

Supporting adults, children and young people with autism in Ayrshire

Draft Delivery Plan for 2014-2024



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About this plan

This document sets out our proposed plan for delivering the priorities set out in the Scottish Strategy for Autism at the local level in Ayrshire. The draft Delivery Plan specifies actions and sub-actions to be taken forward to meet the 10 good practice indicators outlined in the national strategy. Included in the plan are proposals for ongoing engagement with service users and carers, establishment of an Ayrshire Autism Strategy and development of decision-making structures for supporting autism.

The draft Delivery Plan has been developed on an Ayrshire-wide basis, led by officers from each of the three Ayrshire local authorities and NHS Ayrshire and Arran. The draft plan builds on the findings of the National Autism Mapping Services Project published in September 2013. The Mapping Project involved desktop research and consultation with local people with autism, carers and service providers.

A further consultation exercise was carried out in October / November 2013 to support the development of the plan. This involved stakeholders from a wide range of relevant agencies as well as service user and carer groups. An electronic survey was widely disseminated with responses submitted by parents / carers, people with autism and practitioners. The survey asked for views on the emerging plan, as well as comments on the wider approach to supporting people with autism in Ayrshire, and views on best approaches for engaging with people with autism locally. A total of 41 submissions were made during the consultation either to the survey or by other methods (e.g. email, telephone). A brief summary of the survey results is included as Appendix One.

Why do we need to take action on supporting people with autism?

Autism is a general term sometimes referred to as autism spectrum disorder (ASD) or autism spectrum condition. It includes conditions such as classic autism and asperger syndrome. Some characteristics are shared by all those on the spectrum; some are very specific to individuals. The needs of people with autism vary significantly.

We want to make life better for all people in Ayrshire with autism – whatever their age, circumstances or level of ability. We want to ensure that services work together to help people with autism, and that all services respond to the different needs of people with autism.

The Scottish Strategy for Autism was launched in November 2011. It states that supporting people with autism is a national priority and calls for action to be taken at local and national levels.

Across Scotland there are examples of good practice where people with autism feel well supported – but this varies from place to place. The aim of the 10 year national strategy is to help people with autism to feel supported no matter where they live.

The national strategy calls for more consistent service standards and better matching of resources to need. It says that there should be a holistic, joined-up approach and that people with autism and their carers need to be supported by a wide range of services including social care, education, housing, employment and other community-based services.

Local authorities and their partners have been asked to develop plans showing how they will deliver a more joined-up approach. This includes developing a local strategy for autism. In Ayrshire, it has been proposed that the best way to bring about a more coordinated approach is to develop an Ayrshire-wide strategy for autism.

The Scottish Strategy for Autism cites the estimated prevalence of autism as 90 cases per 10,000. Applying this prevalence rate to Ayrshire's population at the time of the 2011 Census gives an estimated prevalence of 2,263 individuals with autism living in the three Ayrshire local authority areas. Monitoring of people with autism using statutory services is limited and will only record members of the population currently in contact with services. Nevertheless, Table 1 illustrates the significant gap between estimated prevalence and the numbers of people with autism that are known to services.

| Area | Population - 2011 | Autism prevalence estimate - 2011 | Adults with autism using LD services – 2011* | Children and YP with autism in education – recorded 2013** | Total people with autism known service users | % of estimated prevalence |
|----------------|-------------------|-----------------------------------|--|--|--|---------------------------|
| East Ayrshire | 122,767 | 1105 | 40 | 120 | 160 | 14.5% |
| North Ayrshire | 138,146 | 1243 | 32 | 165 | 197 | 15.8% |
| South Ayrshire | 112,799 | 1015 | 46 | 217 | 263 | 25.9% |

Table 1 – Estimated prevalence of autism in Ayrshire and recorded service use

* eSAY return, 2011

** Additional Support for Learning and Young Carers Report to Parliament (Scottish Government, 2013)

In South Ayrshire, approximately a quarter of the anticipated autism population are known to providers through education or adult learning disability services. This figure is lower for East and North Ayrshire at between 14% and 16%.

During the Mapping Project people with autism and their carers made the following comments about their experiences of receiving support in Ayrshire:

"I find that not everyone is as understanding and caring about my difficulties as I would like sometimes and find that they don't always offer the service they should." - Person with ASD

"It's great when professionals have a personal understanding of autism – they have more empathy when interacting with us." - Person with ASD

"There's a lack of imagination in existing services" - Carer

"Everything is very disjointed – there is no communication between the different services, statutory agencies and the parents." - Carer

"The nursery staff went out of their way to find the right support for [my son] and worked closely with us to gain a better understanding of his needs. They were innovative in their approach and not afraid to try things with him. Some worked, others didn't, but at least they made the effort." - Carer

"Possibly a way to start educating the community is to educate the peer group and their parents by sending appropriate information to them via school." – Carer.

"Services are not tailored to the needs of people with ASD and they are often not accessible enough because of geographical boundaries. It's a 'postcode lottery'." - Carer

"There needs to be much better communication, coordination and cooperation between all those working in ASD" - Carer

Our emerging vision

Based on the discussions that have taken place, and in line with the priorities set out in the Scottish Strategy for Autism, we are proposing the following vision and local outcomes for supporting autism:

“Our vision is that all people with autism are respected and accepted for who they are, are valued for what they contribute to our communities, and are able to live the life they choose.”

We will know we are working towards achieving this if, by 2024:

1. All services that support people with autism are effectively planned through cooperation between the three local authorities, the NHS in Ayrshire and our local and national partners¹.
2. It is a straightforward and timely process for people to find out if they (or their child) have autism.
3. People with autism, their families and carers understand the condition and are well supported.
4. The wider community and mainstream services fully support people with autism because they know and understand the condition.
5. Everyone with autism is supported to make full use of the opportunities and services available to meet their needs.

¹ This will take place in the context of health and social care integration. From 2015, new Health and Social Care Partnerships will be established in each of the three local authority areas to oversee the delivery of health and social care services.

How can we achieve this?

Our draft Delivery Plan sets out key action areas for delivering our vision for autism and meeting a range of good practice indicators set out in the national strategy.

These indicators commit local partners to delivering the following:

- a local Autism Strategy - developed in co-operation with people across the autism spectrum, carers and professionals;
- better staff training / development on ASD to improve understanding (coordinated through a Training Plan);
- easy access to useful and practical information about ASD;
- better data collection on ASD to improve service planning;
- a multi-agency care pathway for ASD;
- a framework for better engagement;
- service delivery that is multi-agency in focus (and clear multi-agency plans and procedures);
- a self-evaluation framework in relation to ASD.

The draft Delivery Plan on the following pages sets out what we will do to deliver:

- better coordination and cooperation;
- better understanding across services and environments; and
- better ongoing engagement with people with autism and carers.

Draft Delivery Plan

All services that support people with autism are effectively planned through cooperation between the three local authorities, the NHS in Ayrshire and our local and national partners.

Related national milestones:

- Implementation of existing commissioning guidelines by local authorities, the NHS, and other relevant service providers. (2YM² 5)
- Consistent adoption of good practice guidance in key areas of education, health and social care across local authority areas. (5YM³ 3)
- Meaningful partnership between central and local government and the independent sector. (10YM⁴ 1)

| The strategy says... | What needs to be done? | Lead responsibility | Timescale |
|--|---|-----------------------------|---------------|
| 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. (GPI ⁵ 1) | Establish Ayrshire Autism Partnership <ul style="list-style-type: none"> - Lead officers at LAs and NHS identified - Wider membership agreed - Terms of reference - Support structures / sub-groups established | EAC / NAC / SAC / NHS AA | December 2013 |
| | Consultation on local Autism Strategy for Ayrshire – engagement with stakeholders including people with ASD, families and carers | | Dec 13-Feb 14 |
| | Development of Ayrshire Strategy | | Feb 14 |
| | Publication and promotion of Ayrshire Strategy | | March 2014 |
| A process for data collection which improves the reporting of how many | Review existing monitoring of ASD service users across relevant services | Ayrshire Autism Partnership | July 2014 |

² 2YM – 2-year milestone

³ 5YM – 5-year milestone

⁴ 10YM – 10-year milestone

⁵ GPI – Good Practice Indicator

| | | | |
|--|---|-----------------------------|---------------|
| people with ASD are receiving services and informs the planning of these services. (GPI 5) | Develop shared approach to monitoring of diagnosed ASD (by type) with GP practices in Ayrshire – and data sharing agreement | NHS AA | |
| | Explore scope for periodic surveys of people with autism and carers on support needs and experience of service provision | Ayrshire Autism Partnership | July 2014 |
| | Explore information sharing arrangement with support providers (services users; referrals / signposting into services) | | July 2014 |
| A framework and process for seeking stakeholder feedback to inform service improvement and encourage engagement. (GPI 7) | Consult with local people with ASD and carers on best approach for ongoing involvement and engagement | EAC / NAC / SAC / NHS AA | Oct 13-Feb 14 |
| | Agree structure for involvement of people with ASD carers in the Ayrshire Autism Partnership (<i>direct membership, service user reference group...?</i>) | Ayrshire Autism Partnership | March 2014 |
| | Develop an engagement plan for wider consultation with people with ASD and carers | | May 2014 |
| | Build capacity of advocacy services to respond to the needs of people with ASD (<i>Independent advocacy; training for self-advocacy and citizen leadership..?</i>). | | March 2015 |
| A self-evaluation framework to ensure best practice implementation and monitoring. (GPI 10) | Performance monitoring framework developed for the implementation of the Ayrshire Strategy and Action Plan | Ayrshire Autism Partnership | July 2014 |

| It is a straightforward and timely process for people to find out if they have autism. | | | |
|--|--|--------------------------------------|----------------------|
| Related national milestones: <ul style="list-style-type: none"> • Removal of short-term barriers such as unaddressed diagnoses and delayed intervention. (2YM 3) • Access to appropriate post-diagnostic support for families and individuals (particularly when there is a late diagnosis). (2YM 4) | | | |
| The strategy says... | What needs to be done? | Lead responsibility | Timescale |
| A multi-agency care pathway for assessment, diagnosis and intervention to improve the support for people with ASD and remove barriers. (GPI 6) | Review of holistic care pathways developed elsewhere | NHS AA / Ayrshire Autism Partnership | Oct 2014 |
| | Ensure pathway(s) are person-centred and recognise the multiple needs of the person with ASD. <i>(Will cover children, adults and role of multi-agency partners - inc education, criminal justice, housing, employability...)</i> | | Oct 2014 |
| | Awareness raising and training on pathway across relevant service areas <i>(including training on recognising signs of ASD for 'named person', health and other agency staff)</i> | | Oct 2014 and ongoing |
| | Build capacity across services to provide post-diagnostic support – counselling and training available for people with ASD and families following diagnosis | | Oct 2014 and ongoing |

| People with autism, their families and carers understand the condition and are well supported. | | | |
|--|--|-----------------------------|----------------------|
| The strategy says... | What needs to be done? | Lead responsibility | Timescale |
| A process for ensuring a means of easy access to useful and practical information about ASD, and local action, for stakeholders to improve communication. (GPI 3) | Support the ongoing development of information and advice services in Ayrshire | Ayrshire Autism Partnership | Dec 2013 and ongoing |
| | Ensure information and advice is widely accessible across Ayrshire (websites, community portals, service directories) | | |
| | People with ASD and families are able to support each other through social activities, email, telephone, social media. | | |

The wider community and mainstream service providers fully support those with autism because they know and understand the condition.

Related national milestones:

- Access to mainstream services where these are appropriate to meet individual needs. (2YM 1)
- Access to services which understand and are able to meet the needs of people specifically related to their autism. (2YM 2)

| The strategy says... | What needs to be done? | Lead responsibility | Timescale |
|--|---|-----------------------------------|--------------------------|
| Access to training and development to inform staff and improve the understanding amongst professionals about ASD. (GPI 2) | Provide awareness training for all staff dealing with the public across statutory services - including the 3 councils, NHS, criminal justice services and others (and including commissioned services). | Ayrshire Autism Partnership | October 2014 and ongoing |
| | Agree service areas where ASD training is mandatory (e.g. primary healthcare providers; teachers / classroom assistants; pre-school providers; social work...) | | |
| | Support training / awareness raising for local businesses and organisations | | |
| | Regular public awareness events will be delivered across Ayrshire | | |
| | Develop stronger links with employers to increase employment opportunities | | |
| 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. (GPI 4) | Shared ASD training plan to be developed in conjunction with Community Planning Partners. | Ayrshire Autism Partnership / CPP | October 2014 |

Everyone with autism is supported to make full use of the opportunities and services available to meet their needs

Related national milestones:

- Access to integrated service provision across the lifespan to address the multi-dimensional aspects of autism. (5YM 1)
- Access to appropriate transition planning across the lifespan. (5YM 2)
- Capacity and awareness-building in mainstream services to ensure people are met with recognition and understanding of autism.(5YM 4)
- Creative and collaborative use of service budgets to meet individual need (irrespective of what the entry route to the system is). (10YM 2)
- Access to appropriate assessment of needs throughout life. (10YM 3)
- Access to consistent levels of appropriate support across the lifespan including into older age. (10YM 4)

| The strategy says... | What needs to be done? | Lead responsibility | Timescale |
|--|--|-----------------------------|--------------------------|
| Services that can demonstrate that service delivery is multi-agency in focus and coordinated effectively to target meeting the needs of people with ASD. (GPI 8) | Ayrshire Autism Partnership, as a multi-agency partnership, will monitor needs and scrutinise service planning | Ayrshire Autism Partnership | March 14 and ongoing |
| | Integrated service plans are developed which reflect the needs of people with ASD. | | |
| | Regular communication with people with ASD and carers (through the Partnership and planned engagement) to identify gaps and issues with service delivery | | |
| | Deliver outcome-focused / goal-based planning for people with ASD and support the uptake of Self-directed Support | | |
| Clear multi-agency procedures and plans which are in place to support individuals through major transitions at each important life-stage. (GPI 9) | Ensure multi-agency transition plans and protocols are in place for key life-stages | Ayrshire Autism Partnership | October 2014 and ongoing |
| | Ensure transition pathways are person-centred and respond to the needs of people with ASD | | |

Appendix – Consultation response

This short summary report highlights the main points from the response to the online survey for the draft Delivery Plan. In October 2013, a Survey Monkey survey (and paper questionnaire) was circulated to local support organisations and service providers to accompany the draft plan.

Response

Who responded to the survey?

| | | |
|---|----|-----|
| Person with autism | 2 | 6% |
| A parent / carer of a person with autism | 14 | 42% |
| Other family member of a person with autism | 0 | - |
| Support provider (voluntary / community and statutory sector providers) | 17 | 52% |

Vision and priority outcomes

Do you agree with our vision?

| | | |
|-----|----|-------|
| Yes | 28 | 87.5% |
| No | 4 | 12.5% |

Do you agree with our 5 priority outcomes?

| | | |
|-----|----|-----|
| Yes | 29 | 91% |
| No | 3 | 9% |

Sample comments in relation to vision and priority outcomes

Respondents were asked for views on the proposed Vision and Outcomes and for any changes they would like seen:

- A diagnosis of an ASD to be made within a reasonable timescale
- Yes, these are good aims to have as far as they go. They do not go far enough [...] While it is excellent that the "wider community" should be made aware of autism, a priority must be the early identification of autism and rigorous training of GPs and Health Visitors in spotting the early warning signs of Autism. With respect to point (2), the words "timely" should be inserted, and a clear commitment made to the promotion of early identification, diagnoses, and intervention.
- Get a diagnosis quickly, stress-free (for the person on the spectrum and the family involved) and ensure future help if needed no matter what the person's age.
- Greater emphasis on services / facilities for adults with autism.
- Adults with autism should have access to expert advice and support from health professionals.
- Rather than just saying (3) that people with autism, siblings and carers should feel supported, I think your vision should prioritise putting in place methods to support each of these groups, and for them to be able to support themselves, exchanging local information and emotional support.

Priority Outcomes 2 and 3 were reworded to reflect these comments

The draft Delivery Plan

Do you agree with the actions set out in the draft delivery plan?

| | | |
|-----|----|-----|
| Yes | 26 | 84% |
| No | 5 | 16% |

Sample comments in relation to the actions set out in the plan

Respondents were asked for views on the actions in the draft Delivery Plan and for any changes or additions they would like to see. Many of the comments supported the issues that are covered in the plan but considered actions at a more detailed level. Comments focused on diagnosis, training and improving engagement with service users and carers.

Training

- There is a lot of emphasis on autism awareness rather than good training for professionals across the board, especially those that can have an impact on the lives of those with autism. More needs to be done regarding health services especially for adults.
- Focus on all aspects of someone with ASD life, i.e. access to education, health services, housing, SW. As well as stating that parents/carers / service users need support to understand ASD, there should also be mandatory training of health professionals that come into contact with those with ASD.
- Mandatory autism training for social work staff.

Engagement

- I think the creation and maintenance of various local face-to-face support groups for people on the spectrum, siblings and carers, should be an explicit action, rather than left to vague "social networks" etc.

Diagnosis and post-diagnostic support

- A commitment to diagnosing and accurately recording the true prevalence of ASD in Ayrshire and Arran, feeding back into local and national frameworks.
- The person with ASD to have regular contact with the diagnosis clinic even after the diagnosis.

Greater detail and practical measures

- These [actions] are not rigorous enough, and will not deliver the changes we need to see.
- Next steps would be to add more specific information about how these could be achieved.
- More practical support. Less policy and planning.
- I'm a bit sceptical about the creation of another "partnership". So much money is wasted on reporting and coordinating that could be far better spent on practical support. We, and the professionals, are drowning in paperwork. Most of this is the same thing being said over and over again in a slightly different way.

Changes were made to the draft Delivery Plan to reflect these comments as appropriate. More detailed commitments in relation to these issues will be for future discussion as decision-making structures are developed.

Future engagement

Respondents were also asked how they would like to be engaged in future and the best approach for involving service users and carers in decision-making structures (i.e. the proposed Ayrshire Autism Partnership).

How should we gather views from people with autism and their carers?

| Options | No. | % |
|---|-----|-----|
| Questionnaires | 11 | 85% |
| Interviews in-person | 10 | 77% |
| Discussion groups | 9 | 69% |
| Public meetings | 8 | 62% |
| Social media (e.g. Facebook, Twitter etc) | 7 | 54% |
| Telephone interviews | 7 | 54% |
| Website / web forum | 5 | 38% |
| Other | 5 | 38% |

The table above shows responses only from people with autism, family members and carers. The most popular options for engagement were questionnaires, face-to-face interviews, discussion groups and public meetings. There was more limited support for the use of social media and telephone interviews. The idea of web forums was the least popular option. Additional comments related to ensuring a wide range of engagement methods are used and it was suggested that engagement could take place through local autism support groups.

How should people with autism and their carers be involved in the proposed Ayrshire Autism Partnership?

| Options | No. | % |
|--|-----|-----|
| Establishment of an ASD service user / carer sub-group | 9 | 69% |
| Membership of the main Partnership group | 8 | 62% |
| Scheduled meetings with ASD service users / carers | 8 | 62% |
| Regular questionnaires / surveys | 7 | 54% |
| Web forum / social media | 4 | 31% |
| Other | 3 | 23% |

Respondents with autism, family members and carers were asked how people with autism and their carers should be involved in the proposed Ayrshire Autism Partnership. There was no clear result although establishment of an ASD service user / carer sub-group was the most popular response. There was also support for direct membership of the main Partnership group, scheduled meetings with services users and carers, and regular surveys for people with autism and carers.