

A report into the E-Learning Adult Autism Training Materials funded by the Department of Health

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Introduction

During the listening stage of the Review of the Adult Autism Strategy which took place from April to November 2013, I was asked to carry out a piece of work for the Department of Health's Adult Autism Programme Board to look at autism awareness training.

Following the publication of "Fulfilling and rewarding lives: the strategy for adults with autism in England" (2010) and "Implementing Fulfilling and Rewarding Lives: Statutory Guidance for local authorities and NHS organisations to support the implementation of the Autism Strategy" (2010) the Department of Health commissioned a series of on-line resources and information about autism for those working in the health and social care sector to increase awareness, and understanding of autism across all public services. Funding of £500,000 was awarded to the Royal Colleges of Nursing, GPs and Psychiatrists, the Social Care Institute for Excellence, the British Psychological Society, Skills for Health and Skills for Care and the National Autistic Society to produce these materials.

I have written this report to look at how these materials have been developed and used, and what the plans are for the future. I spoke to most of the organisations in person, by email and telephone.

Organisations and named contact

The people and organisations I spoke to:

- British Psychological Society – Ian Jeal, BPS Learning Centre Manager
- Health Talk Online – University of Oxford – Sara Ryan, Senior Research Lead, Health Experiences Research Group, University of Oxford
- Royal College of General Practitioners – Sam McNabb, E-Learning Programme Manager
- Royal College of Nursing – Ann Norman, Learning Disabilities and Criminal Justice Nursing Advisor and Laura Downes, Group Educational Projects Manager
- Royal College of Psychiatrists – Dr Tom Berney, Honorary Consultant in Developmental Psychiatry, Northumberland Tyne and Wear NHS Trust
- Skills for Health/Skills for Care (jointly produced resource) Marie Lovell, Skills for Care Project Manager and Marc Lyall, Regional Director (West) Skills for Health
- Social Care Institute for Excellence – Patricia Kearney, Director of Innovation and Development
- National Autistic Society – Matthew Swindells, Network Autism Manager

The Questions

With the exception of the National Autistic Society, whose brief was slightly different (see page 22) I asked all other organisations the same set of questions:

Q1. Which staff did you target with your resource and why? What are you looking for as the end result? Did you target any groups of staff other than those who work for your organisation?

Q2. Did you measure how many people used the resource and did you obtain any internal feedback?

Q3. How was the resource developed, who was involved in the development process and why? Were people on the autism spectrum included in the development of the resource? How did you decide the important areas to focus on?

Q4. What did you anticipate people's knowledge was before they used the resource?

Q5. Do you have any plans for developing the resource? Are there any issues around maintaining the resource in its existing form?

Q6. Was your organisation involved in the production of any of the other Department of Health funded resources? Does your resource signpost to any other Department of Health funded online training packages?

My conclusions can be found on page 23 of this report.

John Simpson
Autism Programme Board member and
self-advocate
20 January 2014

British Psychological Society

The Society has developed three e-learning modules on autism which appeal to a range of learners by delivering knowledge and understanding from introductory to specialised levels. The e-learning modules are delivered via the BPS Learning Centre. The BPS has worked in partnership with psychologists who have expertise in autism and an e-learning provider to produce and deliver these modules. Two modules are freely available to both members and non-members of the BPS and the third is aimed principally at psychologists and all professionals working in this field.

Link to resource: <http://www.bps.org.uk/events/e-learning/e-learning>

Q1. Which staff did you target with your resource and why? What are you looking for as the end result? Did you target any groups of staff other than those who work for your organisation?

Response:

The first two resources are aimed at anyone, not just BPS staff. The third resource carries a charge of £12.50. Part of the rationale behind this is to dissuade the general public from using this part of the package as it contains concepts that require a psychological background to fully understand. This charge also helps cover in part the

cost of maintaining the resource, although the numbers of people completing this third module are small in comparison to the two free modules (see response to question 2).

Q2. Did you measure how many people used the resource and did you obtain any internal feedback?

Response:

MODULE 1 – 7,555 people

MODULE 2 – 3,250 people

MODULE 3 – 474 people

Total – 11,279 (as of September 2013)

91% of those using the resource rated it as good or excellent, and 88% rated the delivery of the resource as good or excellent. The Society has 50,000 total members, 16,000 of which are chartered psychologists.

Q3. How was the resource developed, who was involved in the development process and why? Were people on the autism spectrum included in the development of the resource? How did you decide the important areas to focus on?

Response:

The development of all three resources was primarily down to two people, Dr Sally Twist and Dr Anna Dodd. They are Chartered Psychologists for Pennine Care NHS Trust and have considerable clinical experience. The content was based upon real life cases experienced by the authors and attempts to replicate situations that may be experienced by psychologists. Once the content was decided upon the e-Learning Developer was then consulted. In terms of quality-assuring the interactive aspects of the resource, the first two are self-moderated, allowing those using the package to see the answers other users have provided to the same questions. The third resource requires members of the Society using it to enter their Society online username and password, which offers the opportunity for peers to see any common areas of difficulty in understanding.

Q4. What did you anticipate people's knowledge was before they used the resource?

Response:

The first two resources were produced so that they could be used by anyone regardless of their level of understanding of autism. It was anticipated that the third package would be used by a psychologist with at least a postgraduate qualification, because the person using it would need to have an in-depth understanding of the field.

Q5. Do you have any plans for developing the resource? Are there any issues around maintaining the resource in its existing form?

Response:

In terms of on-going development, ideally Ian Jeal and the team would want to give the resource a complete review and update, especially as there is currently no audio visual content available. Additional audio content would also be desirable. The only income which currently maintains the resource is that which is received from those paying to access the third set of materials. Whilst the administration cost of the resource is negligible, the cost of hosting and software are not covered by the income generated. One possible solution to the funding gap is to sign block contracts with NHS Trusts.

Two trusts have mandated all of their staff to undertake the packages. (Northumberland and Tyne and Wear) However, they asked staff to register via the BPS system and they did not pay to use the resource. Norfolk and Suffolk and Newcastle-upon-Tyne councils are currently talking to the BPS about adding this resource to their training programme. However, they are reluctant to pay for this themselves. This places a considerable burden upon the Society, as they are effectively subsidising NHS Trusts' training budgets. Unless new sources of funding are found, the Society will either have to charge everyone to do the course (which would likely

reduce the numbers of those participating in the course) or withdraw the resource.

Q6. Was your organisation involved in the production of any of the other Department of Health funded resources? Does your resource signpost to any other Department of Health funded online training packages?

Response:

There was no input into the course content from the providers of any other resource.

Health Talk Online – University of Oxford

The Health Talk Online website lets you share in other people's experiences of health and illness. This information is based on qualitative research into patient experiences led by experts at the University of Oxford.

Link to resource:

www.healthtalkonline.org/Autism/

Q1. Which staff did you target with your resource and why? What are you looking for as the end result? Did you target any groups of staff other than those who work for your organisation?

Response:

The resource was aimed at people with autism, parents/carers of children/adults with autism, Health and Social Care professionals and policymakers. The developers felt it was of particular use to parents and individuals who had just received a diagnosis. They felt it was especially useful in explaining to people who were unsure as to the value of being diagnosed why this process is so important.

Q2. Did you measure how many people used the resource and did you obtain any internal feedback?

Response:

The website receives around 29,120 hits a month across the whole Autism section. As was indicated above, parents in particular evaluated this resource as being very useful. It has also been used extensively by providers of academic courses. Examples of organisations which have made use of the package are the University of Birmingham and the University of Sheffield.

Q3. How was the resource developed, who was involved in the development process and why? Were people on the autism spectrum included in the development of the resource? How did you decide the important areas to focus on?

Response:

The resource was developed using the tried and tested methods of the Health Experience Research Group. An advisory panel comprised of leading academics, clinicians, third sector organisations and Autistic people advised on the development of the project. The areas of importance emerged through the research process; it was an iterative approach allowing participants to talk about the issues that were important to them.

Q4. What did you anticipate people's knowledge was before they used the resource?

Response:

The general expectation was that people's knowledge level would be fairly low, as stated above, it is particularly useful for adults who have just received a diagnosis.

Q5. Do you have any plans for developing the resource? Are there any issues around maintaining the resource in its existing form?

Response:

Recently, the entire Health Talk Online website was completely redesigned. This upgrade has meant the site now has better Google analytics, meaning that in future Health Talk Online will have a much clearer idea of who is using the site and how much time they are spending looking at different parts of the resource. It now also includes a Scrapbook feature to enable academics and casual users to tailor the resource content to meet their own needs. None of this required any funding directly related to the Autism Strategy, but came from charitable funding. Information on the site is updated every 18 months in order to comply with DoH information standards, this happens automatically. The information and knowledge obtained in producing this package also contributed to the writing of several academic papers and book chapters,

including a chapter in the book "Worlds of Autism" and a paper in the journal "Using patient experience in e-Learning", written by Susie Soar and Sara Ryan.

Q6. Was your organisation involved in the production of any of the other Department of Health funded resources? Does your resource signpost to any other Department of Health funded online training packages?

Response:

A member of the research group worked with the Royal College of General Practitioners on developing their resource. Sara Ryan was unsure about signposting to the other resources but that she would be happy to do so if it would be helpful.

Royal College of General Practitioners

The Autism in General Practice course enables GPs to improve the care they provide for patients with Autistic Spectrum Conditions (ASC). Using video clips of real patients and carers recounting their experiences, this course helps to understand the challenges that people with ASC face on a daily basis.

Links to resources:

[www.elearning.rcgp.org.uk](http://elearning.rcgp.org.uk)

<http://elearning.rcgp.org.uk/course/view.php?id=78>

Please note: Whilst these links direct you to the Royal College of General Practitioners (RCGP) Website, a charge of £35 is required to access the resource for people who are not RCGP members.

Q1. Which staff did you target with your resource and why? What are you looking for as the end result? Did you target any groups of staff other than those who work for your organisation?

Response:

The resource was free for an initial one year period. After this period the resource remained free to RCGP members but non-members were asked to pay a charge of £35 to access it. This funding is used to

maintain the website. However, given the numbers of GPs paying to access this training, the resource does not currently cover the costs for support, hosting and updating the websites. Whilst this situation is currently not a major concern for the Royal College, there are no plans to update the resource. This may lead to information becoming out of date (see Q5 below).

Q2. Did you measure how many people used the resource and did you obtain any internal feedback?

Response:

Of those accessing this package, an average starred rating of 4.1 out of 5 was awarded. This is slightly above the average level of satisfaction normally recorded for an RCGP resource.

Q3. How was the resource developed, who was involved in the development process and why? Were people on the autism spectrum included in the development of the resource? How did you decide the important areas to focus on?

Response:

The training was written by Dr Nigel Scott, a GP with a special interest in autism. The College followed an established process in producing the resource. Once funding from the Department of Health was obtained, a scoping meeting was held and Dr Scott was recruited. Once Dr Scott had developed the material it was peer reviewed by other General Practitioners and by the Department of Health. The decision was taken to form a partnership with Health Talk Online, another provider funded by the Department of Health (see information on Health Talk Online found separately within this report), in order to ensure that what was produced was centred on the patient experience. However, other than Health Talk Online, there was no real input from people with autism.

Q4. What did you anticipate people's knowledge was before they used the resource?

Response:

The material's content was not necessarily based upon a supposed level of knowledge; but rather by incorporating five areas essential to Primary Care of people on the spectrum. These were the foundations behind the four unit titles which can be found within the resource. Most GPs who begin using the

resource take a pre-course questionnaire then work through all four sessions:

- Recognising Patients with an ASC;
- Improving Communication with Patients with an ASC;
- Supporting and Managing Patients with an ASC; and
- Improving the Service offered to People with an ASC and their carers.

GPs are then able to leave reflective comments on their learning and complete a post-course assessment.

Q5. Do you have any plans for developing the resource? Are there any issues around maintaining the resource in its existing form?

Response:

The information contained within the resource was reviewed in 2012. However, a review and amendments are not possible now unless further funding is made available. The RCGP would normally review content every 2-3 years. Whilst current running costs are limited to platform support and user technical support, the College remain content to leave the information in its current form. However, developments not just around research and practice in autism but also the way GP services are organised and commissioned may lead to the resource becoming outdated within the next couple of years. If this happens, the College may

need to remove the resource from their site. The RCGP would normally charge an annual delivery and hosting fee incorporating a content update and, if the resource remains an RCGP member benefit (i.e. only free to RCGP members), then it would be around £3,500 for any future update.

Q6. Was your organisation involved in the production of any of the other Department of Health funded resources? Does your resource signpost to any other Department of Health funded online training packages?

Response:

No other Department of Health funded training provider other than the University of Oxford's Health Talk Online was contacted whilst developing this training.

Royal College of Nursing

These resources were produced by RCN Publishing, a wholly owned subsidiary of the Royal College of Nursing, which publishes a weekly magazine for nurses. They produced a poster with basic information about the condition, as well as a more detailed booklet “aimed at people in a specialist role who will lead the planning, development and commissioning of services with local authorities and GP consortia”.

There is also an online centre signposting to all of the other materials discussed in my report. These links are available as free downloads for all healthcare professionals that may come into contact with people who have autism, highlighting key issues to consider.

Links to resources:

<http://rcnpublishing.com/userimages/ContentEditor/1373363796507/Autism-poster.pdf>

<http://rcnpublishing.com/userimages/ContentEditor/1373364280087/Autism-booklet-2011.pdf> (Developing specialist skills in autism practice, page 4)

<http://rcnpublishing.com/page/ns/resources/autism-online-resource-centre>

Q1. Which staff did you target with your resource and why? What are you looking for

as the end result? Did you target any groups of staff other than those who work for your organisation?

Response:

At RCN Publishing, Laura Downes set up an autism resource centre comprising most, if not all, of the resources funded at the time. They have provided the link as open access – most of their online resources are only available to their magazine subscribers. Jill Aylott, author of the guide, is a senior lecturer and research lead at the Centre for Professional and Organisational Development, Sheffield Hallam University; she has published several papers on autism. Laura Downes, project manager, is a registered nurse and has had over 20 years experience of commissioning and publishing educational guides and research for nurses.

Q2. Did you measure how many people used the resource and did you obtain any internal feedback?

Response:

In the last year, the autism resource centre homepages on the Learning Disability Practice, Mental Health Practice, and Nursing Standard and Primary Health Care websites has received 3,963 page views.

Laura Downes was project lead for the key stakeholders on the poster. Several thousand copies were printed and distributed. Through their journals, they distributed approximately 20,000 copies. Ann Norman also distributed through the RCN. The poster is also available for download and printing. Laura was also contacted by the Criminal Justice Department and sent several copies of the poster for use in prisons. Additionally, she was contacted by teachers. This means that the news and resources have stretched far beyond nurses, which is of course the RCN/RCN Publishing's core business. The autism guide that RCN Publishing produced was distributed through their journals *Learning Disability Practice* and *Mental Health Practice*, free to readers. Approximately 15,000 hard copies were sent out.

Q3. How was the resource developed, who was involved in the development process and why? Were people on the autism spectrum included in the development of the resource? How did you decide the important areas to focus on?

Response:

As with all of the RCN'S resources and publications, the guide went through double-blind review thereby guaranteeing quality assurance. This means that the author does not know who the reviewer is and the reviewer does not know who the author is, therefore ensuring impartiality. The poster was developed by RCN Publishing with key

stakeholders who have expert knowledge of autism, including The National Autistic Society.

Q4. What did you anticipate people's knowledge was before they used the resource?

Response:

The poster is aimed at people whom it is assumed have little or no knowledge of autism and acts as a quick checklist/guide to aid communication and understanding of particular needs and behaviour patterns. The guide is aimed at nurses working in learning disability and mental health practice with specialist knowledge of autism. It is intended to raise knowledge and understanding of the DH Autism Strategy.

Q5. Do you have any plans for developing the resource? Are there any issues around maintaining the resource in its existing form?

Response:

RCN Publishing has no plans to update the guide or poster, but if funding is available to update or add to these resources they would be happy to take this on as a project. RCN Publishing/the RCN generally assume a three year 'shelf life' for information to be current. When DH strategies are reviewed it is optimal to provide nurses with the most up to date information to guide them in clinical practice.

Updates also help to raise awareness and remind nurses of important issues that need taking into consideration.

Q6. Was your organisation involved in the production of any of the other Department of Health funded resources? Does your resource signpost to any other Department of Health funded online training packages?

Response:

Laura worked very closely with the National Autistic Society when developing the poster. They worked with people who have autism and their parents and carers to ensure that the messages were appropriate and clear.

Royal College of Psychiatrists

The Royal College of Psychiatrists aims to engage in expanding knowledge about the psychiatry of learning disability and autism.

The resource consists of a standard diagnostic interview guide, available to anyone and free to download from the College website. It is intended to assist psychiatrists in the diagnosis of “straightforward” autism (see below). College members can also access video clips of interviews with people on the autism spectrum and their families. The college also organised several training events (see below). The diagnostic guide was produced by:

- Dr Tom Berney, Honorary Consultant in Developmental Psychiatry at Northumberland Tyne and Wear NHS Trust
- Dr Peter Carpenter, Consultant Psychiatrist in Learning Disabilities, Avon and Wiltshire Partnership NHS Trust and Honorary Senior Lecturer in Mental Health, University of Bristol
- Professor Terry Brugha, Professor of Psychiatry at the University of Leicester and Honorary Consultant Psychiatrist at Leicestershire Partnership NHS Trust

Link to resource:

<http://www.rcpsych.ac.uk/>

Q1. Which staff did you target with your resource and why? What are you looking for as the end result? Did you target any groups of staff other than those who work for your organisation?

Response:

The funding from the Department of Health was used to further a programme of training primarily aimed at helping those psychiatrists unfamiliar with autism (i.e. in specialties other than child psychiatry or intellectual disability psychiatry) to become better able to recognise, diagnose and manage it. The basic purpose of the resource was to assist in the diagnosis of straightforward autism. It was recognised that more subtle forms of the condition and those with comorbidities would probably require much longer diagnostic interviews than those based on the diagnostic guide.

The programme of training consists of three one-day modules. Module One is a general introduction, Module Two focuses on diagnosis and Module Three on management. Each module includes a presentation by a volunteer with Asperger syndrome and the module on diagnosis largely comprises interviews with the volunteer as well as an informant (who may be a friend, family member or carer). Dr Berney also stated that the publicity

generated by both the Autism Strategy and the presence of autism in the media were a great help. The diagnostic form is designed so that it can be used by anyone wishing to make a diagnosis, although it is preferable for those using it to have been present on the training days. The funds provided by the Department of Health paid for the production of the film which was used in the training modules to provide a wider exposure to symptomatology than could be gained from the volunteers.

Q2. Did you measure how many people used the resource and did you obtain any internal feedback?

Response:

Dr Berney stressed that the general diagnostic tool can be used by anyone, though obviously it is preferable for anyone using it to have been present on the training courses and to have seen the video clips.

Q3. How was the resource developed, who was involved in the development process and why? Were people on the autism spectrum included in the development of the resource? How did you decide the important areas to focus on?

Response:

The videos were made with the assistance of a professional filmmaker. In these,

six volunteers and their accompanying informants were interviewed by either Dr Carpenter or Dr Berney. Each of these contributors was paid a small fee for their contribution. Their consent specifies that the videos are restricted to psychiatric training so that the material is on members' section of the College website (which is not available to public access). However, this material is primarily intended for use in the training modules and attendees are encouraged to use the website to clarify and reinforce what they have learnt.

Q4. What did you anticipate people's knowledge was before they used the resource?

Response:

Part of the rationale behind the production of the resource was an understanding that the capability of doctors to diagnose autism varies across psychiatric specialities. Whilst child and adolescent and adult learning disability psychiatrists generally have a good knowledge and understanding of autism, general adult psychiatry is less familiar with autism and it was for this reason that this group was targeted. The individual's age and the lack of informants meant that general psychiatry tends to put a greater emphasis on the person's immediate presentation rather than their earlier development. Therefore, this became an important point of emphasis in the programme.

Q5. Do you have any plans for developing the resource? Are there any issues around maintaining the resource in its existing form?

Response:

One possible area for improvements is that the clips lack examples of how individuals with autism are affected by sensory differences. The video material had been selected to illustrate the characteristics identified by ICD-10/DSM IV as diagnostic. DSM V has put more emphasis on sensory symptomatology, and while this has been incorporated into the teaching programme, the diagnostic guide and the video material has yet to be updated.

Note: DSM and ICD are the two main sets of criteria used for diagnosing and classifying “mental disorders” in Britain and as such Autism is included as a diagnosis in both DSM and ICD. DSM V was produced by the American Psychiatrists’ Association, whereas ICD is the International Classification of Diseases produced by the World Health Organisation. Its 11th revision is due to be published by 2015.

Skills for Health/Skills for Care

Skills for Health and Skills for Care have developed a framework to guide the delivery of autism training for the mainstream health and social care workforces.

Representatives of Skills for Health and Skills for Care were interviewed together as they collaborated jointly to produce this resource. Skills for Care are responsible purely for the workforce development of adult care staff in England only, whereas Skills for Health have responsibility for the workforce development of all health staff across the whole of the UK.

Link to resource:

<http://www.skillsforcare.org.uk/Document-library/Skills/Assisted-Living-Technology/Autism/Autismskillsandknowledgelist.pdf>

Q1. Which staff did you target with your resource and why? What are you looking for as the end result? Did you target any groups of staff other than those who work for your organisation?

Response:

This resource was not developed just for autism specific services, but for generic services that everybody uses. The resource was not designed simply for those doing entry level jobs, but for all staff involved in health and care jobs, such as receptionists, doctors, dentists – the vast majority of whom

will have received little or more likely no autism training. Part 4 of the resource **www.skillsforhealth.org.uk/service-area/autism/** is considered to be suitable for psychiatrists and psychologists as it focuses on planning of services and developing diagnostic and assessment skills – however given the remit of the work this section is very short and largely points to the need for further work.

Q2. Did you measure how many people used the resource and did you obtain any internal feedback?

Response:

Last summer an evaluation was undertaken and repeated again this summer. Responses were received from a range of individuals including those who develop training, health and social care workers, and family members of people who have autism. 110 people responded to the survey in 2012 with further responses received in 2013.

Q3. How was the resource developed, who was involved in the development process and why? Were people on the autism spectrum included in the development of the resource? How did you decide the important areas to focus on?

Response:

The resource was developed as a result of a contract jointly set up with the National Autistic Society to provide focus groups direct or indirect consultation with 2,315 people, including Health and Social Care managers and professionals, 836 family carers and 80 people with autism. The rationale behind the development of the resource can be found using: *Getting it right for people with autism – the research behind the ‘autism skills and knowledge list’* on the Skills for Health/Skills for Care websites. The organisations then used the findings to identify the main issues for people with autism in using generic services. Once they had done this, they produced the draft list and then checked this with the focus groups described above.

Q4. What did you anticipate people’s knowledge was before they used the resource?

Response:

The general assumption made was that those using Parts 1, 2 and 3 of the resource would have a baseline or low level of knowledge. Part 4 of the resource is considered suitable for psychiatrists and psychologists or others planning services.

Q5. Do you have any plans for developing the resource? Are there any issues around maintaining the resource in its existing form?

Response:

Whilst both organisations are happy to cover the current costs of maintaining the resource, and many of the skills and techniques advocated by the training package are not likely to change in the near future, developments may occur which require changes to the content. There was a suggestion that a Skills for Health/ Skills for Care qualification in autism could be produced but a similar qualification in learning disabilities produced a low take-up so the organisations are wary of doing this.

Q6. Was your organisation involved in the production of any of the other Department of Health funded resources? Does your resource signpost to any other Department of Health funded online training packages?

Response:

The producers of this resource had difficulty talking to the providers of the other resources with the exception of the National Autistic Society. However, they would see no problem in joint referencing with other organisations should those organisations want this.

Social Care Institute for Excellence

This training package looks at the techniques and skills that care workers and social workers need to support people with autism and help them achieve their goals. The link will take users directly to the page with two Autism films on it.

Link to resource:

<http://www.scie.org.uk/socialcaretv/topic.asp?t=workingwithpeoplewithautism>

The Social Care Institute for Excellence (SCIE) has also produced a guide titled *SCIE's Guide 43: Improving Access to Social Care for Adults with Autism*. The link below provides access to the full guide, an at-a-glance summary of it, an easy-read of the summary, and the underpinning research from the University of Sussex. This guide was not produced using the same funding from the Department of Health as other resources mentioned in this report.

Link to guide:

<http://www.scie.org.uk/topic/careneeds/autism>

Q1. Which staff did you target with your resource and why? What are you looking for as the end result? Did you target any groups of staff other than those who work for your organisation?

Response:

The resource was developed with the intention of containing inclusive language which would be appropriate to any care services, not just Autism Specific Social Care Services, and to be appropriate to care workers and social workers.

Q2. Did you measure how many people used the resource and did you obtain any internal feedback?

Response:

The SCIE recorded people visiting the site in two separate groups. The first were those who visited any part of the site (4,130) and also those who specifically watched the video clips of individuals on the spectrum (1,346).

Q3. How was the resource developed, who was involved in the development process and why? Were people on the autism spectrum included in the development of the resource? How did you decide the important areas to focus on?

Response:

The guide was produced in conjunction with an advisory group, which included academics, representatives of autism

charities and organisations, parents of people on the spectrum and people with autism themselves. The guide is NICE evidence accredited, with an evidence base for the final recommendations. In common with all other resources produced by the SCIE it is currently in a three yearly review cycle. The information within it is scoped every year, but in the case of most resources produced by the SCIE, it would not normally undergo wholesale changes until it had been online for three years. It can be maintained as it is until 2014 unless research is produced or policies change and in doing so either of these invalidate some of the information contained within it.

Q4. What did you anticipate people's knowledge was before they used the resource?

Response:

The development of the guide was predicated upon the user having low knowledge. It contains information that is not obvious but is evidence based common sense. It is designed so that it not only provides important information but also the reasons why a particular approach is important.

Q5. Do you have any plans for developing the resource? Are there any issues around maintaining the resource in its existing form?

Response:

If the Department of Health wanted an update or for the resource to be changed, they can ask the SCIE to cost it. There is no direct cost of maintaining the resource as it currently stands. If a large scale change to the content was needed a commission would be required, but the SCIE would be happy to absorb the cost of smaller updates. As much of the information contained within is practice based, the need for an update is not as pressing as for a more technical resource.

Q6. Was your organisation involved in the production of any of the other Department of Health funded resources? Does your resource signpost to any other Department of Health funded online training packages?

Response:

As was stated above, the guide was put together by an advisory group, all of whom are acknowledged within the guide. This included representation from the National Autistic Society.

National Autistic Society

Link to the National Autistic Society (NAS) website: <http://www.autism.org.uk/>

The role of the NAS was somewhat different to the other training providers as they did not develop their own piece of e-learning. Instead the funding was used in the following ways:

The funding given to the NAS served two purposes. Firstly, it enabled the creation of online web resources with the intention of assisting the implementation of the strategy. These included an Autism Hub, which aimed to provide a “one-stop shop” for contact details of relevant autism stakeholders and services across the country, including many Diagnostic and Local Authority Leads. Secondly, it enabled a conference in Central London to take place and the setting up of four focus groups across the different regions of the country: North, Central, South East and South West. These were attended by both providers, and Local Authority and NHS Commissioners. However, these two groups were consulted separately due to potential conflicts of interest. A survey was run alongside the focus groups to find out what professionals knew and what they needed more help with.

The NAS was not the central focus of the other providers when they developed their resources, but help was sought by some of them as and where appropriate. There is no direct feedback from those using

the resource, but since the resource was launched over 200,000 visits have been recorded.

In terms of ongoing development, clearly there are aspects of the resource in need of updating. It is probable that some information regarding Local Authority Autism leads is out of date, as some of the Local Authority and Diagnostic Leads will have moved on since the directory was produced. Maintenance of the resource rests with the NAS Policy team, and whilst they are able to update on an ad hoc basis, they are not funded to do so and are unable to keep all of the information up to date. There is also a concern that areas recognised in the resource as examples of “good practice” may themselves have undergone considerable change since the resource was published.

Whilst no plans are currently in place to upgrade the resource, the conference and focus group process and resulting conversations with commissioners and providers lead to the establishment of Network Autism. It was recognised that professionals needed an opportunity to share good practice. As a result of the focus groups, the NAS researched viability of such a network and invested separately in the Network. This network now has over 4,200 professionals registered as users and is a continuing legacy of the money spent.

Conclusions

It is important to acknowledge that these resources are the first step that many of these training organisations have taken in specifically including autism in any form as part of their e-Learning packages. Autism is an extremely complex condition, one which many of us who consider ourselves to be “experts” often struggle to understand fully. Most of the providers felt that the majority of people using their packages would have little or no knowledge of autism, and I believe this was the correct assumption to make.

Some organisations chose not to directly engage with people on the spectrum in developing their training, but I was satisfied in all cases that an appropriate level of autism knowledge had been included to make the resources worthwhile. However, I would prefer to think going forward that all training providers would see the value of direct input of people with an Autistic Spectrum Condition into any resources produced. I believe that people on the spectrum provide a unique insight that cannot be matched by even the most empathetic neuro-typical person. For any training in the field of autism to be of maximum value, the voices of people on the spectrum must be represented. I think it is vitally important to understand that being an expert in any medical or care field does not automatically make a person an expert in Autism, and I was satisfied that

training providers for professional groups had acknowledged this in their development.

It must also be acknowledged that many of the organisations are currently maintaining their resources at a cost to themselves. Most providers currently allow open access to their resources free of charge. Some have chosen to include a fee for access; usually as a means of covering some of the expense of maintaining the site. Whereas in some cases they are happy to do this, others are considering what future their resource has if changes are not made, and for some this may mean removing their work from their websites if further funding is not forthcoming. This is particularly important for providers which have created resources that rely on up-to-date information about practice in their area of specialism. The web hosting of interactive resources is also in itself a cost, as DSM V starts to be used and ICD-11 becomes active in the UK in the future.

Many of the organisations also routinely review their training materials on a cyclical basis, and it was disappointing but understandable that of most concern was often maintaining the resources in their current state rather than developing them further. It would seem to me that the cost of developing these resources would often be considerably less than creating them in the

first place, as much of the ground work is already done.

A relatively small amount of investment per resource could work to “future proof” them for several years; I believe this would be a wise investment. It would seem a great shame if the good work that all of these providers did in producing these resources, not to mention the initial £500,000 total investment, was wasted when a spend of around £5,000 for some of the providers may be enough to give them another three years of validity (though for others the cost may be greater). As was pointed out to me during my research, updates themselves can be of some use in generating publicity and awareness.

Most of the resources I looked at did have interactive elements to them, including an opportunity for people to check their knowledge at the end. However, whilst many of these offered the opportunity for peer review of answers, there appeared to be no formal way for any of the providers to check whether there were any particular knowledge gaps for those people doing the training. Generally, feedback from those using the resources tends to be positive, though for the reasons listed above it is difficult to be able to judge the difference this training has made to practice. However, from my own perspective, the resources do deal with a lot of the basic issues that people with autism contend with when trying to access support from health or social care professionals.

One area of difficulty for many organisations was gaining input from other Department of Health funded partners in the production of their resources. I do not feel that all organisations were fully aware of what other Department of Health funded groups were doing and many of these resources do not signpost to the work of other organisations. More collaborative working between these providers could produce more streamlined packages and also help reduce the overall cost of any potential updates across the providers.

Going forward, the main area of concern is maintaining the existing resources. I believe that what has already been produced is a good starting point; however, funding is needed in order to maintain what has already been produced, and providers and the Department of Health need to find a way to produce more concrete evidence of the benefits of this training to health and social care professionals. It would also be good if the training teams involved in producing these resources were able to use the expertise and experience they have accrued over many years together with the focus they gained from producing the e-Learning to inform better face to-face-training. One of the things that was mentioned to me was that the current heightened publicity around autism, both because of the strategy and high-profile cases in the media, means that projects such as these pieces of e-Learning can gain extra impetus.

In conclusion, I believe the review of the Autism Strategy in 2014 offers the Department of Health an excellent opportunity to help these providers build on the positive momentum that has already been generated to further develop their resources.

Appendix A: The 2010 Adult Autism Strategy

1. The Autism Act 2009 was followed in 2010 by the Adult Autism Strategy and strategic guidance for LAs and the NHS which set out five areas for action aimed at improving the lives of adults with autism:

- increasing awareness and understanding of autism;
- developing a clear, consistent pathway for diagnosis of autism;
- improving access for adults with autism to services and support;
- helping adults with autism into work;
- enabling local partners to develop relevant services.

2. The overall aim was that:

“All adults with autism are able to live fulfilling and rewarding lives within a society that accepts and understands them. They can get a diagnosis and access support if they need it, and they can depend on mainstream public services to treat them fairly as individuals, helping them make the most of their talents.”

3. The strategy is built on a fundamental recognition that too many people with autism are missing out on the chance of the quality of life that others enjoy. This is a denial of their potential, their personal aspirations,

their hopes for the future and places a heavy burden on their families. Change is, however, a long-term process and the strategy offered a practical approach for that, including identifying how to make existing policies work better for adults with autism. This did not depend on new investment and focused on ensuring mainstream services actively identify and respond to the needs of adults with autism.

4. The strategy aimed to put in place central structures and statutory guidance to support implementation of specialist services and joint working by local commissioners, LAs and the NHS, responsible for planning and funding services for people with autism – and public, private and third sector delivery organisations, responsible for providing services for people with autism. The Department of Health is the lead policy department for the strategy, but with delivery shared across a range of Government departments and agencies and reflecting the move to local accountability, health and social care service providers.

Appendix B: Links to all the Autism Training and Awareness On-line Training Resources

ROYAL COLLEGE OF NURSING

These links are available as free downloads for all healthcare professionals that may come into contact with people who have autism, highlighting key issues to consider.

<http://rcnpublishing.com/userimages/ContentEditor/1373363796507/Autism-poster.pdf>

<http://mentalhealthpractice.rcnpublishing.co.uk/>

<http://rcnpublishing.com/userimages/ContentEditor/1373364280087/Autism-booklet-2011.pdf>

www.rcn.org.uk – this link provides a general link to RCN resources, which include links to professional forums for members and publications.

<http://rcnpublishing.com/page/ns/resources/autism-online-resource-centre>
– RCN autism resource centre.

ROYAL COLLEGE OF GENERAL PRACTITIONERS

The Autism in General Practice course enables GPs to improve the care they and their practice provide for patients with Autistic

Spectrum Conditions (ASC). Using video clips of real patients and carers recounting their experiences, this course helps to understand the challenges that people with ASC face on a daily basis.

www.elearning.rcgp.org.uk

<http://elearning.rcgp.org.uk/course/view.php?id=78>

ROYAL COLLEGE OF PSYCHIATRISTS

The Royal College of Psychiatrists aims to engage in expanding knowledge about the psychiatry of learning disability and autism.

If you encounter any difficulties opening these links, please contact the Royal College of Psychiatrists on Tel: 020 7235 2351.

<http://www.rcpsych.ac.uk/>

SKILLS FOR HEALTH & SKILLS FOR CARE

Skills for Health and Skills for Care have developed a framework to guide the delivery of autism training for the mainstream health and social care workforces.

SKILLS FOR HEALTH

www.skillsforhealth.org.uk/service-area/autism/

SKILLS FOR CARE

<http://www.skillsforcare.org.uk/Document-library/Skills/Assisted-Living-Technology/Autism/Autismskillsandknowledgelist.pdf>

SOCIAL CARE INSTITUTE FOR EXCELLENCE

This training package looks at the techniques and skills that care workers and social workers need to support people with autism and help them achieve their goals. The link will take users directly to the page with two Autism films on it.

<http://www.scie.org.uk/socialcaretv/topic.asp?t=workingwithpeoplewithautism>

SCIE have also produced a guide titled *SCIE's Guide 43: Improving Access to Social Care for Adults with Autism*. The link below provides access to the full guide, an at-a-glance summary of it, an easy-read of the summary, and the underpinning research from the University of Sussex:

<http://www.scie.org.uk/topic/careneeds/autism>

BRITISH PSYCHOLOGICAL SOCIETY

The Society has developed three e-learning modules on autism, which appeal to a range of learners by delivering knowledge and understanding from introductory to specialised levels. The e-learning modules are delivered via the BPS Learning Centre. The BPS has worked in partnership with psychologists with expertise in autism and an e-learning provider to produce and deliver these modules. Two modules are freely available to both members and non-members of the BPS and the third is aimed principally at psychologists and all professionals working in this field.

<http://www.bps.org.uk/events/e-learning/e-learning>

UNIVERSITY OF OXFORD

The Health talk online website lets you share in other people's experiences of health and illness. This information is based on qualitative research into patient experiences led by experts at the University of Oxford.

www.healthtalkonline.org/Autism/

NATIONAL AUTISTIC SOCIETY

The National Autistic Society website provides increased awareness and understanding of autism. It also details some of the examples of autism awareness training that currently exist.

<http://www.autism.org.uk/>