



Department of

**Health, Social Services
and Public Safety**

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AN ROINN

**Sláinte, Seirbhísí Sóisialta
agus Sábháilteachta Poiblí**

MÁNNYSTRIE O

**Poustie, Resydënter Heisin
an Fowk Siccar**

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

June 2009

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FOREWORD BY HEALTH MINISTER MICHAEL MCGIMPSEY

The need to develop and improve health and social care services for people of all ages who are affected by Autism Spectrum Disorder (ASD) has been clear for some time.

One of my first actions as Health Minister was to establish an Independent Review of Autism Services, chaired by Lord Maginnis. That Independent Review, together with a series of other documents, informed a draft ASD Strategic Action Plan, which was consulted upon in late 2008.

I now have pleasure in publishing the ASD Strategic Action Plan (2009-2011) which includes advice and input received as part of that consultation exercise. The overwhelming majority of people who responded to the consultation supported the further development of ASD services. There was a clear view expressed that there should be promotion of a more seamless, coordinated range of services for children, adolescents and adults living with ASD. The responses also underlined the need to involve individuals, families, carers, voluntary and community sector groups, and representatives from other departments and agencies, in the further development of ASD health and social care services.

Through a new Regional ASD Network Group, I intend that partnership approaches, commissioning, service redesign, delivery, and performance improvement will be further developed so as to enhance outcomes for children and adults with ASD, their families and carers.

A key element of the work of the Regional ASD Network Group is to develop collaborative approaches, recognising the valuable contribution that service users, families and carers can make, together with other statutory, voluntary and community organisations. All have developed considerable expertise in raising awareness on ASD, and in training and ASD service provision.

Team based approaches are important and I am happy to report that the multidisciplinary Regional ASD Network Group commenced work in April 2009, under the chairmanship of Dr Stephen Bergin from the Public Health Agency (PHA) . This Group will drive forward implementation of the ASD Strategic Action Plan, working in collaboration with the new HSC Board.

The Regional ASD Network Group will be accountable to the HSC Board. It will produce an annual report on progress against the ASD Strategic Action Plan. This will be linked to the broader implementation of *Delivering the Bamford Vision*.

MICHAEL McGIMPSEY
Minister for Health, Social Services & Public Safety

INTRODUCTION

1. On 26 June 2008 the Health Minister, Michael McGimpsey announced his intention to develop a Strategic Action Plan for ASD Services across Northern Ireland. Consultation on the draft Strategic Action Plan closed on 12 December 2008. The response to the draft Action Plan was overwhelmingly positive. The attached Autism Spectrum Disorder (ASD) Strategic Action Plan (2009 – 2011) covers a broad range of actions intended to improve services for children, adolescents and adults with ASD, and their families and carers.
2. Whilst the Action Plan is primarily directed towards health and social care services, it recognises the importance of partnership working to promote a person centred approach to ASD service provision.
3. The Action Plan also requires the active involvement of individuals, families, carers, voluntary and community sector groups, together with representatives from other Northern Ireland Departments to promote the development of complementary, coordinated services across other Departmental responsibilities including housing, education, employment, social security and leisure activities.

WHAT IS AUTISM SPECTRUM DISORDER?

4. Throughout this document, we have used the term Autism Spectrum Disorder (ASD). In 1979, Wing and Gould¹ introduced the notion of an autism spectrum disorder covering a range of levels and severities, but characterised by qualitative impairments in *social, communicative* and *imaginative* development. It is this “triad” of impairments that is captured in international classification systems.
5. Diagnosis is sometimes complicated by the range of manifestations of each of the triad of impairments. In addition, these can look very different in childhood when compared to adulthood. It is clear, however, that ASD persists, and that children with ASD become adults with ASD, with their own individual needs.
6. This ASD Strategic Action Plan recognises that ASD is a life long condition, and that whilst early interventions, assessment, diagnosis and support in childhood are absolutely essential, so too is coordinated planning into adulthood with the management of transition between childhood and adulthood of pivotal importance.

¹ Wing,L. & Gould,J. (1979).- *Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification*. Journal of Autism and Developmental Disorders,9, 11-29

HOW MANY PEOPLE HAVE ASD IN NORTHERN IRELAND?

7. The incidence of ASD (new cases) and prevalence (new and existing cases at a point in time or over a defined period) is unknown in our society. This is no different to other parts of the developed world where, despite better diagnostic criteria and ASD assessment tools, diagnosis in childhood and in adulthood remains challenging. Population estimates can vary; however, the Medical Research Council's Review of Autism Research (December 2001) suggests that there is fairly good agreement between epidemiological studies that ASD, if broadly defined, affects around 60 per 10,000 children under 8 and, if narrowly defined 10-30 per 10,000.
8. Current estimates from diagnostic trends suggest that approximately 200 new ASD cases can be expected per year in Northern Ireland. It is also estimated that for every three suspected cases referred for diagnosis and assessment services, one case will be confirmed. In addition to these numbers of new referrals and new cases, there are an unknown number of older people still to be identified. Issues outlined in the Action Plan include the need for more reliable data on ASD cases and services.
9. ASD occurs more commonly in boys than girls at a ratio of at least 4:1, although this varies across the ASD spectrum.
10. The evidence available on ASD shows that many of those affected will have other co-existing conditions. Overlapping conditions

require an integrated approach to service delivery with sufficient flexibility to address individual needs. These needs continue to evolve throughout the lifetime of the person affected. These factors all contribute to the requirement to build service capacity, and to have an effective structure to promote, monitor and co-ordinate services.

THE BENEFITS OF AN ASD ACTION PLAN

11. The individual nature of ASD serves to underline the need for a “person-centred approach” to ASD service provision. Individuals of all ages, families and carers affected by ASD need to become an established part of the process for identifying and organising ASD services which should focus on a “whole life” approach with appropriate intervention and provision of health and social care services. The spectrum of disorder associated with ASD requires an effective response and must, therefore, include the statutory, private, voluntary and community sectors, each of which will have a role in promoting engagement and co-ordination of services at relevant levels.

12. ASD poses many challenges and can sometimes be complex and difficult to diagnose. In addition, it is recognised that there are an increasing number of people being diagnosed with ASD. Therefore, there is a real need now to improve commissioning and provision of ASD services, and training and education, so that there is earlier recognition, intervention and support for individuals with ASD and their families. As a general principle, services should be developed based on assessed need. This document

sets the strategic policy direction to develop these health and social care services to meet the future needs of individuals of all ages and their families. Specifically we will drive change by:

- service redesign, to promote a co-ordinated approach to assessment, diagnosis, care and support for people of all ages;
- reducing waiting times for assessment, diagnosis, treatment and care;
- developing specialist teams at local level linked to a regional multi-disciplinary network group;
- placing a clear focus on the development of a regionally agreed care pathway and standards for early referral, assessment, diagnosis and support;
- performance improvement by having specific time-bounded actions and measurable performance indicators;
- promoting training and education to support parents and professionals in the earlier recognition of “alerting signals” to ASD and evidence based approaches to assessment, diagnosis and interventions;
- improving communication and information provided to individuals and families; and
- acknowledging that partnership working within Government with service users and carers, voluntary/community groups and other agencies is required, especially to raise awareness of ASD, enhance communication and promote integration of ASD service provision.

HOW THE ACTION PLAN LINKS TO OTHER POLICIES AND DOCUMENTS

13. Preparation of this Action Plan follows publication of a series of documents, including the Independent Review of Autism Services, the Bamford Autistic Spectrum Disorder recommendations and the Bamford Equal Lives Report. These documents, which have informed the process of preparing the ASD Action Plan, can be found on the DHSSPS website². In addition, the Action Plan draws on local, national and international work carried out in this field.

14. It is recognised that individuals living with ASD sometimes have other conditions which could adversely impact on their health and wellbeing such as, epilepsy, ADHD, mental health, or a learning disability. In addition, families and carers of individuals with ASD may also have needs. The soon- to- be published *Delivering the Bamford Vision Action Plan* is important as it incorporates actions to improve mental health, resilience and wellbeing, and also supports the development of “talking therapies” which will be so important for those individuals and carers who may develop, for example, an anxiety or depressive disorder. In addition, a “lifelong approach” to care and support for those with a learning disability is advocated. A pivotal element of the *Bamford Vision* is cross departmental and interagency working; such an approach is vital for those individuals with ASD, their families and carers.

² www.dhsspsni.gov.uk

15. Therefore, this ASD Action Plan recognises that important work is being carried out by Health and Social Care organisations and other Government Departments. The DHSSPS Action Plan on ASD acknowledges that effective coordination and sharing of information and best practice with other agencies and sectors is essential.

FAMILY SUPPORT

16. The principles of family support services for individuals with ASD and their families will be informed by the strategic context set out in *Families Matter: Supporting Families in Northern Ireland*, published March 2009. The provision of family support to children, young people, adults and their families requires an integrated interagency approach. Working in partnership across communities is an integral part of family support.
17. It is important that family support Interventions should be needs led and strive for the minimum intervention required. There should also be a clear focus on the wishes of the family/carer which strengthen informal support networks.
18. Family support services should be accessible and flexible in respect of location, timing, settings and changing needs, and multi access referral paths should be available.
19. The services should be facilitated to provide a range of support services including, early years support; pre and post diagnosis

support; befriending, social support programmes, citizenship / learning for life programmes, and parenting programmes.

20. The involvement of users and providers in the planning, delivery and evaluation of family support services should be promoted. Services should also aim to promote social inclusion and address issues around ethnicity, disability and rural/urban communities.
21. As part of evaluation, measures of success should be built into the provision of family support services; these should include enhancing outcomes for service users and improving the quality of service based on best practice models.

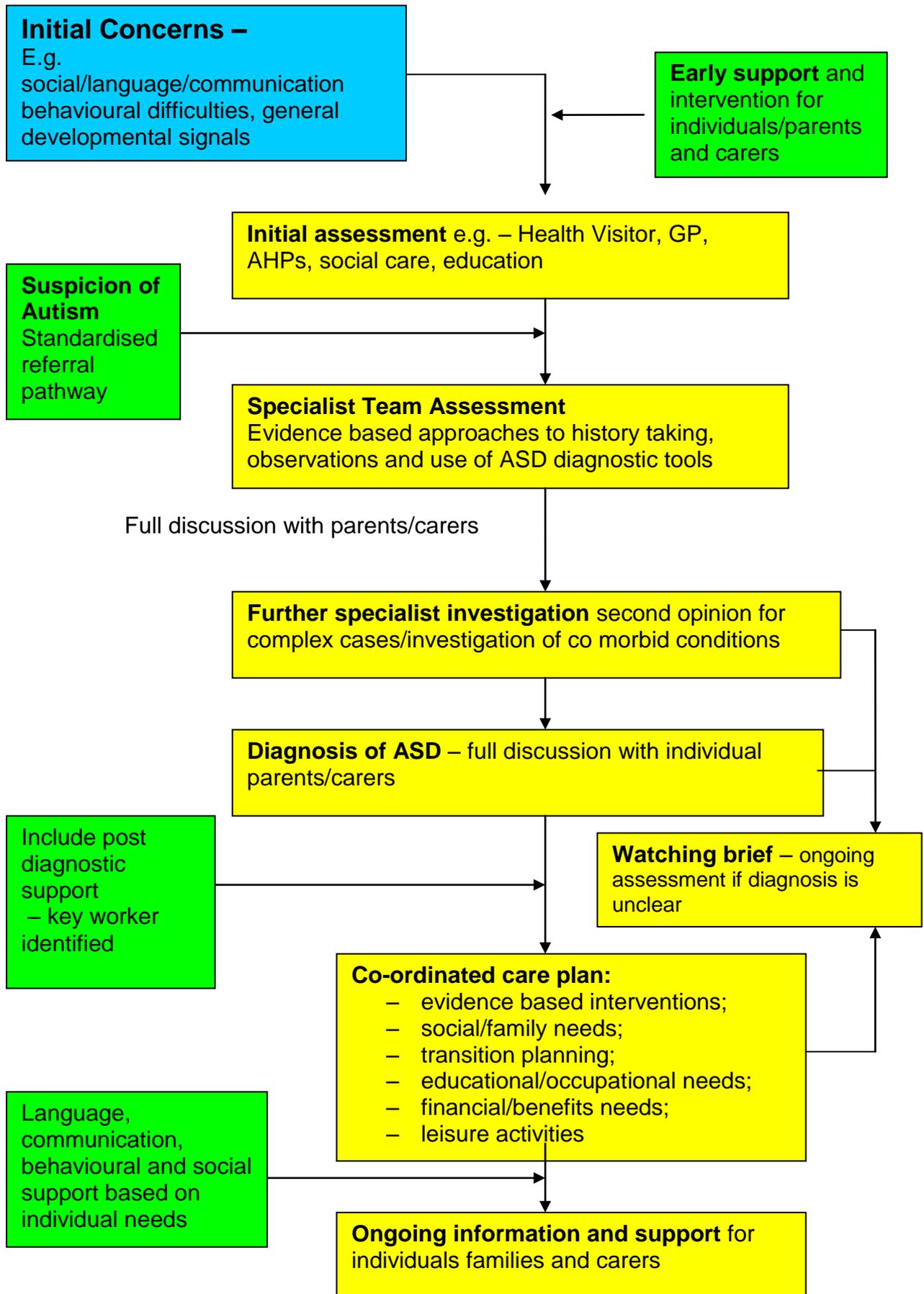
KEY ELEMENTS OF THE ASD STRATEGIC ACTION PLAN

22. The ASD Strategic Action Plan seeks to promote a service which will meet the assessed needs of individuals, families and carers. The plan highlights key actions, a timetable for completion, the outcomes required and the benefits of each action for individuals and families.
23. The Action Plan is organised around 5 key themes:
 - service redesign to improve ASD care;
 - performance improvement of ASD services;
 - training and raising awareness;
 - improving communication and information for individuals and families; and
 - effective engagement and partnership working.

CARE PATHWAY FOR ASD SERVICES

24. The five themes and underpinning actions are all linked to a care pathway approach which will be designed to enhance early recognition, integrated assessment, diagnosis, evidence based interventions and ongoing support. An integral part of this care pathway approach is the recognition of co-morbidities and, where appropriate, lifelong support for those living with ASD. Standards will be developed for key stages along the care pathway and measurable performance indicators will be developed to drive improvement.

CARE PATHWAY FOR ASD SERVICES



25. The diagram above highlights key stages along the care pathway. It is recognised that parents and professionals need to be aware of the “alerting signals” for ASD and that following initial assessment, usually by a primary care professional e.g. Health Visitor, GP, Allied Health Professional (AHP) or School Nurse, there is a need for early referral to a multi-professional specialist team for assessment. Key individuals within this specialist team could include speech and language therapists, occupational therapists, clinicians, psychologists and social workers, with input from other specialists as required, based on the needs of the individual; for example, individuals with mental health and/or learning disability needs.
26. For complex cases, further investigations and ongoing assessment may be necessary before a diagnosis of ASD is made. Throughout this pathway full involvement of parents and carers is essential and a nominated lead should support the individual and the family.
27. Following diagnosis there should be a co-ordinated care plan which documents the specific interventions, therapies, support and training needed for the individual and their family. Included in this will be a recognition of educational/occupational/social housing/financial needs relevant to the individual to be co-ordinated and provided by partner organisations and other agencies.

28. Regional standards will be developed for key stages along this care pathway including:

- initial assessment and referral pathway for specialists assessment;
- specialist team assessment and use of diagnostic tools; and
- evidence based interventions, therapies and support; and
- transition planning, -recognising that living with ASD is a life long condition which may require ongoing support, especially at points of transition, from childhood to adolescence, and from adolescence to adulthood and old age.

29. In services for adolescents and adults, two distinct groups of individuals must be provided for:-

- those individuals diagnosed in early childhood, perhaps with more symptoms and associated difficulties, who have been managed with an ASD –sensitive approach since early childhood; and
- those individuals presenting to services for the first time in adolescence or in adulthood³.

30. A number of individuals will present to services for the first time in adulthood when there is a loss of the protective supportive factors

³ Independent Review of Autism Services (2008)

of childhood and adolescence, alongside increased responsibilities and relative lack of structure. Similarly, ASD may come to light when the individual develops associated mental health difficulties, such as anxiety, depression, obsessive compulsive or psychotic disorders.

31. In addition, ASD may come to light when a young person or adult comes in contact with the criminal justice system, where it is known that the prevalence of mental health, communication and learning difficulties is higher than in the general population.

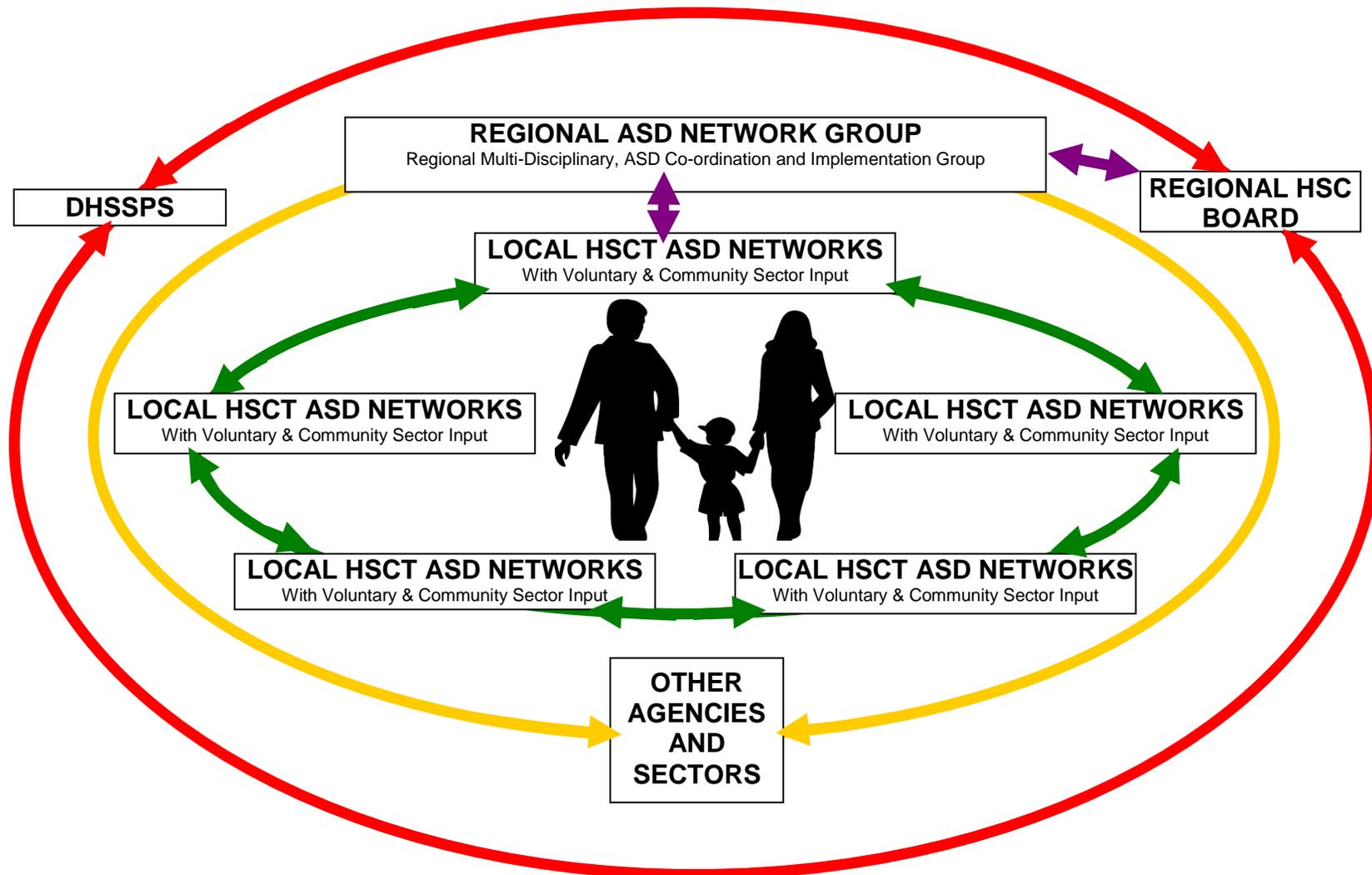
SERVICE REDESIGN

32. To become effective the care pathway will require partnership working and service redesign. At the heart of this redesign are individuals with ASD, their families and carers.
33. The diagram on page 19 is illustrative of this “person centred” approach. A key element of redesign will be the development of local specialist teams and a HSC Trust led local integrated network in each of the five Trusts to assist in assessment, diagnosis and interventions with close linkage to the ASD regional group network.
34. Nominated lead Directors and co-ordinators have been identified in each HSC Trust. The current list of Lead Directors and Coordinators is set out in Appendix A. The coordinators will drive the local ASD network and will ensure integrated working and the prevention of the “silo effect” across Programmes of Care. Details are listed in Appendix A.

35. The local multi-disciplinary network in each Trust will link to the ASD Regional Network Group, which is responsible for the development of the care pathway, regional standards and performance indicators. It will also have input into the commissioning of ASD services. Where there is a complex ASD case and, with the agreement of the individual and/or parents, this Regional Group will provide a facilitative role to explore access to other highly specialist services. This Group had its introductory meeting in April 2009 and is chaired by Dr Stephen Bergin, the Regional ASD Co-ordinator. Details of the structure of the Regional ASD Network is contained in Appendix B.

36. The Regional ASD Network Group became accountable to the Health and Social Care Board from April 2009. Through the Health and Social Care Board, the Regional ASD Group will communicate with the Department. The DHSSPS will recognise its responsibilities in, policy development for ASD services, the need for partnership working and will link with other Departments and inter-governmental groups, as appropriate.

**REGIONAL ASD NETWORK GROUP
AND LOCAL HSC TRUST ASD NETWORKS**



MONITORING AND EVALUATION

37. The Action Plan will be subject to ongoing monitoring by the Health and Social Care Board and will require evaluation to ensure effective implementation and to inform the need for any future resource allocation from 2011/12 onwards.

38. A new “Priorities for Action” target has been included in the DHSSPS Priorities for Action 2009/10. This Action is designed to enhance earlier recognition, intervention and support. The target- *by March 2010, to ensure that all children wait no longer than 13 weeks for assessment following referral and a further 13 weeks for commencement of specialised treatment* – will be subject to regular monitoring by the HSC Board and progress will be reported to the DHSSPS.

RESOURCES

39. Following the announcement of the Independent Review of Autism Services (September 2007), additional resources were secured by the DHSSPS. An extra £2.02million is available to underpin this three year Action Plan (2008/9-2010/11). This forms part of the additional resource of £17million for learning disability services including respite care.

40. The Action Plan promotes an approach which directs resources towards front line services rather than administration, and which encourages, wherever possible, the reorganisation of existing service capacity to create new ASD structures and pathways.

PRIORITIES WITHIN THE ACTION PLAN

41. In summary our priorities are:

- a. Leadership to effect change through the development of the Regional ASD Network Group with a clear programme of work and the development of a lead director and co-ordinator in each HSC Trust thus preventing “silo” working, and the commencement of local ASD networks and development of integrated specialist teams at local level.
- b. Earlier detection, intervention and improved communication and support to enhance outcomes for individuals, their families and carers.
- c. Reduction in waiting times for access to assessment, diagnosis and intervention.
- d. An agreed referral pathway for people with suspected ASD.
- e. Development of multi-disciplinary, multi-agency approaches to intervention and support recognising the importance of the points of transition, e.g., between adolescence and adulthood, to include the need for signposting and liaison with organisations responsible for education, housing, benefit support, employment and leisure activities.

- f. Service mapping on current service provision led by the Regional ASD Network Group to include caseload, current workforce, skill mix and use of assessment tools and interventions.
- g. Improved and standardised data collection to further inform gaps in service provision, future workforce planning and predict future demands.
- h. Clarification and standardisation of definitions, assessment and diagnostic criteria.
- i. Development of an ASD education and training plan to promote an interdisciplinary approach to training and especially to improve early detection of “alerting signals” of ASD.

ASD Strategic Action Plan

2008/09 – 2010/11

Key Themes

S = Service redesign to improve ASD care

P = Performance improvement of ASD services

T = Training and raising awareness

C = Communication and information for individuals and families

E = Effective engagement and partnership working

Theme – Service Redesign to Improve ASD Care (S)

ASD Action Plan Point Ref No	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
S - 1	Establish the current levels of ASD service provision	HSC Board/PHA and Regional ASD Group	Complete service mapping of current ASD service provision to include workforce, skill mix, tools and interventions used	31 Dec 2009	Service mapping will have been completed to inform regional approach to ASD treatment and care, and the standardisation of definitions, tools and interventions used in health and social care services
S - 2	<p>Establishment of Regional ASD Network Group</p> <p>Create a regional multi disciplinary, multi agency ASD co-ordination and implementation infrastructure accountable to the HSC Board, working in collaboration with other agencies and services</p>	<p>DHSSPS</p> <p>HSC Board/PHA</p>	Lead HSC Board identified to take forward formation of ASD Regional Group in advance of formation of Regional HSC Board (from April 2009).	<p>31 March 2009</p> <p>COMPLETED</p>	<p>The early commencement of an integrated ASD Regional Group will mean that the structure is in place in advance of formation of the new HSC Board, from April 2009</p> <p>The ASD Group will provide a forum for interdisciplinary, multi-agency working</p>
S-2 (a)	<p>The Regional ASD Network Group will:-</p> <p>a) Co-ordinate regional planning and the development of ASD specialist teams at local level;</p>	Regional ASD Group accountable to HSC Board	Regional planning, commissioning and co-ordination of HSC Trust specialist teams	Develop a prioritised action plan by 30 Sept 2009	Co-ordinate approach to service planning using best practice examples, - e.g., Wraparound

ASD Action Plan Point Ref No	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
S-2 (b)	b) Standardise care pathways across Northern Ireland and share examples of best practice	Regional ASD Group; Primary Care; and Other sectors	Standardised referral pathway for initial assessment and information provided to specialist teams Agree integrated care pathway for children, adolescents and adults with suspected ASD	Completed by March 2010	Clear understanding of pathway of care, and the services that a service user, family or carer can expect for an individual with a potential diagnosis of ASD
S-2 (c)	c) Promote agreed service standards	Regional ASD Group	Development of clear service standards for assessment, diagnosis and interventions within HSC services	March 2010	Agreement on definitions and criteria for assessment, diagnosis and evidence-based interventions for delivery within HSC services
S-2(d)	d) Horizon scanning – for example, recent innovations and developments	Regional ASD Group in collaboration with other sectors	Clear mandate to keep abreast of innovation and evidence based practice	Ongoing	Translation of best evidence into practice – for example, NICE, SCIE and robust guidance on cost-effective ASD treatment and care
S - 3	At sub regional level, create a local ASD co-ordination and implementation network in each HSC Trust area. To include:	HSCB/PHA and Trusts in collaboration with the Regional ASD Group	Multi-disciplinary working at HSC Trust level, recognising the importance of links to other sectors, e.g. education, and other sectors and agencies	September 2009	This can be a virtual network within existing Trust services cutting across children's and adults Programmes of Care. The infrastructure is intended to promote integrated working and consideration of best practice models such as Wraparound model

ASD Action Plan Point Ref No	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
S - 3(a)	a) Identification of a lead ASD director in each HSC Trust	HSC Trusts	An existing named director/assistant director in each HSC Trust responsible for ASD services	Named ASD director on the HSC Trusts' websites by 30 April 2009 COMPLETED	The ASD director will be responsible for effective planning and service co-ordination of ASD-related services across all Programmes of Care within the Trust. The director will be responsible to the Senior Management Team of the Trust The ASD director will be a member of the Regional ASD Group
S-3 (b)	b) Identification of ASD - co-ordinator in each Trust's Local ASD Network	HSC Trusts	A named co-ordinator in each HSC Trust to ensure that the various strands of service provision communicate with each other and with other statutory and non statutory services	Named ASD co-ordinator on the HSC Trusts' websites by 30 April 2009 COMPLETED	The role of co-ordinator will be a new function for existing manager post, accountable to the ASD director In establishing Local Trust ASD network the co-ordinator will ensure user/stakeholder involvement, including, for example, involvement in relevant agencies and centres

ASD Action Plan Point Ref No	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
S- 3 (c)	<p>c) Building multi-disciplinary specialist teams within HSC Trusts by:</p> <ul style="list-style-type: none"> - identifying gaps at local level by participation in current service mapping processes, co-ordinated by Regional ASD Group - pursue the development of a reliable means of identifying the number of people affected by ASD - build upon existing Trust specialist teams based on assessed need, taking account of available resources 	<p>Regional ASD Group HSC Board/PHA HSC Trusts Local ASD Networks</p>	<p>Teams of specialist ASD practitioners in all HSC Trusts providing effective & consistent ASD therapies & specialist interventions by 31 December 2009</p> <p>Contribute to training needs analysis taking account of existing skills baseline</p>	<p>Baseline current service provision by 30 Sept 2009</p> <p>Identification of workforce requirements in each HSC Trust area by March 2010</p> <p>Enhanced teams in place by Sept 2010</p>	<p>Following mapping of current service provision, there will be further development of specialist teams at local level, to deliver treatment and care to agreed standards and care pathway for assessment, diagnosis, interventions and ongoing support</p> <p>These teams will need a co-ordinated training and development plan to address service priorities</p>
S- 4	<p>Adoption of standardised assessment, diagnosis, intervention and care procedures</p> <p>To include:</p>	<p>Regional ASD Group to lead in collaboration with HSC Board/PHA and HSC Trusts</p>	<p>Standardisation of care pathway recognising the needs of individuals and existence of other complex conditions</p>	<p>30 June 2010 and ongoing</p>	<p>Promotion of a more consistent approach across NI to the diagnosis & treatment of ASD- a person centred approach to care</p>
S-4 (a)	<p>a) Adoption by all HSC Trusts of standardised referral processes / protocols across Northern Ireland for cases where there is a suspicion of ASD</p>	<p>Regional ASD Group, HSC Trusts in collaboration HSC Board/PHA</p>	<p>Standardised referral pathway to include agreed information requirements</p>	<p>30 June 2010 and ongoing</p>	<p>Streaming information makes specialist assessment easier and assists in monitoring of waiting times</p>

ASD Action Plan Point Ref No	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
S-4 (b)	Delivery of seamless care including access to specialist expertise, treatment and support in transition stages from early years to childhood, childhood to adolescence and adolescence to adult hood. To include bespoke care plan for smooth transition and promote effective linkages with other services	Local ASD Networks , Regional ASD Group, HSC Trusts in collaboration with other partners	Evidence of care planning process in place to include a nominated key worker to co-ordinate interventions and support services at relevant life stages of the individual, recognising the need for partnership working and resource constraints in the system Evidence that measures of IQ and age are not barriers to co-ordinated care	Aim to complete by 31 March 2010 with interim report on progress September 2009	A focus on the individual and a multi-agency approach to promote seamless care Through service redesign and care planning, this will involve not just health and social care, but also education, employment, services, supported housing, carer's assessments and direct payments, as appropriate to the needs of the individual with ASD and their family
S-4 (c)	Consider need for early package of care services from initial concern of ASD and/or point of referral to cover the period between suspected/provisional diagnosis of ASD and receipt of specialist services and interventions	Local ASD Networks, Regional ASD Group, HSC Trusts in collaboration with other partners.	Individually tailored packages of care services available to families to provide initial advice and support between provisional diagnosis and the receipt of specialist ASD services Allocation of a key worker from the MDT to family for support at each key stage, recognising the need for partnership working with other agencies, and resource constraints in the system	31 March 2010	Family support through initial stages of referral and assessment, provisional diagnosis, especially for complex cases. This should be available regardless of the age of presentation of ASD –i.e. not just in childhood

ASD Action Plan Point Ref No	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
S-4 (d)	Ongoing and early identification of developmental delay in all children, including ASD, through home based visits by Health Visitors (HVs) around 24 months	DHSSPS, HSC Board, PHA, Regional Health for All Children Group and School Nursing/Health Visiting Review Group	Redesign of preschool programme carried out by HVs to include home based 24 month review of development ASD awareness training for all HVs (including those undertaking training) to support early identification of ASD	Included within Review of SN/HV with full implementation from 1 January 2010	Early identification of ASD

Theme – Performance Improvement (P)

ASD Action Plan Point Ref No	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
P - 1	Reduction in waiting times from identification of initial concerns of ASD to assessment and diagnosis and from diagnosis to treatment and care	HSCB HSC Trusts	Compliance with current and future PfA targets	Agree Trust plans for reduction of waiting times by 30 September 2009	<p>Earlier diagnosis of type of ASD</p> <p>There will be an incremental approach to reduction in waiting times for assessment, diagnosis and treatment.</p> <p>The management of the current waiting times will be subject to scrutiny by the HSC Board and each Trust will be held accountable for its own performance against baseline.</p>
P - 2	Scope adult ASD needs for further development of ASD adult services recognising the importance of transitions	Regional ASD Group HSC Board/PHA	<p>Establish adult ASD needs</p> <p>Enhance transitions between childhood and adolescence, adulthood and old age.</p>	Completed needs assessment by April 2010	<p>Better services for adults with ASD and their carers.</p> <p>It is recognised that ASD services for adults are underdeveloped. There is a need for such service provision to be scoped, prioritised and aligned to other service provision for adults and older people. This will take time to achieve and will require assessment of resources to inform future decisions.</p>

ASD Action Plan Point Ref No	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
P – 3	<p>A focus on performance improvement</p> <p>Establishment of a regional performance improvement system with specific ASD quality indicators (including mean age of diagnosis), taking account of standards developed.</p>	Regional ASD Group, in collaboration with HSC Board/PHA and Local ASD Networks and agree with partner organisations	<p>Development of performance indicators covering:</p> <ul style="list-style-type: none"> - recognised standards of care; -service user and carer satisfaction; and - value for money 	31 March 2010	Performance indicators will drive improvement and will contribute to the documentation of these improvements at HSC Trust and regional level
P – 4	<p>Supporting research into ASD services and outcomes</p>	Regional ASD Group, in collaboration with PHA, research network, and national and local bodies involved in research activities, for example, education sector	Clear prioritisation of research needs in ASD for adults, adolescents and children	30 April 2010	Promoting and sharing of best practice, for example, treatment, care and support for adults with ASD

Theme – Training and raising awareness (T)

ASD Action Plan Point Ref No	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
T - 1	<p>Develop and implement ASD training strategy,</p> <p>to include :</p>	Regional ASD Group in collaboration with Local ASD Network, and partner organisations	<p>Enhance skill mix in workforce</p> <p>Promotion of ASD awareness training in other Departments, Agencies and Sectors.</p>	30 June 2010	A skilled workforce with a common understanding of criteria for assessment, diagnosis and evidence based interventions
T-1 (a)	Raising awareness of ASD and sharing examples of best practice	<p>Recognised training providers as agreed by local ASD networks and Regional ASD Group, in collaboration with partner organisations</p> <p>Providers of undergraduate /postgraduate education - for primary and community care practitioners</p>	<p>Promotion of early recognition of ASD</p> <p>Earlier recognition of “alerting signals” and knowledge of referral pathway by e.g. GPs, health visitors, and school nurses</p>	<p>Identification of HSC/primary care training needs by 31 December 2009</p> <p>Identification of appropriate training resource by 31 Dec 2009</p> <p>Delivery of programme by 30 September 2010</p>	<p>Promotion of earlier recognition of ASD and appropriate referral to specialist teams</p> <p>Training provided in-house or via a suitable external provider providing that it is delivered by professionals who are ‘accredited’ or who have recognised expertise in ASD</p>

ASD Action Plan Point Ref No	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
T-1 (b)	Specialist training for staff in frontline posts to promote harmonisation of assessments, diagnosis, evidence based interventions and ongoing support to individuals and families	Recognised training providers as agreed by local ASD networks and Regional ASD Group, in collaboration with partner organisations	Standardisation in use of assessment criteria, tools and evidence –based interventions, recognising the importance of improved support for individuals and parents	<p>Identification of appropriate training resource by 31 December 2009</p> <p>Delivery of programme by 30 September 2010</p>	<p>Promotion of standardised approach to assessment, diagnosis, interventions and support for individuals, carers and families</p> <p>Internet based support systems for training parents and professionals (e.g. Autism Pro), should be considered alongside other options.</p>

Theme – Communication and Information (C)

ASD Action Plan Point Ref No	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
C - 1	<p>Communication & Information Plan</p> <p>Produce a communication plan to provide information to people with ASD, their family and carers, to include:</p>	Regional ASD Group in collaboration with local ASD networks, families affected by ASD, and partner organisations	Integrated communication and information plan taking account of the needs of individuals/families and the expertise of ASD voluntary and community groups	<p>Components of communication plan agreed by 31 December 2009</p> <p>For full implementation by 31 December 2010</p>	Development and standardisation of ASD information available within HSC provided services
C-1(a)	Provision of appropriate and timely information to parents in Northern Ireland about developmental milestones.	DHSSPS to lead in collaboration with HSCB, PHA, HSC Trusts and Regional ASD Group	Inclusion of appropriate information on age specific child development within parent held records with signposting to national and international models	Recommendation to be reflected in the SN/HV review process with implementation from 1 January 2010	Parents supported with access to information to support early recognition of potential developmental delay including difficulties with language, communication and/or behaviour
C-1(b)	Innovative ways of supporting individuals with ASD taking account of developments in other countries	Regional ASD Group in collaboration with local Trusts' networks, with input from individuals and families affected by ASD, and partner organisations	Use of new electronic technologies and links	31 December 2010	People with ASD have different communication needs and would benefit from innovative ways to address those needs including access to agreed electronic links and technologies

ASD Action Plan Point Ref No	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
C- 1(c)	Public access to information on disability and services, including advice and information on ASD services, available through, for example, Health and Care Centres in Primary Care	<p>Development in line with roll-out of HSC Health and Care Centres</p> <p>HSCB/PHA</p> <p>HSC Trusts</p> <p>DHSSPS</p>	<p>Individuals, parents and carers know where and how to access information about disability services including ASD.</p> <p>Availability of a range of services of benefit to individuals/families affected by ASD in a single location; timescale in line with rolling out of Health and Care Centres</p>	In line with rolling out of Health and Care centres	<p>Over time, this action will recognise the importance of an integrated approach to provision of information on a range of disabilities, including ASD. It should include relevant information including housing, education, citizen's advice, etc</p> <p>Where appropriate, it will act as a "sign posting service" and will promote an integrated approach to provision of HSC services.</p>

Theme – Effective Engagement and Partnership Working (E)

ASD Action Plan Point Ref No	Key actions and service need	For Action By	Outcome required	Timetable for completion & key milestones	Benefits
E-1(a)	Promote effective working and the sharing of information and best practice with other sectors and agencies	DHSSPS, with cooperation from other NI Departments, and Agencies, including the Criminal Justice System	<p>Access to, and engagement with interested parties, to take forward the ASD Strategic Action Plan. Appointments to the Regional ASD Group from other NI Departments</p> <p>Outcomes to complement other Government Action Plans</p>	Regular discussion and co-ordinated action	This action is intended to enhance integration and to share information and best practice in the interests of providing appropriate ASD services to individuals and their families
E-1(b)	Service user involvement in planning, commissioning and delivery of ASD services	Regional HSC Board/PHA/PCC Regional ASD Group, Local ASD Networks, and HSC Trusts in collaboration with other statutory, voluntary and, community sectors and local government	Evidence of service user, family and carers involvement in HSC commissioning of ASD services	Structured involvement in commissioning arrangements for ASD, and co-ordinated action through Regional ASD Group	The recognition that service users, families, carers and advocacy groups have developed expertise on what is required to promote effective ASD services and care

Regional ASD Network Group

Lead Directors and coordinators by Health and Social Care Trust

Organisation	Name	Position
Public Health Agency	Dr Stephen Bergin (Chair of Regional ASD Network Group)	Consultant in Public Health Medicine
Regional HSC Board	Siobhan McIntyre (Deputy Chair of Regional ASD Network Group)	Assistant Director

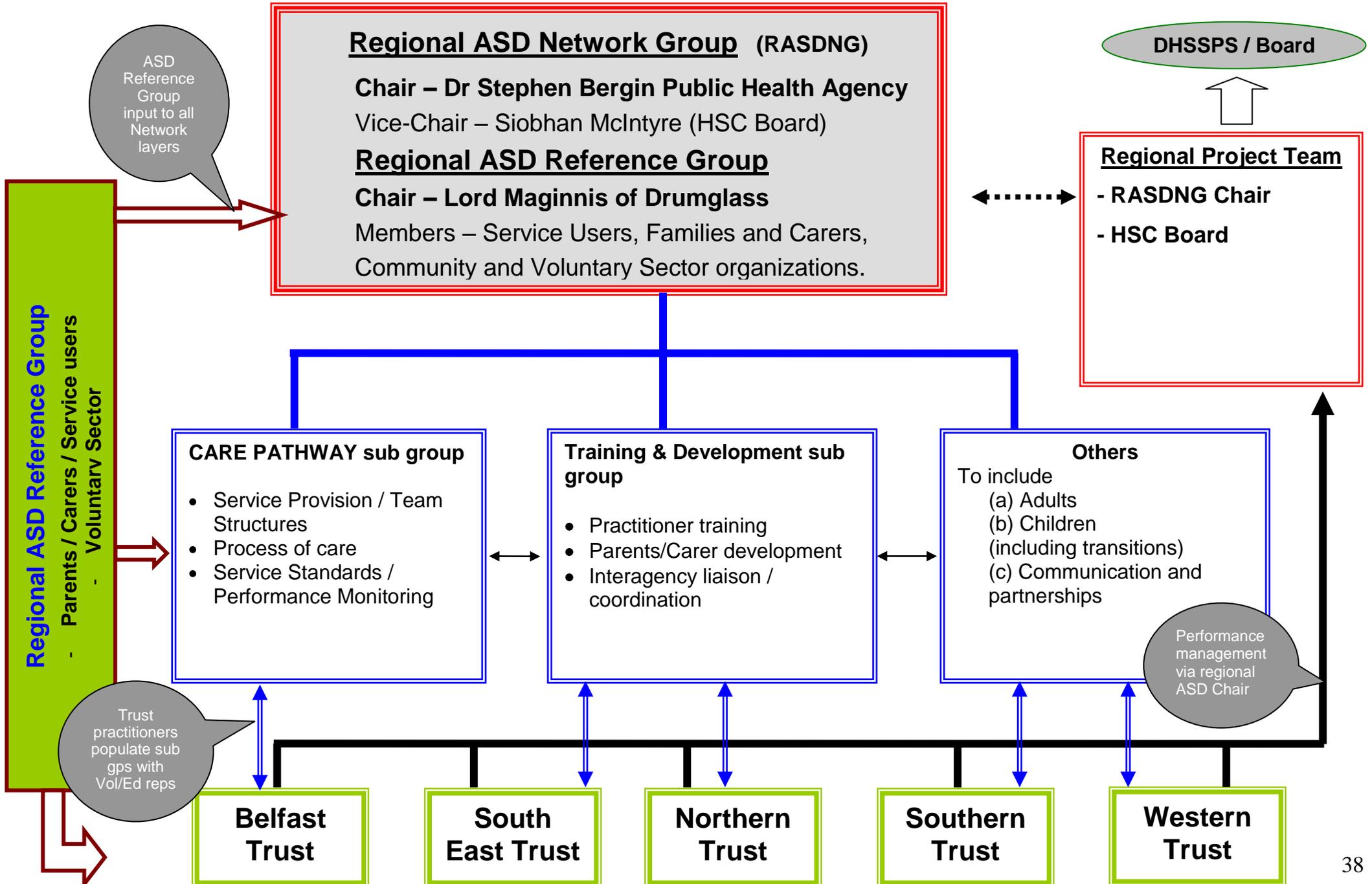
Lead Directors

South Eastern Trust	Desi Bannon Regional ASD Director	Director of Adult Services and Learning Disability
Belfast Trust	Brendan Mullen Regional ASD Director	Director of Mental Health and Learning Disability
Western Trust	Trevor Millar – Regional ASD Director	Director of Adult Mental Health and Disability Services
Northern Trust	Oscar Donnelly Regional ASD Director	Director of Mental Health and Disability Services
Southern Trust	Brian Dornan Regional ASD Director	Director of Children and Young People's Services

Trust coordinators

South Eastern Trust	Bria Mongan Local ASD Coordinator	Assistant Director Disability Services
Belfast Trust	Miriam Somerville Local ASD Coordinator	Co-Director of Learning Disability
Western Trust	Garry Hyde Local ASD Coordinator	Assistant Director of Adult Mental Health & Disability Services
Northern Trust	Roberta Alexander Local ASD Coordinator	Mental Health and Disability Services
Southern Trust	Peadar White Local ASD Coordinator	CAMHS Manager

Structure of the Regional ASD Network Group - APPENDIX B



References

Bamford, D (2006), *The Bamford Review of Mental Health and Learning Disability (NI) Autism Spectrum Disorders Recommendations*, DHSSPS.

Department of Health, Social Services and Public Safety (pending) *Review of School Nursing and Health Visiting*

Department of Health, Social Services and Public Safety (2008), *Understanding the Needs of Children in Northern Ireland (UNOCINI)*

Maginnis, K.(2008) *Independent Review of Autism Services*

Medical Research Council, (2001), *Review of Autism Research : Epidemiology and Causes*. London

Office of the First Minister and Deputy First Minister (2006) *Our Children and Young People – our pledge. A ten year strategy for children and young people in northern Ireland 2006 – 2016*.

Wing, L., & Gould, J. (1979). *Severe impairments of social interaction and associated abnormalities in children: epidemiology and classification*. *Journal of Autism and Developmental Disorders*, 9, 11-29.

Bibliography

Bamford D (2005) *The Bamford Review of Mental Health and Learning Disability (NI) Equal Lives*, DHSSPS

The Bradley Report (April 2009) *Review of People with mental health problems or learning disabilities in the criminal justice system*

Department of Education & Science (2001), *The Report of the Task Force on Autism*, TSO, Dublin.

Department of Health (2007) *National Service frameworks for Children*

Department of Health, Social Services & Public Safety (2006/07), *Project Funding – ASD Training in Northern Ireland* (unpublished)

Eastern Health and Social Services Board (2004), *Four Board Paper on the development of Autistic Spectrum Disorder Services*

APPENDIX C

Kelly G., McConkey R., Casey K., (2007) *A Strategy for the delivery of Autism Services in Northern Ireland*, University of Ulster

Maginnis, K.(2008) *Independent Review of Autism Services*

Northern Health and Social Services Board (2008) *Colouring Lives – A Strategy for Autistic Spectrum Disorders*

Scottish Intercollegiate Guidelines Network (2007) *Assessment, Diagnosis and Clinical Interventions for Children and Young People with Autism Spectrum Disorders*

Southern Health and Social Services Board (2004) *Southern Health and Social Services Board Children's Autism Strategy*

Welsh Assembly Government (2007), *The Autistic Spectrum Disorder (ASD) Strategic Action Plan for Wales*

Western Health and Social Services Board (2007) *A Strategic Framework for Autistic Spectrum Disorders Services in the West*

ACRONYMS

ADHD	Attention Deficit Hyperactivity Disorder
AHP	Allied Health Professional
ASD	Autism spectrum disorder.
DHSSPS	Department of Health, Social Services and Public Safety
CAMHS	Child and Adolescent Mental Health Service
ELBs	Education and Library Boards
GP	General Practitioner (i.e. Doctor)
HSC	Health and Social Care
HV	Health Visitor
HSCB	Health and Social Care Board (HSC Board)
HSCT	Health and Social Care Trust
MDT	Multi-Disciplinary Team
NICE	National Institute for Health and Clinical Excellence
NICS	Northern Ireland Civil Service
PfA	DHSS Priorities for Action
PCC	Patient and Client Council
PHA	Public Health Agency
SCIE	Social Care Institute for Excellence
SEN	Special Educational Needs
SN	School Nurse
UNOCINI	Understanding the Needs of Children in Northern Ireland assessment tool
WRAPAROUND	Wraparound Project' provides tailored services to meet the needs of children and young people with disabilities in the SHSSB area