



# Autism: The Costs

September 2007





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- Making History: Westminster (Mar 2006)
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## Autism:

### The Costs

#### The Political and Legislative Context

The uniqueness and complexity of ASD is now widely acknowledged in N Ireland. Increasingly policy makers and public representatives are accepting that at the very least we should have a N Ireland wide strategy for ASD. There is a growing momentum and increasing Ministerial interest in legislation for ASD in N Ireland based upon a need to address the deficit in existing (mental health, physical and learning disability focused) legislation regarding the unique manifestation of Autism as a social and communication disability.

Previous Autism NI literature (“Autism and Government; Opportunities and Solutions”, “Autism in N Ireland; Past and Future Directions”) provide a national and international context for legislative and strategic initiatives for ASD. It is therefore worth bearing in mind that legislation for ASD is now a reality in the USA, Canada, Sweden, Australia and New Zealand, meanwhile Wales, Scotland and Denmark have finalised their respective national plans for ASD.

This publication provides policymakers and public representatives with background financial information and some of the speculated costs of ASD based on prevalence studies; recommendations will also be made as to the way forward for the future financial security of ASD services and any potential new developments at a strategy or legislative level. Primarily this publication is a synthesis of financial reports into the cost of ASD however some suggestions and recommendations are made on the basis of this.

This publication is the latest document in a series of resources supporting the establishment of the Northern Ireland Autism Act.

## Canada

### A Global Balance Sheet

Individual members of the Canadian Senate requested an inquiry into funding for ASD in Canada and on the need for a national strategy for ASD in Canada. These issues were referred to The Standing Senate Committee on Social Affairs, Science and Technology for study and report. The result of this is the review Buy Now or Pay Later (Autism Families in Crisis). The Committee's primary focus was federal funding for ASD treatment; they acknowledged that some families and caregivers experience excessive financial burdens and some solution must be found.

The Committee recommends that a "federal / provincial / territorial ministerial conference is initiated to:

- Examine innovative funding arrangements for the purpose of financing ASD therapy;
- Establish an appropriate level of funding for ASD by the federal government;
- Identify measures of accountability in the use of federal funds for ASD treatment;
- Define the feasibility of introducing measures such as supports for caregivers, respite, family training, and assistance, assisted living and vocational training.

The report also discusses the idea of introducing tax breaks for the families of children with ASD, this is in addition to existing tax credits available to families with children with a disability. The financial recommendations come amongst a package of recommendations dealing with other issues e.g. housing, research and consultation. The overarching recommendation is that. The federal government, in collaboration with the provinces and territories establish a comprehensive ASD strategy.

Overall the Canadian Senate document is useful because it highlights the need for a ministerial collaboration and accountability for developing a budget for ASD. The report also corroborates the Autism NI campaign for a regional ASD strategy in N Ireland.

## USA

### Combating Autism Act

President Bush signed the landmark Combating Autism Act of 2006 (S. 843). The Act has the support of all major autism advocacy groups and authorizes nearly \$1 billion over the next five years to combat autism through research, screening, early detection and early intervention.

This legislation will increase federal spending on autism by at least 50 percent. It includes provisions relating to the diagnosis and treatment of persons with Autism Spectrum Disorders, and expands and intensifies biomedical research on autism, including an essential focus on possible environmental causes.

### The legislation aims for

“Individuals with ASD to have the same rights as others to exert control and choice over their own lives, to live independently and fully participate in and contribute to their communities” The Act recommends the establishment of a “treatments, interventions and services task force” consisting of appropriate professionals, including a health economist or individual with experience in cost-benefit analysis and health policy. After one year the task force will produce a report into pertinent issues i.e. intervention, treatment, and importantly the economy of ASD. Monies will be made available almost immediately e.g. 2008 /2009 the allocation of this is into specific services to be delivered or specific aims of the legislation. 24 months after the enactment of the Act a “demonstration grants programme” will be initiated. This will provide opportunities for separate US States to produce evidence based Autism treatments and services. These demonstration services will then be evaluated after 36 months. Similarly for adult services the establishment of:

- A once off single year planning grant programme for selected States
- A multi year service provision demonstration grant.

Both planning programmes and demonstration services will be evaluated; it is also noted in all cases that additional funding will “supplement not supplant” existing treatments / services for individuals with ASD. Monies will be made available for post diagnostic care and also to develop a national training initiative on Autism; funds will be allocated to a national not for profit organisation to provide “technical assistance” for service providers, individuals and families, and to give some financial security to this indigenous non-service providing family support entity. In Northern Ireland, DHSSPS and Autism NI (PAPA) are already committed to a Northern Ireland ASD Training Service and Strategy. A strategic development which began with seed funding, monitoring and commendation of ACT (Autism NI’s Training Service) and which is ongoing in the development of a Northern Ireland Training Strategy which will link to work in Wales and Scotland through the Celtic Nations Autism Partnership (CNAP). This is one of a number of examples which profiles the strategic role of Autism NI underpinned through funding, annual monitoring and stringent evaluation by DHSSPS/SSI. Thus making Autism NI the logical candidate to carry on its role of providing an expert “technical assistance” role for service providers, individuals and families.

The Combating Autism Act is essentially investing monies into ASD in the first instance to gauge how much a comprehensive programme of care will actually cost; the strategy of time limited “demonstration” services which are subsequently evaluated allows the efficacy and cost effectiveness of different services to be evaluated. This is an acknowledgement that funds must be invested to truly calculate the cost of legislation for ASD.

## Cost of ASD

### A review of prevalence based cost analysis of ASD.

Both the Canadian and American legislative frameworks detailed above acknowledge that funds need to be invested to completely gauge the cost of effective and comprehensive legislation for ASD. However some researchers have attempted to gauge the economic cost of ASD. Such research has been based on reviews of existing information about ASD, learning disability, health and education services and prevalence and producing an estimate of the overall costs. This of course is an inexact science however they provide a useful guide to the estimated costs and also where and how money is being spent.

Researchers have attempted to assess the costs of ASD in the UK. Notably the research led by Martin Knapp initially in 2001 and then updated in 2007. Knapp acknowledges in 2001 that “little is known about the economic impact of ASD” (Knapp et al, 2001, p. 7). Knapp goes on to acknowledge that the lack of absence of the realistic consequences of ASD complicates planning and “hampers policy change” (p.7).

Knapp and Jarbrink (2001) reviewed spending into the following:

<b>Hospital services</b>	<b>Medication</b>
<b>Sheltered work</b>	<b>Family expenses</b>
<b>Other health and social services</b>	<b>Day activities</b>
<b>Lost productivity</b>	<b>Living support</b>
<b>Voluntary support</b>	<b>Family member’s time costs.</b>
<b>Special education</b>	

They were calculated separately as far as possible for individuals with autism and learning disability and individuals who had High Functioning Autism (HFA). They found overall average lifetime cost of ASD to be:

- For an individual with ASD and a learning disability £ 2,940,500
- For an individual with HFA £784,800.

The largest percentage of spending for both autism and HFA is identified as living support; the second largest percentage being spent on day activities.

Prevalence rates have increased between the years of 2001 – 2007; the researchers updated their calculations in line with new, increased prevalence rates. In 2007 Knapp and Romeo produced the following statistics:

## Estimated number of individuals with ASD in the UK:

### Cost Implications

**Autism and learning disability – 296,872**

**HFA – 242,894**

This gives an overall total of 539,766 individuals with ASD in the UK; considering that N Ireland homes around 3% of the total population of the UK it would be reasonable to suggest that taking 3% of this UK estimate might give an estimate of the number of individuals with ASD in N Ireland. Thus it is estimated that there are around 17000 individuals with ASD in N Ireland; which is in line with the most recent prevalence rate of 1% (Baird et al, 2006). The study gives the overall figure of £28 billion per annum as an aggregate cost for children and adults across the spectrum in the UK. Extrapolating this aggregate cost to N Ireland produces the figure of £840,000,000; this working on the most up to date figures provided in this study it could be estimated that the total cost of ASD in N Ireland is £840,000,000 which may seem like a huge and unrealistic sum, however when you consider that 17000 individuals in N Ireland live with ASD this works out at roughly £5000 per person with ASD per year which is not an immense amount of money when one considers the unique and complex challenges of ASD.

Research on behalf of the Autism Early Intervention Outcomes Unit (AEIOU) into the costs of ASD in Australia produced a preliminary estimate of \$4.5 - \$7.2 billion dollars. The researchers admit this may be a conservative estimate and did not take into account, notably the cost of early intervention strategies. Recent research in the USA (Ganz, 2006) identifies an annual cost of \$35 billion in the USA again this figure is dubbed a conservative estimate. In both the American and Australian studies the majority of the funds are spent on “direct non-medical” costs e.g. day care, intervention and childcare. This is congruent with the spending in the UK where the majority was invested in day care.

However it is worth bearing in mind that comparison between such studies is not always advisable as they use different indices of costing.

## Prevalence or Incidence Approach

Existing research into the cost of ASD has used a prevalence approach; this approach identifies a cohort of individuals with ASD and then estimates the direct and indirect lifetime costs for this group for a given year; these estimates can be extrapolated to produce lifetime costs.

Alternatively an incidence approach can be used. In an incidence approach a cohort is identified over a specific time frame – generally a year and their costs are calculated; these costs can then be extrapolated over a lifetime. Incidence based approaches are useful to use to understand the dynamic patterns for making decisions about resource allocation and when making decisions about future treatment or strategic plans.

Current cost of ASD research is based on prevalence based information much of it draws on extrapolations from mainstream disability and government statistics; a recent review of the literature revealed no incidence based costings for ASD; it would be an interesting exercise to conduct such a study in N Ireland, particularly in the current climate of dynamic change and policy review.

### Recommendations

Some individuals with ASD dislike the idea of ASD being costed as an illness using a medical derived model of health economics. This implies that ASD is a disability that should be eliminated or cured. There is a fear that by placing a price on ASD that individuals and families have an increased sense of being a burden on the taxpayer and that by costing ASD we are viewing individuals with ASD as economic units, an indignity that is not imposed on individuals who do not have ASD.

Notwithstanding this very valid caveat there are definite benefits to examining the cost of ASD, especially in a climate increasing awareness of ASD and during a drive to secure better services of individuals with ASD, and guarantee services suitable to their needs into the future. Costings based on prevalence figures can only provide us with a guideline and a basis for extrapolation. The notion of an incidence based study on the cost of ASD here in N Ireland is a realistic and practical way forward not just in N Ireland but would be a useful point of reference for policy makers world wide. The “technical assistance” role (provided by Autism NI (PAPA) to the Northern Ireland Education, Health and Social Services sectors and respective departments since 1990) would be critical to the further development of this concept.

## References

Baird, G., Simonoff, G., Pickles, A., Chandler, S., Loucas, T., Meldrum, D., Charman, T. Prevalence of disorders of the autism spectrum in a population cohort of children in South Thames: the Special Needs and Autism Project (SNAP). *The Lancet*, Volume 368, Issue 9531, Pages 210-215.

Economic Costs of ASD Synergies Economic Consulting Ltd on Behalf of the Australian Autism Early Intervention Outcomes Unit (AEIOU).

Knapp, M., Jarbrink, K. (2001). The economic impact of autism in Britain. *Autism*, 5, p.7-22

Knapp, M., Romeo, R., Beecham, J. (2007). Autism in the UK new cost estimates . Unpublished

The Enquiry on the Funding for the Treatment of Autism. Pay now or Pay Later Autism Families In Crisis. The Standing Senate Committee on Social Affairs, Science and Technology Canada.



# Vision Statement

Autism NI (PAPA) is a parent led partnership organisation having been formed to promote positive collaboration between parents, professionals and individuals with Autism to address the need for appropriate services. This partnership ethos extends to the Charity's promotion of a multi disciplinary, cross agency response to issues such as assessment, diagnosis and intervention. The Charity's mission to support parents and individuals with an Autistic Spectrum Disorder is core to its work and is based on individualised assessed need. The charity is committed to promoting best practice, accessible to all, irrespective of family circumstances.



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