

ALL AGE AUTISM SPECTRUM DISORDER (ASD) STRATEGY

“Our 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”

(Scottish Autism Strategy 2011)

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Executive Summary

Autism is a national priority with the creation of the 'The Scottish Autism Strategy', launched by the Scottish Government in 2011, which identifies what services need to provide for people with autism across Scotland. Strategic action is required both nationally and locally.

Children and adults on the autism spectrum each have a unique set of needs which will not necessarily fall within the areas of learning disabilities or mental ill health, although these conditions may be present. Autism is a pervasive disorder which impacts on the whole life experience of people. They need to be supported by a wide range of services such as social care, education, health, housing, employment and other community based services.

The Scottish Autism Strategy (2011) directs local authorities and the NHS, as the joint commissioning bodies, to give high priority to redesigning services around the principles of prevention, early identification of problems, early intervention, assessment, diagnosis, support and management of transition throughout the lifespan of autism.

This local autism strategy is based on to the framework of the Scottish Autism Strategy (2011). It is linked to the priorities and values of the Orkney's Community Planning Partnership – Community Plan (2011-2014) and incorporates the findings and recommendations of the Orkney Health and Care (OHAC) – Autism Spectrum Disorder (ASD) Report and Action Plan (2013). Consultation and engagement with people with autism and service providers was the first priority in the local mapping exercise and compilation of this strategy. The priorities set out a clear strategic direction for improvement and development of services in Orkney by ensuring that specific and measurable actions are undertaken based on evidence and localised mapping analysis.

Throughout this strategy, reference will be made to Autism or Autistic Spectrum Disorder (ASD), including Asperger's Syndrome, and there will be an attempt to reflect the diversity and range of needs and challenges experienced by people with autism and their families, carers, statutory, independent and voluntary services.

There is recognition and acknowledgement that there is a priority need to increase awareness and understanding of autism across all sectors and services. Autism poses many challenges that are often multi-faceted and complex, requiring a range of services and sectors to work together in order to clearly understand and address need. Too often, because of the nature of autism, people fall into gaps between services. It is paramount that eligibility criteria and referral routes are clear and understood to enable access to mainstream services.

Recommendations to achieve appropriate and sustainable improvements in the provision of person-centred services and support arrangements are incorporated throughout the thematic structure of the strategy and linked to the OHAC – ASD Report and Action Plan' (2013). OHAC is based upon a model of integrated service provision with joint governance and accountability arrangements in place for achieving outcomes to deliver improved services. Services for autism should be embedded into this approach and be linked with the expectations of the national strategy which needs to remain the primary focus of development and improvement of services for people with autism.

1. Introduction

1.1 Autism has been the subject of a number of initiatives over the past decade. Considerable efforts have been made to improve diagnosis and assessment to create consistent service standards, to match resources to need, and to underpin this with appropriate research and training opportunities. These significant contributions have been harnessed within a national 10 year autism strategy that addresses the entire autism spectrum and the whole lifespan of people living with autism in Scotland.

1.2 The Scottish Government, working in partnership with the Convention of Scottish Local Authorities (COSLA), and the two national autism organisations, has spoken to individuals on the spectrum and their families to find out what their concerns are and what changes are required. The national strategy sets out the vision that all people 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 lead meaningful and satisfying lives'. It provides a comprehensive review of current and best practice in the provision of services for those with autism spectrum disorders, and suggests various means of building on these foundations. Its recommendations are far-reaching and will impact upon all professions, across all disciplines involved in the provision of public services.

1.3 The development and compilation of an 'Orkney Health and Care – All Age Autism Strategy' is now fundamental to delivering on the Scottish Government's key policy for improving care for people with autism. The plans outlined in this strategy are supported by the framework of the national strategy and the priorities and values of 'Orkney's Community Planning Partnership – Community Plan (2011-2014) which aim for public services which are high quality, continually improving, efficient and responsive to local peoples' needs. The strategy also incorporates the findings and recommendations of the 'OHAC – ASD Report and Action Plan' (2013), which involved a mapping exercise of existing service provision in Orkney and identified priority areas for action based on local need.

1.4 Orkney is experiencing the pressures of recent global recession and a national reduction in government funding, which creates further challenges in relation to service delivery. There was common expression, throughout the mapping exercise, that people with autism and their families felt they were at crisis point. The personal distress caused by late/crisis intervention is profound. The financial costs of late intervention can also be significant and lifelong. Supporting people to make change at this point is typically more costly, time consuming, and less effective than early/pro-active intervention. With the numbers of people with autism on the increase, there will continue to be increased recurring costs if we do not change traditional patterns of service delivery. The local strategy focuses upon reorganisation of existing service capacity to create new autism structures and pathways. This will minimise duplication and overlap in service delivery, and will result in much more effective and efficient ways of integrated working.

2. What is Autism Spectrum Disorder (ASD)

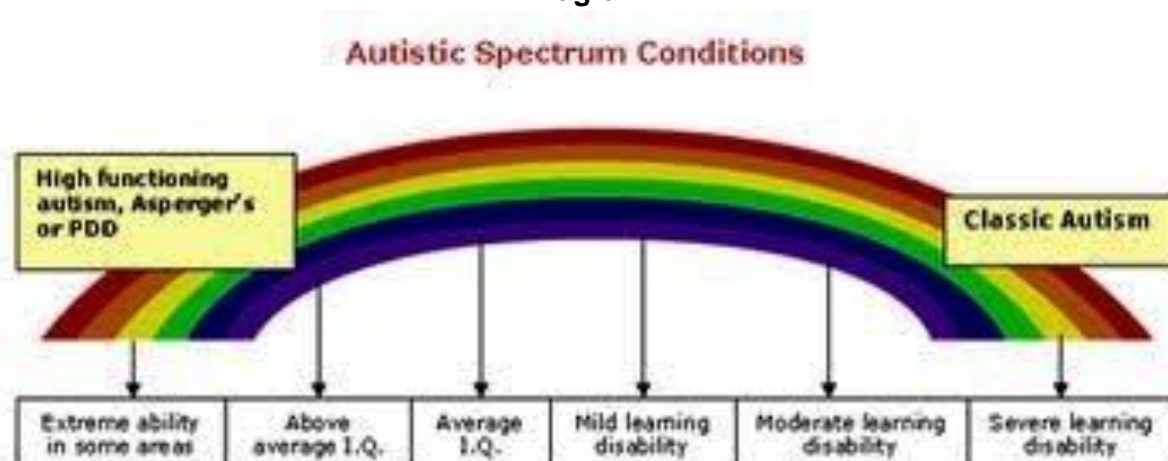
2.1 Wing and Gould (1979) have undertaken much research in development disorders and particularly in autism spectrum disorders. They introduced the notion of an autism spectrum disorder covering a range of levels and severities, but characterised by qualitative impairments in social, communicative and imaginative development.

2.2 The National Autistic Society describes autism as a lifelong developmental disability that affects communication and interaction with others. It also impacts those affected with regard to how they make sense of and interpret the world around them. It is a spectrum condition, which means that, whilst all people with autism share certain difficulties, their condition will affect them in different ways and to different degrees (see Diagram 1). Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support.

2.3 Diagnosis is sometimes complicated by the range of manifestations presented. In addition, these can look very different in childhood when compared to adulthood. It is clear, however, that autism is lifelong: children with autism become adults with autism, with their own individual needs. However, individuals often develop management strategies to help them function more effectively and minimise their autism driven anxieties.

2.4 This autism Strategy recognises that autism is a lifelong condition and that whilst early interventions, assessment, diagnosis and support in childhood are essential, so too is co-ordinated planning into adulthood with the management of transition between childhood and adulthood being of pivotal importance.

Diagram 1



3. Prevalence of ASD in Orkney

3.1 The Medical Research Council's review of autism research suggests that there is fairly good agreement between epidemiological studies that autism, if narrowly defined, currently affects 10-30 per 10,000 children under 8 and, if broadly defined, 60 per 10,000. The Public Health Institute in Scotland has also examined a range of epidemiological studies and concurred that the best estimate for the population prevalence of autism in Scotland was 60 per 10,000 children under 8. Further research conducted by the Office for National Statistics, indicates that 90 per 10,000 of children aged 5-16 years, across Great Britain have autism.

3.2 In 2005 the Scottish Government, using a prevalence figure of 90 per 10,000, produced data for age groups in local authority areas. A ratio of 4:1 (male: female) was identified as the distribution of the condition between male and female. The data for Orkney (see Diagram 2 and 3) revealed a higher prevalence of autism than anywhere else in Scotland. It was reported that Orkney was confident about the accuracy of data for children but that figures for adults were underestimated as diagnosis had not been made and access to specialists was variable.

Diagram 2: Children and young people diagnosed as having ASD, including Asperger's syndrome. (All figures show rates per 10,000 population and the population figures used in the denominator relate to the whole NHS Board area)

| NHS Board | Pre-School | Aged 5-10 | Aged 11-15 | Aged 16-18 in school | Aged 16-18 not in school | Total |
|------------------------------------|------------|-----------|------------|----------------------|--------------------------|-------|
| Argyll & Clyde | 23.7 | 35.7 | 25.1 | 7.4 | 4.9 | 26.3 |
| Ayrshire & Arran | 15.3 | 38.5 | 15.4 | 5.7 | 1.4 | 22.3 |
| Dumfries & Galloway | 29.1 | 53.0 | 27.2 | - | - | 32.0 |
| Fife | 59.7 | 86.0 | 21.1 | 1.5 | - | 43.3 |
| Forth Valley | 10.7 | 15.8 | 6.1 | 3.7 | 0.9 | 9.9 |
| Grampian | 15.6 | 24.0 | 19.6 | 11.2 | 3.8 | 19.9 |
| Greater Glasgow | 42.5 | 41.2 | 25.4 | 13.4 | 2.0 | 31.0 |
| Highland | 21.3 | 101.6 | 76.8 | 20.8 | 7.8 | 70.7 |
| Lanarkshire | 78.2 | 56.8 | 31.9 | 41.1 | 4.5 | 49.1 |
| Lothian | 45.8 | 69.8 | 29.5 | 3.3 | 0.7 | 41.7 |
| Orkney | 242.2 | 298.5 | 222.2 | 42.7 | 42.7 | 228.4 |
| Shetland | 38.1 | 0.0 | 68.8 | 12.0 | 12.0 | 31.2 |
| Tayside | 67.0 | 44.0 | 33.0 | 20.2 | 4.0 | 39.0 |
| SCOTLAND (ex. Borders and W Isles) | 41.6 | 48.9 | 27.2 | 12.8 | 2.8 | 35.3 |

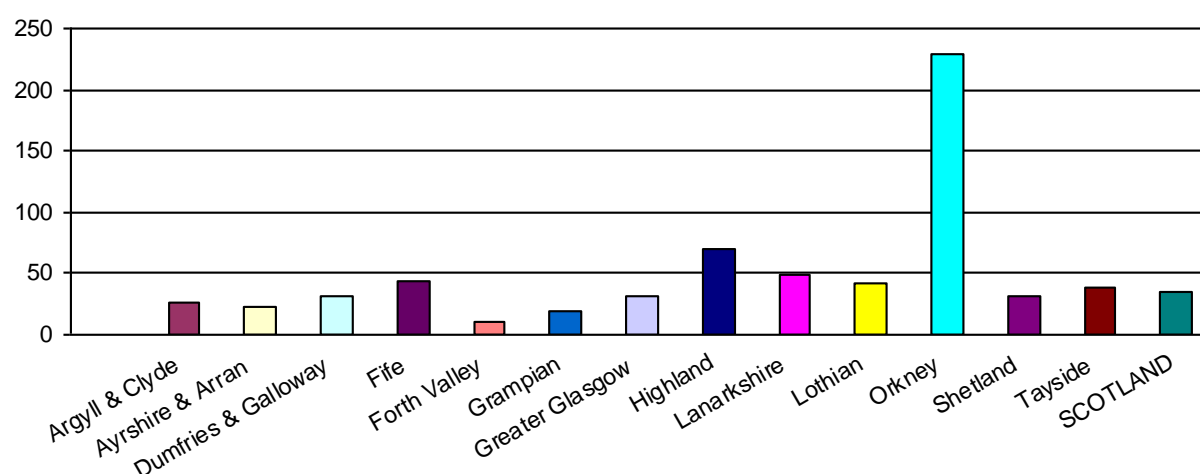


Diagram 3: Adults diagnosed as having ASD disorders, including Asperger syndrome

| NHS Board | 18-24 | 24-49 | 50+ | Total |
|---------------------|--------------|--------------|------------|--------------|
| Argyll & Clyde | 17 | 27 | 0 | 44 |
| Ayrshire & Arran | - | - | - | 36 |
| Dumfries & Galloway | 0 | 15 | 1 | 16 |
| Fife | 4 | 37 | 3 | 44 |
| Grampian | 37 | 53 | 5 | 97 |
| Highland | 18 | 20 | 0 | 38 |
| Lanarkshire | 13 | 21 | 3 | 37 |
| Lothian | 30 | 174 | 61 | 265 |
| Orkney | 11 | 2 | - | 13 |
| Shetland | 3 | 5 | 1 | 9 |
| Tayside | 16 | 30 | 0 | 46 |
| Total | 149 | 384 | 74 | 645 |
| % of total | 24% | 63% | 12% | 100% |

3.3 However, more recent prevalence studies of autism indicate that 1.1% of the population in the UK may have autism. This suggests that over 695 000 people in the UK have autism, an estimate derived from the 1.1% prevalence rate applied to the 2011 UK census figures. The interpretation of a study of children (Baird G. et al.' 2006) suggests that the prevalence of autism is substantially greater than previously recognised. Whether the increase is due to better ascertainment, broadening diagnostic criteria, or increased incidence is unclear. Services in health, education, and social care will need to recognise the needs of children with autism, who constitute 1% of the child population. The study of adults was published in two parts, Brugha et al (2009) and The NHS Information Centre, Community and Mental Health Team, Brugha et al (2012). This is the only known prevalence study of an adult population, suggesting that an increasing number of adults are seeking and receiving a primary diagnosis and that recorded prevalence of adults reflects the "tip of the iceberg".

3.4 Numbers of people with autism in Orkney are recorded on individual service databases, with no central overview. OHAC's Joint Commissioning Strategy (2012-2022) outlines plans to support OHAC priorities and values, providing care and support for those who need it, promoting equality, and working with communities, whilst constantly aiming to improve quality and effectiveness of services. Accurate prevalence data is paramount for future planning and predicting demand on services. A standardised data collection system is required to improve on reporting, share with commissioners, and to improve future shaping and co-ordination of services for people with autism.

4. National and Local Policy Drivers

4.1 The Scottish Strategy for Autism (2011) has a linkage with a range of policies and frameworks from which people on the spectrum may benefit and which will be pivotal to success. The National Performance Framework sets out strategic objectives, and national indicators and targets which public bodies will work together to deliver in Scotland. These are supported by Single Outcome Agreements (SOA) which set out local priorities, expressed as high-level outcomes, which public sector partners will work together to deliver for their communities.

4.2 To cover the entire lifespan, policy drivers range from mainstream approaches targeted at improving outcomes for children and young adults such as 'Getting it Right for Every Child' (2008), to those in transition to adulthood and further service provision. Other people with autism may benefit from policies that have a particular theme, such as employment, independent living, or self-directed support; whilst mainstream or a combination of mainstream services will not suit everyone and specialist support may be the most appropriate option.

4.3 OHAC's main aim is to provide and improve quality health and social care services and reduce inequalities for people in Orkney. One of the main legislative drivers for change in OHAC is the upcoming legislation which the Scottish Government is bringing forward in order to improve service delivery. The rationale behind the legislation is that there is too much variability in health and social care services and therefore a need to focus on statutory and non-statutory agencies working together to tackle access to services, social exclusion, co-production, and capacity building within the community. To ensure a consistent approach across OHAC and other sectors in meeting the needs of people with autism in Orkney this strategy needs to be linked to other local strategies and policy developments which underpin the context and aspirations of the following: prevention, early intervention, re-ablement, personalised approach to services with an outcome focus, proactive planning rather than reactive approaches, meeting key drivers in children's services, effective transition planning, focusing on a more consistent and person centred approach to supporting employment opportunities and wider availability of housing, leisure and lifelong learning opportunities. These principles focus on optimising independence and wellbeing for the people of Orkney, regardless of age.

5. Local Needs Analysis

5.1 Orkney's Community Planning Partnership – Community Plan (2011-2014) aim for public services which are high quality, continually improving, efficient and responsive to local peoples' needs. The priorities are to move forward and develop integrated service provision, encourage innovative partnership approaches to service provision and shift resources towards preventative services. To achieve this it is important to remove any duplication of effort and to improve co-ordination between different public, private and third sector organisations. Services for people with autism should be embedded within this approach by building partnerships and developing a shared understanding of inclusion which also underpins the values and vision of the strategy.

5.2 In order to formulate this strategy, the first priority was to engage with people who are affected by autism. A local mapping exercise has been completed on existing provision of services. It sought to glean the views of people with autism and focused on mapping out existing services and identifying gaps in service provision whilst highlighting areas for action reflecting on local need. The framework of the Scottish Autism Strategy (2011), along with Orkney's Community Plan – Community Plan (2011-2014) guided the preparation of the local 'ASD Report and Action plan (2013). This will ensure that the expectations of the national strategy remain the focus of development and improvement of services for people with autism, whilst linking with the values and priorities of the local community plan.

5.3 The individual nature of autism serves to underline the need for a person centred approach to ASD service provision. People of all ages affected by autism and their families need to become an established part of the process for identifying and organising services which should focus on a 'lifespan' approach with appropriate intervention and provision of services.

5.4 The purpose of the 'ORAC - ASD Report and Action Plan' (2013) is to set out a clear direction for the improvement and development of services in Orkney for people with autism and their families. Specific and measurable actions have been recommended, on the basis of consultation and feedback with services and service users, gathering evidence, and reporting on localised mapping analysis. It is vital that the local strategy links and cross references with the report and action plan to ensure strategic direction for improving outcomes for people with autism and their families/carers across the lifespan.

5.5 Following on from this work, OHAC's Autism strategy is fundamental to delivering on the Scottish Autism Strategy's 26 recommendations and the plethora of related national and local policy objectives. The central aim of the local Autism Strategy is to commission effective services of the highest possible quality, led by demand and the needs and desired outcomes of people with autism in Orkney, covering the entire lifespan. This is intended to improve the quality of life and wellbeing of the people that use services, their families and carers.

6. Key Elements of the Local Strategy

6.1 The policy context that heralds the Scottish Autism Strategy (2011) gives a framework for implementation and encompasses 26 recommendations about how to improve support in order to improve the quality of life of people with autism. The recommendations lead to six aims and linked actions offering clarity about what needs to be done within 2 years, 5 years and by the end of the 10 year strategy. For successful implementation it is recognised that it is essential that there is strategic leadership, an intention to achieve best value for services, collaboration and involvement in decision-making, cross agency working through stronger networks, high quality diagnosis, intervention and support, ensuring improved quality of life and leading to wider opportunities including employment.

6.2 The Scottish Autism Strategy (2011) also incorporates ten indicators for current best practice in the provision of autism services. These indicators should be used to establish a baseline measurement of practice in each local area and have been incorporated into each action plan in the OHAC – ASD Report and Action Plan (2013).

6.3 This local strategy is based on the framework of the Scottish Autism Strategy (2011) and linked to the ‘OHAC – ASD Report and Action Plan’ (2013). The report addresses and identifies priority areas for action reflecting local need and sets out the strategic direction for improving outcomes for people with autism and their families, across the entire lifespan.

6.4 It is recognised that autism is a spectrum condition which means that, while all people with autism share certain difficulties, their condition will affect them in different ways and to different degrees. Some people with autism are able to live relatively independent lives but others may have significant learning disabilities or mental health needs.

6.5 The next section is divided into the six key themes to provide a strategic overview, whilst the full version and linked action plans (OHAC – ASD Report and Action Plan 2013) sets out the short, medium and long term recommendations. It is important that the framework is used locally to help focus and achieve successful implementation of the long term vision and expectations of the national strategy. The key themes are:

- Theme 1: Strategic Leadership
- Theme 2: Achieving Best Value for Services
- Theme 3: Collaboration and Involvement
- Theme 4: Cross Agency Working through Stronger Networks
- Theme 5: Diagnosis, Intervention and Support
- Theme 6: Wider Opportunities and Access to Work

7. Theme 1: Strategic Leadership

7.1 National strategic leadership will be provided by the Scottish Government who have reconvened an ASD reference group to oversee developments and provide guidance to local authorities over the ten year period of the national strategy. The autism reference group will request progress reports from local authorities.

7.2 Local authorities and NHS Boards are the statutory sector commissioners of local services to meet identified needs and to determine the local level of funding required to address these needs. Orkney Health and Care's vision is to make a real difference to the lives of people living in Orkney by improving health and social wellbeing and delivering high quality services closer to home. The vision is underpinned by a set of important values, drawn from parent bodies and the Orkney Community Planning Partnership.

7.3 To provide local strategic leadership and direction, an 'All Age Autism Strategic Group' has been established. This group is composed of multi-agency members and is inclusive of people with autism, their family members, and carers. This group will be responsible for putting robust arrangements in place to ensure direction of this strategy, delivery of the action plan, monitoring and tracking improvements in service provision and ensuring progress is communicated across all agencies and to members of the public.

7.4 New ways of working also involves the need to share information and data. Data sharing, underpinned by robust governance arrangements, is a key way of improving the speed, efficiency and effectiveness of many processes across services. There is an information sharing protocol in place between health and social services. To effectively predict future service demand and meet the requirements of the national strategy this arrangement needs to be extended to include other services whilst complying with relevant legislation and guidance

7.5 The OHAC – ASD Report and Action Plan (2013) overviews the strategic direction locally and recommends the recruitment of an Autism Lead/Coordinator to drive this agenda forward, with the societal and cultural changes that are required, to ensure a strategic focus is maintained, as well as to work with people with autism and their families. The 'OHAC – ASD Report and Action Plan' (2013) has been submitted to Scottish Government to strengthen the opportunity to bid for funding through a process of bids for initiatives that demonstrate a willingness to meet the expectations of the strategy

7.6 It is important that the national strategy framework is used locally to help focus and achieve successful implementation of the expectations of the strategy. Recommendations to achieve appropriate and sustainable improvements in the provision of person-centred and support arrangements are incorporated in the action plan throughout the six key themes. The local autism strategic group in Orkney plan to adhere to this thematic framework and has established direction by forming sub-groups and leads to ensure implementation with the strategic group overseeing the process (Theme 1) and ensuring collaboration and involvement with people with autism and their families (Theme 3) across all sub-groups (see Diagram 4).

Diagram 4

| |
|--|
| <p align="center">THEME 1 – Strategic Leadership</p> <p align="center">All Age Strategic Autism Group/Lead</p> |
|--|

| THEME 2 | THEME 4 | THEME 5 | THEME 6 |
|-----------------------------------|--|-------------------------------------|--|
| Sub-Group/Lead | Sub-Group/Lead | Sub-Group/Lead | Sub-Group/Lead |
| Achieving Best Value for Services | Cross Agency Working through Stronger Networks | Diagnosis, Intervention and Support | Wider Opportunities and Access to Work |

| |
|--|
| <p align="center">THEME 3</p> <p align="center">Lead - Collaboration and Involvement</p> |
|--|

7.7 To implement and deliver these improvements and strategic actions, we need to ensure that decision making includes the budget holders and managers of resources across the whole care economy. This will include commitment to pooling resources and finding new ways of working together to ensure positive outcomes for people with autism in Orkney in the current economic climate.

7.8 There are a number of governing principles which will be integral to the successful delivery of this agenda; primarily joint planning, partnership working and integration, whole system approach, involvement of people with autism and their families, joint commissioning and workforce development. These principles will be addressed throughout the strategy and reflect key areas which acknowledges that effective coordination and best practice with other agencies and sectors is essential.

7.9 An overview and recurring themes following completion of the mapping exercise under strategic leadership are highlighted in 'OHAC – ASD Report & Action Plan' (2013) which incorporates the full action plan in Appendix 1. The priority areas for action to inform future shaping and coordination of services under this theme are:

- Establishing and Co-ordinating an 'All Age Autism' Strategic Group and Sub-Groups
- To monitor progress - agreed strategic aims, priorities for action and timescales
- Communication Strategy
- Appointment of a local Autism Lead/Coordinator
- Compilation of a local Autism Strategy
- Inclusion of autism within strategies and services, across all partner organisations
- Develop a process of sharing data collection and sharing of information

8. Theme 2: Achieving Best Value for Services

8.1 Achieving Best Value for Services for people with autism will ensure that resources are effectively targeted. A study by researchers at King's College London estimated that autism costs the UK economy around £28.2 billion a year (£25.2 billion for adults and £2.7 billion for children) (Knapp et al 2007). Of the costs for adults, 59% is accounted for by services, 36% by lost employment for the individual with autism, and the remainder by family expenses. Therefore it is important that services are strategically commissioned.

8.2 The OHAC – ASD Report & Action Plan (2013) focuses on the importance of commissioning and implementation of clear and concise pathways allowing people with autism to access and move between services. The report highlights evidence on the economic and financial benefits costs of intervening late and how this can lead to significant, lifelong and profound effects on people with autism. It identifies how the emphasis must shift to focus on increased intervention and prevention, which will result in economic and social benefits.

8.3 Policy and practice for commissioners of health and social services for people of the autism spectrum was published in 2008 which sets out existing models of good practice to inform service developments in local areas. Local authorities and NHS Boards are the statutory sector commissioners of local services for people who have autism and have to take responsibility to make informed judgements as to the most appropriate balance of local services to meet local identified needs and to determine the local level of funding required to address these needs.

8.4 Informed commissioning relies on a full analysis of incidence, of needs, and a mapping of existing services across all agencies to identify strengths and deficits in service provision. Additionally, there is a requirement for commissioners to promote the development and implementation of clear concise pathways which can demonstrate services' ability to work in close collaboration to achieve and meet the needs of people with autism.

8.5 Increased focus on early intervention and prevention will have economic and social benefits. The financial costs of intervening late can be significant and lifelong and can have profound effects on people with autism. There is strong evidence to suggest that early preventative services for those at the more able end of the spectrum would reduce criminal behaviour, mental health problems and dependence on benefits, while increasing employment, independent living and inclusion.

8.6 Orkney Health and Care, Joint Commissioning Strategy (2012-2022) outlines plans to support Orkney Health and Care's priorities and values, providing care and support for those who need it, promoting equality and working with communities whilst aiming to improve services. It is important that this work to improve future shaping and co-ordination of services for people with autism is shared with commissioners and is incorporated into the commissioning strategy.

8.7 Recurring service priorities and themes following completion of the mapping exercise are highlighted in 'OHAC – ASD Report & Action Plan' (2013), which incorporates the full action plan in Appendix 2. The priority areas for action under this theme are:

- Working closely with commissioning leads – current and future service provision
- Standardised data collection system
- Embedding early intervention approaches
- Developing a 'Menu of Interventions'
- Ensuring links with 'All Age Learning Disability Blueprint'
- Providing networks of support
- Compilation of clear and consistent pathways

9. Theme 3: Collaboration and Involvement

9.1 Collaboration and Involvement of people with autism and their families is essential at all levels of decision making. 'The Scottish Strategy for Autism' (2011), reflects the views of a wide range of service users and professionals. This is reflected throughout the national strategy and is underpinned by the vision and underlying values that need to be at the heart of autism strategy implementation.

9.2 OHAC – ASD Report & Action Plan (2013) reflects inclusion and feedback from people with autism and their families throughout the mapping period. This is underpinned by the vision and underlying values of the national strategy and need to be at the heart of all local action plans.

9.3 The local autism all age strategy group will promote collaboration and involvement of people with autism and their families in each sub-group and will ensure that progress and developments will be communicated as detailed in adjoining communication strategy.

9.4 There is a need locally to ensure that people with autism are represented within strategic planning forums and commissioning processes and are provided with many other opportunities to ensure that plans reflect the needs, preferences and capabilities of people with autism and their families.

9.5 This strategy also supports the national vision for people to gain access to information about the full range of services in their local community, as well as having access to clear consistent pathways for diagnosis and post diagnosis support and signposting to a range of other, community based services.

9.6 An overview from the mapping exercise, including recurring points relating to the theme of local collaboration and involvement, are highlighted in 'OHAC – ASD Report & Action Plan' (2013), which incorporates the full action plan in Appendix 3. The priority areas for action to inform future shaping and coordination of services under this theme are:

- Involvement of people with autism in the development of plans, strategies and single outcome agreement in relation improved service delivery
- Representation from people with autism on the 'All Age Autism Strategic Group'
- A framework and process in place to inform service improvement and encourage feedback
- Link with the work in Orkney on implementation of 'Self Directed Support'

10. Theme 4: Cross Agency Working through Stronger Networks

10.1 Cross Agency Working through Stronger Networks and joint working has become a dominant concept running through public services policy in Scotland. This requires integration of services, which is a key policy objective of Scottish Government. Integration of services is intended to reduce frustration, delay, inefficiency, and the gaps that frequently exist in the system nationally. It provides opportunities to build clear and concise pathways to ensure a more seamless journey, whilst also providing a more flexible response to the needs of individuals. The national autism strategy recommends access to integrated service

provision across the lifespan to address the multi-dimensional aspects of autism. Orkney has a strong record of joint working, integration of services and sharing ideas across services and sectors and has adopted the single authority model for integrated service provision (OHAC Service Plan April 2013-2016). We now need to build on this to ensure people with autism are supported to be effective and contributing members of society, and are at the heart of our developments.

10.2 The OHAC – ASD Report & Action Plan (2013) focuses on integration within a best practice framework, and the need for awareness and increasing understanding of autism through structured and planned training. The report suggests through the mapping and feedback sessions, a number of actions that can be implemented to work towards putting the person with autism at the centre of all service delivery and planning. This will provide the right support at the right time in the right place by addressing the entire range of needs and will require barriers to be removed across organisational boundaries. This approach will ensure that health, social, housing, employment, education, independent and voluntary sectors work together in a single, integrated whole system.

10.3 There was a need identified throughout the mapping period for the need for accessible information that is required for people with autism and their families, from the point of diagnosis and beyond. It was suggested that there is a need for a central, accessible hub of specialist advice, information and practical support covering all services and sectors within Orkney and externally. This would enable people with autism, their families and service providers to access information, at a central point, that is evidenced and appropriate. Within the mapping period, work on compiling information about the availability of services was collated which could now be used to build a service directory along with an information hub.

10.4 The mapping exercise also revealed that there was little evidence of general awareness training. It was highlighted consistently that this was required across all services and sectors as well as across a range of public services and employers. People with autism identified difficulties that they have encountered in accessing mainstream services and foregrounded a lack of autism awareness and understanding in health and social care, public transport, further education, welfare benefits and banking and other services. The compilation of a structured training plan is required and there is an opportunity in Orkney to use the expertise across services and sectors to introduce and establish multi-agency training in autism.

10.5 Another key area which has been identified in the national autism strategy is the need for good practice guidance to be developed, to support the lifelong challenges facing people with autism as they make daily and life-stage transitions. The mapping exercise confirmed that the majority of respondents with identified plans were involved in transitional educational processes; whereas there was little evidence of transitions used in adulthood. It was recommended that the 'Orkney Transition Planning Guidance and Procedures – Transition to Post-School Services' (2011) be reviewed with the involvement of employment and the health sector. There was an identified gap in plans to support adults through major transitions at each life-stage which now requires to be addressed.

10.6 In addition it was identified throughout the mapping exercise that individualised key workers to provide continuity and support for people with autism, their families, and support

agencies during transition stages would be of great value. Such a role resource needs to be explored.

10.7 An assessment of needs is a vital first step towards improving access to mainstream services and gaining the support and services people with autism and their families require. It was highlighted during the mapping exercise that assessments should be informed and detailed with an understanding of issues across a range of need. It was also foregrounded that all areas of the community need to be geared up to understand the individual needs of people with autism. The Social Care (Self Directed Support – Scotland 2013) Act will require OHAC to implement a new personalised approach to assessment of needs and service delivery.

10.8 The role of carers as equal partners and the importance of carers' assessments in the planning and delivery of care and support were recognised throughout the mapping phase. There is a strong case for such an approach based upon human rights, economic efficiency and quality of care. Without the valuable contribution of Orkney's carers, the health and social care system would not be sustained. Activity should focus on identifying, assessing and supporting carers in a personalised and outcome focused way and on an equitable and consistent basis.

10.9 The Scottish Autism Strategy (2011) specifically recommends consistent adoption of good practice in key areas of education, health and social care across all local authorities. Whilst these sectors have been incorporated in broad terms within the action plans, there are also specific actions identified within each sector, during the mapping exercise. These sectors have their individual statutory key strategies and policies for guidance highlighting the need for more autism specific developments.

10.10 An overview and recurring themes following completion of the mapping exercise, focussing upon cross agency working through stronger networks, are highlighted in 'OHAC – ASD Report & Action Plan' (2013), which incorporates the full action plan in Appendix 4. The priority areas for action to inform future shaping and coordination of services under this theme are:

- Develop an Integrated Training Plan
- To increase awareness, knowledge and understanding of autism across all sectors
- To increase awareness, knowledge and understanding of autism through public services
- Training for staff in frontline services to promote good quality assessments, evidence based interventions and on-going support for families
- Access to an information hub of specialist advice and information
- Good practice transitional to be developed to support lifelong challenges
- Review and evaluate existing transitional guidance

- Review the use of 'Moving on Passport'
- Develop transitional guidance post education
- Identification of a 'Key Worker'

Education:

- Individualised Educational Plans – more specific and encompass a personalisation approach
- More support for career support
- Access to specialist teaching input
- To ensure that regular review meetings are planned
- Autism aware environments in classrooms
- Individual arrangements and support – SQA examinations

Health:

- Changes in visits to GP Practices
- Increased capacity in Occupational Therapy services
- Social Care
- Review of eligibility criteria within local authority
- Streamlined referrals process

11. Theme 5: Diagnosis, Intervention and Support

11.1 Consistent evidence based Diagnosis, Intervention and Support are fundamental to both children and adults. Such practice will help people with autism understand their condition, allowing recognition of individual strengths and challenges, and promote the best support available. The SIGN Guideline no 98 (2007) for children and young people up to the age of 18 summarised the evidence base on autism, suggested audit targets and research ideas and describes how to share information with families and carers. It has been internationally acclaimed as ground-breaking and it is recommended that a request is made

to NHS Quality Improvement Scotland (QIS) being the body within which SIGN has been integrated, to develop guidelines for evidence-based approaches to the diagnosis and management of autism in adults.

11.2 The OHAC – ASD Report & Action Plan (2013) focuses and builds upon an evidence base for diagnosis, intervention and support across the lifespan, with the intention of promoting equity in standard of service provision locally. The report incorporates a number of actions to improve quality of assessment, establish pathways for diagnosis, as well as focusing on the support that is required post diagnosis.

11.3 Research on early identification suggests that the majority of children with autism will display some signs of autism during the first three years of their life, but their needs may not be identified within this period. This can be due to the signs of a mild disorder being difficult to pick up with certainty. In other circumstances, it is possible to recognise and diagnose autism by the time a child is 18 months old. Early assessment and intervention is central to maximising opportunities for improving emotional, educational, social and cognitive development opportunities as well as health and wellbeing. Early action may also help to tackle some of the many social and physical barriers faced by children with autism and enable a fuller participation in society. Appropriate plans for their assessment and intervention can help all children and young people with autism to achieve their full potential within available resources.

11.4 It is recognised that there have been many improvements in children's identification and diagnosis process recently, such as a multi-disciplinary pathway inclusive of health involvement. This provides the opportunity to assess children's presentation and co-morbidities, which was welcomed by a visiting Consultant Paediatrician from Grampian. There was further recognition in 2012 that training with ADOS (Autism Diagnostic Observation Schedule) would improve professional skills and develop additional skills in the assessment process; there was a consensus within the autism strategic group in children's services to apply for funding, although this was an unsuccessful bid. Through the implementation of the strategy, money was secured to offer this training in Orkney. This training took place in February 2014: a cross section of professionals, from health, educational and social care backgrounds attended. They represented an 'all age' perspective/reach. They have agreed a strategy for maintaining their skills in ADOS assessment on a continuing basis.

11.5 In Orkney the process of identification and assessment of children is conducted as per ASD pathway (November 2011). This can vary depending on the individual case, from involvement of a minimum of two professionals undertaking multi-disciplinary autism assessment, to other professionals being asked to contribute or be involved in the process. The pathway recommends that the G.P will always be informed that autism assessment is taking place and may contribute to the assessment and/or refer to a paediatrician. Parents will be involved in the overall assessment. The diagnostic criteria used, is the DSM IV with a move to DSM 5 in May 2013. This pathway was due for review and evaluation in September 2013 and will be updated to ensure the latest evidence is incorporated.

11.6 Following diagnosis of a child or young adult, families often experience high stress levels. SIGN Guideline 98: Assessment, Diagnosis and Clinical Interventions for Children

and Young People with Autism Spectrum Disorders (2007) cites that education and skills intervention should be offered to parents of all children and young people diagnosed with autism. During the mapping exercise, parents who had participated in the 'ASD Parent Support Programme' in Orkney reported that this was extremely beneficial in helping them to implement strategies to meet the individual needs of their child. However, there is a need to increase the number of trainers to run the programme and also ensure the capacity and dedicated time to carry out the programme to ensure continuity of support. There is also a need for systems to be put in place for implementation and monitoring of programme

11.7 At present there is no diagnostic service for adults in Orkney, with no current regular visiting Consultant Psychiatrist or Psychologist for Learning Disability services. In December 2012, a letter was sent to all G.P's to advise of a route through the Non Commissioned Activity Panel (NCAP) for referral for assessment and diagnosis for adults. This was a temporary arrangement whilst discussions with Grampian was taking place in relation to service level agreements and establishing a local pathway for adult diagnosis.

11.8 There was an overall and consistent view throughout the mapping exercise, that a service for diagnosis locally for adults is paramount and that there needs to be acknowledgement of the increased anxiety and stress that this service deficit is causing adults who are currently seeking diagnosis. It was expressed that a formal diagnosis should not be viewed as attaching a "label" to a person, but should rather be viewed as a liberating experience that consolidates knowledge and understanding of the person's need and generates options for change and future support. The importance of clear routes to diagnosis and access to a robust pathway was highlighted along with establishing consultant psychiatric and psychological services. It was recommended that a focused needs led clinic would be invaluable with arrangements for follow up via Video Conferencing or other alternatives. In addition, the need for post diagnostic support was highlighted and the difficulties people had encountered with access to services, lack of understanding and awareness among service providers, and lack of information and sign posting. The support required can vary across services and requires effective interagency working across a range of statutory and third sector organisations. The post diagnostic adult pathway should identify clear and structured routes into support options and incorporate specific and targeted interventions.

11.9 An overview from the mapping exercise, including recurring themes related to diagnosis, intervention and support, are highlighted in 'OHAC – ASD Report & Action Plan' (2013), which incorporates the full action plan in Appendix 5. The priority areas for action to inform future shaping and coordination of services under this theme are:

- Establish progress of the implementation and evaluation of the ASD Assessment template and protocol
- Work towards SIGN 98 guidelines
- Embed ADOS-2 training and implementation
- Improve parental and carer support during and post diagnosis
- Increase number of trainers to run ASD Parent Support Programme

- Consistency and continuity of planning – post diagnostic support
- Robust links between school, families and other services
- Ensure parents are supported at review meetings
- Establish a local service for adult diagnosis
- Develop a clear and consistent pathway for adult diagnosis and post diagnostic support
- Explore possibility of adapting a support programme for newly diagnosed adults

12. Theme 6: Wider Opportunities and Access to Work

12.1 Wider Opportunities and Access to Work is supported by The Scottish Government, which is committed to removing barriers in the way of effective transitions into employment. It has developed, together with COSLA, a Supported Employment Framework for Scotland.

Its aim is to provide the mechanisms necessary to support a move into paid employment in the open labour market in a systematic and effective way. At its heart is the desire to see a more consistent, person-centred approach to supporting those who want to work. The Framework has been launched and will be further promoted amongst local authorities. To ensure that the needs of people with autism are taken account of, there is an autism representative on the national employment working group, which focuses on employment for people with autism.

12.2 In Orkney, there are some very good examples of working with people with autism to help them maximise their potential in the labour market and with regard to their skills development. Skills Development for Scotland, Employability Orkney and Connect were highlighted as providing much support in varying ways, in preparation for employment, including compiling C.V'S, job analysis, application forms, interview techniques and supported placements and employer visits. However, due to constraints and funding, these latter two providers can only support small numbers of people with autism.

12.3 The OHAC – ASD Report & Action Plan (2013) focuses on the barriers to employment at a local level, the areas of service provision that are working well, and the gaps that to be addressed, to meet the particular requirements of people with autism, who are seeking employment. The Orkney Youth Employment Activity Plan (May 2013) is based on local partnership delivery arrangements, including key contacts for local provision, and details on referral routes for 16+ opportunities. This Activity Plan is a working document for use by partners rather than a strategy. The Employability Strategic Group brings together organisations and resources to address the barriers and gaps to employment locally and this work will link closely with this group, to ensure continuity across the lifespan.

12.4 As part of this work, a clear pathway should be developed that supports people with autism into employment, including sign-posting to support options for the recruitment process and opportunities for job coaching. The pathway should have a particular focus on engaging with employers and businesses that will support people with autism.

12.5 Wider opportunities for people with autism are also overviewed, in the context of leisure, further education, health and housing, which are important throughout life and have the obvious potential to result in improved wellbeing.

12.6 One of the major life changes in adulthood for individuals with autism can be moving from their family home or residential provision into their own accommodation. People with autism and their families reported that access to housing in supported “safe and quiet” areas was paramount to them. Safety was a major concern expressed, as was the perception that neighbours did not understand their difficulties. The requirement for workmen to enter homes to carry out repairs was another cause of anxiety. Such visits, it was felt, need to be carefully planned.

12.7 The people with autism and their families who participated in this mapping exercise were very satisfied with housing through Orkney Islands Council and Orkney Housing Association Ltd. They reported individual arrangements that had been made in the way of equipment/adaptations or tele-care equipment to meet their individual needs. Others had not required such support but expressed that it was difficult at times to understand the process

and policies with regard to housing allocation. It was also highlighted that some people with autism choose to live in housing in remote and or quiet areas. Whilst requesting advice and support for planning to build a house in such a location, it was felt that professionals did not always understand the reasons for this.

12.8 Orkney's Local Housing Strategy (2011-2016) details the housing outcomes, objectives and actions which will be undertaken during the strategy timeframe to increase the supply of affordable housing and to reduce homelessness. It will address the critically important issue of providing housing support to the more vulnerable members of our community. Finally it incorporates our approach to improving private sector housing in line with Section 72 of the Housing (Scotland) Act 2006, and looks at improving housing through adaptations etc.

12.9 People with autism are entitled to be able to live satisfying and meaningful lives within a society that accepts and understands them. This includes forming relationships and building social networks and having access to lifelong learning opportunities. The leisure and lifelong service in Orkney covers a huge range of facilities and services including museums, libraries and archive, swimming pools, fitness centres, community centres and town halls, play parks, campsites and hostels, Active Schools, the Community Learning and Development Service, the Learning Link and Orkney College. Learning and development is not just for the classroom and learning is viewed as a lifelong process aiming to create learning and leisure opportunities with easy access for people with a wide range of needs.. <http://oic-spoint-04/services/serv/educleisure/eduleis/SitePages/Home.aspx>. This information should also become available through the information hub and be an integral part of structured pathways. Staff working in these facilities should be included in the integrated training plan.

12.10 An individual with autism may face more risks when they try alcohol or drugs due to difficulties relating to social etiquette rules and norms, and reduced ability to self-regulate the effects of stimulants. Early preventative measures and appropriate support should be identified for any individual with autism who potentially could be vulnerable to this risk. Additionally, and for related reasons, people with autism have an increased risk of involvement within the criminal justice system whether they are a victim, witness or a perpetrator of crime. Police officers and probation courts need to be aware of the communication challenges experienced by people with autism in their interactions with other people and should be included in awareness training.

12.11 An overview of the recurring themes, identified during the mapping exercise, relating to Wider Opportunities and Access to Work are highlighted in 'OHAC – ASD Report & Action Plan' (2013), which incorporates the full action plan in Appendix 6. The priority areas for action to inform future shaping and coordination of services under this theme are:

- Supporting adults with autism into work
- Development of a clear pathway that supports people with autism
- Increase awareness of autism with employers/local community in Orkney
- Increase awareness of staff that work in leisure facilities
- Access to a range of social groups and opportunities to enhance interaction

- To increase awareness and understanding of the process and policies in regards to housing
- Explore the possibility of 'autism' flagging system to housing databases
- To ensure that lifelong learning opportunities are an integral part of a clear and consistent pathway

13. Evaluation Framework

13.1 An evaluation framework will ensure a best practice overview and ensure that all actions in the plan are progressed, reviewed and monitored to meet the expectations of the strategy in accordance with the ASD reference group at Scottish Government.

14. Conclusion

14.1 Autism is a national priority and strategic action is now required both nationally and locally. The creation of 'The Scottish Autism Strategy' (2011) has a linkage with a range of policies and incorporates an implementation framework which will be pivotal to its success. It is underpinned by quality research which should be disseminated and put into

practice. Guidance on further research recommendations will be circulated by the ASD Reference Group.

14.2 Consultation and engagement with people with autism and service providers was the first priority in the compilation of this strategy. This focused on mapping out existing services and identifying gaps in service provision. The framework of the Scottish Autism Strategy (2011), along with Orkney's Community Plan – Community Plan (2011-2014), guided the preparation of the local ASD Report and Action plan (2013). This will ensure that the expectations of the national strategy remain the focus of development and improvement of services for people with autism, whilst linking with the values and priorities of the local community plan.

14.3 The strategic context means that by their nature, these recommendations are far-reaching with the intention to drive change, and increase knowledge and understanding of autism. This will result in the best possible services and in people with autism being treated with respect, fairness, acceptance. It will promote positive aspirations.

14.4 There is clear recognition that to drive this agenda forward with the societal and cultural changes that are required, a lead autism/coordinator is essential to ensure a strategic focus is maintained as well as working and listening to people with autism and their families.

14.5 There are a number of governing principles which will be integral to the successful delivery of this agenda, primarily joint working and partnership working, a whole system approach, involvement with people with autism and their families, joint commissioning and workforce development and integration. There has been a great deal of work in Orkney to develop and implement an integrated structure to meet current service needs and develop an approach and a workforce that is fit for the future. Orkney Health and Care has now adopted a model of integrated service provision with joint governance and accountability arrangements in place to deliver improved services for people with autism and their families.

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