



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

www.dhsspsni.gov.uk

**The
Autism Strategy
(2013 – 2020)
and
Action Plan
(2013 – 2016)**

**Progress Report
September 2015**

CONTENTS

PAGE NUMBER

1. INTRODUCTION	1
2. KEY THEMES	2
UPDATE SUMMARY OF KEY THEMES	
3. AWARENESS	5
4. ACCESSIBILITY	7
5. CHILDREN, YOUNG PEOPLE AND FAMILY	9
6. HEALTH AND WELLBEING	11
7. EDUCATION	13
8. TRANSITIONS	16
9. EMPLOYABILITY	18
10. INDEPENDENCE, CHOICE AND CONTROL	26
11. ACCESS TO JUSTICE	28
12. BEING PART OF THE COMMUNITY	30
13. PARTICIPATION AND ACTIVE CITIZENSHIP	31
14. LEADERSHIP AND IMPLEMENTATION	33
15. INNOVATIVE ACTIONS	34
16. KEY ISSUES	37
17. IDENTIFIED RISKS	39

1. INTRODUCTION

- 1.1 The Autism Act (NI) 2011 required the Department of Health, Social Services and Public Safety (DHSSPS) to lead on the development; implementation; monitoring and reporting of a cross-departmental Autism Strategy. The Autism Strategy (2013 - 2020) and Action Plan (2013 - 2016) was subsequently approved by the NI Executive and launched in January 2014.
- 1.2 The Autism Act also states that the DHSSPS must prepare and lay a monitoring report on the implementation of the Strategy before the Assembly every three years, with other Departments statutorily obliged to cooperate. Although an initial report is not due until January 2017, it was agreed wherever possible, to provide the Assembly with an annual update on the overall progress of the Strategy, with cross-Departmental and inter-Agency input.
- 1.3 The progress of the Autism Strategy is being monitored through the Autism Strategy Inter-Departmental Senior Officials Group, chaired by the DHSSPS. Oversight of specific actions is the responsibility of the Regional Multi-Agency Implementation Team, chaired by the Regional Autism Coordinator.
- 1.4 This Report provides a summary on the status of each of the actions contained in the Strategy, together with a brief narrative highlighting key areas of progress over the past twelve months, and a look ahead to challenges in the coming year.

2. KEY THEMES OF THE ACTION PLAN

2.1 The structure of the Action Plan sets out thirty-four cross-Governmental actions reflecting the following eleven themes and associated strategic priorities. (Full details on the strategic priorities, outcomes, lead responsibilities and timescales are at:

<http://www.dhsspsni.gov.uk/index/asap/asap-section5.htm>)

- **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 (ALBs), and to commission and plan a public awareness campaign.

- **Accessibility**

There are two strategic priorities within this themed area, aiming to eliminate barriers; increase and improve access to services (especially transport and travel), and to inclusive communication of information - for people with autism; their families and carers.

- **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.

- **Health and Wellbeing**

There are two strategic priorities within this themed area, 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.

- **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 meet their needs appropriately.
- **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.
- **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.
- **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.
- **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.
- **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.
- **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.

- There is also a section within the Action Plan on **Leadership and Implementation.**

3. UPDATE SUMMARY OF KEY THEMES – AWARENESS

- *Deliver an autism awareness programme within Government Departments for frontline staff;*
- *Promote opportunities to raise awareness about autism generally.*

- 3.1 Most Government Departments have delivered autism awareness training to their frontline staff and ALBs. This training was designed by the Northern Ireland Civil Service Centre for Applied Learning, however some ALBs delivered awareness training for front-line staff in partnership with voluntary organisations such as Autism NI, and the Northern Ireland branch of the National Autistic Society.
- 3.2 The exceptions are the ***Department of Education***, who are delivering awareness training to relevant frontline staff on a request basis, and the ***Department of Enterprise Trade and Investment***, where staff are encouraged to avail of awareness training, but is not mandatory. The ***Department of Finance and Personnel*** is also still reviewing this training for staff.
- 3.3 Within the ***Department of the Environment***, awareness training was to be rolled out to its frontline staff to meet the March 2015 target; however, the bulk of the latter was based in the business areas of Driver and Vehicle Agency and Planning. The transfer of the vehicle licensing function to DVLA in Swansea meant that, from April 2014, the focal point for management was the re-deployment of approximately 270 mainly front line DVLA staff. Similarly, the transfer of planning staff to Local Government necessitated a substantial amount of preparatory capacity-building, whilst simultaneously maintaining levels of service. This, combined with other training priorities throughout the year, has resulted in only a small number of frontline staff having undertaken the training. DOE will ensure that this training will be made a priority during the 2015/16 year for any remaining staff.

- 3.5 Departments and their ALBs have also raised awareness about autism by organising a range of annual events to celebrate World Autism Awareness Day. Information is now available in various formats through a range of resources for all staff. Examples include: factsheets; leaflets; conferences and seminars, through a range of methods such as team briefs; corporate communications and intranet websites. Specific examples of awareness-raising initiatives were to be created via a public awareness advertising campaign; however this was cancelled due to financial pressures. Emphasis will now centre on no-cost awareness initiatives and unpaid publicity, particularly events focused on autism awareness month in April each year.
- 3.6 There are various links provided on the NI Direct and the Family Support NI websites which give details of Autism services, including accessing benefits; guidance on travel, and a range of employment and learning programmes and services. This includes i-provisions which offer additional support to people with autism.

4. UPDATE SUMMARY OF KEY THEMES – ACCESSIBILITY

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

4.1 These actions have been advanced and the following examples include a range of services provided by Government Departments and their ALBs.

4.2 ***The Department for Employment and Learning*** provides a range of impartial and professional services to clients of all ages and abilities. This service is available to people in education; training; employment, and to the unemployed, including those with autism. Professionally qualified Careers Advisers can help the above realise their career aspirations and achieve their full potential in education, training or employment. They can also assist and inform people with autism and their parents/guardians of all the various career pathway options and the associated support that may be available.

4.3 DEL Careers Advisers are also actively involved in the transition planning process for young people who have a statement of special educational need, including those with autism. Working with multi-disciplinary teams including teachers and educational psychologists, Careers Advisers contribute to the young person's Transition Plan, by providing impartial careers guidance on the range of available educational; training and employment opportunities. These meetings also enable them (and their parents/guardians) to access information and guidance, regarding the options and support available to them on leaving school.

4.4 Student Support Officers (SSO) at the College of Agriculture, Food and Rural Enterprise, assume an advocacy role for students and their families across all three campuses, particularly during periods of transition. Due to the

difficulties with social communication that students with autism face, the SSO acts as an intermediary, and will trouble-shoot any issues that arise on campus for students (and their families).

- 4.5 ***The Department of the Environment's Driver and Vehicle Agency*** offer a range of adjustments to the theory and practical driving test to accommodate candidates with disabilities, including additional time in certain circumstances.
- 4.6 In the completion of the driving theory test, a voiceover facility is available to assist candidates with dyslexia, learning or literacy problems. The test instructions, questions and answers can be read to a candidate by an authorised reader in addition to extended time and a separate room. The customer can choose a combination of these facilities, and arrangements can also be tailored to meet individual requirements, including the delivery of a home test. These facilities are available at all theory test centres throughout Northern Ireland.
- 4.7 When booking a driving test, the candidate is asked whether they have any physical disabilities or special circumstances. It is also possible for a family member or friend to accompany them on the practical driving test. Driving examiners are trained to understand any special needs that may arise from disabilities, and may determine the length of the time-slot required to conduct the test.
- 4.8 ***The Department of Justice*** has produced a guide for criminal justice professionals in Northern Ireland to assist all practitioners who may come into contact with someone with autism. This was produced in partnership with the National Autistic Society Northern Ireland and launched in February 2014.
- 4.9 The majority of Government Departments and ALBs have also increased access to information for people with autism through Information Hubs; signposting to services via Advice Services; links provided on NI Direct to autism voluntary organisations and Health and Social Care (HSC) Trust websites, giving details of Autism services and advocacy services.

5. UPDATE SUMMARY OF KEY THEMES – CHILDREN, YOUNG PEOPLE AND FAMILY

- *Provide timely joinedup support services for families living with autism;*
- *Promote awareness regarding the availability of support services available to families in their area; and*
- *Ensure that support and interventions is provided for carers of people with autism.*

5.1 Government Departments and their ALBs have been working closely to advance these actions, including the following exemplars.

5.2 There are currently joint working arrangements in place between HSC Trust Autism services, and Education and Library Board (ELB) autism intervention and advisory services (now amalgamated into the newly established Education Authority), from point of assessment through to end of post primary education. Whilst Early Intervention is also carried out by the HSC Trust's Autism services, this often involves working closely together with Education colleagues. HSC Trust staff and ELB staff regularly meet to discuss families, and ensure support is coordinated, especially for children in the post-primary sector. The Southern ELB Autism Advisory Service works alongside the Southern HSC Trust's diagnostic team in a small number of assessments for more complex children, and they are then notified when a diagnosis of autism is confirmed.

5.3 Support provision for families with children who have autism is available via Family Support Hubs. Autism services in each HSC Trust, receive referrals from the Family Support Hubs, as well as being a point of contact for queries and advice.

5.4 Autism-specific fields have now been developed on the 'Family Support NI website,' and list all Autism services available in each HSC Trust area. The search facility on the website has also been developed to enable families and

carers to identify and locate childcare providers with the appropriate skills to care for children with autism.

- 5.5 There is a Parents and Carers Education Programme available from Autism Paediatric services within HSC Trusts, to 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.
- 5.6 In order to provide support provision for families, in particular siblings of children with autism, the Southern HSC Trust run sibling groups. There is also the option for one-to-one support for siblings to help them understand their brother/sister's autism.
- 5.7 ***The Northern HSC Trust***, in partnership with the Children and Young People's Strategic Partnership (CYPSP), completed a Supporting Siblings Engagement Feedback report in order to ascertain the level of support being provided to families and siblings of children with autism. Sibling Workshops were also held in April 2015.
- 5.8 Carers are advised of their right to a formal Carers Assessment as outlined in the Six Steps of Autism Care and the Adult Autism Care Pathway. The Southern HSC Trust now provides all families with written information on Carers Assessments at point of diagnosis, and monitors the uptake of these.
- 5.9 HSC Trusts provide a range of short break opportunities based on assessment of need, including day activities and residential openings.
- 5.10 A programme of Autism Awareness training is also being provided through the Southern Child Care Partnership on an ongoing basis.

6. UPDATE SUMMARY OF KEY THEMES - HEALTH AND WELLBEING

- *Enhance access to health and wellbeing programmes for people with autism;*
- *Enhance and promote early recognition and early intervention for people with autism; and*
- *Promote and introduce best practice and service improvement through continuing review of care pathways for children, young people and adults with autism.*

- 6.1 As with other population groups who may have particular needs, it is incumbent on service providers to make reasonable adjustments to ensure that service users with autism can access universal health and social care services in various settings.
- 6.2 A range of group health and wellbeing programmes are offered across the HSC Trusts, which include: looking at helping young people understand their diagnosis; fitness programmes in partnership with local leisure centres; group work targeting specific areas. Referrals to these services are made as needs indicate.
- 6.3 In April 2014 a brief '*Autism Awareness Factsheet*' was produced by DHSSPS, drawing on information produced by the National Autistic Society and the Centre for Research in Autism and Education. This brief introduction to autism received wide distribution throughout the HSC. It was also utilised as a template for other Departments and agencies to inform their frontline staff who may be in contact with people with autism, their families and carers.
- 6.4 The factsheet highlighted the difficulties people with autism have with social interaction; social communication and social imagination, and other behaviours; hyper-sensitivities; anxieties and routines which they may have. It also suggested a number of possible strategies which can be adopted to minimise stress or other problems, and ensure the individual is able to access

the services they require. The focus is on ensuring that people are not deterred from attending regular healthcare appointments and check-ups, or availing of services and supports which are nothing to do with their autism.

- 6.5 Targeted material is also available for specific professionals eg a '*GP Guide for Autism*' produced by Autism NI in cooperation with the RCGP. More detailed training and management is available for other HSC staff, including '*Autism Diagnostic Observation Schedule*' Training, for clinicians working in Trust ASD Teams.
- 6.6 A referrals system is in place in both paediatric and adult autism services throughout the region, however, due to the level of demand and a finite service capacity there is a delay in assessments.
- 6.7 The HSC Board and Trusts seek to promote and introduce best practice and service improvement through continuing review of care pathways for children; young people and adults with autism. They have also introduced a number of innovative services and supports in partnership with other sectors, agencies and service providers, including the community and voluntary sector. Many of these developments are covered elsewhere in this update.
- 6.8 Although the HSC Trusts have made considerable progress in addressing these priorities and in the implementation of the National Institute for Health and Care Excellence (NICE) Guidelines, challenges remain in meeting target timescales due to capacity and demand issues, therefore these actions have only been partly achieved.

7. UPDATE SUMMARY OF KEY THEMES – EDUCATION

- *Continue to build capacity in schools to effectively meet the needs of children and young people with autism;*
- *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;*
- *Formalise collaboration between health and social care and education sector to help improve support, including specialist support; and*
- *Expand trans-disciplinary assessments, interventions and support for children and young people with complex needs.*

7.1 These actions have been advanced and the Department of Education (DE) have provided the following exemplars.

7.2 School Training Programmes delivered between April 2014 and March 2015 includes direct support provided to 3,500 pupils with autism. Autism Awareness and Support Training was provided to 2,982 school staff and 2,623 pupils (peer group training). Autism specific resources have been uploaded on C2K for school staff who attended training and consultation, and targeted advice has been provided to school staff for children without a confirmed diagnosis of autism, or who are on a waiting list for diagnostic assessment.

7.3 A DE Resource File, which includes an Autism chapter, has been highlighted to schools as a reference and the ELBs, in collaboration with the Middletown Centre for Autism, are delivering focused autism training to schools. An ELB representative has been appointed to the Northern Ireland Autism Strategy Research Advisory Committee; the Northern Ireland Autism Strategy Implementation Team, and the Northern Ireland Autism Strategy Prevalence Group, to ensure collaborative working with all Government Departments.

7.4 There has also been ELB consultation with the Middletown Centre for Autism on research bulletins and the continued up-skilling of front line staff. The

centre has also provided training to 3,825 education professionals in Northern Ireland as at the end of February 2015. These sessions are delivered in collaboration with ELB services and are designed to complement and build upon training provided by ELBs.

- 7.5 Education and Library Boards have also provided Autism Awareness and Support Training to 148 youth workers and volunteers. Arrangements for the delivery of this training, is available on a rolling basis. A Buddy Programme in youth clubs has also been established in order to engage young people with autism.
- 7.6 There has been Autism Awareness and Support Training provided to parents of children with autism, including Social Skills training; Life Skills; Post-diagnostic Parent Training and many more.
- 7.7 The Middletown Centre for Autism has also provided training to parents designed to complement and build on training provided by ELB services. An audit of training services offered to parents in Northern Ireland has been completed by the Centre, and data collected in this audit will be used to inform the continued development of the Centre's parental training service.
- 7.8 A Common Support Framework was established in June 2014, and following a review of autism specific provision and support pathways, agreed procedures have been put in place for pupils moving between support areas. The Inter-board Autism service anticipates that the common model of support will be fully implemented and strengthened under the newly established Education Authority.
- 7.9 Formal arrangements are now in place for collaborative working between Autism services in Education and Health, and exemplars include: joint work on diagnostic assessment with the Paediatric service and Child and Adolescent Mental Health Service (CAMHS); initial parent training; training in adolescent training programmes (CAMHS), and joint attendance at multi-disciplinary meetings, and consultations relating to individual pupils.

7.10 The Middletown Centre's Learning Support and Assessment Service have provided direct trans-disciplinary support to 60 referred children and young people with autism presenting with complex needs.

8. UPDATE SUMMARY OF KEY THEMES – TRANSITIONS

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

- 8.1 There are a number of ongoing cross-Departmental initiatives for improving the transition from children to adult services for those with autism. Examples of effective collaborative working are evident with HSC Trusts and ELBs, having joint early intervention models for Autism services, including: bespoke training to clusters of Nursery, Playschool and other Early Years settings; Transfer preparation for children in the P7 year; and joint ELB/HSC Trust Life Skills awareness training to parents and individual pupils.
- 8.2 ***The Health and Social Care Board*** has committed additional funds for support to carers of children with a disability, including autism. This investment is focused upon increasing opportunities for additional short breaks, direct payments and cash grants. In addition, the HSC Board has committed £1m to enhance services to support children with a disability who present with challenging behaviours - inclusive of all disabilities, including autism.
- 8.3 ***Children in Northern Ireland*** provided a training programme for childcare providers under the Bright Start Strategy (the NI Executive's programme for affordable and integrated childcare), which included modules on autism. This training programme was subject to independent evaluation and received positive endorsement from the independent evaluator's report. Training is subject to continued funding provided by OFMDFM, which is currently under review.

8.4 In Further Education colleges, there has been an expansion of training for pupils transitioning, to include follow-up visits to employment and education settings.

9. UPDATE SUMMARY OF KEY THEMES – EMPLOYABILITY

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

9.1 Considerable and continuing progress has been achieved in advancing these actions.

9.2 ***All Further Education (FE) and Higher Education (HE) Colleges*** promote Transition Support; Learning Support and Progression Support to all students. Students attending FE Colleges (at all levels), who declare any disability including autism at application/enrolment stage. They are interviewed and offered tailored support, based on their assessed needs. Meetings are conducted with parents/guardians as appropriate, and needs are reviewed and assessed throughout the year through the Supplementary Agreement mechanism. Learning Support teams are available to provide support and guidance, and to create a supportive learning environment for the duration of the student's course.

9.3 Colleges provide information to students with autism, and their guardians through a number of methods including: marketing literature; web-based information; open days; close working relationships with local schools; ELB Transitions Teams; DEL Careers Service, and other related professionals in the education and health care sectors.

9.4 DEL has provided funding for an information/advocacy resource hub to signpost services for both existing and potential learners, to improve access to information about college provision; services, and the support available for everyone with a disability, such as autism. DEL have also provided funding for the development of online access guides for people with severe learning

difficulties/disabilities, which provide information on campus layout and help learners, visitors and staff access college premises and make best use of facilities.

- 9.5 The **Entitlement Framework**, through which many school pupils attend colleges as part of the curriculum, is another important vehicle in creating awareness of the support available in FE colleges.
- 9.6 **'Reach Higher'** is the DEL higher education awareness raising campaign. It consists of TV; Press; outdoor multi-format and digital advertising. The aim is to raise awareness of the potential value and accessibility of higher education in particular for those groups who are currently under-represented, including students with disabilities and learning difficulties. The campaign literature and posters instruct interested students (and/or their parents or guardians) to go to the NI direct website where they can obtain a wide range of information relating to HE colleges, including details on: routes into higher education; choosing a University; how to apply to HE, and the financial support available to students such as Disabled Students Allowances, which cover the extra costs of any support the student may require as a direct result of their disability; mental health condition, or specific learning difficulty.
- 9.7 **'Steps to Success'** is DEL's main employment programme, designed to assist participants to prepare for, and to find and sustain suitable employment. The three organisations contracted by the Department to provide this programme, have a supply chain that includes specialist organisations which can assist participants with autism. Assistance is continued when the participant enters employment to help them sustain this work.
- 9.8 **'Training for Success'** involves provision for disability support across the spectrum of disabilities, including physical; sensory; and behavioural and learning disabilities. The provision is contracted to four Disability Support Suppliers; Ulster Supported Employment Limited; the Cedar Foundation; Sensory Learning Support, and Disability Action. The latter also provides a specialist service for young people with autism under sub-contract with the

National Autistic Society. Training Suppliers may engage the services of any of the above organisations and the costs are met wholly by the Department.

- 9.9 In addition, a Pre-Entry Training referral process for disability support is offered to any young person with autism, who is considering training as an option on leaving post-primary education. This service aims to ensure that appropriate support is in place as soon as possible after the young person joins the programme. It is also obtained from the Disability Support Suppliers. Referral is through the DEL's Careers Service following discussion and agreement of the young person's parents/guardians.
- 9.10 DEL's Careers Service also provides an impartial and professional careers service to clients of all ages and abilities. This is available to people with autism in education; training; employment, and to the unemployed. Professionally qualified Careers Advisers can help people with autism realise their career aspirations and achieve their full potential in education, training or employment. They can inform on all the various career pathway options and the associated support that may be available.
- 9.11 The Careers Service in Ballymena is currently participating in a 12 month multi-agency pilot service initiated by the Northern Adult Autism Advice Service. The Service is for adults (16+) who reside in the Northern HSC Trust Area with a diagnosis of autism, and those who support them.
- 9.12 Higher Education providers who charge higher than the basic level tuition fee are required to have in place a **Widening Access and Participation Plan** approved by DEL. These plans are produced annually and include information on what the institution plans to do to encourage students from disadvantaged backgrounds (including those with disabilities and learning difficulties) to apply to/enrol on its courses; and then support them to progress through this, achieving a successful outcome.
- 9.13 In addition, Further Education Colleges and Universities carry out a disability needs assessment on each higher education student who present with

autism. This is an evaluation of the support needs of the student, including their specialist equipment requirements and non-medical provider needs. Based on the medical evidence provided by the student as part of the assessment, institutions put in place a package of measures, and will make reasonable adjustments to allow students with learning difficulties and/or disabilities access to the mainstream curriculum, or discrete provision as appropriate.

- 9.14 There is a **Register of Support Providers** in each of the two Northern Ireland universities. The Register is a unique service which provides one-to-one support to disabled students registered on recognised higher education courses at any of the colleges or universities in Northern Ireland. It maintains and develops a resource of freelance professional and non-professional providers, who act in specialist roles to support disabled students. They include: audio-typists; note-takers; dyslexia coaches; study skills mentors; sign language interpreters and campus assistants.
- 9.15 Students on the autism spectrum are well represented in HE colleges in Northern Ireland (0.45% of the HE student body). They are supported effectively through widening participation and individual assessments of need. Reasonable adjustments are made if necessary.
- 9.16 Apart from widening participation, universities fulfil other important roles in relation to autism, including training and research. Both Queens University Belfast (QUB) and University of Ulster (UU) offer extensive training in autism at Masters Level; open learning (Undergraduate level) and pre-degree levels. The training meets international standards of best practice in autism.
- 9.17 The final draft of the **Economic Inactivity Strategy** will be considered by the Executive in near future. Once Executive approval has been secured, the implementation process will commence immediately. The key proposed intervention is to undertake a regime of competitive pilot project testing to identify and test a range of approaches to tackling economic inactivity amongst people with a work-limiting health condition/disability; lone parents

and carers. Whilst the final strategy will not specifically target people with autism, it is likely that some individuals in this group will fall within the 'work-limiting health condition/disability' group.

- 9.18 DEL's Careers Service provides a universal service to clients of all ages and abilities, with a priority focus on those who are at risk of or vulnerable to social exclusion, including those with autism. As a key contributor to DEL's **Pathways to Success Strategy**, the Careers Service case manages all 16 and 17 year olds who do not progress into training, education or employment on leaving school.
- 9.19 **The Local Employment Intermediary Service (LEMIS)** is a community employment initiative designed to help the 'hardest to reach' in targeted areas. LEMIS is available on an outreach basis throughout Northern Ireland to young people aged 16-24 not engaged in education, training or employment. Mentors travel to meet clients with a common employability barrier in their local area. Within the period April 2014 to February 2015, 1,155 individuals Not in Education, Employment, or Training (NEETs) were case-loaded, and at the end of February 2015, 463 individuals (40%) moved into positive destinations. Current contracts ran until 31 March 2015, and through the European Social Fund (ESF) 2014-2020 Programme, there was an opportunity for unemployed adults with autism to avail of qualifications up to level 1, and level 2.
- 9.20 **The Collaboration and Innovation Fund (2012-2015)** is part of the 'Pathways to Success Strategy' for young people aged 16 to 24 who are not in education, employment or training (NEET). The programme aims to improve the employability skills of young people who are experiencing general or specific barriers to employment. It is delivered by 24 projects which aimed to support 6,000 young people by the end of March 2015. The Print Room Project delivered by The Appleby Trust provides support specifically to young people with autism, and has assisted 38 persons to date. Other projects are available to all young people in the NEET category and have supported over 100 young people with autism.

- 9.21 The Community Family Support Programme (CFSP)** is a 'Pathways to Success' initiative, designed to support families with a high level of need to develop the capacity to reach their full potential. During the 26 week programme, families will receive help to address the health, social, economic, educational, employment and training issues that impact on their daily lives.
- 9.22** The CFSP aimed to support 720 disadvantaged families from November 2013 and March 2015. To date, 480 families have been supported in cycle 1 and 2. During cycle 1 and 2, 319 NEETs participated on the programme, with 206 (65%) progressing to positive destinations in education, employment and training. A total of 312 potential NEETs were also supported with issues such as school punctuality; attendance; behaviour; homework and academic performance. A further 240 families commenced cycle 3 of the programme in September 2014. It has supported 28 individuals with autism.
- 9.23** Full-time and part-time Further Education provision is available at a range of levels to suit students with autism. Discrete provision at Entry Level and Level 1 is available for students who have a learning difficulty in addition to autism, with progression and work experience opportunities. Students with autism are treated with fairness and without discrimination when applying for mainstream FE provision, and those with autism on discrete or mainstream courses, are offered tailored assistance, based on their assessed needs through the Additional Support Fund.
- 9.24** Further Education students who choose to disclose their autism are assessed to identify their individual learning needs and, if required, additional learning support is provided. Details of learning support needs are contained within an individual Supplementary Learning Agreement (SLA) which is jointly completed by the college representative and the learner. This agreement is reviewed twice a year to ensure it remains effective and appropriate.
- 9.25** Students with autism, who are enrolled in mainstream provision, can receive classroom support including one-to-one mentoring which is tailored to the

individual needs. In addition, FE colleges offer discrete vocational and life skills courses for people with moderate/severe learning difficulties and/or disabilities, including those with autism. These programmes are aimed at students who, given the nature of their learning difficulty/disability, are unable to access mainstream provision. This involves developing personal and social life skills, occupational and employability skills.

- 9.26 DEL provides £4.5 million per year, ring-fenced funding to FE colleges through the Additional Support Fund (ASF) to support students with learning difficulties, such as autism. The fund is used to help provide additional support to complete a course of study, and progress to further study; employment, or to independent living. £2.5 million of this is used to facilitate appropriate additional technical and personal support, and £2 million is utilised to accommodate students who, by nature of their difficulty/disability, are unable to access mainstream provision. This contributes towards covering the cost of providing smaller class sizes and classroom assistants. The fund has been increased by £1 million over the last two years.
- 9.27 DEL, working in collaboration with the Equality Commission NI; Employers for Disability NI; Belfast City Council and the Northern Ireland Union of Supported Employment, organised a major conference entitled 'Making equality work - recruiting disabled people'. It was held in Belfast City Hall on 9th April 2014.
- 9.28 The purpose of the event was to highlight examples of positive action and practical steps that employers could take to recruit, employ and retain employees with disabilities, including people with autism. It was attended by over 80 employers as well as representatives from the disability sector.
- 9.29 ***DEL's Disability Employment Service*** offers a range of specialist disability employment programmes to assist and support people with disabilities, including those with autism, to prepare for, enter and retain employment.

9.30 In 2012, the Disability Employment Service established a two year pilot project with Northern; North Western and Southern Regional Colleges, to improve the relationship between services, and enhance the transition for young people with disabilities, between the college's vocational programmes and the Employment Service. The majority of students involved, have a learning disability, and are on the Autistic Spectrum Disorder. Some also have additional conditions. Since 2012, 137 students have been referred to the project, 15 of which have autism, and eight of which, have secured employment through this pilot.

10. UPDATE SUMMARY OF KEY THEMES - INDEPENDENCE, CHOICE AND CONTROL

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

10.1 Progress has been made in advancing these actions.

10.2 Awareness training for self-directed support; direct payments and personalised budgets for individuals and families living with autism is due to be implemented by the HSC Trusts on a regional basis. Training however, continues to be offered to individuals and families based on assessment of need.

10.3 The **Northern Adult Autism Advisory Service (NAAAS)**, a multi-agency advice service was piloted in the Northern HSC Trust area from Jan 2014 – Dec 2014. The Northern Trust; National Autistic Society; the SSA Improving Benefit Uptake Team; Citizens Advice Bureau; DEL; the Disability Employment Service and Northern Regional Colleges were all involved in the pilot, an evaluation of which is currently being undertaken by QUB.

10.4 Training in life skills is a core focus of all training for those with autism. Capacity building in schools and with parents in preparing young people for independent living is a process that begins early in a child's life. Focused life skills training is available in Special Schools, and bespoke life skills instruction can also be provided to pupils on an individual or small group basis. Middletown Centre for Autism provides life training to both parents and

professionals. This includes specialist modules in promoting life skills for children and young people with complex needs.

- 10.5 ***The Department for Social Development*** (DSD) has made the Supporting People Programme a priority in 15/16 with the budget being ring-fenced. DSD continue to provide housing related support services to people with a learning disability and/or autism.
- 10.6 In order to ascertain the impact of Welfare Reform on people with disabilities, including those with autism, their families and carers, DSD have briefed their Customer Representative Group (in which Autism NI and the National Autistic Society NI are represented), in respect of the introduction of Personal Independence Payment. Due to the delay in the Welfare Reform Bill becoming law, there has however been no engagement with the Customer Representative Group since September 2013, and there will be no further engagement until a decision regarding the Welfare Reform Bill has been made. Once this happens, it is planned for an information booklet to be issued to all customers.

11. UPDATE SUMMARY OF KEY THEMES - ACCESS TO JUSTICE

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

11.1 Progress has been achieved in a number of areas to advance these individual actions.

11.2 **The Department of Justice** (DOJ) in partnership with the National Autistic Society Northern Ireland produced a guide for criminal justice professionals in Northern Ireland, to assist all practitioners who may come into contact with someone with autism. This was launched in February 2014.

11.3 A strategy to train justice sector staff was developed and implemented in partnership with Autism NI and delivered for staff across the DOJ family.

11.4 Pilot **Registered Intermediaries (RI) Schemes** were launched on target and an evaluation report has been completed and published. To date there have been 50 referrals for Registered Intermediaries for victims, witnesses and suspects.

11.5 DOJ are working collaboratively with Victim Support (as part of the Victim Strategy) to provide a range of advocacy models, including the provision of disability hate crime advocates from a local charity.

11.6 **The Police Service of Northern Ireland** (PSNI) provides support to vulnerable persons detained by the police. This includes: medical support; a

Forensic Medical Officer assessment on the suitability of persons for detention/interview; support during interview, and an Appropriate Adult Scheme and Interpreter's Service.

- 11.7 A Needs assessment for victims and witnesses are carried out by the PSNI and the Victim Witness Care Unit.
- 11.8 A new **Victim Charter** was published in December 2014, along with a summary version, easy-read version and young person's guide.
- 11.9 Work continues to raise autism awareness in criminal justice organisations, through internal and external publications, and articles produced for staff briefings.

12. UPDATE SUMMARY OF KEY THEMES - BEING PART OF THE COMMUNITY

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

12.1 These actions have been achieved and are ongoing.

12.2 *The Arts Council NI*, the *Museums Sector* and the *Inland Fisheries Group* provide regular programmes working with children with autism, and on the autism spectrum. Some of these innovative initiatives are detailed in **section 5** of this report.

12.3 Autism NI is the National Museums' official 'Charity of the Year'. Working in partnership to raise autism awareness, in 2014-15 it plans (subject to resource availability), to deliver weekly learning programmes (in conjunction with Autism NI and the Leonard Chesire foundation) for up to 20 people with disabilities.

13. UPDATE SUMMARY OF KEY THEMES - PARTICIPATION AND ACTIVE CITIZENSHIP

- *Involve people with autism in the design, development and review of relevant policy across Government Departments*

13.1 This action is ongoing.

13.2 All **HSC Trusts** have representatives of people with autism, parents and/or carers on reference groups and local foras that meet on a regular basis.

13.3 The **DHSSPS** hosted an **Autism Workshop** in March 2015. Facilitated by the HSC Leadership Centre, this included speakers from the **HSC Board**, the **SELB**, and **Together For You**, and involved a number of key Community and Voluntary Sector organisations and Service Users. The aim was to seek ways of improving engagement with, and representation of, this sector in the implementation of the Autism Strategy and Action Plan. A key next step will be to secure representation of the C&V sector on the Multi-Agency Implementation Team.

13.4 **The Department of Justice (DOJ)** held a workshop prior to the launch of the **DOJ Victims and Witnesses Strategy**. Invitations to the workshop included people with autism; parents and carers, in order to ensure the needs of those with autism were included in the Strategy.

13.5 **The Department of Employment and Learning** (in conjunction with main NI disability organisations) is currently developing a new '**Employment and Skills Strategy for People with Disabilities**.' There has been extensive engagement with various groups of people representing a range of disabilities, including people with autism. Their feedback and input will be reflected in the public consultation document.

- 13.6 One of the key aims of this strategy is to provide a clear transitions pathway from education through to economic employment; one that will offer a menu of tailored, quality services and support, to assist young disabled people in their pursuit of new skills, employment opportunities and career development.
- 13.7 The Department intends to carry out a public consultation exercise on the proposals contained within the strategy document in April/May 2015, with a target date for the launch of the strategy later this year.

14. UPDATE SUMMARY OF KEY THEMES - LEADERSHIP AND IMPLEMENTATION

- *Provide governance, leadership and direction;*
- *Provide statistical data for autism;*
- *Equality.*

14.1 A number of specific actions have been taken to advance these themes.

14.2 The Department of Health, Social Services and public Safety has provided governance, leadership and direction to all Government Departments and ALBs, and has promoted cross-Departmental working in order to improve the lives of those -with autism, and their families/ carers.

14.3 The DHSSPS and HSC Board publish data on autism services and will now publish data on referrals, people seen and diagnosis. The statistical publication 'Prevalence of Autism (including Asperger's Syndrome) in School Age Children in Northern Ireland 2015' which updates data on prevalence of ASD in school children aged 4-15 years (to include the 2014/15 year), was published by DHSSPS on 30 July 2015. In the last three years, the number of children in Northern Ireland diagnosed with ASD has increased each year from 858 (2012/13); 954 (2013/14) and 1126 (2014/15).

14.4 All Departmental and ALB policies are screened for equality impacts under S75 of the NI Act 1998. Impacts are assessed against all 9 categories under S75, including disability. All Departmental and ALBs' statutory S75 consultee lists contain disability representative groups, which are updated on a regular basis.

15. INNOVATIVE ACTIONS

- 15.1 **The Northern HSC Trust** launched a 'One-Stop' **Adult Autism Advisory Service** in Ballymena in January 2014 servicing the Northern HSC Trust Area. This pilot advice and signposting service, (the first of its kind in Northern Ireland), is available to people aged 16 and over with a diagnosis of autism.
- 15.2 The Service was set up to help provide advice and support to people with autism on key aspects of their daily lives including health; education and social security benefits. Partners include: the Department of Employment and Learning Careers Service; Jobs and Benefits office; Occupational Psychology Service; Disability Employment Service; Department of Social Development; Northern Ireland Housing Executive; Northern Regional Colleges student services; Citizens Advice Bureau, and the National Autistic Society.
- 15.3 Facilities for service users include:
- One-to-one time limited advice sessions;
 - Signposting to services across a range of agencies including housing and social security;
 - Supporting individuals to develop a range of natural supports, including self-advocacy to assist them towards independence and social inclusion;
 - Post diagnostic group support.
- 15.4 A similar service called a 'First Stop Shop' was also launched by **Belfast HSC Trust** in January 2015, in the Belfast Library called Belfast Adult Autism Advice Service (BAAAS). This operates as a drop-in facility for clients with employment-related queries; Careers Service or benefits advice.
- 15.5 An **Asperger's Bootcamp** provided by the **Northern HSC Trust** offers direct intervention for young people to increase their awareness of their diagnosis, and provide them with practical strategies to manage the impact of autism in

everyday life. Feedback from both participants and their parents was very positive, highlighting that the Bootcamp is a very useful programme to run.

- 15.6 The *Northern HSC Trust* also provides an **Autism Paediatric Intervention Initial Advice Clinic**, via a telephone call appointment offered to those referred for specialist treatment. Initial autism specific advice will be provided to help parents/carers to manage the difficulties discussed. In addition to this initial advice, the most appropriate intervention for the child/young person and their family will then be identified.
- 15.7 The *Northern HSC Trust* are also currently working on a joint project with the *North Eastern ELB* youth provision to develop an ‘app’ to make all youth provisions more accessible to individuals with autism.
- 15.8 The *Department of Regional Development* launched the **Access Travel Wallet** following consultation with the autism sector in April 2014. It is designed to assist people with a disability and/or communication difficulties; such as people with autism. The free wallet is the latest initiative to help encourage people with autism to travel independently and with confidence. It is easily recognisable with its yellow fluorescent cover, and has credit card sized plastic pockets. It can be used to display written phrases or pictures to describe, for example, where the user wishes to travel.
- 15.9 The ‘Wallet’ is designed to carry information that the holder may consider helpful to share with public transport staff. This will also help public transport staff have a better understanding of the travel requirements of such passengers.
- 15.10 In June 2014 the *Department of Employment and Learning* launched its **Assured Skills**, a project for investors interested in creating jobs in Northern Ireland. They engaged with Specialisterne through their fourth Software Testers’ Academy to pilot four of the thirty seven places for participants with autism. Specialisterne not only recruited the four participants and identified job placement opportunities, but delivered training to the Assured Skills team;

the two training providers - South Eastern Regional College and Belfast Met, and to staff within the placement companies.

15.11 The sixteen week Academy started in October 2014 with a ten week college-based training, followed by a six week work placement completing in February 2015. One of the four participants achieved employment prior to the work placement, and the remaining three achieved employment with their placement company.

15.12 **The Arts Council NI** is providing regular weekly music programmes working with children with autism and on the autism spectrum. The Museums sector provides the following Lifetime Opportunities:

- Intensive, supervised therapeutic work experience for two young adults with separate and complex needs, working on separate projects for half a day each, every week throughout the year. They will also be offering free visits for 40 special schools each year. Therapeutic work placements are available to two adults with complex needs.
- Free visits to the Armagh Planetarium are offered to all forty special schools in Northern Ireland; Rhythm and Rhyme sessions and story times on a monthly basis for children aged 2 – 4 years with special needs, including developmental delay and autism.

15.13 **The Inland Fisheries Group** has established a **Community Outreach** team to increase participation in angling, either directly or through Angling First Ltd (AFL). The Institute for Government (IFG) has provided £10k to the charity which uses angling to address a range of issues. IFG/AFL has worked with various groups including individuals and parents, or representative groups on autism at the local level.

16. KEY ISSUES

Implementation Structures

- 16.1 The Autism Act requires the DHSSPS to lead on the progress of the actions in the Autism Strategy, which requires co-operation and input from all Northern Ireland Government Departments, and input from service users and carers, as well as the Community and Voluntary sector.
- 16.2 The *DHSSPS* hosted an **Autism Workshop** in March 2015. Facilitated by the HSC Leadership Centre, with speakers from the *HSC Board*, the *SELB*, and *Together For You*, this involved a number of key Community and Voluntary Sector organisations and Service Users. The aim was to seek ways of improving engagement with, and representation of, this sector in the implementation of the Autism Strategy and Action Plan. DHSSPS are currently reviewing a number of suggestions to ensure that there is adequate representation of Service Users and of the Community and Voluntary sector in delivering the Strategy; monitoring progress across the key themes, and in planning and developing future actions. Key next steps will be to secure representation of the C&V sector on the Regional Multi-Agency Implementation Team, and to broaden representation of key Agencies; C&V sector and Service Users on local Trust-level forums.

Prevalence

- 16.3 Using data from the schools census, the estimated prevalence of autism (including Aspergers Syndrome) has increased across Northern Ireland between 2009/10 and 2014/15 - from 1.3% of the compulsory school age population to 2.2%, with males almost five times more likely to be affected by autism (including Aspergers Syndrome) than females. The increase in prevalence may indicate that, as awareness of autism has increased, there is an increased focus on early identification of the disorder.
- 16.4 In general, children in the least and most deprived areas (as defined by the Multiple Deprivation Measure - MDM) appear to have the highest prevalence rate of autism, with those children in MDM deciles closer to the middle of the

scale, having the lower rates of autism. 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 better access to services.

- 16.5 In addition to the above, Trusts are gathering their own data on incidence of autism within their respective areas. Over time this will build into prevalence figures for children and adults at both Trust and regional level.

The information for autism relating to children's services is provided by the Trusts to the HSC Board on a monthly basis. Specific data relating to referrals, assessments and diagnosis is provided from the HSCB to the DHSSPS on a quarterly basis

- 16.6 Information for adults is still under development by the HSC Board, via a monthly return. There is no current formal mechanism for transmission of this information from the HSCB to the DHSSPS, but it is presently dealt with on an ad-hoc basis.

- 16.7 The data is published on the DHSSPS web site

at:<http://www.dhsspsni.gov.uk/index/statistics/downloadable-data.htm>

Audit of Paediatric Autism Services

- 16.8 A regional Sensemaker Audit of paediatric autism services is to commence in October 2015. Organised by the Health and Social Care Board in conjunction with the Public Health Agency, (as part of the 10,000 Voices Project), this audit involving service users; carers and staff from all five Health Trusts, will be carried out to gain feedback on their experience of Health and Social Care Services. The project is to be completed by summer 2016, and the findings and recommendations from the Audit will inform service change, improvements and future development of Autism services.

17. IDENTIFIED RISKS

Regional Autism Services

- 17.1 As a result of increased demand in autism services (which has risen from approximately 1,500 children and young people referred in 2010, to 2,936 in 14/15), it is not possible, based on current service capacity, to provide assessments in line with the 13 week autism access standard. This position is further compounded by current fiscal constraints.
- 17.2 In this context it is not currently possible to guarantee early intervention as outlined in the Autism Strategy, without additional funding to further develop autism specific assessment services, and to extend the portfolio of available family support. However, as noted below, provision of general support is not predicated on a diagnosis.

Clinicians

- 17.3 In line with NICE Guideline 128 '*Autism Diagnosis in Children and Young People*' and the '*Six Steps of Autism Care for children and young people in Northern Ireland*' (2011) Care Model, the assessment and diagnosis of children and young people will involve a minimum of 2 clinicians (combination of Paediatrician; Psychologist; Occupational Therapist and/or Speech and Language Therapist).
- 17.4 The current number of clinicians trained to diagnose autism is not sufficient to meet overall demand in Northern Ireland. Each child and young person would require up to 44 hours care to address the demand capacity gap, and it is estimated, to achieve that, an additional 48 WTE clinical staff would be needed. In order to reduce waiting time breaches of the 13 week target, it is approximated that an additional 19,500 care hours would be needed this equates to 20-23 WTE Clinical Staff, at a cost of approximately £1m. However, given the current financial constraints no further investment has been identified to meet this need at present.

Service Model

17.5 Whilst additional resources are required to address the current demand on regional Autism services, the Health and Social Care Board is working with all HSC Trusts to develop a new standard operating model. This model will focus on developing early intervention teams and will seek to integrate and align autism services with other child development and young people's mental health services. It is anticipated that, in the medium to longer term, this will help in the development of new ways of working with a view to improving access to a timely assessment.

Family Support

17.6 The DHSSPS acknowledges that the increase in waiting times is unhelpful and can delay autism specific intervention; however, it is important to note that child and family support is not predicated on a diagnosis. Each HSC Trust, as part of its triaging process, is required to identify risks and provide families with information about how to access family support services whilst waiting on autism specific assessment. This could include: Community Paediatrics; Speech and Language Therapy; Occupational Therapy; Psychology; CAMHS; Social Services or Educational Psychology.

Assessment

17.7 It should be stressed that diagnosis as to whether or not a child has autism, only occurs after a thorough process of assessment, involving a number of professionals over a period of time which may last a number of months. It is therefore inevitable that there will be a period when children are awaiting diagnosis, as the assessment is not yet completed.

**Prepared by: DHSSPS
Learning Disability Unit
Room D1, Castle Buildings
Stormont Estate**