



## SCOTTISH EXECUTIVE

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Health Department  
Community Care Division 1

18 February 2003

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Dear Colleague

### **SERVICES FOR PEOPLE WITH AUTISTIC SPECTRUM DISORDERS**

1. The Autistic Spectrum Disorders Needs Assessment Report published by the Public Health Institute of Scotland (PHIS) (available on [www.phis.org.uk/](http://www.phis.org.uk/)) requests that local authorities and NHS Boards develop plans based on an audit of current service provision, training and expenditure in their areas. This letter asks for this audit to be undertaken now with a view to plans being in place in 2004-5.

#### **Background**

2. The report should be considered within the wider policy context of the Joint Future agenda. This will deliver joint management structures and joint resourcing across health and social care by April 2004 and will implement single, shared, assessment and address consequent workforce development needs.

3. The PHIS report was commissioned by Ministers to provide:

- information for service commissioners on the best available knowledge about autistic spectrum disorders (ASD) and current service provision in Scotland, and
- guidance on how these services might better meet the needs of both children and adults with ASD in the future.

4. It found that while current service provision in some local authorities is developing through joint audit, planning and commissioning of services, the picture across Scotland is inconsistent and inadequate for the number of individuals with ASD requiring support. Health care, education and social services vary depending on local resources and there are marked differences in ease of access to services due to limited facilities

#### **Addresses**

##### For action

Chief Executives, Local Authorities  
NHS Board Chief Executives  
Directors of Education  
Directors of Social Work

##### For information

Chief Executives Primary Care NHS  
Trusts  
Voluntary Organisations  
Professional Bodies

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in some geographical areas. Although there are some examples of good, innovative and multi-agency practice across Scotland, some areas and some client groups, particularly adults, and their families experience delays and inconsistencies in the delivery of services and inadequate support after diagnosis.

5. The report notes that to meet the diverse needs of people with ASD, a continuum of services must be available which are co-ordinated, multi-agency and seamless. It makes 32 recommendations to achieve this. Some of these can be picked up in the work underway to implement *The same as you?* review of services for people with a learning disability; others form part of ongoing developments in the education and health services; while others will be new work.

## Action

6. The report is commended as the way forward in developing services in Scotland for people with ASD, subject to the caveat that it is written from a health perspective. It has a key role to play in shaping the strategic direction of services for people with autistic spectrum disorders and would be best managed within the Joint Future and *The same as you?* Partnership in Practice frameworks. Many of the recommendations do mirror those in *The same as you?* and while there are common points of reference between learning disabilities and autism, the constituencies are different, and service requirements are different.

7. The recommendations set out a large agenda for health and social work authorities. This letter is primarily about health and social work authorities working together to develop services for individuals with autism. They should be aware, however, that there is already a substantial and developed education response to autism, and that they need to make appropriate links to education. The audit covers both children and adults and while duplication is to be avoided, we would be particularly grateful if some detailed information could be provided about post-school transitions.

8. The Executive's view, consistent with the report, is that early priorities must include:

- improvements to early assessment and intervention;
- improvements in diagnosis;
- integrated joint planning and joint working between agencies, and aligned or pooled budgets for autism services;
- involving individuals with ASD and their families or representatives; and
- a coherent approach to research, training and workforce development.

9. The report specifically recommends that development of services for people with autistic spectrum disorders should be achieved through local health and joint planning mechanisms (recommendation 5).

At a local level local authorities and NHS Boards are therefore asked to carry out a **joint audit** of:

- current service provision and expenditure across relevant agencies (health, education, social services and the voluntary sector) (recommendations 5 and 6)
- relevant training in their area, and identify gaps (recommendation 20); and
- develop plans for services, informed by the audit.

10. An audit template is attached to assist with this. COSLA has indicated that local authorities would be willing to take on a co-ordinating role. Completion may be best achieved through a meeting of those with responsibilities across this area within education, health and social work. It would be helpful if a Head of Service took the lead in that they are best placed to reflect back both operational and planning considerations.

11. The National Autistic Society and the Scottish Society for Autism recently undertook a mapping exercise of service provision, and while the findings are not finalised, a copy of this information may be obtained from either of the Societies. Local authorities and NHS Boards may also have some information on service provision for those with autistic spectrum disorder from other audits of services. Developing plans in line with recommendations of the PHIS Report will be a longer exercise, and we would ask that Health Boards and their partners develop such plans over the year 2003-04, with a view to putting them into place in 2004-05.

12. Planning and provision of services for people with autism are not done in isolation, and need to relate to various plans agencies prepare. These include Partnership in Practice (PiP) agreements, local plans that show how agencies will work together to deliver the recommendations of *The same as you?* review of services for people with learning disabilities. Other relevant plans include Children's Services Plans, Community Care Plans, Community Plans, Education Improvement Plans, Joint Health Improvement Plans and Local Health Plans.

13. The Annex sets out recommendations that are particularly relevant to the Scottish Executive and to health, education and social work authorities, with appropriate action to implement the report's recommendations listed against each. It also describes work the Executive has taken and is taking to implement recommendations in the report.

14. I would be grateful if the audit could be carried out and the results sent to me **by Friday 25 April 2003** and if plans for services for people with autistic spectrum disorders could be developed for inclusion in Partnership in Practice agreements scheduled to be submitted in June 2004.

Yours sincerely

Thea S. Teale

**THEA S TEALE**

## RECOMMENDATIONS FOR EDUCATION, HEALTH AND SOCIAL WORK AUTHORITIES

**Recommendation 5** (part) – *The Chief Executive of each local authority and each NHS board should ensure that the relevant joint planning groups carry out the audit of current service provision, expenditure and training, and develop plans for future provision.*

**Action:** This Health Department letter has been negotiated with and agreed by Cosla and the Chief Executive Health Group and is the primary means by which this recommendation will be met.

**Recommendation 7** – *Chief Executives of NHS boards and local authorities should identify officers as local co-ordinators for ASD services, who will audit local practice in health, education and social services against the published national standards (recommendation 1) and be able to report on progress towards these standards to the appropriate national monitoring body (recommendation 2).*

**Action:** Education, health and social work services are likely to have identified officers as local co-ordinators for ASD already. Where they have not done so, we recommend they should do so now to co-ordinate services, and ensure the aims set out at recommendation 5 above are achieved. It will be some time before national standards can be prepared (recommendation 1), and monitoring of standards can only take place after this.

**Recommendation 9** – *Local authorities and NHS boards must ensure that the needs of children and adults with ASD are included in relevant plans, such as Children's Service Plans and Community Care Plans, and that appropriate opportunities for developing further services are exploited, e.g. through Children Services Funds, etc.*

**Action:** Local authorities and NHS boards should do this.

## MAJOR RECOMMENDATIONS TO THE SCOTTISH EXECUTIVE

**Recommendation 1** – *The Scottish Executive should establish a working party with appropriate representation to develop global standards for lifelong services for those people with ASD that require it.*

**Action:** The Executive has asked the PHIS Report Working Group to become a Reference Group to oversee implementation of its report. Two meetings have taken place to date.

Developing global standards (described elsewhere in the report as national standards for services for people with ASD) is a major and ambitious task. It will involve work with all sectors that support people with ASD in their everyday living. The Executive believes this is more appropriate for a research project.

**Recommendation 10** – *The recommendations in The same as you? review of services for people with learning disabilities are welcomed and endorsed. However clarification is required from the*

*Scottish Executive on whether these recommendations include or exclude people with autistic spectrum disorders but without a learning disability.*

**Action:** The Executive has confirmed that people with ASD are included in *The same as you?*, even if they do not have a learning disability. We recognise that services for people with Asperger's will require to be tailored to meet the different needs that they may have.

**Recommendation 11** – *Local PiP (Partnership in Practice) agreements should be required to include proposals for how local authorities and their partners will meet the needs of people with ASD in the area and cover both mainstream and specialist services. The Scottish Executive is asked to confirm whether these PiPs should address the needs of all those with ASD irrespective of a co-existing learning disability.*

**Action:** PiPs are plans that show how agencies will work together to implement the recommendations of *The same as you?*. The Executive has made it clear that PiPs should address the needs of all those with ASD irrespective of a co-existing learning disability. Where PiPs submitted in mid-2001 did not do so, the Executive asked that they be amended.

**Recommendation 26** – *Priority should be given to the establishment of a database on persons with ASD in Scotland. A working group should be convened to develop this initiative.*

**Action:** This is in process. A Modernising Government Fund project has just been announced to set up a database for people with learning disabilities, including those with ASD.

THE SCOTTISH EXECUTIVE  
18 February 2003

**AUDIT OF SERVICES FOR PEOPLE WITH AUTISTIC SPECTRUM DISORDERS (ASD)**

**SECTION A NUMBERS**

**CHILDREN AND YOUNG PEOPLE**

1. How many children and young people in your area are diagnosed as having an autistic spectrum disorder - 1. Including Asperger's Syndrome?

1. Definition of autistic spectrum disorders from The PHIS Report  
 Autistic spectrum disorders (ASD) are typically characterised by a "triad of impairments". The following description of the triad has been adapted...

\* Social - impaired, deviant and delayed or atypical social development, especially interpersonal development. The variation may be from "autistic aloofness" to "active but odd" characteristics.

\* Language and communication - impaired and deviant language and communication, verbal and non-verbal. Deviant semantic and pragmatic aspects of language.

\* Thought and behaviour - rigidity of thought and behaviour and impoverished social imagination. Ritualistic behaviour, reliance on routines, extreme delay or absence of "pretend play".

All of the above behaviours should be out of keeping with the individual's mental age. Individual manifestations vary with an individual's degree of intelligence, with their individual personality and with the presence of additional disorders. In addition, changes in the way the disorder presents itself occur with age, especially in the more able individuals. Many people with an ASD also have an over-sensitivity to sound, smells, touch, taste and visual stimulation.

PRE-SCHOOL	
AGED 11 - 16	
AGED 16 - 18 in school	
AGED 16 - 18 who have left school	
<b>TOTAL</b>	

2. How many children and young people with ASD including Asperger's Syndrome have other needs?

**(Please avoid double counting wherever possible)**

Learning disability	
Physical disability	
Learning and physical disability	
Mental health problems	
Other behavioural or biomedical conditions	
<b>TOTAL</b>	

3. What type of schools do they attend? (I.e. where more than 50% of time is spent in this resource)

Nursery	
Mainstream Primary	
Mainstream Secondary	
Specialist Primary	
Specialist Secondary	
Specialist Out of Area Schools	
<b>TOTAL</b>	

4. How many children and young people are specifically diagnosed as having Asperger's syndrome?

5. How many children and young people with Asperger's syndrome have no learning disability?

**ADULTS**

6. How many adults in your area are diagnosed as having ASD including Asperger's Syndrome?

18 - 24	
24 - 49	
50+	

7. How many adults with ASD including Asperger's Syndrome have additional needs?

Learning disability	
Physical disability	
Learning and physical disability	
Mental health problems	
Other behavioural or biomedical conditions	
<b>TOTAL</b>	

**(Please avoid double counting wherever possible)**

8. How many adults are diagnosed as having Asperger's syndrome?

9. How many adults with Asperger's syndrome have no learning disability?

10. Research tells us that prevalence rates of autistic spectrum disorder represent an underestimate. To what extent do you consider the numbers above to be an accurate reflection of all those who live in your area?

11. What changes are there in demand in the last 5 years? Are there increased numbers? If so, what do you attribute this to?

**SECTION B**

**DIAGNOSIS**

12. What structures, systems and procedures are there for diagnosis of both children and adults?

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13. Who is **responsible** for diagnosis?

Psychiatrist	
Clinical Psychologist	
Educational Psychologist	
Speech and language therapist	
Teacher	
Other e.g. multi-disciplinary team	

14. Who **makes** the diagnosis?

Psychiatrist	
Clinical Psychologist	
Educational Psychologist	
Speech and language therapist	
Teacher	
Other e.g. multi-disciplinary team	

15. Which diagnostic tools are used?

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**SECTION C**

**ASSESSMENT OF NEED**

16. Which agencies are involved in assessment?

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17. Who carries out the assessment?

Social worker	
Psychologist	
Health professional	
Teacher	
Other e.g. multi-disciplinary team	

18. How many assessments were undertaken from April 2001 to March 2002?

Children and young people	
Adults	

19. What are the average times between:

Referral to diagnosis	
Diagnosis to assessment	
Assessment to service delivery	

20. What plans do you have to develop a single, shared assessment tool for ASD?

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21. How is information on assessment gathered for planning purposes?

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22. How do you foresee these systems linking with the national database for people with learning disabilities?

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**SECTION D**

**SERVICES**

23. Describe the range of services provided in your area.

24. How are those services addressing needs at different life stages, particularly the transition from children's to adult's services?

25. How are housing support needs for those with ASD inc. Asperger's Syndrome met in your area?

26. How many children and adults are cared for in the community and how many in residential settings and in hospitals?

**Please describe the different kinds of resources e.g. education, day services and respite and who provides this e.g. local authority or independent provider.**

27. Where are children and adults located when their needs cannot be met locally?

	NUMBERS	LOCATIONS
Out of area		
Delayed discharge		
Other		

28. How are people with autistic spectrum disorders and their family carers involved in the planning and delivery of services?

29. What developments in working with children and adults with autistic spectrum disorders do you consider are particularly successful in your area? E.g. multi-agency working.

30. What are the gaps in services?

**SECTION E**

**TRAINING**

31. What types and levels of training on autistic spectrum disorders do you provide for:

Service commissioners	
Senior staff	
Frontline staff	
Care providers	
Users & Carers	

32. Describe any significant good practice and any gaps in autistic spectrum disorder training.

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**SECTION F**

**FUNDING**

33. What joint funding arrangements are there between local partners?

34. What mechanisms are there in place to resolve any funding disputes?

35. What forward planning takes place about funding from children as they move on to adults services?

36. Can you provide cost estimates for young people in transition based on your planning assumptions? Please provide details.

**SECTION G PLANNING AND COMMISSIONING**

37. Do you have or are you developing joint planning structures within Joint Future with a specific emphasis on ASD?

38. Do you have joint commissioning structures involving health and local authorities? Are plans in place to develop appropriate accommodation and support, day services, respite services and continuing care structures?

**LOCATION**

Please state which local authorities and NHS boards were involved in completing the audit.

**CONTACT DETAILS**

Please provide the name, position and location of the person who co-ordinated and completed the audit.