

Adults with Autistic Spectrum Disorders Planning Group

Outline Recommendations for Chief Officer Group – Community Care

Overview

- The number of adults in Highland with a diagnosed Autistic Spectrum Disorder (ASD) is increasing rapidly. The total cost of out-of-area placements is also rising.
- In Highland, services for adults with Asperger Syndrome are extremely limited. Young people and adults with Asperger Syndrome are generally excluded from LD services, are often not served by Mental Health services, and are often left to depend on their families for support.
- Services for adults with Autism and LD are often not ASD-appropriate. This is partly due to the absence of an operational lead person for ASD service provision ⁽ⁱ⁾ and is counter to Scottish Executive LD policy ⁽ⁱⁱ⁾, which applies to all adults with ASD.
- There is risk inherent in failure to provide proactive ASD-appropriate services. Key risks include mental ill health, suicide, and escalation of service needs.
- Outline recommendations are given below. These are based on group and individual consultations with service providers, service users and carers, including a Highland Audit of Services for Adults with ASD.
- Full recommendations will incorporate additional high-priority needs of adults with ASD and their carers. A Survey of Needs is being undertaken, and adults with ASD and carers are now more involved in the formation of recommendations. Direct consultation with young people in transition to adulthood will be undertaken once appropriate methods have been established.

Required outcomes with objectives

1 Rationalised expenditure on current out-of-area placements (page 2)

1A Develop specialist ASD Adult Services to support mainstream services within Highland

1B Ensure consistent care and treatment and equity of service provision for adults with ASD across Highland

2 Minimised future need for out-of-area placements for adults with ASD (page 3)

2A Prevent escalation of needs

2B Avoid lifelong out-of-area placements

3 Reduced suicide risk amongst adults with Asperger Syndrome (page 4)

3A Improve detection of Asperger Syndrome within Mental Health Services

3B Apply the Highland Choose Life Plan to adults with Asperger Syndrome

(i) NHS QIS: NHS Highland Local Report on Learning Disability Services, February 2006

(ii) 'The same as you? A review of services for people with learning disabilities', May 2000

Outcome 1

Rationalised expenditure on current out-of-area placements

Objective 1A: Develop specialist ASD Adult Services within Highland

Specialist services for adults with ASD in Highland are extremely limited at present.

Recommended method: Enhance and reorganise specialist service provision

- Provide dedicated ASD Adult Services. Initially, use these services to support a return to Highland for some of those people with ASD who are currently in out-of-area placements.
- Use ASD Adult Services to provide expertise to those services which support young people with ASD and 'very high needs', who are in transition to adulthood and who would otherwise be placed out-of-area.
- Use ASD Adult Services to support mainstream providers pan-Highland, to ensure that other high-needs adults with ASD can be maintained within appropriate environments.
- This service could be established with a combination of:
 - redesignated posts
 - agreed contributions from professionals / services who have, or wish to develop, expertise in ASD
 - commissioning of a new service
- These developments could be part-funded through reductions in the use of out-of-area placements.

Objective 1B: Ensure consistent care and treatment for adults with ASD across Highland

A critical escalation of need can occur, and has occurred previously in Highland, due to inconsistent and inappropriate service provision for adults with ASD.

Recommended method: Ensure robust inter-service management within ASD Adult Services, and between Children's Services and Adult Services

- With Social Work Area and Team Managers, and within nursing and other health professions, clarify arrangements for care management of adults with ASD. This is particularly important for adults with Asperger Syndrome who may not be seen as the responsibility of any team.
- Consider the need for an ASD Adult Service Co-ordinator or Lead Professional within Social Work or Health ⁽ⁱⁱⁱ⁾, to ensure appropriate commissioning and provision of services for adults with ASD and their families.
- Promote multiagency working between services for adults with ASD, and between Children's Services and Adult Services, to ensure smooth transitions to adulthood.
- Establish standard referral procedures from Children's Services to Adult Services through the Transitions Protocol
- When additional training is made available, ensure that this training is targeted where it is most needed.
- Ensure that all those who work with adults with ASD and their families in Highland communicate with other service providers who support adults with ASD in their care, and have ASD training appropriate to the services that they provide.

(iii) Bamford, D.R. (2005) *A Strategic Framework for Adult Mental Health Services* p.126; Powell, A. (2002) *Taking Responsibility: Good practice guidelines for services – adults with Asperger Syndrome*, NAS, p.4; North West Autism Commissioning Standards Working Group (2006) *Improving Standards in Services for Children and Adults with ASD*

Outcome 2

Minimised future need for out-of-area placements for adults with ASD

Objective 2A: Prevent escalation of needs

In order to prevent escalation of service needs, existing staff in all services require training to allow them to improve their understanding of Autistic Spectrum Disorders.

Recommended method:

Increase availability of ASD training for service providers

- Provide more basic ASD training, and much more advanced ASD training, as required by service providers.
- Give generic services access to ASD awareness-raising.
- In order to provide ASD-appropriate services for adults with ASD who have Learning Disabilities, existing Learning Disability services need to have opportunities to increase their expertise on ASD.
- Adult Social Work teams and most Health professionals need training in how to provide appropriate support to adults with Asperger Syndrome and their families.
- Out-of-hours Social Work Services, NHS emergency services and the Police need information and guidance on how to support adults with ASD and their families during crises.
- Service users and unpaid carers require training to help them to manage their own needs ^(iv).
- Mental Health services need to develop their understanding of ASD (see Objective 3B), including an understanding of the exceptional toll on the mental health of carers.

Objective 2B: Avoid lifelong out-of-area placements

See Appendix 4. Some young people with ASD who are out-of-area want to return to Highland, but it can be very difficult to facilitate return.

Recommended method: Retain young people in crisis within Highland

- Young people with ASD in crisis should be retained within Highland and supported by a dedicated service (yet to be defined) for young people with disabilities.
- The standards and specifications of this service should be informed by the successful out-of-area crisis service which Children's Services are using for young people with ASD.

Recommended method:

Support young adults to develop independent living skills

- Provide training in social and independent living skills to school-age young people with ASD. Such skills would enhance the employment expectations of these young people ^(v).
- Establish a support service for young adults with ASD in crisis within Highland. This service should also provide support and training that aims to maximise independence.
- Build capacity of local services through training and opportunities to develop appropriate levels of expertise (see Objectives 1A to 2A).

(iv) 'Changing Lives: Report of the 21st Century Social Work Review'

(v) Highland Wellbeing Alliance: *For Highland's Children 2 (2005-2008)*, p.88

Outcome 3

Reduced suicide risk amongst adults with Asperger Syndrome

Objective 3A: Improve detection of Asperger Syndrome

There will be many adults in Mental Health Services in Highland who have Asperger Syndrome but are currently undiagnosed. These adults may be the most vulnerable ASD group. Mental Health Services cannot provide appropriate services for adults with Asperger Syndrome until expertise is developed within these services. Lack of expertise, leading to professional anxiety, prevents Mental Health Services from diagnosing Asperger Syndrome and providing appropriate treatment to these adults.

Recommended method: Develop detection and diagnosis of Asperger Syndrome within existing NHS services

- Develop the use of Asperger Syndrome screening tools within Mental Health and Learning Disability Nursing. This development should be part of an agreed pathway for care and treatment of adults with ASD in Mental Health Services.
- In the short term, consider buying in the services of a diagnostic consultant who can diagnose adults with Asperger Syndrome.
- In the medium term, consider the development of a multidisciplinary diagnostic team for adults with Autistic Spectrum Disorders in Highland.

Objective 3B: Apply the Highland Choose Life Plan (suicide prevention strategy) to adults with Asperger Syndrome

Suicide risk (and depression) can be manifested unusually in Asperger Syndrome. For example, a person with Asperger Syndrome may not have a 'plan' for suicide but can still be at high risk of suicide. Services should be proactive in detecting and addressing risk.

Recommended method: Develop ASD-appropriate Mental Health services

- Clarify the referral procedure for psychiatric support for adults with Asperger Syndrome who are at risk of suicide. Through Clinical Governance, set minimum standards for care and treatment of adults with Asperger Syndrome within Mental Health Services.
- Develop an understanding of Asperger Syndrome within hospital psychiatric services through training. Training should include risk assessment (including suicide risk) and protection planning, unusual effects of medications with Asperger Syndrome, minimum standards expected, and training on the impact of ASD on family members.
- Provide ASD training to agencies which provide support to adults with ASD in the community who are at risk of suicide (e.g. GPs, Community Mental Health Teams, Samaritans, Drop-in centres in Highland).
- Ensure that adults with Asperger Syndrome obtain access to new resources (guided self-help workers and computer-based depression treatment packages). Guided self-help workers may require ASD training, and adults with Asperger Syndrome may require ASD-appropriate information on how to obtain access to resources.
- Make existing support groups ASD-appropriate, or provide new support groups.

Recommended method: Develop suicide-aware ASD services

- Provide suicide risk detection training (ASIST) to carers, and to staff who work with young people with Asperger Syndrome (e.g. teachers, social workers, ASD voluntary agencies).