive in that NHS rules have to be obeyed. He is currently looked after by fully competent, well-trained, reasonably well paid staff. What will it be like in the community, when he is being looked after by staff who may be less well trained, less well paid, maybe not as caring? Who knows? Yes, it's a worry for us, as we're getting older and want him to be in a good situation when we are no longer around to observe. As with everyone, he deserves a meaningful life, with things to look forward to and familiar surroundings that he is comfortable in. He also deserves to be able to form intimate relationships, which are not possible in his current environment.*

We also asked if there was one improvement the carers would like to see made.

Having their own opinion and unique knowledge of the individual acknowledged and respected was important. Better availability and range of activities for individuals was mentioned with well-trained understanding staff available to facilitate this

Co-ordination of all aspects of care and adequate support for the individual's physical needs was also highlighted (see page 40 and Recommendation 6).

> *I would like someone who has an understanding of LD and autism to oversee the day to day health care of his complex needs. The care providers chart everything on a daily basis but no-one looks at these with an informed eye or consider the interplay between all of the care.*
>
> *Improvement for us is when we hear that he has gone somewhere and taken part in a social activity. What we would love is for somebody to be able to give him true independence.*

Carers Assessment of Needs

Most of the carers we spoke to had not been directed to any support for themselves and had not had a Carer's Assessment. Just two carers we spoke to had been offered an Assessment although not all carers wanted one. One carer thought he was too old to be eligible for a Carer's Assessment and overall there was a lack of clarity about carers' rights.

The Carers (Scotland) Act 2016 places a duty on local authorities (delegated to HSCP's) to offer any individual they identify as a carer an adult carer support plan, regardless of age and based on an assessment of the carer's needs. We were disappointed that this legislation did not appear to be having a material impact.

One carer pointed out that Carer's allowance stopped when a carer begins to receive state retirement pension, despite continuing to provide the same level or more care. Being in receipt of retirement pension, however, does not alter eligibility to have a carer's assessment carried out.

Guardianship

Of the 54 individuals we saw, 46 were subject to welfare guardianship – 27 had private guardians and in 19 the guardian was the Chief Social Work Officer of the relevant local authority.

Most had three or more powers included in the order, with the most common powers being to decide where the adult lives, what daily activities they are involved in and to make decisions about medical care and treatment.

We saw a good example of supported decision making where parents used the order to advocate on their daughter's behalf but were clear about where she was able to make/reach decisions with the provision of clear and accessible information.

> *Family feel the guardianship is valuable in giving them a voice to focus their concerns when appropriate and also advocate for their family member. They have a good understanding of support decision making.*

In four of the private guardianship orders there was a power which specifically authorised restraint.

Of the adults we met, 18 were able to express a view on being subject to a guardianship order and the majority of these were positive.

> *I didn't like it at first but I know it is there for a reason.*
>
> *I feel mum helps me with things in my life that I find difficult to do "like money".*
>
> *It helps keep me feeling safe.*

Very few of the individuals we met were aware of their rights in relation to the guardianship order but we saw examples of the involvement of advocacy support in a number of instances.

Carers views on guardianship

We heard from carers that having guardianship powers supported them to be consulted and fully involved in decisions about care and treatment, including planning for future care arrangements in the community.

Most of those carers who had a welfare guardian in place were happy with it and felt staff respected their position.

However this was not always the case.

At points of crisis our role is not always understood. I carry a copy of the Court Order with me at all times to evidence my powers if I have to.

Staff recognise role "mostly". [Carer] said she is not always consulted about medical treatment – changing of dosage of medication. "It's better now than it was".

Yes, most of the time I am involved in meetings. However a recent LA OT Assessment was conducted and finalised without any input from me and I have asked for a copy of the report which I have been refused. I am attending a meeting this week and will present again a copy of my WG power including power to access reviews.

We have an Anticipatory Care Plan in place which as guardians we have signed off with agreement from GP and specialist medical care. This is to prevent unnecessary admissions to hospital as this is traumatic for him and rarely results in treatment once assessed. This has been shared with the ambulance service, yet we have to argue with them at each intervention and my role as guardian is not understood at these times and I am advised 'this is not your decision' despite having been granted power to consent/withhold consent to treatment.

Of the 27 private guardianship cases, only eight adults had been visited by the local authority supervising officer.

Following bureaucratic procedures is not something carers are necessarily trained for, and it should not be expected of them. They need and deserve support for engagement with professionals and agencies

Training

What we expect to find

We expect that all staff working with autistic people should have received autism specific training appropriate to their needs.

In 2014, NHS Education for Scotland published the Autism Training Framework: Optimising Outcomes[61]. This framework details the knowledge and skills required at different levels within the health and social care workforce to achieve key outcomes for autistic people, their families and carers.

What we found

We found that staff were aware of the Training Framework, but there was little evidence of their actually having used it, and there appeared to be a poor understanding in practice about the implementation of the framework.

Scottish Autism are a national organisation who provide training in autism in their own right. They have access to NES training framework in Autism and are strongly of the view that this training should be linked to providers of all services from the generic to the highly specialised and practice within these areas should be linked with a competency framework to ensure practice is informed by evidence.

There were comments on the value of a person-centred approach to care and treatment, with an awareness of the need for more formalised training in ASD.

The need for staff training in relation to ASD, nothing formal in place.

The staff feel that most of the knowledge and skills are learned through the individual and their presentation. Following an assessment the staff would then plan care in a person centred approach. The staff feel there is a lack of access to the training listed within [the Commission's] questionnaire, and the team would benefit from access to this and formalised training.

No formal training in ASD, we receive input from psychiatry, psychology, speech and language and occupational therapy all the input focusses on the individual having a learning disability and not on the ASD, we would benefit from ASD specific training.

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[61] http://www.knowledge.scot.nhs.uk/media/9595218/asd%20web%20final%20%282%29.pdf

We were told of some good examples of in-house training in ASD and the positive impact this had.

> *There has been considerable training for all staff involved in the patient's care, with more intensive training targeted at a core group who deliver most of his care. The turnaround for this young man has been remarkable and a testimony to the investment and time and effort from the MDT.*

The issue of ASD training in third sector and private organisations was also raised, with concerns about poorly paid staff with no prior experience or training supporting autistic people with complex needs.

> *Non statutory care providers often initially have little experience in autism and staff training. There are often difficulties with understanding some of the core principles of supporting an autistic person. There can be issues with ensuring consistency to reduce anxiety and also some of the services, do not retain staff there is a rapid turnover of staff and this can impact on the individual.*

Suicide prevention

A small body of research is showing worryingly high rates of suicidality in people with autism[62]. The risk factors for autistic people can be very different than those in the general population and therefore require tailored prevention strategies.

The NHS Health Scotland's National Suicide Prevention Programme offers suicide prevention training. 15/18 of the staff interviewed commented that their service had participated in this training and all comment it was generic and not ASD specific. 3/18 services said that they had not received any training.

Supervision

We were concerned to hear from a range of professional staff that clinical supervision was not consistently available across all services. Some areas rarely or never had access to supervision.

> *There is a need for both ASD specialist training and clinical supervision for this complex group. No specialist supervision available*

One service told us that due to time constraints it was difficult to arrange supervision for the staff group.

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[62] Understanding and prevention of suicide in autism Cassidy & Rodgers. The Lancet Psychiatry 4 (6) e11 2017: Volume 4, Issue 6, Pe11, June 01, 2017

We saw a good example of the provision of peer supervision, and access to external expert supervision from psychology.

> *We receive supervision on a peer basis and also at clinical meetings within the team. We have access to external expert supervision from a senior psychologist, which the team and the people with ASD benefit from.*

Commission observations

We were concerned by the significant gaps in training and supervision. It cannot be stressed enough that autistic people have different needs from other people with learning disabilities or mental illnesses, but they often find themselves in settings which are not designed for those needs. Specialist support, where it is available, is usually highly stretched. It is therefore vital that frontline staff have the right skills and knowledge to support well people with autism and complex needs. The NES publication provides a good framework for this, which should be delivered through local, multi-disciplinary training created and delivered by experienced staff, which is evidence based, and provided as a sustainable rolling programme.

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.

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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