



Autism Spectrum Disorder

A Draft Agenda for Europe

Report on the Third Panel of Experts on Autism Spectrum
Disorder

A meeting hosted by the European Commission Directorate for Health and Consumers (DG-SANCO), Jean Monnet House, Luxembourg.

11-12 March, 2010

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A Draft Agenda for Europe

Introduction

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition that affects approximately 1 in every 100 individuals in a population (according to reports from the UK in 2006 and 2009). Those affected by autism lie along a spectrum ranging from severe autism, as originally described by Kanner in 1943, through to the more subtle but often equally challenging behaviours of Asperger syndrome and Pervasive Developmental Disorder not otherwise specified (PDDnos). Although ASD is not as yet fully understood, some things are generally accepted: ASD is caused by a mixture of predominantly genetic but also environmental factors; symptoms of ASD are present from as early as 12 months of age; the best outcomes for children are often achieved through early diagnosis and early intervention; few countries have as yet developed a national strategy or legislation and there is widespread ignorance about ASD within broader society. ASD does not only affect the individual and their families but it also impacts on society at large, possibly having direct relevance to roughly 5% of any population and coming with substantial economic costs (approximately €32bn annually to the UK economy).

This report represents the completion of the first stage of a long-term project: the design and implementation of coherent recommendations for a public health policy across the EU on ASD. This report will offer a summary account of the meeting of the Third Panel of Experts on ASD, held in Luxembourg on 11-12 March 2010, and also provides the basis for further regional conferences in Budapest and Majorca to be held in September 2010, before the strategic public health plan for autism is presented at an event to be held in Dublin in November 2010.

The Luxembourg meeting identified that there must be at least three dimensions to any public health policy addressing ASD in the EU. These are a policy dimension, a responsibility dimension, and a national dimension. The first dimension has five major strands:

- research;
- provision of services (health and educational);
- active development of ASD policies;
- awareness and advocacy;
- surveillance and monitoring (i.e. collecting data to monitor changes in the population).

For each strand, consideration needs to be given to the second dimension, which is where the primary responsibility lies, and we identify five potential leaders:

- people with ASD;
- their families and carers;
- health, education and policy professionals;
- national governments;
- the EU itself.

The third dimension is the diversity of the 27 EU member states. Inevitably, each country differs in their approaches to ASD and the policies and services they have for individuals on the spectrum. There are also differences between countries in terms of priorities for, and requirements from, any public health policy for ASD across Europe.

Below is a summary of the content and outcomes of the Third Panel of Experts Meeting on Autism (see Appendix 1 for the meeting agenda).

Third Panel of Experts Meeting on Autism Spectrum Disorder

The Third Panel of Experts meeting on ASD was a vital opportunity for many voices from the European community to be heard and for opinions to be shared as to how best meet the goal of improving the lives and opportunities of individuals with ASD and their families.

Day 1 and Setting the Context

Invitations from DG SANCO (EC's Directorate General, Department for Health and Consumers) went to a broad range of stakeholders and there was representation from 14 European countries. The Panel of Expert's task was to discuss a strategic direction for the continent on public health and ASD, and so delegates were selected to represent expertise in research, clinical services (health and educational), awareness and advocacy, policy, and surveillance/monitoring (e.g. data registries & epidemiology).

On the first day, Mr Nick Fahy and Mr Antoni Montserrat of DG SANCO set out their commitments to ASD and a roadmap of how advances in public health and ASD should be made (an overview of DG SANCO and their commitments to ASD can be found in Appendix 2). It was made clear to those present that it is not the role of the Commission to decide on health policy, as that is the responsibility of national governments, but what must be decided upon in implementing a public health strategy is the key objectives and what is to be left for national governments to decide upon.

Day 1 also included a series of presentations and discussions to "*set the context*" on the current landscape of ASD in Europe; to identify particular challenges and where there is an opportunity for the European community to work to its unique strengths. Professor Anthony Bailey from the University of Oxford presented on priorities and objectives for European

research; Professor Tony Charman from University of London presented on the evidence base for intervention and educational provision; Dr Manuel Posada from Carlos III Institute, Madrid, summarised current autism prevalence research; Dr Michel Favre from Autisme Europe outlined the organisation's leadership in advocacy, special initiatives and information sharing; Dr Alvaro Ramirez presented on the findings of the EC funded European Autism Information System (E AIS) and a vision for autism in Europe through the recently formed European Autism Public Health Alliance (**eapha**) (see Appendix 3 for further information on E AIS and **eapha**).

From the presentations and subsequent discussion, there was a consensus that more research is needed, especially into the prevalence and causes of autism in both children and adults; there was a call for better services, especially those related to early diagnosis and intervention, as well as the support of adults and professional training. In the area of policy, there was felt to be a need for better co-ordination, the definition of minimum satisfactory standards, and the creation of a strategic plan for a European public health policy for autism. There was a strong call for steps to be taken to increase public awareness of autism, and to monitor the effects of interventions and treatments rigorously and with regard to quality of life. Also discussed was that some services available to families in Europe were neither evidence-based nor properly scrutinized.

Day 2 and the Small-Group Workshops

On Day 2 of the meeting the participants were divided into four working groups to discuss strengths and weaknesses, needs and priorities, in each of the five areas of research, services, policy, awareness and advocacy, and surveillance/monitoring. There were innovative recommendations from each of the groups and the main needs and some of the priorities identified were as follows:

- 1. Research:** more research into the evidence base of interventions and educational provision; greater use of randomised control trials; studies of aetiology including associated co-morbidities (like mental health difficulties, epilepsy and gastro-intestinal problems); more longitudinal research, especially that which follows individuals into adulthood; an increase in the number of prevalence studies and consensus over study design; increased number of studies of the economic cost of ASD to be used as part of cost-benefit arguments; application of neuroscience, molecular studies and biological research to diagnosis, treatments and educational interventions.
- 2. Services:** increased training in early detection and screening protocols; improved professional training in the delivery of early intervention and educational provision; consensus on European training protocols and minimum satisfactory standards in screening, intervention/education and diagnosis; prioritising services to prepare people with ASD for the workplace and the workplace for people with ASD; services to be developed specifically for the adult and ageing autism population.

- 3. Policy:** identification and dissemination of current national legislation and policy guidelines on ASD; harmonisation of national policies towards emergent best practice; improved coordination and communication across community services (e.g. health, education and social care sectors); awareness that ASD is a lifelong condition and services should be designed accordingly. Existing policy documents, such as the European Declaration on the rights of people with autism, the UN Convention on the Rights of Persons with Disabilities and others, should be used to support development of national policies and lobbying activities.
- 4. Advocacy and Awareness:** importance of self-advocacy and listening to the voices of individuals with ASD; improved access to high quality, evidence-based information (e.g. web-based dissemination); challenging the stigma of ASD via public awareness campaigns; increased awareness in schools to the problems of bullying; access to information and awareness raising for professionals only indirectly involved with ASD – e.g. the police and employees.
- 5. Surveillance and Monitoring:** the need to collect accurate prevalence data; services should be continuously monitored and improved; children with ASD should be identified early and then surveyed throughout their life so they do not fall out of the system; existing national databases should be updated; provision of data ‘for the sake of data’ is an expensive luxury.

Conclusions

The final session of the meeting focused on the task of identifying a shortlist of themes that came through strongly during the discussion, recognising that budgets are inevitably limited and not everything can be done at once. The following items were those themes that the panel of experts identified but the list is not exhaustive and should be regarded as a guideline to use during the consultation at the upcoming regional meetings in Budapest and Mallorca in September 2010.

Research

1. The identification of biomarkers to be included in treatment studies (e.g. using neuroimaging pre- and post-intervention)
2. Review of the efficacy and cost-effectiveness of early intervention programmes
3. Research into the co-morbidities of ASD and appropriate treatments

Services

1. Diagnosis and support of adults with autism
2. Increased training for parents and carers
3. Needs assessments with regular reviews

Policy

1. Co-ordination of policy amongst agencies and dissemination of models of good practice
2. Agreed protocols for professional training
3. Harmonisation of national policies for autism

Advocacy

1. Recognition of the importance of self-advocacy
2. Creation and coordination of lobby groups across the EU
3. Need for accessible information for all and effective communication about autism to reduce stigma

Monitoring

1. Establish a unique code for ASD in national registries
2. Compatible databases and methods for prevalence
3. Prioritise what data is important to collect for surveillance

It was further agreed that the principles of cost-effectiveness, rigorous research methodology and quality of life must underpin all this work, if it is to be truly effective.

Findings and Recommendations

The first finding to emerge from these discussions is a consensus that the project to develop a public health policy for autism across Europe is desirable, worthwhile and timely. The second finding is the importance of exploring each one of the three dimensions detailed in the introduction: the five major strands of any public health policy; the five main contributors to the process of implementing such a policy; and the range of nations comprising the EU. The third is the importance of careful and wide-ranging consultation.

Participants in the Luxembourg Panel of Experts meeting unanimously agreed that this Report should be drafted and circulated to each one of them for comment. Following receipt of these comments, the Report has been redrafted and will be posted on the website www.autism2010.eu. A consultation process involving as many stakeholder organisations as possible throughout Europe will be carried out through the website. This will ensure that stakeholders have the opportunity to comment on the report or to make a contribution concerning the strengths and needs in relation to their area of focus in their own country/region. The final draft document will provide the input for the sub-regional meetings to be held in Eastern and Western Europe in September 2010. The final strategic public health plan with recommendations on ASD for the EU will be written during October 2010, including specific recommendations for action, and will be presented to Ministers and other delegates at the European Autism Action Conference to be held in Dublin on 29th November 2010.

Appendix 1



EUROPEAN COMMISSION
HEALTH AND CONSUMERS DIRECTORATE-GENERAL
Public Health and Risk Assessment
Health information

SANCO/C2/Version 2

AGENDA **3rd Panel of Experts on Autism Spectrum Disorder**

11th March – 10:00

INTRODUCTION

- **10-10.15**
Chairman's opening comments and objectives for the meeting
 - Sir Christopher Ball
- **10.15-10.30**
DG SANCO and a strategic vision for health in Europe
 - Mr Antoni Montserrat DG-SANCO

SETTING THE CONTEXT

- **10.30-11.10**
European autism research: where are we now and what does the future hold?
 - Professor Anthony Bailey, University of Oxford
- **11.10-11.50**
An overview of autism prevalence research
 - Dr Manuel Posada, Carlos III Institute, Madrid
- **11.50-12.30pm**
Evidence based provision for individuals with autism
 - Professor Tony Charman, Institute of Education, London

LUNCH

- **1.30-2.10**
Autism and advocacy in Europe
 - Dr Michel Favre, Autisme Europe
- **2.10-2.50**
A public health vision for autism in Europe
 - Dr Alvaro Ramirez, European Autism Alliance

COFFEE BREAK

OUTLINING A PUBLIC HEALTH STRATEGY ON AUTISM FOR EUROPE

- **3.15-4.15:**

Panel Discussion

The chairman, Antonio Montserrat and the five presenters from SETTING THE CONTEXT will constitute a panel to lead a Q&A session on points raised from the presentations.

- **4.15-5.30**

Roundtable discussion

Panel members will have been asked prior to the meeting to prepare a short list of specific needs and strengths in terms of autism research, services, policy, advocacy and surveillance within their country/region. A discussion will be held around these issues to identify country, regional and continent wide challenges that need to be addressed and to search for models where there are proven successes.

12TH March – 09:30

- **9.30-11**

Small group workshop

In the morning session panel members will break out into small groups to discuss what was covered on the first day and their task is to list areas of particular need for autism in Europe around the key public health topics of research, services, policy, advocacy and surveillance. They will also be tasked to list particular objectives for Europe in the medium term (next 10 years) and a strategy for how those should be achieved.

- **11-12.30**

Outlining a European public health strategy on autism

A roundtable discussion will be held to outline a strategy for Europe over the next 10 years around the key public health areas of research, services, policy, advocacy and surveillance. Group leaders from the Small Group Workshop will feedback to the panel.

Discussion will focus on the potential for using the strength and diversity of the European Union, the need for Eastern European countries to be supported in terms of increasing autism awareness and developing evidence based services, and how through defining sustainable organisational structures the European community can show international leadership and strength.

The group will outline a series of recommendations, milestones and measurable objectives for a European public health strategy on autism.

- **12.30-1pm**

Conclusion and future directions

The final session will include summarising common themes from the meeting and a strategy to communicate these to the EU and the wider community. A subcommittee of the expert panel will be identified to write up the outcomes of the meeting and to disseminate to European partners.

Appendix 2

DG SANCO and ASD

DG SANCO is the EU's Directorate General for Health and Consumers, and oversees health for citizens of European member states. Policies on health are typically set by the government of each member state country and although DG SANCO is in a position to draw up EU wide legislation it typically acts to pool European expertise on health, to identify and share models of best practice and to help coordinate recommendations on specific diseases or conditions.

DG SANCO has a website through which information on diseases and conditions can be disseminated. Contained within this site is a very useful page on Autism Spectrum Disorders (http://ec.europa.eu/health/major_chronic_diseases/diseases/autistic/) that provides an overview of current European activities. The site also has an important section on the rights of people with ASD and their families, and in particular the vital work of Autisme Europe in bringing together European autism advocacy organisations, promoting inclusion and legislating against discrimination of people with ASD (<http://www.autismeurope.org/>).

It has been important for autism stakeholders in Europe that EU Work Plans on ASD were included as part of implementing the programme of Community action in the field of public health (2003-2008). As part of these Work Plans the European Autism Information System (EAIS; see following section) <http://www.eais.eu> and the European Network of Surveillance on risk factors for Autism and Cerebral Palsy (ENSACP) <http://www.ensacp.eu> studies were funded. DG SANCO hosted two previous European Panel of Expert meetings on autism in 2006 and 2007 (see minutes from these meetings at: <http://www.eais.eu/content.php?page=146>), and in 2010 funded a conference grant "European Autism Action 2020: Working Conference on a Strategic Plan for Autism" <http://www.autism2010.eu>

Appendix 3

The EAIS and eapha: a vision for the future

The European Autism Information System (EAIS) project was implemented in 2006, co-funded by the European Commission DG-SANCO. This project established protocols, guidelines and a network of professionals and researchers to initiate a Europe-wide information and knowledge management system for ASD. An important outcome of the EAIS project was to lay the foundations for the creation of a new sustainable network on ASD, the European Autism Public Health Alliance (**eapha**) <http://www.eapha.eu> (website under construction), as a multi-stakeholder forum to facilitate communications between and co-ordination of professional expertise in the EU on:

- Early detection and diagnosis of autism
- Management and monitoring of data systems (surveillance)
- Prevalence and economic impact of ASD in the EU
- Interventions and treatments of ASD
- The ageing population with ASD
- Public and professional awareness of ASD
- EU policies

Essentially, **eapha** aims to bring together the various ASD stakeholders from across Europe, comprising the five main groups below:

- Individuals with ASD and their families
- Organisations representing individuals with ASD, their families and carers, in different European countries
- Research and academic institutions
- Professionals who work with individuals with ASD from health, education and the social care fields, and the organizations representing these professionals
- Government departments and agencies

These five groups represent those who are affected by ASD and its consequences, as well as those who are seeking to identify its causes and effects, and therefore guide future treatments. In addition, they represent public bodies that are responsible for the development and provision of services. By bringing these five stakeholder groups together it is anticipated that major advances could be made to elaborate, endorse and implement an agreed regional public health approach on ASD.

The process of forming a public health vision for ASD in Europe will take into account that a number of EU member States are relatively advanced in their own national policies on ASD, whilst others have very little policy at all. **eapha** looks forward to the involvement of the stakeholders from these countries in future discussions and to build on their experiences to

provide targeted and detailed support to those most in need. The approach of **eapha** embraces the true spirit of the European Union.

Appendix 4

Acknowledgements

The authors of this report would like to thank DG SANCO for sponsoring and organising this meeting and making important contributions throughout the two days. The authors would also like to thank Anna McElhinney and Abigail O'Donovan for taking notes. Our final thanks must go to all those who gave up their time and contributed as experts. These individuals are listed below:

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Prof Ricardo Canal, University of Salamanca, Spain
Prof Tony Charman, University of London, UK
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Dr Daniel David, University of Cluj, Romania
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