

Report To: **Community Health & Care
Partnership Sub Committee**

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Report No:
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Subject: **The Scottish Strategy for Autism – Inverclyde’s Draft Local
Strategy and Associated Action Plan**

1.0 PURPOSE

The purpose of this report is to inform the Sub-Committee of the development of a local autism strategy and associated action plan which incorporates services delivered by Inverclyde CHCP, Education, Third Sector organisations and carers.

2.0 SUMMARY

2.1 Inverclyde’s draft local autism strategy and associated action plan have been developed in line with and drawing from the 10 year national Scottish Strategy for Autism.

2.2 The development of Inverclyde’s local plan for Autism gives cognisance to the outcomes for people with ASD and their families and carers and relates directly to the following key services in Inverclyde:

- Care and support
- Health including primary and community healthcare services
- Employment opportunities
- Education including further education opportunities
- Transition between children and adult services
- Housing
- Community Support
- Criminal Justice
- Service planning and commissioning of services.

2.3 The development of a local ASD plan will directly correlate with the Single Outcome Agreements for all agencies and organisations with a commitment to the inclusion of people with ASD and their families and carers.

3.0 RECOMMENDATION

3.1 The Sub-Committee is asked to note the development of Inverclyde’s draft local autism strategy and associated action plan.

- 3.2 Approval is sought from the Sub-Committee to progress Inverclyde's draft local autism strategy and associated action plan through a local launch and a wider three month consultation period with service users, carers and third sector organisations

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4.0 BACKGROUND

- 4.1 In October 2012 the Scottish Government indicated that in consultation with COSLA, and as a result of the launch of the Scottish Strategy for Autism, one off funding of £35,000 would be released to all local authorities to develop a local autism strategy and associated action plan.
- 4.2 Each local plan incorporates the recommendations of the national 10 year Scottish Strategy for Autism and is fully inclusive of the views of people with ASD and their carers. The intension of the Scottish Government will be all local plans across Scotland will be collated and made publicly available through the web-site of the Autism Spectrum Disorder Reference Group.

5.0 PROPOSALS

- 5.1 It is proposed to progress the development and delivery of services for people with autism in Inverclyde based on nine essential themes underpinned by the perspective and wishes of people with autism:
 - **Understood, Valued and Safe** - We want to be understood, valued and safe in the community in which we live.
 - **Independence and support** - We want the opportunity to have meaningful, independent active lives, using mainstream services when we can, but accessing support to overcome barriers when we need it
 - **Social networks** - We want opportunities to develop positive, supportive and enabling social networks
 - **Training Plan** - We want a coordinated Autism Training Plan for Inverclyde so that people with autism, their families and carers, and those people working with them all have the attitudes, knowledge and skills they need
 - **Pathway for Diagnosis** - We want equal and timely access to a standard evidence-based pathway for assessment, diagnosis and the support that follows
 - **Information and Advice** - We want a coordinated system for information and advice about autism, that allows people not only to access good quality printed and electronic information when they need it, but also allows people to speak to others about how autism affects their lives.
 - **Coordinated services based on accurate data** – We want coordinated services that speak to each other and that identify and meet the needs and aspirations of people with autism in Inverclyde.
 - **Included and Involved** - We want to be involved in decisions that affect our lives, and to play a role in implementing the Inverclyde Strategy for Autism.
 - **Evaluation** - We want services to check on a regular basis that they are doing a good job for people with autism in Inverclyde.

6.0 IMPLICATIONS

Legal

6.1 None.

Finance

6.2 The £35,000 funding from Scottish Government has been allocated to the development of this strategy.

Cost Centre	Budget Heading	Budget Year	Proposed Spend this Report	Virement From	Other Comments
Autism	Various	13/14	£35,000	N/A	N/A

Human Resources

6.3 None.

Equalities

6.4 An equalities impact assessment will be completed during the three month consultation period.

Repopulation

6.5 None.

7.0 CONSULTATION

7.1 All organisations listed and service users.

8.0 LIST OF BACKGROUND PAPERS

8.1 Scottish Government – National Strategy for Autism.

8.2 Scottish Government – Keys to Life Learning Disability Strategy.

inverclyde autism Strategy

Action Plan 2014-2024

Inverclyde
council

INVERCLYDE
CHCP
Community Health
& Care Partnership

NHS
Greater Glasgow
and Clyde



Nine themes were identified in the Strategic Report:

- 1 **Understood, Valued, and Safe** - We want to be understood, valued and safe in the community in which we live.
- 2 **Independence and support** - We want the opportunity to have meaningful, independent active lives, using mainstream services when we can, but accessing support to overcome barriers when we need it
- 3 **Social networks** - We want opportunities to develop positive, supportive and enabling social networks
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- 8 **Included and Involved** - We want to be involved in decisions that affect our lives, and to play a role in implementing the Inverclyde Strategy for Autism.
- 9 **Evaluation** - We want services to check on a regular basis that they are doing a good job for people with autism in Inverclyde.

These themes can be arranged into six priority areas for action:

- A. Assessment and Care Pathways
- B. Communication Planning
- C. Training Planning
- D. Transitions, Independent Living and Social Networks
- E. Stakeholder Involvement
- F. Measuring Performance

It is proposed that:

- An Inverclyde Autism Strategy Implementation Group (IASIG) is formed, chaired by a senior manager and with representatives from carers and people with autism, to oversee the implementation of the action plan.
- An Inverclyde Autism Coordinator should be appointed to drive forward the action plan and ensure that the work proceeds in a coordinated way.
- An Inverclyde Autism Reference Group, made up of people with autism, is formed to give expert advice and guidance on how the plan should be implemented.
- Six working groups are formed to address each of the six priorities for action, reporting to the IASIG. The groups should refer to the appropriate sections of the Strategic Report and set goals for two years, five years and ten years so that progress can be measured.
- Early intervention, prevention, co-production, multi-agency working and the coordination of services are integral to the delivery of all priorities for action.

A ASSESSMENT AND CARE PATHWAYS					
Our 10-Year Vision	How will we get there?	How will we know that we have got there?	Strategic Fit	Who will be involved?	Timescale
All mainstream services will be aware of the signs of autism and how to signpost people to appropriate diagnostic services.	Establish an Inverclyde-wide Autism Diagnosis Group to look at earlier recognition, referral pathways, equity of service, information and best practice guidelines and to ensure that best practice is at the core of services in Inverclyde.				
Autism diagnostic services will be available to all people in Inverclyde who need it and waiting times kept to a minimum.					
A diagnostic and care pathway that is evidence-based and standard across Inverclyde, wherever you receive your assessment.					
A pathway that is no longer and more complex than necessary but which involves gathering information from all stakeholders.					
There is regular audit of compliance with pathway and the pathway is adapted in the light of findings.					
All people and carers who receive a diagnosis of					

autism receive standard high-quality information pack after diagnosis that is appropriate to their needs.					
Clear pathways exist with transparent eligibility criteria so that people who need support do not fall through gaps.					
There are good links between statutory bodies and other organisations to improve post-diagnostic support.					
Autism-aware crisis intervention support is available to people with autism and their families when they need it.					

B COMMUNICATION PLANNING					
Our 10-Year Vision	How will we get there?	How will we know that we have got there?	Strategic Fit	Who will be involved?	Timescale
Raised awareness and acceptance of people with autism across the community, but especially within Inverclyde Council and CHCP services.	A coordinated communication plan on how autism awareness can be promoted and sustained across Inverclyde. The plan should also include coordination of the sourcing and distribution of information resources, so that people with autism and their carers/families have easy access to accurate information and advice when they need it.				
Local businesses and organisations take responsibility for making sure that they are accessible to people with autism, with a network of supported Autism Champions in organisations across Inverclyde					
Raised awareness of autism in older people's services in the light of high levels of undiagnosed autism.					
Wider awareness of the Autism Alert Card					
People with autism and their carers/families have easy access to good quality information and advice on autism and local services – both physical and online - including the ability to speak to someone who can tailor the advice to their specific circumstances					

<p>The agencies involved in supporting an individual with autism work closely together and share information, while protecting the individuals' right to confidentiality.</p>	<p>A review of communication channels - between different agencies, between statutory bodies and third sector and voluntary organisations and between all agencies and people with autism and their carers - and how these can be made to work more efficiently.</p>				
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C TRAINING PLANNING					
Our 10-Year Vision	How will we get there?	How will we know that we have got there?	Strategic Fit	Who will be involved?	Timescale
There is a coordinated programme of training relating to supporting people with autism in Inverclyde.	<p>A coordinated training plan that maps ALL training needs against current and future training provision for:</p> <p>People with autism Parents and carers Practitioners supporting people with autism Mainstream students Mainstream services Autism specialists/diagnostic teams</p> <p>There should be a focus on coordination to prevent any gaps or duplication and quality assurance.</p> <p>The plan should take into account the need for local services that people with autism and their carers/families can access easily.</p>				
People with autism have the opportunity to attend groups that help them to understand autism and how it may impact on their lives.					
People with autism have the knowledge and skills they need to lead active, independent lives and to access the community safely.					
The carers of people with autism have the knowledge and skills they need					
People with autism of all ages are supported by staff who have the right mindset, the right knowledge and the right skills					
Students in mainstream schools will have a better understanding of autism and a more					

positive inclusive attitude towards people with autism					
People with autism and their carers are involved in the design and delivery of autism training.					
A Training calendar is produced so that those wishing to attend have plenty time to make arrangements.					
Best practice and minimum standards for services for people with autism rolled out across Inverclyde	Formulation of best practice standards and agreements with service providers across the lifespan re provision of training in return for commitment to introduce best practice standards in working with people with autism.				
Specialists will receive support from other specialists working within Inverclyde and have access to specialist training as required.	Establish circle of support to keep up with research evidence and new developments				
There will be a mechanism in place to ensure that after training, the receiving organisation takes responsibility to take action and sustain change in relation to their practice with people with autism.	Explore options for school- and service-wide autism friendly protocols.				

D TRANSITIONS, INDEPENDENT LIVING AND SOCIAL NETWORKS					
Our 10-Year Vision	How will we get there?	How will we know that we have got there?	Strategic Fit	Who will be involved?	Timescale
Individuals with autism of all ages will be able to access support with transitions and challenges, when they need it, throughout their lives	<p>A wide-ranging review of support across all agencies and across the lifespan:</p> <ul style="list-style-type: none"> • Support at school • Access to therapies, e.g. communication support, sensory support • transition services • addressing common barriers and challenges relating to independent living for people with autism and their carers • building capacity through social networks • best model of service delivery – e.g. making better use of current services, specialist team, one stop shop. 				
There are close links between children and young people’s services and adult services.					
Individuals with autism will be supported to develop coping strategies and their own solutions to problems to promote independence.					
There is equity of service relating to transitions across Inverclyde with individuals with protocols in place so that all people with autism receive the support they need, regardless of whether they access mainstream or specialist provision.					
All people with autism will have access to meaningful activity, depending on their individual needs and aspirations, and personal development opportunities, with the level of support they need.					

More people with autism experiencing success in employment, work placements, voluntary work, education or training					
People with autism are able to access support with independent living skills, when they need it.					
People with autism are given access to housing services that understand their needs.					
People with autism are given support to make friends, access social activities and deal with social situations					
Carers of people with autism will have their needs assessed.					
Carers and the families of people with autism have social activities and networks that support them in their daily lives					
Carers of people with autism are able to access respite support, when required.					

E STAKEHOLDER INVOLVEMENT					
Our 10-Year Vision	How will we get there?	How will we know that we have got there?	Strategic Fit	Who will be involved?	Timescale
There is good communication between service providers and people with autism and their carers.	Development of an Autism Involvement Plan, highlighting mechanisms for user and carer involvement in the design, delivery and evaluation of services for people with autism				
There is an Inverclyde Autism Reference Group, made up of people with autism, who give expert advice and guidance on service design.					
The views of people with autism and their carers are identified and taken into account in the design of services for people with autism in Inverclyde.					
Visual communication supports are routinely used to ensure that people with autism are empowered to express their views and have these views heard.	Development and distribution of visual aids that will make it easier for people with autism to express their views.				
Where appropriate, people with autism should have access to independent advocacy.					
The views and needs of people with autism and their carers are taken into account in all local strategies and policies.					

F MEASURING PERFORMANCE					
Our 10-Year Vision	How will we get there?	How will we know that we have got there?	Strategic Fit	Who will be involved?	Timescale
We know about people with autism in Inverclyde, their needs and aspirations and those of their carers.	Review current data gathering systems and establish a robust data gathering system in Inverclyde for people with autism of all ages.				
We have evidence that we are making a positive difference to the lives of people with autism in Inverclyde.	Establish a robust system for measuring outcomes for people with autism and a process for monitoring these outcomes				
Our services for autism have protocols to ensure that they are following best practice and evaluating their performance on a regular basis.					

inverclyde autism Strategy



Strategy Report 2014-2024

Cover planned and designed by a group of young people from Reach for Autism, Inverclyde – Lucy, Kira, Jamie, Jade and Ally.



A vision for the future, according to the people living with autism who contributed to the Inverclyde Autism Strategy

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Foreword

On behalf of people with autism, their carers, families and friends and all the practitioners working to provide services for them, we are delighted to introduce the Inverclyde Autism Strategy 2014-2024.

In the last few months, we have listened to the people of Inverclyde who are living with autism. We have listened as people with autism have told us their stories, told us what they need and told us their aspirations for the future - what works well for them and how they feel services can be improved. In all of our work on the Strategy, we have embraced the values of co-production, recognising that citizens have a major contribution to make and aspiring to deliver services with people with autism and their families, rather than for them.

The work on the Inverclyde Autism Strategy comes at an interesting moment for the area. The current financial climate makes it vitally important that organisations use their precious resources wisely. In Inverclyde, we have a large number of individuals working on behalf of people with autism – from the parents running local support groups, the workers in schools identifying and supporting the individual needs of the child, the local employers offering work placement and jobs – and this strategy celebrates many areas of best practice. But still we have individuals with autism and families who feel isolated and abandoned.

In this Inverclyde Autism Strategy 2014-2024 we strive to ensure that people with autism in Inverclyde and their families, like all other citizens of Inverclyde, are:

- Safe – Protected from abuse, neglect or harm and supported when at risk. Enabled to understand and take responsibility for actions and choices. Having access to a safe environment to live and learn in.
- Healthy – Achieve high standards of physical and mental health and equality of access to suitable health care and protection, while being supported and encouraged to make healthy and safe choices.
- Achieving – Being supported and guided in lifelong learning. Having opportunities for the development of skills and knowledge to gain the highest standards of achievement in educational establishments, work, leisure or the community
- Nurtured – Having a nurturing place to live and learn, and the opportunity to build positive relationships within a supporting and supported community.
- Active – Having opportunities to take part in activities and experiences in educational establishments and the community, which contribute to a healthy life, growth and development

- Respected and Responsible – Respected and share responsibilities. Citizens are involved in decision making and play an active role in improving the community.
- Included – Overcoming social, educational, health and economic inequalities and being valued as part of the community.

The challenge now is to see how people with autism in Inverclyde can be empowered to make their aspirations a reality, with the support not only of the Scottish Government and national organisations, but , most importantly, by bringing together the Inverclyde community – our Council, our Community Health and Care Partnership, our schools and colleges, our local employers, our service providers, our social enterprises, our voluntary organisations, our friends and families and the people of Inverclyde themselves.

The hard work lies ahead. The success of the Inverclyde Autism Strategy will depend on whether it leads to lasting change for people with autism. Let's get to work and ensure that we all Get It Right for people with autism in Inverclyde and their families.

Brian Moore

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Acknowledgements

More than 100 people have contributed to the preparation of this Strategy. We would like to thank each and every one of you for your contribution, but particularly the individuals with autism and carers who told us their stories.

Note

Individuals and groups use a range of different terms for autism - including autistic spectrum disorder, autistic spectrum condition, autistic spectrum difference and neuro-diversity. In this strategy, we use the term "autism" as an umbrella term for all such conditions, including Asperger's Syndrome and high functioning autism. This is in line with the approach to terminology adopted by key autism representative organisations, including the National Autistic Society (NAS).

1 What is the Inverclyde Strategy for Autism?

1.1 What is autism?

1.1.1. Autism is a lifelong developmental condition that affects how an individual communicates with and relates to other people and the world around them. The condition covers a wide range of symptoms, often grouped into a 'triad of impairments', namely:

- Impaired language and communication skills, both verbal and non-verbal – for example, language delay, difficulties adapting your language in different social situations, difficulties understanding indirect language, difficulties in the understanding and use of intonation, facial expression and gestures.
- Difficulties with social interaction, such as difficulties understanding how others are feeling and what others are thinking, as well as managing the 'give and take' of conversations
- Restrictive, repetitive and stereotypical routines of behaviour – e.g. pre-occupation with special interests, repetitive movements and the desire for routines and rituals.¹

1.1.2 Autism is often described as Autism Spectrum Disorder (ASD) or Autism Spectrum Condition (ASC). This reflects the fact that although people with autism share certain characteristics, the condition takes many forms – with some people living independently and others requiring high levels of specialist support. The condition also varies in the way it impacts on the individual. For some people with high functioning autism and Asperger's Syndrome (those with average or above-average cognitive abilities and sometimes mistakenly referred to as having a 'mild' form of autism), the expectations of society and their expectations of themselves lead to severe anxiety and stress as they encounter a myriad of challenges in getting on with their daily lives, often without any support from services.

1.1.3 The diagnostic criteria used in the United Kingdom (ICD-10 from the World Health Organisation) are due for revision in 2015. The new DSM-5 diagnostic criteria² (from the American Psychiatrists Association) were published in 2013 and include for the first time the acknowledgement that many people with autism experience sensory processing differences and difficulties (such as hyper- or hyposensitivity to light, sound, smell, touch, proprioception) which have a major impact on their daily lives.

1.1.4 Recent studies estimate prevalence rates for autism to be about 1 in 100 of the general population, with about 40 per cent of those also having a learning disability and 60 per cent with no learning disability.³ The ratio of males to females tends to be quoted as 4:1,

¹ Scottish Government (2011) *The Scottish Strategy for Autism*, Scottish Government, Edinburgh
<http://www.autismstrategyscotland.org.uk/>

² <http://www.dsm5.org/Documents/Autism%20Spectrum%20Disorder%20Fact%20Sheet.pdf>

³ <http://www.scotland.gov.uk/Resource/Doc/217371/0058243.pdf>

although an increasing number of girls are being diagnosed (usually later than boys). Many people with autism have other conditions that impact on their lives – for example, learning disability, sensory impairment, attention deficit hyperactivity disorder (ADHD), dyslexia, dyspraxia.

1.2 Background to the Strategy

1.2.1 In November 2011, the Scottish Government published a ten-year plan to improve services for people with autism in Scotland, *The Scottish Strategy for Autism*. The strategy set out a vision for people with autism⁴:

We aspire to give individuals on the autism spectrum a meaningful and satisfying life built on:

- ✓ People being given the care and support they need in a way which promotes their independence and emotional well being and respects their dignity
- ✓ People being 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
- ✓ Services being personalised and based on the identified needs and wishes of the individual
- ✓ People being supported to feel safe and secure without being overprotected
- ✓ People having the opportunity to achieve all they can
- ✓ People having access to information, assessment and services with agencies working to redress inequalities and challenge discrimination

1.2.2 To achieve that vision, each local authority in Scotland was asked to carry out a review of services for people with autism across the lifespan in their area, to consult with people with autism, their families and carers and people who worked to support them and to develop a local strategy and action plan that would lead to an improvement in outcomes for people with autism over the following 10 years. Local authorities were also provided with the goals that were to be reached after two, five and ten years, as well as indicators of best practice against which their services could be mapped (see Appendix). We have carried out that work over the last few months and this strategy sets out what we have learned about the needs of people with autism, their families and carers, about the services we offer and about our priorities for action for the future.

1.3 Understanding the cost implications of service delivery

1.3.1 This is a time during which we are all being asked to ‘pull in our belts’, ‘to live within our means’. It is therefore a difficult time to think about introducing service developments. It

⁴ <http://www.autismstrategyscotland.org.uk/>

can be argued, however, that in periods of financial restraint, it is even more important that the valuable resources we do have are being used well. Many of the service developments that people with autism, their family and carers and people working in services have suggested do not involve new funding; they simply involve partnership, better coordination and the best use of resources.

1.3.2 The best practice indicators included in the Scottish Strategy for Autism (see Appendix) emphasise the importance of the involvement of people with autism, recognition and early identification, prevention, access to assessment and diagnosis, as well as the management of transition throughout the lifespan. There is a growing body of evidence in relation to services for people with autism that suggests that investment in appropriate services to facilitate independence and active community involvement, particularly for adults with high functioning autism and Asperger's Syndrome, brings significant benefits to public expenditure, in addition to the benefits it brings the individuals with autism and their families and carers. The Scottish Government has made £10 million available over the next ten years to support the development of services across the country.

1.3.3 Recent studies have estimated the annual cost of supporting people with autism⁵. Supporting a young person with autism and learning disability aged 12-17 costs an average of £62,500 (2005-6 prices) per year if living in residential or foster placements and £36,400 if living with their families (costs do not include the cost of informal care). For people with autism and no learning disability aged 12-17, living with their family, the costs were £21,000.

1.3.4 A report by the National Audit Office in 2009⁶ included a cost/benefit analysis of providing services for adults with high functioning autism and Asperger's Syndrome (in England). Costs were calculated based on:

- NHS Costs (inpatient care, crisis resolution, accommodation and treatment)
- Local government costs (social services, employment support, housing, adult education, day services)
- Central government costs (employment support)
- Costs to private individuals (accommodation, family expenses, carers' lost earnings)

The research found that if only 4 per cent of people with high functioning autism or Asperger's Syndrome were offered access to the individualised multi-disciplinary support they needed to have active independent or semi-independent adult lives, the provision of that service would be cost-neutral, but would result in additional income and reduced outgoings for the individuals involved. A realistic identification rate of 8 per cent of adults

⁵ Knapp, M, Beecham, J, Romeo, R (2007) *The economic consequences of autism in the UK*. Foundation for People with Learning Disabilities

⁶ National Audit Office (2009) *Supporting People with Autism through Adulthood*, The Stationery Office, London.

with high functioning autism and Asperger's Syndrome could lead to annual savings of £67 million (a well-established Asperger's Team in one part of the country achieves 14 per cent!).

Beresford et al, in their study of the experiences of young people with high functioning autism and Asperger's Syndrome, concluded⁷ that:

'Young people ... are at risk of being invisible to strategic groups and commissioners of adult statutory services ... This and other research call for 'low intensity', early intervention/preventative holistic support for young people with HFA [high functioning autism] and AS [Asperger's Syndrome], and believe that this can be cost effective ... Crucially, any study of effectiveness needs to take a cross-agency view on costs and cost-effectiveness.'

By working in a more joined up way and building capacity in the long run, by streamlining services and using people with autism, their carers, third sector organisations, volunteers, we can make better use of the resources we have, as well as ensure that funding applications are submitted to cover services that we cannot offer locally.

1.4 National and local policy drivers

1.4.1 The Scottish Strategy for Autism (2011) is the main driver for the development of this strategy. However, the values, goals and actions described in the Inverclyde Strategy for Autism also correspond to those expressed in a number of national and local policy frameworks.

1.4.2 National Drivers

National Performance Framework

The Children and Young People Bill 2013

The Public Bodies (Joint Working) (Scotland) Bill 2013

Education (Additional Support for Learning) (Scotland) Act 2004 (amended 2009)

Standards in Scotland's Schools etc Act 2000

Caring Together 2010-1015

Disability Discrimination Act

Human Rights Act

⁷ Beresford, B, Moran, N, Sloper, T, Cusworth, L, Mitchell, W, Spiers, G, Weston, K and Beecham, J (2013) *Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions. Final Report*. Department of Health Policy Research Programme/Social Policy Research Unit, University of York. P viii

Adult with Incapacity Act

Realising Potential

National Performance Framework

SIGN Guidelines

NICE Guidelines

Royal College of Speech and Language Therapists Clinical Guidelines

The Keys to Life

1.4.3 Local Drivers

Inverclyde Single Outcome Agreement

Getting It Right for Every Child, Citizen and Community

Inverclyde Carers' Strategy 2012-15

Inverclyde Community Engagement Strategy

Equality and Diversity Strategy

People Involvement Framework 2012

Facing the Future Together (NHS Greater Glasgow and Clyde)

1.5 Who will deliver the strategy?

1.5.1 In order to achieve the best outcomes for people with autism and their families in Inverclyde in the next 10 years, we are going to have to learn to work better together and to build capacity for the future.

1.5.2 For some of our action points, we will be able to call on the help of the Scottish Government and organisations such as Autism Network Scotland, NHS Education Scotland (NES), the National Autistic Society (NAS) and Scottish Autism, and the Scottish Council for Learning Disability (SCLD). The Inverclyde community is also going to be asked to come together, however, to work to improve the lives of people with autism - for example, people with autism, their families, our support groups (such as the Inverclyde Autistic Support Group), our young people, our active voluntary sector, our social enterprises (such as Reach for Autism) as well as statutory services (health, education, social work) and other service providers, such as ENABLE, Barnardo's, Quarriers, Turning Point, Richmond Fellowship.

It is hoped that we will all feel a sense of ownership of the strategy and its priorities for action.

- 1.5.2 The next ten years are likely to bring big changes in the way our services are organised with a number of legislative changes in the pipeline - The Public Bodies (Joint Working) (Scotland) Bill 2013 (integration of adult health and social care), The Children and Young People Bill 2013 (greater coordination of services and carer involvement), Social Care (Self-Directed Support) (Scotland) Act 2013 (families receiving direct payments with which they can buy their own services) to name but a few.
- 1.5.3 The National Strategy for Self Directed Support (SDS) in Scotland⁸, launched in November 2010, is a ten-year strategy that aims to drive a cultural shift around the delivery of support that views people as equal partners with rights and responsibilities, rather than the passive recipients of services (draft regulations and guidance were published for consultation in April 2013). Individuals are encouraged to think about what they want to achieve and are supported to plan for this. In the future, the implementation of Self Directed Support and the move to the personalisation agenda will result in a change in the provision of support for people with autism. Instead of considering 'What services do we need to provide to ensure a person's needs are met?', service providers will consider how they can support a person to think about what they want to achieve (outcome) and to how they will achieve it. This move from a needs-led assessment to a person-centred approach puts the person – as well as their family, carers and the community in which they live - at the centre.

⁸ <http://www.scotland.gov.uk/Publications/2010/11/05120810/0>

2 Autism and Inverclyde

2.1 People with autism

2.1.1 There are no exact data on how many people in Inverclyde have autism. Recent studies estimate the prevalence of autism in children and adults in the United Kingdom is 1 in 100, with 40 per cent having a learning disability and 60% having no learning disability. This would indicate that there are approximately 800 people in Inverclyde with autism, including 480 people with high functioning autism or Asperger’s Syndrome. The Scottish Strategy for Autism included the following Office of National Statistics⁹ data relating to Inverclyde, although acknowledged that the 2005 data were based on a 1 in 90 prevalence rate rather than the 1 in 100 prevalence rate the Scottish Strategy now accepts:

Population of Inverclyde	81540
Estimated ASD population	734
Of whom	
Aged 0-4	44
Aged 5-9	46
Aged 10-14	48
Aged 15-19	47
Aged 20-29	96
Aged 30-65	343
Aged >65	Not known

2.1.2 The Additional Support for Learning and Young Carers Report to Parliament (published 18 February 2013)¹⁰ includes data on the number of children and young people reported as having additional support needs, and those who have a coordinated support plan, individualised education programme or child’s plan. It identifies 1981 children and young people with recorded additional support needs in Inverclyde, of whom 189 have an Autistic Spectrum Disorder (9.5%). (The figures for Scotland are 117818 and 8650 respectively.)

⁹ Office of National Statistics, from <http://www.autismstrategyscotland.org.uk/>

¹⁰ <http://www.scotland.gov.uk/Publications/2013/02/7808>

- 2.1.3 As of August 2013, 204 children in Inverclyde have been identified with a confirmed diagnosis in the 0-18 age group (i.e. 1 in 83 children in Inverclyde) which suggests that the great majority of children are now being picked up by the paediatric diagnostic process. In 2012, 54 children were referred to the Skylark Centre for diagnostic assessment, and 53 assessments were carried out. 55% of these children received a diagnosis of Autism or Asperger's Syndrome.

An NHS Greater Glasgow and Clyde-wide central database is being developed that will record the outcomes of all autism diagnostic assessments for children and young people carried out by teams across the region – both those cases where a diagnosis is given, and those where no diagnosis is given.

- 2.1.4 The data for adults with autism in Inverclyde is far from complete. It is generally accepted that autism in the adult population is under-diagnosed due to the absence of robust diagnostic services when those individuals were at school. When the Skylark ASD Diagnostic Service for children and young people started in 2002, there were approximately 20 children known to have a formal diagnosis of autism within Inverclyde, compared to the 204 children with this diagnosis now recorded. These statistics suggest that a number of children with autism may have completed their school education before 2002 without receiving a diagnosis.

Teams carrying out adult diagnostic assessments in Inverclyde will record the decisions in case notes and on their own data systems and send copies of reports to the individual's GP and, with consent, other involved agencies, but there is currently no process in place for collating that information in a central database. Diagnoses made by other teams out of area – for example, when individuals move into the area from other parts of the country - may not be recorded.

- 2.1.5 The local authority collates data on adults with learning disability and autism who have used their services in the last 3 years. This information is submitted to the Scottish Council for Learning Disability (SCLD) ESAY database, which publishes national data annually. The most recent statistics for Inverclyde identifies 43 people. The SCLD are currently consulting with local authorities regarding how they can improve their recording in relation to people with autism.

2.2 Agencies in Inverclyde currently providing services to people with autism and their families

We asked services to tell us how they supported people with autism at the current time. This is by no means a comprehensive list, but gives a flavour of the current service provision in Inverclyde.

2.2.1 Services for all people with autism, regardless of age, ability or health status

R.E.A.C.H. for Autism

Offers support, services and ultimately training and employment opportunities that are person-centred, to children, adults and families who are living with autism. Parental and family support is provided through voluntary advocacy, mentoring, peer-led workshops, confidence building and peer support groups. Training and volunteering opportunities are offered to all family members, including individuals with autism. REACH also provides youth social groups, children's social activity groups, arts and crafts club and more. The family and community hub which will open in the near future will consist of a Community Cafe, Training Cafe, Sensory room, Art Studio, and a number of function and therapy rooms

Carers' Centre

The centre is run by carers for carers. Offers support to all carers in terms of befriending, emotional support, short breaks, training, long-term planning, advice around hospital discharge.

Your Voice Inverclyde Community Care Forum (ICCF)

A not-for-profit organisation that aims to bring together local voluntary organisations and to empower local people to influence and inform the planning, development and provision of local services, with a specific focus on individuals and under-represented groups who face discrimination and social exclusion.

Youth Connections

Voluntary organisation running Connect youth club for people with autism two nights a week.

Inverclyde Advocacy

This project, an independent advocacy service, provides support to people with autism and their families.

2.2.2 Services for Children and Young People

Assessment and Diagnosis

Skylark Autism Spectrum Disorder (ASD) Diagnostic Service (Ward L North, Inverclyde Royal Hospital)

A multi-agency diagnostic team – paediatricians, speech and language therapists, educational psychologist and the support of social workers – offering assessment for ASD to children and young people throughout Inverclyde. Post-diagnostic liaison with families, schools and other agencies.

Child and Adolescent Mental Health Service (Larkfield Child Development Centre)

Offers an ASD Diagnostic Service to children and young people referred to their service for the assessment and treatment of moderate to severe mental health conditions

Scottish Centre for Autism, Yorkhill

Offers a mentoring service to paediatric diagnostic services in Inverclyde, as well as second opinion service

Health Professionals

Community Paediatricians

These doctors specialise in the assessment and management of children and young people (0-18 years) with a wide range of neuro-developmental conditions including autism.

Health Visitors

Health visitors assess each child and family by the time the child is 16 weeks old in order to determine the level of support the family requires from health visitors and partner agencies. If concerns are raised, the health visitor discusses best way forward with the family and GP and may agree to work directly with the family or child (either 1:1 or in groups), to work jointly with other agencies (e.g. speech and language therapy, nurseries), or to make referrals to other agencies, e.g. specialist children's services, ADHD nurse specialist.) They

provide ongoing information, practical care and support to help families cope with difficulties. A recently introduced 30-month assessment programme should contribute to early intervention.

School Nurses and Community Children's Nurses

Provide an important link between children and young people with autism, their families, education and community health.

Speech and Language Therapy

The Speech and Language Therapy team provide a range of services to support children and young people with autism in Inverclyde. They participate in autism diagnostic assessments at the Skylark ASD Diagnostic Clinic, provide speech, language and communication assessments and reports on children attending for assessment at the clinic, provide interventions for pre-5 and school age children and provide training for other professionals and parents/carers. This training includes running courses such as Early Bird, Early Bird Plus and Cygnet programmes. A recent service redesign and reallocation of resources across speech and language services in NHS Greater Glasgow and Clyde, aimed at improving outcomes for children via the care aims approach, have resulted in significant changes in staffing levels. There are concerns about the sustainability of the current level of service the department offers, unless alternative funding for speech and language therapy can be secured.

Occupational Therapy

Dietetics

Child and Adolescent Mental Health Service (CAMHS)

CAMHS is a multi-disciplinary outpatient service, consisting of psychiatry, psychology and nursing with access to social work. The service provides assessment and treatment of moderate/severe mental health problems which arise during childhood and adolescence (0-18 years of age). We know from research that there is a high prevalence of co-morbid psychiatric conditions in the autism population. Children and young people who have previously been diagnosed with autism access CAMHS for assessment and treatment of co-existing mental health difficulties. In addition, CAMHS clinicians are often involved in the assessment and diagnosis of autism in children and young people who present to the service with complex mental health difficulties. A detailed assessment is undertaken by those clinicians in the team with expertise and training in autism. Post-diagnostic support is provided in terms of information, multi-agency meetings, access to social work services and benefits support, training programmes and onward referrals, e.g. speech and language therapy, occupational therapy. The team also offers a range of other activities such as

consultation and liaison with health professionals and other agencies working with young people and their families; teaching and training; research and audit activities; reports to the Children's Panel and other medico-legal services where appropriate.

Sleep Scotland counsellors

Counsellors help parents and carers by giving them specific tried and tested behavioural and cognitive techniques to adapt their child's night-time behaviour.

Early Years Settings and Early Years Outreach Team

Early Years Language Centre (EYLC) The Early Years Language Centre is a small base located within Blairmore Nursery, providing additional support to children with communication and language needs. Children attend on a part-time basis whilst also attending their local early years provision. The staff team at EYLC also provide outreach support to children with communication and language needs in local early years provision.

Hillend Children's Centre. An integrated pre-5 centre providing a national curriculum for children both able-bodied and who have additional support needs, such as autism.

The **Early Years Outreach Team** aims to build the capacity of staff in nursery and school settings to support children with autism and their families. The team provides support and training for staff in nurseries and schools, including modelling of good practice, training on autism and how it can affect the child and family, strategies to support the child and family in school, visual supports with training on how to use them. The team also provides detailed reports on individual children who are being assessed by the Skylark Autism Diagnostic Service. Team members are licensed by the National Autistic Society to deliver the Cygnet, Earlybird and Earlybird plus training for parents and staff supporting children and young people with autism.

Mainstream Education

All Saints Communication and Language Department (Primary)

The Communication and Language Department is located within All Saints Primary School and works with pupils who have autism or a communication disorder and who need extra support to access the curriculum and enjoy their life at school. The aim is to enable pupils to reach their potential in learning

One pupil who has autism was struggling with mainstream primary school. He was transferred to the Communication and Language Base at All Saints. As his confidence and feelings of security grew within the base, he was able to transfer the learning skills and coping strategies he had developed there to mainstream classes. He now spends more and more of his time within the mainstream community.

new knowledge and skills, developing relationships and being included in the mainstream community of the school.

Stella Maris Communication and Language Department (Secondary) Notre Dame High School, Greenock

The Communication and Language Department was set up to meet the needs of secondary aged young people, with autism in Inverclyde. The aim of the department is to ensure that students have the level of support, appropriate to their individual needs, which allows them to be independent, included and achieving while at school and beyond. Individual needs are assessed, working collaboratively with the students, their parents, partner agencies, mainstream colleagues and other educational departments. Individualised education plans/personal plans are drawn up to meet the needs of students, with support with planning for transitions which occur throughout the academic year, and in respect of key stages. Targeted support involves support in classes, personalised timetables and personal learning pathways, support from outside agencies, as required, and pastoral support aimed at personal and social development.

Inverclyde Communication Outreach Service (ICOS)(Primary and Secondary)

Specialist teachers provide individualised support in the form of direct support with children with autism in the classroom, group work, support and training for additional support needs assistants and teachers, whole school staff training, individual parent and family support. They also submit reports for diagnostic clinics, the Child and Adolescent Mental Health Team and other agencies. ICOS are closely involved in running the Cygnet parent training programmes and supporting students and families through the transition process. The team is involved with schools in the strategic development of services for children and young people with autism.

Specialist Provision

Craigmarloch School

In early 2014 the new school campus at Craigmarloch opens, welcoming the pupils who previously attended Glenburn School and Lilybank School. The school provides education for children and young people with additional support needs aged 5 to 18, including pupils who have autism (with and without learning disability). The staff:pupil ratio is high and classes small (7 pupils is the average, maximum 10) and strategies to support children and young people with autism are embedded in practice. The school has been accredited by the National Autistic Society.

Private education settings

Cedars School, Greenock has a number of students with autism.

Education Psychology

An educational psychologist participates in the Inverclyde Autism Diagnostic Clinic (see above), offering a perspective on the child within school. The service also offers support to the children and young people and their families during the period of assessment. Educational psychologists also work with individual children and young people and their schools to help identify any changes that need to be made to allow the individuals to reach their potential. They provide a designated service - involving staff training, individual consultation, joint assessment and support for individuals and families - to the Primary Communication and Language Base (All Saints), the Secondary Communication and Language Base (Stella Maris, Notre Dame High School) and other educational settings which offer additional support for children and young people with ASD. Educational psychologists offer consultation and support to the Inverclyde Community Outreach Service, contributing to their 2013-1015 Improvement Plan. The service has also taken part in the Communication Friendly Schools working group which has been addressing the needs of the students and schools in the transition to the new and amalgamated schools in Inverclyde.

Children and Disabilities Team (Social Services)

The Children and Disability Team is one part of the Children and Families Team of Inverclyde Community Health and Care Partnership. The team specialises in supporting children, young people and families affected by disability. The majority of children and young people referred in recent years have autism. Main source of referral is the Skylark Autism Diagnostic Service, but referrals can also be made by the Child and Adolescent Mental Health Team, Education and the parents/carers of the children affected by autism. Social workers from the team are part of the multi-agency Skylark Autism Diagnostic Service and are responsible for the post-diagnostic support to children and their families.

Skills Development Scotland/ More Choices, More Chances

Offering advice to school leavers on career, employment and education options.

Support Groups for Individuals with Autism and their Carers

Inverclyde Autistic Support Group. Run by parents and carers, the group offers support and advice to families, as well as social opportunities for children and young people with autism (up to age 16) with Enterprise Childcare.

The Saturday Club (juniors 5-11, seniors 12-16)

Playscheme (age 5-11) and Holiday Club (age 12-16)

Both run on behalf of the Inverclyde Autistic Support Group by Enterprise Childcare. The Saturday Club runs on alternate Saturday afternoons. Playscheme and Holiday Club help to bridge the long Easter and Summer breaks for children and young people with autism.

The You Matter Club (All children with disabilities)

Respite and Social Support

Barnardo's Inverclyde Family Support Team

Offers a befriending service to children and young people with autism and their families. Also offers a sitter service and a short-break service. Autism groups, Easter and Summer supports, parent and carer support groups. Referrals from CAMHS, Children with Disabilities Social Work Team and from individuals. Staffing ratios high, 30 volunteers who support staff.

Countryview, Quarriers Village, Bridge of Weir

Offers short breaks to families who are caring for a child or young person with autism and learning disability (aged 5 to 19 years)

Activities in the Community

Funworld – hold Autism-friendly sessions. Unfortunately, these sessions do not take place during the school holidays which is when families need them most.

Waterfront Cinema – holds Autism-friendly screenings.

2.2.3 Services for Adults with Autism with Learning Disability

Community Learning Disability Team (CLDT)

A multi-disciplinary team, consisting of psychiatry, nursing, speech and language therapy, psychology, occupational therapy, physiotherapy and dietetics, for adults with learning disability (including those also with autism) who have health needs. There is currently an open referral system. Team will accept referrals for adults who have a learning disability and are waiting for diagnostic assessment, adults with a diagnosis of autism and a learning disability, or young people with autism and a learning disability who are in the process of transition to adult services. Assessment and interventions are individualised and often multi-disciplinary in nature and are based on client need and the impact of the client's presentation on his/her daily life. Referrals enter one of two multi-disciplinary pathways depending on the individual's needs – a diagnostic pathway or an intervention pathway.

Working closely with the individual's care manager, the CLDT offers a number of interventions for people with ASD with health needs, including:

- Behavioural assessments/therapy
- Sensory assessments/therapy
- Communication assessments/therapy
- Intensive Interaction
- Mental health assessments, e.g. in relation to anxiety
- Support with physical health
- Transition support
- Counselling
- Access to Activities (occupational therapy, physiotherapy)
- Advice re nutrition (speech and language therapy/dietician)

Intervention may take the form of advice or training for individuals, their carers, other people with a support role – e.g. client-specific ASD awareness training, Total Communication Training, Intensive Interaction/Sensory Needs Training. A standard information pack to be given to the individual and his/her carers post-diagnosis is in process of development.

Where the individual has needs which are not necessarily health needs, and relate more to the need for a better understanding of ASD or to a specific aspect of the individual's life (e.g. community activities, support, housing) the CLDT will refer the individual on to other parties.

The Community Learning Disability Team worked with a specialist autism day service to draw up a support plan for an individual with severe autism who spent a great deal of time alone. By introducing more structure and predictability into the individual's daily routine, taking sensory needs into account and using Intensive Interaction, staff were able to engage with the person and, once trust and confidence grew, the person was then able to access a much wider range of activities, both within the unit and out in the community.

Learning Disability Team (Social Work)

This team provides assessment and care management for adults with autism and learning disability. It coordinates the assessment, implementation, monitoring and review of care packages – both community and residential. It works closely with GPs, Community Nursing and third sector organisations and families and has a coordinating role, in terms of making onward referrals to other agencies, e.g. Community Learning Disability Team (health). The Team also has a role in supporting service users in relation to a range of legislative frameworks, e.g. NHS Community Care and Health Act, Adults with Incapacity Act, Adult Support and Protection Act. (Some people with autism and learning disability are managed by assessment and care management teams.)

NHS Greater Glasgow and Clyde Adult Autism Team

This boardwide team provides support and a diagnostic service to adults with autism (with and without a learning disability in Inverclyde).

Day Opportunities (Learning Disability)

Golf Road Autism Project. Located in a residential setting, this service provides support for five service users with autism and learning disability. Individualised support plans are drawn up to allow the individuals to be able to enjoy a supportive, relaxing environment and to access the community with staff who are in tune with their needs and preferences. The service also offers consultancy to other day opportunities supporting adults with learning disability and autism.

The Fitzgerald Centre supports people with autism and learning disability to access activities both within the centre and in the community – e.g. gym, bowling, college.

The McPherson Centre supports people with autism and learning disability with more complex needs.

Outreach Service. A person-centred plan is drawn up for the adult with autism and learning disability and then an individualised programme is put together that gives the adult the opportunity with support to access community settings with a group or on a 1:1 basis.

Unity Enterprise

Unity Enterprise supports people with autism and a learning difficulty through work experience in a catering setting. It focuses on learning and the development of skills that are transferable into a job or everyday life.

Parklea Branching Out Project

The project helps to develop local individuals with support needs to fulfil their potential. Using horticulture, they provide opportunities for training, work experience, recreational and social activities. Training to SVQ level in horticulture and employability programmes.

Supported Living Team

Offering individualised support to individuals with autism and a learning disability who are able to live independently in their own home – ranging from a few hours per day to 24 hour support depending on the person's needs. The service offers personal safety courses to the people who use their service to help them to be less vulnerable when they are out in the community.

Carewatch

Carewatch provide support to people with autism and learning disability who are living independently in the community if the person is accessing that support through the Independent Living Fund (ILF).

ENABLE (Support for Employment)

Employment advisers from ENABLE help adults with autism and learning disability to find and keep a job. They also work with adults with autism at West College Scotland (formerly James Watt College) to make the transition from further education to employment.

Turning Point Scotland

Supports adults living with autism in various settings – e.g. care homes, care at home and social opportunities service. Working closely with families and other agencies, such as the Community Learning Disability Team and Social Work Department, Turning Point offers a person-centred approach to ensure that the individual's personal outcomes are being achieved. The service has been involved in some complex transitions for people with autism. Providing a range of personalised support options to help individuals with learning disabilities and autism gain access to opportunities within the local community – social opportunities and supported living.

Richmond Fellowship

Staff at the Burns Road service, a residential unit for 6 adults with learning disability (many of whom have autism and very complex needs), have developed creative, person-centred support packages to enable the individuals to participate in meaningful activities important to them, to support individuals to build relationships and grow in confidence, to maintain and hold their own tenancy and participate in all areas of interest within the community. Richmond Fellowship also offers short break opportunities to support individuals with autism and their families. Some individuals with autism are supported by Richmond Fellowship but live either in the family home or in their own tenancy.

Quarriers

Quarriers offers adults with autism and learning disability a range of services, including befriending, short breaks, social opportunities and residential support.

West College Scotland (formerly James Watt College)

The college offers two different services to people with autism – courses with extra support and mainstream courses. The STEP and related courses offer people with autism a supported learning environment (whether they have a learning disability or not). The learning support department ensures that students with additional support needs are given appropriate advice and support – e.g. escorts, counselling, technology. The department allows students to show their abilities in different ways – e.g. via poster presentations, videos. Some students offer support to other students, e.g. acting as a scribe.

2.2.4 Services for Adults with High Functioning Autism or Asperger's Syndrome

Community Mental Health Team (CMHT)

Provide community-based mental health care to adults with autism with a moderate to severe mental illness. Services are delivered through integrated Health and Social Care teams undertaking assessment, care and treatment interventions and providing care management appropriate to the level of need. Referrals usually come via the persons' GP. When patients present with a mental illness, and an ASD diagnostic assessment is required as part of the care management, a referral will be made to the NHS Greater Glasgow and Clyde Adult Autism Team, based in Glasgow.

Gateways To

Gateways To supports people with autism with mild mental health conditions and people with difficulties caused by addiction to access meaningful activity and personal development opportunities in Inverclyde.

NHS Greater Glasgow and Clyde Adult Autism Team

This boardwide team provides support and a diagnostic service to adults with autism (with and without a learning disability in Inverclyde).

West College Scotland

People with high functioning autism or Asperger's Syndrome often choose to attend mainstream courses, e.g. construction, beauty therapy.

ENABLE (Employment Support)

ENABLE offers people with high functioning autism and Asperger's Syndrome attending West College Scotland support in finding and keeping a job.

3 Hearing the voice of people with autism, carers and practitioners

A number of groups have come together to produce this Strategy and will play an important part in its successful implementation.

3.1 Consultation

A National Mapping Project took place in early 2013 to map services for people with autism all over Scotland. The data collected for Inverclyde has been taken into account in preparing this Strategy, although with some caution as there were significant concerns that the service map produced by the project for Inverclyde was not complete. The consultation and co-production methods used in developing this strategy (see below) have led to a fuller picture of the current services in Inverclyde.

The local Inverclyde consultation project has involved a large number of stakeholders including people with autism, their families and carers and the organisations that provide services for them – e.g. statutory services such as health, education and social work, voluntary support groups and social enterprises, such as The Inverclyde Autistic Support Group, Reach for Autism and the Inverclyde Carers' Centre.

With the help of the Clinical Governance Support Unit (Partnerships), NHS Greater Glasgow and Clyde, we produced a number of questionnaires for people with autism and their carers and families and these were distributed by health, education, social work and the support groups mentioned above. We also held focus groups and some 1:1 interviews. The consultation was also promoted on the Inverclyde Council website and the Solus Screens located in health centres and other health settings across Inverclyde.

We spoke to people working with individuals with autism, including third sector service providers (via their regular liaison meeting), such as Quarriers, Turning Point, Barnardo's and ENABLE, health teams, social work departments, staff working in education and further education. We asked them to tell us about the services they currently provide people with autism and how they would like their services to develop in the future.

Finally, we sent out a questionnaire to a sample of mainstream services in Inverclyde to gauge what they knew about autism and how confident they were that they could adapt their services to make them more accessible to people with autism. The response rate was very low, but those who did respond gave us an invaluable insight into the progress that mainstream services still need to make in supporting people with autism.

Unfortunately, pressures of time mean that there are bound to be gaps, but it is hoped that we have been able to capture the main themes. The strategy report and action plan have been put together on the basis of the information supplied by the people who did engage in the process. We are extremely grateful for their assistance with this.

In this work, it has become clear that working with people with autism and their families gives services a much clearer picture of what is important. Carers understand that organisations can't always deliver the services they would like to, but, given these limited resources, people with autism and their carers want to be involved in the decisions around making choices and setting priorities.

3.2 Hearing the voice of adults with high functioning autism and Asperger's Syndrome

One of the challenges during the preparation of the Strategy was allowing the voices of those people with autism who are currently not known to services in Inverclyde to be heard. We know from anecdotal evidence that there are a large number of adults with autism in Inverclyde who are not using services but who are experiencing major challenges in their daily lives - attending further education, getting a job, forming relationships. As one carer told us, 'People with Asperger's become invisible when they leave school'. It was very difficult to gather the views of this group of individuals and so, with the help of Tracey McKee, specialist librarian at NHS Greater Glasgow and Clyde, we looked to research evidence to give us an insight into their needs. We have made particular reference to Beresford, B, Moran, N, Sloper, T, Cusworth ,L, Mitchell, W, Spiers, G, Weston, K and Beecham, J (2013) *Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions. Final Report*. Department of Health Policy Research Programme/Social Policy Research Unit, University of York.

4 Delivering for people with autism in Inverclyde – Nine key themes

In the preparation of this strategy, we considered the vision, values and best practice indicators included in the Scottish Strategy for Autism (see Appendix) and other national guidelines on best practice for autism, the evidence base relating to autism, and, most importantly, we consulted local people with autism, their families and carers and practitioners supporting people with autism. The same common themes relating to the needs and aspirations of people with autism, their families and carers were expressed over and over again.

- 1 **Understood, Valued, and Safe** - We want to be understood, valued and safe in the community in which we live.
- 2 **Independence and support** - We want the opportunity to have meaningful, independent active lives, using mainstream services when we can, but accessing support to overcome barriers when we need it
- 3 **Social networks** - We want opportunities to develop positive, supportive and enabling social networks
- 4 **Training Plan** - We want a coordinated Autism Training Plan for Inverclyde so that people with autism, their families and carers, and those people working with them all have the attitudes, knowledge and skills they need
- 5 **Pathway for Diagnosis** - We want equal and timely access to a standard evidence-based pathway for assessment, diagnosis and the support that follows
- 6 **Information and Advice** - We want a coordinated system for information and advice about autism that allows people not only to access good quality printed and electronic information when they need it, but also allows people to speak to others about how autism affects their lives.
- 7 **Coordinated services based on accurate data** – We want coordinated services that speak to each other and that identify and meet the needs and aspirations of people with autism in Inverclyde.
- 8 **Included and Involved** - We want to be involved in decisions that affect our lives, and to play a role in implementing the Inverclyde Strategy for Autism.

- 9 **Evaluation** - We want services to check on a regular basis that they are doing a good job for people with autism in Inverclyde.

There was widespread agreement that by investing in a robust infrastructure to support people with autism in the community, we would make significant savings in the long term in reducing the need for people with autism to access specialist health, mental health and social work services. If we are to achieve the vision of the strategy, collaboration, coordination and commitment will have to be at the core of the strategy. In the coming sections, we will explore each of the 9 themes in more detail.

Theme 1 Understood, Valued and Safe

We want to be understood, valued and safe in the community in which we live.

'People told me I was naughty. Now they tell me I'm rude. I just want people to understand my autism.'

'Our children should be praised for what they put up with day after day'

'You need to tell really young children about autism. Bullying starts young.'

'I'm not sure about telling other pupils that someone has autism. It might lead to bullying.'

What people said

Autism is to a great extent a hidden disability. Many people with autism told us of times – at school, at college and in the community – when they have been described as naughty, lazy or rude by others, simply because those people did not understand the nature of autism and how it impacts on people's lives. People with autism and carers wanted people to be more aware of their sensory

difficulties (for example, relating to noise, light, busy environments, touch), difficulties understanding social rules (for example, relating to how people speak to each other, personal space), difficulties seeing the world from other people's points of view, and a host of other difficulties – these hidden difficulties all present daily challenges to people with autism. *A priority for the Strategy has to be to raise awareness of autism across Inverclyde, but particularly in the services that support people with autism.*

Parents told us how their children love the Saturday Club, run by the Enterprise Childcare on behalf of the Inverclyde Autistic Support Group. They know that they will have fun, and they will be supported by people who understand them.

Individual education plans (IEPs) were produced by the Early Years Outreach Team in visual form so that young children with autism could understand the targets being set by parents/carers and staff.

There are many places in Inverclyde where people with autism feel accepted and valued, and as a result develop self-confidence and resilience. Unfortunately, carers felt that other settings were very different. *They wanted to know why models of good practice are not replicated across Inverclyde.*

For adults with autism, life can be even more difficult, as society has higher expectations in relation to social behaviour. People with autism told us that verbal abuse and harassment 'happened

all the time' when they were in the community. Many had also experienced bullying online. One young person reported a facebook post: 'You are a Go end your life'

All students within Notre Dame High School receive information about autism through the Peer Awareness Raising programme. This is delivered each year to students in 1st, 3rd and 5th year. The people we spoke to felt that this should be rolled out across Inverclyde and be available to much younger pupils to promote the acceptance and valuing of people with autism by students.

We sent a questionnaire round a few mainstream services – e.g. housing, health teams, GPs, prison services – asking them how confident they were about recognising people with autism and adapting their services to meet their needs. Despite there being individuals with good knowledge and skills relating to autism in their teams, the vast majority of staff felt they needed more support to improve their awareness of autism and their ability to support people with autism. Older people's services may need particular support as they are likely to be working with a high number of people with undiagnosed autism.

Carers felt that organisations, such as supermarkets, leisure centres, shopping malls, should have an Autism Champion in the same way as they currently have First-Aiders – that is, one person within the organisation who receives extra training in order to support anyone with autism who is having difficulty using their services and to ensure that the other people working for the organisation have good autism awareness.

Using public transport was a particular challenge for young people with autism, severely limiting their ability to live independently. Some also found it difficult to identify and cope with social situations in the community where they could be particularly vulnerable – e.g. in pubs, outside after dark. *Young people told us they would like support on how to keep safe in the community – 'a kind of map that shows where we are safe and where we need to be careful'.*

The people with autism we spoke to did not know about the Autism Alert Card, a credit-card sized card that individuals with autism can show members of the public if required. There are currently two types of card – one being a registered card (Police Scotland) and the other unregistered and available online. The National Autistic Society is currently leading on developing a national autism alert card. The cards are currently available via the National Autistic Society website and the Autism Resource Centre in Glasgow. The card needs to be more widely promoted.

What is happening already?

- Early Years Outreach team provide Autism Awareness Training (involving people with autism as co-trainers) for the mainstream settings who refer children to their team.
- Reach for Autism has provided some Autism Awareness Training to local supermarkets.
- Golf Road Autism Service has provided Autism Awareness Training to other day service staff.
- Stella Maris Communication and Language Department, Notre Dame High School has provided Autism Awareness Training to staff from mainstream.
- Community Learning Disability Team offers Adult Support and Protection Training and Outreach Services offer training in Keeping Safe to people with autism and learning disability in Inverclyde.

Consider for the future

Greater awareness and acceptance of people with autism across the community, but in particular in mainstream schools, across Inverclyde Council and Community Health and Care Partnership mainstream services, and within other organisations (such as third sector) who work with people with autism.

Support for older people's services due to high level of undiagnosed autism and potential unmet need

Best practice and minimum standards for services for people with autism rolled out across Inverclyde

A network of supported Autism Champions in organisations across Inverclyde

People with autism will have access, if they need it, to training and support that increases their confidence and ability to keep safe in the community.

Theme 2 Independence and support

We want the opportunity to have meaningful, independent active lives, using mainstream services when we can, but accessing support to overcome barriers when we need it

'I would like a 'safe place' to go to when things get too much.'

'The other students were doing my head in so I just stopped going'

'If you're not an adult with a learning disability or a mental health problem in Inverclyde, you are invisible.'

'People have autism their whole life. It doesn't just go away at 18'

'I wish they learned more everyday skills at school, so that they can be more independent when they leave.'

'There is nowhere to let off steam when you are an adult'

The Scottish Strategy for Autism states:

*'Achieving best value for services for people affected by autism will ensure that resources are effectively targeted and that the outcomes in improving people's lives are the best we can achieve.'*¹¹

One of the principles underlying The Scottish Strategy for Autism is that everyone should have the same outcomes and opportunities and that those at risk of not achieving those outcomes should be identified and steps should be taken to prevent that risk materialising. There is a focus on building capacity and preventing problems before they happen by offering the right support at the right time. When problems do arise, however, it is important that individuals have access to the services they need.

The strategy also emphasises the need for agencies to take a 'personal outcomes' approach¹² rather than a 'service-led' approach. Instead of considering 'Which of our services are you eligible for?', we should be asking 'What is important to you?', 'What do you want to achieve?' 'How do we get there?'. For some people with autism, holding down a full-time job or attending a college course could be very difficult because of the way autism impacts on their lives – e.g. sensory difficulties, anxiety levels – but having an active life, working on a voluntary basis or working flexibly, with the option of taking time out when it is necessary, would be a very positive outcome.

¹¹ <http://www.scotland.gov.uk/Publications/2011/11/01120340/0>

¹² <http://www.jitscotland.org.uk/action-areas/talking-points-user-and-carer-involvement/>

It has not been possible to consider all the areas which may present challenges to people with autism in their daily lives, but we have attempted to describe some of the most common areas of difficulty.

People with autism have told us that they aspire to live independently in the community, only accessing specialist teams for support when they need to. They do not want their condition to be seen as an 'illness' that requires 'treatment'. For decades now, organisations have been required under the law to make 'reasonable adjustments' to make it easier for people with disability (including autism) to access their services. We have a number of specialist teams with knowledge and expertise in relation to autism in Inverclyde. The emphasis in the Scottish Strategy for Autism is to move from a reliance on referrals to specialist teams (which are often over-stretched) towards a model of building capacity and resilience in the community so that people with autism can be well supported in their daily lives.

People with autism, their carers and practitioners all highlighted the need to identify crisis intervention support that would be available to people with autism and their families at times of crisis.

When people with autism are at school, if they are having difficulties, they are considered to have 'additional support needs' which will require an individualised support plan with a range of agencies contributing to it. When the young person moves into adult life, however, if he is having difficulties, the support he will receive from statutory bodies depends not on his needs, but on whether he fits into one of the structures that services have created – i.e. learning disability, mental health condition, addictions, and so on. This is obviously an area of concern for the local statutory bodies who aim to redress inequalities of service.

The National Autistic Society has gathered together some 'real life stories', describing the experiences of people with autism and their families in trying to live as independently as possible and access services when they needed them.¹³

The menu of interventions recommended as part of the Scottish Strategy for Autism are outlined in the Appendix.

The Scottish Strategy has funded the setting up of a number of One Stop Shops throughout Scotland that are able to offer people with autism and the people who support them a range of supports depending on their needs¹⁴.

Support at school

What people said

Many children attend mainstream schools and their families and carers described a very patchy picture with regard to autism-friendly support for their children – particularly in relation to coping at

¹³ <http://www.autism.org.uk/living-with-autism/real-life-stories.aspx>

¹⁴ <http://www.scottishautism.org/family-and-professional-support/one-stop-shops/>

breaks, coping with isolation in a crowd. Some primary schools were singled out for praise; others were named repeatedly for lack of support. There was an impression that those children and young people attending specialist provision were better supported than those in mainstream schools, despite the best efforts of the much praised Outreach Teachers. Carers felt that there should be a minimum standard of knowledge of autism in every school – not just the condition, but how it impacts on a person’s life and what you can do to help - and that staff showing inappropriate attitudes to students with autism should be challenged.

Within Craigmarloch School, pupils with autism are enabled to access specialist music ‘notation’ through the use of a specialist software programme, Inclusive. This enables children and young people to play alongside peers who are reading music in the traditional way. This has led to greater self-esteem and improved wellbeing and emotional intelligence for the pupils who have taken part.

A number of practitioners expressed concern at the recent changes in Speech and Language Therapy (SLT) provision, as communication is often at the heart of the difficulties and challenges experienced by people with autism. Developing positive communication experiences for people with autism, establishing a functional communication system, the use of social stories, working on social communication skills – these are all key elements of support plans. Improved access to occupational therapy services was also considered a priority for services across the lifespan, particularly given the increased awareness of the sensory difficulties many people with autism experience and how they impact on their lives.

The Communication and Language Department at Notre Dame High School was praised by parents as a place where their children felt understood and where they could make friendships, bringing them greater feelings of confidence and happiness. They felt they were far more likely to learn if they felt secure and valued.

What is already happening?

For some individuals with autism, ‘support when I need it’ is a reality. Children and young people attending specialist education settings, such as Hillend Children’s Centre and Craigmarloch School, or the Communication and Language Departments of All Saints Primary and Notre Dame High School, are supported by teachers and classroom assistants who understand their needs and who work to help them to learn and develop their knowledge and skills. The ASD Outreach teaching support service also provides training and advice as well as direct support input to children and young people in mainstream primary and secondary schools.

In children and young people’s services ‘additional support needs’ are defined very broadly, so that the students can access extra support when they need it – e.g. if they have had a period of illness or personal problems, as well as when they have a disability. An individualised plan of support is then drawn up. Children and young people may also have a Coordinated Support Plan in instances where the number of agencies beyond education are involved in supporting them to achieve their educational objectives – for example, speech and language therapist input.

In Craigmarloch School, pupils with autism who are selective eaters access a ‘Fun with Food’ programme led by a paediatric dietician and school staff. Parents receive a weekly update.

The Inverclyde Communication Outreach Service was set up in 2012, within Children and Young People’s Services, and is working towards drawing up a local planning framework for students with

autism to ensure a consistency of approach across Early Years, Primary and Secondary teams and to promote best practice in supporting children, young people and families in mainstream education.

Access to Therapies and Counselling

The Scottish Strategy for Autism has identified a range of recommended therapies for people with autism across the lifespan (see Appendix). People with autism and their carers wanted easier access to these therapies depending on need at different points in their lives. Examples included Intensive Interaction, social skills training, use of communication supports such as Talking Mats and IPADs. Carers and practitioners wanted there to be greater access to information about the interventions that work best for specific individuals so that they can be used outside the school settings.

Transitions

What people said

Times of transition can be a time of stress and anxiety for people with autism and their families. One autism specialist we spoke to described life as 'a series of transitions' and pointed out that young people with autism have to be supported to develop strategies and resilience to cope with change when it happens. If people have not received that support in their school setting, it is going to be difficult to manage as an adult.

There is a fear that the young people attending mainstream schools do not get the support with transition (for example, that offered by Skills Development Scotland) that students attending specialist settings access. Students attending independent schools are not able to access local authority transition and local authority education services.

Carers felt that some of the transitions involved 'too big a change at once' for the young person with autism. For example, one child went from a class of 5 in primary school to a mainstream secondary class. It was not a surprise to the parents, when their child refused to go to school altogether.

Carers told us that they found the transition from school to adult life very stressful. They felt that in practice, the process seemed last minute and rushed (unlike many professionals who described a more planned and gradual process). They felt the process should start much sooner and be more gradual. Many also wanted to be more involved in the process.

Some practitioners welcomed the idea of transition starting earlier, so that the process could be adapted to the specific needs of the individual, both with regard to content and pace.

Some service providers felt that the transition process was made more stressful for the young person with autism and the family or carer because everything changed at once. They questioned whether that was necessary.

Inverclyde has one of the highest positive outcome rates in Scotland for its school leavers – in 2012, 94.8% per cent of school leavers were in employment, education or training by the Easter after leaving school.¹⁵

This is a very narrow definition of transition, however, and does not reflect the stories of the people who spoke to us. While there were many people who managed well at college, particularly if they were attending the supported courses, others reported ongoing difficulties making the transition into adult life in terms of accessing further education, employment, independent living and adult relationships and interests.

A transition group of 5 children with autism was formed. They were all moving from nursery to the same primary school. The Early Years Outreach team helped to develop the children's confidence and support the children to follow a class timetable, making the transition from nursery a more positive experience than it would otherwise have been.

Hudson (2006)¹⁶ describes the transition from school to college as the *visible transition*, but the transition from college to post-college options the *invisible transition* – a much more difficult one. Beresford et al comment:

'Whilst transition is often discussed in terms of transfer of responsibility from children's to adult services in health, social care and education, it is important to recognise that for the young person, transition to adulthood also encompasses a range of different processes. These include for example, leaving home, entering further education and employment, and taking more responsibility for health, nutrition and finances.'¹⁷

What is already happening?

The Inverclyde Communication Outreach Service is working on developing protocols for all transitions, so that transitions for individual young people with autism are organised on a less ad hoc basis. It was felt that students should be more involved in the decision-making process relating to transitions and that communication supports should be in place to facilitate that involvement.

Every school in Inverclyde receives a Transition Pack, with resources to help students cope with transitions.

Educational Psychologists contribute to transition planning at key stages within a young person's development, where appropriate. They develop strong links with post-school providers and other stakeholders, such as More Choices, More

The transition programme from primary to secondary school run by the Inverclyde Communication Outreach Service provides extended transition support to enable young people to settle into their secondary placement. Runs February to June while the young person is in P7 and then primary staff support pupil in secondary school, October to December depending on student need.

¹⁵ Skills Development Scotland, 2012 School Leavers Destination Return

¹⁶ Hudson, B (2006) 'Making and missing connections: leaving disability services and the transition from adolescence to adulthood', *Disability and Society*, 21, 47-60

¹⁷ Beresford, B, Moran, N, Sloper, T, Cusworth, L, Mitchell, W, Spiers, G, Weston, K and Beecham, J (2013) *Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions. Final Report.* Department of Health Policy Research Programme/Social Policy Research Unit, University of York.

Chances, Skills Development Scotland, Community Learning Disability Team and ENABLE. Clear multi-agency procedures and plans are in place, particularly to support young people who are looked after and away from home and who have a diagnosis of autism. If the young person is known to the Child and Adolescent Mental Health Team (CAMHS), an enhanced transition programme will be put in place.

For some pupils, the concept of change and the move towards adult services is introduced as early as Third Year, according to the professionals we spoke to. The Children and Disabilities Team carry out an initial assessment and identifies what support each person requires. A multi-agency meeting is then held to discuss how the individual young person's needs will be met. Support from the Department of Work and Pensions is also sought to ensure that the family is able to maximise their income. A transition worker is then appointed for each child who will coordinate the supports required for that child during the transition process.

There is a protocol in place between adult learning disability day opportunities and specialist schools that describes how the respective services will support the transition process, with the focus gradually moving away from the adult services staff visiting the young person in school and towards the young person spending increasing time in adult settings. Post-placement reviews take place after the young person has had time to settle in (usually after 12 weeks).

West College Scotland (formerly James Watt College) runs a STEP Link Week in March each year so that school students can try out the courses.

Day Opportunities

For adults with autism and learning disabilities, there are a wide range of services available to support them to lead active lives within the community with regard to day opportunities (see section 2.2.3). The Golf Road Project, a small-scale community-based unit for people with autism, learning disability and complex needs, was praised by carers as it gave the young people the support they needed to access the community. Carers felt there should be more services like Golf Road. There are no specialist day opportunities services for people with autism that do not have a learning disability.

At West College Scotland, the Welfare Support Workers attached to the Learning Support Department play an important role as a discreet source of support, available 'in the background', as and when required, for young people who may encounter difficulties in some of the busy communal areas, such as the cafe.

College

What people said

Carers were concerned that there were not many options for school leavers living with autism, particularly if they are not able to travel independently. Research has shown that further education courses aren't always a realistic option for some people with

autism without support. They may have the intellectual abilities to cope, but they are not able to cope with the sensory stimulation, social demands and unstructured routines of college life.¹⁸

What is happening already?

Adults with autism and learning disability in Inverclyde have access to a range of services that support them to overcome challenges – e.g. community learning disability team, day services, supported living, support at college.

The STEP courses at West College Scotland (formerly James Watt College) provide a supportive environment for people with autism who require continuing help to access courses, although with much lower staff: student ratios than school. There are a number of options available, depending on the needs of the individual students, ranging from high level support for young people with severe learning disability to mixed options with the student spending some of the week in STEP and some in mainstream courses. For some students the courses will lead on to further training, including employability and enterprise. A number of work placements are available within the college and this year, the local council has offered 16 students guaranteed paid fixed-term employment places. Students are encouraged to support each other and there are a growing number of 'break-out' social spaces about the college where students who might not want to use the busy mainstream facilities can spend time with others.

Many young people with autism choose to attend mainstream vocational courses, such as construction and beauty therapy, at West College Scotland rather than STEP. The professional support services available to young adults who attend the STEP courses is not available to young people attending mainstream courses. The drop-out rate and the reasons behind it are currently being reviewed by the college. One difficulty is that adults entering the college are not obliged to tell the college about their condition. Beresford, in his report into the experiences of young people making transitions into adult life, describes:

'The greatest area of concern was with regard to suspensions, expulsions and/or simply dropping out of college. These were typically viewed by parents and practitioners as outcomes of colleges failing to properly support young people with ASC [autism spectrum conditions] and manage any challenging behaviours. This was particularly felt to be an issue in mainstream college settings ... Young people who left college prematurely were identified as a highly vulnerable group. The circumstances of their departure precluded any advice or planning around next steps, and, if ineligible for support from adult social care, they were often invisible to statutory services'¹⁹

Not all the young people we spoke to had negative experiences of adult life, however. Some reported a reduction in bullying when they left school as their peers matured and became more

¹⁸ Chown, N and Beavan, N (2011) 'Intellectually Capable but Socially Excluded? A Review of the Literature and Research on Students with Autism in Further Education', *Journal of Further and Higher Education*, DOI:10.1080/0309877X.2011.643771

¹⁹ Beresford, B, Moran, N, Sloper, T, Cusworth, L, Mitchell, W, Spiers, G, Weston, K and Beecham, J (2013) *Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions. Final Report.* Department of Health Policy Research Programme/Social Policy Research Unit, University of York, York, p vi

tolerant. One of the young people we met had started attending a college up in Glasgow and was very happy. She felt much more accepted than she had been by her peers at school.

Employment

What people said

Many adults with autism find it difficult to find and keep a job. Almost every person with autism we spoke to wanted to find a job or wanted advice and support in coping with a job. 'I want a job', 'I need help to find a decent job', 'I need more education', 'I find interviews intimidating', 'People were putting me down'.

People with autism and learning disability and those attending West College Scotland are supported by college staff and ENABLE to find employment (young adults aged 18 to 24). There was widespread praise for the work these employment support workers do. Concerns were expressed for the more able young people who don't want to go to college, struggle at college and drop out or leave college to take up a job or work placement, only to find themselves unemployed after a few months. The people we spoke to praised the disability advisers at Job Centre Plus, but they found the people they saw each week much less sympathetic. (This view was echoed in the Beresford et al research paper.)²⁰ These same individuals found the whole job application and interviewing process very confusing and stressful.

What is happening already?

According to the National Autistic Society, only 15 per cent of adults with autism are in full-time paid employment²¹ but a research study in 2007²² commented that the NAS employment service, Prospects, which provided job-hunting and employment support for individuals with autism, and post-recruitment assistance for employers, managed to find jobs for 67 per cent of its clients. The research study concluded that this would have saved the government almost half a million pounds in less than three years

The people we spoke to were very positive about work placements that they had experienced and volunteering. They were just frustrated that there were so few opportunities for work.

Public Transport, Housing and Independent Living

What people said

²⁰ Beresford, B, Moran, N, Sloper, T, Cusworth, L, Mitchell, W, Spiers, G, Weston, K and Beecham, J (2013) *Transition to Adult Services and Adulthood for Young People with Autistic Spectrum Conditions. Final Report.* Department of Health Policy Research Programme/Social Policy Research Unit, University of York.

²¹ <http://www.theguardian.com/money/2012/apr/06/autistic-workers-employers-ignorance>

²² Reid, B (2007) *Moving On Up? Negotiating the Transition to Adulthood for Young People with Autism*, National Autistic Society.

Many of the carers we spoke to were concerned about how few independent living skills, like cooking, using public transport, managing their money, the young people had acquired during their time at school and college. Some asked whether the focus could shift towards these activities of daily life when it became clear that the young person was struggling with more academic subjects.

People with autism may have difficulty with relationships with neighbours, sensory processing problems relating to noise, lighting and other sensory stimuli, difficulties around timekeeping, organisation, need for order and routine. All of these difficulties may impact on the individual's ability to live independently.

Many of the young people we spoke to were uncertain about using public transport, and this was seen as a major barrier to doing more activities in the community. For many, travelling independently up to Glasgow was out of the question. Difficulties using public transport came up again and again. 'I feel intimidated', 'I need a friend with me travelling long distances', 'Crowds are a problem for me.'

What is happening already?

For people with autism and a learning disability, there is a robust service of supported living in Inverclyde, but this is not available to people with Asperger's Syndrome. There is currently no autism-specific housing in Inverclyde. RiverClyde Homes, the local provider of social housing, has asked for support in raising autism awareness in its organisation, so that they are better able to meet the needs of people with autism using their service. Organisations like Richmond Fellowship and Turning Point do support people with autism and learning disability with their own tenancies, but there is no such service for people with Asperger's or high functioning autism.

Health Services

What people said

We asked a number of groups of health professionals to complete a questionnaire relating to their understanding of autism and experience of adapting their service to meet the needs of people with autism. No responses were received from GPs (there was a very tight deadline!), but members of the Joint Addictions Teams (Alcohol and Drugs) and Community Mental Health Team did respond and, while some clinicians had a high level of knowledge, many expressed a need for further training in supporting people with autism. Many carers felt that GPs should be supported to increase their knowledge of autism. The National Autistic Society stresses the high incidence of mental health conditions in people with autism²³. In

With the help of the Supported Living Team, a man with autism and learning disability who was having difficulty living alone, has been able to enjoy increased independence, to get out and about in the community more and to have quality time and a closer relationship with his family. He is closely involved in decisions affecting his life.

²³ <http://www.autism.org.uk/working-with/health/mental-health-and-asperger-syndrome.aspx>

a study by Simonoff (2008)²⁴, 70 percent of the children with autism he studied had at least one co-morbid psychiatric disorder and 41% had two or more. The most common diagnoses were social anxiety disorder (29.2%), attention-deficit/hyperactivity disorder (28.2%), and oppositional defiant disorder (28.1 %).

The Child and Adolescent Mental Health Service are responsible for young people up to the age of 18, but concern was expressed that during the years when the young person is likely to experience higher levels of stress and anxiety as they move into adult settings, the young person has to form new therapeutic relationships with the adult mental health team. Carers hoped that decisions regarding when to transfer patients to adult mental health services would be taken on a case by case basis.

What is happening already

People with autism and learning disability are often supported by the Community Learning Disability Team when they need specialist health support – e.g. when they have to attend hospital. Hospital Passports are prepared that give hospital staff the key information about the individual. These are not currently made available to people with autism and no learning disability.

An online module is available through the NHS Education for Scotland (NES) website which aims to help primary care health professionals to better meet the needs of people with autism using their services. Most of the health professionals we spoke to were unaware of the module.

Police, Criminal Justice and Prison Services

What people said

People with autism are far more likely to become the victims of crime than the general population and so are more likely to come into contact with criminal justice services. The National Autistic Society has produced a really useful guide to help criminal justice professionals²⁵

The people with autism we spoke to had a range of experiences of the police. 'I would like a relationship between the police and the Reach for Autism group', 'There are saints and sinners in the police', 'It would be nice if the police smiled'.

What happens already

Police Scotland are aware nationally and locally that it is important for officers to receive regular training in understanding the needs of people with disability, including people with autism. This training takes place in Inverclyde on an annual basis. The service uses a DVD from the National Autistic Society which has examples of people with autism and their experience of police services,

²⁴ Simonoff, E, Pickles, A, Charman, T, Chandler, S, Loucas, T, Baird, G (2008) 'Psychiatric Disorders in Children with ASD: Prevalence, Co-morbidity and Associated Factors in a Population-Derived Sample', *Journal of the American Academy of Child and Adolescent Psychiatry*, 47 (8), 921-929.

²⁵ <http://www.autism.org.uk/products/core-nas-publications/autism-a-guide-for-criminal-justice-professionals.aspx>

highlighting what officers need to be aware of. There is also information about autism on their Intranet.

The National Autistic Society has been involved with a pilot with Police Scotland, based in Maryhill, Glasgow. People with autism have opted in to their name being included on an information system so that if they ever have any contact with police services – as a witness, victim or potential perpetrator of crime - it will be flagged up that the person has autism and may present or need to be supported in a different way. The project has proved successful, but has not yet been rolled out nationally. Police Scotland are also working with Cornerstone to produce a pack on learning disability for police officers working in custody division.

HM Prison Greenock has a specialist nurse who is a learning disability specialist. It is unclear how many people with autism, or undiagnosed autism, are in the prison, but it is felt that staff would benefit greatly from autism awareness training. With the individual's consent, the nurse specialist gives prison staff an information booklet with advice on how to support the individual, if it is known that that person has a diagnosis of autism. NHS Greater Glasgow and Clyde has appointed an autism specialist to determine what services are required for people with autism in the three prisons in the NHS Greater Glasgow and Clyde area. The prison currently contacts the Adult Autism Team in Glasgow when it needs specialist assessments.

Consider for the future

Until mainstream services are improved, people with autism will from time to time need to access support services to help them overcome difficulties.

- Access to support for children and young people in mainstream schools when they experience difficulties in their daily lives, which develops their capacity to cope with change and builds their resilience.
- Consider the one-stop-shop option that is established in other parts of Scotland where people with autism and the people who can support them can access a range of supports depending on their specific needs.
- Clear pathways with transparent eligibility criteria so that people who need support know how to access it.
- A review of crisis intervention support across the lifespan to make sure that it is robust with regard to supporting people living with autism.
- Informal and specific support for people with high functioning autism or Asperger's Syndrome from people who understand their condition and who can help them to find solutions to their problems, particularly for the 16 to 25 age group.
- A smoother, more robust and more planned transition for all pupils with autism, regardless of where they go to school
- Protocols for all transitions to be formalised and embedded in policy – from pre-school all the way through to the transitions of adult life.

- Consideration of how transition can be gradual, with some children and young people's services handing over to adult services over a period of years, rather than everything changing for the young person at once.
- Closer links with West College Scotland to support them to identify any barriers to people with autism coping with mainstream college courses.
- Specialist support with employment for people with high functioning autism or Asperger's Syndrome and more supported employment, work placements and voluntary opportunities for people with autism
- Access to support in developing independent living skills
- Statutory bodies reviewing the provision of supported employment, work placements and involvement of volunteers

Theme 3 Social networks

We want opportunities to develop positive, supportive and enabling social networks

'My son flourished in the Stella Maris unit. He made friends and was much happier'

'I want a place to go to meet others on the autistic spectrum and people from the community'

'I would like buddies'

What people said

One of the myths around autism is that people with autism are not interested in friendships and social relationships. All of the young people with autism we spoke to said that they wanted more opportunities to make friends and to be with other young people. The reality of living with autism doesn't make it easy to develop friendships. Children are often not attending the local school. In the school holidays, they don't see their friends for six or seven weeks at a time. Social activities often revolve around large groups, noisy environments and lots of 'banter' – all of which can be quite difficult for people with autism. Carers told us that they find that friends and family members often don't understand the nature of their child's difficulties and so visits become stressful and often gradually fall away. Service providers told us that they worked with families who were very isolated and who felt that they were left to manage challenges alone.

Inverclyde Communication Outreach Service and the Child and Adolescent Mental Health Team run a joint group for girls with mental health problems.

Children at mainstream schools often struggle in the unstructured times, such as breaks and lunch, when friendships are formed, and in some cases lack the social skills they need to make new friends.

Ironically, the good social networks that would make their lives so much easier are often lacking in the lives of people with autism and their families and carers. One young person we spoke to said 'How come when I got to 16 and my life was changing in so many ways, I had to stop going to my club and seeing my friends?' The young people we spoke to asked for buddies who would help them overcome barriers like public transport and who could gently support them to improve their social skills so that they could become more independent. Carers told us how much they valued the opportunity to speak with families in the same situation.

When asked 'What support would you welcome the most?', the most common responses from carers who completed our questionnaires were 'Respite' and 'Social Opportunities for the person with autism'. Very few of the carers we spoke to had completed Carers' Assessments or had their needs assessed despite providing high levels of care for their family members. We understand that

the Carers' Self-Assessments which will be introduced in the near future will be coordinated via the Carers' Centre.

Barnardo's offers carers a sitting service to give carers some respite, but many carers felt they would benefit from greater access to short breaks.

What is happening already

Reach for Autism run a **drop-in session in the local library for family** carers. Friendships are formed, and carers can exchange experiences and support each other through difficult times.

Youth Connections run a youth club, Connect, two evenings a week for young people with autism.

A good example of the fragile nature of the current infrastructure in Inverclyde for individuals with autism and their families is the current situation of the Holiday Playscheme run by Enterprise Childcare for the Inverclyde Autistic Support Group. The Scheme – an Inverclyde success story - has until now relied on funding from Children in Need, but has now been informed that that source of funding is no longer open to them. These committed parents and carers are having to seek alternative funding for this invaluable community resource. They feel that this task should be supported by other agencies, and not just left to parents.

Some schools, such as Whinhill Primary, have buddy projects, where students from the school are matched with children and young people with autism to give them peer support.

Some voluntary organisations in Inverclyde (that rely on high levels of commitment from parents) try to bridge the gap but budget constraints mean that they can only provide a very limited service. Clubs are only available to young people up to the age of 16 because of the demand for places (currently a waiting list for the Saturday Club).

Of course, many social relationships develop as people participate in community activities, e.g. by attending college, going to work, etc - and the action points listed in the previous section should help to improve these options for people with autism in Inverclyde. Carers told us about positive experiences - such as students with autism running the school cafe – where the young people with autism are supported to participate in social activities by being given a particular role.

Over the last ten years, the Holiday Club, run by Enterprise Childcare on behalf of the Inverclyde Autistic Support Group (a group of very committed parents and carers), has offered children and young people with autism the opportunity to meet together in the school holidays. Outings are organised. Demand for places far exceeds supply. There is a waiting list, places are limited and children can only

attend for one or two days a week. This is a rare opportunity over the summer for children and young people with autism to enjoy leisure activities, as many of the mainstream facilities are too busy for them, as well as being a welcome respite for families (see box).

There are far fewer social opportunities for young people from age 16 onwards – a period in their lives when they need good social relationships the most.

The Befriending Service offered by Barnardo's was much appreciated but carers wanted more opportunities for befriending, especially at weekends. Many felt that this would be a good way of giving people with autism good social role models to learn from, rather than their families having to be responsible for keeping them straight.

The Carers' Centre offers a number of supports for carers of people with autism, and is very much valued by carers. The Carers' Centre is a good example of a community resource, which with relatively modest funding from the local authority, fulfils an invaluable role in supporting carers, through advice, respite and social support.

West College Scotland is working with Common Knowledge in Glasgow to offer students training in how to keep safe online. Common Knowledge is setting up its own social network, an alternative to facebook, where young people can be in contact with their peers, but with filters to prevent cyberbullying.

Consider for the future

More opportunities for children and young people to be matched with other students in order to give them extra support with social situations in school.

Increased support for voluntary organisations offering social opportunities for children and young people with autism in terms of training staff and helpers, supporting applications for funding.

Social opportunities for adults with autism

Carers of people with autism to have access to Carers' Assessments.

Social opportunities for carers and access to short breaks from time to time.

Theme 4 Training Plan

We want a coordinated Autism Training Plan for Inverclyde so that people with autism, their families and carers, and those people working with them all have the attitudes, knowledge and skills they need

What people said

One of the aims of the Scottish Strategy for Autism is to build capacity so that the people with autism, their families and carers and the people working with them become a sustainable community of support. Services, carers and people with autism alike, all called for an Autism Training Plan for Inverclyde that looked at the whole picture and came up with an action plan to address local training needs. It is hoped that Scottish Strategy for Autism funding may be made available over the next few years to support training initiatives across the area.

The consultation process has highlighted a number of different training needs throughout Inverclyde.

- 1 Individuals with autism have told us that they would like to understand their condition better and would welcome training on specific areas of difficulty, such as using supermarkets and public transport. Many may be diagnosed in childhood and as they get older, they have questions to ask. Many do not have the opportunity to attend post-diagnostic groups because of the fact that they are currently only available in Glasgow. Me Myself and ASD courses, for 16-25 year olds, who have recently received a diagnosis of autism would be ideal if they were available locally. Parents and practitioners wanted individuals with autism to have better access to training on adult protection and keeping safe, as they felt that individuals were vulnerable when out in the community.
- 2 The questionnaire we sent out to mainstream services indicated a widespread demand for more autism awareness training so that those services are more able to recognise people using their services who might benefit from an assessment for autism, to adapt the way they provide their services to better meet the needs of people with autism and to signpost people with autism or suspected autism to appropriate services.
- 3 Carers of people with autism were very enthusiastic about the local National Autistic Society Earlybird, Earlybird Plus and Barnardo's Cygnet training, delivered by a range of professionals, offered to parents after their child is diagnosed. The positive impact of such programmes on parental mental health is now well evidenced.²⁶ They asked for more resources to be provided for this service so that it could be made available to more people,

²⁶Tonge, B, Brereton, A, Kiomall, M, Mackinnon, A, Neville, K (2006) Effects on parental mental health of an education and skills training program for parents of young children with autism: a randomized controlled trial *Journal of the American Academy of Child Adolescent Psychiatry*, 45 (5)

e.g. people who were not previously able to attend, people who moved into the area, people whose children were diagnosed before the courses were introduced. They also felt it should be available to other family members if these people played a major role in the care of the child. Similar courses for carers of adults with autism should be provided.

- 4 Carers felt that they were not always able to access other training which was available to staff – e.g. Intensive Interaction, Makaton, Total communication, Sensory Processing. There was concern that recent cuts to paediatric speech and language therapy services might mean that these course would be even more difficult to access in the future.
- 5 Autism specialists – for example, those involved in diagnostic teams and supporting individuals with autism and complex needs - told us that they were able to access external training courses, clinical excellence forums and conferences in order to keep their knowledge and skills updated. They would welcome the opportunity to join with other autism specialists in Inverclyde to share experiences and developments in the evidence base related to autism.
- 6 Some non-specialist staff had studied autism as part of their training – e.g. teachers, nurses, social workers – but felt that training provided by autism specialists to refresh their knowledge and skills would be beneficial. Carers wanted professionals to be better informed about the impact of sensory difficulties on someone with autism.
- 7 Staff working for service providers, such as Turning Point, Richmond Fellowship, Quarriers, Barnardo’s and ENABLE, access autism training through their organisations, but often worked with volunteers who required autism awareness training.
- 8 Mainstream services, such as RiverClyde Homes (housing) and primary care health teams, indicated that they would welcome autism awareness training in order that they could support people with autism and improve their ability to perhaps recognise people using their service who were potentially undiagnosed.

Recent Autism Awareness Training delivered to a number of local primary schools by the Early Years Outreach Service with the help of some people with autism resulted in immediate change – the identification of a ‘place of safety’ in each school where a student with autism could go to chill when he or she was finding school life difficult.

The training is delivered to all classroom staff supporting the child – that is, teachers, classroom assistants, deputy head teacher, Early Years Education Coordinator – so that there is a shared understanding of autism and staff are supported to make their schools more autism-friendly. Family carers have suggested that janitors and admin staff be included in the training as they are often the people supporting children with autism in the playground.

Budget constraints are impacting on the ability of the service to roll out the training more widely.

What is happening already

There was widespread agreement throughout our consultation that a training needs analysis is required to ensure that the training needs of people affected by autism in Inverclyde are

Staff from the Stella Maris Communication and Language Department provide input to Newly Qualified Teachers at local authority level on an annual basis.

mapped to the services available and any gaps or barriers to delivery are identified²⁷. A coordinated system in which knowledge and skills are cascaded down was suggested, so that as many people as possible benefit from the expertise of the trainers.

The Inverclyde Communication Outreach Service (ICOS) is looking at a coordinated training plan for children's services to ensure that all staff are adequately training to support children and young people with autism.

There are a number of different training providers in Inverclyde – e.g. health teams, day opportunities teams, education services, third sector service providers, support organisations such as Reach for Autism. There is, however, no coordination, so there is likely to be duplication and gaps. There is often no mechanism for ensuring that the training that is being provided is the best and most appropriate for that particular need. The inclusion of people with autism and their carers as co-trainers is becoming more common and their contributions are often the key to opening the eyes of others to what it feels like to live with autism.

There are a number of arrangements for identifying training needs at present – Craigmarloch School has a Staff Development Coordinator, health staff have annual knowledge and skills framework (KSF) reviews.

There are a number of training courses offered on a regular basis in Inverclyde free of charge to practitioners working with people with autism – e.g. Autism Awareness, Total Communication Training, Intensive Interaction training, Picture Exchange Communication System (PECS), Sensory Processing Training. Feedback on current training programmes indicates a high level of participant satisfaction. Many staff mentioned that training was only available sporadically due to the work pressures of the people who delivered it and there was no obligation on services to attend the training, so the good services put their staff forward for training, while others services refused with no consequence for service.

Multi-disciplinary teams, such as Child and Adolescent Mental Health Team and Community Learning Disability Team, often offer individual-specific training to teams for people with autism known to their service. Third sector service providers, such as Barnardo's, ENABLE, Quarriers and Turning Point, not only provide their own staff with Autism Awareness training, but in some cases offer such training to people from outside their organisations. They do seek training regarding the support of individuals with complex difficulties from specialist teams. Reach for Autism has provided Autism Awareness Training to local supermarkets.

The Scottish Strategy for Autism has funded a number of training projects with the aim of building up the skills of the 'autism workforce' – e.g. NHS Education for Scotland (NES), Autism Network Scotland, Open University and the University of Strathclyde. Unfortunately, the information

²⁷ See MacKay T & Dunlop A W (2004) *The Development of a National Training Framework for Autistic Spectrum Disorders; A study of training for professionals working in the field of ASD in Scotland* (National Autistic Society)

regarding these initiatives is not being collated centrally and so there is widespread confusion regarding what is available. NHS Education for Scotland (NES) has developed online training for GPs and is currently doing further work on training for other NHS staff. Richmond Fellowship received funding to offer parent training courses in Inverclyde.

Scottish Autism have an online training resource (Right Click) for parents and families (cost is included in membership fee (£15(individual) £25 (family) at Nov 2013)) which includes 50 videos and additional support materials. This may be more appropriate for families who struggle to attend other training.

The Autism Resource Centre in Glasgow provides Autism Awareness courses (one day) and Advanced Autism courses (one morning a week for 8 weeks) in Glasgow. The Autism Awareness courses are available to anyone interested in learning more about autism. Applicants for the Advanced Autism course need to meet some minimum criteria with regard to experience. None of the courses provided by the Glasgow Autism Resource Centre are provided free of charge for participants from Inverclyde; participants will also have transport costs on top of attendance fees.

Consider for the future

Establishing that a lack of awareness of autism and the strategies that help people with autism should not be acceptable for people responsible for supporting individuals with autism across the lifespan.

With such a wide range and high level of training needs, a coordinated approach, both locally and nationally, will be necessary – An Inverclyde Autism Training Plan

Major national commercial organisations, such as supermarkets, cinemas, transport organisations, need to be encouraged to contribute to raising awareness and fulfilling their duty to make their services accessible to people with disability.

National training initiatives, such as the development of online training modules, need to be identified and promoted.

Individuals with autism and their carers should be given the opportunity to be involved in the design and delivery of training, when appropriate.

Regular time allocated off timetable to construct training programmes and materials.

The accreditation of training courses would not only give participants a credit towards a qualification, but would also ensure that training courses were meeting national standards.

Explore ways in which individual settings and organisations can be helped to take responsibility for taking action and sustaining change after training

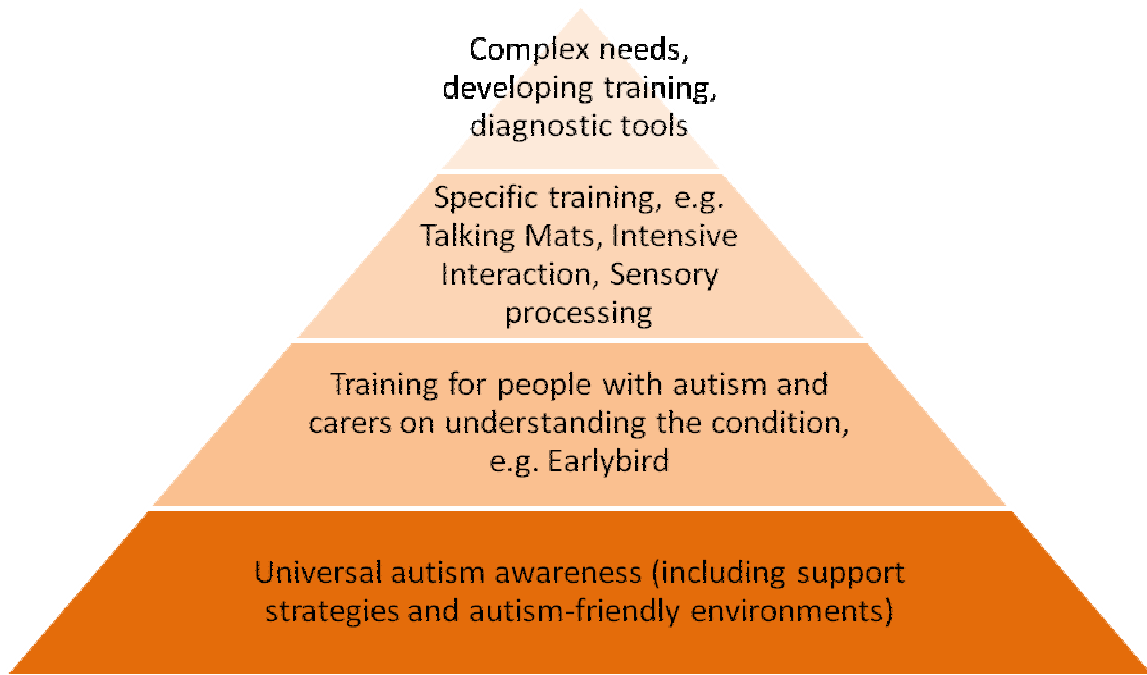


Figure 1 The possible shape of an Inverclyde Autism Training Plan

Theme 5 Pathway for Diagnosis

We want equal and timely access to a standard, evidence-based pathway for assessment, diagnosis and the support that follows

'Six months is a long time when you have a child at home who is not happy.'

What people said

Most of the carers who spoke to us were very positive regarding the assessment and diagnostic services in Inverclyde. They felt that it would be better if autism could be recognised and assessment could take place earlier and the waiting times for assessment were addressed. The pre-diagnosis period was identified as a very stressful time for carers. They felt that they could benefit from more information at this point.

(Teaching staff and educational psychology stressed that appropriate supports for a child were put in place as and when the child needed them and did not depend on an autism diagnosis. Ongoing assessment (psychological and communication, for example) took place and support plans were drawn up for the child. The diagnostic assessment was an important tool as it gave the team a comprehensive picture of the child or young person's abilities and needs and, in some cases, a diagnostic label.)

Services expected that the increasing awareness of autism in mainstream services might lead to earlier recognition of autism and fewer undiagnosed cases in the adult population.

Carers also wanted to be more closely involved in the assessment and for the child to be observed outside the school setting as part of the standard assessment. There was some concern from carers and some practitioners that there was not equality of service across Inverclyde with regard to post-diagnostic support, with children diagnosed at the Skylark Diagnostic Clinic receiving a higher level of support than those being diagnosed at other centres.

Some carers thought that longer-term follow up should be considered, with teams making contact after a year or so to make sure that the individual is being appropriately supported post-diagnosis.

What is happening already?

Autism Diagnostic Assessments take place in a number of services across Inverclyde. In the case of children and young people:

- The Skylark Autism Spectrum Disorder (ASD) Diagnostic Clinic (children and young people) which is responsible for the majority of autism diagnostic assessments in Inverclyde and

- The Child and Adolescent Mental Health Service (CAMHS) (children and young people referred to team for complex mental health conditions and during the process of assessment and treatment a social communication difficulty comes to light)
- The Scottish Centre for Autism, Yorkhill, for second opinions

In the case of adults:

- The Community Learning Disability Team (adults with learning disability) (ASD Diagnostic Group)
- The Community Mental Health Team (adults referred for a mental health condition)
- The NHS Greater Glasgow and Clyde Adult Autism Team, based in Glasgow (adults who have neither a learning disability nor are known to the Community Mental Health Team)

Referrals to the Skylark ASD Diagnostic Clinic come from GPs and a range of community based professionals with a knowledge of autism, e.g. Community Paediatricians (most referrals), speech and language therapists, specialist nurses, specialist teachers, and social workers with a particular interest in autism from the Children with Disabilities team. Discussions around referrals often take place at review meetings in the child or young person's school. The Community Learning Disability Team has an open referral system, but would consult the GP before proceeding. The Community Mental Health Team referrals work with people with autism who also have a moderate to severe mental health condition, with most referrals coming via the GP; if a diagnostic assessment is required, the team works with the Adult Autism Team in Glasgow.

The Adult Autism Team in Glasgow currently accept referrals for autism diagnostic assessments for people without a learning disability from GPs in Inverclyde; the case does not need to be open to the Community Mental Health Team, but these referrals go via the Community Mental Health Team in order to exclude any mental health conditions. The Adult Autism Team does not carry out diagnostic assessments for people with learning disability as these are carried out by the Community Learning Disability Team. The Adult Autism Team will support the Community Learning Disability Team with complex cases open to the CLDT, if required.

Many individuals on the mainstream teams we spoke to – for example, the Integrated Addictions Team – were not sure if they would recognise someone who should be referred for an autism diagnostic assessment and how they would go about doing that. There is obviously work to be done in raising awareness of autism and the pathway for diagnosis.

All of the diagnostic teams have a responsibility to follow best practice guidelines and international diagnostic criteria laid down for their patient groups, when they are carrying out assessments - e.g. ICD 10 (World Health Organisation diagnostic criteria), SIGN Guidelines (2013), Scottish Executive ASD diagnostic standards, NICE guidelines (2013), Public Health Institute of Scotland report (2001), NIASA Guidelines. The Autism Achieve Alliance audited the Skylark ASD Diagnostic Service against these standards in 2012. Teams have a responsibility to regularly review their practice against these standards and/or have them audited by external sources.

The Scottish Strategy for Autism has the provision of pathway for assessment and diagnosis as one of its best practice indicators. Currently, there is no single pathway in Inverclyde and a number of practitioners suggested that the current process should be reviewed to see if it could be streamlined without affecting the quality of the diagnostic assessment. Services in Inverclyde provide the following services, in line with best practice:

- **Assessment by a multi-disciplinary team** (paediatricians, speech and language therapists, educational psychologist in the case of the Skylark Service and psychiatrists and representatives from nursing, psychology, speech and language therapy or occupational therapy in the case of the other teams.

If the child or young person being assessed is known to either the Child and Adolescent Mental Health Team (CAMHS) or the Community Learning Disability Team (CLDT) as he/she is in the process of transition to adult services, representatives from these teams would be invited to join the diagnostic team at Skylark for the child's assessment.

The Skylark team is also supported by 4 social workers with a particular knowledge and experience of autism. There are no social workers currently participating in diagnostic assessments in the other teams, although this addition is under consideration.

- **Assessment involving detailed information gathered on the individual from a variety of sources and settings** (speech and language assessment, detailed autism specific developmental history, information from other professionals involved in the individual's life, e.g.nursery/educational/further educational settings, day opportunities or employment, educational psychology, community paediatrician, child and adolescent mental health team (CAMHS) , Community Learning Disability Team (CLDT) , service provider, GP. Observations of the individual may also be carried out.
- **Team access to mentoring and capacity for second opinions.** The autism diagnostic services for children and young people in Inverclyde access mentoring and second opinion support through the Scottish Centre for Autism at Yorkhill. The autism diagnostic services for adults in Inverclyde access mentoring and second opinions, when necessary, through the Adult Autism Team in Glasgow.
- **Appropriately trained staff.** The clinics may use different diagnostic assessment tools in order to inform their clinical decisions, but all staff involved in diagnostic clinics have had extensive experience of autism diagnostic assessment and specialist training in using standardised diagnostic assessments such as ADOS (Autism Diagnostic Observation Schedule), DISCO (Diagnostic Interview for Social and Communication Disorders) , 3Di, ADI-R. All team members have autism as part of their continuing professional development.

- **Discussion with the individual and family and, finally, consideration of all the relevant information by the team members before coming to a joint decision regarding the result of the assessment.**
- **A detailed report reflecting information from all sources** - produced after the diagnosis has been given, and with the individual's or, if appropriate, family's consent this report is distributed to the people involved with the individual.
- **Information for parents.** The different diagnostic clinics each have different processes for sharing information about autism with individuals and carers after diagnosis. Staff felt that it would be useful to agree a best-practice pack for all diagnoses in Inverclyde that included the most appropriate information for the individual (e.g. child, young person or adult) and information or links on local services. The information should be relevant, accessible and up-to-date and carers should also have the opportunity to ask any questions of someone who knows the individual and how autism is likely to impact on his/her life. Some parents told us that they needed access to advice and information on autism right after diagnosis, rather than waiting to meet up with the social worker.
- **Onward Referrals** (with appropriate consent) to other agencies as appropriate, e.g. speech and language therapy, occupational therapy, Child and Adolescent Mental Health Team, social work). Referrals for genetic testing may also be offered.

Some educational establishments expressed a desire to be more closely involved with the ASD diagnostic assessments of the children and young people they support.

Support after diagnosis

Carers gave very varying views about the support for people with autism and their carers after diagnosis. They described how they were in a state of shock after the diagnosis and took some time to come to terms with it. Families of children and young people who are diagnosed at the Skylark ASD Diagnostic Clinic welcomed the visit and involvement from social work, but wished that it could take place as soon after diagnosis as possible. They also wanted to be more closely involved in drawing up the support plans after diagnosis, so that they could be supporting the child or young person at home, in the same way as they were being supported at school.

The social worker from the Skylark team provides focussed post-diagnostic support over a 4-6 week period, and this opportunity is very rarely declined. Depending on individual need, support includes:

- An initial assessment of need (practical and emotional support)
- Representing the child from a social work perspective at all relevant meetings, including school reviews, respite reviews, Children's Hearings (emotional support)
- Offering advice, guidance and support to the child's family and colleagues (practical and emotional support)

- Co-ordinating the provision of residential respite and community respite, if necessary (practical and emotional support)
- Working closely with other agencies involved with the child – e.g. Education, Health, Voluntary Organisations
- Supporting the family with income maximisation, including an application for Disability Living Allowance (practical support)
- Signposting families to community support groups that do not require a referral (emotional and practical support)
- Supporting and empowering families to participate fully in the community and to overcome any social barriers to inclusion.

The Child and Adolescent Mental Health (CAMHS) Clinic do not have dedicated support from social work in the same way and this disparity in the service is being considered.

There is a robust programme of training in Inverclyde for parents whose children have been recently diagnosed – National Autistic Society Earlybird and Earlybird Plus, and Barnardo's Cygnet training – which carers acknowledge as being very helpful. People supporting the child in school will be released to attend the training with the parents. Some practitioners felt that the programmes needed to be reviewed and any changes that increased access for vulnerable families or families in crisis considered. There is no such programme for the families of adults recently diagnosed. Some carers questioned why they could not be trained up to be EarlyBird Trainers.

There are no post-diagnostic groups for individuals who receive a diagnosis of autism in Inverclyde, although individual schools will work with children and young people to help them to understand their diagnosis. The Adult Autism Team in Glasgow run peer groups there, but these are not easily accessible to adults from Inverclyde.

Post-diagnostic links with education and other services

The diagnostic process needs to link smoothly into the support services and for many children with autism the main provision will be from the Education Authority. The educational psychologist provides a link between the autism Diagnostic team, Inverclyde Communication Outreach Service and the other people involved in the child's education. A meeting will be held including the child's carers to ensure that the coordinated plan for the child reflects all of the identified needs, and has interagency working as an integral part. A plan is drawn up to support the young person both in the classroom and in less formal settings, such as the playground. Educational establishments felt that receiving feedback on diagnostic assessments, regardless of where these assessments took place (e.g. out of area), was invaluable as they helped to inform the work of supporting the child appropriately at school.

The Community Learning Disability Team offers review appointments (and, if appropriate, ongoing support) to individuals who have been recently diagnosed and their families. Where appropriate, the team works with and refers on to other services to ensure that the individual is getting the support he or she needs. The team would like there to be more post-diagnostic groups for adults with

autism in Inverclyde. Support staff working with people with autism and learning disability wanted to be more closely involved in diagnostic assessments.

Consider for the future

Better access to diagnostic assessments and post-diagnostic support

Better and more timely access for families to post-diagnostic training

Clearer pathways and better multi-agency working to improve support after assessment, whether a person has a diagnosis of autism or not

Greater involvement of education services/adult support services in diagnostic assessments

Consistent follow-up service for parents after diagnosis, regardless of where the diagnostic assessment takes place.

Improve access to diagnostic assessment and post-diagnostic support and clarify pathways for people not presenting with LD or Mental Illness.

Identifying opportunity to improve post-diagnostic support and linkage with existing services – e.g. Gateways To service in mental health.

Theme 6 Information and Advice

We want a coordinated system for information and advice about autism, that allows people not only to access good quality printed and electronic information when they need it, but also allows people to speak to others about how autism affects their lives

We currently have information on autism and local services for people with autism in specialist schools (the new Craigmarnock School will have a parents' room) and departments, support groups, reception areas, websites, newsletters, but there is no way of ensuring the quality and availability of the information.

This seems to be an area where all agree that a coordinated information and advice plan is required in order to bring all the different forms of information and sources of information together to make sure that individuals and families are receiving the best information at the best time.

For Individuals with autism, their families and carers

What people said

People with autism, their family and carers felt that they needed advice and information at different points in their life, not just at diagnosis. They wanted advice on common problems without the need for a referral to specialist services. They wanted to know what services were available to them and how to access them.

People with autism and their carers wanted someone to talk to who knew about autism and local services, but who also understood them. Carers felt that advice and information was all over the place, but there was no single source of comprehensive and reliable information locally about autism, about help with autism and about local services for people with autism. A directory of services for individuals with an autistic spectrum disorder, their parents and families was produced some years ago by a local support group, Inverclyde Council and the National Autistic Society. This is in urgent need of updating, but provides a useful guide to a whole range of services available in Inverclyde. Many carers were unaware of this.

People felt that there was better access to advice and information in specialist schools than there was in mainstream, particularly those who do not have a Communication and Language Base. Some families felt well supported with regard to information; others felt out of the loop. There was an impression that the provision of information was ad hoc – 'it depends who you know'. Some families and staff members had accessed the National Autistic Society Website, but they wanted more information about how autism related to their individual lives, not general information.

Carers pointed out that the Inverclyde Centre for Independent Living provides a hub for people with physical disability, hearing impairment or visual impairment, with experienced staff who understand the difficulties that the people accessing their service are experiencing. There is no such place for people with autism in Inverclyde, despite their having significant barriers to independent living.

What is happening already

Carers use local support organisations, such as Reach for Autism and the Inverclyde Autistic Support Group, for information on autism and local services – through direct contact, telephone enquiries and their websites and facebook pages. Many welcomed the opportunity to speak to someone; others wanted to be able to access information and advice independently.

Parents praised the work of the Early Years Outreach Service. Once a child has been referred to the team, parents are offered direct contact via phone calls, emails, home visits and nursery meetings, which allows them to access information and advice on autism and how it is affecting their child.

*The Autism Toolbox*²⁸, a resource for schools published by the Scottish Government, contains information from research and practical experience that is applicable to the classroom, playground and home. This is currently available on the internet, but needs to be more widely promoted.

The Autism Resource Centre in Glasgow also holds information on services for people with autism throughout Glasgow, but it was not clear how accurate or up to date the information on Inverclyde was. Autism Network Scotland also collates a lot of useful information on autism and on forthcoming training events.²⁹

For adults with learning disabilities and autism, a new online information and referral system is about to be launched – Positive Pathways. Visitors to the Inverclyde Council website will be signposted to useful information and local services, such as assessment and care management, transition support, Job Centre Plus, Skills Development Scotland, community supports, leisure and libraries, day opportunities. The site is currently only set up for people with learning disability (including those with learning disability and autism).

For Staff Working with People with Autism

What people said

Staff working with people with autism wished there was more time to access sources of advice and information and improve their knowledge and understanding of autism.

The multi-agency nature of the way in which services work with people with autism facilitates information sharing. For example, staff at Barnardo's felt that their close links with health visitors, schools and social work gave them the opportunity to talk to people about autism and how best to support the individuals they worked with.

Some staff members suggested that online forums could be used by individual staff members to share best practice throughout Inverclyde.

²⁸ Scottish Government (2009) *The Autism Toolbox*, Scottish Autism Service Network and National Centre for Autism Studies, University of Strathclyde <http://www.scotland.gov.uk/Publications/2009/07/06111319/0>

²⁹ <http://www.autismnetworkscotland.org.uk/events/>

What is happening already

The Inverclyde Communication Outreach Service is a group of professionals working in children and young people's services. The group meets each term to share useful and practical information about ASD. This information is then disseminated to education establishments through meetings with senior management teams. There is no such group for adult services.

Where services have professionals with a special interest in autism, staff often reported that they felt they were able to speak to that person for advice and information and that person often took responsibility for sharing information. There were also opportunities during supervision and team meetings to ask questions. However, in mainstream services, staff reported that they would access the National Autistic Society website for information and that they were not sure what services were available locally so would find it difficult to signpost other people to services. Services such as the specialist autism day service at Golf Road and the Community Learning Disability were often approached for advice and information.

Autism Specialists are often members of Clinical Excellence groups or networks that facilitate the sharing of best practice and developments in research around autism. They may also have close links with local university departments.

Consider for the future

- A coordinated information and advice plan
- Easy access to information at different times, not just as diagnosis on common problems, services available, referral routes
- Someone to talk to who knows about autism and who will be able to explain how information relates to personal circumstances.
- Online information on autism, including information on local services, along the lines of the Positive Pathways resources for learning disability
- All organisations providing services to people with autism in Inverclyde having an advice and information protocol that includes the identification of a named person (an Autism Champion) for advice and information, the availability of standard information packs and information displayed in reception areas, as well as appropriate links on websites.
- Online groups for interested parties

Theme 7 Coordinated services based on accurate data

We want coordinated services that speak to each other and that identify and meet the needs and aspirations of people with autism in Inverclyde.

'People don't talk to each other'

'We are asked the same questions over and over again'

Coordinated Services

Autism impacts on many areas of an individual's and a family's life. People with autism also often have a number of co-morbid conditions, such as ADHD, dyspraxia, dyslexia, mental health conditions. It is therefore essential that assessment and planning for individuals with autism are multi-agency in nature at all ages, the precise involvement depending on the individual's needs – e.g. health, educational psychology, social work. It is also important that the needs of people with autism and their carers and families are embedded in all the local planning structures.

What people said

When carers were asked 'Do you feel that services work well together in Inverclyde ... to meet the needs of people with autism', the majority answered 'no'. In contrast, 80% of the individuals with autism who completed our questionnaire (n=10) (most of whom were adults) felt that people did work well together. This may reflect the fact that carers may see professionals individually and may also have greater insight into the need for joint working.

Carers expressed some frustration that professionals didn't share information more freely if it was obviously in the interest of the individual with autism. Practitioners are obviously obliged to work within the law with regard to protecting the individual's right to confidentiality and the requirement to obtain consent to share information. Carers felt that more should be done to make that consent process easier. The Community Learning Disability Team have produced easy-read consent forms which make it easier for some individuals with autism and learning disability to give consent. For more severely disabled individuals, the processes under the Adults with Incapacity Act need to be followed.

Practitioners described many examples of good multi-agency working, but also felt that this needed to be developed further, given the multi-dimensional nature of the condition. They told us about the ASD Liaison Group, a multi-agency group of professionals who meet a couple of times a year to exchange experience and research findings about autism. Some practitioners suggested that carers and voluntary organisations should be included in these meetings.

There are a number of other strategies and collaborations in Inverclyde that are very relevant to people with autism and their families – e.g. the Carers' Strategy, the Public Involvement Strategy, Inverclyde Joint Commissioning Strategy, The Early Years Collaborative. Carers and practitioners hoped that the Inverclyde Strategy for Autism would result in people with autism being better represented with regard to the other initiatives within Inverclyde. The Scottish Strategy for Autism

makes particular reference to the need to include people with autism and their families in the work around introducing Self Directed Support to local areas.

Practitioners also told us that the multi-agency working which is more common in settings that have a significant number of children with additional support needs needs to be encouraged in other mainstream settings. The need for joint working should be highlighted, when appropriate, and staff in mainstream settings should have easy access to information on referral pathways for other agencies, such as speech and language therapy, occupational therapy and educational psychology.

What is happening already?

As a small local authority, multi-disciplinary working in Inverclyde tends to be easier than it is, say in cities like Glasgow.

For services across the lifespan, review meetings, joint support plans and protocols and service provider meetings are all examples of multi-agency working. There are a number of multi-disciplinary teams supporting people with autism – e.g. the Child and Adolescent Mental Health Team, the Community Learning Disability Team, the Community Mental Health Team. They are either integrated with social work, or have very close links with social works colleagues. They also work very closely with third-sector service providers. Many of the interventions, particularly for those people with complex needs, are multi-agency in focus.

When an individual with autism is having particular problems, at any age, a core group meeting involving all the important people in that person's life will be held in order to agree the best way forward.

In early years settings, particularly those closely involved with children with additional support needs, the Early Years Outreach Team, Speech and Language Therapy, Occupational Therapy and Physiotherapy work jointly with nursery and school staff to support children with autism. Social workers from the Children and Disabilities team may complete an Integrated Assessment (IAF) for the child and family, which requires contributions from all the agencies supporting the child.

Craigmarloch School felt that the NAS Accreditation Scheme encouraged a holistic approach to the support they offered their pupils with autism.

The Children and Young People Bill 2013 is currently before the Scottish Parliament. When this bill is enacted, it is likely to change the way in which statutory bodies, such as health, social work and education, work together to meet the needs of children and young people with additional support needs, including autism. It is based around the Getting It Right for Every Child Principles (GIRFEC) and stresses well-being outcomes and the importance of the provision of good quality information for children, young people and their families and their close involvement in choices and decision making. It recommends that a child or young person should have one overall assessment and a single plan that brings together the support required to meet education, health and social care needs. Services and partners in Inverclyde are working towards the development of a single plan.

The Single Shared Assessment Framework used by adult services allows an individual and/or his family (when appropriate) to provide 'their whole story' so that that information can be shared with their consent with other professionals who may come into contact with them in the future.

The need for accurate data

Services that meet the needs of people with autism can only be provided if we know who these people are and what they need. The information currently gathered in Inverclyde is patchy.

See Section 2.1 for details on what information is currently known about people with autism in Inverclyde.

What people said

People with autism and their carers felt that it was too easy to fall off the radar, to fall between the gaps in services, to become invisible. People with autism talked a lot about 'giving up'. Practitioners working with people with autism of all ages felt that there was a high level of unmet need.

In general, at the present time, most organisations providing services to people with autism in Inverclyde are not collecting data in a systematic way on how many people are being diagnosed, how many people with autism are using their service, how many people with autism are having problems accessing their service. However, services are increasingly aware of the need to do this and are introducing protocols for this.

There is very little information on outcomes for people with autism. We need to identify a robust system of outcomes for individuals with autism and then apply them to ensure that we are doing our best for people with autism. Applying an outcome measure, such as the Spectrum Star(tm), as the young person leaves school and at regular intervals in the first five years after school would be a good way of measuring how well we are supporting people with autism.

Consider for the future

- Set up an Inverclyde Strategy for Autism Implementation Group, chaired by a senior manager, with representatives from carers and service users to oversee the implementation of the Action Plan
- Appoint an Inverclyde Autism Coordinator to drive forward the action plan, develop projects, and improve joint working across the area.
- Set up a framework that facilitates closer joint working between children and young people's services and adult services
- Better coordination between agencies and between agencies and families
- Streamlined process for obtaining consent to share, while respecting individual's right to confidentiality (using easy read materials and tools such as Talking Mats, when necessary).

- Review of data gathering by data professionals.
- A central database to record all new diagnoses and numbers of people with autism in Inverclyde
- A longitudinal study into outcomes for people with autism in their early adult years
- The ability to identify subgroups so that local services can be adapted in response, e.g. girls diagnosed with Asperger's
- Clear identifiable pathways with eligibility criteria for referral so that people with autism do not fall through gaps.
- A single plan for each child that would involve contributions for all the required agencies and a mechanism for coordination. Plans rely on accurate assessment and coordinated, effective and timely implementation.
- The views and needs of people with autism and their families being better represented in other strategies and collaborations within Inverclyde.

Theme 8 Included and Involved

We want to be involved in decisions that affect our lives, and to play a role in implementing the Inverclyde Autism Strategy.

'I want to be able to support others with autism like me and future generations.'

'I want to lay down foundations for a legacy'

'People shouldn't wait till parents' night. If there is a problem and I can help, I need to know.'

What people said

People with autism, their families and carers all wanted to be more closely involved in the decisions affecting their lives and in influencing the design of the services they used. This means not only receiving information, but also having the opportunity to actively contribute and to have their contribution valued.

They also felt they had an important role in raising awareness of autism and delivering training. Many people with autism told us that they didn't like being sent questionnaires to complete. They would prefer to have small group meetings or electronic questionnaires.

People with autism wanted to be consulted in the design of services. For example, some told us that they often had difficulty sleeping and so struggled to attend appointments in the mornings. Afternoon appointments would be far better.

Practitioners in a wide range of services were aware of the move towards co-production in the delivery of services and had already identified a need to improve their communication with and involvement of people with autism and their carers in their services.

What is happening already

Organisations told us of review meetings, newsletters and websites which were all used as a way of informing and engaging people with autism and their families/carers. An open door policy was common, which meant that individuals or carers could approach staff if they had any concerns. Carers were closely involved in meetings around the preparation of Coordinated Support Plans and Individual Education Plans. In some schools children and young people with autism were often asked to express their views and become involved in school committees and fundraising. A Parent Reference Group for parents and carers of children and young people had been set up by education in the past, but it had not been well attended. Education are reflecting on the reasons for this – time of day, venue, publicity – and how such a group could be organised in future.

Many services – e.g. education, health – described gathering feedback on training courses or group sessions, at the end of the piece of work, the analysis of which was then used to make any necessary adaptations. This was often the only example of user or carer involvement.

At West College Scotland, students are given Personal Learning Support Plans which are put together with their tutors at the start of the year and they are asked for feedback at the end of courses, but the views of students on more strategic matters are not currently gathered.

Adult learning disability services have a Health Advocacy Group consisting of people who use learning disability services. The group comments on resources produced and has recently begun to be involved in the interviews of recruits to the service. People with autism and learning disability can be members of this group.

There were few examples of people with autism, their families and carers being asked their opinions of services or being involved in the design of services.

The Inverclyde Advocacy project, an independent advocacy service, provides support to people with autism and their families. Your Voice Inverclyde Community Care Forum (ICCF) is a not-for-profit organisation that promotes the involvement of local people in Inverclyde in decisions that affect them.

Consider for the future

- We can only be sure that we are meeting the needs and aspirations of people with autism and their carers if they are involved in the design and implementation of services.
- Set up an Inverclyde Autism Reference Group, made up of people with autism, to give expert advice and guidance on how the Action Plan should be implemented.
- Explore ways in which people with autism and their carers can be more closely involved with the services.
- Agencies to show how they have involved people with autism, their families and carers in delivering services, when appropriate (e.g. as co-trainers), and in decisions that affect their lives.
- Where appropriate, people with autism should have access to advocacy services.
- Fully developed system for gathering feedback from people with autism and their families on their experience of services, with a formalised mechanism to address concerns and deal with complaints

Theme 9 Evaluation

We want services to check on a regular basis that they are doing a good job for people with autism in Inverclyde.

Organisations providing services to people with autism and their carers in Inverclyde need to have mechanisms in place to ensure that they are using best practice and continuing to meet the needs of the people who use their service.

The introduction of more minimum diagnostic and care standards and pathways will give us the framework that will enable us to measure our performance on a regular basis. More structured routes for learning will ensure that evidence relating to changes in best practice guidelines are shared with all parties.

For people of all ages in Inverclyde, the principles of Getting It Right for Every Child, Citizen and Community are the measure against which services can evaluate their performance. These are the outcomes we should be striving towards:

- Safe – Protected from abuse, neglect or harm and supported when at risk. Enabled to understand and take responsibility for actions and choices. Having access to a safe environment to live and learn in.
- Healthy – Achieve high standards of physical and mental health and equality of access to suitable health care and protection, while being supported and encouraged to make healthy and safe choices.
- Achieving – Being supported and guided in lifeline learning. Having opportunities for the development of skills and knowledge to gain the highest standards of achievement in educational establishments, work, leisure or the community
- Nurtured – Having a nurturing place to live and learn, and the opportunity to build positive relationships within a supporting and supported community.
- Active – Having opportunities to take part in activities and experiences in educational establishments and the community, which contribute to a healthy life, growth and development
- Respected and Responsible – Respected and share responsibilities. Citizens are involved in decision making and play an active role in improving the community.
- Included – Overcoming social, educational, health and economic inequalities and being valued as part of the community.

The Children and Young People Bill 2013 currently before the Scottish Parliament puts the GIRFEC principles at the heart of health, education and social work services for children and young people. Identifying better data with regard to outcomes for people with autism in Inverclyde will allow us to see whether we are delivering these.

At a service level, all of the statutory bodies are also evaluated on a regular basis by their relevant inspection services, such as the Care Commission, HM Inspectors of Schools. The communication and language departments within mainstream schools compare their service with the How Good Is

Our School Indicators, but practitioners feel it would be good for autism-specific practice to be linked with the indicators in the future. Craigmarnock School finds the National Autistic Society Accreditation Scheme a good way of evaluating the service they provide to children and young people with autism and their families.

SIGN and NICE best practice guidelines in relation to people with autism are a useful tool for evaluation and for the identification of service improvements.

Service providers told us that they review performance, operational issues and staff training needs on an ongoing basis. However, they would welcome the development of standards, procedures and evaluation processes based on the Inverclyde Strategy for Autism that could be used in the future to evaluate their service.

Despite there being some examples of good practice in relation to using feedback from people with autism and their carers to evaluate services, this is an area that has been identified as a priority area for development (see previous section 'Included and Involved').

At a practitioner level, professionals have to evidence on a regular basis that they are working to the performance standards laid down by their professional bodies. Formal staff appraisals, observations, joint working – all give an opportunity to reflect on practice. Group reviews and team meetings are used to give practitioners working for the organisations the opportunity to comment on current services and to make suggestions for service improvements.

In relation to individuals with autism, the regular review of support plans, action points from review meetings and the use of protocols for key processes (such as the transition from school) are used to show services how well they are meeting the individual's needs.

Consider for the future

- Specific goals should be identified for the implementation of the Inverclyde Strategy for Autism so that progress towards the vision for autism can be monitored and evaluated.
- Minimum standards and best practice guidelines should be used to evaluate services.
- Outcome measures for people with autism (e.g. the Spectrum Star (tm)) should be explored so that we have evidence that the services we provide are making a difference to the lives of people with autism and their families
- Annual evaluation of the service, using ASD-specific Indicators from the *Autism Toolbox*³⁰

³⁰ Scottish Government (2009) *The Autism Toolbox*, Scottish Autism Service Network and National Centre for Autism Studies, University of Strathclyde <http://www.scotland.gov.uk/Publications/2009/07/06111319/0>

5 Conclusion

This Strategic report has identified a number of recurring themes and considerations for the future that need to be addressed if the services for people with autism in Inverclyde are to be improved.

The themes are:

- 1 **Understood, Valued, and Safe** - We want to be understood, valued and safe in the community in which we live.
- 2 **Independence and support** - We want the opportunity to have meaningful, independent active lives, using mainstream services when we can, but accessing support to overcome barriers when we need it
- 3 **Social networks** - We want opportunities to develop positive, supportive and enabling social networks
- 4 **Training Plan** - We want a coordinated Autism Training Plan for Inverclyde so that people with autism, their families and carers, and those people working with them all have the attitudes, knowledge and skills they need
- 5 **Pathway for Diagnosis** - We want equal and timely access to a standard evidence-based pathway for assessment, diagnosis and the support that follows
- 6 **Information and Advice** - We want a coordinated system for information and advice about autism, that allows people not only to access good quality printed and electronic information when they need it, but also allows people to speak to others about how autism affects their lives.
- 7 **Coordinated services based on accurate data** – We want coordinated services that speak to each other and that identify and meet the needs and aspirations of people with autism in Inverclyde.
- 8 **Included and Involved** - We want to be involved in decisions that affect our lives, and to play a role in implementing the Inverclyde Strategy for Autism.
- 9 **Evaluation** - We want services to check on a regular basis that they are doing a good job for people with autism in Inverclyde.

An Action Plan has been developed (see separate document) to ensure that there is a coordinated approach to implementing change over the next ten years. The Action Plan calls for the following:

- The formation of an Inverclyde Autism Strategy Implementation Group (ISAIG), chaired by a senior manager, with representatives from carers and people with autism.
- The appointment of an Inverclyde Autism Coordinator to drive forward the Action Plan.
- The formation of an Inverclyde Autism Reference Group, made up of people with autism, to give expert advice and guidance on how the plan should be implemented.
- The formation of a number of working groups to address specific priorities for action, e.g. assessment and care pathways, communication planning, training planning, transitions/independent living/social networks, stakeholder involvement and measuring performance.
- Working groups will be encouraged to use the Strategic Report to guide their discussions and to establish goals for two years, five years and ten years.

Early intervention, prevention, co-production, multi-agency working and the coordination of services are integral to the delivery of all priorities for action. We hope that this will ensure that everyone in Inverclyde comes together to make the aspirations of people with autism and their carers a reality.

Appendix

The Scottish Strategy for Autism

Ten Indicators for current best practice in Autism Spectrum Disorder services

A local Autism Strategy developed in co-operation with people across the autism spectrum, carers and professionals, ensuring that the needs of people with ASD and carers are reflected and incorporated within local policies and plans.

Access to training and development to inform staff and improve the understanding amongst professionals about ASD.

A process for ensuring a means of easy access to useful and practical information about ASD, and local action, for stakeholders to improve communication.

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.

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

A multi-agency care pathway for assessment, diagnosis and intervention to improve the support for people with ASD and remove barriers.

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

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 self-evaluation framework to ensure best practice implementation and monitoring

Two-year, Five-Year and Ten-Year Goals

Foundations: by 2 years (November 2013)

1. Access to mainstream services where these are appropriate to meet individual needs.
2. Access to services which understand and are able to meet the needs of people specifically related to their autism.
3. Removal of short-term barriers such as unaddressed diagnoses and delayed intervention

4. Access to appropriate post-diagnostic support for families and individuals (particularly when there is late diagnosis)
5. Implementation of existing commissioning guidelines by local authorities, the NHS and other relevant service providers.

Whole Life Journey: by 5 years (November 2016)

1. Access to integrated service provision across the lifespan to address the multi-dimensional aspects of autism
2. Access to appropriate transition planning across the lifespan
3. Consistent adoption of good practice guidance in key areas of education, health and social care across local authority areas
4. Capacity and awareness-building in mainstream services to ensure people are met with recognition and understanding of autism.

Holistic personalised approaches: (November 2021)

1. Meaningful partnership between central and local government and the independent sector
2. Creative and collaborative use of service budgets to meet individual need (irrespective of what the entry route to the system is).
3. Access to appropriate assessment of needs throughout life.
4. Access to consistent levels of appropriate support across the lifespan including into older age.

Menu of Interventions

Developmental level and difficulty, ability to learn and stage of life mean that interventions and support should be customised to meet the needs of each individual with an autism spectrum disorder and the needs of their families. (Interventions to include advice, therapeutic interventions and counselling.)

1. Understanding the implications of an autism diagnosis

Post diagnostic discussion (s) and individualised counselling

The provision of good quality education and information packs for individuals, families/carers along with appropriate verbal discussion at time of need. Use of visual props if needed. Signposting to useful websites and forums.

2. Development of effective means of communication

Individualised language therapy assessment. Updated as required. Alternative and augmentative communication systems introduced where required. Work to ensure language system (regardless of form) is used functionally and is therefore effective on an individual basis. Teaching/learning on internet etiquette and supervision.

3. Social communication

Targeted social communication programmes delivered either individually or in a group setting as required and appropriate to the individual to include internet etiquette and promotion of online safety.

4. Developing and maintaining relationships

Work to assess the understanding of relationships and promotion of skills to develop relationships including sexuality issues and intimate relationships. Access to social groups, friendship circles etc

5. Social isolation for individual with autism

Accessible social groups and opportunities, support in the community. Befrienders. Respect the need to be alone at times. Acceptance by families that friendships can take many forms

6. Social isolation for family

Family/ Partner/ Carer support, opportunity for respite. Access to autism friendly Environments

7. Learning to learn skills

A functional assessment of the person's cognitive abilities and learning style leading to a planned programme both directly with the individual and indirectly with the family, carers etc. Formal psychometric testing may be conducted if appropriate to inform intervention.

8. Predicting and managing change

Timely individual direct work with individuals to teach methods where required. Family/carers /employer guidance/education in these methods
Visual supports; timetables, timers, text alerts, choice boards etc to be used as Appropriate

9. Behaviour and emotional regulation protecting wellbeing

Knowledge development in understanding behaviour in the context of ASD. Individual work with the individual on assessing behaviour, recognising triggers and developing and managing the implementation of strategies to help. Behaviour support plans, cognitive interventions, psychotherapy or counselling as required and indicated by life circumstances eg around transitions of all types including bereavement. Work with the individual's family/carers, criminal justice, social work, Police as appropriate. Autism Alert card possession

10. Restricted and repetitive interests and behaviours

Assessment and positive day to day management on an individualised basis. Treatment by mental health clinician if required

11. Motivation issues Structured programmes as appropriate to the individual linking to the other core challenges as required. Career guidance, employer/HE/FE support.

12. Sensory issues Assessment of sensory difficulties.

Identification and implementation of strategies. Environmental adaptation on an individual basis with individual control working towards reducing the impact of sensory sensitivities

13. Daily living skills Assessment of core life skills as required across the lifespan and to take account of changing needs at various transitions. Specific individual programmes to teach and maintain these skills where needed. Involvement of families/carers in assessment and implementation of new learning. Education for families/employers/ care providers/housing dept re practical needs

14. Co existing conditions- examples

epilepsy, dyspraxia, dyslexia, disorders of attention, sensory impairment, anxiety, sleep disorder, addiction, anger management, depression, self harm, psychosis, personality disorder, OCD, disordered eating patterns etc. These require assessment and treatment/management by appropriate specialist clinician. Joint working is crucial across specialities with a clear case co-ordinating lead identified.