

European Autism Action 2010

Conference Report
Executive Summary

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Autism Spectrum Disorder: a Vision for Europe

Introduction

Autism Spectrum Disorder (ASD) is a significant public health challenge. Current estimates are that approximately 1% of the US and UK population has ASD, which, if one were to extrapolate, means five million people in EU member state countries are on the autism spectrum. These current estimates show that ASD is more common than childhood cancer, juvenile diabetes and paediatric AIDS combined. European countries and the European Commission should act now to alleviate some of the challenges that are faced by people with ASD and their families.

The European Autism Action 2020 (**aaa2020**) project is both timely and necessary. Awareness and prevalence of ASD has increased rapidly over the last ten years but there is still a lack of knowledge of the landscape of ASD in European countries. Many families and individuals on the autism spectrum have a daily struggle, so understanding, support and guidance is needed. The annual economic costs of ASD for the UK economy are over €32bn but with the right services and opportunities individuals with ASD and their families can become important contributors to society.

Autism Spectrum Disorder¹

ASD is a lifelong disorder that has profound effects on a person's development. Within the autism spectrum there is enormous diversity. Some individuals live in their own world and don't engage in social interaction; whereas others desire social contact but understand the rules governing social interaction. Some individuals never develop speech; whereas others may have an extensive vocabulary but fail to understand how to engage in a conversational to-and-fro. Some individuals spend much of their time engaging in solitary repetitive behaviours (e.g. lining up objects); whereas others have restricted interests but identify practical ways to use their skills.

ASD is more common in males than females. Approximately half of individuals with ASD have an additional intellectual disability (i.e. they have an IQ below 70). Individuals with ASD are at increased risk of additional medical diagnoses. Rates of epilepsy, sleep difficulties, feeding and gut difficulties, mental health problems, other developmental disorders and learning difficulties are higher in individuals with ASD. Diagnosing autism still remains a significant challenge. Tools to screen for and diagnose autism have been developed and improved our conceptualisation of the autism spectrum. However, good professional training remains key to the accurate and early diagnosis of ASD.

There are likely to be many causes of ASD. The genetic basis has been well researched and there are findings to suggest that approximately 10% of ASD cases can be explained by small mutations in the genetic code. It is likely that these genes affect early brain development and the way that brain cells communicate with each other (synaptic functioning). Environmental factors also play a role in a person's susceptibility to ASD but currently these factors are under-researched and not well known.

Although medication is often given to patients on the autism spectrum, there are currently only two Food and Drug Administration (FDA) pharmaceutical treatments approved for treating irritability in ASD: Risperdal and Aripiprazole. In most cases, treatment for ASD is behavioural. Applied Behaviour Analysis (ABA) and Treatment and Education of Autistic and Communication related handicapped CHildren (TEACCH) are common intervention approaches used but broadly speaking the evidence base for any approach or intervention is mixed. The situation for adults is much worse. ASD-specific interventions and services for adults are almost non-existent, reflecting the lack of understanding and investment in provision for adults.

¹ There is much debate as which term should be used to describe individuals on the autism spectrum, which includes the clinical diagnoses of autism, Asperger Syndrome and Pervasive Developmental Disorder not otherwise specified. For the purposes of this report, and in line with the future adjustments to DSM, we have chosen to use Autism Spectrum Disorder.

European Autism Action 2020: developing a public health framework

Real progress has been made in our understanding of ASD but there is much still to do. The purpose of the European Autism Action 2020 (**ea2020**) programme, which was proposed by the European Autism Public Health Alliance (**eapha**) in 2009, is to execute an immediate, sustainable and organised response to the public health challenges faced by the ASD community across Europe. ASD does not just affect the individuals, but also their families, the local community, clinicians, educators, researchers and policy makers. So when creating a vision for Europe on ASD one must consider the various roles that are to be played and how that fits within a public health framework.

In March 2010, the European Commission's DG-SANCO funded a Panel of Experts Meeting in Luxembourg, organised by eapha and Autism Speaks, as a preliminary meeting for the **ea2020** programme. Those that contributed to the Panel of Experts meeting realised that there must be at least three dimensions to any public health policy addressing ASD in Europe. These are a content dimension, a responsibility dimension, and a national dimension. The first dimension requires a focus on knowing:

- how to raise public and professional awareness;
- how many individuals in a population have autism (epidemiology);
- what are the causes of autism (research of risk factors);
- what are the best treatments or services;
- what policies and guidelines should be in place for future planning.

For each strand from the content dimension, consideration needs to be given to the second dimension, which is where the primary responsibility lies. Five potential leaders were identified:

- people with ASD;
- their families and carers;
- health, education and policy professionals, both public and private sector
- national governments;
- the EC itself.

The third dimension is to consider the diversity of the 27 EU member states and the additional non-EU European countries. Each country differs in their approaches to ASD and in the policies and services they have for individuals on the autism spectrum.

This dimensional framework guided the consultation exercise that took place in 2010 and the structure of the final report. The activities of **ea2020** in 2010 started with the Panel of Experts Meeting in Luxembourg, followed by a consultation exercise with stakeholders in two sub-regional meetings, before the final presentation of the findings in Dublin in November.

Findings from the sub-regional consultation exercise

As a result of a grant from EC's Executive Agency for Health and Consumers to Irish Autism Action (IAA), and additional financial support from Autism Speaks and the Irish Department of Health and Children, two sub-regional meetings were organised by **eapha** and held in September. For the meeting in Budapest, 41 delegates were invited from a total of 17 countries; for the Majorca meeting a total of 18 countries were represented by 59 delegates.

Representatives from each country were set the challenge of describing ASD in their country using the public health dimensional framework described in the previous section. There were also small and large group sessions to list recommendations for a public health vision on ASD in Europe.

The findings from these meetings, as well as from an online consultation that has taken place since September, are as follows:

Awareness

In most European countries public and professional awareness of ASD remains limited. Particularly in central and Eastern Europe, families and individuals on the autism spectrum struggle with the negative stigma associated with ASD and face barriers to accessing services and employment opportunities. Awareness of adults and the elderly with ASD is particularly poor. Autism Europe is a successful point of information dissemination and coordination of parental and advocacy groups across Europe.

Epidemiology

Countries tend to fall into three categories in terms of prevalence data. They either have no data, they calculate estimated population prevalence based on the UK/US 1% figure or they have their own national prevalence figure. The prevalence figures that were collected during the meetings fell across a large range, from regarding ASD as quite rare through to greater than the 1% population rate. Clear differences in methodology underpinned this range of estimates. A further feature was the lack of individuals with ASD registered on public service databases or surveyed over time.

Research

There is a lack of research funding or collaborative efforts to identify (genetic or environmental) risk factors for ASD. However, the findings of the ENSACP project are important to this evidence base. Few research designs explore the uniqueness of European populations (e.g. varying parental age; migrant populations), utilise existing European research networks (e.g. BrainNet Europe) or coordinate large-scale data collection across countries. The evidence base for early and school-delivered interventions is poor or inconsistent in terms of reported outcomes. The amount of ASD research in central and Eastern Europe is small, as a result of limited funding and capacity. There is also a lack of research governance in this region of Europe.

Services

No consensus exists on how to screen, diagnose, provide clinical care or educate people with ASD. Most countries do not have guidelines on how to develop a service infrastructure for ASD, although there are some examples (particularly from the Nordic countries) of excellent practice. The situation is particularly bad for adults and the elderly with ASD, who are often left undiagnosed, receiving inappropriate services or without access to enabling environments (e.g. employment; independent living). One of the clearest statements from all delegates is that professionals and caregivers need access to knowledge and training in the most effective approaches.

Policy

A number of countries have specific ASD legislation or related special educational needs legislation. There is also the European Charter for Persons with Autism and UN declarations on human, children and disability rights. Knowledge and dissemination of these documents is poorly coordinated. In some countries, when legislation has been passed, there is poor planning or implementation of the law.

There was general agreement that the ten-year strategic health plan of **ea2020** is desirable, worthwhile and timely. On the one hand, it is clearly not fair to autistic people, their families and carers, that the provision of support across many parts of Europe is far from excellent, and in many places not good enough to meet their needs. On the other, it is argued that it will provide a more economic deployment of resources to develop a coherent strategic public health plan for autism, than to fail to do so.

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Recommendations and conclusions

The **ea2020** public health strategy has a ten year timeline, for which **eapha** will be the driving force. ASD is in a constant state of flux and so the recommendations below are short term. In 2014 we recommend that the EC fund a review of the landscape of ASD in Europe with a series of meetings similar to those that have been held this year. As part of this review there should also be a revision of the recommendations set out below based on how the ASD landscape has changed and the progress made towards meeting these objectives.

A cornerstone of the recommendations from **ea2020** is that progress should be evaluated. We encourage those organisations and agencies that will take these recommendations forward to measure progress over time and make sure the outcomes are properly disseminated across the European autism community.

Each of the three conferences agreed both a 'long list' of what needs to be done and a 'short list' of the most urgent items. For this Executive Summary we set out below the short list.

Awareness

There is a clear need for accurate and accessible information on autism to be made available across Europe, both in the major and minor languages of Europe, so that no-one is excluded from the knowledge-base.

We received compelling evidence to suggest that where strong advocacy groups of parents and professionals exist and co-operate, they are able, first, to collect prevalence data, and then to use this to persuade national governments to develop appropriate policies for autism.

Accordingly, we recommend that:

1. In each nation both parents and professionals organise powerful advocacy groups to co-operate (a) to provide accessible and accurate information in the local languages, and (b) to create political pressure on national governments to develop coherent national policies for autism.
2. Autism Europe organises and leads on a European awareness campaign on ASD.

Epidemiology

All three conferences were united in the belief that we need systematic prevalence studies across Europe. This will require agreement on a common basis of measurement using the European Autism Information System protocol. Since this kind of research is difficult and costly, we suggest that a start be made with a sampling approach across a relatively small number of diverse nations.

Accordingly we recommend that:

3. Collaborative action be taken to study the prevalence of autism across Europe: as a first step a sampling approach should be used to collect data from a relatively small, but diverse, group of nations.

Research

All three conferences were united in emphasising the need for more research, but equally united in their demand that such research must be scientific and rigorous, with appropriate use of randomised controlled trials in intervention studies. Those attending the conferences also felt that one particular area demanded more research attention: the question of co-morbidities.

Accordingly, we recommend that:

4. DG-Research should make a specific call for proposals on the causes of ASD and encourages researchers to use and link with open data resources in the US.

5. Strategic and comparative research studies of various interventions and treatments should be conducted.
6. Researchers should calculate the economic value of 'early diagnosis & early intervention'.
7. There should be more research into the causes and treatments of co-morbidities in ASD.

Services

All three conferences stressed the need for the development of a model framework for services, so that the nations of Europe could reach agreement on the essentials of good practice. There is an immediate need in many countries for help with the training of parents, carers and professionals involved with ASD. While most nations have begun to recognise the challenge of childhood ASD, and make some provision for it, adults with ASD are largely ignored across many parts of Europe. This also needs immediate attention.

Accordingly, we recommend that:

8. The upcoming DG-SANCO Panel of Experts Meeting in 2011 should bring together professionals associated with ASD to design a coherent model framework for broad service provision (including training).
9. **eapha**, Autism Europe and Autism Speaks should take responsibility for providing an exchange of information about local training needs and high-quality training provision for parents, carers and professionals to encourage the dissemination of good practice.
10. All the nations of Europe should review their provision for adults with ASD and plan good care and support.

Policies

As set out above, the case for political action to provide for people with ASD, their families and carers depends equally on arguments derived from equity and economy. As long ago as 1996 the Charter of Rights of Persons with Autism was adopted as a Written Declaration by the European Parliament. It declares that people with autism 'should share the same rights and privileges enjoyed by all of the European population where such are appropriate and in the best interests of the person with autism. These rights should be enhanced, protected and enforce by appropriate legislation in each state'. Governments have a duty to enshrine these and other international rights (e.g. UN declarations on Human Rights, Rights of the Child and Rights of the Disabled) in law. Furthermore, we recognise a need for systematic study of the argument from economy. Is it true, as we believe it is, that failing to provide adequately for ASD will prove more costly in the long run than acting now?

Accordingly, we recommend that:

11. Each member nation of the EU should develop a national strategy for ASD seeking to implement the 1996 Charter of Rights, and make legislative and mandatory provision for the support services needed by people with ASD, their families and carers.
12. The EC should sponsor research to establish whether or not it is more economical in the longer run to make appropriate provision for people with ASD, than to fail to do so
13. Autism organisations should continue to press for an EU Communication, and EU Council and Parliament Recommendation, on ASD - as well as seeking the support of one of the EU trios of Presidency in declaring ASD as a health priority.

General

We recommend that:

14. A second survey of public health and ASD across European nations should be undertaken not later than 2014 and be compared with the findings of this report.

Responsibilities

One of the principles underlying the formation of the EU is subsidiarity. This means the location of responsibility as far down the chain of command as possible, consistent with effective action. Parents should encourage and enable their children to be responsible for their own lives, professionals should encourage and enable parents to be responsible for their families; governments should encourage and enable professionals to take responsibility for observing good practice – and aspiring to best practice; the EU should encourage and enable the nations of Europe to govern and manage themselves. That said, the principle of subsidiarity implies its converse: supersidiarity. If efficiency and effectiveness requires a matter to be dealt with at a higher level, then the responsibility should be located appropriately. For example, there is a case for arguing that defence and foreign policy should now be located at the highest level (with the EU) rather than at the national level. A similar case could be made for strategic health planning and research.

Accordingly, we suggest the following distribution of responsibilities:

- The EC should take responsibility for recommendations 4, 8, 12, and 14.
- The nations of Europe should take responsibility for recommendations 10, 11.
- The research community should take responsibility for recommendations 3, 5, 6, 7.
- The parents and professionals should take responsibility for recommendations 1.
- European autism agencies should take responsibility for recommendation 2, 9 and 13.

None of these things will happen without an assertion of political will, accompanied by popular support and directed through decisive leadership. The translation of aspiration into reality cannot be achieved by governments alone. It requires the co-operation, effort and enterprise of many agencies and all parts of society. But political leadership can shape the general will. Progress is possible. Nations have learned to free slaves, end child labour and extend the franchise to women. We can decide to stop neglecting the needs of people with ASD, and start to provide adequate opportunities so they can become included within, and become active contributors to, society. We can expect a range of economic, social and personal benefits, if we do so. But these are not the most compelling reasons for action. We should act because it is the right thing to do.