NORTHERN ADULT AUTISM ADVISORY SERVICE (NAAAS)

AN EVALUATION OF THE PILOT PROJECT WITHIN THE NORTHERN HEALTH AND SOCIAL CARE TRUST

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Abbreviations

ASD Autism Spectrum Disorder

CAB Citizen’s Advice Bureau

CDC Centers for Disease Control and Prevention

DEL Department of Employment and Learning

DES Disability Employment Service

IT Information Technology

JBO Jobs and Benefits Office

NAAAS Northern Adult Autism Advice Service

NAS National Autistic Society

NHSCT Northern Health and Social Care Trust

NRC Northern Regional Colleges

PDG Post Diagnostic Group

QUB Queen’s University Belfast

UU Ulster University (formerly University of Ulster)
Executive Summary

This Executive Summary is based on an evaluation of the Northern Adult Autism Advice Services (NAAAS) and the Post Diagnostic Support Group (PDG).

Northern Adult Autism Advisory Service

In January 2014, the Northern Health and Social Care Trust (NHSCT) started piloting a ‘One-Stop-Shop’ for Northern Adult Autism Advice Services (NAAAS) that was available for one afternoon each week at the Braid Centre, Ballymena, Co. Antrim. This service provided advice and support to adults with autism on key aspects of their daily lives including health, education, social security benefits, training and employment. The multi-agency advisory team which facilitated NAAAS was comprised of representatives from NHSCT, the Department of Employment and Learning (DEL), the Disability Employment Service (DES), Northern Regional Colleges (NRC), the ‘Improving Benefit Uptake Team’ from the Social Security Agency, and two voluntary sector providers, the National Autistic Society (NAS) and the Citizen’s Advice Bureau (CAB).

NAAAS Service users

Forty-nine service users\(^1\) from across the NHSCT area attended the NAAAS between January and December 2014 (a total of 47 sessions); of these, one in seven (14.3%) were female. The majority of service users (67.4%; n= 33) were young adults (aged between 16 and 25 years of age), of whom almost a third (n=10) were between 16 and 17 years of age.

Post Diagnostic Support Group

Twelve individuals who had recently received a diagnosis were offered a time limited post-diagnostic support group. The aims of this group were to support individuals in learning about autism, how it affects them and to discuss the experience of receiving a diagnosis.

Participants

Service users (adults with autism and their caregivers) and professionals from the partner organisations delivering services were invited to complete short surveys to explore their experience of NAAAS during the period from January to December 2014; eligible adults who had not used NAAAS were also invited to participate to determine reasons why they had not

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\(^1\) ‘Service user’ refers to all those who used NAAAS, i.e. individuals with autism and their families/carers
attended.

**Service users**

Adults with autism (aged 18 years and over) and their parents/carers who used the NAAAS were invited to participate in a short anonymous on-line survey. A hard copy version was available as alternative for service users aged 16 years\(^2\), or if preferred.

Ten valid completed responses to the on-line survey were recorded, and two hard copies were returned, a total of 12 responses (representing 24.5% of service users). Three respondents were adults with autism, while two were family members/carers attending on behalf of an adult with autism. The remaining seven respondents were family members/carers who had attended NAAAS on their own behalf. All the adults with autism who had attended were diagnosed as children, ranging from 5 to 16 years at the time. Four respondents were male and eight were female, and the majority (n=8) were aged 30 years and over.

**NAAAS service providers**

Northern Health and Social Care Trust staff and their partner agencies who provided services to NAAAS were invited to take part in a short anonymous online survey to measure their current input, training, tracking systems and satisfaction. There were 10 responses from staff providing services/advice in education, employment, benefits uptake and health and social care; they were not asked to provide information on their age or gender as this could potentially be disclosive.

**Eligible adults who had not used NAAAS**

An invitation to participate in the focus groups or the on-line survey was circulated by a number of gatekeeper organisations (e.g. NHSCT contacts, autism and carers’ voluntary groups) to individuals with autism and their parent/carers who had not used the service. Very few adults with autism (or caregivers) who had not used the service came forward and thus focus groups were not feasible. Therefore, this evaluation includes findings from the on-line survey (n=5) and additional e-mail responses (n=15).

\(^2\) Ethical consent considerations for legal minors who could be considered vulnerable precluded the use of on-line surveys for service users less than 18 years of age.
**Post-diagnostic support group**

NHSCT also run a post diagnostic group for service users with a recent diagnosis of autism. A total of 12 individuals (9 males and three females) took part in three groups of two sessions each at the Braid Centre, following which they were invited to complete a questionnaire on their experiences. Results from completed evaluation forms for the post-diagnostic support groups (collected by NHSCT) were analysed to determine user perceptions of satisfaction and any benefits in relation to follow-on uptake of the NAAAS.

**Round table discussion**

Findings from all these surveys formed the basis of a round table discussion with 17 professionals from the agencies who were involved in the pilot service to determine the strengths and challenges, what would be required for on-going partner participation and the future direction of NAAAS.

**Summary of findings**

**Awareness of NAAAS**

- Half of service user respondents were signposted by their NHSCT contacts
- Over half of the eligible adults who had *not* used the service were unaware that it existed; a quarter had found the time or location unsuitable

**Satisfaction with venue and service**

- The majority of service user respondents found the venue, time and atmosphere of the service suitable
- All service user respondents had found the advice useful or partially useful

**Service provision at NAAAS**

- The majority of providers indicated that adults with autism were the most numerous contact group, but most also offered advice and support to family members; this included employment support, education and careers advice, benefits uptake, community services and adult autism provision within the NHSCT.
- Half of the partners who responded were present every four weeks; the remaining partners were there on a weekly basis (n=3) or by request (n=2).
Of the ten partners who responded, the majority had received autism training; two at Level 1 (basic awareness), one at Level 2 (more specific training in communication, adapting work practices and dealing with challenging behaviour, if required) and three at Level 3 (specialist training for those taking a lead in autism provision). None had undertaken autism training provided at the Universities in NI.

All respondents indicated they tracked client outcomes; initial visits generated substantial follow-on services.

The majority of respondents felt that facilities at The Braid were adequate for service users and also for providers; all felt working at NAAAS helped them achieve Autism Strategy objectives.

One respondent commented that the geographical area covered was too wide to allow all potential clients to access the service.

**Suggestions for service improvement**

All respondents were asked to select suggestions for improving NAAAS, with an option to make additional suggestions.

- Operate in other areas (n=6), or offer an on-line advice service (n=4)
- Offer a greater range of advice and services (n=4) and longer opening hours (n=3)
- Greater advertising (n=2)
- Provision of a key worker/ advocate (n=2).
- Offer a drop-in service with more facilities (n=2)

**Post Diagnostic Group findings**

- The great majority of participants felt the information they received was well-presented and easy to understand; the venue for the group was felt to be suitable.

- Participants reported that they would like further information or support particularly on issues around emotions (managing difficult feelings and relating to others), understanding autism, benefits and employment.

- Ten participants said that they would be willing to attend further sessions.
Round table analysis

- It was generally acknowledged as a strength that NAAAS offered a centralised point for service delivery, which could then direct individuals to other ‘core services’ if needed; it was an accessible route for information and services for individuals with autism and their families.

- NAAAS was seen as useful for young people ‘transitioning’ from NHSCT paediatric autism services who could otherwise have been left without support had the pilot scheme not been in place.

- Challenges included relatively intensive resources needed from some partner agencies, which may not always have had the expected uptake.

- It was felt that geographical location had possibly deterred clients from outside the immediate area; to some extent this was supported by NHSCT user profiles, which showed that almost 40% of the service users had come from the nearby Ballymena or Antrim areas.

Future direction

There are a number of options available for NAAAS.

Option 1: That NAAS continues as it currently stands, offering a centralised service one afternoon each week. This has limitations in terms of general access for people living outside the Ballymena/Antrim/Ballymoney areas, and on the capacity of some of the partner organisations to commit their time. Some flexibility in use of resources/ additional capacity could be gained by some partners offering e.g. a telephone advice service. A much expanded ‘One Stop Shop’ (as with the Autism Initiatives model³ in the City of Derry, funded by the Big Lottery) offering ‘lifespan’ services which includes drop-in advice, social and support groups and community links would require additional resourcing, and would still offer services from one central location.

Option 2: That the present format of the service remains similar (a ‘one stop shop’), but is offered in more locations, and subsequently held weekly, fortnightly or monthly depending on the availability of resources (possibly in conjunction with existing provision for other disability groups). This has the advantage of using local expertise and of distributing the workload of the current partner organisations (thereby reducing their present time commitment to NAAAS),

³ http://www.autisminitiatives.org/where-we-are/northern-ireland/one-stop-shop-derry.aspx
although it will also require more autism training for new local partners. However, often problems cannot be put on hold for a month or a fortnight and service users may well end up travelling outside their local area for help and advice.

**Option 3:** A web-based ‘signposting’ service could help fill the gap, but a more developed web-service would be necessary. Key Action 1(b) in the Autism Action Plan states that autism information should be co-ordinated on NI Direct but to date this site merely signposts people back to providers, such as the Belfast and Northern Adult Autism Advice Services, NAS and the Middletown Centre for Autism. An interactive website (in conjunction with a ‘face-to-face’ service) could resolve some of the accessibility problems; for those who were unfamiliar with IT, the suggestion of library access (where the staff could advise and support use of the website) would offer a solution.

**Conclusions**

It is clear that the service acts as originally intended, as a ‘hub’ for direction to appropriate services, and considerable ‘follow-on’ work is generated. For future service development, bearing in mind not just the present population of adults with autism and their families but the children and young people who will leave Children’s Services in due course, NAAAS and follow-on services will need additional resourcing, co-ordination and monitoring, whichever of the options is chosen.

The present limit on resources for adult services is acknowledged within the Strategy and Action Plan (NI Executive, 2014) but it is noted that ‘departments and their service commissioners may need to consider if shifts in investment or innovative approaches are required to deliver the priorities identified in the initial Action Plan’ (ibid., p.85). This is of particular relevance to NAAAS, which has made ground-breaking use of existing resources to produce the first adult autism service in NI; the approach however has limitations as noted above (particularly in making available the expertise across the largest HSC Trust in NI). Accordingly, as well as ensuring the service continues, adequate planning and funding for adult services should be considered as a priority in the review of the current Action Plan.

**Recommendations**

There is an obligation under the Autism Act (and within the Autism Strategy and Action Plan) to meet the needs of adults as well as those of children (particularly in respect of Strategic Priorities
The Strategy and Action Plan also makes it clear that there is an obligation to ‘[e]nsure that an appropriate, sustainable and affordable implementation infrastructure is put in place’ (p.19). Discontinuing this service following a successful pilot would be a backward step. The upcoming review of the current Autism Action Plan (which ends in 2016) should consider adult services as a priority for resourcing as they have been considerably under-funded in the past.

Although some options are outlined in the previous section, the future format of the service is the decision of the Steering Group of the present NAAAS in conjunction with the lead organisations identified in the Autism Strategy. However, there are some overall recommendations for the effective development of any future service.

- Autism training at Level 2 tailored to specific roles should be offered by partner organisations to staff working with NAAAS and reviewed regularly; local University-based autism training should be considered for key personnel;

- An Adult Autism Services Lead position, under the management of the Autism Coordinator, is necessary to oversee the further development of NAAAS;

- An interactive on-line ‘signposting’ service for adults with autism and their carers should be provided to augment ‘face-to-face’ services (this could have multiple functions and become quite sophisticated, depending developmental resources);

- A further range of services for adults, e.g. specialist counselling, peer support and social groups, should be established (possibly in partnership with voluntary organisations) and better signposting/advice on funding applications for such developments should be available;

- Tailored training and awareness for participating employers should be provided by DEL/Department for the Economy and representatives from employer organisations should be more closely involved with NAAAS (e.g. as steering group members);

- Prevalence and employment rates for adults with autism should be established as a priority.

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4 Following proposed departmental re-organisation in 2016
1. Introduction

The need for services for adults with Autism Spectrum Disorder (ASD) and their families/carers has been identified as a priority in the Autism Strategy (2013-2020) and associated Action Plan (2013-2016) because these services are currently underdeveloped in Northern Ireland. Increases in funding for these services were not anticipated (Poots 2014).

NAAAS ‘One Stop Shop’

In January 2014, the Northern Health and Social Care Trust (NHSCT) started piloting a ‘One-Stop-Shop’ for Northern Adult Autism Advice Services (NAAAS) that was available for one afternoon each week at the Braid Centre, Ballymena, Co. Antrim. This service focussed on adults with autism and provided advice and support on key aspects of their daily lives including health, education, social security benefits, training and employment. The aims of NAAAS were to facilitate self-help by signposting support services, and to operate as an ‘umbrella service’ to provide the widest reach, promote social inclusion, equity and high quality services across all communities in a Health and Social Care Trust area with a large and dispersed population.

Post Diagnostic Support Group

Individuals who had recently received a diagnosis were offered a time limited post-diagnostic support group. The aims of this group were to support individuals in learning about autism, how it affects them and to discuss the experience of receiving a diagnosis.

Future demand for adult autism services within NHSCT

As of March 2015, the NHSCT covered ten local council areas and provided services for the ‘largest resident population in Northern Ireland’ (NHSCT, 2013a, p. 10). Between 2011 and 2021 the overall population in the Northern Health and Social Care Trust area is estimated to increase from 468,520 to 489,449, a growth of 6% (NHSCT, 2013b). Although there is no reliable means of calculating ASD prevalence for adults in Northern Ireland, which makes service planning difficult, increasingly robust child data allow for prediction of future prevalence. Internationally, adult prevalence rates are estimated to be 1.1% (1/88), and rates for children are now estimated at 2% (1/50) according to Centers for Disease Control and Prevention (CDC), the U.S. equivalent of the Public Health Agency (CDC; 2012; 2013). In the UK, analysis of the Millennium Cohort Study (following the progress of 18,000+ children born in 2000)
revealed that prevalence rates increased significantly as the children grew older. When the children were aged 5 years (in 2005), autism prevalence was reported to have been 0.9%; by the time the children were aged 7 years, in 2007, this had risen to 1.8%, and autism prevalence was 3.5% when the children were aged 11 years, in 2011 (Dillenburger, Jordan, & McKerr, 2014).

To date, the prevalence of autism in school children in Northern Ireland is an average of 2% and varies between Education and Library Boards (from 1.3% - 2.6%; Megaw, 2013). This indicates a 67% increase over the past four years; this means that some 500 young people with autism reach school-leaving age annually. In the Northern, prevalence rates vary between 1.4% in urban areas and 1.7% in rural areas (Megaw, 2013); the number of school leavers with ASD from mainstream schools (leavers data from Special Schools are not available) was predicted to rise between 30-50% in the next 3 years (Dillenburger, Jordan, McKerr 2014a). Results from the Kids Life and Times (KLT) and the Young Life and Times (YLT) surveys found that 2.7% of 11-year olds and 3.1% of 16-year-olds self-declared as having autism (Dillenburger, McKerr, & Jordan, 2015).

**Health and social care support for adults with autism**

As well as the rising prevalence of children and young people diagnosed with autism who will require adult services, the Adult Care Pathway (RASDN 2012) means that an increasing number of adults with autism (who were not diagnosed as children) are now requiring access to diagnostic services. Relevant health, education, and social care professionals play an important role in providing support and facilitating independence. People with autism and their families may seek support from a multidisciplinary group of professionals (such as occupational therapists, behaviour analysts, social workers and clinical psychologists); however, these services are not always available and basic training for professionals does not commonly include training in autism (Dillenburger, Röttgers, et al., 2014; Dounavi, 2014; Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010). While carers usually consider support services such as respite care and social skills training to be important, UK studies indicate that very few families are in receipt of these services (Broach, Camgöz, Heather, Owen, Potter & Prior, 2003; NAS 2013).

Overall, research regarding adults with autism lags behind research on childhood autism, and it is difficult to measure effectiveness and availability of services. However, in a UK survey of
more than 1,000 adults with autism, the majority reported that social services did not provide them with the support they need (National Autistic Society, 2013).

**Employment**

Higher than average rates of unemployment and associated risks, such as mental illness, social exclusion and poverty, can affect both individuals with autism and their families, as many carers cannot take up employment or leave employment because of their responsibilities at home (Dillenburger, Jordan, McKerr & Keenan, 2015). Official employment statistics for individuals with autism are not available in the UK, because a question on autism does not feature in employment surveys (Dillenburger, McKerr & Jordan 2014b). However academic studies have shown that the employment prospects of individuals with autism can vary considerably depending on a number of factors, these include autism specific symptoms (particularly the severity of the condition and co-occurring learning disabilities), local variations in the economy and the nature of support being received (Howlin & Moss, 2012). Personal support with travelling, providing employers with interview techniques for those with autism, and finding suitable work were found to be particularly beneficial (Forsythe, Rahim, & Bell 2008).

Where employers are well-informed and positive about employing individuals with autism, it has benefits both for the individual and business. The German firm SAP introduced a scheme to recruit individuals with autism who have IT skills or potential (The Guardian, 2013) and who were supported by Specialisterne, a Danish recruitment agency for individuals on the autism spectrum. This is based on the recognition of the potential of adults with autism having particular ability to focus on detail, and skills in data analysis; Specialisterne in Belfast are currently recruiting software designers and engineers for a number of local companies. The demand for IT skills is expanding in NI and the availability of positions across a range of skill levels means that there is a potential job market, given the correct ‘signposting’ and support, for those individuals with autism with an interest and aptitude in IT.

However, generally many jobs obtained by adults with autism are poorly paid and unskilled (Howlin, Goode, Hutton, & Rutter, 2004), many of the participants in the ‘Prospects’ autism employment scheme reviewed after eight years (Howlin, Alcock, & Burkin, 2005) had obtained

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5 System Analysis and Program Development.
skilled jobs (e.g., web designer, statistician) that matched their level of ability, while those individuals who had more severe social, cognitive and communication difficulties were also able to find appropriate employment. There are few rigorous evaluations of supported employment, either nationally or internationally (Westbrook, Nye, Fong, Wan, Cortopassi, and Martin, 2012) and this is an area in need of further research.

An earlier survey of carers of adult sons or daughters with autism found a full-time employment rate of only 6% (Barnard, Harvey, Potter, & Prior, 2001). It also revealed considerable differences between adults with high functioning autism, 12% of whom were in full-time employment, compared to only 2% of adults with low functioning autism (ibid.). In a survey of 1179 individuals with autism in England, only 15% of these adults were in full time employment (Rosenblatt, 2008) and a guide for employers in Northern Ireland suggested that of the estimated 17,000 individuals with autism in this country, a similar percentage (15%) were likely to be in full-time employment (NAS 2011). These low employment rates do not reflect a lack of willingness to work, as the vast majority of adults with autism want to take up paid employment (Dillenburger & McKerr, 2014; NAS 2011). However, many have experienced bullying or discrimination in the workplace, or had great difficulty maintaining their employment situation; therefore, of adults with autism who have been employed, more than four in ten have left or lost their job (Bancroft, Batten, Lambert & Madders, 2012).

In Northern Ireland, the development of the Autism Strategy (2013-2020) and Action Plan (2013-2016) (Northern Ireland Executive 2014) identified the need for the development of adult autism services; however, as noted earlier, there was no additional funding and the NAAAS pilot service was funded from existing resources to provide for adult support services.

**Roles and Responsibilities of the Northern Adult Autism Advice Service**

The Northern Adult Autism Advice Service (NAAAS) operates on a weekly basis (each Tuesday from 1.30pm - 4.30pm) from the Braid Centre, Ballymena Co. Antrim; Figure 1 shows the central position of this location.

The multi-agency advisory team which facilitates NAAAS is comprised of representatives from NHSCT, the Department of Employment and Learning (DEL), the Disability Employment
Service (DES), Northern Regional Colleges (NRC), the ‘Improving Benefit Uptake Team’ from the Social Security Agency, and two voluntary sector providers, the National Autistic Society (NAS) and the Citizen’s Advice Bureau (CAB). The Lead Officer (who is the contact point for the service) is Heather McCarroll, Autism Co-ordinator in the NHSCT. NAAAS takes a person-centred approach, taking into account the needs and preferences of the individual. Given the range of such needs across the autism spectrum, the NAAAS ‘One Stop Shop’ offers a multi-disciplinary/cross agency approach to provide support and advice in partnership with adults with autism and their families/carers.

**Figure 1: Position of NAAAS premises within NHSCT area**

As young people can transition to Adult Services from 16 years of age, NAAAS services can be accessed by individuals 16+ years of age.

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6 Map reproduced from [http://www.northerntrust.hscni.net/images/Northern_Trust_map.jpg](http://www.northerntrust.hscni.net/images/Northern_Trust_map.jpg)
2. NAAAS Evaluation

Outline of aims

The evaluation reported here aimed to identify baseline measures against which comparisons could be made when designing and developing adult autism services in the future. As such, this evaluation addressed the aims of the Autism Strategy, in particular the themes of Awareness (1), Accessibility (2), Health and Wellbeing (3), Education (4), Employability (7), Independence, Choice and Control (8), Being part of the Community (10) and Participation and Active Citizenship (11).

Specific research objectives

1. To assess service user/carer perceptions of the NAAAS ‘One Stop Shop’ service
2. To assess the level of training and gather the informed opinions of agency advisory staff involved in the service
3. To investigate if (or how) follow-up outcomes are tracked by partners in the multi-agency advisory team
4. To assess the benefits of attending the post-diagnostic support group for adults organised by NHSCT
5. To compare the results of these assessments of the NAAAS with current national and international best practice and to identify the strengths and deficits of the existing service where appropriate.
6. To make recommendations as to any service improvements where relevant.

Service user profiles

Age and gender

Forty-nine service users from across the NHSCT area attended the NAAAS between January and December 2014; of these, one in seven (14.3%) were female (Figure 2). The majority of service users (67.4%; n= 33) were aged between 16 and 25 years of age, of whom almost a third (n=10) were between 16 and 17 years of age.
The NAAAS is situated in the Braid Centre, Ballymena Co. Antrim. Ballymena is well provided with transport links and the Braid is within half a mile from the local bus and rail stations; it also has a large car park in close proximity. The geographical region served by the NHSCT is very large however and access from the more peripheral areas can be difficult.

The breakdown of NAAAS service users by home address region is shown in Figure 3. The majority of NAAAS users (40.8%; n=20) lived close to the Braid Centre (Antrim and Ballymena). Of the other NAAAS users, 16.3% (n=8) came from areas on average less than 20 miles from Ballymena (Magherafelt and Ballymoney), while few (8.2%; n=4) came distances of over 25 miles (Cookstown, Carrickfergus and Moyle). NAAAS partners operated a policy that does not exclude service users from other Trusts who drop in to access advice, and the figures include one individual from outside the Northern Trust area.

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Figures provided by NHSCT

**Home location**

The NAAAS service users profile by age and gender

![Bar chart showing NAAAS service users profile by age and gender](chart.png)

- **Age Bands (Years)**: 16-17, 18-20, 20-25, 25-30, 30-40, 40-50, 50+
- **Female Male**
  - 16-17: 2, 8
  - 18-20: 13, 0
  - 20-25: 1, 9
  - 25-30: 6, 3
  - 30-40: 6, 6
  - 40-50: 2, 2
  - 50+: 1, 1

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7 Mileage based on driving distances between named town/area and Ballymena; this is an approximation of actual distances travelled by service users as anonymised details excluded postcodes. ‘Moyle’ is a council area, not a town and the estimated distance used is an average of the mileage from the most northern and eastern towns within Moyle district (Ballycastle and Cushendall, see Figure 1).
Figure 3: Home address region of NAAAS service users

<table>
<thead>
<tr>
<th>Region</th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antrim</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Ballymena</td>
<td>10</td>
<td>1</td>
</tr>
<tr>
<td>Coleraine</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>Ballymoney</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Moyle</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Magherafelt</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Cookstown</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Larnie</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Carrickfergus</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Newtownabbey</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>Out of Board</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

Figures provided by NHSCT

Services accessed at NAAAS

Partner organisations that supported NAAAS included the Department of Employment and Learning (DEL), the Disability Employment Service (DES), Northern Regional Colleges (NRC), the ‘Improving Benefit Uptake Team’ from the Social Security Agency, and two voluntary sector providers, the National Autistic Society (NAS) and the Citizen’s Advice Bureau (CAB). Of these, DES and the Benefit Uptake team were represented on a weekly basis; the majority of other partners attended by appointment or dropped in, if requested. Where CAB services were needed, these were ‘signposted’ at NAAAS and individuals were asked to contact the office directly.
Figures provided by NHSCT

**Methodology**

**Recruitment and sampling**

*Sampling methodology*

Purposive sampling was used, i.e. non-random selection of particular groups whose experiences were directly relevant to the research questions (Teddlie & Yu, 2007). The link to the online surveys, and also if appropriate the alternate methods of responding, along with an invitation to participate was distributed by the NHSCT autism co-ordinator. This was sent directly (as with partner organisations and NAAAS service users) or through gatekeepers such as voluntary organisations (for eligible adults who had not used NAAAS).

*Sample sizes*

A total of 27 valid survey responses were received (see Figure 5); a further seven incomplete responses were deleted. In addition the NHSCT Autism Co-ordinator received 48 emails from

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8 ‘Incomplete’ surveys are defined as those where the respondent clicked ‘Disagree’ in response to the consent question, or left the survey early
service users detailing their reasons for not using NAAAS during the evaluation period, of which fifteen were from eligible adults (individuals with autism or the parent/carers of adult individuals with autism).

**Figure 5: Valid survey responses**

![Bar chart showing valid survey responses]

**Research tools**

The evaluation protocol and the research tools were designed in collaboration with the NAAAS Steering Group, which was comprised of Trust and partner agency members and service users. These were approved by the School of Education Research Ethics Committee in line with their governance regulations (Queen’s University Belfast 2007). The NHSCT Research and Development office considered the work a service evaluation and therefore did not require full governance approval.

The main research tools used were questionnaires, designed specifically for each of the three participant groups and accessed either on-line or in hard copy. In addition a short agenda was designed for the NAAAS partners for exploration during a roundtable discussion. Copies of all research tools can be found in the Appendices.

Additional information provided

A number of service provider partners (NHSCT, DEL and the Improving Benefits Uptake team) also supplied information on outcomes of NAAAS.
Participants

NAAAS service users

Adults with autism (aged 18 years and over) and their parents/carers who have used the NAAAS were invited to participate in a short anonymous on-line survey, which was designed to measure perception of the service, accessibility, outcomes and service user profiles. A hard copy version was available as alternative for service users aged 16 years, or if preferred.\(^9\)

Ten valid completed responses to the on-line survey were recorded, and two hard copies were returned, a total of 12 responses (representing 24.5% of service users)

Service user profiles

Three respondents were adults with autism, while two were family members/carers attending on behalf of an adult with autism. The remaining seven respondents were family members/carers who had attended NAAAS on their own behalf. All the adults with autism who had attended were diagnosed as children, ranging from 5 to 16 years at the time. Four respondents were male and eight were female, and the majority (n= 8) were aged 30 years and over.

NAAAS service providers

Northern Health and Social Care Trust staff and those from their partner agencies who provided services to NAAAS were invited to take part in a short anonymous online survey to measure their current input, training, tracking systems and satisfaction; again, the link was circulated by the Autism Co-ordinator. There were ten responses, providing information with respect to services/advice in education, employment benefits uptake and health and social care; respondents were not asked to provide information on their age or gender as this could potentially be disclosive.

Eligible adults who had not used NAAAS

An invitation to participate in series of focus groups was circulated by a number of gatekeeper organisations (e.g. NHSCT contacts, autism and carers’ voluntary groups) to individuals with

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\(^9\) Ethical consent considerations for legal minors who could be considered vulnerable precluded the use of on-line surveys for service users less than 18 years of age.
autism and their parent/carers who had not used the service. For those who preferred not to participate in group discussions a short anonymous on-line version of the survey was available. However, very few adults with autism (or caregivers) who had not used the service came forward and thus focus groups were not feasible. Therefore, this evaluation includes findings from the on-line survey (n= 5) and additional e-mail responses (n=15).

**Post-diagnostic support group**

NHSCT also run a post diagnostic group for service users with a recent diagnosis of autism. The objectives of this group were

- To enhance service users’ knowledge of autism
- To learn how autism affects their lives
- To enable discussion of their experiences of the diagnostic process and feelings arising from diagnosis
- To discuss telling family/friends about their diagnosis
- To inform about further support available for adults with autism and their families

A total of 12 individuals (9 males and three females) took part in three groups of two sessions each at the Braid Centre, following which they were invited to complete a questionnaire on their experiences. Results from completed evaluation forms for the post-diagnostic support groups (collected by NHSCT) were analysed to determine user perceptions of satisfaction and any benefits in relation to follow-on uptake of the NAAAS.

**Round table discussion**

Round table discussions were held with 17 representatives from the agencies who were involved in the pilot service, to discuss preliminary findings from the surveys.

**Data analysis**

A mixed methods approach was taken to seek a number of different perspectives (National Institutes of Health 2015), both quantitative and qualitative, using a number of methods (surveys and discussion groups).

For quantitative data from survey respondents, simple descriptive statistics were used to analyse categorical data for all survey groups. For qualitative (narrative) data, thematic
analysis was undertaken to identify themes and patterns in relation to the research questions (Braun & Clarke 2006).

**Results**

*Service users: finding out about NAAAS*

Half of the respondents (n=6) reported that they had found out about the service through their existing contacts in NHSCT (e.g. through current or previous services); a minority (n=2) had responded to advertising or a newspaper article about the services (see Figure 6).

**Figure 6: How service users found out about NAAAS**

![Bar chart showing how service users found out about NAAAS](chart)

Half of respondents (n=6) had attended NAAAS more than once, and of these, four said they had used the service five times or more; another two were unsure how many times they had attended. These numbers are not in agreement with the NHSCT figures (see Table 1), which show only one individual had returned for more than five visits, but participants may have included appointments/contacts with partner agencies ‘off site’ in their estimates.
Table 1: NHSCT figures for frequency of visits to NAAAS

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Service users</th>
</tr>
</thead>
<tbody>
<tr>
<td>One visit only</td>
<td>23</td>
</tr>
<tr>
<td>Returned for second visit</td>
<td>15</td>
</tr>
<tr>
<td>Returned for third visit</td>
<td>7</td>
</tr>
<tr>
<td>Returned for fourth visit</td>
<td>2</td>
</tr>
<tr>
<td>Returned for fifth visit</td>
<td>1</td>
</tr>
<tr>
<td>Returned for sixth visit</td>
<td>1</td>
</tr>
</tbody>
</table>

Services accessed by respondents

Participants reported that they had used a variety of the services available at NAAAS (see Figure 7). Seeking general information on autism, and employment queries were the most common (n=4 respectively) but people had also sought out information on benefits, education, housing and support for cared-for individuals (one parent mentioned transition issues in particular).

Figure 7: Services accessed at NAAAS by survey respondents

Service user satisfaction with NAAAS

The majority of respondents found the venue, time and atmosphere of the service suitable, and all had found the advice useful or partially useful (see Figure 8). Four service users reported that they had not found the Braid Centre easy to get to; of the two people who did not find the time
convenient, one reported that it did not suit the person they were travelling with, and another said it coincided with the school run.

**Figure 8: Service user satisfaction with NAAAS**

Four respondents stated they would be happy to use the service again, and one noted that his/her son was now getting the help he needed. Four people reported that their advice/support was still on-going; one parent said his/her son would need further support with transition issues and another felt the advice would be useful but there were issues around compliance and putting it into practice.

**NAAAS service providers**

*Service provision at NAAAS*

The majority of providers offered advice and support to both adults with autism and family members, although many providers (n=9) indicated that adults with autism were the most numerous contact group; the areas for which respondents offered information included employment support, education and careers advice, benefits uptake, community services and adult autism provision within the NHSCT. Half of the partners were present every four weeks; the remaining partners were there on a weekly basis (n=3) or by request (n=2). In general, service providers found the venue adequate, and felt that the service met their professional
objectives. Most had received autism training (although for the majority this was at a very basic level), and collected follow-on/tracking information on clients (see Figure 9).

**Figure 9: Summary of responses regarding NAAAS from service providers**

![Bar chart showing responses regarding NAAAS from service providers]

Autism training

Of the ten partners who responded, the majority (n=7) had received autism training; two at Level 1 (basic awareness), one at Level 2 (more specific training in communication, adapting work practices and dealing with challenging behaviour, if required) and three at Level 3 (specialist training for those taking a lead in autism provision). One individual indicated they had received training but did not specify the level, instead commenting they had a family member with autism. Those who responded to a follow-up question on desirable levels of training (n=3) believed training should be at least at Level 2. One respondent added a comment suggesting training for providers should be on-going and continuous, as there would be staff turnover among some teams.

Follow-up and tracking

The majority of providers (n= 8) offered the opportunity to follow up on enquiries; of these, two made arrangements at the Braid centre, while six arranged appointments at a different site. All providers tracked the progress of attendees.
Additional information from service providers

A number of providers supplied additional information on outcomes following initial contacts as NAAAS (see Figure 10). DEL provided anonymised figures showing that between January and December 2014, their advisors had engaged with 20 clients with autism initiated through NAAAS. More detailed information was available regarding the outcomes for nine clients (through six Jobs and Benefits Offices in the NHSCT area). Seven individuals had been signposted to relevant additional services such as occupational psychology or a work programme and one client had obtained a 6-month work placement. The majority of the contact was face-to-face, with further follow-ups in two cases by e-mail. Time spent during consultations/contact varied from 15 minutes to an hour, although one client had attended a full-day assessment; for the others, the average time for consultation was 51 minutes.

Figure 10: Follow-on services for clients at NAAAS

NAAAS Braid Centre
49 attendees

DEL
20

*6 local JBOs:
9 clients/13 further contact points

NHSCT
11

Other NHSCT services
4

Interventions service
7

Improving Benefits Uptake
26

Home visits
10

Telephone consultations
8

Total recorded follow-up actions (letters, e-mails, contacts)
117 (69 contacts with individuals with ASD)

*complete details not available from all Jobs and Benefits Offices (JBOs)
NHSCT provided anonymised figures showing that their representatives at NAAAS had engaged with 11 individuals between January and December 2014. Of these, seven individuals engaged with the Trust Intervention service; in addition there were four onward referrals to other NHSCT services, and in total, 117 follow-up actions (e-mails, letters and further contact). There were also telephone enquiries regarding NAAAS outside opening times but contact details from these were not recorded. A breakdown of follow-on figures indicate that 93 contacts involved 21 one-to-one sessions, 21 group therapy sessions, 26 ‘patient and family’ contacts and 25 which involved families only.

The Improving Benefits Uptake team confirmed that they had seen 26 clients at NAAAS during the same period. In addition, their representative had carried out 10 home visits (to assist with forms for DLA, ESA and Appointees) and had assisted a further eight clients with Benefit Entitlement checks in telephone consultations to take into account the needs of all family members, including carers.

**Adequacy of provision**

The majority of respondents (n=9) felt that facilities at The Braid were adequate for service users; the only respondent who did not agree commented that the geographical area covered was too wide to allow all potential clients to access the service.

In terms of facilities for service providers, the majority of respondents (n=8) said they were adequate. The two respondents who felt they were not adequate commented that lack of knowledge about autism, employer understanding and inadequate privacy at the venue were issues. One respondent was concerned that the resources provided were not always justified by client attendance (which was considered low at times).

**Meeting professional objectives**

Of the ten respondents, the majority (n=9) felt that participation in NAAAS helped them fulfil their business objectives and all agreed that it helped them achieve their objectives under the Autism Strategy; seven out of the ten had received autism training, which is a key Autism Strategy priority for frontline staff.
Eligible adults who had not used NAAAS

Five valid responses were received to the survey for eligible adults (individuals with autism and their carers) who had not used NAAAS. These low numbers made it very difficult to generalise the findings; it was also difficult to accurately estimate the number of individuals who may be eligible to use the service. However, as noted earlier these results were supplemented by 48 emails regarding NAAAS to the NHSCT Autism Co-ordinator. The majority of these respondents indicated they had not used NAAAS because their children were not yet 16 years of age; 15 responses were from eligible individuals. In total, 20 responses from eligible adults were received although e-mails only detailed reasons for non-attendance. A summary of responses is presented in Figure 11.

Figure 11: Reasons for non-attendance from eligible adults who had not used NAAAS

The most common reason given for not accessing NAAAS was that respondents had previously been unaware of the service (n= 11; 52.4%); four individuals said that they did not require services, while three found the venue inconvenient, and two stated that the day /time did not suit. One individual stated they could not attend due to ill-health ('Other').

Summary of suggestions for service improvement

All survey respondents were asked for recommendations which they felt could improve the service offered at NAAAS and these are summarized in Figure 12.
Overall, survey respondents made suggestions that would increase both the range and delivery of services offered. As well as a greater range of advice and services (such as counselling, social and life skills), respondents felt there was a need to operate in other areas, or offer an on-line advice service. Other suggestions included the need for greater advertising, longer opening hours and provision of a key worker/ advocate. One respondent felt the age limit should be lowered in effect making this a ‘lifespan’ service. This is a development that could have considerable impact both on resources and the development of a robust adult service, given the high numbers of children diagnosed or awaiting diagnosis with autism but it is an issue that arose again in the Round Table session (see below).

**Post Diagnostic Group (PDG) Findings**

As noted earlier, a total of 12 individuals (9 males and three females) took part in three groups of two sessions each at The Braid Centre, following which they completed a questionnaire on their experiences. These results were collated by NHSCT and summaries are shown in Figures 13 and 14 below.
The great majority of participants felt the information they received was well-presented and easy to understand; the venue for the group was felt to be suitable.

*Useful further information/support requested*

Participants reported that they would like further information or support on a number of topics, particularly on issues around emotions (managing difficult feelings and relating to others), understanding autism, benefits and employment (see Figure 14). Ten participants said that they would be willing to attend further sessions (two participants did not respond to this question).

*Figure 14: Topics on which PDG participants would like more information*
When asked for other comments or suggestions, five participants noted how useful or comfortable the sessions had been; one suggested that viewing video clips of how other people managed with their ASD would be useful, and another mentioned researching ‘Indigo children’ for insights into autism; this is a term sometimes used to describe highly creative and non-conformist children (who may also be diagnosed with ADHD), who have difficulties with traditional teaching methods.

**Round table discussion analysis**

Following a presentation of the interim findings for the NAAAS evaluation, 17 partner representatives from NAAAS and related outside agencies (seated in self-selected groups at three tables) took part in a round table discussion on the service. With the help of a facilitator, each group was asked to identify the *strengths and challenges*, to outline the *future direction of the service*, and to identify *what the partners would need to achieve this* and asked to make brief comments on a summary sheet. At the end of the session, each group was asked to summarize their findings (see Tables 2-4).

**Strengths and challenges**

**Table 2: Strengths and challenges identified by service providers**

<table>
<thead>
<tr>
<th>Strengths</th>
<th>Challenges</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service for people after diagnosis; Strong leadership from Trust Autism Service; No time limit on accessing service; Drop-in facility gives flexibility; No limit on number of drop-ins; Empathic staff resource; Centralised point for multi-agency services; Supports other core services; Creates awareness of ASD in community and across agencies; Available to individuals 16+ years and above; Accessible to carers as well; Good for networking with other service users; Good for networking with agencies.</td>
<td>On-going staff training for partner agencies with staff turn-over; Geographical location; Public transport issues (including cost of travel); Advertising/promotion/awareness of service in all agencies; Only available during working hours; Impact on agency resources (staff time/ competing priorities); Client group numbers low due to lack of resources for adult diagnosis.</td>
</tr>
</tbody>
</table>

It was generally acknowledged as a strength that NAAAS offered a centralised point for service
delivery, which could then direct individuals to other ‘core services’ if needed; it was an accessible route for information and services for individuals with autism and their families. It was also available to young people ‘transitioning’ from NHSCT paediatric autism services who could otherwise have been left without support had the pilot scheme not been in place.

Challenges included the relatively intensive resources needed from some partner agencies, which may not always have had the expected uptake. Providers were concerned that the central location also had a disadvantage in that geographical location had possibly deterred clients from outside the immediate area, and to some extent this was supported by the user profiles, which showed that almost 40% of the service users had come from the nearby Ballymena or Antrim areas (see Figure 3).

**Future direction**

**Table 3: Future direction of the service**

<table>
<thead>
<tr>
<th>Suggestions for service direction</th>
<th>Adjusting the service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continue with present partners</td>
<td>• Alternate weekly/appointment based system for some providers</td>
</tr>
<tr>
<td>Expand pilot to include other Trust areas</td>
<td>• Currently underway in BHSCT, planned in WHSCT</td>
</tr>
<tr>
<td>Offer service on-line</td>
<td>• Could be planned on a regional level for the future, with ‘Skype’-type consultations</td>
</tr>
</tbody>
</table>
| Access additional resources to develop other services | • Additional groups e.g. for women, men, social skills & emotional regulation  
• Locally based ‘drop-in’ centres with social facilities  
• Adults with autism as volunteers (at drop-in, or facilitating groups)  
• ‘Health & Well-being Hubs’ to include ASD  
• Share facilities with other ‘one-stop shops’ in locality  
• Web-based advice service/increased use of Skype & social media  
• ‘Mobile’ centres which travel round Trust area  
• Travel re-imbursement/ volunteer drivers for service users |
| ‘Lifespan’ service               | • Initially reduce age limit to 14+  
• Invite partners from education sector (e.g. careers/transition services)  
• Outreach service for individuals with more challenging conditions |
If the service were to continue in the present venue at the Braid Centre, it was felt that a bi-weekly or appointment system would be better suited to some providers; alternatively, a ‘mobile’ service (e.g. as with library or health information campaigns) could offer the opportunity of greater access for clients, and involve local providers across the Trust area.

Other suggestions included sharing premises with existing ‘One-Stop shops’ to offer more facilities and greater access (e.g. ‘drop-in’ centres with social activities and internet café as well as support and advice), and the increased use of volunteers as facilitators or to provide transport. Web-based services were felt to be a very useful way forward, with the possibility of ‘Skype’-type consultations that would reduce the need for on-site meetings. If a ‘lifespan’ service were to be developed, this would require more resources and a wider range of partner support (e.g. from the education sector) and it was also suggested that those with more challenging needs required the development of an outreach service.

What partners need to achieve a better service/stay involved

Partners identified the need for increased training, tailored to individual roles where appropriate and with different formats for delivery, as a key factor both in their future involvement and the improvement of service delivery. It was felt that more direct ‘sign-posting’ would improve service user awareness of NAAAS, and that more flexible methods of service delivery could be explored, to extend the present provision and to make it more cost-effective. They also felt it was important that senior management acknowledged the contribution of partners to date, and that there could be greater direction from senior levels within their respective organisations.

Better mechanisms for monitoring service provision (e.g. footfall and outcomes) and obtaining qualitative feedback from both service users and the partners involved in NAAAS would also be welcomed (see Table 4).
Table 4: What partners need to achieve a better service/stay involved

<table>
<thead>
<tr>
<th>What is required</th>
<th>Desirable outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td>More training</td>
<td>• At least to Level 1 for all frontline staff*</td>
</tr>
<tr>
<td></td>
<td>• Higher levels for specialist staff</td>
</tr>
<tr>
<td></td>
<td>• E-learning/ ‘Cascade’ training within partner organisations</td>
</tr>
<tr>
<td></td>
<td>• Utilise training offered at local Universities (QUB and UU)</td>
</tr>
<tr>
<td>Greater ‘signposting’ of services from other sources</td>
<td>• NI Direct</td>
</tr>
<tr>
<td></td>
<td>• Libraries across Trust area involved actively e.g. access to on-line services</td>
</tr>
<tr>
<td>More flexible delivery</td>
<td>• Telephone advice service</td>
</tr>
<tr>
<td></td>
<td>• Bi-weekly service for some partners as better use of resources</td>
</tr>
<tr>
<td></td>
<td>• Mobile service</td>
</tr>
<tr>
<td></td>
<td>• Online service</td>
</tr>
<tr>
<td>Acknowledgement of roles</td>
<td>• Senior management to recognise value of commitment</td>
</tr>
<tr>
<td></td>
<td>• More direction/leadership from senior levels in partnership organisations (i.e. should not be sole responsibility of Trust)</td>
</tr>
<tr>
<td>Active feedback process</td>
<td>• Regular monitoring of service input/ ‘footfall’/productivity of services</td>
</tr>
<tr>
<td></td>
<td>• Qualitative feedback on user &amp; provider satisfaction</td>
</tr>
</tbody>
</table>

* This is Key Action 1.1 in the Autism Strategy and Action Plan, to be achieved by March 2015, and is the responsibility of individual departments.
3. Discussion

This short evaluation examined information from the NHSCT and partner organisations as well as seeking the views and experiences of people who had availed of the NAAAS, the Post Diagnostic Group and eligible adults who had not used the NAAAS.

Response rates

The survey responses from service users, although numerically low, represented almost 25% of those who had attended NAAAS. The responses from eligible adults who had not used NAAAS were also low; it should be acknowledged that these individuals with autism and their families were always going to be a ‘hard to reach’ population, geographically dispersed and perhaps more socially isolated if currently receiving limited support. It is known that study compliance for any ‘hard-to-reach’ group depends on recruitment techniques as well as group characteristics and their interest in the survey subject (Shaghaghi, Bhopal, & Sheikh, 2011).

A longer term evaluation could attempt to include more individuals with autism and their families by increasing public awareness of the service (and the importance of the evaluation) as well as using a variety of additional recruitment techniques appropriate to health and well-being studies including, for example, community or facility-based sampling (ibid.)

In the period January-December 2014, forty-nine individuals used the NAAAS ‘One Stop Shop’ at the Braid Centre in Ballymena. However, footfall alone does not indicate the level of service provision. NAAAS was for most the entry point to other services and the work for both NHSCT and partner organisations generated by these initial visits was substantial.

These figures may not be representative as prevalence of adults with autism in the NHSCT area (or within Northern Ireland as a whole) remains unknown. It is of strategic importance to establish the prevalence rate of autism in adults in Northern Ireland, and to effectively monitor the outcomes of education, employment, housing, benefit and health and social care uptake; future planning can only be effective if there is an accurate picture of existing (or projected) needs.

User satisfaction

Twelve service user/carers responded to the survey designed to measure perceptions of the NAAAS’ ‘One Stop Shop’ service. These numbers represent 24.5% of the individuals who used
the service during the evaluation period. The surveys indicated high levels of participant satisfaction with the existing service and venue, and this was also the case with the vast majority of the service provider partners. The majority of service user participants found the opening times convenient. High levels of participant satisfaction were also recorded in the Post Diagnostic Group (PDG), with regard to suitability of the venue and the quality of information at the sessions. When adults obtain a diagnosis of autism, this often answers questions about their lives and relationships but also has an impact on their future plans. The PDG offered a practical transition after diagnosis, a space to seek further answers and solutions that may be provided by the other service provider partners within NAAAS.

Service development

Service users (including the PDG) and providers favoured further development of a range of services, including counselling and support groups, web-based services, and a number of ‘drop-in’ or mobile centres that would increase accessibility for clients. It was suggested that local libraries could act as the ‘hub’ for web-based services and also as a source of general information on services that could support individuals with autism and their families/carers.

Increasing access to the service

The need for more publicity was identified by all survey participant groups, including the eligible adults who had not used the service; the majority of service users had been directed to NAAAS by existing contacts within the Trust or from friends and family. A small number of service users and partners suggested lowering the age range for accessing the service (i.e. for those under 16 years and their families/carers). This fits with the Autism Strategy Priority 6, to ‘deliver co-ordinated and integrated seamless care across transition stages for people with autism throughout their lives’ (2014, p13).

However, increasing awareness and accessibility of the service also carries the responsibility for tailoring the service to meet the potential increase of uptake. As well as requiring an increase in resources, the rising rate of prevalence and diagnosis of children may put pressure on existing children’s services, and there is the possibility that the adult service could be marginalised by demand from younger service users and their families/carers. If such a development were to be undertaken, the services would need to be expanded, with new partners involved (particularly
from the Department of Education); resources for the adult services would need to be ring-fenced.

Improving the service provider experience

While generally finding the service they offered at NAAAS a positive experience, meeting their business and Autism Strategy objectives, some partners expressed concerns about the viability of what was for them a resource-intensive service, and felt that more engagement and support from senior management would be helpful. It was felt that some of the demand could be met locally, which would take some of the pressure off the small teams currently working at NAAAS at the Braid Centre. It was also felt that training should be more targeted and specific; the majority of partners (outside NHSCT) had accessed only Level 1 (basic awareness) and would have preferred training tailored to their roles, which would be updated regularly.

Delivering employment support

As part of defining and developing a service tailored to the needs of adults with autism and their families, NAAAS offered advice and signposting for educational options, employment, benefit support, and access to therapy. The most frequent enquiries recorded related to Benefit Uptake (26 clients), while employment advice and support was sought by 20 clients. Although benefit assessment was not necessarily an autism-specific service (that is, individuals with autism and their families can access ‘mainstream’ services), the partners at NAAAS extended their provision to clients through home visits and telephone consultations, where necessary. Employment support for individuals with autism required more individual tailoring to particular skills and challenges (NAS, 2011).

NAAAS was committed to improving employment rates and some service providers raised important issues around employer awareness, involvement, training and expectations in the workplace. The Autism Strategy (2013-2020) emphasised the responsibility of the Disability Employment Service to ‘continue to help to raise awareness with employers on the benefits of employing people with autism and provide tailored support for people with autism’ (Northern Ireland Executive, 2014, p. 70). While DEL Occupational Psychology Services offered some training opportunities, resources (both in terms of time and funding) were limited, and cost-effective alternatives (such as an adaptation of the on-line NHSCT autism training) should be considered.
Improving opportunities for employment of individuals on the autism spectrum is a key objective of the Autism Strategy (Strategic Priorities 10 & 11); although not directly within the remit of the NAAAS pilot, this evaluation identified the need for support programmes with engaged and supportive employers that are appropriately funded.

**Future direction**

There are a number of options available for NAAAS.

**Option 1:** That NAAS continues as it currently stands, offering a centralised service one afternoon each week. This has limitations in terms of general access for people living outside the Ballymena/Antrim/Ballymoney areas, and on the capacity of some of the partner organisations to commit their time. Some flexibility in use of resources/ additional capacity could be gained by some partners offering e.g. a telephone advice service. A much expanded ‘One Stop Shop’ (as with the Autism Initiatives model\(^\text{10}\) in the City of Derry, funded by the Big Lottery) offering ‘lifespan’ services which includes drop-in advice, social and support groups and community links would require additional resourcing, and would still offer services from one central location.

**Option 2:** That the present format of the service remains similar (a ‘one stop shop’), but is offered in more locations, and subsequently held weekly, fortnightly or monthly depending on the availability of resources (possibly in conjunction with existing provision for other disability groups). This has the advantage of using local expertise and of distributing the workload of the current partner organisations (thereby reducing their present time commitment to NAAAS), although it will also require more autism training for new local partners. However, often problems cannot be put on hold for a month or a fortnight and service users may well end up travelling outside their local area for help and advice.

**Option 3:** A web-based ‘signposting’ service could help fill the gap, but a more developed web-service would be necessary. Key Action 1(b) states that autism information should be co-ordinated on NI Direct but to date this site merely signposts people back to providers, such as the Belfast and Northern Adult Autism Advice Services, NAS and the Middletown Centre for Autism. An interactive website (in conjunction with ‘face-to-face’ services) could resolve some of the accessibility problems; for those who were unfamiliar with IT, the suggestion of library access (where the staff could advise and support use of the website) would offer a solution.

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\(^{10}\) [http://www.autisminitiatives.org/where-we-are/northern-ireland/one-stop-shop-derry.aspx](http://www.autisminitiatives.org/where-we-are/northern-ireland/one-stop-shop-derry.aspx)
4. Conclusions

It is clear that the service acts as originally intended, as a ‘hub’ for direction to appropriate services, and considerable ‘follow-on’ work is generated. For future service development, bearing in mind not just the present population of adults with autism and their families but the children and young people who will leave Children’s Services in due course, NAAAS and follow-on services will need additional resourcing, co-ordination and monitoring, whichever of the options is chosen.

The present limit on resources for adult services is acknowledged within the Strategy and Action Plan (NI Executive 2014) but it is noted that ‘departments and their service commissioners may need to consider if shifts in investment or innovative approaches are required to deliver the priorities identified in the initial Action Plan’ (ibid., p.85). This is of particular relevance to NAAAS, which has made ground-breaking use of existing resources to produce the first adult autism service in NI; the approach however has limitations as noted above (particularly in making available the expertise across the largest HSC Trust in NI). Accordingly, as well as ensuring the service continues, adequate planning and funding for adult services should be considered as a priority in the review of the current Action Plan.
5. Recommendations

The following recommendations arose from the findings of the NAAAS evaluation. There is an obligation under the Autism Act (and within the Autism Strategy and Action Plan) to meet the needs of adults as well as those of children (particularly in respect of Strategic Priorities 6-11). The Strategy and Action Plan also makes it clear that there is an obligation to ‘[e]nsure that an appropriate, sustainable and affordable implementation infrastructure is put in place’ (p.19). Discontinuing this service following a successful pilot would be a very detrimental step. The upcoming review of the current Autism Action Plan (which ends in 2016) should consider adult services as a priority for resourcing as they have been considerably under-funded in the past.

Although some options are outlined in the previous section, the future format of the service is the decision of the Steering Group of the present NAAAS in conjunction with the lead organisations identified in the Autism Strategy. However, data provided in this report provide direction for the development of future services:

- Autism training at Level 2 tailored to specific roles should be offered by partner organisations to staff working with NAAAS and reviewed regularly; local University based autism training should be considered for key personnel;
- An Adult Autism Services Lead position, under the management of the Autism Coordinator, is necessary to oversee the further development of NAAAS;
- An interactive on-line ‘signposting’ service for adults with autism and their carers should be provided to augment ‘face-to-face’ services (this could have multiple functions and become quite sophisticated, depending developmental resources);
- A further range of services for adults, e.g. specialist counselling, peer support and social groups, should be established (possibly in partnership with voluntary organisations) and better signposting/advice on funding applications for such developments should be available;
- Tailored training and awareness for participating employers should be provided by DEL/Department for the Economy and representatives from employer organisations should be more closely involved with NAAAS (e.g. as steering group members);
- Prevalence and employment rates for adults with autism should be established as a priority.
6. References


Appendix 1: Service User Survey

Northern Adult Autism: Service user evaluation survey

I am a service user with autism  

I am the carer/representative of an adult with autism and I am completing this survey on **their** behalf  

I am the carer/representative of an adult with autism and I am completing this survey on **my own** behalf  

Please indicate how many times you have used the NAAAS : _____________________

The first three questions are about you as a service user

Q1. Did you attend NAAAS for advice

☐ For yourself, as a person with autism/Asperger’s (please answer 1b below)

1b. What age were you when you were diagnosed with autism? ________ years

☐ As a family member of a person with autism/Asperger’s

☐ As a friend of a person with autism/Asperger’s

☐ Because you are employed as a carer of a person with autism/Asperger’s

Q2. Are you

☐ Male

☐ Female

Q3. What is your age range? Please circle or underline the correct age range.

  18-20 years
  21-25 years
  26- 29 years
  30-39 years
  40-49 years
  50-59 years
  60-64 years
  Over 65 years

---

11 Filter questions indicated in red
The next 7 questions are about your visit to NAAAS

Q4. How did you find out about NAAAS? (Please tick all that apply)

☐ Just passing by
☐ Recommended by a friend/family member
☐ Newspaper article
☐ Poster
☐ Advert
☐ Website

☐ Other (please give details)

__________________________________________________________________________________

Q5. What was the reason for your visit to NAAAS? Please tick all that apply.

☐ Seeking general information
☐ Seeking information or advice about employment
☐ Seeking information or advice about benefits
☐ Seeking information or advice about education
☐ Seeking information or advice about housing

☐ Other (please give details)

__________________________________________________________________________________

Q6. What happened as a result of your visit to NAAAS? Please tick all that apply

☐ I am making an appointment with another agency (Please also answer question 6b)

6b. Is this appointment with autism team/ GP / other HSC agency / other government agency/ voluntary organisation e.g. autism charity or Citizens’ Advice Bureau? Please circle all that apply.

☐ I am going to follow up with NAAAS / call again

☐ My problem/issue was sorted out, I don’t need to call again about this
Q7a. Was the location of the NAAAS
☐ Easy to get to
☐ Difficult to get to

Q 7b Were the opening time of the NAAAS (please tick all that apply)
☐ Convenient
☐ Not suitable for me
☐ Not suitable for the person I travel with
☐ Not suitable for travel by public transport
☐ Other (please give details)_________________________________________________________

Q8. Was the atmosphere at NAAAS
☐ Relaxed and comfortable
☐ Not relaxed and comfortable (Please answer Q8b. below)

8b. Was it uncomfortable because (please circle or underline all that apply)
It was too formal
I got stressed travelling
The building was too busy
The building was too noisy
It was hard to find the room
I had to wait too long
NAAAS staff weren’t friendly
Braid staff weren’t friendly
Other (please give details)_________________________________________________________

Q 9. How helpful was the information or advice given to you at NAAAS
☐ Really helpful, I have used it a lot since
☐ Partially helpful, I have used some of the information or advice since
☐ Not really helpful, I have not been able to use it since
☐ I have not yet had a chance to use it

Q10. Did you have a chance during your visit to make suggestions about improving the service?
☐ Yes
☐ No

The last question is asking for your suggestions for improving the service

Q11. Is there anything which you think could improve the services offered by NAAAS?
☐ Yes (please answer Q11b below)

I think NAAAS would be a better service if (please circle or underline all that apply)

It offered a greater range of advice
It was a drop-in centre where you could stay longer, use facilities and meet other people
It had services in other towns
It opened more days in the week
It opened all day instead of the afternoon
Other (please give details) ____________________________________________________
__________________________________________________________

☐ No

Thank you for completing the survey- your answers will help NAAAS understand what it can do to improve the service.
Appendix 2: Participant Information for service users (hard copy)\textsuperscript{12}

Participant Information Sheet for NAAAS service users: survey

School of Education
Queen’s University Belfast
Research Project

PARTICIPANT INFORMATION SHEET

You are being invited to take part in a short research study. Before you decide whether you want to take part or not it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

The Northern Adult Autism Advisory Service (NAAAS) evaluation

This research aims to find out how effectively the new NAAAS is meeting the needs of the people who use it. The Research Ethics Committee of the School of Education, Queen’s University Belfast reviewed and approved this research. You have been chosen to take part in the study as an individual with autism, or as the carer of someone with autism. It’s up to you to decide whether or not to take part. If you do decide to take part, you will be given this information sheet to keep and asked to sign a consent form, and you are still free to withdraw at any time and without giving a reason. Your decisions either way will not affect any services you receive.

If you decide to take part, you will be asked to complete a short survey on the service you received at NAAAS.

All information that is collected about you during the course of the research will be kept strictly confidential (except as might be required by law). Any information about you will have your name removed so that you cannot be recognised from it. Once the study is completed, the final report will be available on our website: http://www.qub.ac.uk/research-centres/cba.

My name is Professor Karola Dillenburger, and I am the Principal Investigator on this project. If you have any further questions you can contact me by e-mail at k.dillenburger@qub.ac.uk.

Thank you very much for reading this information sheet

\textsuperscript{12} Participant information and consent were incorporated in the on-line version of the survey as part of the initial access question- if consent was not given (by clicking ‘disagree’), the participant exited the survey.
Appendix 3: Consent form for participants completing surveys in hard copy

(To be on headed paper)

CONSENT FORM

Title of Project: Northern Adult Autism Advisory Service (NAAAS) Evaluation

Researcher: Professor Karola Dillenburger

Please tick and initial box

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. □

2. I understand that my participation is voluntary and that I am free to withdraw at any time up to the point where my information becomes anonymised (because after that, it will not be possible to trace), without giving any reason, without services or legal rights being affected. □

3. I understand that the researchers will hold all information and data collected securely and in confidence for up to five years and that all efforts will be made to ensure that I cannot be identified as a participant in the study (except as might be required by law) and I give permission for the researchers to hold relevant data. □

4. I agree to take part in the above study. □

________________________  ________________  __________________
Name of Participant       Date           Signature
Appendix 4: Service Provider Survey

Northern Adult Autism Advisory Service (NAAAS) on-line Survey

The purpose of this survey is to evaluate the services offered through NAAAS. You are invited to participate in this survey because you provide services for individuals with autism and their families through the NAAAS and your experiences are an important part of the evaluation.

This evaluation is conducted by Queen’s University Belfast (Professor Karola Dillenburger in the School of Education). You are invited to take part because you provide services to the NAAAS. If this does not apply to you, please do not complete the on-line questionnaire.

Your participation is voluntary and you may choose not to take part. If you decide to take part in this survey, you may withdraw at any time. The survey is completely confidential; we do not collect any information which can identify you.

This study has been approved by the Queen’s University School of Education Research Ethics Committee.

The on-line survey will take approximately 10 minutes. Once completed all data are stored in a password protected electronic format. The final report of the findings will be available free to download from www.qub.ac.uk/cba and also on the Northern Health and Social Care website. Findings may be used in academic and Trust publications/presentations and media.

If you have any questions about the study, please contact Professor Karola Dillenburger, at k.dillenburger@qub.ac.uk.

ELECTRONIC CONSENT: Please select your choice below.

Clicking on the "agree" button below means that:

• You have read the above information
• You voluntarily agree to participate
• You are providing services to NAAAS

If you do not wish to participate in the study, please click on the "disagree" button.

☐ agree
disagree

Q1. What is your role in relation to NAAAS?

Q2. How often do you attend the NAAAS sessions?
   - Once per week
   - Once every second week
   - Once every four weeks
   - By request only
   - Other (please specify)

Q3. Who do you meet (please tick all that apply)
   - Adults with autism
   - Adults with autism along with a family member/carer
   - Family member/carer of adult with autism

Q4. Do you arrange follow-up appointments at NAAAS?
   - Yes * Filter question: do you arrange follow-up appointments at a different site (e.g. Benefits office, Housing Executive ) Yes/No
   - No * Filter question: Would this be a useful addition to the service you presently provide? Yes/No

Q5 Have you had specific training for working with adults with autism?
   - Yes* Filter question: What level of training do you have?
     Level 1= Basic awareness
     Level 2=Practical strategies for e.g. effective communication or problem behaviour
     Level 3= Specialist training (e.g. diagnosis/assessment )
     ASD Level 1 training
     ASD Level 2 training
     ASD Level 3 training
     Other (please specify)
   - No * Filter question: What level of training would be useful?
     ASD Level 1 training
ASD Level 2 training
ASD Level 3 training
ASD Level 4 training
Other

Q6. Following contact at the NAAAS, can you track the outcome of the original query for the individuals using your service?
- Yes
- No

Q7. Do service users provide feedback on your service?
- Yes
- No

Q8. Do you think the current provision for service users at NAAAS is
- Adequate
- Inadequate * Filter question: Please give details (e.g. not enough time, inconvenient location, lack of resources etc)

Q9. Do you think the current provision at NAAAS for you as a service provider is
- Adequate
- Inadequate * Filter question: Please give details (e.g. problems with working environment, issues with resources, location of service, capacity of service etc)

Q10. Did participation at the NAAAS help you meet your business objectives?
- Yes
- No

Q11. Did participation at the NAAAS help you to achieve objectives relating to the Autism Strategy?
- Yes
- No
Q12. Is there anything which you think could improve the services offered by you or by partner agencies at NAAAS?

- Yes * Filter question: Please give details
- No

Thank you for taking the time to complete this survey.
Appendix 5: Survey for eligible adults who have not used the service

The Northern Adult Autism Advice Service (NAAAS) for non-users

The Northern Adult Autism Advice Service (NAAAS) wants to make sure that the needs are met of everyone who uses the service. This survey is part of an evaluation of NAAAS, conducted by Queen’s University Belfast (by Professor Karola Dillenburger in the School of Education). You are invited to take part because you have not yet used the NAAAS, and it is important to take your views into account when considering the future of the service. If this does not apply to you, please do not complete the on-line questionnaire.

Your participation is voluntary and you may choose not to take part. If you decide to take part in this survey, you may withdraw at any time. If you decide not to take part or if you withdraw at any time, it will not affect any services you receive, either now or at any time in the future. The survey is completely confidential; we do not collect any information which can identify you.

This study has been approved by the Queen’s University School of Education Research Ethics Committee.

The on-line survey will take approximately 10 minutes. Once completed all data are stored in a password protected electronic format.

The final report of the findings will be available free to download from www.qub.ac.uk/cba and also on the Northern Health and Social Care website. Findings may be used in academic and Trust publications/presentations and media.

If you have any questions about the study, please contact Professor Karola Dillenburger, at k.dillenburger@qub.ac.uk.

ELECTRONIC CONSENT: Please select your choice below.

Clicking on the "agree" button below means that:

• You have read the above information
• You voluntarily agree to participate
• You are at least 18 years of age
If you do not wish to participate in the study, please click on the "disagree" button.

☐ agree
☐ disagree

INTRODUCTION to QUESTIONNAIRE:

Thank you for taking the time to complete this survey.

Any questions marked with an asterisk (*) require an answer in order to progress through the survey.

In order to progress through this survey, please use the following navigation buttons:

• Click the “Next” button to continue to the next page.
• Click the “Previous” button to return to the previous page.
• Click the “Exit the Survey Early” button if you need to exit the survey.
• Click the “Submit” button to submit your survey.

I am a service user with autism

I am the carer/representative of an adult with autism and I am completing this survey on their behalf

I am the carer/representative of an adult with autism and I am completing this survey on my own behalf

Q1. Are you currently using any services from Northern Health and Social Care Trust? (e.g. speech and language therapy, mental health, occupational therapy, social worker)

Yes * Filter: Please give details

No

Q2. Are you currently using any autism services from a local charity or voluntary organisation (e.g. floating support, respite/short breaks, employment support)?

Yes *Filter: Please give details of services (we don’t need to know the name of the organisation)
No

Q3. The Northern Adult Autism Advice Service (NAAAS) runs every Tuesday afternoon in the Braid, Ballymena (except at holiday periods). It is a ‘one-stop shop’ where benefits, housing, education and health advice is available for adults with autism and their families. In order to suggest improvements we would like to know why you have not yet used the service (please tick all that apply).

- I was not aware of the service
- I was not aware of the range of advice available
- The Braid is not convenient for me
- The day/time is not convenient for me
- I am not comfortable in unfamiliar places
- I am happy with the range of advice/services I am currently receiving
- I do not require any specific advice/services at the moment
- Other: Please give details

Q4. What sort of adult autism services would most closely meet your needs? Please tick all that apply.

- Central ‘one-stop shop’ held weekly (as at the Braid)
- ‘One-stop shop’ which moves between e.g. 4 centres each month
- On-line advice service
- An advocate/key worker to help me use existing services
- Employment support
- Education/training support
- More flexible respite/short breaks
- Other: please give details

Q.5. Would you consider using the NAAAS in future?

Yes

No

Thank you for taking the time to complete this survey.
Appendix 6: Question/comment sheet for Round Table discussion

QUESTIONS FOR NAAAS ROUND TABLE DISCUSSION

1. WHAT ARE THE STRENGTHS AND CHALLENGES YOU WOULD IDENTIFY?

2. WHERE WOULD YOU LIKE TO SEE THE SERVICE GOING?

3. WHAT WOULD THE PARTNERS NEED TO ACHIEVE THIS?