

Outer Hebrides Autism Strategy (2014 – 2024)



“If you would help me, don't try to change me to fit your world. Don't try to confine me to some tiny part of the world that you can change to fit me. Grant me the dignity of meeting me on my own terms - recognise that we are equally alien to each other, and that my ways of being are not merely damaged versions of yours. Question your assumptions. Define your terms. Work with me to build more bridges between us.”

(Jim Sinclair 1992)

Contents

Introduction	Page 3
What is Autism?	Page 4
National and Local Policy Drivers	Page 5
The Scottish Autism Strategy	Page 6
Local Needs Analysis	Page 7
Key Elements of Local Strategy	Page 9
Theme 1: Strategic Leadership	Page 10
Theme 2: Achieving Best Value for Services	Page 12
Theme 3: Collaboration and Involvement	Page 17
Theme 4: Cross Agency Working through Stronger Networks	Page 22
Theme 5: Diagnosis, Intervention and Support	Page 26
Theme 6: Wider Opportunities and Access to Work	Page 29
Conclusion	Page 33
Appendix 1 – 26 Recommendations	Page 34
Reference List/Bibliography	Page 37

1. INTRODUCTION

1.1 The Outer Hebrides Autism Strategy and Action Plan sets out the priorities and strategic direction for the improvement and development of services in the Western Isles for people with autism and their families across the lifespan. With the development and creation of the 'Scottish Autism Strategy' (2011), autism is now a national priority and it is vital to ensure that progress is made across Scotland in delivering quality services. Its recommendations are far-reaching and will impact upon all professions, across all disciplines involved in the provision of public services and will require societal and cultural change.

1.2 The Outer Hebrides are located to the north-west mainland of Scotland with a total population of around 28,000. The main islands are Lewis, Harris, North Uist, Benbecula, South Uist, Eriskay and Barra. The length of the islands measures approximately 130 miles from the Butt of Lewis in the North, to the south of Barra and Vatersay. The Outer Hebrides is one of the most sparsely populated areas in Scotland and the location and geography present major social and economic challenges.

1.3 The Outer Hebrides Community Planning Partnership (OHCPP): Single Outcome Agreement (SOA) 2013-2023 cites the challenges facing public services with a difficult financial climate as well as demand for services increasing with an ageing population being a key dynamic. Service providers need to involve more people in service design and delivery; integrate the services provided by different agencies and shift resources towards a focus on preventative services, early intervention and action to reduce inequalities. Services for autism should be embedded into this approach by building partnerships and developing a shared understanding of promoting inclusion which underpins the values and vision of the strategy.

1.4 The framework of the Scottish Autism Strategy (2011) along with 'OHCPP: Single Outcome Agreement 2013-2023' has guided the preparation of this local autism strategy and action plan. This will ensure that the expectations of the national strategy will remain the focus of development and improvement of services for people with autism, whilst linking with the values and priorities of the local single outcome agreement.

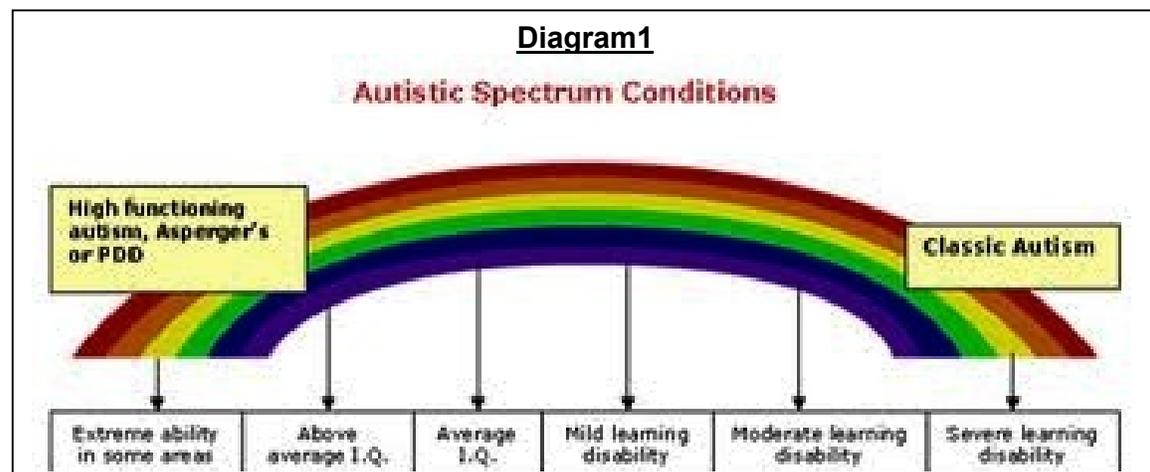
2. WHAT IS AUTISM?

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. It is this 'triad' of impairments that is captured in international classifications systems.

2.2 The National Autistic Society describes autism as a lifelong developmental disability that affects how a person communicates with, and relates to, other people, whilst also affecting how they make sense of the world around them. It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways (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 of each of the triad of impairments. In addition, these can look very different in childhood when compared to adulthood. It is clear however, that autism persists and that children with autism become adults with autism, with their own individual needs.

2.4 This autism strategy recognises that autism is a life long 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 of pivotal importance. In this strategy, the term autism reflects the full spectrum and includes the diagnostic categories of Asperger's Syndrome, High Functioning Autism, Pervasive Functioning Autism, Autism Spectrum Disorder and Autism Spectrum Condition.



3. NATIONAL AND LOCAL POLICY DRIVERS

3.1 The Scottish Strategy for Autism 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, national indicators and targets, which public bodies will work together to deliver in Scotland. These are supported by SOA which set out local priorities, expressed as high-level outcomes, which public sector partners will work together to deliver for their communities.

3.2 To cover the entire lifespan, there are local policy drivers which range from mainstream approaches targeted at improving outcomes for children and young adults such as 'Getting it right for every child' (2008), or at 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, housing, 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.

3.3 Local policy and strategy development needs to ensure that services for people with autism are inclusive and meet all equality and diversity strands.

4. THE SCOTTISH AUTISM STRATEGY

4.1 The policy context that heralds the autism strategy gives a framework for implementation and encompasses 26 recommendations (see Appendix 1) about how to improve support in order to improve the quality of life of people with autism. These recommendations will drive the local strategy and action plan. The summary of the broad recommendations, state that:-

- The Scottish Government will provide strategic leadership and create a vision for the development of services and support for those affected by autism
- There will be greater clarity about the cost of services and resources will be effectively targeted with the aim of improving people's lives
- People with autism and their families will be involved in decision making
- Practice will be improved and there will be increased cross agency working
- Waiting lists for diagnosis will be cut and the diagnostic process will be improved, enabling adults to be able to get a diagnosis and post diagnostic support across the lifespan
- People with autism should be supported into employment
- There will be training, research and scrutiny to support change

4.2 The strategy 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:-

- A local Autism Strategy
- Access to training and development
- Easy access to useful and practical information about autism
- An Autism Training Plan
- A process for collection of data, to improve reporting numbers of people with autism
- A multi-agency care pathway for assessment, diagnosis, intervention and support
- A process to gain feedback to inform service improvement and encourage engagement
- Services that can demonstrate that service delivery is multi-agency and co-ordinated
- Clear transitions at each important life stage throughout the lifespan
- A self evaluation framework to ensure best practice implementation and monitoring

5. LOCAL NEEDS ANALYSIS AND METHODOLOGY

5.1 The National Mapping Project was a short term fact finding exercise and analysis of information relating to the delivery of services for people with autism. It was designed to map out existing service provision across Scotland in order to build up a full picture of the national position which will inform future local decisions on autism co-ordination and also influence national decisions on the investment of Scottish Government funding for autism in the future.

5.2 The National Autism Services Mapping Project: Comhairle nan Eilean Siar (CnES) Service Map (Sep 2013) presents a snapshot of the situation in the Outer Hebrides. The information was gathered by collation from desk research into policies and practices, discussions with people at focus groups and questionnaires completed by individuals in the area. There was not a full representation of all stakeholders in all areas; however the mapping is reflective of the information gathered by those that were. The information gleaned from the national mapping will be used to inform the design and delivery of this local autism strategy and action plan as agreed under Autism Strategy funding to local authorities.

5.3 It was identified that further local mapping was required to overview and establish existing provision of services and gather views from as many people with autism and their families. This is reflected throughout the Scottish Autism Strategy and is underpinned by the vision and underlying values that need to be at the heart of the autism strategy as a whole and at the hearts of the people responsible for implementing it. This exercise was undertaken by an external Project Manager and focused on mapping out local service provision and identifying gaps in service provision whilst highlighting areas for action reflecting on local need.

5.4 An autism conference was undertaken locally to which a large number of services across social, health, employment, housing, criminal justice, education, voluntary sector and a range of other community based services were invited. The conference was attended by 25 people its aim being to increase awareness of the strategy and gain feedback through structured workshops on individual services as well as completion of a questionnaire. There was a 41% response rate in questionnaire returns incorporating qualitative and quantitative data and information. The workshops included participants in establishing local actions for the development of services.

5.5 An integral part of the local mapping was to meet people with autism, their families and carers and discuss what concerns and changes they felt were necessary to improve their quality of life. This was conducted through focused workshops which were advertised in the local press and web-sites and meeting with parents following two local training sessions that were being held. The Project Manager also invited

people with autism and their families to contact her via telephone, email or to set up a video-conference over the two week period of mapping. This resulted in gathering views and concerns in total from 24 people.

5.6 The analysis of the data and information gathered was arranged into six key themes and sub themes from the responses overall and incorporated into areas for action.

5.7 Further opportunities for consultation and feedback were arranged culminating in two workshops, where a presentation was given on the overall findings and recommendations. In total, there was 37 people participated in this process which included senior management, a number of services and people with autism and their families/carers. The workshops involved all participants viewing and commenting on the action plans. Further clarity was sought on a number of points and relevant changes were made. Additional responses were collated and analysed and added to the action plans to inform local context.

6. KEY ELEMENTS OF THE LOCAL STRATEGY & ACTION PLAN

6.1 The strategy and action plan identifies priority areas for action reflecting local needs and sets strategic direction for improving outcomes for people with autism and their families, across the entire lifespan.

6.2 Historically, autism was associated with learning disability; recent research suggests that 40% of people with autism may have a learning disability. This highlights that most people on the spectrum therefore, will not have a learning disability. However, there have been many initiatives leading to service improvements to either improve the care of people with learning disabilities or to help raise awareness of the additional needs of clients through the NHS Western Isles Learning Disability Collaborative Project which have been inclusive for people with autism.

6.3 The core part of the strategy is divided into six main sections to address the main themes and framework of the strategy, with each section having a linked action plan. Each section reflects the theme by providing a strategic overview, gives a local context and overview of the findings of the local mapping exercise with recommendations. Each action plan sets out the recommendations which are planned as short, medium and long term actions aligned and linked to the aims. It is important that this framework is used locally to help focus and achieve successful implementation and monitoring of the long term vision and expectations of the strategy. The main 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

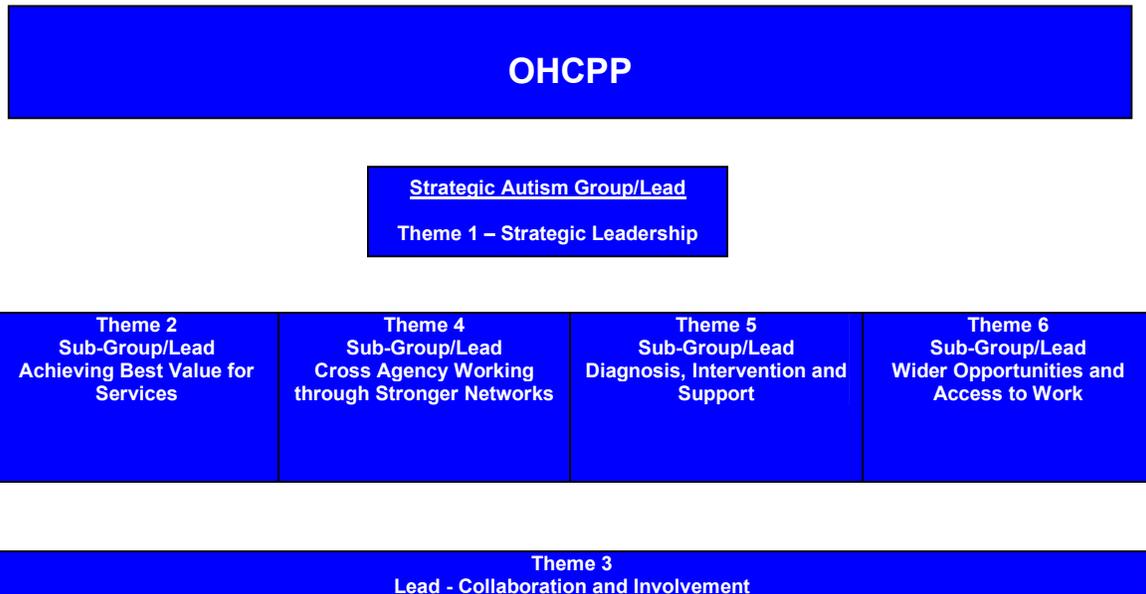
7. THEME 1: STRATEGIC LEADERSHIP

7.1 National strategic leadership will be provided by Scottish Government which has reconvened an ASD reference group to oversee developments and provide guidance to local authorities, over the ten year period of the strategy.

7.2 The Scottish Strategy for Autism (2011) which highlights the importance of immediate steps for delivering change is to set up structures to set direction, oversee delivery, drive implementation and monitor progress. Local authorities have a statutory duty of community planning under the Local Government in Scotland Act (2003). The OHCPP helps co-ordinate initiatives and partnerships that will improve public services for the Outer Hebrides. One of the ways that this takes place is through the implementation of the SOA.

7.3 Following the launch of the Outer Hebrides Autism Strategy & Action Plan, the OHCPP should consider how to establish and co-ordinate a specific autism strategic group to ensure implementation (see Diagram 2). The group should be multi-agency and be inclusive of people with autism. The group would be responsible for putting robust arrangements in place to ensure direction of the strategy, delivery of the action plan, monitoring and tracking improvements in service provision and ensuring progress is communicated across all sectors and to members of the public.

Diagram 2



7.4 The views of people with autism, their families and carers should be considered as a priority as well as people with autism being part of the strategic group and sub-groups. Links and networks should be encouraged with other established groups, such as 'The Western Isles Parent Forum' which was established in 2012.

7.5 The Scottish Government's 'Commissioning Services for People with Autism Spectrum' Policy and Practice (2008) recommended that local authorities and health services should work in partnership to appoint an Autism Co-ordinator to take responsibility for implementation, monitoring, quality assurance and reporting. There are areas in Scotland which did recruit and appoint to these posts and from which evaluations have demonstrated improved outcomes for people with autism.

7.6 To implement and deliver these improvements and strategic actions, decision making should include the budget holders and managers of resources across the whole system. This will include commitment to pooling resources and finding new ways of working together to ensure positive outcomes for people with autism in the Outer Hebrides in the current economic climate.

7.7 New ways of working also includes the need to share information and data. There were consistent views from professionals during the mapping exercise concerning confidentiality and data protection. The sharing of information about individuals across departments is vital to the provision of coordinated and seamless services to those individuals. Data sharing is a key way of improving the speed, efficiency and effectiveness of many processes across services. There is an information sharing protocol already in place between CnES, Health and Action for Children. To effectively predict future service demand and meet the requirements of the autism strategy, this protocol needs to be extended to include other services or alternative measures put in place to improve the speed, efficiency and effectiveness of sharing information

7.8 There are a number of governing principles which will be integral to the successful delivery of this agenda; primarily joint planning and partnership working, whole system approach, involvement of people with autism and their families, joint commissioning and workforce development. There are many good examples of joint working already happening across the Western Isles, such as the Learning Communities, The Early Years Collaborative and Action for Children. 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 Developments under this theme will include:

- Working collaboratively with the ASD Reference Group, Scottish Government to oversee developments
- Establish a governance structure for an autism strategy group and sub-groups, including the development of an implementation plan for the local autism strategy and action plan
- Having a clear communication strategy in place which includes a process to engage effectively with all stakeholders
- Consider the role of Autism Lead/Coordinator
- A process for monitoring and reporting of implementation plan

- Ensuring the inclusion of people with autism within development of strategies and services across all sectors
- Monitoring framework in place to measure against progress and timescales
- Development of an information sharing protocol

7.10 Best Practice Indicator measurements:

- A self-evaluation framework to ensure best practice implementation and monitoring
- A local strategy is developed in co-operation 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

8. THEME 2: ACHIEVING BEST VALUE FOR SERVICES

8.1 Commissioning services for people with autism will ensure that resources are effectively targeted and that the outcomes in improving people's lives are the best we can achieve. 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 2009). 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.

8.2 Policy and practice for commissioners of health and social services for people of the autism spectrum (2008) set 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.

8.3 The Community Health Partnership is in the process of developing a 'Joint Commissioning Strategy' which will be issued for public consultation in the forthcoming weeks. Informed commissioning relies on a full analysis of incidence, of needs and a mapping of existing service across all agencies to identify strengths and deficits in service provision, across the wide range of abilities of people with autism. It is important that the local mapping analysis, compilation of this local autism strategy and action plan is shared with commissioners and is incorporated into the commissioning strategy to improve future shaping, development and co-ordination of services for people with autism and their families.

8.4 Accurate collation of prevalence data is paramount for the future planning and predicting demand on services. From the Scottish Autism Strategy (2011) it is estimated that prevalence figures for autism in the Outer Hebrides going by population figures on the local authority website of 28,000 would be 252 based on a prevalence of 90 per 10,000. The current figure from the school census of 2012 (Scottish Government 2012) records 39 pupils with autism in the Outer Hebrides schools and as current school population in the Outer Hebrides is approximately 3800 (2007) this represents 1 in 100 which would concur with the current estimate of incidence by National Autistic Society. However, mapping analysis has revealed that the figures are much higher, with over 80 pupils with autism known to services. Further work and analysis requires to be undertaken on prevalence figures, as data is fragmented across sectors. The eSAY (2012) return from the Outer Hebrides states there are 19 adults with a diagnosis of autism known to learning disability services. However, few prevalence figures have been carried out in adults across Scotland and information from across services suggests 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". There needs to be standardised data collection system to reflect the numbers of people with autism to provide evidence to assist with and plan future service demand.

8.5 Additionally, there is a requirement for commissioners to promote the development and implementation of clear concise pathways in which people with autism can move between services and which can demonstrate the services' ability to work in close collaboration to achieve and meet the needs of people with autism. Transformational change is required to promote earlier intervention and shared understanding across all services to provide the right care, at the right time by the right professional or service to ensure that people with autism are able to access timely support.

8.6 During the local mapping exercise, services were asked if they had plans to improve services for people with autism. This analysis identified the majority of respondents were looking to improve various aspects of their service, with the rest aiming to continue their current working practice. The information gathered on plans to improve services were in accordance with local identified need, such as improved respite provision, enhanced transitions, housing needs and training. These plans should now be formalised and structured within this local autism action plan.

8.7 Increased focus on early intervention and prevention will have economic and social benefits. Research by Knapp (2009) highlight that financial costs of intervening late can be significant and lifelong which can have profound effects on people with autism. Many of the changes that are currently underway within public services, such as increased personalisation, increased choice and control for individuals, are essential to giving people with autism the right kind of support. This can include referral to appropriate services at an early stage as well supporting voluntary and third sector organisations. Often people with autism reach crisis point, when helping them to make change can be more costly, time consuming and less effective. 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.

8.8 The post diagnostic support and appropriate range of early interventions should be considered to meet each child's and young person's specific needs. The Scottish Autism Strategy recommends that agencies and services develop a menu of interventions including advice, therapeutic interventions and counselling for children, young people and adults with autism, that are appropriate and flexible to individual need. The menu should identify advice and support that is immediately available and set out the referral and assessment process for all other services and interventions.

8.9 The national autism strategy ASD Reference Group in collaboration with service providers will identify the key determinants of service provision that result in improved quality of life for people with autism, across the spectrum and across the lifespan. This recognition of autism as a lifelong condition allows policy and planning to be aware of a life stages approach, of the need for a range of services and of the importance of a holistic view of autism. As part of the local mapping exercise, respondents were asked what strategies and or support it was important to have in place to ensure people with autism have a good quality of life. Broad categories were identified such as: training/education, support and information, multi-agency working,

community awareness, improved transitions, coping strategies, improved assessments, social provision, access to services, appropriate respite provision and person centred planning. These categories and suggestions have been incorporated into this autism strategy and action plan themes.

8.10 There is currently a local review of community day care redesign and the resultant implications for transport. The work around day care provision is focusing on increased flexibility and personalised approaches to service delivery to meet identified outcomes. The development of Ardseileach Core and Cluster, the move to an integrated workforce and Care at Home and overnight support redesign are all factors being taken into account. There are also developments within Back Residential Unit (Ionad na Cloinne) and Rowntree. These developments support the personalisation and increased choice agenda as well as the principles of increasing life skills and independent living.

8.11 This development will also support increased respite services. During the mapping exercise many families who are affected by autism expressed the problems they had encountered around accessing respite. A respite break is necessary for many families and gives them a break from the caring role. There should be development of a policy which gives a clear framework of respite and holiday respite services, which includes the process for access, assessment, timely reviews and decisions made.

8.12 A number of children and young people have required specialist placements (such as respite care for those with autism or residential placement for those with specialist needs). The CnES and its partners are currently examining a number of options which will aim to ensure that more young people are able to remain within the Outer Hebrides and are close to family and friends which may have the effects of reducing costs as well as additional benefits. It is important that a strategy is developed outlining the plans to enhance service provision locally in order to reduce mainland placements.

8.13 Developments under this theme will include:

- Developing a Joint Commissioning Strategy
- Work towards setting up a process and system to improve local autism data
- Linking in with local review of day services
- Increased flexibility and increased respite facilities
- Development of a policy outlining respite provision
- Providing information and guidance on direct payments
- Linking in with the redesign of transport redesign
- Embedding early intervention and prevention approaches
- Developing a Menu of Interventions
- Clear and concise pathways
- Enhancing local service provision and reducing the need for mainland placements

8.14 Best Practice Indicator measurements:

- A process of data collection which improves the reporting of how many people with autism are receiving services and informs the planning of these services

9. THEME 3: COLLABORATION AND INVOLVEMENT

9.1 Prior to the compilation of the 'The Scottish Strategy for Autism', a wide range of service users and professionals, had spoken to individuals on the autism spectrum and their families to hear at first-hand what their concerns were and what changes are required. This is reflected throughout the national strategy and is underpinned by the vision and underlying values that need to be at the heart of the autism strategy as a whole:

Vision:

"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"

Underlying Values:

Dignity: people should be given the care and support they need in a way which promotes their independence and emotional well-being and respects their dignity

Privacy: people should be supported to have choice and control over their lives so that they are able to have the same chosen level of privacy as other citizens

Choice: care and support should be personalised and based on the identified needs and wishes of the individual

Safety: people should be supported to feel safe and secure without being over-protected

Equality and diversity: people should have equal access to information assessment and services; health and social care agencies should work to redress inequalities and challenge discrimination

People with autism should expect to have support of professionals working in their best interests to make these values a reality

9.2 The Scottish Strategy for Autism (2011) states that people with autism and their families and carers, should be involved at all levels of decision making with development of plans, strategies and single outcome agreements relating to services for people with autism. There is a local need to ensure that this level of involvement and inclusiveness takes place and people with autism are represented, to ensure that effective, responsive services and support is offered to enable them to lead a more fulfilled and satisfying life.

9.3 People with autism and their families were encouraged to come forward as part of this mapping with views, concerns and discuss any changes that they would like to be made to services to enable them to work towards a more meaningful and satisfying life. The information was collated and the following are examples of services or processes that they felt were working well locally:

- Advocacy support
- Social Communication team doing adult diagnosis on the island
- Action for Children
- Educational Psychology Service
- Speech and Language Therapy
- Lews Castle College
- Examples of services working together through transition from school
- GP surgeries – ‘red flagging system’
- Autism Alert Card
- Occupational Therapy Services and strategies used
- Communication Booklet – Hospital
- Placement at Yorkhill – support basis
- Provision at Sandwickhill Learning Centre
- Out with school provision – clubs
- Local Coordinator – Life Plan
- Citizens Advice Bureau
- Carers Assessment
- Whole process was fairly positive
- Well supported in primary school, inter-agency working excellent with social worker and school and other agencies involved in a remote setting and brilliant support from social worker
- Parent Forum
- Extended Learning (AFC/LA)
- Communication Book/Moving on Passport
- Very positive journey with good education support and transitions and support in the community

And the following were examples given of services or processes that were felt were not working as well:

- Support – Keyworker/Named person
- Some health services – no awareness
- Support to live independently with key life skills and targeted support when required
- Better understanding of communication problems
- Ignorance – need for increased awareness across all services
- Education provision – (concerns regarding design and future provision for children with autism)
- Inequality, flexibility and lack of respite
- Social Work input
- Inclusion issues
- Culture of having to ‘fight for’ services/respite and detrimental effects of strain and tensions with whole family
- Reactive management leading to crisis management

- No seamlessness, feels like services are disjointed
- Lack of long term planning
- Flexible individual plans
- Funding for placements
- Services to support and increase social skills
- Time and complexities with direct payments
- Living remotely – move to mainland housing
- Lack of supports for parents
- Transition work into university
- Big challenges – learning support within universities
- Transition difficulties – in particular with planning on leaving school
- Elderly parents giving full support
- Feels like services are ‘resource led’ rather than ‘needs led’
- Lews Castle requires to have a quiet area
- Sensory issues not identified
- Employment
- No targeted support to live independently in own home
- Public open space and indoor availability of soft play area
- Concerns about moving into secondary school – remote area

Additionally, there were suggestions on improvements that could be made:

- More case studies/real life stories to be shared to increase awareness
- Use gazette/local media to share news about autism strategy and developments
- Increased awareness and understanding with everyone in schools, including peers
- Need for GIRFEC model to continue into getting it right into adult services
- Promoting awareness and openness
- Access to services and knowing what is available, increased information and signposting
- Predictable sufficient respite
- Overnight/Day Care
- Support Workers in out of school clubs/societies
- One Stop Shop
- More work required with mentoring and transitioning into jobs
- Establishing social networks can be really beneficial

9.4 The analysis of this information has been collated and will be incorporated into the themes of the local strategy and reflected in the action plans.

9.5 During the local mapping exercise, people with autism and their families suggested that the use of case studies could be used in the future as part of increasing awareness sessions. The following case study is from a young adult who has given consent for the story of his autism journey, to be shared. His story conveys a positive story of his experience and the educational support he has received. It demonstrates how continuity and smooth transitional planning can lead to a more meaningful and satisfying life. The names have been withheld to protect anonymity.

The Story of my autism

My mother and father, inform me that from an early age, my behaviour was regarded as 'irregular'. At the age of 1, my parents noticed I was not repeating such words as 'ma' and 'da' as other children of a similar age normally would. At about age 3, I would become frustrated when unable to comprehend simple instructions like being told to put on a jacket. To help combat this, I was given single-word instructions by my parents to allow me to understand them better at this time. I also developed a habit of organising objects like toy cars and shoes into lines. XXXXXXX provided me with preschool support at around this time. After I was introduced to a preschool playgroup at approximately age 3, I was given speech therapy and preschool support. With the agreement of Comhairle nan Eilean Siar's (CnES) Education Department, my parents transported me to the Royal Hospital for Sick Children in Yorkhill, Glasgow for testing on at least three occasions to conduct various assessments of my behaviour in terms of my ability to understand human emotions, questioning me in how I thought about things and asking me to complete special puzzles and other games. It was thought that, unlike many other children of a similar age, I was able to correctly pronounce numbers and letters of the alphabet and exhibited a high level of intelligence for someone of my age.

I was diagnosed with high-functioning autism at the age of 4. My parents declined to waive an Asperger syndrome 'label' for me and instead asked for additional educational support from CnES' Education Department as I entered primary school (XXXXXX School) in the form of continued regular speech therapy and one-to-one assistance in the classroom, as well as occasional meetings with an educational psychologist. At about age 8, the school opted me in to The Listening Program, a series of sessions of listening to classical music in silence while playing with things like toy cars and bricks.

Prior to the five induction days all pupils in my year had at XXXXXX School, I was given an additional individual induction day to be introduced to the structure of the school building and classrooms. In S1, without my knowledge but with the knowledge of my parents, the school recruited one girl to observe my behaviour. She did not report any problems with my behaviour. The school had classroom assistants in place for any S1 pupil who needed them. I continued to receive speech therapy in S1; for me, this particular service concluded at the end of S2. As head of Support for Learning, XXXXXXX was able to arrange for me to have occasional one-to-one sessions with one psychologist called XXXXXXX and later another therapist called XXXXXXX.

The school was able to provide me with a prompt, extra time, ICT and a separate room to facilitate me completing my exams in S4 and S5. This practice is expected to continue for my S6 exams. In organising the police work experience I went on in S5, a deputy head teacher ensured she would keep in contact with the landlady of our accommodation and assured parents / guardians she would contact them had any significant problems arisen.

My guidance teacher kindly arranged for me to have a personal trip to the University of XXXXXXX to allow me to see the XXXXXXX campus firsthand and to reassure me that there would be worthwhile support for me from the university if necessary.

My parents generally regard the support services provided by CnES' Education Department as excellent. I would personally agree with this sentiment; I cannot recall any significant problems arising from any of the Education Department's services. My mother recommends that, assuming they have not been already, all members of staff in the Education Department are given training in understanding and dealing with autistic pupils.

9.6 The Scottish Autism Strategy highlights that seeking feedback from people with autism and their families to inform service improvement and encourage feedback is vital. Information was gleaned through the completed questionnaires from services that there is a variety of methods used, both formal and informal and not necessarily specific to autism. A framework and process requires to be put in place to reduce duplication and overlap of methods, whilst ensuring service improvements and to encourage feedback, as a best practice indicator for current best practice in effective autism spectrum services.

9.7 The Western Isles Parents Forum has been established wherein there is an opportunity for parents/carers who have children with additional support needs to meet other parents and professionals. This forum offers a themed presentation from a relevant professional, with a time for questions and a chance to update parents about anything new within their agency or organisation. Past themes have included transitions, respite and advocacy, with other suggestions covering Sandwickhill Learning Centre and looking at benefits and entitlements for families. This work is underpinned by the vision and values within the Scottish Autism Strategy. It was evident throughout the local mapping exercise that parents had only just become aware of this forum, or had not been aware that the forum has been established. There are other broad ranges of people with autism and their families who could benefit from a support/network group which covers the lifespan and where there could be direct links with the parent forum.

9.8 Developments under this theme will include:

- Ensure inclusion and involvement with development of plans
- People with autism and their families views are fully incorporated into relevant themes/action plan
- Introduce a framework to inform service improvement
- Ensure that people with autism are represented on the strategic autism group
- To help form an autism support group/network which covers the lifespan

9.9 Best Practice Indicators measurements:

- A framework and process for seeking stakeholder feedback to inform service improvement and encourage feedback

10. THEME 4: CROSS AGENCY WORKING THROUGH STRONGER NETWORKS

10.1 The long term recommendation and vision of the Scottish Autism Strategy is access to integrated service provision across the lifespan to address the multi-dimensional needs aspects of autism. This integration of services is intended to reduce frustration, decrease delays and address inefficiencies and the gaps that frequently exist in the system. There are many examples across the Western Isles of joint and partnership working, although further work and development is required to ensure seamless service provision and good practice guidance to support the lifelong challenges facing people with autism as they make daily and life-stage transitions

10.2 The Learning Communities model which was approved by CnES in 2005 and implemented in 2008 is a good example of co-ordinating all multi-agency groups that have a role in delivering children's services in the same geographical area. This model embeds the principles of 'Getting it Right for Every Child' (GIRFEC), promoting earlier intervention, and shared understanding across agencies to provide the right care, at the right time by the right professional. Across all partners there is a range of other joint working examples, initiatives and strategies being implemented, such as the Integrated Children's Plan, Early Years Collaborative, Learning Disability Collaborative, Youth Employability Action Plan and Reshaping Care for Older People. The range of activities is reflected in the SOA and associated logic models. Joint working has become a dominant concept running through public services policy in Scotland and this work, across agencies locally, provides many opportunities on which to build and provide integrated services.

10.3 The Scottish Autism Strategy highlights that the first and fundamental step is to increase awareness and understanding across all public services. A lack of understanding of autism can lead to inappropriate or stereotypical views being held by staff that supports people with autism and this can have negative outcomes, with the strategy stating that training must lead not only to improved knowledge and understanding but also to changing the behaviour and attitudes of health and social staff. A 'National Training Framework for Autistic Spectrum Disorders' by MacKay & Dunlop (2004) revealed gaps in professional training across all disciplines, as well as addressing the need for parents and individuals on the spectrum to have access to training. During the mapping exercise locally, analysis of the questionnaire highlighted that there had been many opportunities for training with good examples of educational psychology offering training which had been well received and the learning disability collaborative training in past two years in relation to autism. However, there was little evidence of general awareness training and respondents' feedback consistently suggested that there was a need for awareness training across all services, a range of public services, the community and employers. The Scottish Autism Strategy highlights the importance of this and links two best practice indicators for current effective autism spectrum practice. These links include the compilation of a training plan and access to training and development to increase awareness and understanding of autism.

10.4 The autism training plan should include detailed levels of training required across all services, public sector, the wider community and include training for people with autism and their families. The training material should utilise technological

innovation, which will also help to ensure staff in front line services across remote and rural areas have equal access.

10.5 An assessment of needs is a vital step towards improving access to mainstream services and gaining the support and services people with autism and their families require. During the mapping exercise, people with autism and their families expressed their reluctance to accessing an assessment, particularly a social services assessment. This was due to their past experiences having suggested a lack of understanding of their condition. The questionnaire analysis highlighted that assessments for people with autism should be adapted to include a personalised approach based on an understanding of the nature of the condition and individual need. The talking points approach should be used as guided by the national strategy, which is a personal outcomes approach to assessment, planning and review. The philosophy of this approach is one that emphasises the strengths, capacity and resilience of individuals, build on natural support systems and includes consideration of wider community based resources. The feedback also highlighted that whilst short term planning following assessment is useful, longer term planning would help alleviate many concerns and worries people with autism encounter.

10.6 The role of carers and the importance of a carer's assessment were highlighted during the mapping analysis. There were a number of older parents who expressed concerns about being able to continue to support their son/daughter who had autism, as they faced difficulties as they grow older themselves. The vital role of carers supporting people at home is recognised in the Western Isles, however further mapping of the number of people with autism that this involves should be undertaken to establish demand of services in the future.

10.7 Individuals with autism and their families need information at the point of diagnosis and beyond. There was a strong emphasis throughout the mapping exercise of the stress that can be placed upon people with autism and their families in trying to locate information about appropriate services. The questionnaire also highlighted that services found it difficult to access information to give to people with autism. It was apparent that services access information from a variety of different sources, however there was no main clear source of information that are accessed by the majority of services. The availability of information is crucial for people with autism and their families, as well as for those who are working with people with autism and who make decisions about accessing, referring or providing support services. Overall and in line with the Scottish Autism Strategy guidance, access to a central hub of information covering specialist advice and information covering all services within Western Isles is essential. In response to this, a directory of services should be compiled. This would include contact details and information about local and national autism specific support, as well as information on support and services appropriate to people with autism and their families. The directory should also include signposting readers to sources of information and support for early years, social care, education, health, employment support, leisure services and lifelong learning opportunities. The information collated during the mapping of services, can be used to start compiling this directory.

10.8 The Scottish Autism Strategy also highlights that disseminating good practice is essential for sustained and meaningful practice on an equitable basis across Scotland. There were many good examples of practice identified across all health, social, third sector and leisure services in the Western Isles. Additionally, there was a

great deal of work in progress to improve services for people with additional support needs, which is inclusive of autism. These developments are reflected throughout this local strategy and action plan.

10.9 Another key area identified, is the need for good practice guidance to be developed, to support people with autism with lifelong challenges encountered daily and life-stage transitions. The questionnaire analysis on the topic of transition, confirmed that there was a number of different assessments, plans, pathways and procedures used to support individuals through transitional stages. However, this was primarily used in educational settings with children and young adults, with only a few examples of transitions used in adulthood.

10.10 Transitions in adulthood can be broad and varied and can involve services from a number of providers. During the mapping analysis, adults with autism expressed that they did not have a designated person to contact, oversee or coordinate their support. It was highlighted that it may be only targeted support that may be required, however the concept of having access to a named person who could do reviews, anticipate their changing needs and provide continuity, would be very beneficial. Further work is required in the development of identification of this role as well as replicating support and services in adulthood.

10.11 A review and evaluation of existing educational transitional guidelines should be undertaken and new guidelines compiled which cover the lifespan.

10.12 The Scottish Autism Strategy specifically recommends consistent adoption of good practice in key area of education, health and social care across all local authorities. Whilst these sectors have been included in broad actions, such as training and awareness, there are also specific actions that were identified. These sectors have their individual statutory key policies and strategies for guidance and the identified actions, highlight the need for more autism specific developments.

10.14 Developments under this theme will include:

- Development of a multi-agency training plan
- Awareness training
- Training on assessment
- Increase and develop awareness campaign in the general public
- Central hub of Information
- Key Worker role for adults with autism
- Specific actions for health, social and education

Education:

- Transitional guidance development
- Specific Plans – Personalisation approach
- Review and evaluate – Moving on Passport/Communication Book
- Links with Integrated Children’s Plan and clarification of lead professional role
- Review meeting developments and SQA specific arrangements

Health:

- Reasonable adjustments across health services
- Links with relevant health strategies and policy

Social:

- Ensuring compliance with corporate standard on communication
- Review process of guidelines on assessment and review
- Further development on continuity and consistency of named worker
- Increased awareness of respite provision and developments for people with autism and family/carer
- Adults – process of targeted support

10.15 Best Practice Indicators measurements:

- Access to training and development to inform staff and improve the understanding amongst professionals about ASD
- An ASD Training Plan to improve the knowledge and skills of those who work with people who have ASD, to ensure that people with ASD are properly supported by trained staff
- Services that can demonstrate that service delivery is multi-agency in focus and coordinated effectively to target meeting the needs of people with ASD
- Clear multi-agency procedures and plans which are in place to support individuals through major transitions at each important life-stage
- A process for ensuring a means of easy access to useful and practical information about autism and local action, for stakeholders to improve communication

11. THEME 5: DIAGNOSIS, INTERVENTION & SUPPORT

11.1 Diagnosis, Intervention and Support are essential to ensuring a good quality diagnosis which is the key foundation for both children and adults. This will lead them to understanding their condition allowing the recognition of individual strengths and challenges, enabling the best support to be made available to them. A major recommendation of the Public Health Institute for Scotland report (2001) was that Scottish Intercollegiate Guideline Network (SIGN) should develop evidence based clinical guidelines on autism. The SIGN Guideline no. 98 (2007) for children and young people up to the age of 18 summarises the evidence base on autism, suggests 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 into which SIGN has been integrated, to develop guidelines for evidence-based approaches to the diagnosis and management of autism in adults.

11.2 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 recognising children's difficulties and needs in order to improve their emotional, educational, social and cognitive development and their health. Early action may also help to tackle some of the many social and physical barriers faced by children with autism and enable their full participation in society. Appropriate plans for their assessment and intervention can enable all children and young people with autism to achieve their full potential.

11.3 The Early Years Collaborative was launched by Scottish Government in 2012 and is the first national, multi-agency group quality improvement programme. This work will take forward the vision and the priorities of the Early Years Framework. Locally, there has been development within this work to establish a process using universal screening assessments for all children aged 3, and in their last year at nursery prior to transition into Primary One. This incorporates a pathway clearly delineated through an interagency flow chart for early identification of autism. The effectiveness of this has been evaluated by using the model of improvement methodology. This resulted in an additional step being added for speech and language therapy assessment and thereafter if appropriate, referral to the social communication team.

11.4 In Western Isles, the process of identification and assessment of children and young adults is conducted as per 'Western Isles Educational Psychological Assessment Tools and recommendations for usage in collaboration with Principal Teachers for Learning Support' (2013). Assessment and intervention are conducted in accordance with national guidance; 'Educational Psychology Assessment in Scotland' and the British Psychological Society's Scottish Division of Educational

Psychology (2005). This encompasses a staged process of assessment and intervention for children who require additional support, psychological advice and intervention which is provided as an integral part of that staged process. The local guidance incorporates a referral pathway and checklist guidance for completion of the inter-agency referral form. The assessment is undertaken by the local Social Communication Team, which is multi-disciplinary and the process involves the child/young person, their parent/carers, teachers and any other professional involved. This guidance should now be reviewed and changes included as local autism strategy implementation progresses.

11.5 There are a number of recommendations in the Scottish Autism Strategy in relation to adults getting a good quality diagnosis, leading them to understanding their condition and for the best support to be made available to them. The Social Communication Team also undertakes assessment for adult diagnosis. There is currently a process in place for referral and each individual person who is referred, receives a letter notifying them of the approximate waiting period. The guidance from the national autism strategy is that each area should have a clear pathway to diagnosis and assessment of needs, including signposting for post diagnostic support. Local guidelines and an adult pathway should now be developed identifying services that can offer additional support, as this work progresses with themes to increase awareness across services, have a central point of information, development of leisure/social opportunities and better access to employment routes.

11.6 There is universal recognition of the importance of ensuring diagnostic processes for autism are robust and high quality. The structure of the Social Communication Team encompassing assessment, intervention and diagnosis across the lifespan is a distinctive feature and strength for people requiring this service. The Scottish Autism Strategy recommends that an assessment of national waiting lists is undertaken to clarify the extent of delays. However, locally targets are currently being met, although the local service requires to give further clarity across services concerning the length of the referral process. At the present time, there are staffing challenges within this team and the continuation of this service is vital to ensure meeting the expectations of the national autism strategy. Maintaining the number of trained professionals should now be seen as a priority, as should developing further links with appropriate professionals as required. This will ensure sustainability of the service and guarantee the application of evidence based clinical standards and guidelines.

11.7 Following diagnosis, what really matters to people with autism is the subsequent quality and accessibility of services and support. The Scottish Autism Strategy highlights the importance of access to appropriate post diagnostic support for families and individuals, access to mainstream services and accessing services which are understood and are able to meet the specific needs of people with autism. This will develop locally with awareness training, having a central point for information, a service directory and the development of structured pathways across the lifespan.

11.8 Following diagnosis of a child or young adult, many parents find themselves in the unenviable position of having to learn a whole new terminology and skill set in a very short and emotionally charged period of time. The Scottish Autism Strategy highlights the importance of redesigning services around the principles of prevention, early identification of problems and early intervention by service providers. Families with children with autism often experience high stress levels as a consequence of

their care giving responsibilities. 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. In addition, the guidelines highlight that professionals should assess the family context and informal support systems and consider supplementing these as appropriate. Therefore, it is essential that an early intervention parenting support programme is an integral part of post diagnostic pathway.

11.9 Many adults with autism are unable to access the support they need, which leaves them feeling isolated and vulnerable. Throughout the local mapping exercise and in meeting with adults with autism, there was identified need to continue the concept of 'Getting it Right for Every Child' into replicating service provision for adults. The lack of timely and appropriate support can result in unnecessary mental health problems and reliance on high cost acute services. The right support at the right time by the right service can have a positive impact on quality of life, outcomes and value for services. The support can vary across a range of services including education and training, employment, housing, social and life skills, relationships, leisure, lifelong learning and benefits. This 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 the support options and incorporate specific and targeted interventions available.

11.10 Developments under this theme will include:

- Focus on the sustainability of the Social Communication Team
- Early Intervention programme for individuals with autism and parents as part of a post- diagnostic pathway
- Review local guidance on children/young adults on assessment, intervention and diagnosis as local autism strategy implementation progresses
- Clear consistent pathways for adults for diagnosis, intervention and support

11.11 Best Practice Indicator measurements:

A multi-agency pathway for assessment, diagnosis and interventions to improve the support for people with autism and remove the barriers

12. THEME 6 – WIDER OPPORTUNITIES AND ACCESS TO WORK

12.1 The Scottish Government is committed to removing barriers which stand 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 The National Autistic Society report that only 15% of people with autism are in full time employment and that there are many adults with autism who want to access work but have not had the right support and opportunities to make their ambitions a reality. The national autism strategy focuses on ensuring adults with autism will benefit from wider employment opportunities, personalising welfare and engaging employers, improving existing provision and developing new approaches that will better support adults with autism.

12.3 There have been many strands of work in the Western Isles focusing on opportunities for employment and barriers to employment. There are local partnerships within the context of employability and key partners who have particular responsibilities within the employability agenda. Across all partners, there is a focus on early intervention and preventative work being undertaken, which is reflected in the SOA agreements and associated logic models. This theme should now link with the needs of people with autism across the lifespan, accessing potential employment and in providing opportunities to those facing multiple barriers to employment through the logic model. Consideration now needs to be given to a structure within the existing work strands and partnerships that will address employability issues for people with autism.

12.4 The questionnaire analysis revealed that the majority of respondents felt that there were limited opportunities for employment locally. Adults with autism, who participated in the mapping, expressed their desire to work and had many skills and talents that would be useful. However, they felt that there was a lack of support for applying for work, interview support and job coaching. Adults with autism are entitled to benefit from all the Scottish Government's wider initiatives to get working age people into employment. There are limited services, such as 'First Steps', 'Include Us' and Occupational Therapy who have become involved. However, these services are all located in Stornoway and are not readily available elsewhere. The feedback also suggested that many employment agencies lack autism awareness and the skills to provide the right kind of advice to support people with autism into employment. Additionally it was felt that employers need to understand the skills and strengths that people with autism can offer and often, it is only reasonable adjustment that is required. The training plan will incorporate awareness training for employment agencies and employers. Thereafter, a clear pathway should be

developed that supports people with autism into employment. The pathway should signpost the support available with the recruitment process and availability of support thereafter. These processes should lead to adults with autism being better integrated into society, reducing isolation and increasing feeling of well-being through greater social support.

12.5 There are many strands of work in the Western Isles focusing on opportunities for employment and barriers to employment. There are local partnerships within the context of employability and key partners who have particular responsibilities within the employability agenda. Across all partners, there is a focus on early intervention and preventative work being undertaken, which is reflected in the SOA agreements and associated logic models. This theme should now link with the needs of people with autism across the lifespan accessing potential employment and in providing opportunities to those facing multiple barriers to employment through the logic model. Consideration now needs to be given to a structure within the existing work strands and partnerships that will address employability issues for people with autism.

12.6 Following on from 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 with job coaching. The pathway should have a particular focus on engaging with employers and businesses that will support people with autism.

12.7 The framework for Supported Employment in Scotland (2010) outlined that this support needs to be personalised and it needs to be consistent. Such personalised support may range from reasonable adjustments being made to ongoing support being required. The implementation of this guidance requires to be reviewed and evaluated along side the work stream on employability.

12.8 In order to develop and promote employability in the Western Isles, consideration should be given to establishing an independent organisation through local and national funding streams. There are areas across Scotland which run this type of organisation and whose main focus is to remove the barriers being faced by socially-excluded people in the community. This type of service aims to support people in a range of employment opportunities for rewarding, meaningful employment. This also involves support through application systems, the recruitment process, job coaching and provides advice and support with benefits and other employment related allowances.

12.9 Assessment of need carried out by adult services teams should include any needs around accessing work. People with autism, eligible for adult services support can use their individual budgets or self-directed support to give them more choice and control to help facilitate their access to work.

12.10 The Outer Hebrides Housing Strategy (2011-2016) details the housing outcomes, objectives, and actions that CnES and local partners believe are the most appropriate for the distinctive local housing system for the period 2011-2016. It provides a framework that focuses on working together to use resources and expertise to improve the housing outcomes for residents of the Outer Hebrides.

12.11 Housing stock in the Outer Hebrides differs greatly from other areas in Scotland. More than 80% of households live in privately-owned or rented housing. Most of the private sector housing stock consists of large houses with 3 or more bedrooms and many are in poor condition. It is projected through the Housing Need and Demand Assessment (2011); that up to 870 additional homes may be required in total by 2020, primarily due to the projected growth in households. Further mapping is required on 'needs assessment' with regards to housing requirements for people with autism. Many individuals with autism are living with elderly parents with no long term planning for housing requirements. During the local mapping exercise, participants expressed that housing needs should be established at the earliest opportunity and that all assessments and plans should incorporate baseline assessment of housing need and wider support required to live independently.

12.12 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. During local mapping exercise, it was evident that there were social and support groups available but parents with children with autism, were not aware of the available options. The groups were mostly for children and young people with autism and many parents felt that having support workers, would enhance the experience and increase social confidence. Parents that participated from the smaller remote areas reported good access to social opportunities. Further work should be undertaken to gain a more in-depth understanding of all the clubs/societies and their remits that are currently available across the Western Isles. This information should be 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. Additional work requires to be undertaken to explore ways for local autism social and support groups for adults, as this is currently a gap in provision. If an adult with autism, is eligible for support from Adult Services, personalised approaches should be used to help them identify their support needs. This can be delivered through direct payments or self-directed support and give them more choice and control how they purchase their support. This can provide more flexibility with support and help in daily routines and social activities, resulting in adults with autism becoming more socially included.

12.14 Access to lifelong learning opportunities for people with autism should be an integral part of pathway for service provision and wider opportunities. The Community Learning & Development (CLD) Strategy for the Outer Hebrides sets out the overall vision, key outcomes and indicators for the period 2013- 2017 to direct youth work, adult learning and community capacity building interventions. The Strategy has been developed with the input of all the key partners with an interest in CLD in the Outer Hebrides and is implemented and monitored through the CLD. To increase the opportunities for people with autism to attain skills and qualifications through access to training and lifelong learning opportunities, direct links should be made.

12.15 An individual with autism may face more risks when they try alcohol or drugs due to social skills, insight and understanding what is appropriate behaviour in a given context. Early preventative measures and appropriate support should be identified for any individual with autism who potentially could be vulnerable to this risk taking. People with autism often experience high levels of anxiety and distress and any confrontation with the police is likely to increase anxiety. Many individuals may

not have been diagnosed and it is only when an incident results in their first encounter with the police, that their condition is recognised.

12.16 Autism Alert Cards were introduced in the Western Isles in and can be used in situations where communication may be difficult. The alert card, developed in consultation with adults who have autism and parents, is designed to tell people about the condition and asks them to show respect and tolerance. It can be particularly useful if a person who has autism comes into contact with emergency services. During the local mapping exercise, it was highlighted that further awareness and development of the use of the card across a range of services would be beneficial.

12.15 Developments under this section will include:

- Consideration of an 'Employability Strategic Group'
- Links to employability within Employability Strategy
- Consideration of setting up a local Employability Support Service
- Employment Pathway
- Raising awareness in the community and engage with employers
- Review progress on Supported Employment Framework
- Housing developments
- Leisure developments
- Lifelong Learning opportunities
- Accessing Justice
- Further awareness of autism alert card

Conclusion

Autism is now a national priority and strategic action is required both nationally and locally. The creation of 'The Scottish Autism Strategy' (2011) has a linkage with a range of policies and an implementation framework from which people on the spectrum will benefit and which will be pivotal to 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.

The National Autism Service Mapping Project: CnES (2013) presents a snapshot of the situation in the Western Isles and is reflective of the information gathered. Further local mapping has been undertaken to overview existing service provision and gather views from people with autism and their families. The local mapping information and information from the national mapping have been incorporated to inform the design and delivery of the 'Outer Hebrides Autism Strategy & Action Plan' (2013), which sets the strategic direction for improving outcomes for people with autism and their families.

The strategic context means that by their nature, these recommendations are far-reaching with the intention to drive change to ensure shifts in knowledge and understanding about autism. This will result in the best possible services and in every individual with autism being met with respect, fairness, acceptance and positive aspirations that ensures a more meaningful and satisfying life.

There are a number of governing principles which will be integral to the successful delivery of this agenda; primarily joint working and partnership working, whole system approach, involvement of people with autism and their families, joint commissioning and workforce development. Local authorities and NHS Boards are the statutory sectors commissioners of local services to meet identified needs and to determine the local level of funding required to address these needs. Therefore, it is paramount that joined up arrangements are in place to assure the appropriate governance and joint accountability for achieving outcomes to deliver improved services for people with autism and their families.

Appendix 1

RECOMMENDATION 1: It is recommended that the ASD Reference Group is reconvened on a long-term basis to include COSLA membership to oversee developments and to progress change. It should produce an annual report to relevant Ministers and the political leadership of COSLA.

RECOMMENDATION 2: It is recommended that the ASD Reference Group works collaboratively, and offer support, to COSLA, NHS, criminal justice and other relevant public bodies to offer support to Local Authorities to effect the implementation of the various autism guidelines.

RECOMMENDATION 3: It is recommended that the ASD Reference Group explores the benefits of ASD lead officers with the Association of Directors of Social Work and with COSLA to establish how rollout across Scotland might best be achieved.

RECOMMENDATION 4: It is recommended that the ASD Reference Group meets with representatives of both SCSWIS and HIS, as well as other relevant regulatory bodies, such as those in education and criminal justice, with a view to learning about current developments and ensure that the needs and wishes of those on the spectrum are taking into account in future programmes.

RECOMMENDATION 5: 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 on 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.

RECOMMENDATION 6: It is recommended that the effectiveness of implementation of the Commissioning guidance is reviewed by the ASD Reference Group by facilitating an audit of current service commissioning.

RECOMMENDATION 7: 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.

RECOMMENDATION 8: 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.

RECOMMENDATION 9: 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 country in a way that is cost-effective.

RECOMMENDATION 10: 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.

RECOMMENDATION 11: It is recommended that consideration is given to the specific supports needed for the more able individuals with ASD.

RECOMMENDATION 12: 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.

RECOMMENDATION 13: It is recommended that the ASD Reference Group explore options for developing user and carer capacity to be able to participate in local planning processes.

RECOMMENDATION 14: 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.

RECOMMENDATION 15: 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.

RECOMMENDATION 16: 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.

RECOMMENDATION 17: It is recommended that the Training Sub-Group 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.

RECOMMENDATION 18: It is recommended that good 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.

RECOMMENDATION 19: 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.

RECOMMENDATION 20: 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.

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.

RECOMMENDATION 22: 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.

RECOMMENDATION 23: 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.

RECOMMENDATION 24: It is recommended that the directory of individuals and teams undertaking assessment and diagnosis of ASD in Scotland is reviewed, updated and re-distributed.

RECOMMENDATION 25: 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.

RECOMMENDATION 26: 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.

Reference List/Bibliography

A Guide to Getting it right for every child (GIRFEC) (2008)

www.scotland.gov.uk/gettingitright

Caring Together and Getting it Right for Young Carers, The Carers Strategy for Scotland 2010-2015, Scottish Government,

<http://www.scotland.gov.uk/Publications/2010/07/23153304/0>

Commissioners of health and social care services for people on the autism spectrum, Policy and Practice Guidance, (2008)

<http://www.sign.ac.uk/Publications/2008/03/27085247/0>

Community Day Care and Education Transport – Redesign Report. Comhairle Nan Eilean Siar. June 2013

Corporate Strategy. Comhairle nan Eilean Siar. 2012-17

Early Years Collaborative Update Report: Education and Children's Services Committee.

Comhairle nan Eilean Siar. September 2013

Getting it Right for Children in the Outer Hebrides: Integrated Children's Plan. Comhairle nan Eilean Siar. 2010-2013

Knapp, Martin and Romeo, Renee and Beecham, Jennifer (2009). Economic cost of autism in the UK. Autism, (3). Pp. 317-336. The National Autistic Society

Management Plan by Department: Education and Children's Services Department.

Comhairle nan Eilean Siar. 2013.

McKay, T & Dunlop, AW (2004) The Development of a National Training Framework for Autistic Spectrum Disorders, NAS & University of Strathclyde

National Autism Services Mapping Project. Comhairle nan Eilean Siar Service Map. September 2013

National Autistic Society

<http://www.autism.org.uk/living-with-autism/employment.aspx>

National Guidance on the Implementation of Local Area Co-ordination, Scottish Government, (2008). <http://www.scotland.gov.uk/Publications/2008/03/27092411/0>

NHS Quality Improvement Scotland

http://www.shinelib.org.uk/cpd/journal/volume_43/nhs_quality_improvement_scotland

Outer Hebrides Community Learning Strategy. 2013-2017

Outer Hebrides Community Planning Partnership: Single Outcome Agreement. 2013

<http://www.cne-siar.gov.uk/cxdir/executiveoffice/documents/Single%20Outcome%20Agreement%202013-23.pdf>

Public Health Institute of Scotland Autistic Spectrum Disorders Needs Assessment Report, 2001

<http://www.scotland.gov.uk/Topics/Health/care/adult-care-and-support/learning-diaability/Resources/PHIS>

Review of Education Provision: Educational Provision Proposal Document. Comhairle nan Eilean Siar. 2012

SIGN publication No 98. Assessment, diagnosis and clinical interventions for children and young people with autism spectrum disorders

<http://www.sign.ac.uk/guidelines/fulltext/98/index.html>

Single Outcome Agreements, Scottish Government, 2007

<http://www.scotland.gov.uk/Topics/Government/local-government/SOA>

Single Shared Assessment of Community Care Needs Circular CCD8/2001

<http://www.sehd.scot.nhs.uk/publications/DC200011129CCD8single.pdf>

Talking Points: <http://www.jitscotland.org.uk/action-areas/talking-points-user-and-caer-involvement/>

The National Autism Mapping Project. Comhairle nan Eilean Siar. 2013

The Framework for Supported Employment in Scotland 2010

<http://www.scotland.gov.uk/Publications/2010/02/23094107/3>

The Outer Hebrides Housing Strategy. Comhairle nan Eilean Siar. (2011-2016).

Transition Planning Guidelines: Department of Social and Community Services. Comhairle nan Eilean Siar. ????

The National Performance Framework, Scottish Government, 2007

<http://www.scotland.gov.uk/Publications/2007/11/13092240/9>

The same as you? (2000), Scottish Government (2001)

<http://www.scotland.gov.uk/ldsr/docs/tsay-00.asp>

The Scottish Autism Strategy, Scottish Government, 2011

<http://www.scotland.gov.uk/Resource/Doc/361926/0122373.pdf>

Western Isles Educational Psychological Assessment Tools and Recommendations for Usage in Collaboration with Principal Teachers for Learning Support. Comhairle Nan Eilean Siar, 2013