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Review of Autism Network Scotland

Final Report

HEALTH AND SOCIAL CARE

social research

REVIEW OF AUTISM NETWORK SCOTLAND
FINAL REPORT

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EXECUTIVE SUMMARY

1. This report presents findings from an independent review of Autism Network Scotland. Autism Network Scotland was established in 2012 as one of the implementation vehicles of the Scottish Strategy for Autism, and is funded by the Scottish Government.

Purpose of the review

2. The Scottish Government wished to 'take stock of the role of the Autism Network Scotland and consider its achievements and impacts to date to inform future decisions on the model and funding of such a network'. The purpose of the review was therefore to inform the development of any future Autism Network Scotland (or other such strategic delivery partner), in the context of a retendering exercise which it is anticipated will take place in 2016.

Aims of the review

3. The aims of the review were to: (i) assess the impact of Autism Network Scotland to date (ii) conduct a 'light touch' health check of current governance and financial arrangements (iii) assess the strengths and weaknesses of the current model and iv) consider the future role of such a network, taking into account the needs of stakeholders and the new Scottish Government Outcomes Framework for Autism.

Scottish Strategy for Autism and establishment of Autism Network Scotland

4. The Scottish Strategy for Autism ('the strategy') – announced in November 2011 – set out an agenda for improving the lives of people with autism and their carers. The 10-year strategy was developed by the Scottish Government working in partnership with COSLA. Progress on the implementation of the strategy is overseen by a Governance Group (until May 2014, the ASD Reference Group), supported by three Working Groups.

5. Autism Network Scotland (ANS) was established in 2012 as one of the implementation vehicles for the strategy. Previous versions of the network had been in existence since 2004.

Autism Network Scotland

6. The network is hosted by the University of Strathclyde and funded by a grant from the Scottish Government. As of January 2016, the grant is equivalent to £420k per annum.

7. The current objectives for ANS are to: (i) deliver a hub of professional autism support (ii) support implementation of autism action plans across Scotland and (iii) provide support to the Scottish Strategy for Autism.

8. The activities of ANS are wide ranging and include: organising and delivering events, establishing and maintaining networks, developing the ANS website, producing newsletters and bulletins, responding to enquiries and signposting, supporting local autism strategies, and supporting the Scottish Strategy for Autism Governance Group and Working Groups.

Methodology for the review

9. A desk based documentary review was undertaken using material provided by both the Scottish Government and ANS staff. The ANS website was also included in the desk based review.

10. Face-to-face interviews were undertaken with all ANS staff and with the financial manager at the University of Strathclyde.

11. Thirty-eight (38) stakeholder interviews were conducted. This comprised 22 stakeholders who are members of the Scottish Strategy for Autism Governance Group and / or one or more of the Working Groups and 16 'wider stakeholders'. This latter group included individuals from local authorities, the NHS, academics, third sector providers and volunteers. Seventeen (17) interviews were undertaken face-to-face with the remaining 21 conducted by telephone.

12. The analysis draws mainly on the documentary review, the views of stakeholders, and the interview with the representative of the University of Strathclyde finance department; the interviews with ANS staff have been used mainly to aid understanding of the role and activities of the network.

13. The conclusions of the review (paragraphs 14-29 below) address the four aims of the review as set out above (paragraph 3).

Impacts of Autism Network Scotland

14. ANS has achieved a range of positive impacts since its inception in relation to: networking and sharing good practice; provision of information and resources; raising awareness; collaborative working; and (local authority) strategy development. There is clear evidence that the work of ANS is highly valued by professionals, especially those working in local authorities and the NHS.

15. The agenda in relation to 'promoting wider engagement of people with autism and their families in ANS work and in the decision-making process', which was identified as a key objective for ANS by Scottish Government is highly challenging. This is a 'work in progress', and ANS's achievements in relation to this objective is commended.

16. The impacts for people with autism and their families and carers are mostly achieved through indirect means. The scale of any direct impacts is unclear given the lack of specific monitoring information.

Governance and financial arrangements

17. The arrangements for the financial management of the grant to the University of Strathclyde for the hosting and running of the network are well organised and satisfactory. No problems with the arrangement were identified.

18. Since 2012, just two formal monitoring meetings between senior ANS staff and the Scottish Government have taken place. Thus, there has been limited opportunity for discussion of potential strategic developments in relation to ANS. This is a deficit in relation to the governance of the network.

Strengths and weaknesses of the model

19. The main strengths of the current model for Autism Network Scotland which were identified are i) the (Scotland-wide) overview of autism practice and strategy development and ii) the independence of ANS.

20. The Scotland-wide overview was highly valued, and was seen to be a unique feature of the current model. The network was credited with providing a bridge between the national and the local landscape, and with joining up the many and varied activities across Scotland. The benefits for professionals, at whom the activities of the network are most obviously directed, were clearly apparent.

21. The independence of the network was very important to stakeholders, especially those from the public sector, who emphasised the particular benefits of the network not having a commercial role in service provision; however there were also concerns expressed about possible compromise to the network's independence either because of a (potential) new role in service delivery or because of its role as the 'voice' of the Scottish Government in relation to the strategy.

22. The main weaknesses of the current model which were identified are i) the lack of clarity about the remit of ANS and its relationship to the Scottish Strategy for Autism, the Governance Group and the Scottish Government and ii) the insufficient delineation of leadership roles.

23. These weaknesses have led to negative stakeholder perceptions about the governance of the network.

24. Other aspects of the model, in particular i) its hosting arrangements, and ii) its focus on professionals and autism practice are seen as both a strength and a weakness.

Future role of a network (or other delivery mechanism)

25. Achievement of the strategic outcomes identified by the Scottish Government will require a network – or some other organisation - which can provide an overview across Scotland in relation to: effective networking and the sharing of good practice; the provision of high quality information and resources; and awareness raising activities (both within services but also more widely for the general public).

26. There is no unique set of organisational and governance arrangements for delivering these functions; a network based largely on the current model is one possible approach, but other approaches (for example the model used within learning disabilities, or that used within the co-production context) are also possible.

27. Whichever model is pursued, there is a requirement for clarity of the remit, and clarity of the relationship to both the Scottish Strategy for Autism and to the Scottish Government. This clarification would require the specification of key performance indicators which could be used to monitor and measure progress. There is also a requirement for a clear governance structure. This would include a regular forum where strategic issues and developments could be discussed, and a clear delineation of leadership roles. Given the importance stakeholders placed on the quality of independence, an articulation of how independence could be achieved would need to be carefully considered and clarified by Scottish Government.

Definition and measurement of outcomes

28. The development of a clear understanding of the inputs, activities, outputs and (short, medium and long term) outcomes of ANS (or any other national autism network / organisation) is required.

Overall conclusion

29. Autism Network Scotland has achieved a range of positive impacts to date, based on a wide range of activities including networking and sharing good practice, providing information and resources, and raising awareness. The achievement of the strategic outcomes identified by the Scottish Government requires these activities to continue. There is no unique set of organisational and governance arrangements for delivering these functions. However, whichever model is pursued, there is a requirement for clarity of the remit and a clear governance structure as well as transparent performance outcome measures.

1 INTRODUCTION

1.1 This report presents the findings from the review of Autism Network Scotland.

Aims of the review

1.2 In November 2015, the Scottish Government commissioned Jennifer Waterton Consultancy to undertake a review of the Autism Network Scotland (ANS).[1] ANS was established in 2012 as one of the implementation vehicles of the Scottish Strategy for Autism[2], and is funded by the Scottish Government.

1.3 In the Invitation to Tender, the Scottish Government set out its requirement to 'take stock of the role of the ANS and consider its achievements and impacts to date to inform future decisions on the model and funding of such a network'. The purpose of the review was therefore to inform the development of any future ANS (or other such strategic delivery partner), in the context of a retendering exercise which it is anticipated will take place in 2016.

1.4 The aims of the review were to: (i) assess the impact of ANS to date (ii) conduct a 'light touch' health check of current governance and financial arrangements (iii) assess the strengths and weaknesses of the current model and iv) consider the future role of such a network, taking into account the needs of stakeholders and the new Scottish Government Outcomes Framework for Autism.

1.5 The objectives for the review were therefore both retrospective (relating to the role of ANS to date) and prospective (in relation to the development of a future network).

Structure of the report

1.6 The structure of the remainder of the report is as follows:

Chapter 2: Background and context
Chapter 3: Autism Network Scotland
Chapter 4: Approach and methods
Chapter 5: Findings
Chapter 6: Defining and measuring outcomes
Chapter 7: Conclusions

[1] http://www.autismnetworkscotland.org.uk/

[2] http://www.autismstrategyscotland.org.uk/

1.7 Annexes to the report present details of the activities of ANS (Annex 1), details of the coverage of the documentary review and interviews (Annex 2) and a list of all stakeholders who contributed to the report (Annex 3).

2 BACKGROUND AND CONTEXT

2.1 The main background and context for the review relates to the Scottish Strategy for Autism, and the arrangements for its implementation, as set out below.

Scottish Strategy for Autism

2.2 The Scottish Strategy for Autism ('the strategy') – announced in November 2011 – set out an agenda for improving the lives of people with autism and their carers. The 10-year strategy was developed by the Scottish Government working in partnership with COSLA. The strategy set out goals in relation to a range of areas including: the development of local autism strategies and plans; the improvement of data collection to inform service planning; the creation of multi-agency care pathways for assessment, diagnosis and intervention; the embedding of processes to seek stakeholder feedback on the quality of care; specialised support for life transitions including into employment; and the removal of barriers for people with autism.

2.3 Progress on the implementation of the strategy is overseen by a Governance Group (until May 2014, the ASD Reference Group). The Governance Group oversees the delivery of the strategy's priorities and (26) recommendations, and provides a structure for governance and accountability. The Governance Group consists of service users, carers, local and central government representatives, voluntary organisations, NHS staff, and academics.

2.4 The Governance Group is supported by three[3] Working Groups which focus on the (four) strategic outcomes identified as priorities for 2015-2017.[4]

Establishment of Autism Network Scotland

2.5 Recommendation 15 of the Scottish Strategy for Autism stated that, 'It is recommended that existing reports on the work of Scottish Autism Services Network are formally evaluated with a view to assessing its long-term viability and effectiveness'. This recommendation was linked to three others (Recommendations 16, 17, and 18) which addressed a theme in the strategy about developing the capacity for cross-agency working through stronger networks, best practice and training which would bring about cost effective support and interventions.

[3] Until May 2014 there were six subgroups. From June 2014 - October 2015 there were four Working Groups. The members of Working Group 3 (Good Practice) are currently transferring to one of the other groups.

[4] See the approved minutes from 24th August 2015 in: http://www.autismstrategyscotland.org.uk/working-groups/working-group-1.html

2.6 In recognition of this recommendation, Autism Network Scotland (ANS) was established in 2012 as one of the implementation vehicles for the strategy. Previous versions of the network had been in existence since 2004.[5]

[5] Autism Network Scotland replaced the previous autism network – the Scottish Autism Services Network (SASN).

3 AUTISM NETWORK SCOTLAND

3.1 This chapter describes the organisational arrangements, the objectives, and the activities of Autism Network Scotland.

Current hosting, staffing and financial arrangements

3.2 The network is hosted by the University of Strathclyde (within the School of Education) and funded by a grant from the Scottish Government. As of January 2016 it has eight members of staff: a lead coordinator,[6] a network coordinator, a project manager, three advisers, and two administrative / communications staff. As of January 2016, the amount of the Scottish Government grant is equivalent to £420k per annum. [7,8]

Objectives for Autism Network Scotland 2012-2014

3.3 From 2012-2014 the main objectives (also referred to in grant award letters as 'expected outcomes') for ANS as set out in the Scottish Government grant award letters were to:

- develop ANS to deliver outcomes for professionals, individuals with autism, their families and carers
- provide an information hub on autism
- support networks and deliver good practice events.

Objectives for Autism Network Scotland 2014-present

3.4 In 2014, when the governance arrangements for the Scottish Strategy for Autism were refreshed and restructured, the objectives of ANS were extended. The current set of main objectives ('expected outcomes') for ANS as set out in the most recent Scottish Government grant award letter (October 2015) are to:

- deliver a hub of professional autism support including information, signposting, networks, best practice and communication
- support implementation of autism action plans across Scotland through the National Coordination Project
- provide support to the Scottish Strategy for Autism ('the expanded role').[9]

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[6] This is a part-time (3 days per week) post.

[7] Additional resources are also provided separately to fund the ANS annual conference.

[8] The ANS grant does not include a specific allocation for website / IT development. However, the overhead payment to the University covers IT services as described in paragraph 5.54 below.

[9] Note that the National Coordination Project is part of the 'expanded' role.

3.5 The expanded role in relation to the Scottish Strategy for Autism (as set out in the grant funding letter of October 2015) covers:

- provision of a complete secretariat service to the Governance, Working, Communication / consultation, and Ad Hoc Expert Groups and those people who have requested to receive 'info only'
- facilitation of the above mentioned meetings
- engagement of people with autism and their families in the decision making process and the work of groups through dissemination of information, events, forums etc.
- develop and manage the Scottish Strategy for Autism website
- organise and deliver events to take forward the working group outputs
- ANS members to sit on the working groups and
- provide support (including communications function) to the Autism Coordination team.[10]

3.6 The aims of ANS as described on their website reflect the objectives as set out by the Scottish Government. ANS in its own words aims to:

- be a hub of impartial and reliable information about autism services across Scotland
- identify gaps in service delivery and information to people with autism and their families and carers
- signpost professionals, people with autism and their families and carers, to the range of services available at both a local and national level
- facilitate professional networks across Scotland to support knowledge exchange and promote awareness of autism
- provide a platform to discuss current research and share good practice in the field of autism
- develop networking opportunities for people with autism
- support better communication between people with autism and local and central government and

[10] Note that the definition of the 'expanded role' / 'extended role' was initially set out in the grant funding letter of March 2014. The definition at that stage was different and covered: i) administration of the meetings and papers for the National Autism Strategy Monitoring Group ii) professional support and parent and user participation iii) professionally support the consultation forum with users and families to feed into strategy decisions and work iv) the delivery of local and national events in relation to the strategy and subgroup activity v) maintaining the Scottish Strategy for Autism website vi) The delivery of events and activity to disseminate and implement the Menu of Interventions in partnership with Subgroup 3 vii) The delivery of events and activity to disseminate and implement the principles of good transitions guidance with Association for Real Change and Subgroup 2 and viii) the delivery of National Coordination Lead post and support activity.

- support the autism strategy through membership of the strategy subgroups and information sharing.

Activities of Autism Network Scotland

3.7 The activities of ANS are wide ranging and cover:

- organising and delivering conferences, roadshows, meetings and events
- establishing and maintaining networks
- supporting and developing the ANS website
- producing newsletters and events bulletins
- enquiries and signposting
- supporting the development of local autism strategies and plans and
- supporting the work of the Scottish Strategy for Autism Governance Group.

3.8 Further details of each of these activities are set out in Annex 1.

4 METHODS AND APPROACH

4.1 This chapter describes the methodology for the review, including both the data collection and the approach to the analysis.

4.2 There are three distinct elements to the data collection which have been undertaken for the review as follows: i) a (desk based) documentary review ii) interviews with ANS and University of Strathclyde staff and iii) stakeholder interviews. Each of these is described briefly below. Further details of the documentary review, together with the topics covered in the interviews are set out in Annex 2.

Documentary review

4.3 A desk based documentary review was undertaken using material provided by both the Scottish Government and ANS staff. (See Annex 2 for details.)

4.4 The ANS website was also examined to ascertain i) what materials and resources were available there and ii) how the website was organised.

Interviews with Autism Network Scotland and University of Strathclyde staff

4.5 The following interviews were conducted with ANS and University of Strathclyde staff:

- Individual interviews with senior ANS staff (the National Autism Lead Co-ordinator, the Autism Network Scotland Co-ordinator and the National Autism Project Manager)
- A group interview with the (3) ANS advisers
- Individual interview with the ANS communications officer (the other administrative officer left her post in December 2015)
- Individual interview with the Research and Knowledge Exchange Support (RaKET) Team Manager with responsibility for the financial management of the Autism Network Scotland project grant at University of Strathclyde.

4.6 In addition, the Project Development Lead for SharePoint at the Centre for excellence for looked after children in Scotland (CELCIS), University of Strathclyde provided a demonstration of the SharePoint management information system which CELCIS currently uses, and ANS is planning to adopt.

Stakeholder interviews

4.7 A total of 38 stakeholder interviews were conducted. Twenty-two (22) individuals who are members of the Governance Group and / or Working Groups were interviewed. In addition, a further 16 individuals were selected for interview. This latter group comprised: autism leads within local authorities

(8) and the NHS (1); academics (2 – both of whom hold joint appointments within the NHS); third sector service providers (3); a consultant (1); and a volunteer (1). This latter group is referred to in what follows as the group of 'wider stakeholders'.

4.8 Sixteen (16) of the Governance Group / Working Group members and one (1) wider stakeholder were interviewed face-to-face. The remaining 21 interviews were by telephone. Each face-to-face interview lasted 1-1.5 hours, whilst telephone interviews took 15-45 minutes.

4.9 The topic coverage for the interviews is set out in Annex 2. A complete list of stakeholders who participated in the review is attached at Annex 3.

Approach to analysis

4.10 The analysis of the material is presented in Chapters 5 and 6.

4.11 In Chapter 5, the analysis has been structured around the four overarching aims set out for the review (see paragraph 1.4 above) namely :

- The impact of ANS to date
- Current governance and financial arrangements
- The strengths and weaknesses of the current model
- The future role of such a network.

A section for 'other issues' has also been included to cover material which stakeholders raised but which does not fit within the four main sections.

4.12 In Chapter 6, the focus is on the defining and measuring of outcomes, with particular reference to the Scottish Strategy for Autism Outcomes Approach.

4.13 The analysis draws mainly on the documentary review, the views of stakeholders, and the interview with the representative of the University of Strathclyde finance department; the interviews with ANS staff have been used mainly to aid understanding of the role and activities of the network and are only occasionally reported on directly.

4.14 In order to preserve the confidentiality of stakeholders, the attribution of comments has been restricted to a 2-way breakdown of stakeholders into: i) Governance Group members and ii) Wider Stakeholders. As appropriate, more specific subgroups (e.g. local authorities, the NHS, third sector organisations, national autism organisations) have been referred to in the text.

5 FINDINGS

5.1 This chapter sets out the findings of the review in relation to the four aims identified in paragraph 1.4 above.

The impacts of ANS

5.2 Stakeholders identified a range of impacts for ANS in relation to: networking and sharing good practice; provision of information and resources; raising awareness; promoting wider engagement; collaborative working; (local authority) strategy development; facilitation; and other activities. These impacts are often overlapping. Each of these impacts is discussed in turn below. Within each section the positive impacts are presented first. Any critical comments are discussed at the end of each section.

5.3 Note that the ANS remit does not currently include the delivery of services to people with autism and their families and carers. Any impacts on people with autism and their carers are therefore indirect, and the result of its remit for information provision, organising good practice and other events, collaborative working, contribution to local strategy development, and its facilitation role in relation to the Scottish Strategy for Autism.

Networking and sharing good practice

5.4 Stakeholders from all sectors emphasised the key role ANS played in providing opportunities for networking and for sharing good practice. This was seen to be of vital importance in developing knowledge and understanding of autism practice across a wide range of disciplines and sectors.

> ANS are aware of what is going on across Scotland. They make connections and join things up. (Governance Group / Working Groups)
>
> ANS facilitate sharing across the health and education fields; they lead those involved in education further in an evidence based practice direction. (Wider Stakeholder)

5.5 Stakeholders highlighted the networking that took place at events, conferences, and within local or subject-specific sub-networks (for example the Borders network, SWAN, the employment network). Even in cases where stakeholders did not find the content of an event or conference particularly relevant or useful, they still placed a high value on the networking opportunities that attendance provided.

5.6 Particular mention was made of the National Coordination Project's Lead Officers Collaborative meetings / events which were highly valued in the context of the development of local autism strategies.

> I have found the Collaborative Lead Officers events and the ANS conferences extremely valuable networking opportunities. The support I get there is invaluable. (Governance Group / Working Groups)

5.7 Stakeholders also discussed the usefulness of ANS's networks in other ways. For example, it was noted that because ANS had access to a wide variety of networks, it was able to respond quickly to queries about the stage of development of autism practice in relation to a wide range of contexts (e.g. palliative care, nursery education). Moreover, ANS had been able to use its networks to ensure that there was good attendance at collaborative events (e.g. the Digging Deeper roadshows and the meetings around the NES Training Framework).

5.8 There were also criticisms and concerns raised in relation to the networking events and the sharing of good practice. Two particular issues were raised as follows:

- It was not clear how the selection of people to do presentations at, for example, annual conferences or other events is made. Stakeholders suggested that good examples of autism practice have not been recognised or given an appropriate platform within ANS events.
- Invitations to the Listening to the Community Event held in Perth in May 2015 were not thought to have included the appropriate people. (Note, however, that this was in the context of an overall positive evaluation of this event, as evidenced by the evaluation forms and social media feedback after the event.)

Provision of information and resources

5.9 The role of the network as an 'impartial hub of information' was established in 2004 and is the part of ANS's role which stakeholders are most familiar with. This part of the network's activity, which includes the ANS website, its role in signposting, the newsletters and information about events, had impacts particularly for professionals working within the NHS or local authorities.

5.10 NHS professionals in particular used ANS resources in relation to their daily work. They highlighted the website as a good place to post and view up-to-date research and exchanges as well as a resource to find local information about services in Scotland. The website had credibility with NHS professionals some of whom regularly directed their patients to visit the website.

> I direct patients to ANS and the website. It fulfils an invaluable role as an impartial source of knowledge and information, and signposts to services. (Wider Stakeholder)

5.11 Local authority professionals also made use of the information resources, especially the website which they found very useful for finding out about events as well as for getting access to presentations, reports and other

materials. This was particularly valuable if they were not able to attend a particular event in person.

> The ANS website is good. The information there is super. The links from the website are good. Get a real sense that this is well organised – we need this kind of information resource for things other than autism! (Wider Stakeholder)

5.12 In addition, the network receives enquiries about autism and autism services in Scotland from, amongst others, people with autism, and their family members and carers. In 2015, 220 enquiries were received although it is not known how many of these were from professionals, and how many from people with autism / family members and carers. According to the most recent ANS Progress Report 'often we are contacted by people who have been unable to find support and direction elsewhere'. When an enquiry is received the individual is provided with relevant information about local and national services and resources.

5.13 There was also criticism of the information resources, especially of the ANS website. This was variously described as 'having a poor interface', 'not very accessible', 'a bit flat', 'clunky', and 'not very well laid out'. The links to the videos from the SWAN network 'still don't work'. Moreover one stakeholder believed that the ANS website was 'not the right location for an Autism Practice hub'. This stakeholder suggested it would be better to host the information on the Public Sector Improvement Framework Knowledge Hub, which is the resource used by local authorities. Other stakeholders said that if they wanted to access information about events they used the National Autistic Society website, not the ANS website.

5.14 Stakeholder criticisms of the design, layout and content of the ANS website chimed with the assessment made as part of the documentary review. This found that the website was difficult to navigate, and its coverage was not comprehensive. For example:

- Reports of conferences and events are not available on a systematic and comprehensive basis
- The 'style' is not consistent across different content
- The calendar of events is not easy to navigate
- The availability / non-availability of content according to ANS membership status seems unhelpful. Why is some content restricted to members?
- The selection of documents hosted on the website seems partial, and not well organised.

5.15 Comments about the part of the ANS website which link to the Governance Group and the Scottish Strategy for Autism are discussed in paragraphs 5.40-5.41 below.

5.16 Finally, there was also criticism from a few stakeholders that the information resources available from ANS duplicated that from other sources. This is discussed in more detail in paragraph 5.77 below.

Raising awareness

5.17 Stakeholders commented positively on the extent to which ANS had helped to raise awareness of autism, both within health and social care and education, but also more widely with the general public. It was thought that this was part of a 'long journey' which was required to build a world where people with autism would be fully valued and integrated.

5.18 For example, ANS take the NHS Education for Scotland Training Framework materials to all their events, which stakeholders said helped to raise awareness about what training was available. ANS also runs (or helps to run) drop in sessions and awareness raising events in a variety of locations.

Promoting wider engagement of people with autism and their families in ANS work and in the decision-making process

5.19 In its relaunched form, ANS has been given a role to involve people with autism and their families in their work and in the decision making process. Stakeholders from all sectors recognised that this was an extremely challenging agenda, and that it required a great deal of skill, sensitivity and resource to deliver.

5.20 A range of stakeholders provided positive comment in relation to ANS's achievement of this objective, and highlighted the extent to which they had begun to make wider engagement 'par for the course'. For example:

> ANS do this well. It is not tokenistic. A good range of autistic people are involved. (Governance Group / Working Groups)

5.21 However, there was also comment that ANS relied too heavily on a few individuals, and they had not been successful in promoting wider engagement of people with autism and their families in their work and the decision making process. For example:

> ANS doesn't seem to be bringing new people into the community. The people with autism who are involved have been involved for a long time. (Governance Group / Working Groups)
>
> There should be more involvement of people with autism and their parents and carers with the network. (Governance Group / Working Groups)

5.22 The views of those with a direct connection to people with autism, their parents and carers were mixed. For example:

> The dissemination of information to the wider autism community has been less successful…. It is a learning curve. They are going in the right direction. (Governance Group / Working Groups)

5.23 The Scottish Women's Autism Network (SWAN) was mentioned frequently in the context of a network which was engaging with people (women) with autism. Strong affirmation of the relevance of SWAN to parents and carers was expressed. However, there were also some more cautious and occasionally negative comments.

> There is an 'ownership issue' in relation to SWAN. ANS do not have the skills to run SWAN themselves, but they want to have ownership of it and to take the credit for it. …. The two recent learning events have been great though. The facilitation / admin support by ANS was fantastic. (Wider Stakeholder)

5.24 This mixed picture is consistent with the documentary review which found both evidence of effort and some success in relation to the wider engagement agenda, as well as an over-reliance on a few key individuals.

5.25 Finally, two stakeholders made comments about the importance of paying volunteers (people with autism, family members and carers) who contribute to the work of ANS for their time. They were not clear if this was currently the case.

Collaborative working

5.26 ANS works in collaboration with a range of organisations and partners in delivering its remit. Stakeholders highlighted some key impacts ANS had achieved through these collaborations. The collaborations which were seen as the most valuable and successful were: the role ANS had played in the dissemination and rollout of the NHS Education for Scotland Training Framework and Training Plan; the 'Transitions' roadshows with ARC Scotland; the Borders and employment networks; and the collaboration with local authorities through the National Coordination Project (discussed in paragraphs 5.32-5.37 below).

5.27 There was widespread praise for the collaboration with NHS Education for Scotland on the dissemination of the NES Training Framework and Training Plan. NHS Education for Scotland itself was clear that the network's input to the launch and rollout of the Training Framework and Training Plan were crucial and other stakeholders provided a range of positive perspectives. For example:

> It was great to see that everything recommended by the wider engagement group was taken on board by ANS and NES in relation to the Training Framework (Governance Group / Working Groups)

5.28 Two stakeholders were rather more critical about the work with NES, although it was not clear whether the criticisms were directed at ANS. One suggested that an updated training framework within education would be helpful, whilst the other thought the content of the meeting was lacking.

> The meeting to discuss the NES Training Framework wasn't very useful. I thought it would be about the pitfalls of implementation. I didn't learn anything. (Governance Group / Working Groups)

5.29 The collaboration with ARC Scotland in relation to the 'Transitions' roadshows was also thought to be positive, although it was thought the report which was produced would have benefitted from a more analytical approach.

> The organising of the roadshows for the Digging Deeper report was a success. ANS performed their role well. The weakness was in the follow through. The report written by ANS was useful, but more analysis / synthesis would have been useful. (Governance Group / Working Groups)

5.30 The (local) Borders network, and the role of ANS in chairing and facilitating this network was valued within the locality. Because of the expertise of ANS staff, impacts on local people, their families and carers had been achieved.

> [Name] keeps us up-to-date with information and developments elsewhere in Scotland. [Name] has negotiated autism friendly cinema sessions and swimming access, run drop in sessions and awareness raising events. (Wider Stakeholder)

5.31 A range of stakeholders commented positively on the meetings for the Research Series led by Strathclyde University, organised in collaboration with (four) Scottish Universities and Scottish Autism, and facilitated by ANS, which took place in 2014. It was thought these meetings had provided an excellent overview of the current research effort in autism. However, these comments were often tempered with disappointment that the report of the research series had not yet been made available by Strathclyde University.[11]

[11] Note that the grant for the Research Series is held by Strathclyde University, which has responsibility for progressing the project.

Local authority strategy development (through the National Coordination Project)

5.32 There was widespread support for the role that ANS had been given in relation to local authority strategy development. Both the local authorities themselves, and stakeholders more generally thought that this was an important and valuable role.

5.33 The way that ANS has interacted with individual authorities varied widely. In some cases the relationship was quite close, and there had been a substantial amount of contact over a sustained period; in other cases contact was of a more limited, although still valuable, nature. In just one case the local authority stakeholder reported that ANS had had 'no discernible impact' on the development of the local plans.

5.34 There was particular support for the lead officer collaborative meetings, which were thought to be very worthwhile in sharing ideas and good practice, and which had provided a good forum for 'grappling with difficult issues together'.

5.35 Lead officers also commented positively on the willingness of network staff to work flexibly with them at a local level to do whatever was required in helping them to develop and improve their plans. For example:

> We took a very different approach to developing our local strategy. [Names] were really good at encouraging us and supporting us, and were very flexible. (Wider Stakeholder)
>
> ANS input has moved recently from discussion around national issues to something more locally relevant. We have found that very valuable. (Wider Stakeholder)

5.36 Other contributions which ANS had made locally and which were valued by stakeholders included: support for helping partners locally with their engagement with people with autism; providing feedback on draft plans including comments on up-to-date terminology; making links between national and local policy; assistance with running local events; giving advice and support based on wide experience and a Scotland-wide perspective; publishing draft strategies (which put pressure on senior managers to progress the development of plans) and keeping local authority leads 'on task'; and building local officers' confidence to continue to argue locally for improvements.

5.37 Stakeholders often commented on how their efforts in relation to autism fitted within the wider context of health and social care integration. For some stakeholders, the focus on autism was seen to be disproportionate; these stakeholders emphasised that 'autism is just one interest among many', and thought that it needed to be considered always within this broader context. For others, the focus (and indeed the pressure) to 'get things right' in relation to

autism was helpful; these stakeholders took the view that if they were able to 'get thing right' in relation to autism, then the other areas for which they had responsibility would also benefit.

Facilitation of Governance Group and Working Group Meetings

5.38 Stakeholders were aware that ANS was involved in Governance Group and Working Group meetings. There was substantial discussion and comment around the role of the ANS Lead Coordinator in chairing the Governance Group, and this is discussed in the section on strengths and weaknesses of the current model (paragraphs 5.74-5.76) below.

5.39 The administration role in convening meetings and taking minutes was thought to be valuable and to be done well on the whole.

5.40 However, there was criticism of the presentation of material about the Governance Group and Working Group meetings on the ANS website. Stakeholders thought that the 'Scottish Strategy for Autism' part of the website was not well integrated into the ANS website, and one stakeholder commented that the material relating to membership of the Governance Group and Working Groups was out-of-date.

5.41 This criticism was supported by the documentary review which found that the material from the Governance Group and Working Group meetings was not well integrated into the main ANS website.

Other activities

5.42 In May 2015, Celtic FC Foundation invited ANS to develop a programme which would support young people with autism and their families and carers in Glasgow. ANS's role covered: i) training for the coaches on autism and ii) training for the parents and carers. This work is currently at a pilot stage. This development appears to move ANS into the territory of 'direct service provision' (with external funding provided), which has not historically been part of its remit. Two stakeholders who knew about this development queried whether it was appropriate.

Current governance and financial arrangements for Autism Network Scotland

5.43 Autism Network Scotland is hosted within the School of Education at the University of Strathclyde. ANS has eight members of staff, all of whom are employees of the University of Strathclyde. Management of ANS staff is undertaken in accordance with University of Strathclyde HR procedures.[12]

[12] The Head of the School of Education at the University of Strathclyde provides line management for the ANS Lead Coordinator. The ANS Lead Coordinator provides line management for the National ANS Coordinator and for the National Autism Project Manager. The National ANS Coordinator provides line management for the ANS advisers and administrative staff.

Current governance arrangements for Autism Network Scotland

5.44 The grant award letters from the Scottish Government to the University of Strathclyde set out the governance arrangements for the network. The grant award letters state that the activities of ANS will be monitored by 'quarterly progress updates and an annual report on outcomes'.[13] These grant award letters also specify that the quarterly update reports should 'include actual expenditure to date compared with profiled expenditure and any change to estimated expenditure for the financial year and / or the Project as a whole, the reasons for any such changes and progress in achieving objectives / outcomes.' No specific outcomes or key performance indicators are set out in the grant award letters.

5.45 Progress reports were produced in: October 2012 (Interim Report 1), March 2013 (Interim Report 2), November 2013 (Quarterly Report), June 2013 (Annual Report 1), March 2014 (Quarterly Report), July 2014 (Interim Report), October 2014 (Interim Report), March 2015 (Progress Report) and December 2015 (Progress Report). In addition, reports on the National Coordination Project and on the facilitation of Working Groups have been considered at the Scottish Strategy on Autism Governance Group meetings (in March 2015, June 2015, October 2015, and February 2016).

5.46 The format of the progress reports has evolved over time. Earlier reports (2012-2014) used a newsletter-type format, with a descriptive account of ANS activities and developments covering a wide range of topics / items.[14] More recent reports (2015) have addressed the three elements of the network's role (core activities, national coordination project, extended role in support of the Scottish Strategy for Autism) in a more succinct way and have attempted to draw out impacts and outcomes more explicitly.

5.47 Another aspect of the governance of ANS is set out in the University of Strathclyde document 'The Workplan Agreement – our contribution to the Scottish Strategy for Autism' (2014). This document sets out how Strathclyde University will deliver the outcomes relating to the implementation of key aspects of the Scottish Strategy for Autism.

5.48 As set out in the workplan agreement, the Executive for the Project will consist of senior representatives of the Scottish Government, senior representatives of Autism Network Scotland, and the 'wider leadership of the School of

[13] Note that the initial grant award letter (covering the financial year 2012/2013) specifically said the monitoring arrangements for the work of ANS were to be achieved through 'quarterly monitoring meetings'.

[14] For example, the July 2014 report contained sections on: learning events, event feedback, face-to-face networks, regional networks, virtual networks, Action on Autism Research Seminars, Partnership working, Project SEARCH, and Newsletters.

Education within Strathclyde University'. The document states that the Executive will meet on three occasions in total. The document also describes 'the Project team' (separate to the Executive for the Project) which consists of representatives of the Scottish Government and Autism Network Scotland. The document states that the Project team will meet bi-monthly to review progress and will 'include a regular formal monitoring component by the Scottish Government to ensure that the Project delivers quality outcomes timeously in relation to available spend'.

5.49 Formal monitoring meetings have not followed the schedule as set out in the workplan agreement. To date there have been two formal monitoring meetings between senior ANS staff and the Scottish Government (in January 2015, to discuss the October 2014 Progress Report and in May 2015 to discuss the March 2015 Progress Report). There are no minutes available from either of these meetings.

Stakeholder views on governance arrangements for Autism Network Scotland

5.50 Stakeholders commented negatively on the governance arrangements for ANS, in relation to: who provided oversight for the network; what the network's powers to hold others to account were; and the hosting arrangement. The issues around the hosting arrangement are discussed below in relation to the strengths and weaknesses of the current model (paragraphs 5.64-5.65, 5.78).

5.51 Previously, a wider range of organisations had been involved in the governance of the network; when ANS was given its 'extended role' in relation to the Scottish Strategy for Autism (in 2014) the governance arrangements for the network changed and some organisations were no longer given a 'seat at the table'. This had caused some concern. There were also more general concerns expressed about the (lack of) oversight of ANS's activities.

> I am not clear about the governance arrangements for the network. Previously, it was clear that the network belonged to the 'Scottish Autism Community' but that is no longer the case. Where are the Key Performance Indicators? Who sets these? Who measures them? (Governance Group / Working Groups)

> Where is oversight for network? The oversight of the network should be with the [Scottish Strategy for Autism] Governance Group. We have not been told what their contractual role is. (Governance Group / Working Groups)

5.52 In addition, stakeholders raised wider questions in relation to the governance arrangements for the Scottish Strategy for Autism (which stakeholders were often not able to separate out from the governance arrangements for ANS). These wider comments are discussed below (paragraphs 5.89-5.91).

Financial arrangements for Autism Network Scotland

5.53 As far as financial governance is concerned, the University of Strathclyde Finance Department provides oversight and documentation of the income and expenditure of the network according to the policies and procedures which operate on a University-wide basis.

5.54 The financial management of the grant is relatively straightforward. The grant pays for the salaries of ANS staff, and some consumables (mainly relating to travel costs, events and event management). There is also an overhead payment to the University (25% of salaries) to cover corporate services (HR, IT[15], Finance[16], and accommodation costs[17]). Additional funds were made available through a separate grant for the ANS annual conference in December 2015.[18]

5.55 Each time a grant award is made, a costing is done to ensure that the amount in the award letter matches the amount being spent through the grant. The budgeting and payment system is available in 'live time' to senior ANS staff, so that ongoing day-to-day monitoring of grant expenditure, including virement between budget subheads can be achieved.

Strengths and weaknesses of the current model

5.56 The strengths (paragraphs 5.57-5.66) and weaknesses (paragraphs 5.67-5.82) of the current model are set out below. For the purposes of this section 'the current model' is taken to be the organisational arrangements for the network, including: i) the wider context within which the network operates ii) the network's role and purpose iii) the network's relationships to other relevant organisations and iv) the leadership of the network. This part of the analysis is at a more strategic level than the analysis of impacts discussed earlier in the chapter; however there is some overlap in the material presented.

Strengths of the current model

5.57 The main strengths of the current model for Autism Network Scotland which have been identified are: the (Scotland-wide) overview of autism practice and strategy development; the independence of ANS; the leadership; the hosting

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[15] The IT component covers all equipment costs, and also the resource which was made available in redesigning the ANS website when the network was relaunched in 2012.

[16] The Finance component includes access to financial expertise for ANS related projects (e.g. for the SWAN Network application for funds to create an independent network through the development fund).

[17] The accommodation costs also include access to University space for learning events and meetings.

[18] An additional £10.5k was made available for this purpose.

arrangements; and the focus on professionals and autism practice. These are discussed in turn below.

Overview of autism practice and strategy development

5.58 The network is seen by stakeholders from all sectors to sit at the centre of autism practice and strategy development across Scotland. This position allows the network to draw on a wealth of information about activity and practice across Scotland, to make links and build bridges between local and national developments, to make connections between individuals, networks and organisations, and to facilitate the development of autism practice and strategy development. This overview provides substantial 'added value' and is seen as something unique about the network.

> The network has the potential to see beyond individual services to get an overview of good practice and what is working well. The network can direct people to what they need. (Wider Stakeholder)
>
> I think it is doing unique things. The national overview and expertise that [Names] have cannot be found elsewhere. The network is supporting local organisations. Where else would local people go for that information? (Wider Stakeholder)

5.59 The delivery of this overview function draws on all the three elements of the network's activities (information hub, national coordination project, and role in Scottish Strategy for Autism).

The independence of Autism Network Scotland

5.60 There was comment from a wide range of stakeholders about the importance of the independence and impartiality of Autism Network Scotland. This was usually raised in the context that ANS did not have a role in providing services, and so had no commercial interests in promoting one service or approach above another. (Note that the potential move into service provision described in paragraph 5.42 above may change this perception.) Comments from stakeholders also often contrasted this independence with the lack of independence of those providing services. For example:

> We particularly valued their independence and impartiality. In contrast to [Names], ANS does not offer services. This is what makes it different. It is not talking about money, or about buying or selling services. By contrast, we can find it awkward to deal with [Names]. We are not always confident / comfortable about quality of service or value. (Governance Group / Working Groups)
>
> The fact that ANS is not a provider of services is a strength. This means they are impartial. ANS provide a more comprehensive response rather than the commercial response that others provide. (Governance Group / Working Groups)

5.61 Independence was also raised in a context of independence from the Scottish Government. This is discussed further in paragraphs 5.72-5.73 below.

5.62 The comment about independence was also raised in a more general way in relation to the 'overview' role discussed above. It was thought that the network's requirement as a national organisation to listen to all views, and not take a partisan approach was a strength.

The leadership of Autism Network Scotland

5.63 There was praise and support from some stakeholders for the leadership of ANS. The lead coordinator was recognised to have wide experience of the autism field, and to understand how to influence the various organisations involved in developing both strategic and operational approaches.

Hosting arrangements

5.64 Some stakeholders viewed the hosting arrangements at Strathclyde University in a positive light. These stakeholders highlighted the status of the university, its independence, its role in research and teaching, the location and quality of the office accommodation, and the access it gave ANS to good conference and meeting facilities. In some cases there was a specific comment to the effect that this arrangement in the round offered good value for money. (See paragraph 5.78 below for comments from stakeholders who were critical of the hosting arrangements.)

5.65 ANS staff also viewed the hosting arrangements in a positive light. ANS staff thought the university provided good terms and conditions, and valued the access to high quality office, meeting and conference space, support in relation to HR, Finance and IT, and the links in relation to teaching and research.

Focus on professionals and autism practice

5.66 Stakeholders thought that ANS, because of its composition and expertise, was able to have a significant impact on professionals and on autism practice. These impacts have been described earlier, in paragraphs 5.4-5.42 above, and are not repeated here.

Weaknesses of the current model

5.67 The main weaknesses of the current model which have been identified were: lack of clarity about the remit of ANS and its relationship to the Scottish Strategy for Autism, the Governance Group and the Scottish Government; insufficient delineation of leadership roles; duplication of services / functions; the hosting arrangements; the ANS membership model; and the focus on professionals and practice. These are discussed in turn below.

Lack of clarity

5.68 There was widespread comment in relation to the lack of clarity about the remit of ANS and its relationship to the Scottish Strategy for Autism, the Governance Group and the Scottish Government.

5.69 This lack of clarity was most often associated with the network's 'extended role' (from 2014) in relation to the Scottish Strategy for Autism. Stakeholders were familiar with the 'original role' of the network (which had been reasonably constant over the period 2004-2014 and through the various iterations of the network) to 'develop ANS to deliver outcomes for professionals, individuals with autism, their families and carers; provide an information hub on autism; and support networks and deliver good practice events' (see paragraph 3.3 above). However, they were unclear about ANS's role in relation to the Scottish Strategy for Autism, including its role in relation to the Governance Group and to the Scottish Government.

5.70 The following quotes illustrate some of the ways that stakeholders described their concerns about the (lack of) clarity of the ANS remit.

> We need – and they need – more clarity about the remit. (Governance Group / Working Groups)
>
> ANS doesn't have a clear purpose. It needs a simple, straightforward remit so that the identity and purpose of the team is clear….. Is the national coordination team part of ANS? I find it confusing. (Governance Group / Working Groups)

5.71 The following quotes illustrate some of the ways that stakeholders described their concerns about the (lack of) clarity about the Governance Group and Working Group remits, and the network's position in relation to these groups as well as its position in relation to the Scottish Government.

> There is not sufficient clarity / demarcation of roles and remits, especially in relation to the division of responsibilities between ANS and the Scottish Government. (Wider Stakeholder)
>
> The strategy section of the ANS website is very messy. The role and remit is unclear. They need an organogram to show the relationships between the various parties. (Governance Group / Working Groups)

5.72 Stakeholders described the relationship between the network and the Scottish Government in a variety of ways including as 'an arm of government' and a 'support wing' to help with the implementation of the autism strategy.

5.73 For some stakeholders, the relationship of the network to the Scottish Government and the Scottish Strategy on Autism was a concern because they saw it as undermining the independence of ANS (which they viewed as vital).

This accounted for what some stakeholders saw as an overly 'self-congratulatory' narrative in relation to ANS. These stakeholders' perception was that ANS was now the 'voice' of the Scottish Government, charged with delivering the Scottish Government 'message' that good progress was being made in relation to the Scottish strategy; these stakeholders dissented from this positive assessment of progress.

Insufficient delineation of leadership roles

5.74 Stakeholders from a wide range of sectors commented that the leadership roles were not well delineated. Specifically, stakeholders thought that a more transparent delineation of roles between: i) the Chair of the Scottish Strategy for Autism Governance Group ii) the lead on the National Coordination Project and iii) the lead coordinator of ANS was required.

5.75 Stakeholders who had a positive view of the ANS leadership (see paragraph 5.63) tended to view the current arrangement whereby all three roles were undertaken by a single individual positively (although they thought more clarity and transparency in delineating the roles would be desirable). In the view of these stakeholders, the combining of roles allowed the Scottish Government to take advantage of the wide experience of the Chair. These stakeholders also emphasised that the Chair was 'scrupulously fair' in relation to her multiple roles.

5.76 However, others thought that this structure resulted in a conflict of interest and should not continue. Views included the following:

> There is a conflict of interest between [Name's] role chairing the Governance Group, and her role as national coordinator / network lead. (Governance Group / Working Groups)

> This is not good governance when the chair of the governance group is also receiving funds for the network. What are the reporting lines? This is an uncomfortable arrangement and is open to criticism. (Governance Group / Working Groups)

Duplication of functions

5.77 For a few stakeholders, there was a view that ANS is duplicating services and functions which are delivered better / elsewhere by other organisations. For example:

> Since the relaunch of the network, there has been duplication. For example, [Name] has a fabulous resource in relation to identifying services / gaps in services. The ANS website is duplicating other information. (Governance Group / Working Groups)

Hosting arrangements

5.78 In contrast to the positive views of the hosting arrangements set out in paragraphs 5.64-5.65 above, other stakeholders focused on what they perceived to be the 'lack of fit' and the disadvantages of locating the network at the University of Strathclyde. The main disadvantages were thought to be:

- The lack of autonomy in relation to meeting the requirements of the University, whose aims were thought to be 'at odds' with the aims of the network
- The expense of the overheads charged by the university, which were thought to be greater than those which would be incurred if the network was constituted as an independent organisation. This led some stakeholders to conclude that the network did not currently offer value for money
- The lack of fit between the core activities of the network (many of which are very close to service provision) and the core activities of the university (i.e. research and teaching).

The Autism Network Scotland membership model

5.79 The membership model for ANS is based on historical arrangements developed at an earlier time before social media and technology developments had taken hold. Stakeholders were unclear about the benefits of membership, and queried why access to information and networks could not be more generally accessible.

5.80 ANS staff recognised that the membership model was out-of-date and needed to be reviewed. There was currently ongoing discussion about moving away from a membership model and replacing this with a subscription model. The documentary review concurred with this analysis.

Focus on professionals and practice

5.81 Some stakeholders thought there was too much focus on professionals, and on autism practice. These stakeholders thought the role of the network should be much more focused on high level, strategic issues with less focus on practice.

5.82 Moreover, notwithstanding the positive comments on the network's approach to wider engagement (see paragraphs 5.19-5.20 above), there were questions raised (especially by those people with autism who contributed to the review) about the balance of the network's current focus. Those stakeholders who were most directly connected to people with autism and their families and carers thought that more needed to be done to redress the balance towards people with autism.

Future role of a national autism network

5.83 Almost all stakeholders think that there is a role for a national network (or other type of related organisation) within the autism field. Only one stakeholder was unsure whether a network was required. However there were divergent views about what the role of any network should be, how it should be constituted and organised, what type of organisation it should be, whether it should be 'stand alone', and how much resource it should be given. Many stakeholders favoured continuing the status quo, albeit with a few 'tweaks' or improvements; other stakeholders had more radical suggestions for the shape of any future network / organisation. These are discussed in turn below.

An 'enhanced status quo'

5.84 Stakeholders who were generally content with the way ANS operates had a range of suggestions for how a national autism network / organisation could evolve in the future. These covered:

- Ensuring greater clarity and transparency in relation to the remit, roles and responsibilities of any future network and its relationship to the Scottish Strategy for Autism, the Governance Group and Working Groups and the Scottish Government
- Increasing the awareness raising and networking in relation to good autism practice amongst other sectors beyond health and social care. In particular, developing the profile within education (including further education and nursery education), criminal justice, employment, and housing
- Extending the geographical reach to ensure that all areas of Scotland benefit from the knowledge and expertise of a national network
- Focusing more on sharing and disseminating the good practice from smaller organisations whose work merited more of a national platform than was currently available
- Extending the responsibilities to give any future national autism network oversight of a training framework and accreditation system. This would enable organisations beyond health to develop standards for the way in which they communicate and interact with people with autism
- Developing clear outcomes and key performance indicators for any future network linked to the Scottish Strategy for Autism priorities for 2015-2017.

More radical suggestions

5.85 A range of more radical developments were suggested. Many, but not all of these came from stakeholders who had significant reservations about the current network model. Suggestions covered:

- Reducing the size of any national autism network to something smaller, and more strategic. This new entity would be less focused on current practice in autism but would instead have a role to spearhead the development of new ideas and new thinking within autism. There would be a focus on learning and sharing international perspectives, and on being a catalyst for setting up (e.g.) new networks rather than providing day-to-day facilitation. The governance and constitutional arrangements in this case would be rather different to current arrangements and would not necessarily link directly to the Governance Group
- Giving (a much smaller version of) a national autism network responsibility for overseeing the delivery of the Scottish Strategy for Autism; and giving it the authority for holding the various players to account. This would require an overhaul of the current governance arrangements not just of any network but also of the strategy
- Relaunching a national autism network as a 'national One Stop Shop'. This would see the current network replaced by a small core resource, to which individual (short term) projects funded from a variety of sources could then be temporarily attached. The future network could be either a 'stand alone' network, or linked to another organisation with responsibilities in relation to the strategy
- Allowing / requiring any revised national autism network to raise funds from other sources (including non-government sources) in order to improve its sustainability. The arrangements for governance and accountability would be revised to reflect the broader funding base of any new network.

5.86 There were highly divergent views about the role of ANS – or any network – in research. Part of the divergence related to differing interpretations and understandings about what 'involvement in research' might mean.

5.87 Stakeholder perspectives on any national autism network's involvement in research included that:

- The website of any national network is a good place to post and to view up-to-date research.
- Strathclyde University does not have a very active presence in relation to autism research.
- The research brief is already covered by the national autism organisations.
- A national autism network should only be hosted in the university if this arrangement offers the benefits of research done in partnership.
- A national autism network should provide networking opportunities in research.
- A national autism network should not get involved in research.

Other issues

5.88 Stakeholders were also asked whether there were any other points they wished to make in relation to ANS or to the wider policy context. The issue which was raised repeatedly related to the role, remit and composition of the Scottish Strategy for Autism Governance Group. Stakeholders also discussed the value of the Working Groups.

5.89 There was a shared view that the Governance Group did not, in fact, have a governance role in relation to the strategy. It was not thought that the Governance Group had the authority to call anyone to account for the delivery (or non-delivery) of the strategy.

5.90 Stakeholders suggested that the remit of the Governance Group should be to provide a forum where high level discussions about strategy and strategy development could take place (especially in relation to the strengths and weaknesses of current progress in delivering the Scottish Strategy for Autism). This was not currently thought to be the case.

5.91 Two main comments were made about the composition of the Governance Group:

- The Governance Group should be chaired by the Scottish Government.
- Membership of the Governance Group should be widened to include people with responsibilities beyond social work and health and social care. Key sectors that should be represented on the Governance Group include education, criminal justice, employment and housing.

5.92 As far as the Working Groups were concerned, there was substantial comment to the effect that the remit of these groups was not well understood. Whilst the Working Group on transitions was thought to have a clear agenda, the other groups were less certain about their role. It was not clear who was supposed to set the agenda for the Working Groups – its members or the Scottish Government (and stakeholders diverged in their view of what was preferable). Moreover, the original idea (that the Working Groups would comment on documents provided by Scottish Government) had not materialised.

5.93 There was frustration that the relationship between the Governance Group and the Working Groups was not clear and information flows between the two were not effective. Several stakeholders commented negatively on the disbanding of (the previous) Subgroup 6.

6 DEFINING AND MEASURING OUTCOMES

6.1 This chapter explores the issue of defining and measuring outcomes for ANS – or any other national autism network – in the context of the 'Scottish Strategy for Autism Outcomes Approach: Priorities 2015-2017' document which was developed in 2015.

Current approach to defining and measuring outcomes for Autism Network Scotland

6.2 As has been described earlier in this report the current grant award letters set objectives for ANS which are framed in terms of activities which the network is expected to carry out. (The range of activities undertaken by the network has been described in detail in Annex 1.)

6.3 No formal 'key performance indicators' or other similar metrics have been developed for the network. ANS progress reports have therefore focused to a large extent on describing the network's activities. More recently, the progress reports (in March 2015 and December 2015) have attempted to draw out impacts and outcomes more explicitly, albeit without any formally stated requirements for monitoring and / or evaluation.

6.4 ANS does invite delegates attending conferences and learning events to complete evaluation forms to capture feedback, to assess how useful participants found the events and to measure overall satisfaction. In general, these show high levels of satisfaction. For example, at the 4th annual national strategy conference in December 2015, 62 delegates (out of around 200 who attended) completed an evaluation form. Around half of these found both the keynote presentations and the workshops 'very useful' whilst the other half described them as 'useful'. There was unanimous agreement that there were enough opportunities on the day to network and connect, and almost 90% of those returning forms said they had made a useful contact at the conference. Virtually no negative comments were made by those who completed an evaluation form.

Future approach to defining and measuring outcomes for Autism Network Scotland - SharePoint Management Information System

6.5 Within the University of Strathclyde – and specifically within the Centre for excellence for looked after children in Scotland (CELCIS) – the SharePoint management information system is used to report on outcomes. This system has been developed over a substantial period and now provides a sophisticated management tool as well as mechanisms for interrogating and presenting inputs, activities, outputs and outcomes from the work of the centre.

6.6 The Project Lead for SharePoint is currently working with ANS staff to adapt the system for use within ANS. In order to maximise the usefulness of this exercise, a clear understanding of the inputs, activities, outputs and (short medium and long term) outcomes of ANS is required.

Scottish Strategy for Autism Outcomes Approach

6.7 In 2015, the Scottish Government developed its 'Scottish Strategy for Autism Outcomes Approach: Priorities 2015-2017' document. This specifies four Strategic Outcomes (SOs) with a descriptor of what requires to be done to achieve each of the outcomes as follows:

- SO 1: 'A Healthy Life: People with autism enjoy the highest attainable standard of living, health and family life and have timely access to diagnostic assessment and integrated support services'. The action is identified as 'Improve access to integrated service provision across the multi-dimensional aspects of autism'
- SO 2: 'Choice and Control: People with autism are treated with dignity and respect and services are able to identify their needs and are responsive to meet those needs'. The action is identified as 'Consistent adoption of good practice guidance in key areas of education, health and social care across local authority areas'
- SO 3: 'Independence: People with autism are able to live independently in the community with equal access to all aspects of society. Services have the capacity and awareness to ensure that people are met with recognition and understanding'. The action is identified as 'Capacity and awareness building in mainstream services to ensure people are met with recognition and understanding of autism'
- SO 4: 'Active Citizenship: People with autism are able to participate in all aspects of community and society by successfully transitioning from school into meaningful educational or employment opportunities'. The action is identified as 'Improve access to appropriate transition planning across the lifespan'.

6.8 The current version of the Outcomes Approach document (December 2015) sets out what has been achieved, and what will be done next, in relation to each of these four outcomes. Scrutiny of this document shows that ANS has contributed to the outcomes including in the following ways:

- SO 1: by i) facilitating the rollout of the Menu of Interventions and ii) working strategically with local authorities in the development of local autism strategies and plans
- SO 2: by i) disseminating and sharing the web based Autism toolbox developed by Scottish Autism, ii) running a wide range of conferences and events aimed at sharing good practice in autism and iii) developing and

facilitating networks and events for professionals (e.g. in employment, early years, speech and language therapy, and education)

- SO 3: by i) delivering a symposium in collaboration with NHS Education for Scotland to promote the NES Autism Training Framework which identifies training provision and gaps for further development ii) providing a national information hub for autism iii) developing and facilitating networks for professionals and iv) running a lead collaborative officers event on complex needs and out of area placements which was attended by 55 delegates
- SO 4: by i) facilitating the (10) 'Digging Deep: Exploring Transitions' roadshows across Scotland which were attended by 200 delegates and which focused on promoting the Principles of Good Transitions for professionals ii) encouraging employers to increase opportunities for people with autism and to promote positively evaluated models of supported employment through the autism and employment network and iii) providing opportunities for employment through working in collaboration with Project Search.

6.9 Much of the work described in paragraph 6.8 above is ongoing, and will continue to contribute to the achievement of the outcomes identified in the future.

6.10 It is clear from the analysis in paragraph 6.8 above that the activities of ANS (or of any reformulated national autism network or other organisation) underpin the achievement of all the identified outcomes. In particular, networking and sharing good practice (paragraphs 5.4-5.8), provision of information and resources (paragraphs 5.9-5.16) and raising awareness (paragraphs 5.17-5.18) are all necessary activities in relation to any / all of the identified outcomes.

Stakeholder views of the defining and measuring of outcomes for Autism Network Scotland

6.11 In general, stakeholders were unable to comment in relation to the defining and measuring of outcomes. There were two main reasons for this:

- First, as set out above (paragraphs 5.68-5.73), stakeholders were not clear about the remit of ANS and were therefore not able to comment either on what outcomes they were expected to achieve nor on how these could be measured
- Second, stakeholders in general were not familiar with the Scottish Strategy for Autism Outcomes Approach and did not therefore feel able to comment on the extent to which the activities of ANS were well aligned to this. However, one stakeholder did express the view that 'the strategic outcomes are so broad that the work of our organisation can fit under any of the outcomes'.

7 CONCLUSIONS

7.1 This chapter draws together the conclusions under each of the four main aims, as well as in relation to the definition and measurement of outcomes. A final, overall conclusion, completes the report.

Impacts of Autism Network Scotland

7.2 ANS has achieved a range of positive impacts since its inception in relation to: networking and sharing good practice; provision of information and resources; raising awareness; collaborative working; and (local authority) strategy development. There is clear evidence that the work of ANS is highly valued by professionals, especially those working in local authorities and the NHS.

7.3 As far as the impact in relation to 'promoting wider engagement of people with autism and their families in ANS work and in the decision-making process' is concerned, the picture is mixed. Whilst there is evidence of effort and some success in relation to the wider engagement agenda, there is also an over-reliance on a few key individuals. Moreover, there is a lack of monitoring information in relation to the numbers of people with autism and their carers who have been involved. However, this is in the context of a highly challenging agenda; the 'work in progress' should be commended.

7.4 The impacts for people with autism and their families and carers are mostly achieved through indirect means. The scale of any direct impacts is unclear given the lack of specific monitoring information.

Governance and financial arrangements

7.5 The arrangements for the financial management of the grant to the University of Strathclyde to run the network are well organised and satisfactory. Each time a grant award is made, a costing is done to ensure that the amount in the award letter matches the amount being spent through the grant. The budgeting and payment system is available in 'live time' to senior ANS staff, so that ongoing day-to-day monitoring of grant expenditure, including virement between budget subheads can be achieved. No problems with this arrangement were identified.

7.6 A range of progress reports in different formats (9 in total) have been submitted during the period since ANS was established in 2012. Two formal monitoring meetings between senior ANS staff and the Scottish Government have taken place during that period. (There are no minutes available from either of these meetings.) Thus, there has been limited opportunity for discussion of potential strategic developments in relation to ANS (e.g. the development of external funding possibilities such as that offered by Celtic FC Foundation, or the potential for the network to develop its research profile). This is a deficit in relation to the governance of the network.

Strengths and weaknesses of the model

7.7 The main strengths of the current model for Autism Network Scotland which were identified are i) the (Scotland-wide) overview of autism practice and strategy development and ii) the independence of ANS.

7.8 The Scotland-wide overview was highly valued, and was seen to be a unique feature of the current model. The network was credited with providing a bridge between the national and the local landscape, and with joining up the many and varied activities across Scotland. The benefits for professionals, at whom the activities of the network are most obviously directed, were clearly apparent.

7.9 The independence of the network was also very important to stakeholders, especially those from the public sector, who emphasised the particular benefits of the network not having a commercial role in service provision; however there were also concerns expressed about possible compromise to the network's independence either because of a new role in service delivery (specifically in relation to Celtic FC Foundation) or because of its role as the 'voice' of the Scottish Government in relation to the strategy.

7.10 The main weaknesses of the current model which were identified are i) the lack of clarity about the remit of ANS and its relationship to the Scottish Strategy for Autism, the Governance Group and the Scottish Government and ii) the insufficient delineation of leadership roles.

7.11 These weaknesses have led to negative stakeholder perceptions about the governance of the network.

7.12 Other aspects of the model, in particular i) its hosting arrangements, and ii) its focus on professionals and autism practice are seen as both a strength and a weakness.

Future development of a network or other mechanism to support strategy delivery

7.13 Achievement of the strategic outcomes identified by the Scottish Government will require a network – or some other organisation - which can provide an overview across Scotland in relation to: effective networking and the sharing of good practice; the provision of high quality information and resources; and awareness raising activities (both within services but also more generally within the general public).

7.14 There is no unique set of organisational and governance arrangements for delivering these functions; a network based largely on the current model is one possible approach, but other approaches (for example the model used

within learning disabilities, or that used within the co-production context) are also possible. [19,20]

7.15 Whichever model is pursued, there is a requirement for clarity of the remit, and clarity of the relationship to both the Scottish Strategy for Autism and to the Scottish Government. This clarification would require the specification of key performance indicators which could be used to monitor and measure progress. There is also a requirement for a clear governance structure. This would include a regular forum where strategic issues and developments could be discussed, and a clear delineation of leadership roles. Given the importance stakeholders placed on the quality of independence, an articulation of how independence could be achieved would need to be carefully considered and clarified by Scottish Government.

Definition and measurement of outcomes

7.16 The development of a clear understanding of the inputs, activities, outputs and (short, medium and long term) outcomes of ANS (or any other national autism network / organisation) is required.

Other issues

7.17 The ANS website, and the membership model which underpins it, require further development to ensure that comprehensive information and resources are available in a user-friendly and accessible format to as wide a constituency of users as possible.

Overall conclusion

7.18 ANS has achieved a range of positive impacts to date, based on a wide range of activities including networking and sharing good practice, providing information and resources, and raising awareness. The achievement of the strategic outcomes identified by the Scottish Government requires these activities to continue. There is no unique set of organisational and governance arrangements for delivering these functions. However, whichever model is pursued, there is a requirement for clarity of the remit and a clear governance structure as well as transparent performance outcome measures.

[19] http://www.scld.org.uk/

[20] http://www.coproductionscotland.org.uk/

ANNEX 1: ACTIVITIES OF AUTISM NETWORK SCOTLAND

Details of the activities of Autism Network Scotland are given below.

Conferences, roadshows, meetings and events

ANS is involved in planning, developing and delivering a wide range of conferences, roadshows, meetings and events. These are often organised in collaboration or partnership with other organisations and networks. These events often aim to include people with autism and their families and carers as well as practitioners and professionals.

The network supports the dissemination of 'products' of the Scottish Strategy for Autism. For example both the 'Menu of Interventions' and the 'Exploring Transitions' documents were launched at roadshows organised and facilitated by ANS which health and social care professionals attended.

ANS hosts the annual national strategy conferences. In 2015, the 4th annual conference focused on the theme of 'Good autism practice' and was attended by 200 delegates. In 2014, the 3rd annual conference was entitled 'From foundation to whole life journey' and was attended by 126 delegates.

Other ANS events held in 2015 included:

- Two learning events for women and girls with autism (co-hosted with the Scottish Women's Autism Network) each of which was attended by 65-70 delegates
- Three Autism Strategy Collaborative meetings involving lead officers within local organisations and partnerships to discuss, respectively, good practice, complex care and out-of-area placements, and transitions across the lifespan each of which was attended by around 50-60 delegates
- A 'Listening to Community' event in Perth (delivered in partnership with members of the autistic community) attended by over 35 people with autism, and their parents and carers
- Two afternoon workshops for mid-range providers and those involved in commissioning services to hear about the strategy, the NHS Education Training Framework and Action Plan, and service provision. These were each attended by 40-50 delegates
- An 'Autism and Employment' event to examine the employment process from the perspectives of people with autism, services that support them, and employers, and to launch the new Autism and Employment Network website. The event was attended by over 90 people including people with autism, parents, carers and practitioners
- A good practice symposium for support and intervention for people with ASD (co-hosted with NHS Education for Scotland) to share existing

examples of good practice in adapting support and intervention within social care settings. This was attended by over 70 delegates

- A collaborative event with the Royal College of Speech and Language Therapists to update Speech and Language Therapists on national developments in autism. There were around 50 delegates, most of whom were Speech and Language Therapists
- A collaborative event with Project SEARCH targeted at employers was attended by 25 delegates representing a range of businesses across Glasgow
- An event specifically for the Borders region about 'Understanding Behaviours' was attended by 66 delegates.

Establishing and maintaining networks

ANS is involved in both establishing, facilitating and developing a range of networks. In the past, there was also a focus on developing virtual networks; however more recently issues relating to privacy and security, particularly in relation to those in the NHS having difficulty accessing virtual networks has meant that the main focus is now on face-to-face networks.

The main active networks currently are both geographic (Borders, Dumfries & Galloway, North Lanarkshire) and topic specific (Early Years, Education, Employment, Transitions, and the Scottish Women's Autism Network - SWAN).

Supporting and developing the ANS website

A new website for ANS was developed with the help of the IT department of the University of Strathclyde in 2012. The website has continued to evolve ever since. In 2014, an additional element was added to the ANS website, to reflect ANS's expanded role in relation to the Scottish Strategy on Autism.

Newsletters and events bulletins

ANS produces regular (bi-monthly) newsletters which report on both ANS events and activities and autism events and activities more broadly. The newsletters have a small amount of more discursive content.

Events bulletins are circulated on a fortnightly basis. The bulletins advertise events on a wide geographic basis, and include notification of events run by the national autism organisations as well as more local events.

The information in both the newsletters and the events bulletins is gathered through the wide range of contacts which ANS has with service providers, service users and other stakeholders.

Enquiries and signposting

In 2015, ANS received 220 enquiries. It is not known how many of these were from professionals, and how many from people with autism / family members and carers.

When an enquiry is received the individual is provided with relevant information about local and national services and resources and / or put in touch with a specific individual or service.

Supporting the development of local autism strategies and plans

ANS engages to some degree with the development of all (32) local autism strategies across Scotland. The type of engagement is specifically tailored to the needs of the local area. The types of support which are offered include:

- Organising local events and roadshows (including on Transitions and the Menu of Interventions)
- Attending local strategy meetings (including consultation events and strategy implementation events)
- Facilitation of meetings to engage parents and others with local strategies
- Conference calls, meetings and discussions with local lead officers
- Establishing and servicing / facilitating local networks (including developing local newsletters)
- Providing comment and feedback on draft local strategies and plans (including improving alignment with national outcomes)
- Facilitating visits to facilities which offer insights into good practice or innovative solutions.

Supporting the Scottish Strategy for Autism

ANS staff attend meetings of the Governance Group and Working Groups, and provide a secretariat / facilitation role which includes organising meetings, taking minutes, and posting details on the ANS website. ANS also organises and delivers events which are linked to the strategy (for example the 'Exploring Transitions – Digging Deeper' roadshows described above is linked to the Working Group on transitions).

ANNEX 2: DOCUMENTARY REVIEW AND INTERVIEW TOPIC COVERAGE

Documentary review

The documents which were made available for the documentary review included:

- Scottish Government grant award letters (August 2012-October 2015)
- ANS progress reports (October 2012 to December 2015)
- Strathclyde University workplan agreement (2014)
- ANS Workstreams 2015-2016 (a document which maps ANS activities to the Scottish Government Strategic Outcomes Framework for Autism)
- ANS communications plan and content strategy and the project plan for the national autism coordination plan
- Minutes of Governance Group (November 2014-October 2015) and Working Group (December 2014-July 2015) meetings
- Materials relating to Menu of Interventions, Autism Toolbox, etc.
- Information about events, conferences, presentations, networks, enquiries and social media including bulletins and newsletters and reports of collaborative working and events.

Topic coverage of interviews

The topics included in the interviews covered: (i) ANS's role, successes and impacts since its inception in relation to professionals, organisations and individuals with autism (ii) the challenges ANS is facing (iii) the strengths and weaknesses of its current model including its host environment, governance arrangements and funding model (iv) its alignment with the (new) Outcomes Framework (v) the strengths and weaknesses of positioning the National Coordination Project within the network (vi) stakeholders' perspectives on the priority areas for an autism network going forward, taking into account the strategic outcomes identified as priorities for the period 2015-2017, and its future funding arrangements (vii) ideas for self-evaluation approaches and (viii) opportunities and threats in the wider policy arena. Stakeholders were also invited to comment on any other aspects which they thought were relevant to the consideration of the network's achievements and challenges.

Since stakeholders differed substantially in their understanding of, and exposure to ANS, the topics covered in specific interviews were adapted to cover those areas where stakeholders felt able to offer views. In some cases, interviews covered a single aspect in depth (for example, the engagement of ANS with people with autism, or the support provided to a local authority through the national coordination project) whilst in other cases interviews were wide ranging and covered many elements of ANS's current remit.

The interview with the RaKET Team Manager focused on questions relating to the policies and procedures in relation to financial management of the grant award.

ANNEX 3: LIST OF STAKEHOLDERS

Governance Group and / or Working Group Members

Richard Ibbotson	Third Sector	National Organisation
Charlene Tait	Third Sector	National Organisation
Alan Somerville	Third Sector	National Organisation
Jenny Paterson	Third Sector	National Organisation
Ian Hood	Third Sector	Learning Disability Alliance Scotland
James Fletcher	Third Sector	ARC Scotland
Beth Hall	Local Authority	COSLA
Peter McCulloch	Local Authority	Social Work Scotland
Zoe Robertson	Local Authority	Perth & Kinross / Social Work Scotland
Anne Marie Gallagher	NHS	NHS GG&C
Carolyn Brown	NHS	NHS Fife / Fife Council
Dr Iain McClure	NHS	NHS Lothian
Janine Robinson	NHS	NHS Education for Scotland
Marie Clare Shankland	NHS	NHS Education for Scotland
Arlene Johnstone	NHS	NHS Highland / Social Work Scotland
Prof Aline-Wendy Dunlop	Academic	Strathclyde University
Dr Anna Robinson	Academic	Strathclyde University
Dr Jane Neil-MacLachlan	Consultant	Independent Advisor
Alison Leask	Volunteer	Autism Argyll
Kabie Brook	Volunteer	Autism Rights Group Highland
Michael Dawson	Volunteer	Person with autism
Thom Kirkwood	Volunteer	Parental peer advocate

Wider Stakeholders

Chris Melling	Local Authority	Glasgow City Council
Sarah Fitch	Local Authority	Borders Council
Duncan Macintyre	Local Authority	Midlothian Council
Peter MacDonell	Local Authority	Aberdeen City Council
Alan Best	Local Authority	Inverclyde Council
Kenny Leinster	Local Authority	Ayrshire (combined)
Gordon Murray	Local Authority	Argyll and Bute Council
Clare Scott	Local Authority	Shetland Council
Kirsten Haughey	NHS	NHS Borders
Marion Rutherford	Academic/NHS	Queen Margaret University/NHS
Prof Anne O'Hare	Academic/NHS	Edinburgh University/NHS Lothian
Vicky McCarthy	Third Sector	Reach for Autism
Angie Ferguson	Third Sector	Perth Autism Support
Eileen Waugh	Third Sector	Hope for Autism
Julie Haslett	Consultant	SSSC
Dr Catriona Stewart	Volunteer	SWAN network

How to access background or source data

The data collected for this social research publication:

☐ cannot be made available by Scottish Government for further analysis as Scottish Government is not the data controller.

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