

# **Highland Adults with ASD Project**

## **Final Recommendations for Chief Officer Group – Community Care**

### **Overview**

- **These Recommendations have been developed entirely through consultation with service users and carers. They should be read in conjunction with the Outline Recommendations from this project, which are generally consistent with the Final Recommendations.**
- Community Care services should be accessible to all adults with ASD. Access to services should not be limited to only those adults with ASD who also have a Learning Disability or mental health problem. The Outline and Final Recommendations advocate equal access to services for all adults with ASD.
- Consultation methods have included a questionnaire-based Survey of Needs for adults with ASD and for carers, and two regular formal meeting groups in Inverness (the Adults with ASD Consultation Group and the Adults with ASD Carers Group). Contributions to these groups were made by post, by email and in person, and these groups had representation on the Adults with ASD Planning Group. More informal meetings with service users and/or carers took place in all Highland Council areas.

### **Outcome 1**

#### **Rationalised expenditure on current out-of-area placements**

##### **Objective 1A: Develop specialist ASD Adult Services within Highland**

- Adults with ASD experience discrimination in attempting to access appropriate services. Specialist services, which can recognise and support their needs, must be developed locally.
- ASD Adult Services are also required because many of those families who have been providing all support to their adult children cannot continue to provide this support, due to strain and age. The needs of carers, including carers' own aspirations, are being ignored.

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

- Points of access to services for adults with ASD must be clearly designated, ASD-appropriate and well advertised.
- 'Autistic Spectrum Disorders' should be made a priority for Advocacy Highland, so that all adults with ASD have equal access to this service. The service should also be more clearly advertised.
- Some independent advocates should be trained to work with adults with ASD and should specialise in ASD. 'Person centred' methods, which centre on the social relationship, are not ASD-appropriate.

## **Outcome 2**

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

#### **Objective 2A: Prevent escalation of needs**

##### **Recommended method: Increase availability of training for service providers**

- Adults with ASD should be given opportunities to educate service providers.
- Management should require staff to take up ASD training. Otherwise, training will not be undertaken by those staff who most need it.
- Anti-discrimination training should be made available, to help service providers to understand how they discriminate against people who have an ASD.
- Social Work adult services need a lot more training if they are to provide an effective crisis management service. There should always be someone available for people with an ASD to talk to in emergencies.
- Social care staff require more training on how to work with adults with Asperger Syndrome.
- More ASD-specific training should be made available to existing housing support and care home providers, and to housing providers.
- ASD training should be given to existing advocacy services, to help them to accommodate the needs of service users who have an ASD, including training on communication needs.

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

##### **Recommended method:**

##### **Support young adults to develop independent living skills**

- So that young adults with ASD can be supported to develop independent living skills, clear decisions must be made by Community Care management on who has responsibility for providing services to adults with ASD.
- The Survey of Needs for Adults with ASD and their Carers in Highland identified social skills training as a highest-priority need. This training should begin in schools, and additional resources should be provided for this purpose.
- The Survey also identified several independent living support services as highest priority service needs: support for employment; health advice service; money advice service; support for preparing food. Training to meet these needs should also be provided in schools, with additional resources for this purpose. A pilot of independent travel training in schools has been successful.
- For independent living skill development in transition to adulthood, young people who have an ASD also require a skilled occupational therapist.
- There is a need for employment advisers and employment support that is tailored to the needs of individuals with ASD.

## **Outcome 3**

### **Reduced suicide risk amongst adults with Asperger Syndrome**

#### **Objective 3A: Improve detection of Asperger Syndrome**

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

- A consultant specialising in ASD or Asperger Syndrome should be bought in from elsewhere for a regular clinic.
- After diagnosis, people require information directly from staff, not just written information.
- When people are assessed and diagnosed, they should be given information on what services exist and on how to apply for benefits and services.
- When a diagnosis is made in adulthood, the process should involve the person's partner.
- Psychology assessments should be provided. These can be immensely helpful, simply because other professionals will take these assessments seriously. Psychology should be accessible for all adults with ASD.

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

##### **Recommended method: Develop ASD-appropriate Mental Health services**

- The Survey of Needs clearly identified 'psychology for autistic thinking' as a highest priority service need. This service should be provided by psychologists and/or by nursing or counselling staff with appropriate additional training.
- Training on raising self-esteem and improved crisis management are required.
- Management of suicide risk has to start with prevention. Parents, carers and spouses need training on how to support and maintain self esteem in people who have an ASD. Difference is not wrong - staff should not try to 'fix' people.
- For times of crisis, there should always be direct access to someone who understands ASD, depression and suicide. People with an ASD may not be able to talk to their own family in time of crisis and may need to talk to someone else, but GPs and NHS 24 generally don't meet this need.
- Support staff need specific training on how to deal with suicide risk, and reception staff should be trained to detect suicide risk.
- Continuity of staffing is required in mental health services. Adults with ASD can only build a relationship with a psychiatrist or nurse when staffing is consistent. Several appointments are needed to establish trust, and more than 20 minutes per appointment will be required by most people who have an ASD.
- Staff should not lower people's self esteem further by questioning existing diagnoses, or by failing to read patient notes before appointments.
- People with an ASD who are at risk of suicide may have no plan for suicide. Staff should not base their estimate of suicide risk on the presence of a plan.
- Counselling should be made available to people who have attempted suicide.

### **Transition to adulthood**

- Professionals should not assume that young people with ASD should try to fit into a 'neurotypical' (normal) ideal of adulthood.
- To support decision making, information on all possible options should be provided to young people and carers in an autism-appropriate way.
- Schools should be taking responsibility for the transition to college or university. There should be an information resource on colleges and universities, which states which ones offer good support and which ones have failed to support students.
- Parents need workshops on transitions issues, well before the transition to adulthood, on a range of critical issues (e.g. legal authority after age 16, major changes to levels of service, emergency care arrangement)
- Information on benefits should be given to young people before they leave school, and to adults too. Information on how benefits will affect other finances is also required.
- ASD-appropriate services must be made available. Parents can only 'let go' and allow their children to live independently if appropriate support is available, as they know that they'll have to pick up the pieces if support falls apart.
- Families who suddenly have a child full-time at home should be given support. No support is available at present, and it's not clear how parents can obtain an emergency care plan from Social Work.
- More information on Highland social care providers should be made available.
- Transitions happen throughout adult life – in relationships, work, study and living arrangements - and adults with ASD should be supported through all transitions.

### **Employment support**

- Employers should be offered seminars on employment and disability, including free ASD training. Adults with ASD who are in employment, or who have been employed, can give ASD training to employers. Formal arrangements should be made to support such training.
- Supported employment organisations should ensure that staff who have training and expertise in working with people with ASD, are allocated to work with people who have ASD.
- Parents who have ASD require extra guidance to support their children through work experience.

## **Housing**

Housing services have no understanding of the needs of people with ASD, who are not being prioritised for appropriate housing through the current system.

- The procedure for allocation of housing should be changed to ensure that appropriate housing is provided. It is usually impossible for people with an ASD to tolerate noise from neighbours in flats, for example.
- A fair proportion of new-build housing should be designed for the disability-specific needs of adults with ASD.
- When supported accommodation is commissioned for people with ASD, specific projects should be set up to ensure that housing providers and Social Work Services work together. This should be a priority for the Council.
- It is impossible for people with an ASD to comply with the current procedure for applying for housing. Reasonable adjustments should include:
  - a contact assessment procedure for staff to use when people begin to apply for housing, so that people are given all the information that they need.
  - provision of housing-specific support for completion of application forms.
  - information for staff on the housing needs of people with ASD.
- The process of applying for housing should be made much simpler, and people with ASD should be allocated a named member of staff to contact with all enquiries about their application.
- Information on housing should be given to parents of people with ASD well before adulthood so that planning for housing provision can begin.
- For some people who are unable to live independently, there should be care homes which have a particular understanding of ASD.

## **Other issues**

- Recommendations on Criminal Justice Services will be developed through the National Autistic Society's CJS Working Group for Children & Adults with ASD in Highland.
- Recommendations on transitions also take the form of guidance for professionals who support transitions planning. Parts of this guidance are based on direct consultation with young people who have an ASD.
- Service users and carers initially expressed an interest in formulating recommendations on 'Social activities, leisure, respite and support for carers', and 'Counselling for people with ASDs and for carers'. There was insufficient time to discuss these issues at the Consultation Group and Carers Group, and suggestions for service developments in these areas were not received by post, email or telephone.