



Department of

**Health, Social Services  
and Public Safety**

[www.dhsspsni.gov.uk](http://www.dhsspsni.gov.uk)

AN ROINN

**Sláinte, Seirbhísí Sóisialta  
agus Sábháilteachta Poiblí**

MÁNNYSTRIE O

**Poustie, Resydènter Heisin  
an Fowk Siccar**

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

**CONSULTATION RESPONSE  
DOCUMENT**

**June 2009**

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

The ASD Strategic Action Plan was issued for public consultation from 17<sup>th</sup> September to 12<sup>th</sup> December 2008. Over 450 consultation responses were received.

In addition to the formal responses many views were taken into account at the various discussions and meetings held during the consultation process. Comments and suggestions received from these discussions are also presented in this document.

### **Number of Responses**

355	National Autistic Campaign Postcards Responses
104	Other Responses
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459	Total Responses

### **Details of Responses**

#### **Health Boards**

1. WHSSB
2. EHSSB
3. NHSSB – FPLL
4. SHSSB – Parents Cares Council on Disability

#### **Health Councils**

5. All four Health Councils

#### **Health and Social Care Trusts (HSCT)**

6. Belfast (BHSCT)
7. Southern (SHSCT)
8. Western (WHSCT)

#### **HSC Trust Directorates**

9. NHSCT - Womens & Childrens
10. NHSCT – Child Clinical Psychology
11. NHSCT - Autism Diagnosticians Forum
12. WHSCT – Adult Mental Health and Disability Services
13. WHSCT – Autism Diagnosticians Forum

- 14. SHSCT – Autism Diagnostic & Intervention Service
- 451. Learning Disability Team NHSCT
- 453. Social Services Department NHSSB

### **Local Councils**

- 15. Cookstown
- 16. Newry & Mourne
- 17. Lisburn
- 18. Belfast
- 19. Craigavon
- 20. Limavady
- 21. Ards
- 22. Larne
- 23. Magherafelt
- 24. Ballymena

### **Councils (continued)**

- 446. Castlereagh Borough Council
- 447. Coleraine Borough Council
- 448. Lisburn City Council
- 449. Armagh City & District Council
- 450. Omagh District Council

### **Government Departments**

- 25. Northern Ireland Office
- 26. Department of Social Development
- 27. Department of Health, Social Services and Public Safety
- 28. Department of Education

### **Education Boards, Schools and Universities**

- 29. Belfast Education and Library Board
- 30. Southern Education and Library Board
- 31. Tor Bank School
- 32. Clarawood School
- 33. Newstart Education Centre
- 34. University of Ulster
- 35. University of Ulster – Applied Behaviour Analysis
- 36. St Marys University College
- 37. Royal College of Nursing
- 38. Royal College of Psychiatrists
- 39. Stranmillis University College
- 459. School of Education, Queen’s University of Belfast

### **Other Statutory**

- 40. Northern Ireland Commissioner for Children & Young People (NICCY)
- 41. British Association of Social Workers (BASW)
- 42. Probation Board for Northern Ireland (PBNI)
- 43. British Diabetic Association
- 44. Northern Ireland Guardian Ad Litem Agency
- 45. Mental Health Commission
- 46. British Psychological Society
- 47. Northern Ireland Health Committee
- 48. Northern Ireland Music Therapy Trust

### **Voluntary and Community Sector**

- 49. National Autistic Society
- 50. Barnardos
- 51. Middletown Centre for Autism
- 52. Parents Education as Autism Therapists (PEAT)
- 53. Autism Initiatives
- 54. Helping Hands Autism Support Group

### **Voluntary and Community Sector (Continued)**

- 55. North-West Community Network
- 56. Presbyterian Church in Ireland
- 57. Oakleaf Rural Community
- 58-75. Autism NI
- 76-83. Private Individuals
- 84-438 National Autistic Society - Individually signed campaign postcards
- 439 Autism NI Lisburn Branch
- 440 Autism NI Client Response
- 441 Autism NI Mid-Ulster Branch
- 442 Autism NI
- 443 MENCAP
- 444 Autism NI Client Response
- 445 SPEAC

### **Others**

- 452 College of Occupational Therapists
- 453 Southern Regional College

### **Individuals**

- 455-458

### **Acknowledgements**

Strabane District Council  
Help the Aged  
Department of Enterprise, Trade & Investment

## **CONSULTATION QUESTIONS**

### **Theme S – Service redesign to improve autism care**

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

Agree 98.9%

Disagree 1.1%

“Formal links to other statutory agencies essential”

“Need strong local/regional ASD Group linkages”

“Need to avoid ASD resources going to managerial posts - rather than front line services.”

“Other Agencies should have membership of ASD Group(s)”

“Need to clarify issues linked to definitions, budgets and services within the action plan”

“Mapping should include health, education, housing etc.”

“Diagnosticians forum could act as a reference group to Regional ASD Group.”

“Additional Monies should provide services, not bureaucracy”

“Would welcome a mapping exercise, to consider and identify the services that this might involve”

“Good communications with other agencies and Departments must be established, to arrange collaboration and an efficient, co-ordinated approach”

**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?**

Agree 98.3%

Disagree 1.7%

“Standardising Pathways and services should allow for individually tailored services”

“Needs better co-ordination of services – too many different services, and different waiting lists”

“Actions and funding must be put in place to meet the needs of adults”

“The pathways can work, but needs 100% coverage”

“Standard pathways are good practice”

“Services need to keep pace with standardisation”

“This needs to include adult services”

“24 month developmental screening is a significant advance”

“The need is recognised for seamless care, clear pathways, standardisation of best practice.”

## **Theme P – Performance improvement of autism services**

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

Agree 99.1%

Disagree 0.9%

“Important to develop standards and performance measures”

“Needs to be qualitative as well as quantitative”

“Parent and carer view of the services.”

“Impact on individual child and family functioning”

“Need to be standard, not open to misinterpretation”

“Improved incidence figures needed – including high functioning and Asperger’s cases”

“Performance Indicators can be indicative and informative, but not a sole determinant”

“Agreed – but not to the point where service provision loses out to box ticking and red tape”

“Yes, but not to a point where ticking a box is more important than service provision”

### **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?**

Agree 99.6%

Disagree 0.4%

“Extend training to improve access to good quality services for adults”

“Training plans should include scope for advice to staff from parents who may be a useful training resource.”

“Training needed at all levels, but resource implications must be considered”

“Specialist training will be needed as more professionals have contact with children and adults affected by ASD”

“Training should roll out beyond health and social care”

“University of Ulster will launch an elearning module on foundation studies in autism spectrum disorders – this would provide an introduction for generic HSCT staff.”

“Development of an ASD training plan – should recognise ASD as a spectrum disorder”

“Training should be extended to include parents, spouses, employers and others who are involved”

“Training is paramount in ensuring the people with autism are understood and respected”

“More in house training is needed, using knowledge and expertise of HSCT staff. Education Trusts have an awareness training model – HSCT should consider a similar model”



## **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?**

Agree 99.6%

Disagree 0.4%

“All information must be impartial.”

“Essential help but information made available must be quality assured”

“The need for direct communication during assessment and diagnosis from professionals is a key element”

“Communication should be two way”

“Waiting for Health and Social Care Centres might delay sharing information – this should be disseminated by a website, with current health and social care venues providing literature”

## **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?**

“DHSSPS personal and public involvement strategy should show how service users / parents / carers are being involved in decision making”

“Development of user involvement strategies for Trusts”

“Mandatory user satisfaction surveys”

“The action plan would benefit by articulation the roles played by public service providers outside DHSSPS”

“Consider engaging with services elsewhere in UK for advice”

“Involvement online / virtual groups would be innovative”

“The voluntary and community sector have a role in managing and supporting autism as a lifelong condition”

“A reference group should be formed including representation from users and carers – this would however be quite challenging”

“Establish a working group reflecting adequate representation of all stakeholders”

## **Human Rights and Equality Implications**

**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?**

No 98.9%                  Yes 1.1%

“Services for adults have to be improved”

**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?**

No 98.7%                  Yes 1.3%

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

94.5%                  No comment/no detail provided  
Yes 5.5%              Comment provided -

“Will promote engagement in more activities by people affected by ASD”

“Placing service users at the heart of planning arrangements promotes equality”

“Need to ensure equality for people affected by learning disabilities – with and without ASD”

“Consistency of services across NI will promote equality of opportunity and equity”

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

No 98.9%            Yes 1.1%

“Need to consider implications of diagnosis – particularly in high-functioning ASD cases to avoid negative impact of diagnostic labelling”.

“Some very mild cases are forced through to diagnosis by parents against views of specialists.”

**General Comments**

“Need to prepare for emerging needs in community, school, workplace and home given numbers being diagnosed”

“ASD and learning disability (20-25% of cases) need more, individual services”

“More emphasis needed on adult services”

“The improvements to ASD services must not disadvantage other Groups”

“Learning Disability needs should be recorded in same Programme of Care to ensure consistency”

“Regional ASD Group should be held to account after 1<sup>st</sup> year to check progress”

“Timeframes for action plan too tight – unrealistic”

“ASD services must not be improved to the detriment of other services”

“All those involved in decision making should have an understanding of the motional rollercoaster ride faced by families after a diagnosis of autism”

## **Equality, Good Relations, Disability and Human Rights Screening**

Following initial screening, and public consultation on the ASD Strategic Action Plan on the overall actions within the action plan, the Department is not aware of any evidence to indicate that any adverse impact is likely to arise and responses to consultation did not raise any concerns or provide any evidence to indicate that an adverse impact is likely to arise.