Autism Strategy
(2013 – 2020)
and
Action Plan
(2013-2015)

Consultation Questionnaire

RESPONDING TO THE CONSULTATION

The NI government departments are seeking your views on the draft cross-departmental Autism Strategy and Action Plan. Please use this questionnaire to tell us your views on the draft document.

Please send your response, no later than 15 March 2013, to:

DHSSPS Autism Strategy Core Team
Room D1
Castle Buildings
Stormont Estate
BELFAST BT4 3SQ

Tel: 028 9052 2153
Fax: 028 9052 2500
E-mail: Autism.Strategy@dhsspsni.gov.uk

Please note that all responses will be treated as public and may be published on the DHSSPS website. If you do not want your response to be used in this way, or if you would prefer for it to be used anonymously, please indicate this when responding (See Statement of Confidentiality and Access to Information Legislation below).
Confidentiality and Access to Information Legislation

Information provided in response to this consultation, including personal information, may be published or disclosed in accordance with access to information legislation: these are chiefly the Freedom of Information Act 2000 (FOIA), the Data Protection Act 1998 (DPA) and the Environmental Information Regulations 2004 (EIR).

If you want the information that you provide to be treated as confidential, please be aware that, under the FOIA, there is a statutory Code of Practice (section 45) with which public authorities must comply and which deals, amongst other things, with obligations of confidence. In view of this, it would be helpful if you could explain to us why you regard the information you have provided as confidential. If we receive a request for disclosure of the information, we will take full account of your explanation, but we cannot give an assurance that confidentiality can be maintained in all circumstances. An automatic confidentiality disclaimer generated by your IT system will not, of itself, be regarded as binding on the DHSSPS.

For further information about confidentiality of responses please contact the Information Commissioner’s Office

Information Commissioner’s Office Northern Ireland
51 Adelaide Street
Belfast, BT2 8FE

Tel: 028 9026 9380
Fax: 028 9026 9388
Email: ni@ico.gsi.gov.uk
Website: http://www.informationcommissioner.gov.uk/

Please tick the box below if you do want your response to be treated as anonymous.

[ ] I want my response to be treated as anonymous.

Thank you for completing this questionnaire and providing input to this consultation.
### SECTION 1: ABOUT YOU

#### Consultee Details

**Question 1(a):**

I am responding as... *(Please tick one option only)*

- [ ] A person with autism
- [ ] A parent / carer of a person with autism
- [ ] A family member of a person with autism
- [X] On behalf of an organisation
- [ ] Other.........................................................*(Please specify)*

**Question 1(b):**

Please enter your details below:

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<thead>
<tr>
<th>Name:</th>
<th>Karen Hagan</th>
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<tr>
<td></td>
<td>Dr Frances Morton</td>
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<tr>
<td>Job Title: <em>(if applicable)</em></td>
<td>Staff Tutor/Senior Lecturer</td>
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<td>Policy and Public Affairs Executive</td>
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<tr>
<td>Organisation: <em>(if applicable)</em></td>
<td>The Open University</td>
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<td>Address:</td>
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<td>Email Address:</td>
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**SECTION 2: VISION, VALUES, AIMS AND OBJECTIVES**

**Question 2:**

Do you agree with the vision, values, aim and objectives for the Strategy?

*(Please tick one option only)*

- [ ] Yes
- [ x ] No

If no, please explain why and / or let us know how you think these could be improved.

The Open University considers the values, aims and objectives for the Strategy to be excellent but suggest an addition.

In line with the United Nations Convention on the Rights of Persons with Disabilities and the Strategy Vision it would be useful to include ‘Respect’ in the list of underpinning values in Section 1.4 Vision and Values. The inclusion of the notion of respect for, and acceptance of, difference would allow perspectives of people with autism to be included.

Section ‘1.5 Aim’ is excellent but might be seen as a stepping stone to responding directly to needs as perceived by people with autism. An opportunity exists to go beyond raising awareness, support and social inclusion to promoting reasonable adjustments in society. This would relate better to valuing and accepting difference. This is managed to some degree in ‘Section 1.6 Objectives’ under the term ‘inclusive’ and in later sections, e.g. ‘3.2 Accessibility’, but there is a need to ensure that the level and quality of inclusion and input are underpinned more deeply by respect/acceptance of difference and the promotion of reasonable adjustments.
The themes of the Strategy have been developed in consideration of some of the articles in the United Nations Convention on the Rights of Persons with Disabilities. They include:

- Awareness
- Accessibility
- Children, Young People and Family
- Independence / Choice and Control
- Transitions
- Employment and Employability
- Accessing Justice
- Being Part of the Community
- Participation and Active Citizenship

Question 3:

Do you agree with all the themes in the Strategy? *(Please tick one option only).*

[X] Yes
[ ] No

If no, please explain why and let us know how you think the themes could be improved.

The Open University is ‘open to people, places, methods and ideas’. The themes identified for this Strategy all resonate with our mission to widen participation and to increase social mobility, particularly for students who are disabled, or who are carers. With over 17,000 declared disabled students registered at October 2012, The Open University has the largest community of disabled student of any UK university. A significant proportion of students with disabilities and long-term health conditions choose the OU because it suits their lifestyle.

Our disabled students report that they could not have participated in HE level study and completed assignments without the adapted learning materials, access to technology and the support we provide.

442 students in September 2012 declared Autism spectrum as a disability.
### Section 4: Strategic Priorities and Action Plan

The NI Government Departments are aiming to implement the strategic priorities of the Autism Strategy over a **seven-year period (2013 – 2020)**.

They will aim to achieve the actions and outcomes measures as set out in the initial ‘Laying the Foundations’ Action Plan, over a **two-year period (2013 – 2015)**.

A further two Action Plans will be developed to fully deliver the strategic priorities in terms of ‘Whole-life Journey’ and ‘Holistic Personalised Approach’.

#### Question 4(a):

Do you agree with the strategic priorities on Awareness for this Strategy? *(Please tick one option only)*

- [ X ] Yes
- [ ] No

If no, please explain why and let us know how you think these could be improved.

The Open University welcomes the strategic priorities on Awareness and is willing to provide information or case studies which can assist awareness-raising, especially on students with autism who study with the OU.

#### Question 4(b):

Do you agree with the actions and outcome measures on Awareness in the Action Plan (2013 – 2015)? *(Please tick one option only)*

- [ ] Yes
- [X] No

If no, please explain why and let us know how you think these could be improved.

The Open University would welcome how reports of experiences will be collected, if any mechanism is in place or is to be put in place to do this, and if an existing baseline will be made available for comparison.
In terms of frontline training referred to (Action 1.2), The Open University currently offers relevant education opportunities through a level one, online module, Understanding the autism spectrum. The Open University also provides a free course entitled The autistic spectrum: from theory to practice available on its OpenLearn website. This website is the UK’s largest source of free university learning materials, with over 19 million unique visitors since 2006.
The Open University welcomes the strategic priorities defined under Accessibility. Widening access and success to achieve social mobility is core to the The Open University’s mission.

The Open University has a Disability Advisory Service which supports staff with disability-related enquiries, resources and training, and can provide expert advice in relation to autism, and the multifarious requirements for students across the autism spectrum.

In Northern Ireland we have a dedicated Student Services Manager for disabled students, who regularly deals with the additional needs and requirements of students with autism, and their advocates, if necessary.

The Open University is willing to provide information on its support services as part of this strategy and action plan consultation. Further detail can be accessed at http://www.open.ac.uk/disability/

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<th>Question 5(a):</th>
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<tr>
<td>Do you agree with the strategic priorities on Accessibility for this Strategy? (Please tick one option only)</td>
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<th>Question 5(b):</th>
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<td>Do you agree with the actions and outcome measures on Accessibility in the Action Plan (2013 – 2015)? (Please tick one option only)</td>
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Accessibility is a significant and positive section in the Action Plan, however some of the actions and outcomes are worked up in detail while others seem quite general or vague. The development of a transparent pathway for parents to access services pre-diagnosis, and when a full diagnosis has not been forthcoming, would be helpful to include as an outcome.

There are lots of fitting proposals in this section in particular, the ‘one-stop shop’ where accessing service provision might be tailor-made. This would rationalise the time and effort parents and people with autism must spend to have needs addressed.
### SECTION 4: STRATEGIC PRIORITIES AND ACTION PLAN

**Question 6(a):**

Do you agree with the strategic priority on *Children, Young People and Family* for this Strategy? *(Please tick one option only)*

[X] Yes  
[ ] No

If no, please explain why and let us know how you think these could be improved.

The Open University welcomes this strategic priority.

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**Question 6(b):**

Do you agree with the action and outcome measures on *Children, Young People and Family* in the Action Plan (2013 – 2015)? *(Please tick one option only)*

[ ] Yes  
[X] No

If no, please explain why and let us know how you think these could be improved.

We would welcome further clarification of Action 3.1.2. ‘Support provision for families and in particular siblings of children with autism scoped/ scaled’. At present it is not clear what ‘scoped/scaled’ means.
SECTION 4: STRATEGIC PRIORITIES AND ACTION PLAN

Question 7(a):

Do you agree with the strategic priority on *Independence, Choice and Control* for this Strategy? *(Please tick one option only)*

[ ] Yes  
[ ] No

If no, please explain why and let us know how you think these could be improved.

The Open University encourages a holistic and personalised approach to health where individuals are able to take ownership of their health, the services they receive and the care they wish to access. The OU is committed to educating individuals and communities in order to enable informed decisions to be made about personal health care. It also assists professionals to understand the implications of personalisation proposals on delivering care.

Currently, the OU offers a short (non-accredited course) in *Personalisation in Health and Social Care*. This module espouses the proposals of the consultation ‘Transforming Your Care’ in providing information on self-directed care. We also offer a standalone module in *Managing care (K303)*.

In particular, The Open University can contribute to the proposal to train staff and raise awareness through its free online learning resources, for example “What is Autism?” and the course on “The Autism spectrum – from theory to practice”. The Open University also facilitates this informal learning into formal learning, and provides a number of standalone modules on autism, such as “Understanding the autism spectrum” in addition to qualifications.

Question 7(b):

Do you agree with the action and outcome measure on *Independence, Choice and Control* in the Action Plan (2013 – 2015)? *(Please tick one option only)*
[ X ] Yes
[   ] No

If no, please explain why and let us know how you think these could be improved.
Question 8(a):
Do you agree with the strategic priority on Transitions for this Strategy? (Please tick one option only)
[X] Yes
[ ] No
If no, please explain why and let us know how you think these could be improved.

As stated above, The Open University provides information, advice and guidance services for any potential students who have autism, and may be considering entering higher education.

Question 8(b):
Do you agree with the action and outcome measure on Transitions in the Action Plan (2013 – 2015)? (Please tick one option only)
[ X ] Yes
[ ] No
If no, please explain why and let us know how you think these could be improved.
SECTION 4: STRATEGIC PRIORITIES AND ACTION PLAN

Question 9(a):

Do you agree with the strategic priorities on Employment and Employability for this Strategy? (Please tick one option only)

[X] Yes
[ ] No

If no, please explain why and let us know how you think these could be improved.

The Open University welcomes this strategic priority to increase the opportunities for people with disabilities to attain skills and qualifications through access to appropriate training and lifelong learning opportunities.

With over 17,000 declared disabled students registered at October 2012, the OU has the largest community of disabled student of any UK university. Disabled students represent approximately 9.5% of our student body, and 11% of our student body in Northern Ireland.

The Open University’s range of support for disabled students is extensive, including alternative formats, assistive equipment and special arrangements for tutorials, residential schools and examinations.

The Securing Greater Accessibility (SeGA) Project is a major initiative launched recently by the OU to create an ‘access hub’ for the sector, focusing on the development of good practice in teaching and learning for disabled students.

The OU is developing a pan-institutional approach to accessibility and inclusivity, all of which delivers, promotes, reinforces and further influences the disabled student learning experience. Our on-going research and evaluation into the disabled student learning experience and new assistive technologies is shared with the wider education community to foster good practice. We welcome the opportunity to share this with the health sector. Disabled students are one of the target groups of the OU’s recently launched Access to Success Widening Participation strategy.

The Open University welcomes the opportunity to work with a number of government departments, particularly DEL, to support people with disabilities to develop new or existing skills, and to gain and retain employment.
Question 9(b):

Do you agree with the action and outcome measure on *Employment and Employability* in the Action Plan (2013 – 2015)? *(Please tick one option only)*

[ X ] Yes  
[   ] No

If no, please explain why and let us know how you think these could be improved

The Open University will work with DEL to achieve these actions and outcome measures.
### Question 10(a):
Do you agree with the strategic priority on Accessing Justice for this Strategy? *(Please tick one option only)*

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If no, please explain why and let us know how you think these could be improved.

### Question 10(b):
Do you agree with the action and outcome measures on Accessing Justice in the Action Plan (2013 – 2015)? *(Please tick one option only)*

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If no, please explain why and let us know how you think these could be improved.

The output/outcome measures throughout this section were significantly detailed. We would seek a similar level of detail in the User/Carer Defined outcomes to break down exactly what constitutes ‘better support’ through the justice system.
### Question 11(a):

Do you agree with the strategic priority on *Being Part of the Community* for this Strategy? *(Please tick one option only)*

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If no, please explain why and let us know how you think these could be improved.

The Open University welcome this strategic priority, noting the opportunity within it to enhance access and community participation for people with autism. We would seek further clarification on the concept of community and whether this includes interests and preferences as defined by people with autism.

### Question 11(b):

Do you agree with the action and outcome measure on *Being Part of the Community* in the Action Plan (2013 – 2015)? *(Please tick one option only)*

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If no, please explain why and let us know how you think these could be improved.

Given that enhancing and increasing social mobility and student success is key to the OU mission, we welcome these actions.
### SECTION 4: STRATEGIC PRIORITIES AND ACTION PLAN

**Question 12(a):**

Do you agree with the strategic priorities on *Participation and Active Citizenship* for this Strategy? *(Please tick one option only)*

[ ] Yes  
[ ] No

If no, please explain why and let us know how you think these could be improved.

Given that widening participation is key to the OU mission, we welcome this priority.

**Question 12(b):**

Do you agree with the action and outcome measures on *Participation and Active Citizenship* in the Action Plan (2013 – 2015)? *(Please tick one option only)*

[ ] Yes  
[ ] No

If no, please explain why and let us know how you think these could be improved.
SECTION 5: EQUALITY IMPACT ASSESSMENT QUESTIONS

In this section of the questionnaire we are asking you to tell us if you think the draft Autism Strategy (2013 – 2020) and initial Action Plan (2013 – 2015) have promoted equality of opportunity in the Section 75 groups between persons of:

(1) Different religious belief,
(2) Different political opinion,
(3) Different racial group,
(4) Different age,
(5) Different marital status,
(6) Different sexual orientation;
(7) Different gender
(8) With a disability and persons without; and
(9) With dependants and persons without.

Question 13:

Are the actions / proposals set out in this consultation document likely to have an adverse impact on any of the nine equality groups identified under Section 75 of the NI Act 1998? (Please tick one option only)

[ ] Yes
[x] No

If yes, please state the group or groups and provide comment on how these adverse impacts could be reduced or alleviated in the proposals.
SECTION 5: EQUALITY IMPACT ASSESSMENT QUESTIONS

Question 14(a):

Are you aware of any indication or evidence – qualitative or quantitative - that the actions / proposals set out in this consultation document may have an adverse impact on equality of opportunity or on good relations?
(Please tick one option only)

[ ] Yes
[ x ] No

If yes, please give details and comment on what you think should be added or removed to alleviate the adverse impact.

Question 14(b):

Is there an opportunity to better promote equality of opportunity or good relations?
(Please tick one option only)

[ x ] Yes
[ ] No

If yes, please give details as to how.

The Open University considers the themes and values in this strategy to be excellent and provide a framework for real progress for people with autism. Suggested opportunities have been noted throughout but in summary there are opportunities to:

- Encourage and support society and organisations to respect and accept differentness in people with autism
- Not just expect people with autism to fit into existing communities, structures and ways of being but to open up these concepts to allow people with autism to be have communities and organisations which are truly inclusive and accept their interests
- Encourage and support reasonable adjustments by expanding on the level and quality of accessibility – though this is a great starting point.
Parents and people with autism often have difficulty accessing and using services supportively despite improved service protocol and increased resources so there is an opportunity to consider an advocacy service to support them in accessing services.

**Question 14(c):**

Are there any aspects of this action plan where potential human rights violations may occur? *(Please tick one option only)*

[ ] Yes
[ x ] No

If yes, please give details.
The Open University’s flexible, part-time distance learning offer plays an important role in increasing social mobility and widening participation to non-traditional learners in Northern Ireland, and across the UK, and therefore is uniquely placed to support this strategy and action plan.

The OU is the largest academic institution in the UK and a world leader in flexible distance learning. Since it began in 1969, the OU has taught more than 1.8 million students.

- Given the focus on frontline training to give people with autism and their carers more access, choice and control means that there is greater demand for well-trained and multi-skilled people across a range of rewarding employment opportunities.
- The Open University currently offers relevant education opportunities through a level one, online module, Understanding the autism spectrum. The Open University also provides a free course entitled The autism spectrum: from theory to practice available on its OpenLearn website. This website is the UK’s largest source of free university learning materials, with over 19 million unique visitors since 2006.

- The Open University already has training materials for Associate Lecturers teaching students on the autism spectrum and currently supports a number of successful students with Asperger’s/autism.

We have been consistently rated by students as one of the top three teaching universities in the UK (and specifically in Northern Ireland) in the annual National Student Survey, since its inception in 2005.

The combination of excellent teaching materials and outstanding student support makes the OU ideally positioned to support students with particular needs.

The Open University has a dedicated Service for Disabled Students.