

From the Director of Mental Health and Disability
Dr Maura Briscoe



Department of
**Health, Social Services
and Public Safety**

An Roinn

**Sláinte, Seirbhísí Sóisialta
agus Sábháilteachta Poiblí**

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Date: 17 September 2008

Dear Consultee

**CONSULTATION ON AN AUTISM SPECTRUM DISORDER (ASD) STRATEGIC ACTION PLAN
2008/09 – 2010/11**

I am writing to seek your views on the draft Autism Spectrum Disorder (ASD) Strategic Action Plan which has been developed by the Department of Health, Social Services and Public Safety.

The ASD Action Plan is focused on development and improvement of health and social care services for all individuals, families and carers affected by autism. It is designed to provide a clear direction to help us move forward with person-centred, co-ordinated, high quality services to those with autism over the next 3 years.

The goal is earlier detection and recognition of autism, prompt assessment and diagnosis, and appropriate intervention and support for individuals affected by autism, and their families.

I enclose a consultation response pro-forma to help you set out your views. If you have any questions about this consultation exercise, or if you would like to request paper copies or alternative formats or languages, or if you would like to meet someone to discuss the draft Strategic Action Plan, you should contact Hannah Cavalleros (028) 90 522153 hannah.cavalleros@dhsspsni.gov.uk or Michael Swann (028) 90 528374 michael.swann@dhsspsni.gov.uk.

The ASD Strategic Action Plan consultation document and response pro-forma are also available online at <http://www.dhsspsni.gov.uk/index/consultations.htm>.

I look forward to receiving your response which should be returned by **12 December 2008**.

Yours faithfully,

MAURA BRISCOE

Director of Mental Health and Disability Policy



CONSULTATION ON AN AUTISM SPECTRUM DISORDER (ASD) ACTION PLAN RESPONSE DOCUMENT

Before responding to this consultation please take note of the Freedom of Information requirements in Appendix 1 at the end of this questionnaire.

Responses should be sent to:

Hannah Cavalleros
Learning Disability Unit
Room D1
Castle Buildings
Stormont,
BELFAST, BT4 3SQ
Tel: 028 905 22153
Fax: 028 905 22500
E-mail: Hannah.Cavalleros@dhsspsni.gov.uk

Please reply by 12th December 2008

Please tick

I am responding as an individual

Or on behalf of an organisation

**Name (Print): MAUREEN GORMLEY...Job title: BUSINESS SUPPORT
MANAGER**

Organisation:...WESTERN HEALTH & SOCIAL SERVICES COUNCIL

Address:...HILLTOP, TYRONE & FERMANAGH HOSPITAL, OMAGH

Email address:maureen.gormley@whssc.n-i.nhs.uk

Date:...24/11/08

THEME S – Service redesign to improve autism care

Q1: Do you agree that a Local ASD Network and Regional ASD Regional Co-ordination Group should be created to promote and complete the actions as suggested in sections S-2 to S-3(c)? Please tick

Yes

No

If you answered “no” to this question please outline the reasons for your answer

The Council would like to be assured that there will be strong links between the Local ASD Network and the Regional ASD Regional Co-ordination Group to ensure that the local voice is heard and acted on. However we are also anxious to ensure that the funding allocated is not spent on high level managerial posts but on services which are required to be delivered on the ground. We would like to see clearly identified lines of accountability and follow-up with evidence to show that the recommendations are being implemented. Those given responsibility for implementing the recommendations should have ASD services as their primary focus so that they can concentrate their efforts on delivering the outcomes – this should not be tagged on to other competing roles.

We understand officials from the Department made themselves available to speak directly to parents and ASD activist groups and we welcome this approach. It is very important that service users/parents/carers are represented at all levels – local and regional – where decisions will be made. The Council would also wish to emphasise that organisations should not become the proxy service user but that there is of right appropriately supported representation from service users, parents and carers at all levels.

THEME S – Service redesign to improve autism care

Q2: Do you agree with the proposal to standardize the processes for referral to services and to create a more seamless, less rigid approach to the early provision of services? Please tick

Yes

No

If you have answered “no” what type of pathway or processes would you prefer to have in place?

The Council supports the standardisation of referral processes as we have been concerned for some time at the ‘postcode lottery’ which determines access to these services across Northern Ireland.

The care pathway outlined in the consultation document will only succeed if the appropriate level of staffing is in place to support it at all stages. Theoretically the model should deliver but only if a dedicated team is in place to support it.

The funding needs to be ring-fenced to ensure that resources remain secured to deliver the model.

The Council remains concerned that the model described might not be delivered if any geographical area is unable to recruit staff as is currently the case in the West.

THEME P - Performance improvement of autism services

Q3: Do you agree that standards and performance measures should be developed to improve autism services? Please tick

Yes No

If you answered "no" to this question please outline the reasons for your answer

We would agree that it is very important to develop standards and performance measures to improve autism services.

The Council would want to see service users, parents and activist groups involved in the setting of these standards. It is imperative that those setting the standards and performance measures should be independent of service providers.

THEME T - Training and raising awareness

Q4: Do you agree with proposals to provide ASD awareness training for HSC staff in contact with those affected by autism, and specialist training for key front line staff? Please tick

Yes No

If you answered "no" to this question please outline the reasons for your answer or any additional groups needing training.

Training must be properly funded – there is a concern that the funding available for front line ASD services will be further eroded if it has to be used for training. Training must be mandatory to ensure that all appropriate staff avail of it. The Council agrees that there should be specialist training for key front line staff. The standards and performance measures referred to in Q3 should include monitoring staff training. Parents are also a very valuable resource in providing staff with information on children's needs and this information source should be incorporated into the training.

THEME C - Communication and information

Q5: Do you agree with proposals to investigate the wider use of communication and information services to help people affected by ASD, their families and carers? Please tick

Yes No

If you answered "no" to this question please outline the reasons for your answer.

Information made available to service users/parents/carers should be impartial, accurate and uniform across Northern Ireland. Although there have been huge advances in technology and this is to be welcomed, not everyone is able to access the internet so consideration needs to be given to providing information by other means.

THEME E – Effective engagement and partnership working

Q6: What practical ways might be developed to involve service users, families and carers in the planning, commissioning and evaluation of ASD services?

The Council feels very strongly that service users should be actively involved in shaping the design and delivery of services. They should also be involved in evaluating and monitoring service delivery.

The principles of the Department's Personal and Public Involvement Strategy must be adopted and service providers should be required to demonstrate how they are involving service users/parents/carers in decision making processes. One of the most important ways to ensure effective ongoing engagement and partnership working is by clearly demonstrating that service user/parent/carer views were listened to and acted upon.

Human Rights and Equality Implications

Section 75 of the Northern Ireland Act 1998 requires Departments in carrying out their functions relating to Northern Ireland to have due regard to the need to promote equality of opportunity:

- ❖ between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation;
- ❖ between men and women generally;
- ❖ between person with a disability and persons without; and
- ❖ between persons with dependants and persons without.

In addition, without prejudice to the above obligation, Departments should also, in carrying out their functions relating to Northern Ireland, have due regard to the desirability of promoting good relations between persons of different religious belief, political opinion or racial group. Departments also have a statutory duty to ensure that their decisions and actions are compatible with the European Convention on Human Rights and to act in accordance with these rights.

The Department is now screening the proposals set out in this Action Plan as part of the screening process and is inviting responses to the following questions:

Q7: Are the actions which are set out in this document likely to have an adverse impact on any group of people in terms of the nine equality dimensions? Please tick

Yes **No**

If you answered yes, please state which group(s) and the reasons why.

Q8: Are you aware of any indication or evidence – qualitative or quantitative – that the actions in this document may have an adverse impact on equality of opportunity or good relations? Please tick.

Yes **No**

If you answered “yes”, please state the reasons why and suggest how these might be mitigated

Q9: Does the proposed action plan afford an opportunity to promote equality of opportunity and/or good relations?

Yes **No**

If you answered “yes”, please outline.

Q10: Are there any aspects of this action plan where potential human rights violations may occur?

GENERAL COMMENTS

The design of the questionnaire does not lend itself to a comprehensive response. It would be difficult to answer 'No' to any of the questions and yet we are only invited to make a comment to a 'No' answer. It is important to be able to qualify a 'Yes' answer with a further statement.

The Council welcomes the Action Plan as an attempt to improve services but feels that the time frame for implementation is too short and that targets in the Action Plan are unrealistic. Service users/parents/carers have waited for a long time for a Strategy and it is very important that the process is not rushed but that the Department takes time to properly consider the recommendations and to ensure that the small amount of funding secured is targeted appropriately on frontline services and not on bureaucracy.

The Council welcomes the fact that there is a dedicated budget for ASD services but feels that £2.2 m is considerably below the funding required.

The Council would have a concern that the information on prevalence rates for ASD is inadequate and misleading and more needs to be done to accurately capture and reflect unmet need.

It has long been recognised that there are particular problems in the West of the Province with regard to lack of services for people with ASD which have been compounded by difficulties recruiting professional staff to ASD teams. The Council feels very strongly that the Department must address the recruitment issues in the West to ensure equity for people living in this area. People with ASD are not having their basic human rights met in terms of the services available to them because of where they live.

There is a concern that ASD services were not managed appropriately within the previous Sperrin Lakeland Trust and parents lost faith with that Trust. It is now concerning to note that the new Western Trust is also reporting that it is unable to attract professional staff to provide ASD services and consequently the Southern sector of the Trust does not provide the same level of service as it does in the Northern sector. The Council would want the Department to give consideration to staff being employed by a Regional body. Staff would then work across the geography to provide services. This would ensure equity across Northern Ireland.

There is an opportunity with the new funding being allocated to provide much needed ASD services in the West and the Council would want reassurance that robust monitoring arrangements will be put in place to ensure this is allocated and managed appropriately to bring about improvements.

It is our understanding that the Department of Education is working on a separate Action Plan for ASD services. We understand that each organisation has an obligation to put forward an Action Plan with regard to their part of the service. However the Council would want an assurance that strategically there is 'joined-up' thinking and that both Health and Education are working collaboratively towards this.

The Bamford Review placed ASD within the Mental Health & Learning Disability

Programme of Care. The Council would have a concern that each Trust will translate this differently. We have an expectation that ASD services should be placed in the same Programme of Care right across the 5 Trusts in order to ensure consistency.

Accountability for implementing this Strategy will rest with the newly established Regional Health & Social Care Body. The Council would want to see implementation of the Strategy monitored and the new commissioning body held to account one year into its existence with regard to progress.

Thank you for your comments. Please return this form by **12th December 2008** to:

**Hannah Cavalleros
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FREEDOM OF INFORMATION ACT 2000 – CONFIDENTIALITY OF CONSULTATIONS

The Department will publish a summary of responses following completion of the consultation process. Your response, and all other responses to the consultation, may be disclosed on request. The Department can only refuse to disclose information in exceptional circumstances. **Before** you submit your response, please read the paragraphs below on the confidentiality of consultations and they will give you guidance on the legal position about any information given by you in response to this consultation.

The Freedom of Information Act gives the public a right of access to any information held by a public authority, namely, the Department in this case. This right of access to information includes information provided in response to a consultation. The Department cannot automatically consider as confidential information supplied to it in response to a consultation.

However, it does have the responsibility to decide whether any information provided by you in response to this consultation, including information about your identity should be made public or be treated as confidential. If you do not wish information about your identity to be made public please include an explanation in your response.

This means that information provided by you in response to the consultation is unlikely to be treated as confidential, except in very particular circumstances. The Secretary of State for Constitutional Affairs' Code of Practice on the Freedom of Information Act provides that:

- the Department should only accept information from third parties in confidence if it is necessary to obtain that information in connection with the exercise of any of the Department's functions and it would not otherwise be provided
- the Department should not agree to hold information received from third parties "in confidence" which is not confidential in nature
- acceptance by the Department of confidentiality provisions must be for good reasons, capable of being justified to the Information Commissioner.

For further information about confidentiality of responses please contact the Information Commissioner's Office (or see web site at: <http://www.informationcommissioner.gov.uk/>).