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Scottish Strategy for Autism: Progress Report – Foundation Stage (0-2 Years)

Scottish Autism Strategy Progress Report – Foundation stage (2 years)

Introduction

The Minister for Public Health launched the Scottish Strategy for Autism on 2 November 2011 and announced an investment of £13.4 million over 4 years to improve the lives of people with autism and their carers, and to build on improvements to autism services and access to these services. The 10 year Strategy, representing a collaboration between the Scottish Government and COSLA, has now reached the end of its Foundation stage (2 years). This report reflects progress so far.

The Strategy's Vision is that individuals on the autism spectrum are respected, accepted and valued by their communities and have confidence in services to treat them fairly so that they are able to have meaningful and satisfying lives.

Implementing the Strategy's 26 recommendations is key to achieving our vision. Some recommendations are about reviewing and consolidating existing practice whilst others are about improving practice. However, all are geared towards ensuring improving services and access to services for people on the autism spectrum.

Overview of Progress

In line with Recommendation 1 of the Strategy, the Reference Group was reconvened, including COSLA, to oversee developments and to progress change. Whilst it maintained a strategic overview of the first 2 years of the Strategy, the Strategy Recommendations for this period were primarily driven forward by Subgroups -comprising professionals and others with a wide variety of expertise and experience- which met on a regular basis to discuss their work in progressing each of their allocated Recommendations.

We asked the Subgroup leaders to provide us with a summary of progress in the first 2 years and an overview of their work can be found in Annex 1.

Other significant work around the Strategy has also been on going and is captured in this report. Further Background Information on the Strategy can also be found at Annex 2.

Key Highlights

Scottish Good Autism Practice Journal and Conference

In line with Recommendation 9 and supported by funding from the Scottish Government, Subgroup 1 collaborated with the British Institute for Learning Disability (BILD) to produce and publish a Scottish edition of BILD's Good Autism Practice (GAP) Journal ('the Journal'); the express aim being to disseminate new and innovative models of good autism practice in Scotland as part of the wider work of the Strategy. The Journal features a wide range of papers from professionals and academics in the field of autism which show case projects and programmes which are ground-breaking and innovative, and which have the potential to enhance the quality of the lives of children, young people and adults on the autism spectrum, as

well as those who work with and care for them. Much of the information and many of the ideas contained within the Journal can be used freely now at no extra cost to services – not only in Scotland but elsewhere in the UK and internationally.

The GAP conference in November 2013 saw the launch of the Journal and brought together a mix of local authorities, autism professionals and people on the spectrum. The keynote address was given by Michael Matheson – Minister for Public Health - who was then followed by a number of other high profile speakers. Participants also attended a series of workshops throughout the day which revolved around some of the key papers in the Journal. All speakers and workshops were very well received as indicated in the positive feedback from the event.

This sharing of best practice contributes to goals 2 and 4 of the Foundation Stage in terms of improving understanding of autism and empowering services to improve their support to people with ASD, and by showcasing examples of good post-diagnostic support.

An overview of the conference is attached at Annex 3 and copy of the Journal can be downloaded from the Strategy website or is available hard copy. It has been internationally acclaimed and several hundred copies have been distributed.

www.autismstrategyscotland.org.uk

Menu of Interventions

In line with Recommendations 10 and 11 of the Strategy, Subgroup 3 collaborated with a multi-agency group, including people on the spectrum and their parents and carers, to produce a much anticipated Menu of Interventions ('the Menu') - a guide to interventions and supports for people on the autism spectrum. The aim of the menu is to help identify available advice and support and set out the referral and assessment process for all other services and interventions.

The menu outlines the background and rationale for the development of the Menu, drawn up to meet the Recommendations 10 and 11 of the Strategy. It lists broad outcomes, restates the requirements of good autism care provision, discusses the potential measurement of outcomes and provides an overview of interventions and supports. In addition, a list of the difficulties and challenges common to people on the spectrum were discerned following lengthy inclusive consultation and it is hoped that identifying ways of addressing these issues provides a practical framework for interventions and supports where required.

This menu is ground-breaking and was much anticipated. It was also launched at the GAP event in November 2013 and will be further disseminated through an event in May and a series of road shows throughout the summer of 2014.

The menu contributes to goals 3 and 4 of the Foundation stage by highlighting the range of interventions available and where they can be used efficiently and effectively in order to support people with ASD.

A copy can be downloaded from the website or is available hard copy.

www.autismstrategyscotland.org.uk

The Mapping Project

In line with Recommendation 8, some of the Strategy funding has been dedicated to mapping out local autism services and improving coordination of these services. Coinciding with a one-off investment of £35k for each local authority in Scotland to develop their own local Autism Action Plans, the aim of the Autism Mapping Project ('the Project') was to:

- consult with people with autism, their families and carers, service providers and local agencies
- map out existing autism service provision in all local areas in order to build up a local and national picture
- identify priority areas for action that reflected local need
- work collaboratively with local partnerships, councils, NHS, criminal justice, third sector organisations and other relevant public bodies
- provide Local Authorities with a 'Service Map' of their area, to inform their Autism Action Plans

The Project was managed by a partnership comprising the National Autistic Society Scotland, Autism Initiatives Scotland, Scottish Autism, the Convention of Scottish Local Authorities (COSLA), the Association of Directors of Social Work (ADSW) and the Scottish Government.

A range of agencies/service providers/individuals from local authority areas contributed data to the Project in varying degrees and a local 'Service Map' – based on an analysis of the data – has been provided to each Local Authority. In turn, the Service Maps have helped inform Local Authority Autism Action Plans/Strategies.

A report of the Project captures the key data gathered and gives a useful snapshot of the landscape of Scottish autism services. Key findings indicate the following areas could benefit from improvement:

- **Inclusion of people with autism and their carers:** people with autism and their carers are not being viewed as 'equal partners' in the planning and design of services for people with autism and the lack of support available
- **Partnerships and multi-agency working:** inconsistencies in multiagency working and information sharing impacting on access to services and early intervention or prevention strategies
- **Information/Knowledge exchange:** information for carers not always accessible at local level
- **Leadership and ownership:** in local areas leadership became interchangeable with the role of coordination. Project data shows that 46.7% of respondents were not sure who had the lead role for autism locally
- **Services:** demand for employment opportunities, access of respite and advocacy services and access to diagnostic services

- **Transitions:** gap in transitions between children and adult services and gaps in support in all other life transitions

- **Training:** knowledge of autism not in the mainstream and could be improved within the public sector

The evidence created by the Project and presented in the mapping report indicates that there are key elements where an investment in autism coordination could support the work of local autism community partnerships and progress the 10 indicators of good practice to bring about better outcomes for people with autism.

This contributes to goals 1,2,3 and 4 of the Foundation stage by setting out the autism services landscape in each local authority, highlighting what's working well and what's not, and providing a framework - in the form of a Service Map - for local authorities to plan and improve future service delivery.

A copy of mapping report is available for download from the Strategy website:

www.autismstrategyscotland.org.uk

Local Authority Action Plans

As part of the Autism Strategy funding, the Scottish Government awarded £35,000 to each local authority in Scotland to support the development of local autism strategies and associated action plans. This is in line with the Strategy's ten indicators of good practice in the provision of effective autism services which includes:

A local autism strategy - developed in cooperation with people across the autism spectrum, carers and professionals - ensuring that the needs of people with autism and carers are reflected and incorporated within local policies and plans.

Plans received so far are publicly available on the Strategy website.

Autism One Stop Shops

In line with Recommendation 11, Strategy funding was dedicated to the roll-out of 6 new One Stop Shops across Scotland. Two successful One Stop Shops had already been established in Glasgow and Edinburgh. Based on voluntary sector models and working in partnership with Local Authorities, the NHS and local groups representing parents and those on the autism spectrum, each One Stop Shop is tailored to local needs. New facilities are now up and running in Fife (Dunfermline),

Highland (Inverness), Lanarkshire (Motherwell), Grampian (Aberdeen), Ayrshire (Kilmarnock) and Perth and delivery within the One Stop Shops is being led by Scottish Autism, National Autistic Society Scotland and Autism Initiatives.

One Stop Shops offer people with autism, their families and professionals information and advice about autism and help people gain access to local support services. As well as acting as an information hub, the One Stop Shops work closely with other groups and agencies, collaborating to understand and respond to the needs of the autism community. Each One Stop Shop will have local variances, however, they each aim to provide:

- support to access services
- guidance to overcome barriers such as an unaddressed diagnosis and delayed intervention of support
- access to a library of information and resources about autism
- a safe and friendly place to speak confidentially to someone who understands autism
- one-to-one sessions, workshops, training days and group activities for children, families and professionals

Autism Initiatives' One Stop Shop – known as 'No.6' - and the One Stop in Dunfermline recently hosted an event for the Scottish Government, supported by young people on the spectrum. The Dunfermline facility show-cased their work, including several written statements of positive feedback from parents and carers saying how much the One Stop Shop had improved the quality of life for their children. Our visitors from England, Wales and Northern Ireland were all extremely impressed with what they saw.

This contributes to goals 1,2,3 and 4 of the Foundation stage by empowering families through increased knowledge and support to access appropriate services and giving them a voice via appropriate advocacy support.

An evaluation of the One Stop Shops is currently underway and a report will be published around November 2014.

Further information about the One Stop Shops can be found on the Strategy website:

<http://www.autismnetworkscotland.org.uk/one-stop-shops/>

Summary Guide to Employment, Policy, Structures and Initiatives in Scotland

In line with Recommendation 26 Autism Initiatives, on behalf of Subgroup 4, has produced and published a Summary Guide on Employment Policies and Initiatives in Scotland ('the Guide'). Supporting people with autism into work is complex and multi-faceted with a range of policies, support programmes and initiatives all aiming to improve employment outcomes for people with disability, however, there are no autism-specific employment strategies or policies. The Guide is intended to provide a background to employment policies and initiatives in Scotland and is illustrated with some examples of services and initiatives. The purpose is to provide an overview, with links to further information which may be useful for staff supporting people with autism who are moving towards employment.

The primary audience for the Guide is professionals who are involved in supporting people with autism but who are not familiar with the complex environment of employment policy and structures. However, it is a useful guide for everyone.

Publication of the Guide also culminated in its launched at a highly successful learning event in October which was hosted by Autism Network Scotland. This included several presentations from young people on the spectrum who had set up their own employment initiatives to gain experience of the work environment.

This contributes to goals 1 and 2 of the Foundation stage by supporting people with ASD to find employment and by supporting and encouraging employers to realise the potential benefits of employing someone with ASD.

The Guide is available for down load from the Autism Network Scotland website.

<http://www.autismnetworkscotland.org.uk/category/resources/>

Autism Network Scotland ('the Network')

In line with recommendation 15 and supported by funding from the Scottish Government, the Network supports the strategy recommendations by hosting and maintaining the Scottish Strategy for Autism website and it serves as a reliable information hub for individuals, families, carers and professionals. It creates opportunities for sharing knowledge and information through its virtual forums and networks, and supports organisations in responding to gaps in knowledge and understanding, service provision, professional development and research. The Network also serves as a catalyst for sharing examples of good practice amongst professionals.

Members of the Network are also active on the ASD Reference group and Subgroups, and Network advisors have worked as part of the Strategy's wider initiatives, including the Autism Toolbox and the Mapping Project.

Furthermore, the Network has hosted and facilitated a series of valuable learning events in support of the Strategy for example:

- an event to launch both the autism strategy and the network websites
- a series of events, in conjunction with the autism Mapping Project team, aimed at gathering opinions and experiences of people working to improve the lives of people with autism around the country
- a 'tackling transitions' seminar which enabled practitioners to come together to problem solve and share experiences with professionals from a wide range of disciplines
- an event for Local Authorities to support them in development of their autism Action Plans/Strategies
- an employment seminar to showcase employment success stories and launch Subgroup 4's 'employment guide'
- a series of early years network events
- social work network event
- education network
- understanding behaviour learning events
- supported charities in hosting events (NAS growing old with autism)
- showcase development fund projects

The Network have also been instrumental in developing an event to launch the Menu of Interventions Guide, which will include a series of road shows across Scotland, and are planning a second Transitions event in the summer of 2014.

This contributes to goals 1,2,3 and 4 of by improving knowledge, allowing opportunities for networking and knowledge sharing and by showcasing examples of good autism practice and successful co-production.

You can access a copy of the Network's first annual report here:

<http://www.autismstrategyscotland.org.uk/news/autism-network-scotland-publish-their-first-annual-report.html>

Introduction of Open University and Strathclyde University courses for university level training

In line with Recommendation 17, Strategy funding was made available over 3 years to the Open University and the University of Strathclyde to offer free distance learning courses to increase the understanding of autism. This training is aimed at professionals and parents and those with an interest in autism and its purpose is to increase awareness of autism and ensure that autism service providers understand the needs of people with autism and are able to respond appropriately.

The OU module has run since 2009. It can be studied as a standalone module or as part of an Honours Degree in Psychology or Health Sciences. The course intake includes parents, people on the spectrum and people working with autism and 200 places were subsidised in the 1st intake. These proved very popular and were snapped up very quickly.

175 students registered at the start of the 2nd intake in November, the Scottish funded places were filled straightaway, and there was a waiting list of people keen to enroll.

The OU with Jane Neil-Maclachlan's help drafted some case studies of autism in adults. These were piloted at some autism workshops. As a result these can be uploaded to our module website for the next presentation.

The University of Strathclyde is a Post Graduate 8 unit module which can be completed with or without assessment. It is a core module and is one third of 3 modules required for the PG Certificate in Autism. 148 places were awarded in the 1st intake and the training was offered On Campus, via Outreach or Distance Learning. The course attracted interest from a broad range of applicants including clinicians, educationalists, parents and individuals on the spectrum and social workers.

This contributes to goals 1 and 2 by raising awareness of autism, improving understanding and building knowledge and capacity.

Further information can be found on the Strategy website here:

<http://www.autismstrategyscotland.org.uk/news/university-of-strathclyde-postgraduate-autism-module-places-available.html>

<http://www.autismstrategyscotland.org.uk/news/the-scottish-government-launches-new-open-university-training-initiative-for-autism-course.html>

Autism Development Fund

The £13.4 million announced by the Minister for the Scottish Strategy has included funding of over £4.5 million towards an Autism Development Fund. The purpose of the Fund has been to encourage both local and national organisations to develop local projects to improve delivery of local autism services on the ground.

The geographical spread of organisations has ranged from the Borders to Shetland and the range of projects has included improvements to local services, employment support, training, early interventions, support to carers and support for transitions.

The Fund has been immensely successful, bringing benefits to many projects within small, local organisations such as schools and community groups.

This contributes to goal 4 of the Foundation stage by supporting local projects which provide post-diagnostic support for families and individuals.

The list of successful projects is set out in Annex 4

Autism ACHIEVE Alliance – Autism Spectrum Disorders: Waiting for Assessment

The Autism ACHIEVE Alliance (AAA) is a Scottish Government funded multi-disciplinary collaboration between Queen Margaret University, NHS Lothian, and University of Edinburgh. The Autism ACHIEVE Alliance (AAA) was asked to investigate waiting times in the diagnosis of Autism Spectrum Disorder (ASD), as per the Scottish Strategy for Autism Recommendation 21: *'It is recommended that an assessment of national waiting lists is undertaken to clarify the extent of delays and that the ASD Reference Group considers and responds to these findings'*.

Phase 1: AAA were asked to not only establish the extent of delays, but to find out what is causing them and what can be done to address this at a national level, so that there is a consistent, sustainable approach across Scotland. In addition, this research was designed to be able to contribute information to other Scottish Strategy for Autism recommendations, including Recommendations 22, 23, 24 and 25.

Phase 2: AAA were asked to work with adult service to support them to reduce their waits.

Progress to date:

- AAA have carried out research with 8 child and 8 adult teams. The main problems found with adult diagnosis is that a) the average age of diagnosis for adults is 31.2 years b) many people throughout Scotland who do not have a co-occurring learning disability or a mental health problem, have no access at all to a diagnostic assessment.
- AAA have clarified the causes and extent of delays in the diagnosis of autism, which is linked to Recommendation 21 of the Scottish Strategy for Autism.
- AAA have created a national action plan to address the causes of the delays and how to reduce them, and have worked with adult services to implement this plan.

We are currently looking at how this work can be shared nationally and will share further information on the outputs from this project as soon as we can.

This contributes to goal 3 of the Foundation stage by supporting health services through training and capacity building, thus empowering them to reduce waiting times and facilitate quicker and smoother diagnosis for individuals.

The Microsegmentation of the Autism Spectrum

The Scottish Government are funding a research project looking at which early interventions work for people with autism and their cost-effectiveness. This builds on earlier work by Professor Knapp and is linked to Recommendation 5 of the Scottish Strategy for Autism.

The primary aim of this study is to identify the escapable costs of autism, that is, those which would not be incurred with early and appropriate interventions for individuals on the autism spectrum, and to provide the evidence base on which these can be applied to the context of the population of Scotland. It will do this by carrying out a *micro-segmentation* of the autism spectrum its co-occurring conditions and its associated issues. This will form a basis for providing a conceptual map of the autism spectrum.

The results will be mapped on to the most accurate demographic data that can be established for the population of Scotland. This will provide a rational basis for planning the services and supports that will be required to meet the needs arising.

The core research team consists of: Professor Tommy MacKay, Professor Martin Knapp, Professor Jim Boyle and Michael Connolly.

Progress to date:

- The first phase of the study was a scoping exercise which focused on the identification of research questions, the exploration of different models to serve as a basis for economic analysis, the identification of some key issues from the current literature and the preparations for a fieldwork study.
- This resulted in three main strands of research, the first two of which are approaching completion. *Strand 1* comprises a systematic review and meta-analysis of prevalence studies on the autism spectrum. The purpose of this is to provide more finely calibrated prevalence data that will inform our understanding of the various segments and facilitate more accurate statistical modeling and economic analysis. *Strand 2* comprises a systematic review and meta-analysis of IQ levels across the autism spectrum population, as a key factor moderating outcomes for individuals. Again, more accurate information on this variable is central to any study relating to economic impact.
- Analysis of the extensive literature relating to the autism spectrum, their comorbidities and their associated features indicates that the multi-faceted ways in which autism presents do not translate readily into practical impact on the actual quality of life and life trajectories of individuals on the spectrum, and of their needs for service provision. A means is required of looking beyond the many

ways in which the population may be segmented to ask what that means in practical terms for individuals, their carers and their families.

The primary focus of *Strand 3* therefore is a fieldwork exercise involving a survey of a sample of individuals on the autism spectrum in Scotland, with data on the sample provided both by the individuals themselves, where possible, and by their parents and carers. This is geared towards illuminating life trajectories across the lifespan in relation to the presentation of autism, its comorbidities and its associated features, together with the implications for service provision. This will be mapped on to the most accurate available demographic data that can be established for the population of Scotland in order to provide a rational basis for planning the services and supports that will be required to meet the needs arising, and for assessing economic impact.

The research is on-going and will conclude in 2014.

This contributes to goal 4 of the Foundation stage by illustrating that, in many cases, individuals with a diagnosis of ASD can have productive working lives and contribute to the economy.

Conclusion and forward look

Much has been achieved in the first two years but there is much still to do. Specific tasks to be carried forward by the groups have been identified as follows:

- Transitions work, including a second event
- NHS Education training framework
- Menu of Interventions event/roadshows and NHS Education training framework
- Second Employment event and Life in Colour Exhibition II
- SIGN guidelines
- Commissioning guidelines

At workshops in May, we worked with key stakeholders to identify priorities for the next phase of delivery of the national autism strategy. A definitive work plan, setting out strategic and achievable goals, is currently being developed and will be shared in due course. We also discussed new structures for the oversight of this work to allow a more focused and streamlined approach to delivering the Strategy's recommendations going forward and we are testing these ideas with stakeholders.

We will also aim to report on progress against the Strategy annually going forward.

Annex 1

Subgroup 1: Achieving Best Value for Services

Recommendation	Progress	Action/Status
<p><u>Recommendation 5:</u> It is recommended that Knapp's work on the economic costs of autism is analysed and applied to the Scottish context to inform strategy and planning in what interventions lead to positive impacts, both for individuals and for the economy as a whole. Particular attention should be paid to his 'invest to save' assertion that if 4% of those with Asperger's were given appropriate support into work, this would ultimately mean that those individuals may not require services and could contribute to the economy.</p>	<p>Tommy Mackay delivered a presentation to the group on the aims and objectives of the Microsegmentation Project.</p> <p>Primary aim of the study is to identify the escapable costs of autism, that is, those which would not be incurred with early and appropriate interventions for individuals on the spectrum, and to provide the evidence base on which these can be applied to the context of the population of Scotland.</p> <p>It will do this by carrying out a 'micro-segmentation' of the autism spectrum, its co-morbid conditions and its associated problems. This will form a basis for providing a conceptual map of the autism spectrum.</p> <p>Tommy's presentation served to further the group's understanding of the Project.</p>	<p>Awaiting outcomes of the Project.</p>
<p><u>Recommendation 6:</u> It is recommended that the effectiveness of implementation of the Commissioning Guidance is reviewed by the Reference Group by facilitating an audit of current [Local Authority]</p>	<p>Initial engagement with commissioners of services via the ADSW Learning Disability Subgroup. The aim being to gain an impression of how the autism commissioning guidance was being used and how it could be improved. Some</p>	<p>Commissioning is a major issue and impacts on delivery of other recommendations. Furthermore, SDS means that the commissioning landscape has changed since the launch of the Strategy, therefore this recommendation may</p>

service commissioning.	engagement and verbal feedback. Intelligence being gathered on approaches to auditing commission in other parts of the UK and a summary will be submitted in due course.	need to be reviewed in that context. To consider discussing further as a main Reference Group item and await feedback from the Microsegmentation project.
<u>Recommendation 7:</u> It is recommended that the ASD Reference Group commissions research to examine and compare the outcomes in relation to quality of life for those who are supported by autism service providers and individuals who access generic provision, and that relevant findings are used to inform revised guidance for commissioners of services for people with ASD.	Been considering what the parameters of this should be and potential links with Recommendation 6.	Need a better understanding of the process of commissioning research and associated costs.
<u>Recommendation 8:</u> The ASD Reference Group, in collaboration with autism service providers, will identify the key determinants of service provision that result in improved quality of life for people with ASD, across the spectrum and across the lifespan.	Met with Subgroup 6 – people with autism and their carers – to discuss and gather feedback. Possible links with Recommendation 7.	Further work to be done in 2014.
<u>Recommendation 9:</u> It is recommended that the ASD Reference Group hosts an event to evaluate and recognise good practice in Scotland to disseminate models of practice, to evaluate success, recognise benefits and limitations and agree how to develop good models across the	Submitted a proposal to collaborate with the British Institute for learning Disability to publish a Scottish edition of their Good Autism Practice (GAP) Journal. GAP conference delivered in November 2013 which was highly successful.	Will consider how to build on this and promote dissemination of good practice e.g. maintaining the journal in some form or perhaps an annual edition. Also some thoughts around developing a Knowledge and Practice portal for sharing and learning across the

<p>country in a way that is cost-effective.</p>	<p>Special Scottish edition of the GAP journal published in November 2013 and launched at the GAP event.</p>	<p>country. To be discussed further.</p>
<p><u>Recommendation 10:</u> It is recommended that agencies and services develop a menu of interventions including advice, therapeutic interventions and counselling for children, young people and adults with ASD that are appropriate and flexible to meet individual need. This menu should identify advice and support that is immediately available, and set out the referral and assessment process for all other services and interventions.</p>	<p>This work has been taken forward by Subgroup 3 – Diagnosis, Intervention and Support.</p>	
<p><u>Recommendation 11:</u> It is recommended that consideration is given to the specific supports needed for the more able individuals with ASD.</p>	<p>Been discussing this under the ‘Quality Scotland: Public Service Improvement Framework’ and looking at ways of increasing awareness and knowledge of autism at a strategic and service level, including their Access to Learning system (A2L). The platform is used by all Local Authorities, Fire and Police Services as well as some voluntary organisations.</p>	<p>This work will also progress the strategic goal of increasing and improving access to mainstream services. This may also be of relevance to Recommendations 6,8 and 9.</p>

Subgroup 2: Cross Agency Collaboration and Involvement

Recommendation	Progress	Action/Status
<p><u>Recommendation 13:</u> It is recommended that the ASD Reference group explores options for developing user and carer capacity to be able to participate in local planning processes.</p>	<p>Carried out a sample scope on what the NHS, LA and voluntary organisations are doing locally in order to establish good practice examples.</p> <p>Reports received from One Stop Shops about how they support involvement from people on all parts of the ASD spectrum.</p> <p>Looked at developing guidelines based on National Standards for Community Engagement.</p> <p>Looked at alternative guidelines based on good practice on engaging carers.</p>	<p>Consultation on proposed guidelines on consultation.</p> <p>To consider launch of guidelines and corporate logo.</p> <p>Training or presentations to Local Authority staff, Community Planning Partnerships etc.</p> <p>To consider resources needed – consultant/employee/funded project/member of the Subgroup.</p>
<p><u>Recommendation 14:</u> It is recommended that the SDS Strategy Implementation Group and the SDS Bill Reference Group ensure representation from the autism community so that their interests are taken into account as further developments take place.</p>	<p>Organised a consultation meeting with people with autism and their families to comment on the proposed guidance and regulations for the Self-directed Support Act.</p>	<p>Current developments in SDS are likely to take account of the interest of people with autism in the same way as other people are considered. To check through the Whole Life Stage.</p> <p>To have future discussion on implementation of SDS and implications for people with autism say 12-18 months after implementation of the Act.</p> <p>To consider resources needed – conference costs etc</p>

<p><u>Recommendation 15:</u> It is recommended that existing reports on the work of Scottish Autism Services Network are formally evaluated with a view to assessing its long-term viability and effectiveness.</p>	<p>Currently the Network is funded for 3 years and it would be advantageous for this to continue for the duration of the Strategy.</p>	<p>The Group is kept up to date with developments but has no plans to take any action until nearer the end of the 3 year funding. (no resource implication)</p>
<p><u>Recommendation 16:</u> It is recommended that the ASD Reference Group contributes to a review of the SIGN guidelines and, in doing so, considers where and how best this innovation might be replicated for adults and other relevant professions.</p>	<p>Currently postponed but the group will monitor.</p>	<p>No resource implications.</p>
<p><u>Recommendations 17:</u> It is recommended that the Training Subgroup of the main Reference Group is reconstituted and strengthened by the inclusion of an SCLD representative to undertake an audit of existing provision and to take evidence from grass roots trainers with a view to recognising strengths and gaps as well as identifying the means by which to further improve what is on offer.</p>	<p>Introduction of Open University and Strathclyde University courses for university level training.</p> <p>Examined and considered the applicability of a Scottish Framework for Autism Training.</p> <p>Supported the application by NES to look at good practice in Autism training in Scotland.</p> <p>Developed a proposed 4 tier model for classifying and standardising autism training in Scotland.</p>	<p>Will work with NES to look at outcomes from the funded NHS autism training project, particularly the effectiveness of training already in place and standards for improvement in delivery.</p> <p>Seek to extend NES 4 tier training project to Local Authorities, voluntary and private sector.</p> <p>Need to consider resources to classify existing training, draw up clear standards for different tiers.</p> <p>Encourage the opportunity for people with autism co-delivering autism awareness training.</p>

<p><u>Recommendation 18:</u> It is recommended that good</p>	<p>Worked with Scottish Transitions Forum to</p>	<p>Continue to work in development of national</p>
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<p>practice transition guidance is developed, building on from existing educational guidance, in order to support the lifelong challenges facing people with autism as they make daily and life-stage transitions.</p>	<p>develop good practice guidance on the support young people receive through life transitions.</p> <p>Introduced the funded projects to the good practice guidance on transitions.</p> <p>Liaised with Autism Network Scotland re. their On-line Transitions Survey and Transitions Event.</p>	<p>good practice transition guidance and monitor implementation and outcomes.</p> <p>Co-organise with other groups a National Transitions event to look at life stage transition for people with autism.</p> <p>(to consider conference resources)</p>
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Note from the group: Future resources will have an impact on the ability to deliver on the Recommendations and consideration should be given to funding some 'project staff' to support the subgroups. Recognise that the funded projects are doing valuable work, however, there will need to be a degree of central coordination to allow them to feed their work into delivery of the Recommendations.

We were going to produce a draft on the Standards for Engagement before we took a pause. This work is underway and it is best to conclude this and then pick up it if appropriate after relaunch.

Subgroup 3: Diagnosis, Interventions and Support

Recommendation	Progress	Action/Status
<p>RECOMMENDATION 10</p> <p>It is recommended that agencies and services develop a menu of interventions including advice, therapeutic interventions and counselling for children, young people and adults with an ASD, that are appropriate and flexible to individual need. This menu should identify advice and support that is immediately available, and set out the referral and assessment process for all other services and interventions.</p>	<p>Menu of interventions drawn up and published.</p> <p>One Stop Shops and some of the Autism Development fund projects already providing a range of interventions</p>	<p>Needs to be rolled out throughout the country at strategic and local levels.</p> <p>Resources may include: funding for large scale event, local events at One Stop Shops and inputs at strategic level conferences. Eg ADSW, NHS Chief Execs etc</p> <p>Materials may need to be developed.</p> <p>Autism Network Scotland can do some of the work but significant additional input may also be required</p>
<p>RECOMMENDATION 11</p> <p>It is recommended that consideration is given to the specific supports needed for the more able individuals with ASD.</p>	<p>Included in menu of interventions</p> <p>One Stop Shops eg No 6. Some local Strategies target this client group. Eg CEC.</p>	<p>As above</p>
<p>RECOMMENDATION 19</p> <p>It is recommended that a request is made to NHSQIS, as the body into which SIGN has been integrated, to develop guidelines for evidence-based approaches to the diagnosis and management of ASD in adults.</p>	<p>New NICE standard for autism was published in Jan 2014.</p>	

<p>RECOMMENDATION 20</p> <p>It is recommended that approaches are made to the Royal College of Physicians and Surgeons to establish the feasibility and desirability of disseminating ASD materials in e- CPD formats.</p>	<p>Done</p>	<p>Will be part of NES training framework</p>
<p>RECOMMENDATION 21</p> <p>It is recommended that an assessment of national waiting lists is undertaken to clarify the extent of delays and that the ASD Reference Group considers and responds to these findings.</p>	<p>Autism Achieve Alliance (AAA) project has gathered a wealth of data showing that improvements in waiting times are achievable.</p>	<p>AAA will publish their data very soon and will be available via the Strategy website. This will also impact on Recommendations 22 and 23.</p>
<p>RECOMMENDATION 22</p> <p>Initiatives to address waiting lists for assessment should include consideration of further training on the use of ADOS, ADI-R, 3di and DISCO to meet increased levels of demand.</p>	<p>AAA project has looked at ADOS as a way of addressing diagnosis in adults.</p>	<p>The NES training framework project is making good progress and will help identify (i) the training and experience required by NHS professionals in a variety of client-centred assessment approaches and (ii) ways in which this could be disseminated.</p>
<p>RECOMMENDATION 23</p> <p>It is recommended that the ASD Reference Group explore the ways diagnostic processes for adults and children are different and how this should inform practice.</p>	<p>AAA project has looked at ADOS as a way of addressing diagnosis in adults.</p>	<p>See Recommendations 21 and 22 above.</p>
<p>RECOMMENDATION 24</p> <p>It is recommended that the directory of individuals and</p>	<p>AAA project drew up a list which is published on the Strategy website however</p>	<p>Will be further considered by AAA.</p>

<p>teams undertaking assessment and diagnosis of ASD in Scotland is reviewed, updated and re-distributed.</p>	<p>it needs updating.</p>	
<p>RECOMMENDATION 25</p> <p>It is recommended that a review is conducted with a view to updating and re-distributing the quality diagnostic standard if it is found to continue to be of benefit.</p>	<p>The standard is being updated.</p>	<p>Will be incorporated into AAA outcomes.</p>

Subgroup 4: Wider Opportunities and Access to Work

Recommendation	Progress	Action/Status
<p><u>Recommendation 26:</u> It is recommended that the supported employment framework for Scotland is evaluated in terms of its impact on employment and employability for people with autism.</p>	<p>The Group has discussed the Supported Employment Framework and produced a short statement to the main Reference Group. The action on this recommendation is now complete.</p>	<p>Having identified the challenge of diversity and lack of coordination in the sector, the group continues to facilitate the important role of developing a network of autism and employment projects.</p>
	<p>A summary guide on employment policy and structures (for professionals not familiar with the complex context of the employment sector) has been produced and published on the Strategy website.</p> <p>This also culminated in a successful learning event in October, hosted by Autism Network Scotland.</p>	<p>Looking at ways to increase dissemination and distribution of the guide and sign-post it on the Strategy website.</p> <p>Aiming to organise a second autism and employment projects networking event around Oct 2014.</p>
	<p>Prior to round two of the development fund, the Group submitted observations and suggestions for what type of activity/project would bring benefits to people.</p>	<p>A number of projects funded through the development fund have also been invited to share information on their activities at the subgroup meetings. This proves to be supportive to the projects and also enables the subgroup to maintain an understanding of what is happening across Scotland.</p>
	<p>The Group has identified that a significant challenge faced by people with autism in the workplace is a lack of understanding of employers about autism.</p>	<p>The Group is planning to produce a document with positive, successful case studies about people with autism who have been successful in finding employment.</p>

		<p>The Group will continue to invite to its meetings, representatives from autism and employment projects, ensuring it keeps up with developments, is involved in a network of activity, and that projects don't work in isolation.</p>
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Subgroup 5: Research

Recommendation	Progress	Action/Status
<p><u>Recommendation 12:</u> It is recommended that an evaluation of existing research is commissioned by the ASD Reference Group as well as consideration given to what further research is necessary with a view to disseminating what is available and to the commissioning some pieces that would be of particular practical value to people with ASD and their carers.</p>	<p>The Group has met regularly over the past 2 years; it's role being a largely reactive one – for example responding to specific requests for information from other Subgroups and the Scottish Government on a number of issues where their relevance to ASD required clarification.</p>	<p>Members of the group are actively involved in the three substantive research projects funded to date through the strategy:</p> <ul style="list-style-type: none"> - The Microsegmentation Project (Professor McKay is a Principal Investigator); - The Waiting List Initiatives Project (Dr McClure is a Principal Investigator); - The National ASD Database and Early Identification Project (Dr Aitken is a Principal Investigator) - Autism Research into Action seminars

Subgroup 6: People with ASD and carers

Subgroup 6 was established in order to give people with ASD and carers an opportunity to actively contribute towards the implementation of the Strategy's Recommendations. Subgroup 6 met regularly during the Foundation period to input and give views from their perspective on the work of the other Subgroups, for example, the Menu of Interventions and case studies for the mapping project. The eConsultation Group is a satellite group of people with ASD and carers who expressed an interest in a virtual network to feed their views into the work of the Reference Group and the Subgroups.

Subgroup 6 received a number of presentations including from Autism Network Scotland and NHS Education, discussed a number of Strategy papers including the Good Autism Practice journal, the Menu of Interventions and the Employment Guide, and members were active in attending the Autism Research Seminars and learning events hosted by the Network including the Employment and Local Authority events.

Annex 2

Additional background

The Strategy's Goals are in place to help make sure we have addressed all the recommendations by the time the Strategy concludes. We have divided the goals into three parts: Foundation (by 2 years), Whole-life journey (by 5 years), and Holistic-personalised approaches (by 10 years). Some goals will principally be for one discipline to deliver, whilst others will require a multi-directional response. All goals and recommendations will be fully explored through the production of a work plan to ensure that the recommendations are appropriate and fulfilled in the time frame.

Foundation (by 2 years)

1. Access to mainstream services where these are appropriate to meet individual needs
2. Access to services which understand and are able to meet the needs of people specifically related to their autism
3. Removal of short-term barriers such as unaddressed diagnosis and delayed intervention
4. Access to appropriate post-diagnostic support for families and individuals (particularly when there is a late diagnosis)
5. Implementation of existing commissioning guidelines by local authorities, the NHS and other relevant service providers

Annex 3

Overview of the Good Autism Practice (GAP) conference November 2014

The Scottish Strategy for Autism recommended the promotion of good autism practice as one of its 26 recommendations. The GAP conference – launched by Michael Matheson, Scottish Minister for Public Health - formed part of that recommendation and aimed to highlight innovative good practice across Scotland. Along with the publication of the special Scottish edition of the GAP journal, the conference was instrumental in recognising and disseminating examples of good autism practice in line with the Strategy's recommendations.

The over-arching aim of the Strategy is to improve the quality of life of people on the autism spectrum and their families and carers. The conference contributed to this by exploring the relationship between good practice and a good quality of life for people of all ages across the spectrum.

Throughout the day of the conference, delegates had the opportunity to discuss and reflect on how we evaluate good practice and consider ways to share ideas on practice and service delivery that lead to positive outcomes for people.

Delegates mainly comprised members of the autism reference group and subgroups, development fund project organisations and local authorities. They heard presentations from several keynote speakers on a range of good practice-related topics and attended a choice of workshops based on papers featured in the journal.

Keynote speakers

David Breslin – a person with Asperger syndrome, who gave his personal experience of good autism practice

Professor Tommy MacKay – Director of Psychology Consultancy Services, Co-founder of the National Centre for Autism Studies at the University of Strathclyde and Clinical Director of the National Diagnosis and Assessment Service for Autism Spectrum Disorders, who gave a presentation regarding implementing a national strategy

Michael McCredie – Consultant Clinical Director for Studio III Clinical Services and Lead Scientist Practitioner of the ATLASS programme, who spoke about good practice and improving well-being

Workshops

1. Why do we need a Scottish Autism Database? – Dr Ken Aitken
2. The Autism One Stop Shop: a developing model in Scotland – Mary Hamilton, Scottish Autism
3. Right Click: an online approach to enabling families – Charlene Tait, Scottish Autism
4. Scottish education and autism: obsessed with data – David Watt, Education Scotland

5. Autism: what helps? Developing a menu of interventions for people with autism and their families – Jane Neil-McLachlan, NHS Lothian

6. Transitions: preparing secondary school leavers for life beyond school – Mary Alexander and Kyle Oram, Transitions Team/Aspire Edinburgh

ANNEX 4 – AUTISM DEVELOPMENT FUND

ANNEX A – 2011/12 ROUND

	Name of Organisation or Consortium	Category	2011/12	2012/13	2013/14	2014/15	TOTAL
40	Aberdeen City Council	Services		£45,000.00	£30,000.00	£45,000.00	£120,000.00
5	Signpost	Services		£22,631.00	£26,854.00	£31,275.00	£80,760.00
73	Achievement Bute	Services	£8,663.55	£27,741.00	£27,741.00	£27,322.00	£91,467.55
80	Inverness Leisure	Services	£3,300.00	£3,300.00	£2,300.00	£3,800.00	£12,700.00
66	Places for People Scotland Care and Support	Services		£65,332.00			£65,332.00
77	Perth Autism Support	Services	£10,731.00	£68,387.51	£80,897.10	£98,459.79	£258,475.40
58	St Modan's Autism Provision	Services	£14,000.00				£14,000.00
64	Barnardo's Scotland (BIBSS)	Services	£10,590.00	£39,214.00	£40,262.00	£29,935.00	£120,001.00
68	Rainbow Rogues	Services	£8,361.60	£8,519.21	£8,662.60	£8,885.95	£34,429.36
2	Autism Initiatives UK	Miscellaneous	£23,393.00	£22,593.00			£45,986.00
62	Parents of Autistic Spectrum Disorder Adults (PASDA)	Miscellaneous	£3,000.00	£39,000.00	£39,000.00	£39,000.00	£120,000.00
19	Central Carers Association	Miscellaneous	£2,000.00	£56,406.00	£57,816.00	£59,261.00	£175,483.00

42	Richmond Fellowship Scotland	Training	£84,463.00				£84,463.00
23	Shetland Islands Council (ASN Outreach)	Training	£6,839.00	£7,321.00	£4,048.00		£18,208.00
15	Moray Council	Training		£55,000.00	£55,000.00	£55,000.00	£165,000.00
75	The Shirlie Project	Employment		£56,750.00	£84,181.00	£122,437.00	£263,368.00
55	City of Edinburgh Council	Employment		£38,782.00	£38,782.00	£38,782.00	£116,346.00
3	IWORKFORME	Employment	£24,400.00	£13,190.00			£37,590.00
21	National Autistic Society	Employment	£18,242.00	£66,040.00	£66,172.00	£66,304.00	£216,758.00
69	West Lothian Council	Employment	£14,200.00	£47,000.00	£47,800.00	£48,600.00	£157,600.00
10	NHS Tayside			£27,082.00	£26,082.00	£26,082.00	£79,246.00
18	Aberdeenshire Council		£31,500.00	£22,500.00	£15,000.00	£13,000.00	£82,000.00
31	Dundee City Council Education Department	Employment	£30,916.00	£124,836.00	£110,418.00	£96,000.00	£362,170.00
TOTAL			£294,599.15	£856,624.72	£761,015.70	£809,143.74	£2,721,383.31

ANNEX B 2012/13 ROUND

	Name of Organisation or Consortium	Category	2012/13	2013/14	2014-15	TOTAL
1	Borders Aspergers and Autism Group	Employment	£14,500.00	£7,500.00	£5,000.00	£27,000.00
4	Nordoff Robins Music Group - Scotland various venues	Early Interventions	£24,526.00	£24,778.00	£24,875.00	£74,179.00
5	Reality Adventure Works - Area covered by Highland Council	Supports Carers		£27,437.00		£27,437.00
7	Central Advocacy Partners - Forth Valley	Transitions	£50,000.00	£50,000.00	£50,000.00	£150,000.00
10	Values into Action - Glasgow	Employment	£24,920.00	£49,996.00	£50,892.00	£125,808.00
14	Cantraybridge - Highland / Moray	Employment	£21,997.00	£21,113.00		£43,110.00
17	Family Planning Association National	Training and Education	£30,390.00	£42,700.00	£43,750.00	£116,840.00
22	Parents of Autistic Spectrum Disorder Autism - Edinburgh and Lothians	Supports Carers		£47,400.00	£49,400.00	£96,800.00

25	Cornerstone/National Autism Society	Transitions	£23,268.00	£43,483.00	£43,774.00	£110,525.00
29	Community Enterprise in Scotland	Employment	£25,000.00	£25,000.00		£50,000.00
32	ENABLE Renfrewshire	Transitions	£41,392.00	£42,007.00	£42,633.00	£126,032.00
37	Autism Rights Group Highland	Employment	£4,185.00	£10,566.00	£11,766.00	£26,517.00
47	East Lothian Council	Early Interventions	£15,311.00	£45,182.00	£46,230.00	£106,723.00
58	NHS Forth Valley	Early Interventions	£14,400.00			£14,400.00
65	South Lanarkshire Council	Transitions	£22,500.00	£41,000.00	£18,500.00	£82,000.00
68	National Autistic Society - Glasgow	Employment	£24,982.74	£49,991.47	£49,882.85	£124,857.06
75	Thistle Foundation - Midlothian	Transitions	£27,742.00	£41,964.00	£32,995.00	£102,701.00
77	Royal National Institute of Blind People Scotland	Early Interventions	£49,909.00	£50,000.00	£50,000.00	£149,909.00
78	Edinburgh Council	Misc Strategy Wide	£10,000.00			£10,000.00
82	NHS child psychology - Fife	Early Interventions	£5,000.00			£5,000.00
85	Voluntary Action Orkney	Early Interventions	£21,499.00	£21,928.00	£22,367.00	£65,794.00
86	Advocacy Orkney	Misc Strategy Wide	£2,875.75	£2,575.75	£1,867.75	£7,319.25
87	Virtual Inclusive	Training and	£10,768.00	£9,010.00		£19,778.00

	Partnership - Kilmarnock	Education				
88	Orkney Islands Council	Early Interventions	£6,558.40	£6,278.40	£6,278.40	£19,115.20
91	Into Work - Edinburgh	Employment	£19,179.00	£35,959.00	£35,984.00	£91,122.00
94	Family Focus Edinburgh Council	Early Interventions	£20,033.00	£20,033.00	£19,783.00	£59,849.00
99	Dumfries and Galloway Council	Training and Education	£8,652.00	£17,304.00	£8,652.00	£34,608.00
100	Scottish Autism	Training and Education	£49,555.00			£49,555.00
102	Glasgow University NHS Lothian	Research	£49,784.00	£49,921.00	£50,000.00	£149,705.00
105	Fragile X Society	Misc Strategy Wide	£25,100.00	£38,863.00	£39,550.00	£103,513.00
TOTAL			£644,026.89	£821,989.62	£704,180.00	£2,170,196.51



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