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Select literature review: Autism and its economic costs

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This briefing paper was commissioned by a Member of the Assembly, to aid consideration of the issue of autism and related economic costs. As requested, the paper provides an overview of key findings arising from a selection of relevant available literature addressing economic and financial costs associated with Autism Spectrum Disorder (ASD) - i.e. costs for both individuals who have ASD and their families, as well as government, when ASD is addressed and unaddressed. The examined literature concerns research undertaken in the United Kingdom, the Republic of Ireland, Canada and the United States.

This information is provided to a Member in support of his/her Assembly duties, and is not intended to address the specific circumstances of any particular individual. It should not be relied upon as legal or professional advice, or as a substitute for it.

Introduction

Autism Spectrum Disorder (ASD) is a lifelong developmental condition that can be experienced by an individual from birth. People with ASD often feel their condition is a fundamental aspect of their identity. According to the National Health Service (NHS), ASD impacts how the brain functions. This, in turn, affects how an autistic person perceives the world, as well as communicates and interacts with others. For this reason, people with ASD experience similar difficulties; but their individual condition impacts them in different ways, consequently contributing to their quite different life experiences.^{1 2 3} For example, some autistic people can lead fairly independent lives, with very limited intervention; while for others this can be less so, requiring greater intervention; and for others again, they can require even greater, more invasive intervention. All this depends on the ASD experienced by the individual, along with, if any, their learning/intellectual disabilities (ID)⁴, mental health issues (such as anxiety or depression) or other conditions, such as attention deficit hyperactivity disorder (ADHD), dyslexia, and epilepsy.

Given the above, economic and financial costs naturally arise from autism, to a lesser or greater extent, throughout the lifetime of the person with the condition. Those costs largely arise for that individual, their family and or carers, as well as government, when the condition is addressed and unaddressed. They can relate to, for example, treatment, care and support, along with lost earnings and productivity.

This briefing paper is prepared for a Member of the Assembly to facilitate consideration of the “economic costs of autism”. The paper provides an overview of key findings arising from a selection of relevant available literature addressing economic and financial costs associated with ASD, i.e. for individuals who have ASD and for their families, as well as government. It is presented as follows:

- **Section 1** briefly provides background information, including identification of: Northern Ireland’s (NI’s) over-arching, autism-specific, legislative and policy provision currently in place; and references statistics recorded by the Department of Health (DoH) on the incidence of autism in NI.
- Against that background, **Section 2** presents key findings arising from a review of a selection of relevant available literature addressing economic costs of autism, with particular focus on the United Kingdom (UK). The review largely

¹ For information on Programmes of Care within the NI Health and Social Care (HSC) System an introduction to the best practice around the use of language in the UK for the diagnosis of autism and to describe autism, see RaISe briefing paper NIAR 36/20, [Autism: \(i\) Programmes of Care and \(ii\) Use of Language](#), 6 August 2020.

² What is Autism? National Autistic Society, <https://www.autism.org.uk/about/what-is/asd.aspx>

³ What is Autism? NHS, <https://www.nhs.uk/conditions/autism/what-is-autism/>

⁴ Defined as: “A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with; a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development.” Department of Health, [Valuing People: A New Strategy for Learning Disability for the 21st Century](#), March 2001.

examined research compiled outside NI, namely the UK, the Republic of Ireland (RoI), Canada and the United States, due to apparent limited relevant study in the area in NI.

- In closing, **Section 3** both summarises common themes arising from that body of literature and identifies existing gaps and potential areas for future study in this area, which appear relevant to NI.

Throughout Sections 2-3 potential issues for consideration are highlighted in blue text boxes, to facilitate the Member's further consideration and deliberation of the issue.

1. Background

This section draws on past RalSe publications addressing autism, (namely NIAR 146-20⁵ and NIAR 645-14⁶) and publications from the Department for Health (DoH) and The Executive Office (TEO). It does this to briefly provide some context for the select literature discussed in the next section of this paper. Specifically, it looks at the prevailing autism-specific legislative and policy provision in NI, and refers to recent statistics.

1.1 Legislation – The Autism Act (NI) 2011

The Autism Act (NI) 2011⁷ (The 2011 Act) came into effect on 9 August 2011. It requires the Department of Health, Social Services and Public Safety - now the DoH - to lead on the: development; implementation; monitoring; and, reporting of a cross-departmental Autism Strategy in NI.

The 2011 Act also stated that the Department is required, every three years, to produce a monitoring report on the implementation of the Strategy to the Assembly; while the other Departments are required to cooperate in this regard. The first Progress Report⁸ was published in September 2015, with a draft second Progress Report⁹ following in 2018.

In addition, The 2011 Act requires the Health and Social Care Trusts to provide and share data with the Department on autism prevalence in their areas.

1.2 Policy – Executive Autism Strategy 2013-2020

The Autism Strategy (2013 – 2020) and related Action Plan (2013 – 2016)¹⁰ were subsequently approved¹¹ by the Executive and launched in January 2014. There are 34 cross-departmental actions in the Strategy; organised under 11 themes, which are outlined in the 2015 Progress Report.¹²

A number of the specified outcomes in the Executive Office's Outcomes Delivery Plan¹³ (2019) have relevance to autism, including, but not limited to: Outcome 3 (We have a more equal society); Outcome 4 (we enjoy long, health, active lives); and, Outcome 8 (we care for others and we help those in need).

⁵ RalSe briefing paper NIAR 146/20, [Autism Training and Capacity Building](#), 26 May 2020.

⁶ RalSe briefing paper NIAR 645/14, [The Provision of Services for Children with Autism](#), 24 October 2014.

⁷ Legislation.gov.uk, [Autism Act \(Northern Ireland\) 2011](#). 9 May 2011.

⁸ Department of Health, [The Autism Strategy \(2013 – 2020\) Action Plan \(2013 – 2016\) Progress Report September 2015](#). 13 November 2015.

⁹ Department of Health, [Draft Second Progress Report 2018](#).

¹⁰ Northern Ireland Executive, [The Autism Strategy \(2013 – 2020\) and Action Plan \(2013- 2016\)](#). January 2014

¹¹ Minister for Health, Edwin Poots MLA. [Ministerial Statement – Autism: Strategy and Action Plan](#). 14 January 2014.

¹² See footnote 7.

¹³ Executive Office, [Outcomes Delivery Plan](#). 13 December 2019.

1.3 Statistics

The most recently published annual and quarterly editions of Health and Social Care Trusts data show that autism prevalence appears to be rising in NI.^{14 15} The introduction of The Autism Act (NI) 2011, policy initiatives and increased awareness among the general public and health and education sectors are likely to have contributed to rising diagnoses and prevalence. But the potential consequence of these rising numbers could be continued rising demand for autism support services.

¹⁴ Department of Health, [The prevalence of autism \(including Asperger's Syndrome\) in school age children in Northern Ireland 2020](#). 21 May 2020.

¹⁵ Department of Health, [Quarterly autism statistics for NI \(July-September 2020\)](#). 4 November 2020.

2 Select literature review

The following paragraphs present an overview of a selection of relevant available literature addressing economic costs arising from autism. Whilst there is quite a large body of published work on this subject, the research focusing specifically on NI is more limited. The RaISe team therefore has focussed on research from the UK, the RoI, Canada and the US, where that literature has some relevance in relation to NI. In cases where cost estimates are presented in a different currency, these have been converted and presented in Pounds Sterling, based on the exchange rate from the same year in which the cost estimate was made.

For ease of reference, key findings are presented below using the following sub-sections:

2.1 UK and RoI-based research

2.2 Northern American-based research

2.1 UK and RoI-based research

This sub-section outlines key findings of relevant literature examined from the UK, listing the source names. Tables summarising costs or other data can be found in Annex 1 to this briefing.

2.1.1 Buescher, AVS., *et al.*, “Costs of ASD in the UK and the United States”. *JAMA Pediatrics* (2014).¹⁶

One of the most recent estimates of economic costs of autism in the UK and the US was compiled in the UK by Buescher *et al.* in 2014. This study pooled existing estimates of family out-of-pocket economic costs associated with ASD and Intellectual Disability (ID), and supplemented it with data on prevalence, annual costs of support, opportunity costs, and productivity losses.

At the national level, assuming a prevalence of ID of 40% among children with ASD, the cost of supporting children with ASD was estimated at £3.1 billion per year in the UK. Assuming a prevalence of ID of 60%, then total national costs rose to £3.4 billion per year. For adults, the total estimated national costs were much higher. Assuming a 40% prevalence of ID, total national costs for adults, excluding benefit payments were £29 billion per year; and assuming prevalence of ID of 60%, total costs were an estimated £31 billion per year.

At the individual level, this research also estimated that the cost of supporting an individual with an ASD and ID during their lifetime was £1.5 million (\$2.2 million) in the UK and \$2.4 million (£1.7 million) in the US. The cost of supporting an individual with

¹⁶ Buescher AVS, Cidav Z, Knapp M, Mandell DS. [Costs of Autism Spectrum Disorders in the United Kingdom and the United States](#). *JAMA Pediatr.* 2014;168(8):721–728.

ASD, but without ID was £0.92 million (\$1.4 million) in the UK and \$1.4 million (£0.92 million) in the US. The total lifetime costs at the individual level are therefore similar in the UK and the US.

This study estimated that: 56% of the total cost was accounted for by services; 42% by lost employment for the individual with an ASD; and, the remaining 2% by caregiver time costs. As shown in Annex 1 of this paper - specifically at Figure 5 - the largest cost components for children were special education services and parental productivity loss. During adulthood, residential care or supportive living accommodation and individual productivity loss contributed the highest costs (at Figure 6, Annex 1). Medical costs were much higher for adults than for children.

Important implications arise from these findings: **estimating the economic costs to society of ASD does not in itself form the basis for how to provide treatment or support. Nonetheless, highlighting both the scale of the economic cost and the component breakdown of those costs can help inform debate about where resources and interventions are needed most.** For example, the estimates provided in this paper of high ASD-related costs in adulthood could mean that NI policymakers may focus their attention on the need for adult interventions for those with ASD. They also may consider allocating more resources to early life interventions, in order to reduce costs later in life. Similarly, the high costs associated with employment disruption for families of those with ASD could be addressed through workplace policies or interventions to help individuals engage more effectively with the labour market.

This study concluded that there was a need to identify a comprehensive picture of the economic and societal costs of ASD. It also concluded that there was a need to understand: how effective current interventions are; and, whether they support those most in need of them? Those economic costs are distributed across many areas, including: health; education; social care; housing; employment; and, welfare. The implication of this is the need for effective coordination across departments and agencies when developing interventions. Indeed, a number of outcomes from the Executive Office's Outcomes Delivery Plan¹⁷ have relevance to autism, such as Outcome 3 (We have a more equal society), Outcome 4 (we enjoy long, health, active lives), and Outcome 8 (we care for others and we help those in need).

Potential Issue for Consideration:

High costs of ASD in adulthood may suggest that there is a need for more early intervention with children who have autism, to reduce costs later in life – both for those children, the families of those individuals and the economy as a whole, in terms of government expenditure spent on, for example, special education services and healthcare support.

¹⁷ Executive Office, [Outcomes Delivery Plan](#). 13 December 2019.

2.1.2 Knapp, M., *et al.*, “Economic cost of autism in the UK”. *Autism* (2009).¹⁸

In 2009, Knapp *et al.* estimated the costs of ASD in the UK. This research was updated in 2014, which was reviewed in section 2.1.1. The authors combined data on: prevalence; level of ID; place of residence with annual costs of services and support; and, opportunity costs of lost productivity.

The authors estimated the costs of supporting children with ASD to be £2.7 billion each year in the UK. For adults, these costs were an estimated £25 billion each year. The lifetime cost for someone with ASD and ID was estimated at approximately £1.23 million, and for someone with ASD, but without ID, it was approximately £0.80 million.

For children, the highest costs were special education, respite care, and health and social care (at Figure 9, Annex 1). For adults with ID, the largest cost elements were staffed/supported accommodation, lost productivity because they were not employed, and hospital services. For adults without ID, the largest elements were lost productivity for the individual, hospital services, and education (see Figures 8 and 10, Annex 1).

This study found that a large share of the total cost of supporting children and adults with ASD fell to the public sector, and particularly to the health system, social care agencies, education and housing budgets. This highlights the breadth of the impact of a complex disorder like ASD. However, it also shows the need for a co-ordinated, cross-departmental approach to provide relevant support and interventions in NI.

The research also identified the continuing large cost to families, in terms of lost employment opportunities/ earnings and other expenses. It, however, also highlighted time spent providing informal care. There can be psychological costs too, as identified by Green *et al's* (2005)¹⁹ finding that about 30 percent of children with autism had a clinically recognisable emotional, anxiety or conduct disorder.

Potential Issue for Consideration:

One consideration raised by these high family costs is the extent to which families should be expected to incur them. If it is not reasonable to expect families to incur the cost, then the question is whether the public sector/government can, given ongoing pressures on public finances, for example, in the wake of the coronavirus pandemic and the UK exit from the European Union.

¹⁸ Knapp M, Romeo R, Beecham J. Economic cost of autism in the UK. *Autism*. 2009;13(3):317-336. doi:[10.1177/1362361309104246](https://doi.org/10.1177/1362361309104246)

¹⁹ Green, H., McGinnity, A., Meltzer, H., Ford, T. & Goodman, R. (2005) *Mental Health of Children and Young People in Great Britain*, 2004. London: Stationery Office

As in their 2014 study, the authors noted the high lifetime costs associated with the cumulative impact of service use, and that these costs therefore may support or inform arguments for early intervention. They also noted that an effective intervention in childhood could help reduce the intensity of support needed in adult life.

Another form of intervention could be in supporting people with conditions such as ASD to move into the labour market. This could help reduce economic inactivity and therefore reduce the economic cost of lost productivity to the economy. Research from the Ulster University Economic Policy Centre²⁰ stated that:

...a relatively low number of disabled people participating in the labour market has significant fiscal consequences.

and:

Over the long term mobilising underutilised groups within the labour force will become important to supply the workers required to facilitate economic growth...

NI has the highest economic inactivity rate of any region in the UK, which has been one of our most persistent economic challenges. The current rate is 26.2%²¹, compared with 20.8% for the UK as a whole; and long-term sickness and disability are the most commonly cited reasons for economic inactivity in NI. The prevalence of disability in NI is only marginally higher than the UK average (21.5% compared with 21.2%)²². Yet, the levels of economic activity for those with a disability is significantly lower than all other regions in the UK (42.9% compared with a UK average of 59.6%).

One of the key conclusions from this research by Knapp *et al.* was that the range of sectors in which autism has an impact shows that there is clearly a need to ensure coordinated action across different parts of government. The authors also stated that there was a need for a better understanding of the cost and cost-effectiveness of various interventions and supports for children and adults, to ensure that decision makers have a stronger evidence base when deciding how to allocate government resources.

²⁰ Ulster University Economic Policy Centre: [An anatomy of economic inactivity in Northern Ireland](#), November 2016. Accessed 3 November 2020.

²¹ NISRA, [Labour Force Survey, October 2020](#). Accessed 3 November 2020.

²² ONS, Annual Population Survey: Percentage aged 16-64 who are Equality Act (EA) core or work-limited disabled, June 2020. Accessed 3 November 2020.

2.1.3 Roddy, A., O'Neill, C., "The economic costs and its predictors for childhood autism spectrum disorders in Ireland: How is the burden distributed?". *Autism* (2019).²³

The paper reviewed in this sub-section was the first to have established the economic cost of childhood ASD in the RoI. It estimated the societal cost of childhood ASD and the variation in costs between state and family expenditure, while looking at sample data from 2014/15 of 195 parents of 222 children, between 2 and 18 years of age, with diagnosed ASD.

The findings show the average annual cost per child for families was estimated at €28,465 (£20,597²⁴) for private ASD services, lost income and informal care. By comparison, annual state expenditure per child on autism spectrum disorder-related health, social and educational resources was €14,192 (£10,269).

This study broke the ASD-related expenditure into two main groups: families' out-of-pocket expenditure; and, state-provided health services. Details of the first of these categories and the overall societal cost of childhood ASD are shown in Figures 11 and 12 in Annex 1.

The authors' analysis showed that increased ASD severity was associated with higher family out-of-pocket expenditures, but not state health expenditures. The results therefore suggested that parents are central to meeting the needs of young people with ASD in the RoI. The policy implication of this is that significant investment and commitment is needed to address the needs of individuals living with ASD and their families.

The mean cost of total out-of-pocket expenditure amounted to €9,490 (£6,867) per family and €8,185 (£5,923) per child. The median cost was lower, at €6,560 (£4,747) per family, which is because of the distribution of costs between families ranging from €0 to €56,160 (£40,637) per family. Living costs (including items such as special diet and repairing household damage) accounted for 29% of total out-of-pocket expenditure with a mean cost of €2,796 (£2,023).

Mean respite care costs were considerably lower than nearly all other types of expenditure, amounting to €82 (£59) on average. Medical costs amounted to 19% of the mean total out-of-pocket expenditure with a mean cost of €1,836 (£1,329). Out-of-pocket expenses for private therapeutic interventions and assessment were the highest category of medical costs incurred; resulting in a mean cost of €948 (£686), with considerable variations in cost ranging from €0 to €14,400 (£10,420). These cost components are summarised in Figure 11, in Annex 1.

²³ Roddy A, O'Neill C. The economic costs and its predictors for childhood autism spectrum disorders in Ireland: How is the burden distributed? *Autism*. 2019;23(5):1106-1118. doi:[10.1177/1362361318801586](https://doi.org/10.1177/1362361318801586)

²⁴ Based on the exchange rate at the end of the 2014/15 financial year – 31 March 2015 – which is the year in which the sample data refers to. Source: <https://www.xe.com/currencytables/?from=EUR&date=2015-03-31> Accessed 4 November 2020.

Overall, this research estimated that in RoI, parental costs (out-of-pocket expenditure, lost earnings and informal care costs) accounted for 67% of societal costs. State expenditure on ASD health services averaged €1,301 (£941) per child. State expenditure on ASD educational services was €12,837 (£9,289) per child; most of which was on special needs assistants, as opposed to specific learning interventions. Average combined state expenditure across health, medications and education was €14,192 (£10,269) per child. In terms of the costs incurred by families, the average per child was €8,185 (£5,923), with costs ranging from €0, to as high as €56,160 (£40,637). The cost of mothers and fathers (in terms of lost earnings), who were in paid employment and taking time off, were €1,151 (£833) and €780 (£564) per child, respectively.

This study found that there is a significant economic burden associated with ASD among children and adolescents in the RoI. It also found that a large majority of that was borne by families, rather than the state.

This study also found that income was not a significant predictor of family expenditure, which may be somewhat unexpected. While families with higher incomes may be better placed to spend more in supporting a child with ASD, the findings here suggested that those on higher incomes are not spending significantly more than those on lower incomes. This may reflect the possibility that the bulk of care is delivered by a primary caregiver, thereby reducing the potential to substitute purchased services for those provided directly by the parent.

Potential Issue for Consideration:

This study showed the significant extent to which costs are borne by families of individuals with ASD. This has implications for further research and policy. Future interventions should take this burden into consideration, when attempting to develop and implement support measures in a cost effective way.

2.1.4 Barrett, B. *et al.*, “Service and wider societal costs of very young children with autism in the UK”. *Journal of Autism and Developmental Disorders* (2012).²⁵

Similar to the Roddy & O’Neill (2019) study reviewed in the previous sub-section, this study by Barrett *et al.* (2012) found that the average out-of-pocket expenditure for families with a child diagnosed with ASD in the UK, aged between 2 and 4 years, amounted to £227 over a period of six months. However, the range of those costs varied significantly, from £0 to £3,350 over that time period. Such spending included a broad range of costs, including home adaptations, overseas travel for health services and assessment, special equipment and diets.

2.1.5 MacKay, T. *et al.*, “The microsegmentation of the Autism Spectrum: Economic and research implications for Scotland”. 2017.²⁶

Some of the most recently published estimates on the economic cost of autism across the lifespan are contained in this paper produced for the Scottish Government by MacKay *et al.*

Estimates showed that the annual cost of ASD in Scotland was almost £2.3 billion, while 93% of the costs were accounted for by adults and 7% by children. In terms of annual service costs for children, the report showed the annual cost was: £13,360 for children with Asperger’s / High Functioning Autism (HFA); and, £26,321 for children with ASD. Educational costs were estimated to account for three quarters of the total.

The paper also estimated the lifetime cost for individuals with and without intellectual disability (ID), at £1.6 million and £0.89 million respectively. The annual national cost of ASD in Scotland was estimated at £2.2 billion.

Among children with ASD, those with co-occurring conditions were found to have higher costs; and for adults with ASD, those living away from their parents had higher social care and total costs. The MLA should note a limitation of this study when

²⁵ Barrett, B., Byford, S., Sharac, J. *et al.* Service and Wider Societal Costs of Very Young Children with Autism in the UK. *J Autism Dev Disord* 42, 797–804 (2012). <https://doi.org/10.1007/s10803-011-1306-x>

²⁶ MacKay, T., Knapp, M., Boyle, J.M., Lemmi, V., Connolly, M., & Rehill, A. (2017). The microsegmentation of the autism spectrum: Economic and research implications for Scotland. Edinburgh: The Scottish Government. <https://www.gov.scot/publications/microsegmentation-autism-spectrum/>

comparing it with others reviewed in this briefing, i.e. no estimates of out-of-pocket expenditure were made.

Potential Issue for Consideration:

This study and related paper was produced partly in response to Recommendation 5 in the Scottish Autism Strategy:

It is recommended that Knapp's work on the economic costs of autism is analysed and applied to the Scottish context to inform strategy and planning on what interventions lead to positive impacts both for individuals and for the economy as a whole.

The authors further stated that providing a basis for such a strategy and related planning was essential to the compilation of more accurate and more detailed economic costings than were available at that time; and that those should relate specifically to the ASD population of Scotland. Therefore, it is possible that further research of this kind, in particular its methodology, could help inform the development of interventions here in NI.

2.1.6 Barrett, B. et al., “Comparing service use and costs among adolescents with autism spectrum disorders, special needs and typical development”. *Autism* (2015).²⁷

In the UK, Barrett *et al.* established the average total cost of health, respite and educational services for four groups of adolescents over a 6-month period. The average total service cost for adolescents with ASD was estimated as £11,029, in comparison to the cost for the three other groups, i.e.: individuals who had other special educational needs (£9,268); those with other ASDs (£8,968); and, typically developing adolescents (£2,954).

By comparison, a similar study by Roddy & O'Neill in 2019 (reviewed in sub-section 2.1.3 of this briefing) found that annual out-of-pocket expenditures in the RoI were €8,185 (£5,923) per child, and that state expenditures were approximately €14,192 (£10,269), of which approximately €12,837 (£9,289) was education-related.

²⁷ Barrett B, Mosweu I, Jones CR, *et al.* Comparing service use and costs among adolescents with autism spectrum disorders, special needs and typical development. *Autism*. 2015;19(5):562-569. doi:[10.1177/1362361314536626](https://doi.org/10.1177/1362361314536626)

2.1.7 Rogge, N., Janssen, J., “The Economic Costs of Autism Spectrum Disorder: A Literature Review”. *Journal of Autism and Developmental Disorders* (2019).²⁸

This paper carried out a wide ranging review of the literature on estimating the economic costs of ASD, sourcing around 50 papers covering multiple countries (including the US, UK, Australia, Canada, Sweden and the Netherlands). A number of those papers also are reviewed in the study.

One of the key findings was that ASD is associated with a high financial burden in a variety of domains, resulting in substantial overall lifetime costs, for both the individual with ASD and their family.

Based on the studies reviewed, the study shows that overall lifetime costs for individuals with ASD were estimated to be:

- Between \$2.4 million/£1.7 million (Buescher *et al.* 2014)²⁹ to \$3.2 million/£1.6 million³⁰ (Ganz 2007)³¹ for the US; and
- From £1.5 million (Buescher *et al.* 2014)³² to £2.4 million (Järbrink and Knapp 2001)³³ for the UK.
- A total figure for the US; Leigh and Du (2015)³⁴ estimated that the combined annual direct medical, direct non-medical and productivity costs was \$268 billion/£182 billion³⁵ (with a range of \$162–\$367 billion or £110–£249 billion) for 2015. The study further forecasted this cost to be \$461 billion/£312 billion (range \$276–\$1,011 billion or £187–£685 billion) by 2025.

The authors stated that these reported cost estimations could be likely to underestimate the full extent of ASD-related costs, due to: omitted health impacts; omitted economic impacts; and, omitted impact on social life.

Another key finding of this paper was that the six cost categories studied in the review estimated costs were higher for individuals with ASD (and for families of children with ASD) than other individuals or families. Furthermore, the estimates of ASD-related costs were shown to be higher costs for individuals with ASD and their families. As noted in the study, one reason for this was that individuals with more severe ASD

²⁸ Rogge, N., Janssen, J. The Economic Costs of Autism Spectrum Disorder: A Literature Review. *J Autism Dev Disord* 49, 2873–2900 (2019). <https://doi.org/10.1007/s10803-019-04014-z>

²⁹ See footnote 10

³⁰ Based on the exchange rate at the end of the 2014/15 financial year – 31 March 2015 – which is the year in which the sample data refers to. Source: <https://www.xe.com/currencytables/?from=GBP&date=2007-12-31> Accessed 11 November 2020

³¹ See footnote 29

³² See footnote 10

³³ Järbrink, K., & Knapp, M. (2001). The economic impact of autism on Britain. *Autism: The International Journal of Research and Practice*, 5(1), 7–22

³⁴ Leigh, J. P., & Du, J. (2015). Brief report: Forecasting the economic burden of autism in 2015 and 2025 in the United States. *Journal of Autism and Developmental Disorders*, 45(12), 4135–4139.

³⁵ Based on the exchange rate at the end of the 2014/15 financial year – 31 March 2015 – which is the year in which the sample data refers to. Source: <https://www.xe.com/currencytables/?from=GBP&date=2015-12-31> Accessed 11 November 2020

require more medical and healthcare, behavioural treatment, therapy and special education during their childhood. Another reason was that individuals with more severe ASD have experienced a higher need to live in supported accommodation and residential care during adulthood. Parents of children or adults with more severe ASD also sustained higher costs due to productivity loss, loss of labour income and loss of leisure time related to the ASD of their child. This was consistent with the findings of other studies reviewed in this briefing paper.

The authors here found that special education services were the largest cost component, followed by the costs of tutorial support. Medical and healthcare costs related to ASD have been found to constitute only a small part of the total costs for individuals with ASD, with medical costs being higher for adults with ASD than for children. The authors' estimates showed that smaller family out-of-pocket expenses (such as travel expenses) cannot be ignored when analysing the costs related to ASD. In this paper, and in others reviewed in this research briefing, out-of-pocket expenses were found to place a significant financial burden on the families of the individual.

2.2 North American-based research

This sub-section reviews key findings of relevant research compiled and reported on in North America, i.e. Canada and the US. Whilst the estimations of ASD-related costs identified in these studies are based on different healthcare, welfare and finance systems to NI, it still is useful to include them. They highlight where resources are allocated and the split between cost components in these countries, potentially providing instructive illustrations for NI.

Tables summarising costs or other data can be found in Annex 1 of this briefing.

2.2.1 Parliament of Canada, *Pay Now or Pay Later: Autism families in crisis (2007)*.³⁶

This study was based on an enquiry by the Canadian Senate Committee on Social Affairs, Science and Technology. Following a series of meetings and interviews with autistic individuals, their families, advocacy groups, health professionals and researchers in late 2006 and early 2007, the Senate Committee reported on the issues of funding and treatment of autism.

At the time this inquiry was conducted, publicly funded health insurance did not pay for the cost of therapy required by a child diagnosed with ASD. As a result, families would have to pay out-of-pocket for a very large portion of treatments. The report found that these costs could be as high as \$60,000 (£31,000) per year.

³⁶ "Pay Now or Pay Later: Autism families in crisis. Final Report on: The Enquiry on the Funding for the Treatment of Autism". The Standing Senate Committee on Social Affairs, Science and Technology. Government of Canada. March 2007.

The key theme of this report was the need to pay more for early interventions, which could reduce the need for costly interventions later in life. As one consulted stakeholder stated:

... if you pay for it now, look at the return you will get on your investment. The people with autism will get out in the real world and get jobs, and that will stimulate the economy. Or you can pay later, which means they will go into group homes and it will cost the taxpayers a lot of money in the long run to keep them there.

The report looked at issues of concern raised by both individuals with ASD and their families. Based on the Senate Committee's findings from its inquiry, the report further outlined recommendations for action that could be undertaken by the Canadian Federal Government to address those concerns.

A primary finding related to people's access to autism treatment. Stakeholders had advised the Senate Committee that access to autism treatment was problematic for different reasons. One reason was that one of the most intensive interventions could cost parents up to \$60,000 (£31,000) per year, if no public funding was provided. Given this high cost, witnesses urged that uniform access to treatment should be made available regardless of ability to pay. They also spoke of the need for flexibility in treatment options as different approaches are needed for different individuals. There was a strong consensus that all available treatment approaches should be monitored for effectiveness and provided based on scientific evidence. Many of those consulted stated that early intervention was critical, regardless of the approach taken for treatment.

The report concluded with a number of recommendations, including, in no particular order of significance:

- **Need for research.** Stakeholders providing evidence to the Senate Committee commended the autism research community in Canada. However, they noted that autism research does not attract significant private industry investment. Therefore, they advised that although the generous charity donations funding research were considered vital, they were insufficient on their own or stable from one year to the next. Stakeholders therefore suggested it was imperative that federal government funding in this area should be substantial and on-going.
- **Consulting with autistic individuals.** There is a wide range of stakeholder opinions concerning the nature of autism, its prevalence, and the effectiveness of treatments. The Senate Committee acknowledged that the complexity of the issue required consultation with all stakeholders and there needed to be consensus around common goals and priorities. They agreed that this consensus could be achieved only through ongoing consultation, particularly with autistic individuals.

- **National Autism Strategy.** The Senate Committee stated that they wanted to see their recommendations implemented as part of a National Autism Strategy. Stakeholders consulted by the Committee were clear that individuals with ASD must be included in further consultation, importantly playing a role in the development of the Strategy.

2.2.2 Ganz, M, L., “The lifetime distribution of the incremental societal costs of autism”. *Archives of Pediatrics & Adolescent Medicine* (2007).³⁷

In 2007, Ganz estimated the age-specific and lifetime societal costs of ASD in the US. The study was based on a literature review of other research from the US, and included UK or Canadian studies where necessary.

Ganz estimated that direct medical costs were quite high for the first 5 years of life (averaging around \$35,000 or £18,000); but started to decline substantially by age 8 years (to around \$6,000 or £3,022), and continued to through the end of life to around \$1,000 (£504).

Direct nonmedical costs were found to range from \$10,000 (£5,036) to approximately \$16,000 (£8,058) during the first 20 years of life; peaking in the 23 – 27 age range at around \$27,500 (£13,850); and then steadily declining to the end of life, to around \$8,000 (£4,029) in the last age group.

Indirect costs also showed a similar trend, decreasing from around \$43,000 (£21,656) in early life; peaking in the 23 – 27 age range at around \$52,000 (£26,188); and declining through the end of life to \$0. The detailed breakdown of these costs is shown in Figure 13 of Annex 1 of this paper. The total annual cost to society of caring for and treating a person with autism in the US was estimated to be \$3.2 million (£1.6 million).

Although much of the focus in this study is on ASD and its prevalence among children, ASD still can incur significant costs well into the adulthood of the person with the condition. As shown by the author, and other studies reviewed in this briefing, there are substantial costs resulting from adult care and lost productivity of both individuals with ASD and their parents. This financial burden is felt not just by those individuals and their families, but by society as a whole.

Potential Issue for Consideration:

It is important to improve understanding around the distribution of costs relating to individuals with ASD, both in terms of age and cost components; and similarly in relation to the families of those individuals and society as a whole. That would better equip decision makers when allocating scarce resources and developing new interventions to effectively and efficiently support individuals with ASD and their families.

³⁷ Ganz ML. The lifetime distribution of the incremental societal costs of autism. *Arch Pediatr Adolesc Med*. 2007 Apr;161(4):343-9. doi: [10.1001/archpedi.161.4.343](https://doi.org/10.1001/archpedi.161.4.343). PMID: 17404130.

3 Common themes and gaps in existing research

This briefing paper has provided an overview of a selection of relevant available literature addressing economic costs associated with ASD. This section outlines key common themes arising from that body of literature. Importantly, it also highlights gaps in that research and potential areas for future study, which appear relevant to NI.

3.1 Key common themes

A key common theme across almost all the literature reviewed in this paper is the need for a **cross-departmental approach to autism support**. The economic costs of autism are distributed across many areas, including: health; education; social care; housing; employment; welfare; and, labour market. This highlights clearly that the responsibility for effectively tackling autism in NI should not necessarily lie solely with the Department for Health. Rather, it concerns multiple departments. Indeed, Strategic Priority 1 under the “Awareness” theme of the Executive Office’s Autism Action Plan (2013 – 2016) is:

... to work in partnership with representatives from all government departments to access a range of awareness training which will support the public and private sector in providing services to people with autism, their families, and carers.

Furthermore, many of the other Strategic Priorities in that Action Plan are listed as the responsibility of “All Departments”. In addition, a number of Outcomes listed in the Executive Office’s “Outcomes Delivery Plan”³⁸ (2019) appear to resonate with available departmental support relating to autism. Targeting study in that area would be needed to identify and track that support. Informing such work could be the forthcoming Executive Programme for Government, which is anticipated in spring 2021.

Given the evidence base highlighted in this select literature review, it is apparent that effective and efficient coordination across departments and related agencies in NI should inform future development of intervention strategies, treatments etc. in this area. Moreover, that development should be informed by experience to date when implementing the Autism Strategy and relevant outcomes in the Executive’s “Outcomes Based Delivery Plan”.

Linked to this is **the apparent need for early intervention in this area**. A number of the studies reviewed in this briefing identified the importance of early intervention. Effective and efficient intervention early in a child’s life could help reduce the scale of support needed in adult life. In turn, such intervention could have long-term gain in many ways, including reducing economic costs incurred by the individual, their family, and society as a whole, including the Executive.

³⁸ Executive Office, [Outcomes Delivery Plan](#). 13 December 2019.

One other key theme emerging from the select literature review was the **split between who incurred the costs for supporting an autistic individual, i.e. families' out-of-pocket expenditure and government expenditure**. In particular, it appears that families bear much of the burden, requiring them to make significant out-of-pocket contributions. One of the more recent estimates compiled by Roddy & O'Neill (2019) found that in the RoI, family expenditure on private services, lost income and informal care accounted for around two-thirds of total costs, with the state accounting for the remainder.

3.2 Gaps in existing research and potential future study

This briefing highlighted key findings of a selection of relevant available literature examining economic costs arising from autism. In particular, the cost of providing support for autistic individuals and their families; and the cost consequences of not providing that support. Most of this has focussed on UK-based research in an effort to make it as relevant to the situation in NI as possible.

Those select literature review findings include a wide range of estimates and related research undertaken to cost autism to date. That body of research takes the examination so far. It also leaves some gaps, meriting further examination. For example, a majority of that literature focusses on the cost to the state, and to families, of providing such support. However, there appears to be very limited research on the economic cost consequences of **not** providing that support. Most helpful in this regard was the Canadian Parliament's Senate Committee study entitled "*Pay Now or Pay Later: Autism Families in Crisis*" (2007), as reviewed in sub-section 2.2.1.

Future research in this area could help to start informing the counterfactual – i.e. of government **not** funding autism support and interventions. Good understanding of these noted costs – including where they are incurred, and when – is vital to help decision makers better target limited resources, to ensure their effective and efficient use.

Finally, when relying on the findings identified throughout section 2 of this paper, limitations should be noted. The findings highlight other countries' and UK regions' estimates of ASD costs by age and component. It therefore may be difficult to make those directly comparable to the situation in NI. How the health and education systems are organised in NI is largely similar to the rest of the UK, but there are many differences in terms of cost of living, incomes and productivity. Therefore, it could be beneficial for an up-to-date estimate of the economic costs of autism at the NI level to be carried out. This would allow for a more accurate assessment of the costs to individuals with ASD and their families, while taking into account the socioeconomic circumstances unique to NI. This could serve to facilitate discussion on autism in NI, helping to ensure that decision makers have the strongest possible evidence base when deciding how to allocate resources.

Annex 1

**Buescher, AVS., et al., “Costs of ASD in the UK and the United States”.
JAMA Pediatrics (2014).³⁹**

Figure 4: Average annual cost per individual, children and adults with ASD (£)

	Age	No. of individuals	Av. annual cost (£)
Individuals with ID	0-1	695	5,904.0
	2-3	680	10,431.0
	4-11	24,492	35,069.0
	12-17	19,574	50,233.0
	18+	196,489	86,981.0
Individuals without ID	0-1	1,043	1,412.0
	2-3	1,020	6,815.0
	4-17	29,361	29,767.0
	18+	294,734	49,804.0

Source: Buescher, AVS., et al., June 2014

Figure 5: Average annual cost per capita for children (0-17 years) with ASD, by cost component, (£)

	Children with ID, by age				Children without ID, by age		
	0-1	2-3	4-11	12-17	0-1	2-3	4-17
Accommodation/residential care	0	37	328	1,240	0	37	0
Respite care	0	0	3,197	4,078	0	0	7,459
Special education	0	2,546	11,831	32,774	0	2,546	14,006
Employment support							
Medical	267	665	988	1,818	267	665	890
Non-medical	0	2,256	7,936	475	0	2,356	1,561
Productivity loss (parents)	608	608	5,314	5,314	608	608	5,314
Voluntary organisation help	0	69	107	107	0	0	0
Benefits	4,154	4,154	4,524	4,427	537	537	537
Total costs	5,029	10,335	34,225	50,233	1,412	6,749	29,767

Source: Buescher, AVS., et al., June 2014

³⁹ Buescher AVS, Cidav Z, Knapp M, Mandell DS. [Costs of Autism Spectrum Disorders in the United Kingdom and the United States](#). JAMA Pediatr. 2014;168(8):721–728.

Figure 6: Average annual cost per capita for adults (18+ years) with ASD, by cost component, (£)

	With ID	Without ID
Accommodation	41,512	0
Education	2,619	3,307
Employment support	290	0
Services		
Medical	5,142	16,044
Non-medical	2,871	3,610
Productivity loss		
Individual with ASD	25,644	21,797
Parents	1,477	1,477
Family expenses	873	1,712
Benefits	5,671	0
Total costs	86,099	47,947

Source: Buescher, AVS., *et al.*, June 2014

Knapp, M., *et al.*, 'Economic cost of autism in the UK'. *Autism* (2009).⁴⁰

Figure 7: National annual costs for children (0-17 years) with ASD (£million, 2005 prices)

	No. of children	Average cost (£)	Total cost (£ million)
Children with ASD and ID - living with family			
Age 0-3	1,467	585	0.9
Age 4-11	30,981	23,869	739.5
Age 12-17	25,078	36,474	914.7
Children with ASD and ID - in residential / foster care			
Age 0-3	53	16,185	0.9
Age 4-11	400	40,578	16.2
Age 12-17	880	62,536	55.0
Children with ASD but without ID - living with family			
Age 0-3	1,243	1,214	1.5
Age 4-11	25,675	21,090	541.5
Age 12-17	21,239	21,090	447.9
All ages and levels of ID	107,016	25,399	2,718.1

Source: Knapp, M., *et al.*, June 2009

⁴⁰ Knapp M, Romeo R, Beecham J. Economic cost of autism in the UK. *Autism*. 2009;13(3):317-336. doi:[10.1177/1362361309104246](https://doi.org/10.1177/1362361309104246).

Figure 8: National annual costs for adults (18+ years) with ASD (£million, 2005 prices)

	No. of adults	Average cost (£)	Total cost (£ million)
Adults with ASD and ID			
Living in private households	83,304	36,507	3,041.2
Living in supported accommodation	16,661	87,652	1,460.4
Living in residential care	123,767	88,937	11,007.5
Living in hospital	14,281	97,863	1,397.6
Children with ASD but without ID			
Living in private households	153,842	32,681	5,027.7
Living in supported accommodation	9,737	84,703	824.8
Living in residential care	31,158	87,299	2,720.1
All levels of disability and places of residence	432,750	58,877	25,479.0

Source: Knapp, M., *et al.*, June 2009

Figure 9: Average annual cost per capita for children (0-17 years) with ASD, by cost component, (£, 2005 prices)

	Children with ID			Children with ID	
	Age 0-3	Age 4-11	Age 12-17	Age 0-3	Age 4-17
Education	0	10,326	28,606	0	12,225
Respite care	0	2,790	3,559	0	6,510
Other health & social care	585	6,908	400	1,214	1,214
Lost employment (parents)	0	2,059	2,015	0	216
Hospital services	0	862	1,587	0	777
Accommodation	544	286	1,082	0	0
Voluntary organisation help	0	832	93	0	0
Treatments for ASD needs	0	18	15	0	148
Total annual cost (excl. benefits)	1,129	24,081	37,357	1,214	21,090
Benefits	3,626	3,949	3,864	469	469
Total annual cost (incl. benefits)	4,755	28,030	41,221	1,683	21,559

Source: Knapp, M., *et al.*, June 2009

Figure 10: Average annual cost per capita for adults (18+ years) with ASD, by cost component, (£, 2005 prices)

	Adults with ID	Adults without ID
Accommodation	36,233	0
Lost employment (person with ASD)	22,383	19,785
Hospital services	4,588	14,004
Education	2,286	2,886
Day services	1,998	2,226
Lost employment (parents)	1,289	2,910
Family expenses	762	1,494
Other health & social care	581	777
Respite care	538	0
Employment support	253	0
Treatments for ASD needs	58	148
Voluntary organisation help	0	0
Total annual cost (excl. benefits)	70,969	44,230
Benefits	4,950	0*
Total annual cost (incl. benefits)	75,919	44,230

Source: Knapp, M., *et al.*, June 2009

* It was not possible to estimate this element

Roddy, A., O'Neill, C., "The economic costs and its predictors for childhood autism spectrum disorders in Ireland: How is the burden distributed?". *Autism* (2019).⁴¹

Figure 11: Out-of-pocket expenditure per family due to having a child/children with ASD, 2014/15

Type of expenses	Mean cost	Mean range	Median cost
Living costs	€2,795.67	€0–€23,920	€1,680.00
Special diet	€918.32	€0–€11,440	€250.00
Special clothing	€221.44	€0–€2,400	€0.00
Continence care (e.g. nappies)	€154.78	€0–€1,680	€0.00
Replacing/repairing damage	€518.46	€0–€10,400	€100.00
Extra heat	€250.65	€0–€3,640	€0.00
Extra electricity	€319.30	€0–€3,640	€0.00
Laundry	€219.71	€0–€2,600	€0.00
Telephone	€193.03	€0–€2,600	€0.00
Care and assistance	€1,564.14	€0–€23,400	€0.00
Childcare/carer during the school term	€1,024.64	€0–€15,750	€0.00
Childcare/carer during the holidays	€457.49	€0–€7,650	€0.00

⁴¹ Roddy A, O'Neill C. The economic costs and its predictors for childhood autism spectrum disorders in Ireland: How is the burden distributed? *Autism*. 2019;23(5):1106-1118. doi:[10.1177/1362361318801586](https://doi.org/10.1177/1362361318801586)

Respite care	€82.01	€0–€4,800	€0.00
Special activities	€777.35	€0–€10,400	€520.00
Autism friendly activities	€777.35	€0–€10,400	€520.00
Educational costs	€1,043.93	€0–€10,439	€580.00
Specialized education	€280.14	€0–€7,800	€0.00
Therapeutic toys and sensory equipment	€380.96	€0–€7,847	€200.00
Electronic items (e.g. iPad)	€382.83	€0–€4,500	€250.00
Medical costs	€1,835.97	€0–€17,140	€925.00
Out-of-pocket expenses for GP visit	€136.60	€0–€2,880	€0.00
Out-of-pocket for specialists	€397.94	€0–€10,400	€0.00
Out-of-pocket expenses for medication/supplements	€307.11	€0–€7,200	€20.00
Out-of-pocket expenses for private therapeutic interventions and assessment	€948.01	€0–€14,400	€100.00
Out-of-pocket expenses for hospital patient fee	€46.31	€0–€3,000	€0.00
Travel costs	€873.98	€0–€4,800	€400.00
Fuel/transport/parking costs	€839.62	€0–€4,800	€360.00
Accommodation	€34.36	€0–€1,700	€0.00
Training/support costs	€297.15	€0–€9,600	€0.00
Skills training course(s)/workshops	€178.85	€0–€9,600	€0.00
Counselling	€118.31	€0–€4,320	€0.00
Autism assistance dog	€140.81	€0–€6,700	€0.00
Training/veterinary bills/feeding	€140.81	€0–€6,700	€0.00
Other	€160.61	€0–€4,800	€0.00
Total out-pocket expenditure	€9,489.60	€0–€56,160	€6,560.00
Total out-pocket expenditure	€9,489.60	€0–€56,160	€6,560.00

Source: Roddy, A., O'Neill, C., 2019

Figure 12: Societal cost of childhood and adolescent ASD, 2014/15

Type of expenses	Mean cost	Median cost	% of mean cost
State expenditure on ASD health services	€1,300.63	€638.82	3%
ASD-related medication costs	€54.75	€0.00	0%
State expenditure on ASD educational services per child	€12,836.50	€9,883.64	30%
Out-of-pocket expenditure per child	€8,184.79	€5,937.50	19%
Lost earnings from having to take days off paid work or reduce working hours			
Mothers	€1,150.63	€0.00	3%
Fathers	€780.47	€0.00	2%
Informal care costs			
Mothers	€16,723.20	€10,774.40	39%
Fathers	€1,625.80	€0.00	4%
Total cost	€42,656.47	€42,965.44	100%

Source: Roddy, A., O'Neill, C., 2019

Ganz, M, L., “The lifetime distribution of the incremental societal costs of autism”. Archives of Pediatrics & adolescent medicine (2007)

Figure 13: Age-specific and lifetime societal costs of autism

Table 1. Age-Specific and Lifetime Incremental Societal Costs of Autism*

Age, y	Direct Medical	Direct Nonmedical	Indirect	Total Costs
3	44 446	6593	42 603	93 642
4	43 149	6401	44 258	93 808
5	42 305	6215	43 241	91 761
6	40 248	17 664	42 821	100 733
7	6704	17 150	42 405	66 259
8	6511	16 650	41 994	65 155
9	6321	16 165	41 586	64 072
10	5914	15 694	41 142	62 750
11	5743	15 238	40 702	61 683
12	5576	14 793	40 268	60 637
13	5413	14 361	39 838	59 612
14	5197	13 946	39 412	58 555
15	4961	13 538	38 076	56 575
16	4819	13 143	37 670	55 632
17	4679	12 762	37 267	54 708
18	4898	12 219	36 869	53 986
19	4756	11 862	36 476	53 094
20	1619	11 516	36 086	49 221
21	1571	12 813	35 701	50 085
22	1549	5192	35 319	42 060
23	1504	29 190	54 314	85 008
24	1460	28 340	64 951	94 751
25	1684	27 516	60 802	90 002
26	1636	26 713	39 533	67 882
27	1586	25 934	39 097	66 617
28	1541	25 181	38 666	65 388
29	1496	24 446	38 242	64 184
30	1453	23 735	37 792	62 980
31	1410	23 043	32 233	56 686
32	1369	22 371	31 850	55 590
33	1328	21 720	31 473	54 521
34	1291	21 088	31 168	53 547
35	1485	20 474	30 901	52 860
36	1443	19 878	30 538	51 859
37	1399	19 298	30 178	50 875
38	1360	18 736	29 823	49 919
39	1321	18 191	29 473	48 985
40	1282	17 660	29 128	48 070
41	1245	17 147	28 787	47 179
42	1207	16 646	28 451	46 304
43	1174	16 161	28 119	45 454
44	1138	15 691	27 791	44 620
45	1678	15 235	25 998	42 911
46	1628	14 791	25 696	42 115
47	1581	14 360	25 398	41 339
48	1535	13 940	25 104	40 579
49	1489	13 535	24 814	39 838
50	1446	13 141	24 527	39 114
51	1404	12 759	24 244	38 407
52	1361	12 386	23 965	37 712
53	1324	12 026	23 689	37 039
54	1284	11 607	19 900	32 791
55	1144	11 268	15 270	27 682
56	1369	10 940	15 096	27 405
57	1328	10 620	14 925	26 873
58	1291	10 059	0	11 350
59	1252	9765	0	11 017
60	1217	9481	0	10 698
61	1181	9205	0	10 386
62	1147	8937	0	10 084
63	1113	8677	0	9790
64	1081	8424	0	9505
65	1077	8179	0	9256
66	835	6352	0	7187
Total	305 956	978 761	1 875 667	3 160 387†

*Costs presented in 2003 dollars. Costs for age 4 years and older are discounted to 2003 dollars using a discount rate of 3%. Life expectancy for men is age 66 years and for women, age 65 years.

†Total costs do not match the total in Table 1 because of rounding.