Northern Ireland Executive
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The
Autism Strategy
(2013 – 2020)

and
Action Plan
(2013 – 2016)

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Appendices

Alternative Formats

This document is available, on request, in alternative formats - Braille, audio, large print, or as a PDF document. The Department will consider requests to produce this document in other languages. If you require the document in these or other formats please contact the DHSSPS Autism Strategy Team:

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NI Executive Ministers' Foreword

The NI Executive is committed to delivering the commitments in the United Nations Convention on the Rights of Persons with Disabilities. As part of that commitment we are pleased to present this cross departmental Autism Strategy and Action Plan which has been developed to set out how the needs of people with autism, their families and carers are to be addressed *throughout their lives.*

The strategy is a key requirement of the Autism Act (Northern Ireland) 2011. It is forging new ground as the first *cross departmental* strategy of its kind, addressing the needs of people with autism and their families and carers. This strategy is the result of two years of collaborative working between Government departments, the voluntary and community sector and most importantly, people with autism, their families and carers.

Even though the initial Action Plan attached to the Strategy realistically assumes that there may be limited additional investment, this does not mean that progress on the development of autism services in the future cannot be achieved. Through more innovative and efficient use of the considerable existing resources invested in this area, we believe much can be done. As part of this, the importance of cross-departmental working is acknowledged and will be increasingly significant as future editions of the Action Plan are developed.

Given the lead role of the Department of Health, Social Services and Public Safety in the development of this Strategy and Action Plan we consider it is appropriate to state that the principles of Transforming Your Care – A Review of Health and Social Care have been reflected in the Strategy. These principles will have particular relevance within the health and social care sector during the implementation of the Action Plan. The priority will be to achieve improvement through service redesign rather than new investment and to deliver those services at a community level which will include services for people and families living with autism.

The NI Executive is pleased to highlight that in November 2012, Parliament Buildings - home to the NI Assembly, became the first public building in the UK to receive the Autism Access Award. This involved the Assembly Commission working on a pilot project to develop the award and is an excellent example of best practice on how to make public buildings accessible for people with autism. The Autism Access Award is now being rolled out across the UK.

The NI Executive wishes to thank people with autism, parents, carers and those community and voluntary groups whose contributions were paramount to the development of the cross departmental Autism Strategy and Action Plan. We would also want to commend departmental officials who worked together to help develop this Strategy and Action Plan.

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Minister for Agriculture and
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Executive Summary

Scope of the Strategy

This Strategy (2013 – 2020) and Action Plan (2013 – 2016) sets out the NI Executive's commitment to improving services and support for people with autism in Northern Ireland (NI). It has been prepared as a result of the Autism Act (NI) 2011 which required the DHSSPS to lead on the development and implementation of a cross departmental Autism Strategy.

The Strategy and Action Plan have been developed in accordance with articles stated in the United Nations Conventions on the Rights of Persons with Disabilities (UNCRPD) to support the values of dignity, respect, independence, choice, equality and anti-discrimination for people with autism, their families and carers. The UNCRPD articles have informed the themes, strategic priorities and actions in the Strategy and Action Plan.

In recognition of the need for a 'whole life' approach to the provision of services and support a cross-departmental Project Board was established to progress the development of the Strategy and Action Plan. Members of the Board comprised representatives from all government departments working, in partnership with people with autism, parents and carers and the community and voluntary sector.

The following paragraphs provide an overview of the document.

Section One - Introduction

This section sets out the vision, values, aim and objectives of the Strategy. It provides a high level summary of the strategic context and introduces the equality considerations relevant to the policy.

This section outlines what we currently know about the prevalence of autism in NI in terms of the data we already hold. It also explains details of future plans for putting in place new arrangements in Health and Social Care Trusts for monitoring, collating and recording of autism specific data in respect of children and adults in NI. Reference is made to the report contained in Appendix 5 entitled 'The Prevalence of Autism in School Age Children (NI) 2013.

The detail of the consultation exercises is described in this section and the way in which the feedback from people with autism, parents and carers has been used to help inform the development of the Strategy and Action is set in context. Extracts of the feedback from the consultation exercises has been included in Sections 3 of the document which helps reinforce a better understanding of what is required in terms of services and support for people and families living with autism.

Section Two – The Law and Existing Service Provision

This section outlines at a high level the range of services and support currently available to people with autism across a range of sectors and departments. It describes the statutory and legislative context of the following:

- UN Conventions on the Rights of Persons with Disabilities (UNCRPD);
- UN Convention on the Rights of the Child (UNCRC);
- The Disability Discrimination Act (1995);
- The Children's Order (NI) 1995; and
- The Autism Act (NI) 2011.

The following paragraphs in this section drill down into more detail on the services and support available within health and social care, education, employment and learning, housing and social security benefits.

The Health and Social Care section sets out the background to the Regional Autism Spectrum Disorder Network (RASDN) and the progress that has been achieved within Health and Social Care Trusts, following the Independent Review of Autism Services in 2008. The children's' care pathway; the Six Steps of Autism: A Guide for Families and the Adult Autism Care Pathway are referenced and details on the progress of work to further embed the implementation of both care pathways is provided.

This section also sets out the way forward as set out in the reports 'Transforming Your Care – A Review of Health and Social Care' and 'Transforming Your Care - Vision to Action.

The Education section sets out the education provision currently available under the special educational needs legislative framework. The section also references the improvement agenda and funding, training and guidance support committed by the Department of Education to enhance the delivery of education services to meet the needs of children and young people with autism. The role of the Middletown Centre is outlined in respect of the training and research services provided and its plans for continuing improvement of services and support.

The SEN and Inclusion Review is also referenced with regard to the timescales for transitioning toward the implementation of the new SEN framework.

The Employment and Learning section outlines the detail of the four main areas of service provision available for people with autism as follows: employment support; careers advice and guidance, further and higher education and professional and technical training.

The Social Development section outlines two key areas in terms of current provision of services for people and families living with autism as follows:

1. To provide access to decent, affordable, sustainable homes and housing support services;
2. To meet the needs of the most vulnerable by tackling disadvantage through a transformed social welfare system.

The section on housing sets out how applications for supported housing services, social housing and or adaptations from people and families living with autism are dealt with by the relevant bodies.

The section on social security benefits outlines the range of benefits currently available to people and families living with autism depending on their individual circumstances. Details of continuing programmes of awareness training and communication regarding the impact and changes proposed through the Welfare Reform are also reflected in this section.

The Justice section outlines the commitment to improving services for people with autism who come into contact with the criminal justice system. This section sets out the plans and proposals as provided for within the Victims and Witnesses Strategy, the Community Safety Strategy and the justice element of the Mental Capacity Bill which is planned to be introduced to the NI assembly in 2015.

Section Three – Themes and Strategic Priorities

This section sets out the eleven key themes within which sixteen strategic priorities are defined in relation to the future development and delivery of services for people with autism. These form the basis for the Action Plan (Section Five).

Theme 1 – Awareness

There are two strategic priorities within this themed area aiming to deliver a comprehensive autism awareness training programme for frontline staff in government departments and their arms length bodies and to commission and plan a public awareness campaign.

Theme 2 – Accessibility

There are two strategic priorities within this themed area aiming to eliminate barriers, increase and improve access to services and communication for people with autism, their families and carers.

Theme 3 – Children, Young People and Family

There is one strategic priority within this themed area aiming to ensure effective and appropriate support for children, young people and families living with autism.

Theme 4 – Health and Wellbeing

There are two strategic priorities within this area themed aiming to promote health and wellbeing and enhance commissioning of health and social care services to ensure they meet the needs of people with autism, their families and carers.

Theme 5 – Education

There is one strategic priority within this themed area aiming to ensure that children and young people with autism are provided with high quality education services which meets their needs appropriately.

Theme 6 – Transitions

There is one strategic priority within this themed area aiming to ensure that a co-ordinated and integrated approach to transition planning, for people with autism is in place.

Theme 7 – Employability

There are two strategic priorities within this themed area aiming to increase opportunities for people with autism to access employment, training, life- long learning and to attain skills.

Theme 8 – Independence, Choice and Control

There are two strategic priorities within this themed area to increase the choices, control and freedom that people with autism have in their lives.

Theme 9 – Access to Justice

There is one strategic priority within this themed area to ensure that people with autism can live safely in their community, have access to and are treated equally in the criminal justice system.

Theme 10 – Being Part of the Community

There is one strategic priority within this themed area to ensure that people with autism can access culture, arts, and leisure services within the community.

Theme 11 – Participation and Active Citizenship

There is one strategic priority within this themed area aiming to increase opportunities for people with autism to be involved in policy development, implementation and evaluation and to be socially included.

Section Four - Implementation Approach

This section describes the implementation structures and monitoring and reporting arrangements to ensure the delivery of the initial Action Plan (2013 – 2016). It highlights the role of the Regional Autism Co-ordinator and sets out the roles and responsibilities of the various governance and implementation structures,

Section Five - The Action Plan

This section sets out the thirty-four cross governmental actions under the eleven themed headings as reflected in Section 3:

1. Awareness

   1. Deliver an autism awareness programme within government departments for frontline staff; and
   2. Promote opportunities to raise awareness about autism generally.

2. Accessibility

   1. Improve accessibility to travel and transport for people with autism;
   2. Ensure that communications and signposting information is available and accessible by people with autism; and
   3. Ensure that a range of advocacy services are available across the various sectors for people and families living with autism.

3. Children, Young People and Family

   1. Provide timely joined up support services for families living with autism;
   2. Promote awareness regarding the availability of support services available to families in their area; and
   3. Ensure that support and interventions is provided for carers of people with autism.

4. Health and Wellbeing

   1. Enhance access to health and wellbeing programmes for people with autism;
   2. Enhance and promote early recognition and early intervention for people with autism; and

3. Promote and introduce best practise and service improvement through continuing review of care pathways for children, young people and adults with autism.

5. Education

1. Continue to build capacity in schools to effectively meet the needs of children and young people with autism;
2. Provide effective support to parents and carers of children and young people with autism to ensure they are involved and informed regarding their child/children's education;
3. Formalise collaboration between health and social care and education sector to help improve support, including specialist support; and
4. Expand trans-disciplinary assessments, interventions and support for children and young people with complex needs.

6. Transitions

1. Ensure that transition planning takes account of the needs of people with autism; and
2. Deliver co-ordinated and integrated seamless care across transition stages for people with autism throughout their lives.

7. Employability

1. Increase awareness about the support available to people with autism to help access opportunities for employment, training, and life-long learning; and
2. Promote opportunities to access and attain employment, training and life-long learning for people with autism.

8. Independence, Choice and Control

1. Provide supported independent living options for people with autism;
2. Provide advice and support on the impact of Welfare Reform for people with autism their families and carers;
3. Increase the use of self directed support within health and social care for people with autism; and
4. Commission and establish a multi-agency autism service pilot for people and families living with autism in NI.

9. Access to Justice

1. Provide protection, support and information for people with autism who come into contact with the criminal justice system;
2. Improve services for victims and witness in the criminal justice system encompassing the needs of people with autism;
3. Review and revise guidance for practitioners within the criminal justice system to take account of the needs of people with autism; and
4. Promote autism awareness across criminal justice organisations.

10. Being Part of the Community

1. Establish and raise awareness about community social activity for people with autism, their families and carers.

11. Participation and Active Citizenship

1. Involve people with autism in the design, development and review of relevant policy across government departments.

The final section of the Action Plan is about leadership and implementation.

Section 1

Introduction

1.0 Introduction

Autism is a lifelong disability which affects the way an individual relates to people, situations and their immediate environment. The term **Autism Spectrum Disorder** (ASD) is often used because the impact of autism varies from person to person.

This Strategy and Action Plan have been developed to help improve access to services and support for people with autism, their families and carers, throughout their lives.

It has been developed through a process of collaborative and consultative working between people with autism, their families and carers, representatives from all NI government departments and some key community and voluntary sector organisations. Representatives from all of these sectors form the membership of the Project Board established to manage and direct the development of the Strategy and Action Plan. Appendix 2 shows the organisation and membership of the Project Board.

1.1 Context

The **Autism Act (NI) 2011,** which received Royal Assent on 9 May 2011, came into operation on 9 August 2011. The Act had two main effects:

1. To amend *Schedule 1 of the* **Disability Discrimination Act 1995 (DDA 1995)** by extending the criteria which must be considered when deciding whether or not a physical or mental impairment is to be taken as affecting the ability of a person to carry out normal day to day activities by adding the following criteria to the existing list;
    i. Taking part in normal social interaction; or
    ii. Forming social relationships.

    These additional criteria will impact upon whether a person then falls within the definition of a disabled person in the DDA 1995.

2. To require the DHSSPS to lead on the development and implementation of a cross-departmental strategy.

1.2 Scope of the Strategy

The NI Autism Act prescribes that the Strategy must:

- Set out how the needs of people with autism are to be addressed throughout their lives including (but not limited to) their educational, health and social needs;
- Set out how the needs of families and carers of people with autism are to be addressed; and
- Contain proposals for promoting an autism awareness campaign.

The Act also gives the DHSSPS power to make regulations in respect of the Autism Strategy.

For the purposes of this Strategy the term “autism” means *Autism, Asperger syndrome, Rett’s syndrome or any pervasive developmental disorder not otherwise specified,* as outlined in the Autism Act (NI) 2011.

1.3 Prevalence

The Act requires Health and Social Care (HSC) Trusts to provide data on the prevalence of autism in order that the Strategy can be published and updated and NI departments can effectively implement the Strategy.

The term ‘prevalence’ is used to describe the total number of cases in the population. A true prevalence figure can be difficult to establish, however, for long term conditions such as autism, as new yearly incidence rates are captured, an increasingly accurate prevalence rate can be established.

A sub group was established to explore existing data sources, within the health and social care and education sectors. The group will also help HSC Trusts to determine and put in place any additional arrangements to capture data on the prevalence of autism in the child and adult population in their areas.

In the development of this strategy, the main sources of available data includes information collected by the Department of Education (DE) and data in relation to autism among the adult population recently published by the National Institute for

Clinical Excellence (NICE). Using these sources gives an estimated prevalence rate of 1.8% for children and 1.1% for adults equating to approximately 5,000 children and 15,000 adults currently being affected by autism in NI. Appendix 5 contains a copy of a report compiled by NISRA statisticians working within the DHSSPS setting out the prevalence rates of ASD amongst school age children (attending grant aided schools) in NI. New monitoring arrangements are being embedded in HSC Trusts and it is anticipated that improved data specific to NI, will be available in the future to help inform development of services.

1.4 Research

The NI Autism Strategy Research Advisory Committee was established for this Strategy during 2013. This Committee brought together a range of stakeholders to ensure that the most recent research findings are available to the Project Board to inform development of the autism strategy and action plan; and to government departments and their agencies to inform the design, planning and delivery of services.

1.5 Vision and Values

Our vision for this Autism Strategy and Action Plan aligns with the overarching principles in the **United Nations Convention on the Rights of Persons with Disabilities (UNCRPD):** dignity; non-discrimination; participation and inclusion; respect for difference; equality of opportunity; accessibility; equality between men and women; and respect for children. We therefore envisage that people with autism will contribute to and benefit from the cultural, social, political and economic life of NI on an equal basis with others.

Our values underpinning this vision are:

- **Dignity:** people should be given the care and support they need in a way which promotes their independence and emotional well-being and respects their dignity;
- **Privacy:** people should be supported to have choice and control over their lives so that they are able to have the same chosen level of privacy as others;
- **Choice:** care and support should be personalised and based on the identified needs and wishes of the individual;

- **Safety:** people should be supported to feel safe and secure without being over-protected;
- **Realising potential:** people should have the opportunity to achieve all they can; and
- **Equality and diversity:** people should have equal access to information, assessment and services and all service providers should work to redress inequalities and challenge and eliminate discrimination.

1.6 Aim

This Strategy aims to ensure that the services commissioned and / or provided by public sector organisations in NI for people with autism, their families and carers will develop in such a way that they:

- Promote awareness and better understanding of the challenges faced by people with autism;
- Support people with autism, their families and carers to become well informed about accessing the services they need;
- Encourage social inclusion of people with autism and work to address discrimination/stigmatisation; and
- Are tailored to meet the changing needs of people with autism over the course of their lifetime.

1.7 Objectives

The objectives of the Strategy are to:

- Support people with autism to better exercise their rights, choices and life opportunities;
- Support the continuing development of an inclusive and effective range of high quality services for people with autism, their families and carers;
- Develop a more integrated approach to the planning, commissioning and management of services within and across public sector organisations and the independent, community and voluntary sectors;
- Develop clear and achievable recommendations and actions which are capable of being monitored and evaluated; and

- Ensure that an appropriate, sustainable and affordable implementation infrastructure is put in place following the publication of the Strategy and Action Plan.

1.8 Development of the Autism Strategy

A comprehensive scoping and pre-consultation exercise was conducted to help inform the remit, themes and strategic priorities for this Strategy and Action Plan. This involved a series of engagement events across Northern Ireland to take the views of people with autism, their families and carers regarding the key issues they wish to see taken forward in the Strategy and Action Plan. Children and young people with autism attended two further engagement events, hosted in Belfast and Omagh. The pre-consultation engagement events were facilitated by some autism voluntary sector organisations with active participation from all government departments and relevant agencies.

In addition to the pre-consultation engagement events, the DHSSPS developed an online questionnaire which was specifically targeted at a wider range of people with autism who were unable to, or did not want to attend and / or participate in the engagement events.

The information and feedback from both the pre-consultation engagement events and the responses to the questionnaires helped to inform the structure and content of the draft Strategy and Action Plan which was launched for formal public consultation on 3 December 2012. The public consultation ended in March 2013. The consultation phases were funded by OFMDFM.

There was a significant response to the public consultation which included **80** responses to the online consultation questionnaire, **46** free style responses and feedback from **7** public consultation engagement events. All of these responses and feedback has been reviewed by government departments and agencies. This final draft version of the Autism Strategy and Action Plan has been revised to reflect some of the key priorities and findings from the public consultation feedback and responses. The consultation response document is available on www.dhsspsni.gov.uk.

1.9 Equality Considerations

Section 75 of the NI Act 1998 requires all public bodies in carrying out their functions relating to NI 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;
- Men and women generally;
- Persons with a disability and persons without; and
- Persons with dependants and persons without.

In addition, without prejudice to the above, public bodies must also in carrying out their functions relating to NI have regard to the desirability to promote good relations between persons of a different religious belief, political opinion or racial group. Appendix 4 provides a copy of the equality screening template completed by DHSSPS in respect of this Autism Strategy and Action Plan.

Section 2

The Law and Existing Service Provision

2.0 The Law and Existing Service Provision

2.1 Legislative Context

The **United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (2008)** is the first such treaty of the twenty-first century. The Convention does not create new rights for disabled people; rather it helps member countries to have a better understanding of disabled people's human rights. Signatory countries are obliged to "promote, protect and ensure full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity".

The **Disability Discrimination Act (1995) (DDA)** was a landmark piece of legislation and the first anti-discrimination legislation which specifically focussed on disabled people. It effectively enshrined, in law, disabled people's rights to participate in civil society by placing duties on employers, service providers, landlords, schools and colleges. Part III of the Special Educational Needs and Disability (NI) Order 2005 focuses specifically on disability discrimination in education.

The **Autism Act (NI) 2011** amends **Schedule 1 to the DDA 1995** by extending the criteria which must be considered when deciding whether or not a physical or mental impairment is to be taken as affecting the ability of a person to carry out normal day to day activities by adding the following criteria to the existing list:

i. Taking part in normal social interaction; or
ii. Forming social relationships.

The Disability Discrimination Act 1995 was further strengthened by the **Disability Discrimination (NI) Order 2006** and required public authorities, when carrying out their statutory functions, to have due regard to the need to:

- Promote positive attitudes towards disabled people; and
- Encourage the participation of disabled people in public life.

The **United Nations Convention on Rights of the Child (UNCRC)** is an international human rights treaty setting out the civil, political, economic, social and cultural rights of the child, defined as any person under the age of 18, unless an earlier age of majority is recognised by the country's law. The Convention requires that States act in the best interests of the child and acknowledges that every child has certain basic rights. It also obliges States to allow parents to exercise their parental responsibilities, while acknowledging that children have the right to express their opinions and to have those opinions heard and acted upon when appropriate.

The **Children (NI) Order 1995** is the primary piece of legislation in respect of children in NI. Article 17 states that a child shall be taken to be in need if "he is disabled." Article 18 determines the statutory responsibilities of HSC Trusts to provide for 'children in need' in their area, including disabled children. In addition, Article 19 provides for support for 'children in need' within early years, which also includes children with disabilities. The Order requires HSC Trusts to take account of the child's individual circumstances and to engage with parents when assessing needs of children with disabilities.

2.2 Understanding the Needs of Children in NI (UNOCINI)

The UNOCINI model of assessment and service planning provides the key pathways within the UNOCINI framework. These are cross-disciplinary and cross-agency and are centred upon the needs of the individual child.

The UNOCINI framework has been agreed as the primary service pathway for children's services within the HSC and for key agencies involved with children and young people. UNOCINI has applicability to all situations where 'children in need' assessments are required and where the outcome of such assessment of needs requires services to be provided. The framework, which is needs-led, includes a 'child in need' pathway which can accommodate children and young people with a disability. It also incorporates a provision to include a carer's assessment, for carers of children with disabilities, including those with autism.

In addition, the UNOCINI framework allows for the undertaking of specialist assessment in cases where, for example, there may be complex physical healthcare needs and where a more in-depth and specifically focused assessment is required given the needs of the child and their carers.

2.3 Children's Services Planning

Schedule 2 of the Children (NI) Order 1995 places a statutory responsibility on the Health and Social Care Board (HSCB) to review services for 'children in need' and their families and publish an annual children's services plan in consultation with a range of agencies. This responsibility is delivered through the **Children and Young People's Strategic Partnership (CYPSP).**

The overall purpose of the CYPSP is to lead integrated planning and commissioning of support and services aimed at improving outcomes for children and young people across the province. The CYPSP includes a number of regional sub-groups which aim to improve outcomes for specific groups of children and young people at a particular disadvantage, and their families, across NI. The CYPSP regional sub-groups which are relevant in the context of this Strategy and Action Plan are:

- Children and young people with disabilities;
- Transitions;
- Children and young people with emotional and behavioural difficulties;
- Young carers; and
- Children, young people and offending.

2.4 Mental Capacity Bill

DHSSPS is currently preparing a new **Mental Capacity Bill** jointly with the Department of Justice. The Bill will put in place a legislative framework for all persons aged 16 and over in society who lack capacity to make decisions about their care, treatment or personal welfare. The need for new legislation was identified by the Bamford Review, which recommended the development of a single legislative framework fusing together mental capacity and mental health law. The primary drivers for this were the removal of the stigmatising effect of separate mental health legislation and to provide greater protections for individuals unable to make decisions for themselves.

The Bill will have a particular relevance for those with autism aged 16 and over in a number of ways. The embedding into legislation of the common law presumption of capacity clarifies and reinforces that, as a starting point, those with autism have the right to make decisions for themselves where they have capacity to do so. A person cannot be assumed to lack capacity merely on the basis of their age or appearance, any condition they have, or any aspect of their behaviour. The Bill will require that all practical help and support must be given to support a person to exercise their capacity to make decisions. Only where it is established that a person lacks capacity, can an intervention in connection with the care, treatment or personal welfare of that person be made and any intervention must be in the person's best interests. Where it is a serious intervention, the Bill provides for an escalating series of safeguards which reflect the seriousness and intrusiveness of the intervention.

2.5 Executive's Disability Strategy - A Strategy to improve the lives of people with disabilities 2012 – 2015

In order to promote consistency in disability policy development and implementation, the themes and strategic priorities in this cross-departmental Autism Strategy align largely with those in the 'Strategy to improve the lives of people with disabilities 2012 – 2015. The work under this Strategy will be taken forward under the auspices of the Delivering Social Change framework. This framework seeks improve the health, well-being and life opportunities of all children and young people and their families particularly those who are most in need.

The purpose of the Executive's Disability Strategy is to:

- Set out a high level policy framework to give coherence and guidance to Northern Ireland Departments' activities across general and disability specific areas of policy;
- Drive improved performance of service delivery leading to improved outcomes for persons with a disability;
- Increase the understanding and importance of the needs of persons with a disability and ensure these needs are recognised when policy is

developed or when implementing initiatives which impact on disabled people; and

- Improve the opportunities for people with disabilities to contribute across all areas of society.

2.6 Existing Service Provision

The following sections drill down into more detail on the commissioning and provision of existing services across a number of sectors as follows:

- Health and Social Care;
- Education;
- Employment and Learning;
- Social Development – housing and social security benefits; and
- Justice.

2.7 Health and Social Care

From a health and social care perspective there are two care pathways which underpin and build on the legislative and statutory obligations requirements and strategic policy commitments in relation to people with autism. These are the **Six Steps of Autism Care** and the **Adult Autism Care Pathway**, which were both developed by the **Regional Autism Spectrum Disorder Network (RASDN)** in 2011/12.

2.7.1 Regional Autism Spectrum Disorder Network (RASDN)

Following the Independent Review of Autism Services (2008), the DHSSPS developed an ASD Strategic Action Plan 2008/09 – 2010/11. RASDN, a multi-agency, multi-disciplinary group, was launched in June 2009 to take these actions forward within HSC Trusts. ASD Reference Groups were also established in each HSC Trust, highlighting the views of parents, carers and service users' to help shape the future of autism services across NI.

The considerable progress in autism-specific children's services in NI can be attributed to RASDN. Their main achievements include.

- The development of specialist children's autism services in each HSC Trust - comprising diagnostic / assessment, early intervention and family support services;
- Waiting times for diagnosis and / or initial assessment of children have improved;[1]
- Regional ASD Co-ordinator post established and filled; and
- Establishment of an ASD Coordinator and cross directorate / cross agency operational group in each HSC Trust.

These local Trust autism groups are working to address issues across the wider age range from children and adolescents into adulthood, overseeing the implementation of the RASDN Action Plan across teams and services. The groups also include representatives from a range of agencies and sectors.

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[1] RASDN Trust Performance Report 1st October to 31st December 2010, HSCB

2.7.2 Children's Services - Six Steps of Autism Care

The *Six Steps of Autism Care* and *Autism: A Guide for Families* was prepared in partnership with the Regional ASD Reference Group. The Guide aims to standardise the process of diagnosis, assessment and subsequent provision of support among practitioners and across the five HSC Trusts. It will also help to ensure closer liaison/partnership with education services. A Care Pathway is being implemented within a regional process to ensure front line practice within HSC Trusts is provided in accordance with this regionally agreed consensus document.

A regional protocol for an interface between autism services and specialist Child and Adolescent Mental Health Services (CAMHS) has been developed as part of the Six Steps of Autism Care model. The protocol sets out the arrangements for joint working between autism services and specialist CAMHS where a child or young person has a co-occurring mental health need or where these concerns exist. This protocol is currently being implemented by all HSC Trusts.

In March 2012, an audit of HSC Trust's implementation of the Six Steps of Autism Care Children's Pathway was completed. The audit demonstrated significant progress had been made across all Trusts in streamlining the care pathway from point of referral, through to diagnosis to the commencement of care and support.

However, in the two years since the publication of the Children's Care Pathway, the number of referrals of children with a suspected diagnosis of autism has continued to increase. As a result of both the increase in referrals and the resulting anomaly in service provision identified during the audit, HSC Trusts produced service improvement action plans which are currently being implemented. In light of the increased referrals HSC Trusts also recognise that further work will be needed on managing the pathway of referrals.

The HSCB will lead a regional validation exercise to evaluate and review implementation of the Six Steps of Autism Care. It is anticipated that this exercise will be concluded by March 2014.

2.7.3 Adult Services - Adult Autism Care Pathway

Less progress has been made towards developing older adolescent/adult autism services. Taking a longer term view, however, the considerable investment in children's services should lead to future dividends given that more robust provision during the early years of development is known to ameliorate the more severe impact of disability in later years. It is evident that the development of services for older adolescent/adults should continue to be a 'main' regional priority.

In June 2012, the journey to redress this imbalance began with the launch of the ***Autism Adult Care Pathway***. This provides guidance to professionals, adults and families on autism. It aims to cover the identification and diagnosis of autism, ongoing assessment and access to interventions and services for adults of all ages with autism. This guidance is intended for use by service users, parents, carers, health care professionals, primary care practitioners, education professionals, careers advisers, social security officers, voluntary organisations, employers and any others who offer guidance to, or are working with adults with autism.

Traditionally, in health and social care, funding to meet the needs of people with autism has been included in other programmes such as within the Learning Disability programme funding and Paediatric Services. It is not, therefore, possible to identify specific expenditure on autism services. However, additional funding of some £1.54m was allocated in 2009/10 towards supporting the implementation of the ASD Action Plan, published in September 2009. In 2010 a further £100k was made available to develop specialist adult autism diagnostic services. HSC Trusts received an additional £250k to develop their adult autism services in 2013. This has resulted in an additional £1.89m being available recurrently from 2013.

2.7.4 Moving Forward with 'Transforming Your Care' (TYC)

In June 2011, the Minister for Health, Social Services and Public Safety, announced a review of the provision of health and social care services in Northern Ireland. The outcome of that review was the Transforming Your Care

Report, published in December 2011, which contained 99 recommendations on the reform of HSC services. A number of recommendations in the report, particularly those relating to areas such as short breaks, day opportunities, direct payments, personalisation of care and support for carers are particularly relevant to the development of services for people with autism.

On foot of this report, a draft Strategic Implementation Plan and allied draft Population Plans were developed to set out how TYC could be taken forward at a regional and local level.

A consultation on ‘Transforming Your Care: Vision to Action’ was launched in October 2012 and concluded in January 2013. The post-consultation report highlighted key issues which emerged from the consultation including the particular needs of carers, the important contribution of the voluntary and community sector, and the need to ensure that alternative services are in place before changes are made to existing service provision.

As work is taken forward on implementing ‘Transforming Your Care’ there will be further opportunities for consultation and discussion. Significant changes will be subject to separate public consultation and local communities will have an opportunity to get involved in the discussion about the future provision of health and social care.

One of the key areas in which implementation of TYC is being taken forward is the roll out of seventeen Integrated Care Partnerships (ICPs) across NI. These collaborative networks are designed to enable health and social care providers to come together to respond innovatively to the assessed care needs of local communities.

The initial areas of focus for ICPs are: frail, elderly and aspects of long term conditions, namely stroke, diabetes and respiratory conditions including end of life and palliative care in respect of these areas. By encouraging all parts of our health and social care system to work closer together, service users and patients will be able to receive more effective and efficient care. In terms of this Strategy and Action Plan this will obviously include people with autism.

2.7.5 Allied Health Profession Review of Provision

A review has also commenced of Allied Health Professionals’ provision for children with special educational needs. This review is being led by the Public Health Agency. It will begin with a scoping exercise, initially in special schools and then move on to consider the Allied Health Profession (AHP) needs of children attending other schools.

2.8 Education

The Department of Education's (DE) primary statutory duty is to promote the education of the people of NI and to ensure effective implementation of education policy. The Department's main statutory areas of responsibility are 0 to 4 provision, primary, post-primary, special education and the youth service.

Education provision for children and young people with autism is made under the special educational needs legislative framework and the statutory Code of Practice (and Supplement) on the Identification and Assessment of Special Educational Needs (SEN). Support is provided according to the learning needs of the individual child or young person and does not depend on the completion of a formal medical diagnosis. The publication of the Report of the Task Group on Autism in 2002 provided an agenda for a ten year period covering improvements in:

- Multi-agency and multi-disciplinary assessment services;
- Training for parents of children with autism, schools and relevant Education and Library Board (ELB) personnel;
- Common frameworks across ELBs for assessment and provision; and
- School-based and home-based educational provision.

The DE provides core funding annually to the ELBs for all SEN, including autism. To meet the challenges of the improvement agenda set by the 2002 Autism report, DE has, since the 2003/04 financial year, provided additional resources of some £17m, over and above the core funding for all SEN, to support various positive measures specific to autism, including:

- Autism related training within the pre-school sector;
- The publication of "Autistic Spectrum Disorders – A Guide to Classroom Practice" for teachers in all schools;
- The production of a range of school / parent resources to support positive interventions for children with autism some of which have been produced on a north south basis (e.g. the CD-ROM "Autistic Spectrum Disorder – A Teacher's Toolkit"; and the DVD "Autism – An Introduction");

- The publication of '*Evaluating Provision for Autistic Spectrum Disorders in Schools'*;
- The Inter-board Autism Group; and
- The Middletown Centre for Autism.

2.8.1 Education support

To enhance the delivery of support to children with autism, many schools have tailored the classroom environment and educational programmes to meet the individual strengths and needs of the children. The training and guidance material available to support schools is enabling teachers and management teams to improve their knowledge of autism and to organise the whole school provision for autism more effectively. The Chief Inspector's Report 2008 – 2010 noted that the provision for learners on the autistic spectrum had improved significantly since the publication of the Report of the Task Group on Autism in 2002.

Developed and delivered in advance of implementation of the proposed new SEN framework, DE published a SEN Resource File in 2011 for schools. The Resource File contains practical materials to be used by school staff in supporting pupils with SEN. A specific chapter is dedicated to providing support to those with autism. In addition, in early 2013, a self-study module (ASPIRE) was issued to schools to help support them in building their capacity in using the SEN Resource File. As an evolving resource, there are plans to review some sections (including the ASD section) in the Resource File and to add others. Both the Resource File and ASPIRE are available to schools in hard copy and through C2K, and for wider access through the DE website.

2.8.2 Inter-board Autism Group

In 2003/04 the Inter-board Autism Group was formed to promote consistency in relation to the identification, assessment and delivery of services to children with autism across the five ELBs. This led to the establishment in each ELB of an autism advisory team comprising a specialist senior educational psychologist, advisory teachers and other autism support officers. The Chief Inspector's Report 2008 – 2010 noted that the inter-board autism advisory service had grown in confidence and expertise, and had developed good practice standards in much of its work.

2.8.3 Middletown Centre for Autism

The Middletown Centre for Autism was established in 2007, funded jointly by the DE and the Department of Education and Skills in the Republic of Ireland (RoI) to work with children and young people whose needs are more persistent, challenging and complex and to provide training and research services. Its services are designed to be complementary to those provided by the education and library boards, broadening the scope of educational support that can be provided to those children with autism. The Centre is still under development, but has trained over 6,500 professionals and parents in NI (and similar numbers in the RoI) as well as providing interventions for children and helping whole schools develop an autism competent environment. Ministers have recently announced a further limited expansion of services to enable support to be provided to more young people with autism who present with complex needs. The Centre has also published a series of research papers.

The Education and Training Inspectorate, NI and the Department of Education and Skills Inspectorate, RoI carried out a joint inspection of the Centre in April 2012. In the work inspected, the quality of the provision was evaluated by the inspectors as outstanding. The Centre is meeting very effectively the needs of the young people, their peers, parents and professionals and has demonstrated its capacity for sustained improvement.

2.8.4 The SEN and Inclusion Review

In July 2012, the Executive agreed to a revised policy for SEN and Inclusion and to the preparation of a Bill amending the existing legislation to implement that policy. The revised framework will ensure the child is placed firmly at the centre of the processes for identification, assessment, provision and review of those with SEN. The key objectives of the revised policy include early identification, intervention and assessment, whilst also ensuring that the SEN support needs of all children and young people (including those with autism) are met. It is proposed that the new SEN framework will commence in the 2014/15 school year followed by a five year transition period.

2.9 Employment and Learning

The Department for Employment and Learning (DEL) is responsible for further and higher education, training and skills, and employment programmes. DEL and its key delivery partners such as colleges, universities and training providers, offer a range of programmes and services, which supports people with autism. These services assist individuals who wish to obtain and sustain work, move towards employment, or develop new/existing skills. Many of these incorporate dedicated funding streams and more flexible entry criteria to better address the various barriers which people with autism may face.

DEL's service provision for people with autism, can be broken down into four main areas; Employment Support; Careers Advice and Guidance; Further and Higher Education; and Professional / Technical Training, including Apprenticeships. The Department has a range of strategies already in place which guide the delivery of its services across these key areas.

2.9.1 Employment Support

Employment Support covers a range of vocational and pre-vocational programmes to meet the needs of people with autism. A range of programmes and services are available including:

- employment assessments carried out by a team of Occupational Psychologists;
- specialist support to find and keep suitable employment;
- residential training for those disabled people who are not ready to access mainstream training; and
- menu-based employment support to better target individuals' barriers to employment via 'Steps to Work' and new 'Work Connect' programmes.

2.9.2 Advice and Guidance

DEL's Careers Service provides impartial careers information and an advice and guidance service to clients of all ages and abilities. The service is delivered through a network of professionally qualified advisers.

The Careers Service has arrangements in place with ninety-nine percent of post-primary schools to support the schools' careers education programmes. Through the partnership agreements the schools' careers advisers are invited to attend transition planning meetings at year-ten and subsequent annual reviews until a young person leaves post-primary education. All Careers Advisers are trained to work with clients with autism.

2.9.3 Further Education (FE)

FE Colleges are responsible for responding to the educational and vocational needs of the local population. Under the Special Educational Needs and Disability (NI) Order 2005, further education colleges make reasonable adjustments to enable students with autism to access the mainstream curriculum. All students with autism enrolling in colleges undergo a needs assessment in order to help identify appropriate additional levels of support. To help meet the cost of any additional support required, colleges can access annual funds of £3.5 million.

2.9.4 Higher Education (HE)

Widening Participation in Higher Education by students from those groups who are currently under-represented is one of DEL's key strategic goals. It is for this reason that DEL led on the development of a Regional Strategy for Widening Participation, called Access To Success, which was published in 2012. Students with learning difficulties and disabilities have been identified as one of the target groups in the strategy.

2.9.5 Professional and Technical Training - Training for Success (TfS) and ApprenticeshipNI

Under DEL's Training for Success (TfS) programme, there is extended eligibility up to age twenty-two for those with autism. Participants with autism on these programmes, who require specialist support, will be given every opportunity to overcome difficulties and to develop using the most appropriate support mechanisms.

2.10 Social Development

The Department for Social Development (DSD) has strategic responsibility for urban regeneration, community and voluntary sector development, social legislation, housing, social security benefits, pensions and child support. Its three key strategic priorities are:

- To provide access to decent, affordable sustainable homes and housing support services;
- To meet the needs of the most vulnerable by tackling disadvantage through a transformed social welfare system;
- The provision of focused support to the most disadvantaged areas and encouraging social responsibility; and
- To bring divided communities together by creating urban centres which are sustainable, welcoming and accessible to live, work and relax in peace.

2.10.1 Housing

In terms of providing supported housing services for people with autism, the DSD's Supporting People Programme enabled the Northern Ireland Housing Executive (NIHE) to establish close working arrangements with the DHSSPS and the HSCB and HSC Trusts through the Supporting People Commissioning Body. Capital and revenue funding is provided to facilitate the development of supported housing services for people with disabilities, including people with autism, through the Programme. Applications for assistance are made via Social Housing Allocations and Private Sector Grants.

Applications for social housing from people with autism or from families that include a family member with autism will be assessed under the Common Selection Scheme for the allocation of social housing in NI. In the same way recommendations from the HSC Occupational Therapy Service for adaptations to a NIHE property to provide for the needs of an occupant with autism will be dealt with on a case by case basis.

2.10.2 Social Security Benefits

Depending on individual circumstances, a range of social security benefits are available to people with disabilities including people with autism and their carers, including:

- Disability Living Allowance;
- Attendance Allowance;
- Employment and Support Allowance;
- Carer's Allowance; and
- Income-related benefits, such as Income Support and Pension Credit.

Proposals contained within the NI Welfare Reform Bill will result in major changes to the current welfare system which may see new benefits and information technology systems introduced. It is anticipated that Personal Independence Payment will be introduced in Northern Ireland during autumn 2014 and will replace Disability Living Allowance for working age customers (age 16 – 64). Universal Credit will replace a range of working age benefits including Employment and Support Allowance. The timing for the replacement of Employment and Support Allowance with Universal Credit has still to be determined.

All existing Disability Living Allowance working age customers will also be required to be reassessed for Personal Independence Payment between autumn 2014 and October 2017. With the exception of those who report a change in their care or mobility needs or those who have a fixed term award of Disability Living Allowance which is due to come to an end, the vast majority will not commence movement to Personal Independence Payment until October 2015 at the earliest.

A key change in the benefit is the introduction of a new assessment for all customers along with the introduction of periodic reviews of all awards and simplification of the application process. The assessment will appraise the impact of the condition and impairments on individual's everyday lives rather than the condition itself. The assessment will make greater use of evidence enabling a more accurate and consistent assessment of individuals to determine who will benefit most with additional support. A key consideration is not just whether they can complete the activities but that they can do so safely, to an acceptable standard, repeatedly and in a reasonable time period. The health professional undertaking the assessment, will be trained to make both a physical and mental health functional assessment, with both being considered whatever the underlying medical condition may be. It is recognised that many conditions have associated complications – physical and mental impairment may co-exist and contribute to the impacts of a condition. The Personal Independence Payment training programme for Health professionals (assessors) covers conditions affecting mental function, including autism spectrum disorders, and includes case studies, role play scenarios and communication/assessment techniques for people with autism.

The Social Security Agency (SSA) will continue to support people with disabilities, particularly those who are vulnerable, including those with autism and their carers, as Personal Independence Payment is introduced. This includes safe guarding measures for those with mental health difficulties who don't return forms or require assistance with completing them.

2.10.3 Staff Awareness

In addition to the standard training delivered to all frontline staff, further awareness sessions, which covered mental health and physical disability, were provided through a disability voluntary organisation for staff working in Disability and Carers Service and Incapacity Division. In April 2010 and March 2012, awareness sessions covering autism were delivered to staff across Disability and Carers Service.

2.10.4 Staff Training

Disability Living Allowance decision-makers undergo a comprehensive twelve-week training programme followed by an extensive consolidation period which includes mentoring by an experienced decision maker. The training package includes key messages in relation to perceptions about disability and the impact of disabilities such as autism.

Medical guidance, which is regularly updated, provides detailed and specific information to help decision makers understand how customers are likely to be affected by disability. The medical guidance is written by the Department of Work and Pensions Medical Advisors with input from an autism organisation. Decision makers are supported in interpreting medical reports and guidance by Medical Officers, who are trained General Practitioners, located on site.

Training for decision makers is kept under continuous review and additional training is provided when any changes to legislation or case law impact on the decision making process. In March 2012, senior management of Disability and Carers Service met with an autism voluntary organisation who provided details of the current issues encountered by people with autism. This fed into the training for decision makers.

Awareness training on autism has also been introduced for staff in the Employment and Support Allowance Centre. The new training, which includes material on autism provided by an autism organisation, assists call agents and those who undertake benefit assessments in dealing with individuals with autism. The training is ongoing and any new staff joining the telephony team will get awareness training in respect of autism. Advocates can assist vulnerable callers in making a claim to Employment and Support Allowance.

In 2011, Benefit Training Services delivered a one-off training to Employment and Support Allowance staff called ‘Customer Service Package’, and autism was referenced as part of ‘working effectively with customers.’

The Employment and Support Allowance Centre has arrangements in place for customers who experience mental health incapacities, such as autism, who fail to attend their medical assessment and who do not subsequently make contact with the Employment and Support Allowance Centre or the Incapacity Benefit Reassessment Office. In this circumstance, a *Safeguard Visit* can be carried out to ensure the customer clearly understands their obligations. The Safeguard Visit is also aimed at preventing unnecessary disallowance of the benefit entitlement of these vulnerable claimants.

Within the Agency’s Incapacity Benefit Reassessment business unit, staff, including those engaged on benefits assessment, have received disability awareness training and also have been trained on how to deal with vulnerable claimants. This covers conditions such as autism but no specific autism awareness training has been delivered. This business unit is due to terminate mid next year and therefore no specific training is envisaged at this stage.

2.10.5 Communication

The Social Security Agency has taken steps to make the claiming process for Disability Living Allowance as straightforward as it can be to ensure that all disabled people, including people with autism, are able to access this benefit. Senior Social Security Agency officials meet regularly with relevant organisations to continually review and revise the claims process. That approach provides a gateway for key client groups to influence the design and content of not only the Disability Living Allowance claim form, but also current processes and new initiatives.

These existing arrangements have been augmented with the establishment of a specific forum for disability groups and the advice sector for the introduction of Personal Independence Payment.

The forum consists of a network of over sixty organisations which includes autism organisations There have been thirteen meetings to date which provides the opportunity to ensure the particular circumstances of individual groups are represented to ensure they are factored into the design of the new benefit. This Customer Representative Forum also gives the opportunity for the Agency to discuss implementation plans, listen to concerns, provide clarification on certain issues and offer reassurance where possible that individuals will be fully supported throughout the process. Customer journeys for various aspects of the Personal Independence Process, including customer notifications, have also been agreed by the forum. In addition to the named forums, several individual disability organisations have been offered the opportunity to avail of one to one meetings.

2.11 Justice

The Department of Justice (DOJ) is committed to improving services for all those who come into contact with the criminal justice system and to ensuring that additional support is available for those who need it, working in collaboration with our statutory and voluntary sector partners. ’Special measures’ are available to help those who are vulnerable or intimidated to give evidence in court, if they wish to use them.

The DOJ has recently published a new five-year strategy for victims and witnesses, and the themes and actions in that strategy will encompass the specific needs of anyone with a hidden disability such as autism who comes into contact with the justice system as a victim or witness. The Department is also considering ways of ensuring that support is available for all those with autism – or, indeed, any form of communication difficulty - who come into contact with the criminal justice system.

In addition, the DOJ Community Safety Strategy 2012 - 2017 recognises the impact of hate crimes against people with a disability, and includes commitments to encourage increased levels of reporting of disability hate crime, ensure effective support to victims of disability hate crime and to challenge attitudes that lead to hate crime. This work will also encompass the needs of people with autism.

As highlighted in section 2.4, a joint Mental Capacity Bill is under development. The Bill will make also make provision for those within the criminal justice system who require an intervention as described above. The DOJ is leading on this aspect of the Bill. The intention is to introduce the Bill within the current NI Assembly mandate.

Several actions have been included under the “Access to Justice” section of the action plan, but this is not because we are assuming that someone with autism is more likely to offend; rather, these actions are intended to recognise that where a person with autism is accused of committing an offence, more support may need to be put in place to ensure their rights are being upheld. A person with autism could, for instance, wrongly incriminate themselves, or they may need help to make a properly informed decision about whether to accept, or to participate in, a diversionary disposal (such as a youth conference).

The DOJ recognises that the types of support required will vary considerably, and so is committed to ensuring that each individual’s needs are assessed as early as possible, and that these needs are kept under review as the person progresses in their journey through the criminal justice process, whether as a victim or a witness or as an accused person, defendant or offender - and that their needs are responded to consistently and appropriately.

2.12 Driving and Driving Tests

The Department of Environment’s Driver and Vehicle Agency can make allowances for customers with disabilities, including those with autism who are taking the Driving Theory and Practical Driving Tests.

For the Driving Theory Test, a number of adjustments can be made to facilitate an individual candidate's requirements and these are available at all theory test centres throughout NI. In some circumstances the delivery of a home test is also an option. The Agency also facilitates customers in the completion of the Practical Driving Test. Depending upon the nature of the customer's disability and subsequent requirements, adjustments can be made to the time allocated and how instructions, during test, are given.

2.13 Culture, Arts and Leisure

The Department of Culture, Arts and Leisure is committed to promoting social and economic equality, and to tackle poverty and social exclusion in the wider context of developing tangible opportunities and measurable outcomes for securing excellence and equality across culture, arts and leisure. In keeping with this the Departments Arms Length Bodies provide various levels of support to children with autism and their carer's.

The Armagh Planetarium offers tailored visits for people and groups with special needs. The Planetarium has catered for people with autism and their families and carers by providing bespoke shows on a Saturday morning.

The Armagh Observatory has also offered part-time employment to individuals with autism spectrum conditions. This is supported by a job coach from an organisation with special expertise in Autistic Spectrum Conditions.

NI Screen, the government-backed lead agency in NI for the film, television and digital content industry, consulted with autism organisations as part of updating the NI Screen Disability Action Plan. This helped increase awareness of autism training programmes and as a result, NI Screen is considering a review of signage at offices to assist people with autism.

All National Museums staff are trained to support children with autism during their visits to their museums. The museum also adjusts opening hours to facilitate visiting groups. The Department recognises that enhanced access to local services such as museums and libraries could be provided in consultation with local autism groups.

Section 3

Themes
and
Strategic Priorities

3.0 Themes and Strategic Priorities

This section focuses on moving forward with rights based strategic priorities under themed headings. These have been developed in consideration of some of the articles in the UNCRPD, UNCRC, the Executive's Disability Strategy '*A Strategy to improve the lives of people with disabilities 2012 – 2015*' and key themes and findings from the pre and public consultation exercises. Collectively they define the *Strategic Priorities* for the future development and delivery of services for people with autism under the following rights based themes:

- *Awareness;*
- *Accessibility;*
- *Children, Young People and Family;*
- *Health and Wellbeing*
- *Education*
- *Transitions*
- *Employability;*
- *Independence / Choice and Control;*
- *Access to Justice;*
- *Being Part of the Community; and*
- *Participation and Active Citizenship.*

Under each of the above headings a number of strategic priorities have been identified. These priorities are explained in more detail within each section. They form the basis for the Action Plan which is contained in Section 5.

3.1 Awareness

Strategic Priority 1

To work in partnership with representatives from all government departments to access a range of awareness training which will support the public and private sector in providing services to people with autism, their families and carers.

Strategic Priority 2

Increase awareness and understanding about autism among the general public with the aim of promoting positive attitudes toward people with autism.

There are many international and national events and symbols which recognise and celebrate autism, such as World Autism Awareness Day[2], Autism Awareness Month which occurs in April each year in Scotland, Wales and NI and the 'Light it up Blue for Autism' Campaign[3]. There is, however, a growing need for the general public in NI to have more awareness about autism, for a variety of reasons.

There needs to be a better understanding of some of the day to day challenges faced by people with autism, their families and carers. There is a general acceptance that negative attitudes and perceptions that exist about people with autism can add to the barriers which they face in their everyday lives. Families and people with autism report experiencing a sense of isolation and of being judged.

A parent told us:

> **"Autism is a hidden disability, our children look 'normal', but they often behave in a way that is far from appropriate for their age or appearance. Often the most difficult thing to deal with, as a parent, is the looks from others when your child 'misbehaves' or has some 'quirky' behaviour that is seen as embarrassing. I have often wanted to yell MY CHILD HAS AUTISM!"**

This Strategy and Action Plan provides an opportunity to advocate and commit to finding innovative ways to raise awareness about the positive contributions

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[2] http://www.un.org/en/events/autismday/index.shtml

[3] http://www.lightitupblue.org/Markslist/home.do

people with autism make in our society. This is also an opportunity to promote positive attitudes towards people with autism across all sectors at a community and regional level in NI and to dispel the myths that exist.

A parent from Magherafelt said:

> ***"Overall, I welcome the recognition that there is a need to improve awareness among service providers and the general public. There are many myths and misconceptions surrounding autism, and this adds to the burdens of parents, carers and people with autism."***

As part of its responsibilities for awareness-raising under Article 8 of the UNCRPD and their commitment to lead on a signature project regarding disability awareness, OFMDFM will continue to ensure they raise awareness of all types of disability including autism. OFMDFM will include autism-specific research as part of its work to identify issues impacting on people with disabilities.

A representative from the HSCB / Public Health Agency (PHA) said:

> ***"Raising awareness across departments and agencies and the general public will bring recognition of this condition and enable people with autism to lead fuller lives."***

The key aspects identified under the 'awareness' theme in this Strategy and subsequently reflected in the associated section in the Action Plan are:

- *Promoting positive attitudes about people with autism;*
- *Training of frontline staff in government departments and arms length bodies; and*
- *Commissioning and planning for the delivery of an autism awareness campaign.*

3.2 Accessibility

Strategic Priority 3

Eliminate the barriers that people with autism face in accessing the physical environment, transport, goods and services so that they can participate fully in all areas of life.

Strategic Priority 4

Increase the level of accessible / inclusive communications so that people with autism can access information as independently as possible.

Article 9 of the UNCRPD states that persons with disabilities, which includes those with autism, should have access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas.

Feedback from the consultation phases shows that while people with autism are an extremely diverse group of individuals they face a variety of challenges in terms of accessing services. These challenges arise across a wide range of areas including health and social care, education, employment and learning, housing, social security benefits and justice.

A young person from Co. Londonderry said:

> ***"My mum has had to fight for every service I received which should not be the case. Although I was diagnosed with autism very early on in my life, I received few services until the age of 14 which I feel was too late. It would be better if these services had been available to me earlier in life."***

The feedback shows that people with autism want access to the same range of opportunities as anyone else. However very often they feel that they are not adequately supported in accessing these services; either because of the lack of awareness about autism among frontline staff or that their specific needs are likely to be poorly understood due to the lack of skills and experience in working effectively with people with autism.

Article 21 of the UNCRPD relates to the right for people to express themselves, including the freedom to give and receive information and ideas through all forms of communication, including through accessible formats and technologies, sign languages, Braille, augmentative and alternative communication, mass media and all other accessible means of communication.

People with autism can have difficulties with social interaction, social communication and social imagination, which is referred to as the '*triad of impairments*'. As previously stated, autism is a spectrum condition which affects every person in a different way and people will experience different degrees of difficulty with social interaction and communication. This Strategy and Action Plan will seek to ensure that the most effective approaches and ways of helping a person with autism to cope with these difficulties are adopted across a wide range of services.

A parent from Belfast told us:

"Accessibility is directly related to the awareness of the people providing the services. If this is poor, the prognosis for accessibility is poor."

The key aspects identified under the 'accessibility' theme in this Strategy and subsequently reflected in the associated section in the Action Plan are:

- *To create supportive environments and putting in place routine and supportive strategies for the person with autism by promoting the importance of visual signage;*

- *Ensuring good communication between service providers and people with autism to help reduce the possibility of misunderstanding or confusion through utilisation of new technologies such as voice and written announcements for transport services;*

- *Ensuring everyone involved with a person with more complex communication needs follows an approved approach tailored to the person's needs; and*

- *Enhancing access to advocacy services and support, where appropriate, for people with autism with a view to increasing: independence, access to opportunities, choices, and encouraging inclusion in services and communities.*

3.3 Children, Young People and Family

Strategic Priority 5

Ensure that children and young people with autism and their families have access to effective and appropriate support, where required, to help them with the everyday challenges of family life.

Article 7 of the UNCRPD states that, government shall take all necessary measures to ensure that children with disabilities enjoy the same human rights and fundamental freedoms on an equal basis with other children.

In terms of this Strategy and Action Plan the focus will be on children and young people with autism and their families having access to services that meet their needs. Specifically this will include education and health and social care such as special education provision, day opportunities and short break services.

The need for early intervention within the early year's sector to support the identification / recognition of early signs of autism spectrum conditions, as well as developing the skills of those working with children with autism in this sector, is of paramount importance. In particular there is a need to ensure that pre-school groups run by private, community and voluntary sector organisations are not overlooked in this regard, as this sector can be in a good position to recognise early signs of autism spectrum conditions in children at an early age.

Parents and families with children who have a disability, including those who have children with autism, can experience difficulties finding appropriate childcare. The reasons for these difficulties can be wide ranging and often include one or more of the following:

- Inability to find a childcare provider who is able to offer the level of specialist support that their child requires;
- Lack of flexibility to accommodate childcare requirements which may change on a regular basis;
- Lack of specialist equipment / accessibility requirements;
- Childcare costs can be cost prohibitive and childcare facilities can be restricted where one-to-one care or specialist support for a child / children is required;

- Parents may feel unable to leave their child in a childcare facility if they do not feel confident their child's needs will be provided for appropriately.

Difficulty in accessing appropriate childcare can have a knock on effect on a parent's ability to pursue, for example, employment which would enhance a family's standard of living.

Funding from the NI Executive Childcare Fund will be deployed to pay for a range of initiatives, including the administration of small grants for specialist equipment, disability awareness and autism specific training for childcare staff.

At public consultation, a parent from Belfast said:

> ***"Families in particular need training to learn how to manage and help their children, this has to be ongoing and available at any stage as those children on the spectrum are always exhibiting new challenging behaviours, and therefore advice is often needed to manage or control."***

The aim of the OFMDFM strategy - "Our Children and Young People, Our Pledge" is to improve the life chances for children and young people to ensure that every child, irrespective of race, gender, religious belief, age, sexual orientation, disability, background or circumstances, gets the best start in life and the support they need to fulfil their potential. The effort to deliver this aim must include responding to the issues that parents will have to cope with as they bring up their children.

The DHSSPS strategic policy entitled *Families Matter* moves parents into a central position in policy terms and provides strategic direction for government on how best to assist parents in NI and also details initiatives and actions to meet those strategic aims.

These strategies acknowledge that support for families cannot be provided by government alone. The statutory agencies, voluntary and community organisations, and most importantly of all parents, must work together to do the best they can, to deliver the best possible future for our children and young people with autism. In the context of this Strategy it is important that families with children and / or young people with autism are able to access services appropriate to meet their needs.

Through the CYPSP work will be progressed to recognise that the needs of children and young people are considered and services will be enhanced to ensure that their needs and the needs of their families are considered.

Articles 7 and 19 from the UNCRPD articulate the importance of parents and families in the care of children with disabilities, but they also acknowledge that some children require additional supports to ensure their rights are protected and safeguarded. In addition, one of the high level outcomes of OFMDFM's Children and Young People Strategy 'Our Children, Our Pledge' is the requirement that children should be afforded the opportunity to live in stability and safety.

A parent of a child with autism told us:

> ***"There has been some success - for example some of the recommendations made following an occupational therapy assessment were taken into consideration by the teacher when planning PE/Games. The success was short lived - a change of teacher very often brings a completely different attitude and approach. Inconsistency and changing habits are hard for an autistic person to cope with."***

The Safeguarding Board for Northern Ireland (SBNI) was established by the Safeguarding Board Act (NI) 2011 in recognition of the fact that children are more likely to be protected when agencies work in an all-inclusive, coordinated and consistent way.

SBNI recognise that children with disabilities are vulnerable to the violation of their rights and require adequate protection. The SBNI will seek to ensure that its member agencies have effective safeguarding arrangements in place for children and young people with a disability, which includes autism. This priority has been included in the SBNI Strategic Plan 2013 – 2017.

There has been a growing recognition that a wide range of adults, for a variety of reasons, are at risk of harm from abuse, exploitation or neglect. The HSC Trusts and the PSNI have a lead role to play in the prevention of harm and abuse and for providing protection to adults, where harm is suspected or has actually occurred. Specifically they seek to ensure that adults at risk of harm or abuse receive protection, support and equitable access to the criminal justice system. Adult safeguarding and protection work must be conducted in a way which is person-centred, underpinned by human rights considerations and guided by the principles and approaches set out in *Safeguarding Vulnerable Adults,* the Regional Adult Protection Policy and Procedural Guidance, published in September 2006 and its associated Joint Protocol, revised and published in July 2009.

The Northern Ireland Adult Safeguarding Partnership (NIASP) is a multi agency regional body charged with the oversight of Northern Ireland's adult safeguarding arrangements. NIASP will determine the strategy for safeguarding vulnerable adults, develop and disseminate guidance and operational policies and procedures, monitor trends and outcomes and monitor and evaluate the effectiveness of partnership arrangements. Five Local Adult Safeguarding Partnerships (LASPs) have been established, located within HSC Trust areas. LASPs will implement locally the NIASP strategy and have responsibility to promote all aspects of prevention activity and oversee protection activity in its area.

This Strategy will take cognisance of the developing Policy Framework and the structures for adult protection and engage at a strategic level with NIASP and locally with LASPs. It will be necessary to ensure that the policy and procedures are implemented at local level to address the needs of adults with autism, who may be at risk of abuse, exploitation or neglect.

The key aspects identified under the 'children, young people and family' theme in this Strategy and subsequently reflected in the associated section in the Action Plan are to:

- *Promote early intervention and early recognition of children and young people with autism;*

- *Support initiatives to increase appropriate childcare provision for families of children with autism;*

- *Provide a single resource for families to identify autism resources available in their area; and*

- *Highlight the safeguarding needs of children, young people and adults with disabilities including those with autism.*

3.4 Health and Wellbeing

Strategic Priority 6

Promote the physical, psychological, emotional and social health and wellbeing of people living with autism and their families and carers.

Strategic Priority 7

Enhance the commissioning and provision of health and social care services to meet the needs of people with autism throughout their lives.

Being physically and emotionally healthy is a fundamental component of health and well-being and in ensuring the best start in life. Research demonstrates that people with developmental needs can experience poorer physical health outcomes, and also have a higher risk of developing emotional and mental health problems all of which compromises development, health and emotional wellbeing. In line with Strategic Priority 6 above we would seek to ensure that:

- Health promotion information / activities are designed and delivered taking account of the needs of people with autism and their families and carers;

- Care planning arrangements for people with autism spectrum conditions include a physical health and emotional wellbeing plan which promotes personal/facilitated responsibility; and

- Care plans should therefore promote:
    - Physical activity, and good nutrition;
    - Sleep;
    - Hygiene;
    - Relationship and sexual health;
    - Psychological and mental health care; and
    - Appropriate health screening to enable early identification of health related problems.

Feedback from the consultation phases highlighted that the health and wellbeing of those who help care for people with autism is paramount to enabling the person with autism to holistically develop.

A parent from Co. Antrim told us:

> **"All my daughter's personal needs are seen to - I am on duty 24/7. She is my job."**

There is a wide range of health and wellbeing strategies that include a particular focus on young people. The main ones cover: obesity (nutrition and physical activity); alcohol and drugs; smoking, sexual health, suicide prevention, and mental and emotional health and wellbeing.

In addition, given the range of factors that influence mental health and wellbeing, cross-departmental strategies, where lead responsibility falls outside of the health and social care sector, are also relevant. These include for example: the Children's Strategy, Early Learning Strategy; and NEETS Strategy.

> ***"There is a need for specific priority of access to services to support the person with autism/their family/carer(s) especially medical services -diagnosis- behavioural support and support for associated disorders such as eating problems"***

A parent told us:

The key aspects identified under the 'health and wellbeing' theme in this Strategy and subsequently reflected in the associated section in the Action Plan are to:

- *Promote an inclusive approach to health and wellbeing programmes and adapt as necessary to support people with autism;*

- *Enable people with autism and their families and carers to access a wide range and choice of health promotional programmes and services to support holistic / person centred needs;*

- *Improve access to health and social care services for adults with autism in terms of identification, assessment, diagnosis and support; and*

- *Support ongoing and continuous service improvement in terms of autism care pathways.*

3.5 Education

Strategic Priority 8

Ensure that children and young people with autism receive a high quality education that prepares them for life and work and enables them to fulfil their potential.

Article 24 of the UNCRPD relates to education and provides for access to an inclusive education system at all levels and to lifelong learning.

The DE's main statutory areas of responsibility are 0 to 4 provision, primary, post-primary and the youth service. The Department's vision is *"to ensure that every learner fulfils her or his full potential at each stage of development".* DE aims to improve the outcomes achieved by every young person by raising standards for all and tackling the barriers to learning that put young people at risk of underachievement. To enable them to achieve good outcomes, particularly in literacy and numeracy, every young person should receive a high quality education and, where necessary, the additional support they need to overcome any specific barrier he or she may have. This aim applies to every young person, including those children and young people with an autistic spectrum disorder.

The Education Minister has put in place a range of policies to raise standards and tackle the barriers to learning that put pupils at risk of underachievement, e.g. Every School a Good School – A Policy for School Improvement; Count, Read: Succeed – A Strategy to Improve Outcomes in Literacy & Numeracy (and is finalising Priorities for Youth; and Learning to Learn – A Framework for Early Years Education and Learning). The Review of Special Educational Needs and Inclusion is also a key initiative, aimed at improving the current support framework for children with SEN.

The policies mentioned above will be delivered by pre-school settings, schools and youth service, where appropriate, working in partnership with the range of statutory and voluntary agencies that support young people and their families.

On foot of one of the recommendations of the 2002 Report of the Task Group on Autism, DE does not advocate exclusive adherence to any specific single intervention or theoretical perspective in relation to autism. The Task Group concluded that interventions should be child-centred rather than method-centred, and should address the observed and unique and changing needs of the child over time. Provision should include strategies and approaches matched to the needs of individual children and delivered in home-based and centre-based settings, as indicated by multi-disciplinary and multi-agency assessments in which parents are fully involved.

A parent of a child with autism told us

> **"It is a constant battle for autistic children without a learning disability but who still have behavioural and sensory issues to get a classroom assistant that is properly trained to help them throughout the school day"**

In line with the strategic priority and building on the education policies already in place, DE identifies the following key aspects for 'education':

- *Schools, in partnership with parents, and supported by the ELBs/ESA and other agencies, should work to improve identification, assessment and appropriate early intervention to support pupils who may have autism;*

- *ELBs/ESA, working in collaboration with health and other agencies, should provide support to schools (including the continuing professional development of staff providing autism support) in working to identify good practice in meeting the needs of their pupils with autism. The Middletown Centre for Autism will continue to provide a range of support and intervention to professionals, parents and children with autism;*

- *Schools, supported by ELBs/ESA, working in collaboration with health and other agencies, should support parents and carers in supporting their child's education and providing appropriate autism interventions. The Middletown Centre for Autism will continue to provide a range of support and intervention to professionals, parents and children with autism; and*

- *ELB youth services should provide a wide range of youth activities for groups with specific and general disabilities as well as training to assist youth workers in providing services for them.*

3.6 Transitions

Strategic Priority 9

Transform the process of transitions for people with autism, so that a co-ordinated approach is adopted in planning and providing for transitional needs, programs and supports for people with autism across their lifetime

In the past autism was thought of as a childhood condition. This was because attention has been focused primarily on children and the importance of early detection and intervention. However there is now widespread recognition that autism is a lifelong condition and the need for support and services changes as people on the spectrum move through major life phases.

Feedback from the consultations shows that people with autism usually rely on routines in order to navigate more easily through social situations and that a sudden change to that routine such as starting a new school, a new job, or moving from child to adult health services can be very disruptive and unsettling.

A parent from Fermanagh said:

> ***"Preparation when it is known things will change. There should be adequate time for a person with ASD to adjust to the changes in routine and supports (e.g. into adult services, and from education to training, benefits to work etc.)"***

As people with autism move through significant life changes, their quality of life depends not only upon the foundation that is provided in childhood, but also on ongoing supports that are specific to the educational, health, social, recreational, family and employment needs of the individual.

As referenced in Section 2 of this Strategy, the CYPSP, which is chaired by the HSCB, includes representatives from key Departments and agencies. Under CYPSP the *Transitions sub-group* is in place to take forward the plan to improve the six high level outcomes for young people with disabilities as they transition into adulthood.

The 'transitions' section in the Action Plan attached to this Strategy should be read in conjunction with the overall Children and Young People's Plan and anticipates that a co-ordinated approach to planning and preparing for these transitions can help to reduce the stress and help support people with autism to manage these difficult phases of their lives with more confidence and comfort.

Stranmillis University College said:

"(We) would agree that transitions are especially important, at all levels, but especially post-19, and between key stages 2 and 3."

The key aspects identified under the 'transitions' theme in this Strategy and subsequently reflected in the associated section in the Action Plan are:

- *Improved transition planning to take account of the needs of people with autism throughout all transition phases in their lives; and*

- *More integrated and co-ordinated transition planning which promotes effective joint working between and across sectors.*

3.7 Employability

Strategic Priority 10

Increase the number of people with autism entering all levels of employment and safeguard the rights of those people with autism already in work.

Strategic Priority 11

Increase the opportunities for people with autism to attain skills and qualifications through access to appropriate training and lifelong learning opportunities.

Article 27 of the UNCRPD relates directly to work and employment and recognises the right of persons with disabilities to work on an equal basis with others. Article 24 of the UNCRPD is in relation to education which includes access to an inclusive education system at all levels and lifelong learning.

The Department for Employment and Learning (DEL) aims to provide opportunities for individuals, irrespective of their individual circumstances, to engage in learning and development that will help them to progress towards or in employment.

Employment and employability are issues which require a number of government departments to work together to support people with autism to gain and retain employment. This work must recognise that those who face greater barriers in accessing work will need more intensive and focussed support.

A person with autism from Portstewart said:

> ***"Employers need to be aware of the difficulties but also the possible benefits to employing someone with autism. Employers need help to make work environments more autism friendly. This could be through Occupational Health, with someone with training on autism. Things that need to be considered are open plan workspaces are not good, and look at lighting, heating, noises etc. Need to have quiet spaces to retreat to. Mentors to support entering and settling into employment may also be helpful."***

DEL and its key delivery partners, such as the colleges, universities and disability organisations, will continue to provide a range of programmes and services to people with autism who wish to obtain and sustain work, move towards employment, or develop new/existing skills.

In response to the public consultation, the Children's Law Centre said:

> ***"There is insufficient choice for young people with autism who require to be supported for longer than their peers in order to attain their true educational, life skills and employment potential."***

Existing provision is wide ranging and includes a guaranteed training place for young people with autism up to the age of 22. This offer, delivered under the Training for success Programme, provides help for school leavers with autism to assist with their transition to training from school. This programme provides training for young people who have not yet found full time employment. It is designed to enable young people to progress to higher level training, further education, or employment. It provides training to address personal and social development needs, develop occupational and employability skills and, where necessary, Essential Skills. It is delivered through two components:

- **Skills for Your Life** - To address the personal and development needs of young people who have disengaged from learning and/or have significant obstacles; and
- **Skills for Work -** To help young people gain skills and a vocational related qualification at Level 1 to be able to gain employment or to progress to higher level training.

In some cases the programme can accommodate reduced hours for a participant who is struggling with full time attendance.

In addition to existing provision, DEL has recently put in place a number of key Strategies and new approaches which will make a difference for people with autism. These include:

- A Strategy to widen participation in higher education from groups which are underrepresented; and
- New initiatives to help young people aged 16 to 24 who are not in employment, education or training.

DEL's Disability Employment Service will continue to help to raise awareness with employers on the benefits of employing people with autism and provide tailored support for people with autism. As part of the Strategic Review of the Disability Employment Service, organisations who represent people with autism, will be directly involved as key stakeholders.

In line with the strategic priorities and building on existing employment, skills and education policies and programmes, DEL has identified the following key aspects for the 'employment' theme:

- *Increase awareness of DEL's services amongst people with autism, their parents and carers;*

- *Provide effective support in higher education for people with autism through the delivery of the Access to Success Strategy;*

- *Improve employment prospects of people with autism through the delivery of an Economic Inactivity Strategy;*

- *Deliver the Pathways to Success Strategy to improve participation in employment, education and training by young people with autism; and*

- *Provide individual support for students with autism in further education.*

3.8 Independence, Choice and Control

Strategic Priority 12

Increase the level of choice, control and freedom that people with autism have in their daily lives.

Article 19 of the UNCRPD relates to independent living, the right to inclusion and participation in the community including choices and about places of residence - where and who to live with, and the range of in-home residential and other community support services, such as personal assistance necessary to support living and inclusion in the community .

Feedback from the pre-consultation shows that there is a lack of understanding in relation to the supported living requirements and housing adaptation needs of people with autism and their families.

An adult with autism said:

"There is a lack of Information regarding housing and supported living. We are not being supported to achieve a degree of independence."

DSD Housing Division is developing a new Supporting People Strategy. The strategy, in development, proposes to assist people with autism by:

- Redesigning services to improve autism care;
- Improve performance in autism services;
- Improve communication and information for individuals and families;
- Contribute to effective engagement and partnership working; and
- Train staff and raise awareness.

Personalisation within the health and social care sector is about giving people much more choice and control with a focus on timely, preventative and high quality personally tailored services with everyone having maximum possible control and power over the support services they receive.

This Strategy and Action Plan seeks to promote this more flexible approach for people with autism and their families and carers as reflected in the principles of Transforming Your Care. It is anticipated that this will offer a broader and more flexible range of opportunities to enable people with autism, their families and carers to access:

- Assistance from professionals who listen to their views, understand the impact of their autism spectrum condition on their life and help them to plan and provide for the support and services they need;
- Sufficient resources, whether in the form of Direct Payment or a budget, to support their needs effectively; and
- Support to broker services to meet needs, where the person or family wishes to manage the budget themselves.

In their consultation response, The Open University said:

> ***"The OU encourages a holistic and personalised approach to health where individuals are able to take ownership of their health, the services they receive and the care they wish to access. The OU is committed to educating individuals and communities in order to enable informed decisions to be made about personal health care. It also assists professionals to understand the implications of personalisation proposals on delivering care."***

The Education and Library Boards, through the autism advisory services, Middletown Centre for Autism and schools, and in partnership with HSC Trusts, provide life skills training for young people with autism in post-primary education to help prepare for their transition to adulthood. This includes training in personal, domestic and community skills; organisation and planning; relationships and sexuality; emotional well-being; managing the work environment; and preparation for higher education environments. Training is also provided for parents/carers of young people with autism so that they are informed and involved at this stage of their child's transition to adulthood.

At public consultation, we were told:

> ***"In order to achieve Independence, Choice and Control, children, adolescents and adults with autism should first be provided with the appropriate educational practises that effectively teach them life skills."***

The Social Security Agency provides advice and support to all disabled claimants, including those with autism. The impact of the Welfare Reform Bill on people with disabilities is being assessed so that full access to services and benefits will continue to be available. The proposals contained within the Welfare Reform Bill for Northern Ireland may result in major changes to the current welfare system. It will see many of the current benefits replaced and new payment systems introduced.

The key aspects identified under the 'independence, choice and control' theme in this Strategy and subsequently reflected in the associated section in the Action Plan are:

- *Facilitating the development of supported housing services for people with disabilities including autism;*
- *Promoting independence, choice and control through the development of self directed support in the form of either direct payments or personalised budgets to those living with autism;*
- *Promoting an increased uptake of life skills training; and*
- *Supporting vulnerable people including those with autism and their carers as Personal Independence Payment is introduced.*

3.9 Access to Justice

Strategic Priority 13

Ensure that people with autism are treated equally by the law, have access to justice and can live safely in their own community.

Article 12 of the UNCRPD relates to equal recognition before the law. It states that people with disabilities have the right to recognition as persons before the law. People with disabilities have legal capacity on an equal basis with others in all aspects of life. Countries must take appropriate measures to provide support to people with disabilities so that they can effectively exercise their legal capacity. In relation to this, work is underway on the development of mental capacity legislation, with the Mental Capacity (Health, Finance and Welfare) Bill currently being drafted.

Article 13 of the UNCRPD relates to access to justice. It states that people with disabilities have the right to effective access to justice on an equal basis with others, including through the provision of appropriate accommodations.

Article 16 of the UNCRPD relates to freedom from exploitation, violence and abuse. It states that people with disabilities have the right to be protected from all forms of exploitation, violence and abuse, including their gender based aspects, within and outside the home.

Feedback from the consultation phases highlighted a number of key areas for people with autism when they come into contact with the justice system. These included:

- The issue of advocacy for witnesses and victims of crime;
- Awareness levels for frontline staff in justice organisations; and
- Appropriate training for relevant staff in justice organisations.

A parent advised:

> ***"My son can get very agitated when confronted or when surrounded with people. When stopped by a police check point one evening my son got very frightened and started talking a lot and repeating himself. The police officer shone his light into his face my son got very loud and distraught. I had to explain to the officer why he was acting that way. Something that simple could have turned into something very bad."***

The DOJ and the criminal justice agencies are committed to ensuring that the needs of all those who come into contact with the criminal justice system are identified early on and acted upon appropriately and consistently through all stages of the justice process. The DOJ and DHSSPS are working together on a Joint Healthcare and Criminal Justice Strategy and Action Plan that will improve and coordinate health and social care provision for those in contact with the criminal justice system.

Victim Support said:

> ***"(We) see considerable potential improvements for individuals with a hidden disability, such as autism, resulting from initiatives such as the Registered Intermediaries Scheme and the Victim and Witness Care Unit."***

In line with this strategic priority, DOJ identifies the following as key priorities for 'justice':

- *A training model should be developed to ensure that staff in the criminal justice agencies have the right level of understanding and awareness of autism for their particular roles;*

- *Guidance should be available to professionals - including police officers, prosecutors, solicitors, barristers, judges and staff in the courts and probation service - to help them to recognise, approach and question someone with autism;*

- *There should be measures in place to ensure the needs of someone with autism are identified and assessed as early as possible and reviewed as they journey through the criminal justice process; and*

- *Improved services should be made available, including advocacy services for victims of crime and intermediaries to help people with significant communication difficulties to give evidence.*

3.10 Being Part of the Community

Strategic Priority 14

Improve access to sport, arts, leisure and other cultural activities so that people with autism can be part of the community.

Article 30 of the UNCRPD recognises the right of disabled people to take part on an equal basis with others in cultural life.

Feeling and being connected to family, peers, friends, community, colleagues, employers' and to those within educational settings is an essential element of social inclusion. People with autism spectrum conditions can struggle to form and maintain connections within some of these areas and settings. This can increase their risk / sense of isolation, social disadvantage, and poor health.

Feeling valued, being engaged in productive activity, and being economically active is central to ensuring good health and emotional wellbeing. Contributing positively to community and society is also important for reducing social vulnerability for people with autism spectrum conditions**.**

An adult with autism told us:

> ***"We need to know the availability of services, including volunteering opportunities or walking clubs etc – it is important for adults with autism to be given the opportunity to be socially connected in the local community."***

The Department of Culture, Arts and Leisure (DCAL) have committed to promoting awareness about autism within the culture, arts and leisure sector with the aim of enabling people with autism to enhance their quality of life through their participation in culture, arts and leisure activities. The aim is that through raising this awareness, specific actions will follow in relation to providing information on availability and enhanced access to the culture, arts and leisure activities that fall within DCAL's remit for people with autism and their carer's. This will enable people with autism to participate more fully in local activities and enhance their quality of life.

The Children's Law Centre said:

> ***"Some young people with autism have reported to us the importance of 'having friends', going out socially and joining in with others. We are also aware that children with autism may require specific supports within social environments and that supported environments are not readily available.***

The main focus of this strategic priority will be to enhance relationships across the statutory, voluntary and independent sectors so as to promote social inclusion of people and families living with autism

The key aspect identified under the 'being part of the community' theme in this Strategy and subsequently reflected in the associated section in the Action Plan is:

- *to promote inclusion in community culture arts and leisure for people with autism and their families and carers.*

3.11 Participation and Active Citizenship

Strategic Priority 15

Increase opportunities for people with autism to influence policies and programmes in Government including the delivery of this Strategy and the subsequent Action Plan.

Strategic Priority 16

Improve interaction between all sectors to achieve the social inclusion of people with autism.

The UNCRPD ‘Preamble’ states that persons with a disability should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them.

Under the Health and Social Services (Reform) Northern Ireland Act 2009, Health and Social Care organisations have a statutory requirement to involve service users, carers and the public in the planning, commissioning, delivery and evaluation of services.

A parent from Fermanagh said:

> ***“As a parent involved in the Regional ASD Network process I agree strongly that people with autism and their families should be involved in a very useful and productive way when government departments develop policy, processes, guidance etc. Those of us with direct relevant experience, particularly those with ASD, often have ideas and answers that should form part of meaningful discussions.”***

In terms of the development of this Strategy and Action Plan, people with autism and parents of children with autism, have been involved through their representative roles on the Autism Strategy Project Board. This involvement will continue throughout the implementation of the Action Plan.

In addition DOJ and DEL will involve and engage with people with autism and community / voluntary sector organisations who represent people with autism in the development of the DOJ Victims and Witnesses Strategy and the review of the Disability Employment within DEL.

Section 4

Implementation Approach

4.0 Implementation Approach

4.1 Action Plans

The Action Plans which will result from the seven-year lifetime of this Strategy will provide a framework which sets out the key actions to be taken forward at strategic level. Departments may develop their own more specific action plans which they will implement at a departmental / agency level or where appropriate on a cross departmental basis. Departmental action plans, where they exist, may provide a useful basis for reporting progress against the strategic level action plans.

The initial **Action Plan (2013 – 2016)** attached to this Strategy seeks to develop a holistic approach and further development of existing services and support for people with autism, their families and carers. Many of the actions within this Action Plan are not resource intensive and are intended to provide a basis for building on existing good practice and multi disciplinary collaborative work within existing resources. Future editions of the Action Plan covering the periods 2016 – 2019 and 2019 – 2021 will seek to develop services further to deliver the vision, objectives and strategic priorities of the Autism Strategy.

Over the course of implementation of the initial Action Plan there may be a requirement to review and revise the Plan to ensure that the actions remain relevant, focused and measurable. This may result in the development of some more detailed actions and or revision to others both at strategic and where appropriate individual departmental level.

4.2 Implementing the Action Plan

The key aim will be to develop and put in place an infrastructure, at a cross departmental level, which will help ensure that all stakeholders are able to contribute to the delivery of the Action Plan. It is envisaged that such support will comprise:

- Analysing and understanding what the prevalence of autism means in terms of societal impact and demand for existing and future services, including mapping services to establish potential gaps in addressing need;

- Designing, together with local service providers, new service models which build on collaboration and partnership working across the sectors;
- Facilitating the sharing of emerging service-based learning and good practice on a UK and wider international basis; and
- Development of accessible communication and training materials, (including where appropriate web-based material) both for those using services and for public sector frontline professionals and practitioners, to improve awareness of autism and facilitate sharing of effective good practice.

4.3 Implementation Structures and Roles

An **Autism Strategy Regional Multi Agency Implementation Team** will be established to direct, co-ordinate and manage the implementation of the Strategy and Action Plan on a cross departmental strategic basis. Membership of the Team will be drawn from a wide range of agencies including health and social care, education, justice, employment and learning, arts as well as community / voluntary organisations and service user / carer representatives. **The full implementation reporting structure is illustrated in Appendix 3.**

This Multi Agency Implementation Team will be led by the **Regional Autism Coordinator**, although each relevant NI government department will be tasked with implementing, monitoring, resourcing and reporting progress on their aspects of the implementation of the Strategy and Action Plan both at an individual departmental / agency level and also on cross departmental basis.

The **Regional Autism Co-ordinator** will be recruited by the HSC Board but the role will encompass a cross-departmental remit in terms of managing and co-ordination of reporting to the **Bamford Interdepartmental Senior Officials Group** and through the DHSSPS to the **NI Executive.**

Five **Local Autism Fora** with their associated **Autism Reference Groups** will be established. These Fora and Reference Groups may in part evolve from the RASDN structure in that they will be chaired / led by the respective local HSC Trust Autism Coordinator. However their remit and mandate will be broadened and renewed to include representation from all sectors responsible for contributing to the implementation of the cross departmental Strategy and Action Plan.

Feedback from the five **Local Autism Fora,** the **Autism Strategy Prevalence Sub-group** the **NI Autism Strategy Research Advisory Committee** and the five local **Autism Reference Groups** will form key elements of progress towards implementation of the Strategy and Action Plan. All of these fora will report into to the **Regional Multi Agency Implementation Team**.

4.4 Duration of the Implementation Team and Terms of Reference

The **Regional Multi-Agency Implementation Team** will continue in existence over the seven year period of the life of the Strategy (2013 – 2021). An initial Terms of Reference will be developed, to set out the remit and specific responsibilities of the Implementation Teams and Groups both in terms of review, monitoring and implementation of the Strategy and Action Plan but also to commission input from relevant departments regarding the development of the **three-yearly report to be laid before the NI Assembly.**

The DHSSPS will review the Implementation Team's Terms of Reference on a biennial basis to determine and effect changes required going forward over the seven year term.

4.5 Monitoring and Reporting

The Autism Act (NI) 2011 stipulates that the Minister for Health, Social Services and Public Safety will lay a report, prepared by the DHSSPS, **before the NI Assembly within three years of publication** of the Strategy. Based on the timescale for the publication of the Strategy in December 2013 and the Implementation Team commencing its work in early 2014, an initial report should be laid before the **NI Assembly by December 2016**.

The **Regional Multi-Agency Implementation Team** will monitor and assess progress on the implementation of the Strategy and Action Plan. The **Regional Autism Coordinator** who will chair the **Autism Strategy Multi-Agency Implementation Team** will prepare an annual report on the implementation of the Autism Strategy Action Plans

An additional key element of evaluating progress on the implementation and delivery of actions in the Strategy and Action Plan will be through direct feedback from user groups. As stated above the five **Local Autism Reference Groups** established and organised within the five **Local Autism Fora** created in the Western, Southern, Northern, South Eastern and Belfast areas will provide this feedback.

4.6 Finance and Future Investment

The Strategy and Action Plan recognise the need for greater cooperation across government departments and agencies in providing services for people with autism and where possible to make more effective use of available resources. In this context and in the circumstances of limited additional investment; departments and their service commissioners may need to consider if shifts in investment or innovative approaches are required to deliver the priorities identified in the initial Action Plan (2013 – 2016).

4.7 Structure of the Action Plan

The structure of the Action Plan mirrors the eleven themes and associated strategic priorities as follows.

Themes:

1. **Awareness;**
2. **Accessibility;**
3. **Children, Young People and Family;**
4. **Health and Wellbeing**
5. **Education**
6. **Transitions**
7. **Employability**
8. **Independence, Choice and Control;**
9. **Access to Justice;**
10. **Being Part of the Community; and**
11. **Participation and Active Citizenship.**

The final section in the Action Plan sets out actions required to provide **leadership and implement** the priorities, actions and outcomes as set out in the Strategy and Action Plan.

Section 5

The Autism Action Plan
(2013 – 2016)

5.0 The Autism Action Plan (2013 – 2016)

1 Awareness

Strategic Priority 1

- *To work in partnership with representatives from all government departments to access a range of awareness training which will support the public and private sector in providing services to people with autism, their families and carers.*

Key Action	Action Summary	Outcome Required / Performance Indicator	Responsibility	Lead Responsibility	Timescale
1a) Awareness Training	**1.1** Promote, organise and deliver autism awareness training for all relevant frontline staff to include; • Relevant NICS Departmental staff; and • Relevant NICS Departmental Agencies. • Voluntary sector delivery partners	**1.1.1** Autism Factsheet made available across NICS	All Departments	Each Department responsible for training their own relevant frontline staff and ALB frontline staff	March 2014
		1.1.2 Autism Factsheet made available to all NICS Departmental ALBs and voluntary sector delivery partners			March 2015
		1.1.3 Autism Awareness Training provided to frontline staff			March 2015

5.0 The Autism Action Plan (2013 – 2016)

1 Awareness

Strategic Priority

- *Increase awareness and understanding about autism among the general public with the aim of promoting positive attitudes toward people with autism.*

Key Action	**Action Summary**	**Outcome Required / Performance Indicator**	**Responsibility**	**Lead Responsibility**	**Timescale**
1b) Raising Awareness	**1.2** Identify opportunities to raise awareness about autism and provide information to the general public	**1.2.1** Structures developed and funding secured to develop a public autism awareness campaign.	All Departments, Community and Voluntary Sector Organisations	DHSSPS	March 2014
		1.2.2 Public awareness campaign initiated.		DHSSPS	March 2015
		1.2.3 Coordinate information about autism through NI Direct		All Departments	September 2014
		1.2.4 Participation in World Autism Awareness Day		All Departments	Annually 2014 & 2015

5.0 The Autism Action Plan (2013 – 2016)

2 Accessibility

Strategic Priority

- *Eliminate the barriers that people with autism face in accessing the physical environment, transport, goods and services so that they can participate fully in all areas of life.*

Key Action	**Action Summary**	**Outcome Required / Performance Indicator**	**Responsibility**	**Lead Responsibility**	**Timescale**
2a) Transport and travel	**2.1** Improve the provision of travel information with a view to making travel / public transport more accessible for people with autism.	**2.1.1** New public information leaflets in a more accessible format for people with autism produced.	Translink	DRD	March 2015
	2.2 Improve the provision of travel training schemes with a view to making travel / public transport more accessible for people with autism	**2.2.1** Barriers removed enabling easier access for people with autism to the physical environment and goods and services	DRD	DRD	March 2015

2 Accessibility

Strategic Priority

- *Increase the level of accessible / inclusive communications so that people with autism can access information as independently as possible.*

Key Action	Action Summary	Outcome Required / Performance Indicator	Responsibility	Lead Responsibility	Timescale
2b) Communication and information	**2.3** Ensure that communication and information is available and accessible to people with autism	**2.3.1** Improvements in signposting to services for people with autism.	All Departments	All Departments – joint responsibility	March 2014
		2.3.2 Improvements and access to a single central source of information and advice about government services and support made available to people with autism.	All Departments – linked to NI Direct	All Departments – joint responsibility	March 2015
	2.4 Complete local service mapping, co-ordinated by Local Autism Operational Groups	**2.4.1** Information about current service provision made available on NI Direct, with appropriate links.	HSCB Local Autism Operational Groups	Regional Autism Coordinator	September 2014
2c) Advocacy	**2.5** Ensure that a range of advocacy models are accessible and available to help maximise decision making and control for people with autism, their families and carers.	**2.5.1** Range of advocacy models made accessible and available to people with autism, their families and carers	All Departments	All Departments – joint responsibility	March 2015

5.0 The Autism Action Plan (2013 – 2016)

3 Children Young People and Family					
Strategic Priority - *Ensure that children and young people with autism and their families have access to effective and appropriate support, where required, to help them with the everyday challenges of family life.*					
Key Action	**Action Summary**	**Outcome Required / Performance Indicator**	**Responsibility**	**Lead Responsibility**	**Timescale**
3a) Family support and services	**3.1** Provide joined-up timely support services to meet the needs of children and young people with autism	**3.1.1** Joint working arrangements put in place between HSC Trust autism services and ELB autism intervention and advisory services from point of assessment through to end of post primary education.	HSCB HSC Trust Autism Teams in collaboration with ELBs	HSCB HSC Trust Autism Teams	September 2015
	3.2 Promote awareness on the availability of early intervention, signposting and other support service available throughout NI at local community level through the website www.familysupportni.gov.uk	**3.2.1** Support provision for families with children with autism made available via Family Support Hubs.	HSCB HSC Trust Autism Teams in collaboration with CYPSP, local councils and ELBs/ ESA	HSCB HSC Trust Autism Teams	March 2015
		3.2.2 Autism specific fields developed on the 'family support website' listing all autism services available in each HSC Trust area.			
		3.2.3 Search facility developed on the 'family support website ' to enable families / carers to identify and locate childcare providers with appropriate skills to care for children with autism.	DHSSPS Family Policy Unit / HSCB	HSCB	March 2014

5.0 The Autism Action Plan (2013 – 2016)

3 *Children Young People and Family*

Strategic Priority

- *Ensure that children and young people with autism and their families have access to effective and appropriate support, where required, to help them with the everyday challenges of family life.*

Key Action	**Action Summary**	**Outcome Required / Performance Indicator**	**Responsibility**	**Lead Responsibility**	**Timescale**
3a) Family support and services	**3.3** Provide joined-up timely support services to meet the needs of families living with autism	**3.3.1** Support provision for families and in particular siblings of children with autism scoped / scaled.	HSCB / PHA in collaboration with HSC Trust Autism Teams	HSCB / PHA	March 2015
	3.4 Ensure that carers caring for a person with autism are made aware of their rights under the Carers and Direct Payments Act (2002), and are benefitting from the application of associated departmental guidance and the Caring for Carers Strategy (2006).	**3.4.1** Increased number of carers of a person in receipt of HSC autism services advised of their right to a formal Carers Assessment as outlined in the *Six Steps of Autism Care* and the *Adult Autism Care Pathway*	HSC Trusts	HSCB	Currently and onward
	3.5 Provide support where required to families and carers of people with autism	**3.5.1** Opportunities provided, premised upon assessment of need to people with autism and their carers to avail of short breaks and appropriate family support services	HSC Trusts	HSCB	March 2015
		3.5.2 Disability awareness training including autism specific awareness courses made available to childcare providers			

4 Health and Wellbeing

Strategic Priority

- *Promote the physical, psychological, emotional and social health and wellbeing of people living with autism and their families and carers.*
- *Enhance the commissioning and provision of health and social care services of people living with autism throughout their lives*

Key Action	Action Summary	Outcome Required / Performance Indicator	Responsibility	Lead Responsibility	Timescale
4a) Enhancing health and wellbeing	**4.1** Promote an inclusive approach to Health and Wellbeing Programmes and adapt where necessary to meet the needs of people with autism	**4.1.1** Accessible health and wellbeing programmes made available to people with autism	HSCB / PHA/ HSC Trusts	HSCB / PHA	March 2015
4b) Early Intervention	**4.2** Ensure that the appropriate support and services are in place across government to evidence requirements for early recognition and early intervention for people with autism	**4.2.1** Improvements made in referral systems from identification to assessment / diagnosis of autism through to intervention including further embedding of Six Steps.	HSCB / PHA, DE	HSCB / PHA	March 2015
4c) Service improvements	**4.3** Promote effective working and sharing of information and best practice with other sectors and agencies	**4.3.1** Arrangements in place to support the delivery / implementation of the Adult Autism Care Pathway.	HSCB / HSC Trusts	HSCB	March 2014
		4.3.2 Progress achieved on the implementation of NICE clinical guidance (CG128, CG142 and CG170) in NI.	HSCB / HSC Trusts	HSCB	March 2015

5.0 The Autism Action Plan (2013 – 2016)

4 Health and Wellbeing					
Strategic Priority • *Promote the physical, psychological, emotional and social health and wellbeing of people living with autism and their families and carers.* • *Enhance the commissioning and provision of health and social care services of people living with autism throughout their lives*					
Key Action	**Action Summary**	**Outcome Required / Performance Indicator**	**Responsibility**	**Lead Responsibility**	**Timescale**
4c) Service improvements	**4.4** Undertake a regional validation review of the Six Steps of Autism Children's Care Pathway and the Adult Autism Care Pathway	**4.4.1** Regional validation exercise completed	HSCB	HSCB	March 2014

5.0 The Autism Action Plan (2013 – 2016)

5 Education					
Strategic Priority • *Ensure that children and young people with autism receive a high quality education that prepares them for life and work and enables them to fulfil their potential.*					
Key Action	**Action Summary**	**Outcome Required / Performance Indicator**	**Responsibility**	**Lead Responsibility**	**Timescale**
5a) Capacity Building for Schools and Youth Service	**5.1** Continue to build the capacity of schools and youth service to meet effectively the needs of children and young people with autism	**5.1.1** Effective autism support, training programmes and research and information for schools provided.	DE, ELBs/ESA, Middletown Centre for Autism (with support from HSCB / PHA, HSCTs)	ELBs/ESA	2013 – 2016
		5.1.2 Potential explored for youth workers to have access to elements of support services deemed necessary, which are currently available to schools, to support young people with autism	DE and ELBs Youth Service	ELBs Youth Service	2013 – 2016
5b) Supporting parents/carers	**5.2** Provide parents/carers of children and young people with autism with effective support and advice which will ensure that they are informed, involved and supported effectively by the school, the ELB/ESA and other agencies.	**5.2.1** Effective autism support training programmes, research and information for parents and carers provided.	DE, ELBs/ESA, Middletown Centre for Autism (with support from HSCB, HSCTs)	ELBs/ESA	2013 - 2016
		5.2.2 Revisions to Middletown Centre for Autism's parent/carer training model scoped and developed and implemented.		Middletown Centre for Autism	2013 – 2016

5.0 The Autism Action Plan (2013 – 2016)

5 Education					
Strategic Priority - *Ensure that children and young people with autism receive a high quality education that prepares them for life and work and enables them to fulfil their potential.*					
Key Action	**Action Summary**	**Outcome Required / Performance Indicator**	**Responsibility**	**Lead Responsibility**	**Timescale**
5c) Support and provision for children and young people	**5.3** Implement a common model of professional support and provision for children and young people with autism to meet their needs	**5.3.1** Regional implementation plan for a common model of support developed.	DE, ELBs/ESA, Middletown Centre for Autism	ELBs/ ESA	September 2014
		5.3.2 Preparation for implementation of common model of support undertaken	DE, ELBs/ESA, Middletown Centre for Autism	ELBs/ ESA	September 2015
		5.3.3 Common model of support fully implemented	DE, ELBs/ESA, Middletown Centre for Autism	ELBs/ ESA	September 2016
5d) Support and provision for children and young people	**5.4** Formalise protocols for collaboration between education and health autism services (including specialist services such as CAMHS).	**5.4.1** Protocols scoped and developed.	ELBs/ESA, Middletown Centre for Autism, HSCB and HSCTs	Joint Lead ELBs/ESA and HSCB	September 2014
	5.5 Expand educational-led trans-disciplinary assessments, support and intervention mainly for children and young people with autism presenting with more complex needs.	**5.5.1** Increased number of children and young people with autism presenting with complex needs receiving support	DE, ELBs/ESA, Middletown Centre for Autism	Middletown Centre for Autism	2013 - 2015

6 Transitions

Strategic Priority

- *Transform the process of transitions for people with autism, so that a co-ordinated approach is adopted in planning and providing for transitional needs, programs and supports for people with autism across their lifetime*

Key Action	**Action Summary**	**Outcome Required / Performance Indicator**	**Responsibility**	**Lead Responsibility**	**Timescale**
6a) Transition planning	**6.1** Ensure that transition plans take account of the needs of people with autism	**6.1.1** Integrated transition plans developed for children with autism.	CYPSP Regional Transitions sub group	CYPSP Regional Transitions sub group	September 2015
	6.2 Delivery of seamless care and support in transition stages: i. early years to childhood; ii. childhood to adolescence; and iii. adolescence to adulthood To include bespoke care planning for smooth transition and promote effective joined up working with all sectors	**6.2.1** Evidence produced of co-ordinating support services at relevant life stages of the individual, recognising the need for partnership working and resource constraints	HSC Trusts ELBs NIHE Other relevant stakeholders	HSC Board	September 2015

5.0 The Autism Action Plan (2013 – 2016)

7 Employability

Strategic Priorities

- *Increase the number of people with autism entering all levels of employment and safeguard the rights of those people with autism already in work.*
- *Increase the opportunities for people with autism to attain skills and qualifications through access to appropriate training and lifelong learning opportunities.*

Key Action	**Action Summary**	**Outcome Required / Performance Indicator**	**Responsibility**	**Lead Responsibility**	**Timescale**
7a) Employment and skills	**7.1** Support for people with autism to access or remain in further and higher education, employment and training.	**7.1.1** People with autism, and their guardians are aware / advised of available support to access and / or remain in: • Further Education; • Higher Education; • Employment; and • Training	DEL, CYPSP Regional Autism Co-ordinator HSC Trusts	DEL	2014 /15 onwards
		7.1.2 Higher education provision offers effective support to people with autism, through the implementation of the Access to Success Strategy.	DEL	DEL	2014 – 2020
		7.1.3 Employment prospects for people with autism improved through the development/ implementation of an Economic Inactivity Strategy.	DEL/DETI (support from other Departments to be confirmed)	DEL	2014/15 onwards
		7.1.4 More opportunities for and engagement in employment, education and training by young people with autism delivered through of the Pathways to Success Strategy.	DEL	DEL	2014/15 onwards

5.0 The Autism Action Plan (2013 – 2016)

7 Employability

Strategic Priorities

- *Increase the number of people with autism entering all levels of employment and safeguard the rights of those people with autism already in work.*
- *Increase the opportunities for people with autism to attain skills and qualifications through access to appropriate training and lifelong learning opportunities.*

Key Action	**Action Summary**	**Outcome Required / Performance Indicator**	**Responsibility**	**Lead Responsibility**	**Timescale**
7a) Employment and Skills	**7.1** Support for people with autism to access or remain in further and higher education, employment and training.	**7.1.5** Suitable Further Education provision delivered and individualised support for students with autism provided	DEL	DEL	2014/15 onwards
		7.1.6 Work completed with organisations to raise awareness with employers on the benefits of employing people with autism	DEL – working in conjunction with others such as the Equality Commission and Employers for Disability NI (EFDNI)	DEL	2014/15 onwards
		7.1.7 Programmes delivered that provide tailored personal support for people with autism. This may include awareness training and education to employers and fellow employees.	DEL – working with local disability organisations.	DEL	2014/15 onwards

5.0 The Autism Action Plan (2013 – 2016)

8 Independence, Choice and Control					
Strategic Priority - *Increase the level of choice, control and freedom that people with autism have in their daily lives.*					
Key Action	**Action Summary**	**Outcome Required / Performance Indicator**	**Responsibility**	**Lead Responsibility**	**Timescale**
8a) Independence for adults with autism	**8.1** Provide supported independent living options for people with autism	**8.1.1** Supported living options available for people with autism through DSD's Supporting People Programme	Supporting People Commissioning Body	DSD / NIHE	March 2016
	8.2 Provide life skills training for young people with autism whilst in post-primary education to help prepare for their transition to adulthood	**8.2.1** Life skills training provided to help support independent living options	DE, ELBs/ESA, Middletown Centre for Autism, HSCTs	ELBs/ESA	2013 – 2016
	8.3 Provide advice and support on the impact of Welfare Reform to people with disabilities including those with autism, their families and carers.	**8.3.1** Impact of Welfare Reform on people with disabilities including those with autism, their families and carers monitored as developments evolve.	SSA / DSD	SSA / DSD	2013 – 2016
	8.4 Increase the use of personalisation to support adults with autism	**8.4.1** Increased use of self directed support, direct payments and personalised budgets for individuals and families living with autism	HSCB, HSC Trusts	HSCB	March 2016

5.0 The Autism Action Plan (2013 – 2016)

8 Independence, Choice and Control					
Strategic Priority - *Increase the level of choice, control and freedom that people with autism have in their daily lives.*					
Key Action	**Action Summary**	**Outcome Required / Performance Indicator**	**Responsibility**	**Lead Responsibility**	**Timescale**
8b) Cross-departmental working	**8.5** Develop / create a multi-disciplinary, multi- agency autism service in collaboration with other agencies and organisations to provide information and access to joined-up services including health and social care, housing, education, employment and benefits for people with autism and their families and carers.	**8.5.1** Multi-Agency Autism Service pilot exercise commissioned and designed in the Northern HSC Trust.	Northern HSCT with input from other stakeholders to be agreed.	Northern HSC Trust	June 2014

9 Access to Justice

Strategic Priority

- *Ensure that people with autism are treated equally by the law, have access to justice and can live safely in their own community.*

Key Action	**Action Summary**	**Outcome Required / Performance Indicator**	**Responsibility**	**Lead Responsibility**	**Timescale**
9a) Protection, support and information within the justice system.	**9.1** Provide additional support for people with autism in the justice system.	**9.1.1** A guide for criminal justice professionals in Northern Ireland in place to assist all practitioners who may come into contact with someone with autism.	DOJ	DOJ	March 2014
		9.1.2 A training model (appropriate to roles and functions) developed for Criminal Justice	DOJ and criminal justice agencies	DOJ	March 2014
		9.1.3 Improved service for victims and witnesses encompassing the needs of persons with autism delivered through a new five-year strategy for victims and witnesses of crime including: • registered intermediaries (RI) schemes to assist those with significant communication difficulties to give evidence; and • advocacy services to help victims access services and information.	DOJ and criminal justice agencies	DOJ	Strategy to be delivered by March 2018. RI schemes piloted from May 2013. Advocacy services to be developed by March 2015.

9 Access to Justice					
Strategic Priority - *Ensure that people with autism are treated equally by the law, have access to justice and can live safely in their own community.*					
Key Action	**Action Summary**	**Outcome Required / Performance Indicator**	**Responsibility**	**Lead Responsibility**	**Timescale**
9a) Protection, support and information within the justice system.	**9.1** Provide additional support for people with autism in the justice system.	**9.1.4** "Achieving Best Evidence" (ABE) guidance for practitioners revised to include a specific section on interviewing witnesses with autism.	DOJ and criminal justice agencies	DOJ	March 2016
		9.1.5 Needs assessment tools / template and screening tool in place for those who come to the attention of the criminal justice system.	DOJ and criminal justice agencies	DOJ	March 2015
		9.1.6 A range of information available for young people and their families about the criminal justice process	DOJ and criminal justice agencies	DOJ	March 2015

5.0 The Autism Action Plan (2013 – 2016)

9 Access to Justice					
Strategic Priority - *Ensure that people with autism are treated equally by the law, have access to justice and can live safely in their own community.*					
Key Action	**Action Summary**	**Outcome Required / Performance Indicator**	**Responsibility**	**Lead Responsibility**	**Timescale**
9a) Protection, support and information within the justice system.	**9.1** Provide additional support for people with autism in the justice system.	**9.1.7** Autism awareness promoted in criminal justice organisations through individual internal and external publications and other communication tools (including staff intranets)	DOJ and criminal justice agencies	DOJ	Annual publications
		9.1.8 Autism Awareness cards produced for use by justice practitioners to ensure that behaviour associated with autism is identified early and that an individual's needs are addressed appropriately.	DOJ and criminal justice agencies	DOJ	Summer 2014

5.0 The Autism Action Plan (2013 – 2016)

10 Being Part of the Community					
Strategic Priority - *Improve access to sport, arts, leisure and other cultural activities so that people with autism can be part of the community.*					
Key Action	**Action Summary**	**Outcome Required / Performance Indicator**	**Responsibility**	**Lead Responsibility**	**Timescale**
10a) Inclusion	**10.1** Establish community social activity programmes for people with autism and their families	**10.1.1** Raised awareness among front line service providers in museums, libraries, arts and sports regarding the needs of people with autism and their families / carers	Culture Arts and Leisure Providers	DCAL	December 2015
		10.1.2 Greater participation levels from people with autism in culture arts and leisure activities	Culture Arts and Leisure Providers	DCAL	December 2015

5.0 The Autism Action Plan (2013 – 2016)

11 Participation and Active Citizenship

Strategic Priorities

- *Increase opportunities for people with autism to influence policies and programmes in Government including the delivery of this Strategy and the subsequent Action Plan.*
- *Improve interaction between all sectors to achieve the social inclusion of people with autism.*

Key Action	**Action Summary**	**Outcome Required / Performance Indicator**	**Responsibility**	**Lead Responsibility**	**Timescale**
11a) Participation and active citizenship	**11.1** Involve people with autism in the design, development and review of policy.	**11.1.1** People with autism, parents, carers represented on the Autism Strategy Project Board.	DHSSPS, HSCB,PHA in collaboration with HSC Trusts	DHSSPS	December 2011 - May 2013
		11.1.2 People with autism, parents, carers involved in the implementation of the Autism Strategy / Action Plan.	DHSSPS, HSCB,PHA in collaboration with HSC Trusts	DHSSPS	September 2013 - March 2016
		11.1.3 People with autism, parents, carers involved in the development of the DOJ Victims and Witnesses Strategy.	DOJ	DOJ	completed
		11.1.4 Organisations who represent people with autism will be directly involved as key stakeholders in the Strategic Review of DES and the disability employment services.	DEL	DEL	March 2014

5.0 The Autism Action Plan (2013 – 2016)

12 Leadership and Implementation					
Key Action	**Action Summary**	**Outcome Required / Performance Indicator**	**Responsibility**	**Lead Department**	**Timescale**
12a) Provide governance, leadership and direction	**12.1** To work in partnership with government departments / agencies, people with autism, their families and carers and the community voluntary sector to implement the Strategy and Action Plan	**12.1.1** Successful launch event delivered; attended by people with autism, their families and carers and other representatives from both the public and voluntary sectors.	DHSSPS to lead with input from all Departments	DHSSPS	January 2014
		12.1.2 Cross departmental implementation structures developed at regional and local levels and arrangements in place to monitor progress on implementation.	DHSSPS to lead with input from all Departments	DHSSPS	February 2014
	12.2 Provide regular progress reports on implementation to the Inter-Departmental Senior Officials Group (IDSOG).	**12.2.1** Annual Report to IDSOG	DHSSPS to lead with input from all Departments	DHSSPS	Annually
	12.3 Provide progress reports on implementation to the NI Assembly every three years.	**12.3.1** Early Report to NI Assembly	DHSSPS to lead with input from all Departments	DHSSPS	September 2016

12 Leadership and Implementation					
Key Action	**Action Summary**	**Outcome Required / Performance Indicator**	**Responsibility**	**Lead Department**	**Timescale**
12b) Provide statistical data for autism	**12.4** Ensure that appropriate protocols and mechanisms are in place to capture relevant and robust statistical information in respect of people with autism to help inform future strategic direction, service commissioning, provision and delivery.	**12.4.1** Structures established and protocols in place for the collection, recording and reporting of the incidence of autism by HSC Trusts, including where possible co-occurring conditions	HSC Board HSC Trusts	DHSSPS	Ongoing
		12.4.2 Protocols established for sharing statistical information / data across government departments to aid joint planning and delivery of services where appropriate.	HSC Board HSC Trusts	DHSSPS	September 2014
		12.4.3 Improved arrangements developed for the collection and sharing of information on numbers of individuals with autism involved with the criminal justice process.	DOJ and criminal justice agencies	DOJ	March 2015
12c) Equality	**12.5** Keep under review the requirement to re-screen the policy proposals with a view to whether a full impact assessment may be required.	**12.5.1** Screenings and impact assessments conducted and consulted on as appropriate throughout the implementation and life of the Strategy.	All Departments	All Departments	As required

List of Abbreviations

AAIS	Autism Advisory and Intervention Service
ABE	Achieving Best Evidence
AD	Assistant Director
AHP	Allied Health Professional
ALB	Arms Length Body
ASD	Autistic Spectrum Disorder
BHSCT	Belfast Health and Social Care Trust
CAMHS	Child and Adolescent Mental Health Services
CNAP	Celtic Nations Autism Partnership
CYPSP	Children and Young People's Strategic Partnership
DARD	Department of Agriculture and Rural Development
DCAL	Department of Culture Arts and Leisure
DDA	Disability Discrimination Act
DE	Department of Education
DEL	Department for Employment and Learning
DES	Disability Employment Service
DETI	Department of Enterprise, Trade and Investment
DFP	Department of Finance and Personnel
DHSSPS	Department of Health, Social Services and Public Safety
DOE	Department of the Environment
DOJ	Department of Justice
DRD	Department for Regional Development
DSD	Department for Social Development
EFDNI	Employers for Disability N. Ireland
ELB	Education and Library Board
EQIA	Equality Impact Assessment
GB	Great Britain
GP	General Practitioner
FE	Further Education
HE	Higher Education
HOS	Head of Service
HSC	Health and Social Care

List of Abbreviations

HSCB	Health and Social Care Board
HSCT	Health and Social Care Trust
IAD	Information and Analysis Directorate
ICP	Integrated Care Partnerships
ICT	Information and Communication Technology
IMTAC	Inclusive Mobility Transport Advisory Committee
JHASG	Joint Housing Adaptations Steering Group
LASP	Local Adult Safeguarding Partnership
LD	Learning Disability
NEETs	(Young People) Not in Education, Employment or Training
NHSCT	Northern Health and Social Care Trust
NI	Northern Ireland
NIASP	Northern Ireland Adult Safeguarding Partnership
NICE	National Institute for Clinical Excellence
NICEM	Northern Ireland Council for Ethnic Minorities
NICTS	Northern Ireland Courts and Tribunals Service
NICVA	Northern Ireland Council for Voluntary Action
NIHE	Northern Ireland Housing Executive
NIPS	Northern Ireland Prison Service
NISRA	Northern Ireland Statistics and Research Agency
OFMDFM	Office of the First Minister and Deputy First Minister
PBNI	Probation Board for Northern Ireland
PCC	Patient Client Council
PHA	Public Health Agency
RASDN	Regional Autistic Spectrum Disorder Network
POC	Programme of Care
RoI	Republic of Ireland
RQIA	Regulation and Quality Improvement Authority
SBNI	Safeguarding Board Northern Ireland
SEHSCT	South Eastern Health and Social Care Trust
SHSCT	Southern Health and Social Care Trust
SEN	Special Educational Needs
SENDO	Special Educational Needs Disability Order

List of Abbreviations

SLT	Speech and Language Therapy
SSA	Social Security Agency
TfS	Training for Success
TYC	Transforming Your Care
UK	United Kingdom
UN	United Nations
UNCRC	United Nations Convention on the Rights of the Child
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHSCT	Western Health and Social Care Trust
YJA	Youth Justice Agency

Autism Strategy Project Board

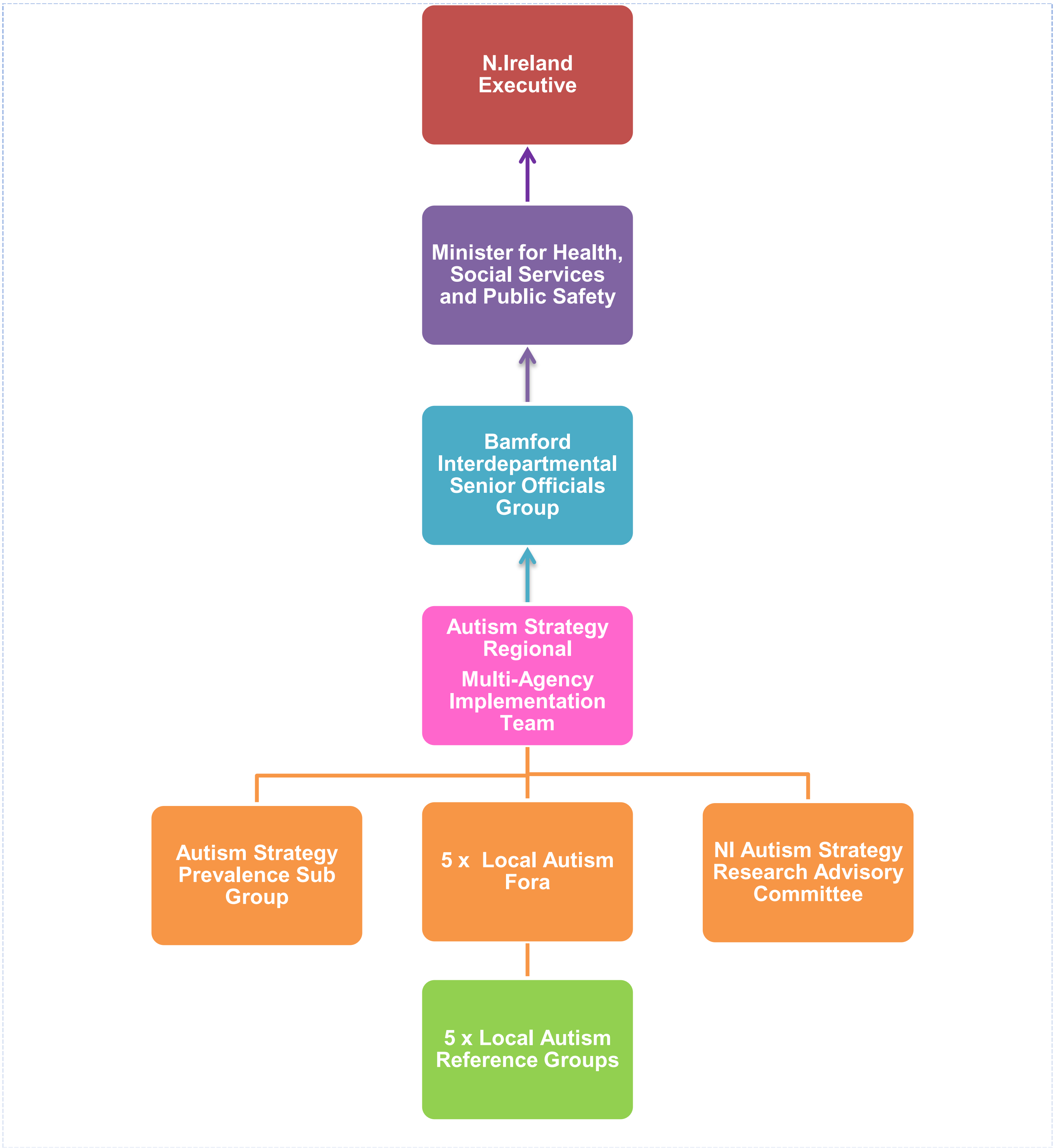
The members of the Project Board are:

Member / Representative	Area	Organisation
Dr Maura Briscoe (Chair)	Director of Mental Health and Disability Policy	DHSSPS (From January 2013)
Christine Jendoubi (Chair)	Director of Mental Health and Disability Policy	DHSSPS
Alan Hanna	Director	Autism Initiatives NI
Derek Doherty	Assistant Director	Autism Network NI
Dr Arlene Cassidy	Chief Executive	Autism NI
Shirelle Stewart	Co-Director	National Autistic Society NI (NASNI)
Monica Wilson	Chief Executive	Disability Action
Michelle Bell	Equality and Better Regulation Branch	DARD
Sharon Fitchie	Equality and Better Regulation Branch	DARD
Colin Watson	Sports Museums and Recreation Division	DCAL
Frances Curran	Special Education Policy Advisory Team	DE
John Leonard	Special Education Policy Advisory Team	DE
Stephen Jackson	Strategy, Equality and European Policy	DEL
Stephen Wilson	Corporate Services, Information Management & Equality &Diversity	DETI
Sharon Smyth	Corporate Services, Information Management & Equality &Diversity	DETI
Carolyn Barr	Equality and Departmental Corporate Services Group	DFP
Jeff Johnston	Private Office and Equality Team	DOE
Brendan Giffen	Central Management	DOJ
Peter Grant	Central Management	DOJ
Jane Holmes	Central Management	DOJ
Mark Higgins	Central Management	DOJ

Autism Strategy Project Board

Alan Heron	Regional Planning and Transport Division	DRD
Alan Preston	Regional Planning and Transport Division	DRD
Keith Walsh	Regional Planning and Transport Division	DRD
Imelda McConnell	Communication, Policy and Strategic Support	DSD
Margaret Sisk	Corporate Services Unit	DSD
Joe Reynolds	Poverty, Social Inclusion and Disability	OFMDFM
Janet Smyth	Equality and Strategy Directorate	OFMDFM
Dr Stephen Bergin	Consultant in Public Health Medicine / RASDN Chair	Public Health Agency (PHA)
Eithne Darragh	Social Care Commissioning Lead	Health & Social Care Board (HSCB)
Bronagh Macauley	Regional ASD Co-ordinator / Service Improvement Project Manager	HSCB
Rodney Morton	Service Improvement Lead MH & CAMHS / Regional ASD Coordinator	HSCB
Karen Buchanan	Service User Representative	RASDN
Maureen Gilroy	Service User Representative	User / Carer
Sharon Fennel	Service User Representative	User / Carer
Eleanor McCann	Service User Representative	User / Carer
Leonard Mullin	Service User Representative	User / Carer
Patricia Beaddie	Service User Representative	User / Carer
Dr Ian McMaster	Medical Allied Health Professional	DHSSPS
Peter Deazley	Autism Strategy Core Team	DHSSPS
Neil Magowan	Autism Strategy Core Team	DHSSPS
Bernie Redmond	Autism Strategy Core Team	DHSSPS
Naomhín McGarrity	Autism Strategy Core Team	DHSSPS

Autism Strategy Implementation Structure



N.Ireland Executive

Minister for Health, Social Services and Public Safety

Bamford Interdepartmental Senior Officials Group

Autism Strategy Regional Multi-Agency Implementation Team

Autism Strategy Prevalence Sub Group

5 x Local Autism Fora

NI Autism Strategy Research Advisory Committee

5 x Local Autism Reference Groups

Equality Screening Template

(1). Information about the policy / decision

1.1 Title of the policy / decision

Strategy and Action Plan to help achieve improved services and support for people with autism, their families and carers throughout their lives.

1.2 Description of policy / decision

What is it trying to achieve:

This Strategy aims to ensure that the services commissioned and provided by NI government departments for people with autism will have developed in such a way that they:

- Promote awareness and better understanding of the challenges faced by people with autism;
- Support people with autism, their families and carers to become well informed about accessing the services they need;
- Encourage social inclusion of people with autism and work to address discrimination/stigmatisation; and
- Are tailored to meet the changing needs of people with autism over the course of their lifetime.

How will this be achieved?

We will achieve this by:

- Increasing awareness and understanding of autism across all sectors;
- Supporting people with autism to better exercise their rights, choices and life opportunities;
- Supporting the continuing development of an inclusive and effective range of high quality services for people with autism, their families and carers;
- Developing a more integrated approach to the planning, commissioning and management of services within and across government departments and the independent, community and voluntary sector.

What are the key constraints (e.g. financial, legislative)

The key constraints are financial although there is also a shortfall/ lack of data and information in respect of the prevalence of autism in NI.

- We are as yet unable to identify additional funding for the Strategy / Action Plan
- There is a lack of resources to build and sustain multi-agency / multi disciplinary team approaches to providing services
- There is a lack of qualitative and quantitative prevalence data / information in respect of the prevalence of autism in NI
- We recognise also that there is a broad range in the type and severity of needs in terms of people on the autism spectrum and that additionally there is a lack of information regarding the prevalence of people with autism with co-existing condition and / or complex needs.

1.3 Main stakeholders affected

Primarily people with autism, their families and carers but also all professionals working with children, young people and adults responsible for implementing this Strategy / Action Plan across a number of NI Government bodies – health and social care, education, employment and learning, justice and social development.

1.4 Other policies / decisions with a bearing on this policy

- A Healthier Future 2005-2025 – DHSSPS;
- Bamford Review of Mental Health and Learning Disability – DHSSPS,
- Six Steps of Autism Care / A Guide for Families – HSCB / PHA
- Learning Disability Service Framework - DHSSPS
- DHSSPS Speech and Language Action Plan 2012 –
- Adult Autism Care Pathway / Guide / Toolkit (In development) – HSCB / PHA

(2) Screening the policy decision

2.1 In terms of the groupings under Section 75 what is the makeup of those affected by the policy / decision?

Group	*Please provide details*
	There is currently no precise data on the prevalence of autism in NI, but this Strategy has adopted the UK prevalence rate of around 1 in 100 as the best estimate of prevalence in children. No prevalence studies have ever been carried out on adults in the UK or in NI. The estimated numbers have been worked out from the population of NI as given in the 2011 census: 1,810,900, of whom 430,080 are under 18. The figure for children and young people is based on prevalence ratios of somewhere between, 1 in 88, to 1 in 100. The number of children and young people under 18 with autism in NI is therefore provisionally estimated to be between 4,000 - 5,000. Given that there is no prevalence rate for adults with autism, the figure for the whole population is a very rough guide, but we estimate that there could be between 10,000 - 15,000 adults who have autism in NI.
Gender	UK national data suggests that girls with autism are a potentially missed cohort in terms of acknowledging and getting a diagnosis / assessment of autism. Evidence suggests that a significant number of girls never come to the attention of services because they are better able than boys to deploy strategies or develop learned behaviours to overcome difficulties with communication and social interaction.
Religion	No data available which suggests any obvious difference between groups of different religion.
Political Opinion	No data available which suggests any obvious difference between groups of different political opinion.

Marital Status	No data available which suggests any obvious difference between groups of different marital status.
Dependant Status	Although there is no data in terms of the Dependant status of people with autism, the Strategy / Action Plan may have a bigger impact on families / parents who have one or more children with autism.
Disability	In terms of the prevalence of disability as a whole in NI, NISRA statistics (2007) show that the prevalence of disability amongst adults varies significantly with age, ranging from a low of 5% amongst young adults aged 16-25 to 60% amongst those aged 75 and above. Although there is a general recognition that disability increases with age, autism is a lifelong condition and is a broad spectrum condition for which people will need varying levels of services and support for throughout their lives. This assessment acknowledges that there is no hierarchy of disabilities and that people with autism have the same rights as others with regard to access to services, social inclusion and equality of opportunity. This strategy therefore seeks to promote equality of opportunity for all people with disabilities, including those with autism recognising that some services may continue to be provided via mainstream services or on a pan-disability basis to people with autism. There are no current valid estimates of the proportion of people with autism who have a co-existing condition / disability – for example a learning disability. It is, in fact, reported that it is likely that over 50% of people with autism have an IQ in the average to high range and may never come to the attention of services due to the fact that they are able intellectually. Despite the fact that we know that autism is not a mental health condition, a 2011 UK study showed that as many as 70% of children with autism have mental health problems such as anxiety, depression, and obsessive compulsive disorders (OCD) and 40% have two or more. Very often this can mean that children and young people only engage with services when their health has deteriorated, to a point of requiring acute interventions. Currently in NI it is felt that there is a significant competency gap amongst staff in CAMHS and adult mental health services in relation to providing appropriate and effective psychiatric support to people with autism.
Ethnicity	No data available which suggests any obvious difference between groups of different ethnicity.
Sexual Orientation	No data available which suggests any obvious difference between groups of different sexual orientation but people from the lesbian, gay bi-sexual or trans-sexual community, who have autism, may experience confusion about their sexual identity.

2.2 Is there any indication or evidence of higher or lower participation or uptake by different groups?

Group	***Yes/No/ Don't Know***	*Please provide details*
Age	Yes	There is evidence to suggest that disability, in general, increases with age. As previously indicated autism is a lifelong condition but there is also evidence to suggest that without access to appropriate timely services and support throughout their lives some people with autism can go on to develop mental health problems.
Gender	Yes	As above there is a suggestion that a significant number of girls with autism do not pursue a diagnosis or assessment of their condition. It is believed that girls are better able to develop coping strategies to overcome challenges with communication and or social interaction. Discussions are ongoing regarding the range of data that the HSC Trusts will record and relate in terms of the prevalence of autism i.e. age, gender and or –co existing condition.
Religion	No	
Political Opinion	No	
Marital Status	No	Disabled people including people with autism who live alone are more likely to suffer social exclusion.
Dependant Status	Yes	Parents of children with autism very often feel excluded from community and other services particularly in circumstance where their child / children present with complex sensory difficulties or other challenging behaviours.
Disability	Yes	People with autism are an extremely diverse group, who face a variety of challenges in terms of accessing services including: • Difficulties relating to other people, and to the 'social world' in general; • High levels of social exclusion – due to low rates of employment and the fact that many live with parents well into adulthood; • Higher probability / incidence rates of developing psychiatric / mental health conditions; • Often feel that they are not adequately supported in accessing mainstream services.
Ethnicity	No	

Sexual Orientation	No	

2.3 Is there any indication or evidence that different groups have different needs, experiences, issues and priorities in relation to the policy / decision?

Group	***Yes/No/ Don't Know***	*Please provide details*
Age	Yes	The challenges faced by people with autism change and can increase as they get older – particularly at key transition stages of their lives – for example from child to adult services and from adult to older people's services. Also, many disabilities increase (deteriorate) with age and some people with autism can go on to develop mental health problems.
Gender	No	
Religion	No	
Political Opinion	No	
Marital Status	No	People with autism face greater difficulties in forming relationships and those who live alone experience more social isolation / become more socially isolated over time.
Dependant Status	Yes	Parents / families with one or more children with autism may have other children / Dependants. This can cause additional stresses and challenges for families and make it more difficult for parents to devote time to all their children because of the more intensive demands of caring for their child/children with autism. Part of the pre-consultation feedback for this Strategy / Action Plan shows that siblings of children and young people with autism also experience stress because of this and also feel that their parents have limited / minimal time to devote to them because of their caring responsibilities for the sibling with autism.
Disability	Yes	As stated above people with autism are a diverse group, who face a variety of challenges in terms of accessing services.

Ethnicity	No	
Sexual Orientation	No	

2.4 Is it likely that the policy / decision will meet those needs?

Group	***Yes/No/ Don't Know***	*Please briefly give details*
Age	Yes	The Strategy and Action Plan promote equality of access to services for people with autism, regardless of age. They also include recommendations and actions around "transitions" to make these changes as seamless as possible for people with autism.
Gender	Yes	The aim of the strategy is to improve outcomes and support for those people with autism their families and carers throughout their lives and includes an action plan with time-bounded actions for achieving these improvements
Marital Status	Yes	The strategy aims to improve access to services for all people with autism.
Dependant Status	Yes	The aim of the strategy is to improve outcomes and support for those people with autism their families and carers throughout their lives and includes an action plan with time-bounded actions for achieving these improvements
Disability	Yes	The aim of the strategy is to improve outcomes and support for those people with autism their families and carers throughout their lives and includes an action plan with time-bounded actions for achieving these improvements
Sexual Orientation	Don't Know	The strategy does not specifically address the needs of either the heterosexual, lesbian, gay, bi-sexual or trans-sexual communities in terms of people with autism. It does however promote equality of access to services for all people with autism and in line with this seeks to support good physical, mental and sexual health for people with autism
Ethnicity	Don't Know	The strategy does not address the needs of any specific racial group / ethnicity of people with autism. There is no available data to provide a breakdown of white, black and minority ethnic groups of people with autism in NI.

Overall Summary		Overall the Strategy / Action Plan should lead to improved quality, consistency and responsiveness of services to meet the needs of people with autism.

2.5 Is there an opportunity to better promote equality of opportunity or good relations by altering the policy / decision or working with others in government or in the larger community?

Group	*Suggestions*
All	No

2.6 What changes to the policy / decision – if any – or what additional measures are suggested to ensure that it promotes good / relations?

Group	*Suggestions*
Religion	None
Political Opinion	None
Ethnicity	None

2.7 Have previous consultations with relevant groups, organisations or individuals indicated that particular policies create problems that are specific to them? *Also please detail information used to answer any of the questions above (e.g. statistics; research reports; views of colleagues; service users or other stakeholders*)

A comprehensive pre-consultation exercise was undertaken with a range of people with autism and their families and carers, including children and young people, on the content of this Strategy. Among the wide ranges of points highlighted were:

From a health and social care perspective:

- People with autism experience difficulty in accessing services such as occupational therapy services Child and Adolescent Mental Health Services (CAMHS) and adult autism services;
- There is a lack of joined up services and appropriate short breaks for children, young people and families; and
- Improved planning is required at key transitions stages for people with autism.

From an education perspective:

- Autism awareness training is required for staff in schools including teachers, classroom assistants and playground staff;
- Early access to statutory ‘statementing’ and assessment process for children and young people with autism; and

- Multi-disciplinary services such as occupational and speech and language therapists and CAMHS should be available in schools/colleges.

From an employment and learning perspective:

- Access to employment support specific to people with autism;
- Autism awareness raising among employers and further and higher education providers; and
- More opportunities for work placements and training for people with autism.

From a social housing perspective

- Better understanding of the housing needs of people with autism; and
- Improved access to housing adaptations for people with autism.

From a social security benefits perspective

- People with autism feel that they do not understand or find it easy to access their entitlement to social security benefits – form filling etc; and
- Concerns about the impact the current Welfare Reform Bill might have on their entitlement to Disability Living Allowance (DLA).

From a justice perspective

- The need for advocacy services for witnesses and victims of crime
- The need for frontline staff in justice organisations to be autism aware; and
- Bespoke autism training for frontline staff in justice organisations.

2.8 Please detail what data you will collect in the future in order to monitor the effect of the policy / decision on any of the groups under Section 75?

The Action Plan includes an action relating to the research and data required to assist with the planning and commissioning of services in the future for people with autism. HSC Trusts will collect and record data on the prevalence of autism in NI including details of age, gender and co occurring conditions for people with autism. HSC Trusts will also record details on the number of referrals and the number of actual diagnosis.

All relevant NI Government Departments will implement and report progress on the part of the Action Plan relevant to them and each Department will also take action to mitigate any evolving equality issues which emerge over time as data is collated.

(3) Should the policy/decision be subject to equality impact assessment?

Equality impact assessment procedures are confined to those policies/decisions considered likely to have significant/major implications for equality of opportunity.

If your screening has indicated that a policy/decision is likely to have an adverse differential impact, how would you categorise it? Please tick.

Significant/major impact	
Low impact	✓

Do you consider that this policy/decision needs to be subjected to a full equality impact assessment?

Yes	
No	✓

Please give reasons for your decision.

Currently there is insufficient data and or information available in relation to the prevalence of autism for people in NI to properly indicate any differential impact in terms of the policies and actions proposed in this Strategy / Action Plan.
The delivery of the policies and programmes and any equality implications arising from specific Departmental actions will be the responsibility of the relevant Department/s.

(4) Disability Discrimination

4.1 Does the policy/decision in any way discourage disabled people from participating in public life or does it fail to promote positive attitudes towards disabled people?

No. The strategy aims to improve outcomes for people with autism, their families and carers throughout their lives including improved social inclusion and participation in society.

4.2 Is there an opportunity to better promote positive attitudes towards disabled people or encourage their participation in public life by making changes to the policy/decision or introducing additional measures?

The launch of the strategy itself will raise the profile of autism. Also specific actions are included about developing an autism awareness campaign which will raise the profile of autism and help promote positive attitudes toward people with autism within the general public.

4.3 Please detail what data you will collect in the future in order to monitor the effect of the policy/decision with reference to the disability duties?

The Action Plan includes an action relating to the research and data required to assist with the planning and commissioning of services in the future for people with autism.

HSC Trusts will collect and record data on the prevalence of autism in NI including details of age, gender and co occurring conditions for people with autism HSC Trusts will also record details on the number of referrals and the number of actual diagnosis

All relevant NI Government Departments will implement and report progress on the part of the Action Plan relevant to them and each Department will also take action to mitigate any evolving equality issues which emerge over time as data is collated.

Following the publication of the Strategy / Action Plan a system for review and evaluation of the implementation will be put in place. The implementation of the Strategy and Action Plan will be the responsibility of all relevant NI Government Departments.

In line with the requirements of the Autism Act (NI) 2011 monitoring reports will be provided to the NI Executive to ensure that the Strategy's recommendations and Action Plan is implemented. This process will measure progress in terms of planned service developments and evaluate the extent to which services are leading to better outcomes for people with autism.

(5) Consideration of Human Rights

5.1 Does the policy/decision affect anyone's Human Rights?

Article	Positive Impact	Negative Impact	Neutral Impact
	(Human right interfered with or restricted)		
Article 2 – Right to life			✓
Article 3 – Right to freedom from torture, inhuman or degrading treatment or punishment	✓		
Article 4 – Right to freedom from slavery, servitude and forced or compulsory labour			✓
Article 5 – Right to liberty and security of person			✓
Article 6 – Right to a fair and public trial within a reasonable time	✓		
Article 7 – Right to freedom from retrospective criminal law and no punishment without law.	✓		
Article 8 – Right to respect for private and family life, home and correspondence.	✓		
Article 9 – Right to freedom of thought, conscience and religion			✓
Article 10 – Right to freedom of expression			✓
Article 11 – Right to freedom of assembly and association			✓
Article 12 – Right to marry and found a family			✓
Article 14 – Prohibition of discrimination in the enjoyment of the convention rights			✓
1st protocol Article 1 – Right to a peaceful enjoyment of possessions and protection of property			✓
1st protocol Article 2 – Right of access to education	✓		

5.2 If you have identified a likely negative impact who is affected and how?

None. The strategy and action plan aim to improve outcomes and support for all people with autism in NI

5.3 Outline any actions which could be taken to promote or raise awareness of human rights or to ensure compliance with the legislation in relation to the policy/decision.

None. The strategy and action plan aim to improve outcomes and support for all people with autism in NI.

Introduction

Purpose of the Report

The need to develop and improve health and social care services for people of all ages who are affected by Autistic Spectrum Disorder (ASD) including Aspergers Syndrome has been apparent for some time. In order to provide effective services knowing the incidence (new cases) and prevalence (new and existing cases at a point in time over a defined period) of ASD including Aspergers is clearly important. Throughout this report, for ease of reading, the abbreviation ASD is used to signify Autistic Spectrum Disorder (ASD) including Aspergers Syndrome.

This report aims to show prevalence rates of ASD amongst compulsory school age children (attending grant-aided schools) (4 – 15 years old at the start of the school year), as it is clear that ASD persists and that children with ASD become adults with ASD, with their own individual needs.

What is ASD?

ASD is a developmental disability that influences a person’s ability to communicate and relate to other people, as well as affecting how they make sense of the world around them. It is a spectrum condition, meaning that while all people with autism will have some similar problems, overall their condition will impact them in different ways. Some people may be able to lead fairly independent lives while others will require a lifetime of specialist support.

Children who have been diagnosed with Aspergers Syndrome have been included in this study. Aspergers Syndrome shares some similarities with Autism; however people with Aspergers Syndrome do not generally experience the same language and learning disabilities associated with autism. They are more likely to have difficulties in the areas of social imagination, social communication and social interaction.

Recent Developments

The recent introduction of the Autism Act (Northern Ireland) 2011 and the accompanying increase in awareness through promotional events, many of which have been championed by the voluntary sector, may well contribute to a rise in the number of assessments and positive diagnoses processing through the system. However it is too early to tell how much of an impact these developments will have on any underlying prevalence estimates.

Current Prevalence Estimates

It is estimated that there over half a million people in the United Kingdom with ASD. This is approximately 1% of the population; if you include their families, autism affects the lives of over two million people[4]. Autism is more prevalent in men than women with findings from a 2007 survey titled ‘The Adult Psychiatric Morbidity Survey’ indicating that 1.8% of men were affected by ASD compared to 0.2% of women[5].

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[4] http://www.autism.org.uk/about-autism/some-facts-and-statistics.aspx

[5] http://www.hscic.gov.uk/catalogue/PUB01131/aut-sp-dis-adu-liv-ho-a-p-m-sur-eng-2007-rep.pdf

Previous estimates suggest that in Northern Ireland around three hundred children will be diagnosed with ASD each year, with a current approximation that 20,000 – 30,000 people living in Northern Ireland have ASD[6].

Methodology

Northern Ireland School Census

The Northern Ireland School Census collects a large amount of information including demographic information (such as gender), free school meal entitlement, Looked After Children numbers, Newcomer Children numbers and assessment data. This includes disability and a breakdown of those children affected by ASD/Aspergers. The Department of Education provided figures from their annual Northern Ireland School Census from 2008/09 through to 2012/13. These figures showed the number of children diagnosed with Autism, including Asperger's, across Health and Social Care Trusts, between Urban and Rural areas within Trusts and across Multiple Deprivation Measure areas as well as supplementary information on sex and school year of the pupils.

All pupils on the rolls of grant-aided primary, post-primary and special schools were included in this return comprising each child who was a registered pupil in a school in October of each given year and who attended for at least one day.

The available data was analysed in a number of ways.

1. Health and Social Care Trust and Urban/Rural area. The classification of urban and rural areas is set out in the Report of the Inter-Departmental Group on Statistical Classification and Delineation of Settlements[7].
2. Multiple Deprivation Measure (MDM), with Decile One relating to the 10% most deprived areas within Northern Ireland and Decile Ten relating to the 10% least deprived areas[8].
3. By sex of pupil. Information for 2008/09 and 2012/13 was available whereby the number of ASD/Aspergers diagnosed children could be identified by gender.
4. By school year. Information for 2008/09 and 2012/13 was available whereby the number of ASD/Aspergers diagnosed children in each school year could be identified.

Statistical Significance

The chi-square test can be used to establish whether or not two variables have any statistical relationship. A resultant value of 0.05 or smaller indicates that the result of the chi-square test is significant and that there is a relationship between the variables in the process.

Prevalence

In order to establish the prevalence of autism within the compulsory school age population, the number of children who were attending school and had been diagnosed with ASD was divided by the total number of compulsory school age

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[6] http://www.autismni.org/statistics.html

[7] NISRA, 2005

[8] NIMDM 2010, NISRA

children attending school. This gave the proportion of children within the cohort who were diagnosed by ASD.

Limitations

There were a number of limitations to the data in this study and its use of establishing prevalence figures for ASD.

1. Data is sourced from the school census rather than a diagnostic source. While this is presently the most comprehensive data source available it only covers children of compulsory school age and those attending school. Figures for 2011/12 suggest that there were approximately 170 home taught children with no further details available.
2. The data only captures those children who have been assessed as having ASD. At any time, additional children may not have gone through the full assessment process and it is possible that a number of children may be diagnosed with ASD at a later date.
3. There may be some sub regional data capture issues within the school census. For example it was not possible to place some children in either an urban or rural location or within a MDM Decile. However this is minimal, accounting for around 1% of the ASD population, and is unlikely to have had a large effect on results.
4. Low numbers in the Belfast Trust rural area in 2008/09 meant figures for children with autism were suppressed.

It should be noted that there are many factors which can lead to variances in the apparent prevalence rates within the different breakdowns commented on in this report, not least the assumption that there is consistency of approach in the care pathways as managed by the different Trusts. In this regard, care should be taken when considering the findings, i.e. it is likely that at least some of the observed variation in prevalence may be attributable to differences in organisational structure and arrangements in place between/within Trust areas.

Findings

School Census Figures

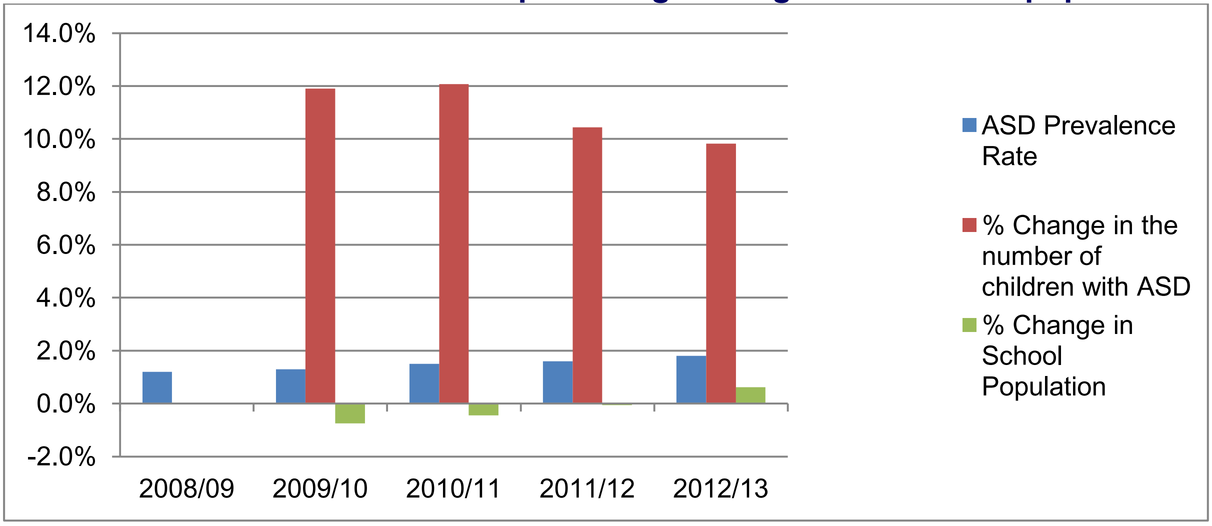
Table 1 below shows the number of children with a diagnosis of Autistic Spectrum Disorder and who were of compulsory school age and attending school in each of the last five years, the total number of children of compulsory school age attending school and the ASD prevalence rate. It can be seen that from the table that between 2008/09 and 2012/13 the prevalence rate rose by 50%.

Table 1: The Number of Children with ASD, the Compulsory School Age Population and the ASD Prevalence Rate

	2008/09	2009/10	2010/11	2011/12	2012/13
Children with ASD	3,278	3,668	4,111	4,540	4,986
Compulsory School Age Population	280,127	278,020	276,776	276,606	278,333
Prevalence	1.2%	1.3%	1.5%	1.6%	1.8%

This prevalence rate increase can be linked to two factors illustrated in Figure 1. There has been an annual average increase of 11% in the number of children diagnosed with ASD, while at the same time the general school population has remained relatively static and did in fact fall by just under 1% between 2008/09 and 2012/13.

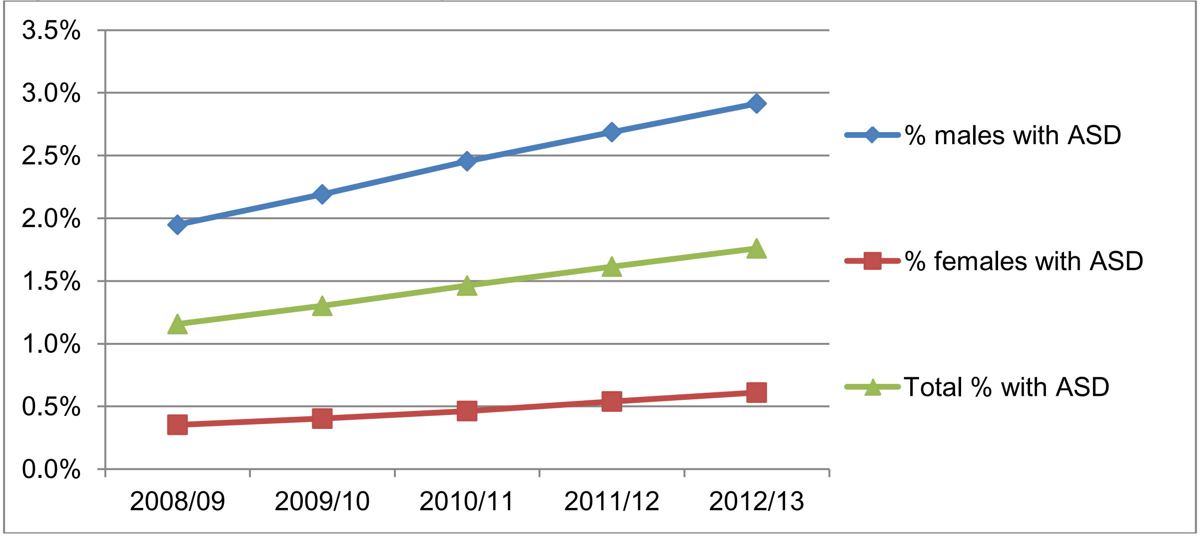
Figure 1: The ASD prevalence rate, annual percentage change in the number of children with ASD and the annual percentage change in the school population



Gender Prevalence

ASD is found to be more prevalent amongst males than females in the general population with a 2007 study[9] estimating that 1.8% of males were affected by ASD compared to 0.2% of the female population. The School Census data provided by the Department of Education gives a gender split for the years 2008/09 – 2012/13. Figure 2, below, shows a steady parallel rise in the prevalence rate of ASD in both the male and female compulsory school age populations.

Figure 2: Prevalence Rates by Gender 2008/09 – 2012/13



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[9] http://www.hscic.gov.uk/catalogue/PUB01131/aut-sp-dis-adu-liv-ho-a-p-m-sur-eng-2007-rep.pdf

Similar to the 2007 study, ASD was more prevalent in males than females. The 2012/13 figures show that Autism was almost five times more prevalent in the male population (2.9%) than the female population (0.6%). The female population with ASD did however increase on average by 14% each year from 2008/09 to 2012/13; in comparison the male population with ASD saw an average increase of 10% over the same period.

Statistical Significance

The following hypotheses were devised to establish any statistical significance in a relationship between the diagnosis of ASD and gender.

Null: The proportion of children diagnosed with ASD is independent of gender
Alternative: The proportion of children diagnosed with ASD is associated with gender
For each year of this study we can say that there is a significant relationship between the proportion of children diagnosed with ASD and gender, as the chi-square scores were significant at the 0.001 level.

Table 2: Chi Square Scores for Multiple Deprivation Measures Decile Statistical Significance Test

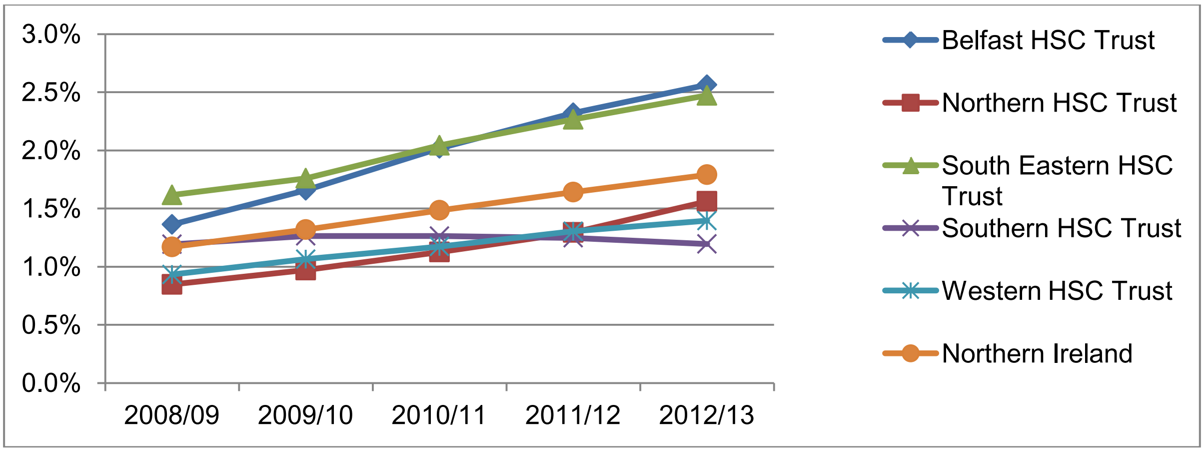
	2009/09	2009/10	2010/11	2011/12	2012/13
Chi Square Score	1503.39***	1661.07***	1820.07***	1911.46***	2025.78***

Note: Significance figures less than 0.05 are statistically relevant. ***, **, * denotes significance at the 0.001, 0.01 and 0.05 levels

Urban/Rural Location Prevalence

The overall prevalence rate for ASD in children of compulsory school age in Northern Ireland rose steadily between 2008/09 and 2012/13 by 0.6 percentage points overall. Figure 3 illustrates that the majority of HSC Trusts saw a rise in the prevalence of school children diagnosed with Autism, except for the Southern HSC Trust which maintained a steady level of around 1.2%. The largest change occurred in the Belfast Trust which saw a 1.2 percentage point increase in those diagnosed with ASD, from 1.4% in 2008/09 to 2.6% in 2012/13.

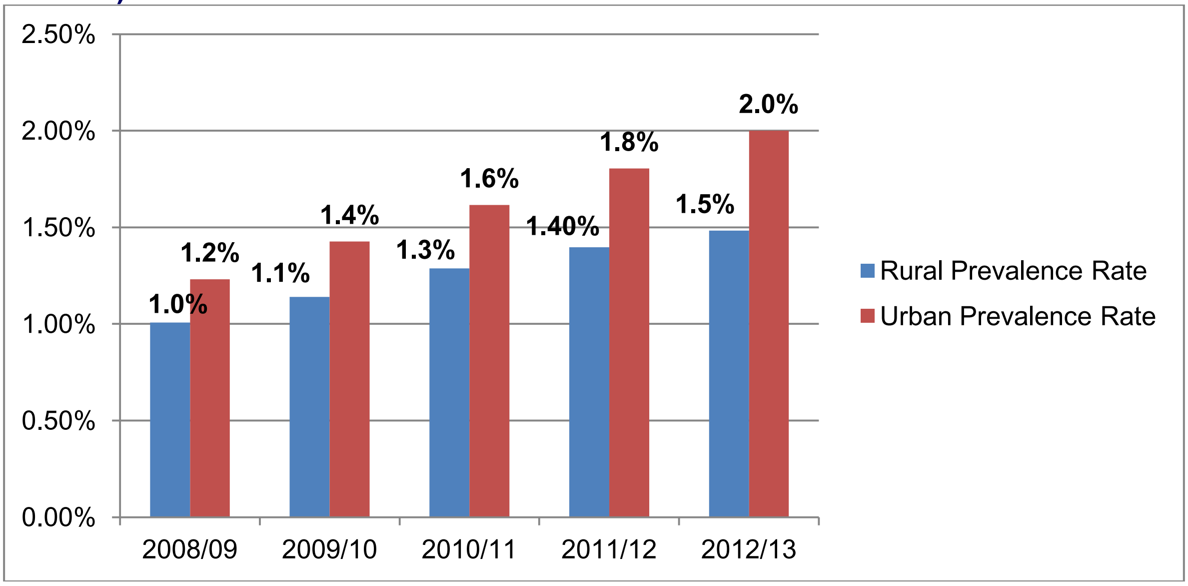
Figure 3: Prevalence Rates for ASD (children of compulsory school age) by Health and Social Care Trust



It is also of note, in Figure 3, that the prevalence levels in the Belfast and South Eastern Trusts were consistently higher than the Northern Ireland average. These are the two Trust areas which have a significantly larger urban than rural population (see annex one).

Both the urban and rural prevalence rates in Northern Ireland, from 2008/09 to 2012/13, have continued to rise (Figure 4). However it is evident that prevalence has been consistently higher in the urban population than the rural population with the largest difference registered in 2012/13 (0.5%). This is due to the year on year growth in the rural ASD population slowing from 13% between 2009/10 and 2010/11 to 7% between 2011/12 and 2012/13. Over the same period of time the urban ASD population has continued to increase at a steady rate of between 11% and 12%.

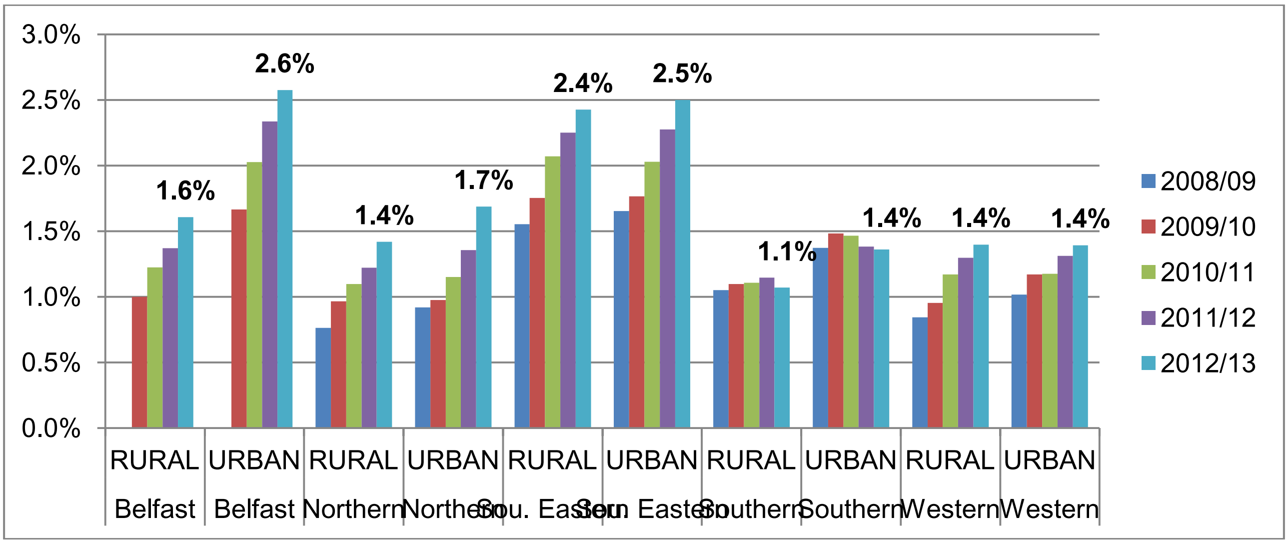
Figure 4: Rural and Urban Prevalence Rates in Northern Ireland (2008/09 – 2012/13)



Note: Figures for 2008/09 exclude the Belfast Trust as it was unable to provide an urban rural split of those diagnosed with ASD due to small numbers.

Figure 5 shows the Urban/Rural difference in prevalence rates across all of the HSC Trusts. The Trust with the largest difference between its Urban and Rural populations was the Belfast HSC Trust, however the Belfast Trust has a very small rural population which may skew the results (see annex 1). In the other HSC Trusts there was a much more even spilt between the populations. However it can be seen in the chart below that ASD is also more prevalent in the Urban population in the Northern and Southern HSC Trusts. The Western and South Eastern HSC Trusts had similar prevalence rates in their urban and rural populations.

Figure 5: Prevalence Rates for ASD (children of compulsory school age) by HSC Trust and Urban/Rural Location



Note: Figures for 2008/09 exclude the Belfast Trust area as low rural numbers prevented a urban/rural split being made

Statistical Significance

To test if a diagnosis of ASD was independent of Urban or Rural location null and alternative hypotheses were established.

Null: The proportion of children diagnosed with ASD is independent of location
Alternative: The proportion of children diagnosed with ASD is associated with location

In each year from 2008/09 to 2012/13, at a regional level, the chi square statistic located on the chi square distribution significance table gave a score lower than 0.05. This meant that the alternative hypothesis was accepted and that the proportion of children diagnosed with ASD was associated with their location, i.e., urban or rural.

Table 3: Chi Square Scores for Urban Rural Location Statistical Significance Test

	2008/09	2009/10	2010/11	2011/12	2012/13
Chi Square Score	40.38***	41.36***	48.21***	67.82***	100.67***

Note: Significance figures less than 0.05 are statistically relevant. ***, **, * denotes significance at the 0.001, 0.01 and 0.05 levels

Performing this test at HSC Trust level resulted in varied outcomes (see annex 2). The results for the Southern HSC Trust consistently indicated that there was a relationship between the proportion of children diagnosed with ASD and location. However no significant relationship was established in either the Belfast or South Eastern Trusts in any of the years studied.

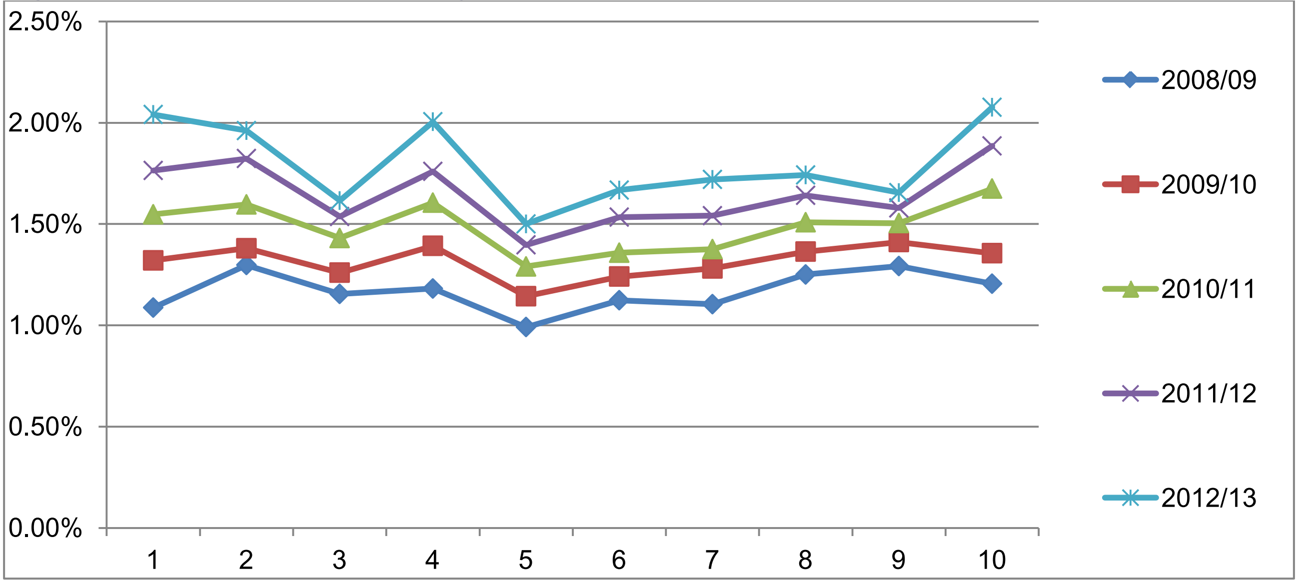
The Northern and Western HSC Trusts produced mixed results. In the Northern Trust the results for the first (2008/09) and last (2012/13) year of the study indicated a relationship between children diagnosed with ASD and location. The Western Trust showed an association between the proportion of children diagnosed with ASD and location for the first two years of the study (2008/09 & 2009/10).

Multiple Deprivation Measure Decile Prevalence

As set out in Figure 6, year on year across all MDM Deciles there was an increase in the prevalence rates of ASD, although it is difficult to interpret a pattern in Figure 6 it appears the extreme deciles appear to have the highest prevalence rates.
This pattern may exist due to access to services, with those in the most deprived areas having a greater level of state intervention in their lives, while those in the least deprived areas have greater levels of resources which allow them to access the best services.

A majority of the most and least deprived deciles are located in urban areas (see annex 3) which is in accordance with previous findings from the urban rural split.

Figure 6: Prevalence of ASD by Year and MDM Decile



An exception to this rule is decile 4, which may be expected to have one of the lower prevalence rates being closer to the middle, but it has consistently had one of the highest prevalence rates.

Statistical Significance

The following hypotheses were devised to establish any statistical significance in a relationship between the diagnosis of ASD and the MDM score of the area in which the child was living.

Null: The proportion of children diagnosed with ASD is independent of MDM Decile
Alternative: The proportion of children diagnosed with ASD is associated with MDM Decile

For 2009/10 the chi square score produced was not significant. For this year the Null hypothesis was accepted meaning that the proportion of children diagnosed with ASD was independent of MDM Decile. However for the other four years the opposite was true with significance levels less than 0.05, meaning that for these years the alternative hypothesis was accepted, the proportion of children diagnosed with ASD was associated with MDM Decile.

Table 4: Chi Square Scores for Multiple Deprivation Measures Decile Statistical Significance Test

	2008/09	2009/10	2010/11	2011/12	2012/13
Chi Square Score	20.27*	13.51	25.29**	35.97***	57.45***

Note: Significance figures less than 0.05 are statistically relevant. ***, **, * denotes significance at the 0.001, 0.01 and 0.05 levels

School Year Prevalence

Data for children in each school year diagnosed with ASD for 2008/09 and 2012/13 was provided from the Northern Ireland School Census. This information can be used to compare school year prevalence rates within and between school years.

Figure 7: Prevalence Rates by School Year for Compulsory School Age Children in 2008/09 & 2012/13

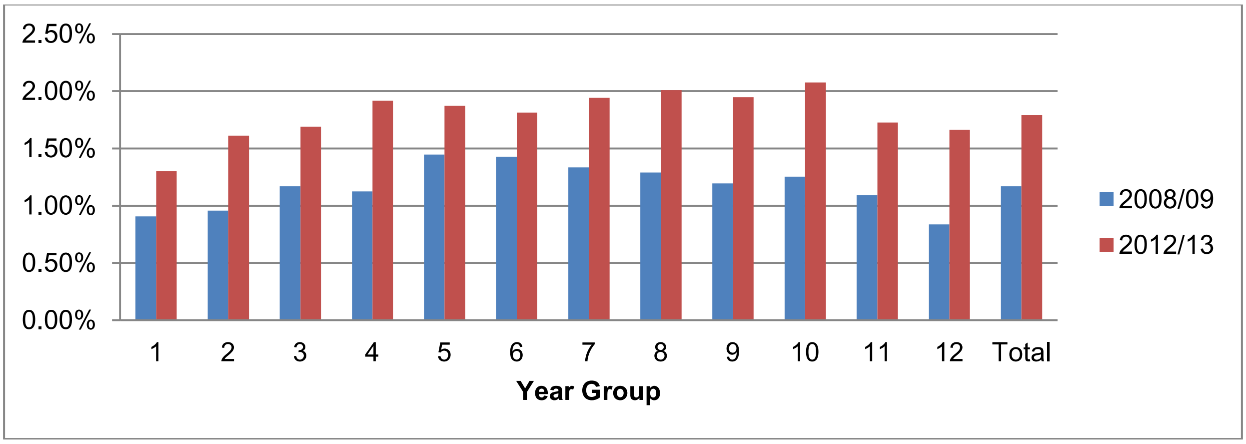


Figure 7 above shows that prevalence across all school years was higher during 2012/13 compared with 2008/09. During 2008/09, 1.4% was the highest prevalence rate (Year 5 – children aged 9) and 0.8% the lowest (Year 12 – children aged 16). In 2012/13, Year 10 had the highest prevalence rate (2.1%) while Year 1 had the lowest prevalence rate (1.3%). Years 10 and 12 had the largest percentage point change between 2008/09 and 2012/13 of 0.8 percentage points.

Looking at Years 1 – 4 (5 – 8 year olds), in 2012/13 there was a steady rise in the ASD prevalence rate. This may indicate that as awareness of autism has increased, there is an increased focus on early diagnosis of the disorder with more children diagnosed at this stage in their development. Table 5, overleaf, would support this conclusion as some of the biggest increases in the numbers of children diagnosed with ASD have occurred in Years 1 – 4.

Table 5: The Number of Children Diagnosed with ASD by School Year (2008/09 & 2012/13)

School Year	1	2	3	4	5	6	7	8	9	10	11	12
2008/09	202	209	256	246	326	337	320	318	283	303	270	208
2012/13	328	385	386	435	419	397	427	442	441	495	419	412
% Change	62%	84%	51%	77%	29%	18%	33%	39%	56%	63%	55%	98%

Note: The percentage change is based on absolute values, the base population for the academic years is different

Conclusions

1. The figures provided by the school census have shown that the estimated prevalence of autism has increased by 50% across all Health and Social Care Trusts between 2008/09 and 2012/13, from 1.2% of the compulsory school age population to 1.8%.

2. There is a significant difference in the estimated prevalence rates of ASD between the genders, with males almost five times more likely to be affected by ASD than females. However the analysis has indicated that the female ASD population (of compulsory school age) in recent years has increased at a slightly higher rate than the male population.

3. The figures also suggest that at a regional level there is a relationship between the estimated prevalence of autism and location, with the urban Northern Ireland population having a statistically significant higher prevalence rate than the rural population. This result was not fully replicated at Trust level, with only the Southern Trust showing consistent significance between location and the number of children diagnosed with ASD.

4. Over time a significant relationship between the estimated prevalence of autism and levels of deprivation has emerged. This can be seen in the fact that those children in the least and most deprived areas appear to have the highest prevalence rate of ASD, with those children in MDM deciles closer to the middle ground having the lower rates of ASD prevalence. There are exceptions to this (Decile 4) which indicates this area may require further study. As many of the most and least deprived MDM deciles are located in urban areas there is likely some cross cutting relationship with the relationship seen for ASD diagnosis and the urban rural spilt (see annex 3).
5. Finally, in looking at prevalence across school years over time we can see that the estimated prevalence of ASD has increased across all school years

with the greatest increases in the numbers of children diagnosed with ASD occurring in the youngest (5 – 8 year olds) and oldest (13 – 16 year olds) groups of children

Annex 1

Figure 8: The Rural and Urban Populations (Compulsory School Age Children) of each Health and Social Care Trust 2008/09 – 2012/13

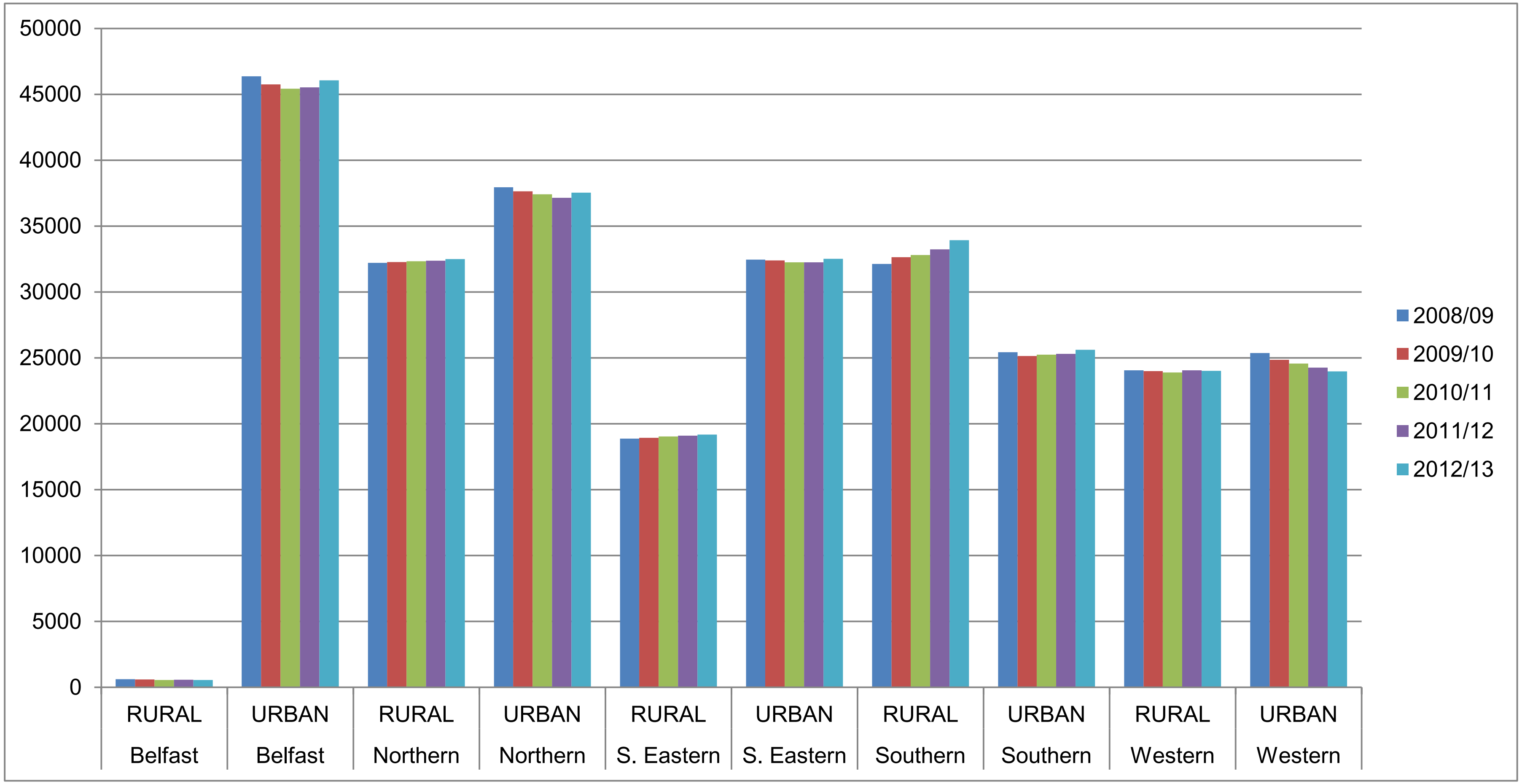


Table 6: Belfast HSC Trust Chi Square Scores for Urban Rural Location Statistical Significance Test

	2008/09	2009/10	2010/11	2011/12	2012/13
Chi Square Score	-	1.61	1.85	2.37	2.08

Note: Significance figures less than 0.05 are statistically relevant, due to small numbers in 2008/09 it was not possible to provide an urban rural spilt for children with ASD. ***, **, * denotes significance at the 0.001, 0.01 and 0.05 levels

Table 7: Northern HSC Trust Chi Square Scores for Urban and Rural Location Statistical Significance Test

	2008/09	2009/10	2010/11	2011/12	2012/13
Chi Square Score	5.06*	0.01	0.46	2.42	8.14**

Note: Significance figures less than 0.05 are statistically relevant. ***, **, * denotes significance at the 0.001, 0.01 and 0.05 levels

Table 8: South Eastern HSC Trust Chi Square Scores for Urban and Rural Location Statistical Significance Test

	2008/09	2009/10	2010/11	2011/12	2012/13
Chi Square Score	0.78	0.01	0.11	0.03	0.28

Note: Significance figures less than 0.05 are statistically relevant. ***, **, * denotes significance at the 0.001, 0.01 and 0.05 levels

Table 9: Southern HSC Trust Chi Square Scores for Urban and Rural Location Statistical Significance Test

	2008/09	2009/10	2010/11	2011/12	2012/13
Chi Square Score	12.33***	17.04***	14.74***	6.49**	10.55***

Note: Significance figures less than 0.05 are statistically relevant. ***, **, * denotes significance at the 0.001, 0.01 and 0.05 levels

Table 10: Western HSC Trust Chi Square Scores for Urban and Rural Location Statistical Significance Test

	2008/09	2009/10	2010/11	2011/12	2012/13
Chi Square Score	3.98*	5.43*	0.00	0.02	0.00

Note: Significance figures less than 0.05 are statistically relevant. ***, **, * denotes significance at the 0.001, 0.01 and 0.05 levels

Annex 3

Figure 9: Map Showing the Most (Red) and Least (Blue) Deprived Areas in Northern Ireland

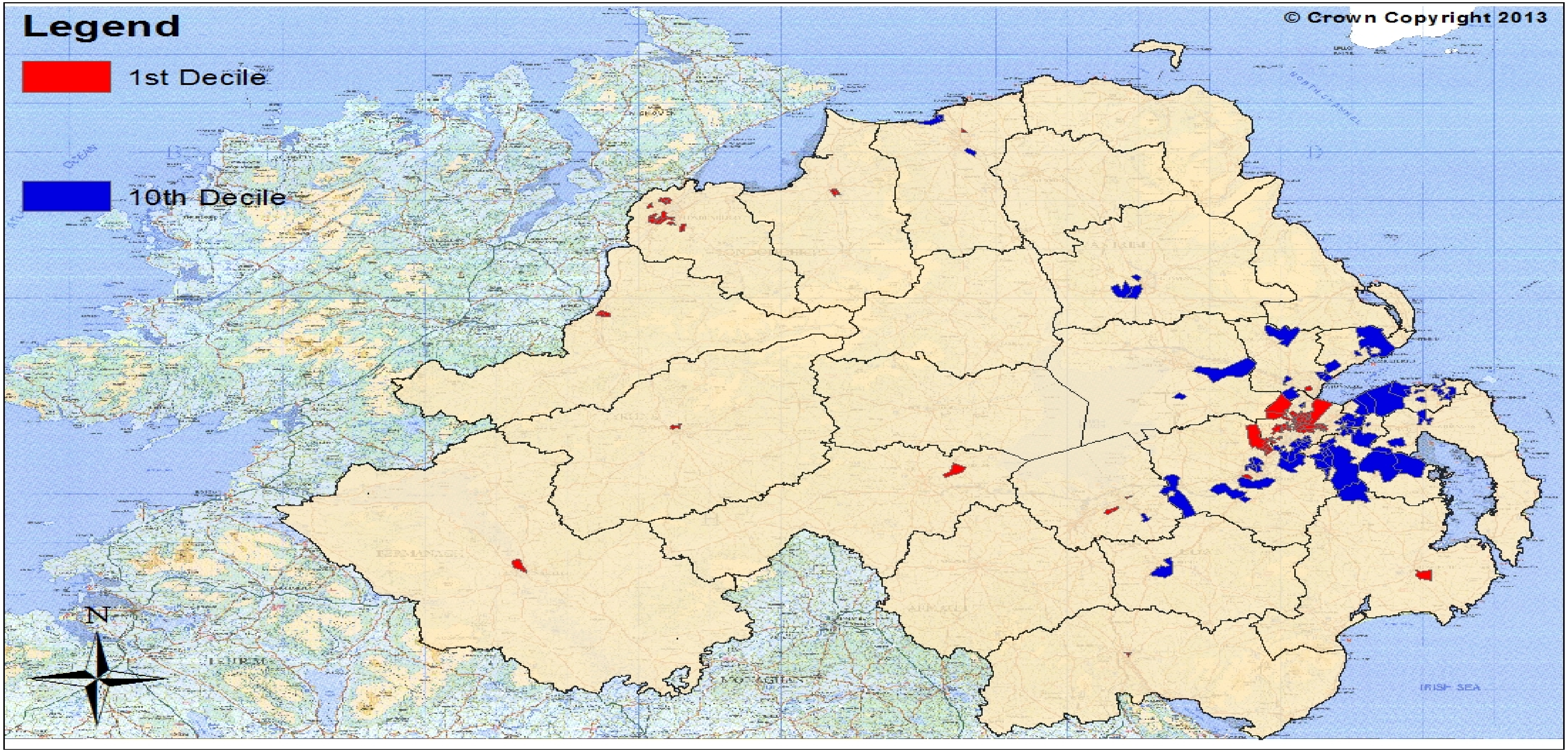


Figure 10: Map Showing the Most (Red) and Least (Blue) Deprived Areas in the Greater Belfast area

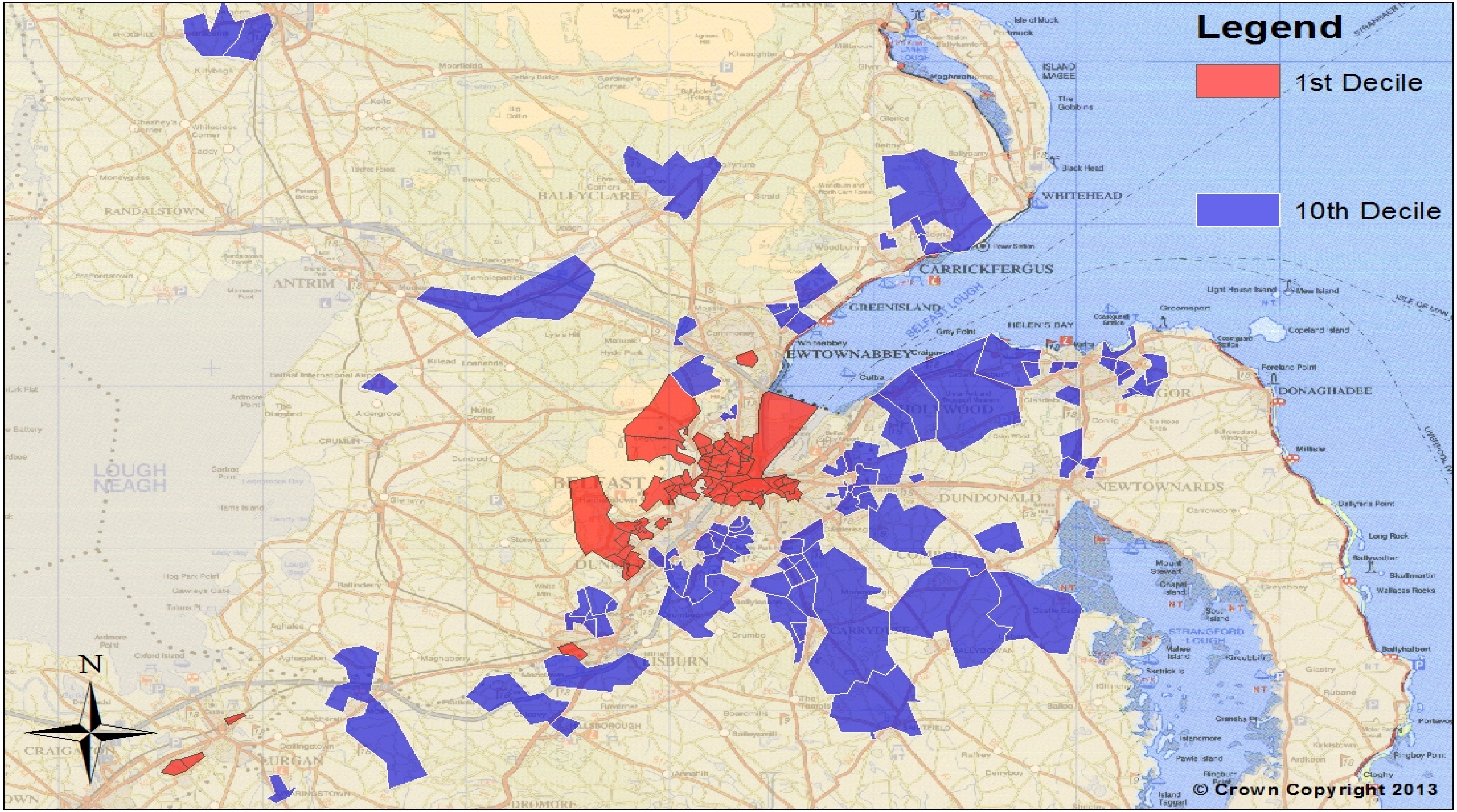
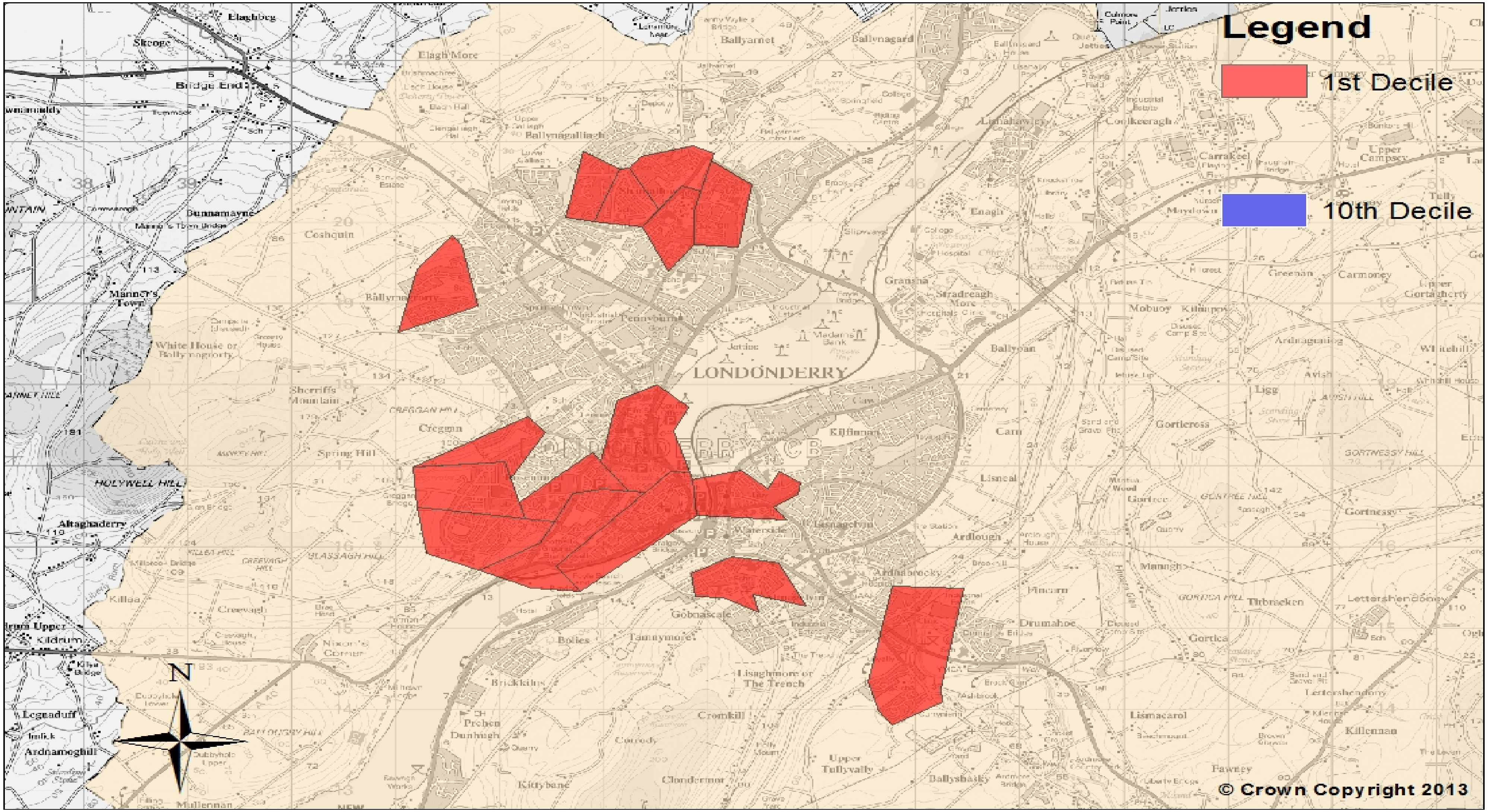


Figure 11: Map Showing the Most (Red) and Least (Blue) Deprived Areas in Londonderry



Additional Information

For further information on **The Prevalence of Autism in School Age Children in Northern Ireland**

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Castle Buildings
Stormont
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This report was compiled by NISRA Statisticians working within the Information and Analysis Directorate of the Department of Health, Social Services and Public Safety

References

Legislation

United Nations Convention on the Rights of the Child 1989 – Summary	www.unicef.org/crc/files/Rights_overview.pdf
The Disability Discrimination Act 1995	www.legislation.gov.uk/ukpga/1995/50/contents
The Children (NI) Order 1995	www.legislation.gov.uk/nisi/1995/755/contents
The Children's Services Planning Order 1998	www.legislation.gov.uk/nisr/1998/261/contents/made
The Human Rights Act 1998	www.legislation.gov.uk/ukpga/1998/42/contents
The Northern Ireland Act 1998	www.legislation.gov.uk/ukpga/1998/47/contents
The Carers and Direct Payments Act (2002)	http://www.legislation.gov.uk/nia/2002/6/contents
Special Educational Needs and Disability (NI) Order 2005	http://www.legislation.gov.uk/nisi/2005/1117/contents/made
The Disability Discrimination Order 2006 / Disability Discrimination (NI) Order 2006	www.legislation.gov.uk/nisi/2006/312/pdfs/uksi_20060312_en.pdf
United Nations Convention on the Rights of Persons with Disabilities 2008	www.un.org/disabilities/default.asp?id=150
Autism Act (NI) 2011	www.legislation.gov.uk/nia/2011/27/pdfs/nia_20110027_en.pdf

Other Documentation

DHSSPS	
Caring for Carers Strategy	http://www.dhsspsni.gov.uk/ec-dhssps-caring-for-carers.pdf

Appendix 6

References

Independent Review of Autism Services – May 2008	www.dhsspsni.gov.uk/independent_review_of_autism_services_final_report.pdf
ASD Strategy and Action Plan June 2009	www.dhsspsni.gov.uk/asd_strategic_action_plan.pdf
Transforming Your Care – A Review of Health and Social Care in NI – December 2011	www.dhsspsni.gov.uk/transforming-your-care-review-of-hsc-ni-final-report.pdf
Six Steps of Autism Care / A Guide for Families – October 2011	www.belfasttrust.hscni.net/pdf/Six_Steps_of_Autism_Care_Pathway_Report.pdf
Speech and Language Therapy Action Plan 2011/12 – 2012/13	www.dhsspsni.gov.uk/speech__language_and_communication_therapy_action_plan_-_march_2011.pdf
Adult Autism Care Pathway / Guide / Toolkit – September 2013	http://www.hscboard.hscni.net/asdnetwork/Publications/Adult%20Care%20Pathway-August%202013%20-%20PDF%20560KB.pdf
Families Matter: Supporting Families in NI – Regional Family and Parenting Strategy – March 2009	http://www.dhsspsni.gov.uk/families_matter_strategy.pdf
Bamford Review of Mental Health and Learning Disability – Current Action Plan 2012 – 2015	www.dhsspsni.gov.uk/bamford_action_plan_2009-2011.pdf
Fit and Well – Changing Lives – A Ten Year Public Health Strategic Framework for Northern Ireland 2012-2022	www.dhsspsni.gov.uk/showconsultations?txtid=57771
Developing Advocacy Services - A Policy Guide for Commissioners - May 2012	www.dhsspsni.gov.uk/Developing-Advocacy-Services-A-guide-for-Commissioners-May-2012.pdf
Learning Disability Service Framework September 2012	www.dhsspsni.gov.uk/learning_disability_service_framework.pdf

References

National Institute for Health and Clinical Excellence Guidance	
National Institute for Health and Clinical Excellence	www.nice.org.uk
CG128 - Recognition, referral and diagnosis of children and young people on the autism spectrum	www.nice.org.uk/CG128
CG142 - Recognition, referral, diagnosis and management of adults on the autism spectrum	www.nice.org.uk/CG142
CG170 - Management and support of children and young people on the autism spectrum	www.nice.org.uk/CG170

DE	
Special Educational Needs (SEN)	www.deni.gov.uk/index/support-and-development-2/special_educational_needs_pg.htm
A Guide for Parents	www.deni.gov.uk/index/support-and-development-2/special_educational_needs_pg/7-special_needs-a_guide_for_parents_pg.htm
SEN Code of Practice	www.deni.gov.uk/index/support-and-development-2/special_educational_needs_pg/special_needs-code_of_practice_pg.htm
Recording Children with SEN	www.deni.gov.uk/index/support-and-development-2/special_educational_needs_pg/7-

	recording_children_with_special_eduational_needs.htm
Reports and Publications	www.deni.gov.uk/index/support-and-development-2/special_educational_needs_pg/special_educational_needs-newpage-2.htm
Resource to Support Children with SEN	www.deni.gov.uk/index/support-and-development-2/special_educational_needs_pg/support-children-with-sen.htm
Review of SEN and Inclusion	www.deni.gov.uk/index/support-and-development-2/special_educational_needs_pg/review_of_special_educational_needs_and_inclusion.htm
SEN Legislation	www.deni.gov.uk/index/support-and-development-2/special_educational_needs_pg/special_needs-legislation_pg.htm
Supporting Pupils with Medication Needs	www.deni.gov.uk/index/support-and-development-2/special_educational_needs_pg/special_educational_needs-supporting_pupils_with_medication_needs-2.htm
Education Support for NI – Special Education	www.education-support.org.uk/parents/special-education
Report of the Task Group on Autism – April 2002	www.deni.gov.uk/index/facts-and-figures-new/departmental-publications/special_educational_needs_-_reports_and_publications-newpage-2/special_educational_needs_-_reports_and_publications-newpage-4.htm
Autistic Spectrum Disorders – A Guide to Classroom Practice	www.deni.gov.uk/asd_classroom_practice.pdf

References

Evaluating Provision for Autistic Spectrum disorders in Schools, 2005	www.etini.gov.uk/evaluating-provision-for-autistic-spectrum-disorders-in-schools-2005.pdf
Education and Library Boards' Good Practice Guidelines – SEN	www.selb.org/specialeducation/Documents/GoodPracticeGuidelines.pdf
Education and Library Boards' Provisional Criteria for Statutory SEN Assessments	http://80.4.159.11/special-needs/PDFs/Provisional_Criteria2.pdf
Middletown Centre for Autism	www.middletownautism.com
Report of an Inspection of Middletown Centre for Autism – September 2012	www.etini.gov.uk/index/inspection-reports/inspection-reports-special-education/inspection-reports-special-2012/joint-inspection-middletown-centre-for-autism.pdf
Every School a Good School – A Policy for School Improvement – April 2009	www.deni.gov.uk/esags_policy_for_school_improvement_-_final_version_05-05-2009.pdf
Count Read: Succeed – A Strategy to Improve Outcomes in Literacy and Numeracy – March 2011	www.deni.gov.uk/count_read_succeed_a_strategy_to_improve_outcomes_in_literacy_and_numeracy.pdf

References

DEL	
Skills Strategy	www.delni.gov.uk/success-through-skills-transforming-futures.pdf
Essential Skills Strategy	www.delni.gov.uk/es/essential_skills_for_living-2.pdf
Employment Service Strategy ***(in development)***	
Higher Education Strategy - Access to Success	www.delni.gov.uk/access-to-success.pdf
Success through Science Technology Engineering Mathematics	www.delni.gov.uk/2857p_stem_booklet_v5.pdf
Pathway to Success Strategy	www.delni.gov.uk/del-pathways-to-success-v6.pdf
FE Means Business	www.delni.gov.uk/es/fe_means_business_implementation_plan_-_june_06.pdf
Preparing for Success – (joint DE/DEL Careers strategy)	www.delni.gov.uk/es/ceiag_pfs.pdf

DETI	
Northern Ireland Economic Strategy	www.northernireland.gov.uk/economic-strategy

References

DOJ	
Community Safety Strategy	http://www.dojni.gov.uk/index/publications/publication-categories/pubs-policing-community-safety/community-safety-strategy-2012-2017.htm

DRD	
Accessible Transport Strategy Action Plan	http://www.drdni.gov.uk/accessible_transport_strategy_for_northern_ireland_2015-10.pdf
Accessible Transport Strategy Action Plan	www.drdni.gov.uk/index/sustainable_transport_branch/the-accessible-transport-strategy-draft-action-plan-2012-2015.htm
Travel Safe Guide	www.drdni.gov.uk/index/sustainable_transport_branch/travel-safe-a-guide-about-community-safety-for-people-with-learning-disabilities.htm
DSD	
General Information on Social Security benefits	www.nidirect.gov.uk
General Information on Social Security benefits	www.dsdni.gov.uk

OFMDFM	
Our Children and Young People – Our Pledge – A Ten Year Strategy for Children and Young People in NI 2006 – 2016	http://www.ofmdfmni.gov.uk/ten-year-strategy.pdf

References

A Strategy to improve the lives of disabled people – 2012-2015	http://www.ofmdfmni.gov.uk/index/equality/disability/consultation-draft-disability-strategy.htm
NI Government Departments Websites	
Department of Agriculture and Rural Development	www.dardni.gov.uk
Department of Culture, Arts and Leisure	www.dcalni.gov.uk
Department of Education	www.deni.gov.uk
Department for Employment and Learning	www.delni.gov.uk
Department of Enterprise, Trade and Investment	www.detini.gov.uk
Department of Finance and Personnel	www.dfpni.gov.uk
Department of Health, Social Services and Public Safety	www.dhsspsni.gov.uk
Department of the Environment	www.doeni.gov.uk
Department of Justice	www.dojni.gov.uk
Department for Regional Development	www.drdni.gov.uk
Department for Social Development	www.dsdni.gov.uk
Office of the First and Deputy First Minister	www.ofmdfmni.gov.uk

References

The official government website for NI citizens	
NI Direct	www.nidirect.gov.uk

Health and Social Care Organisations	
Health and Social Care Board	www.hscboard.hscni.net
Public Health Agency	www.publichealth.hscni.net
Patient and Client Council	www.patientclientcouncil.hscni.net
Belfast Health and Social care Trust	www.belfasttrust.hscni.net
Northern Health and Social care Trust	www.northerntrust.hscni.net
South Eastern Health and Social care Trust	www.setrust.hscni.net
Southern Health and Social care Trust	www.southerntrust.hscni.net
Western Health and Social care Trust	www.westerntrust.hscni.net

Education and Library Boards	
Belfast	www.belb.org.uk
North Eastern	www.neelb.org.uk
South Eastern	www.seelb.org.uk

Southern	www.selb.org.uk
Western	www.welbni.org

Financial Support / Benefits	
Social Security Agency	www.dsdni.gov.uk/index/ssa.htm
HM Revenue and Customs Tax Credits	http://www.hmrc.gov.uk/TAXCREDITS
NI Housing Executive Housing Benefit	http://www.nihe.gov.uk/index/benefits/housingbenefit.htm

Further Education Colleges	
Belfast Metropolitan College	http://www.belfastmet.ac.uk/StudentServices/DisabilityServices/Default.aspx
North West Regional College	www.nwrc.ac.uk
Northern Regional College	www.nrc.ac.uk
Southern Regional College	www.src.ac.uk
South Western Regional College	www.swc.ac.uk
Southern Eastern Regional College	www.serc.ac.uk

References

Higher Education / Universities	
Queens University – Disability Services	www.qub.ac.uk/directorates/sgc/disability
University of Ulster – Student Support	http://www.studentsupport.ulster.ac.uk/disability/disability.html

Community / Voluntary Organisations	
Autism Initiatives NI	www.ai-ni.co.uk
Autism NI	www.autismni.org
Autism Network NI	www.autismnetworkni.org.uk
Barnardo’s	www.barnardos.org.uk
Disability Action	www.disabilityaction.org
Eagle	www.belfastcentralmission.org
Mencap	www.mencap.org.uk
Parent’s Education as Autism Therapists (PEAT)	www.peatni.org
The National Autistic Society (NAS) NI	www.autism.org.uk