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# PEOPLE, PRIORITIES, PURPOSE

OUR SPENDING  
PROPOSALS FOR  
BUDGET 2020

AsIAM Policy Division, part of  
the AsIAM Community Support Department



## Contents

- **Introduction** ..... pg 2
- **Children & Youth Affairs** ..... pg 3
- **Education** ..... pg 3
- **Health** ..... pg 4
- **Social Protection & Employment** ..... pg 4

## Introduction

At a time when many continue to see the benefits of economic growth, Ireland's autism community continues to face enormous inequities. Basic public services, including healthcare and education, continue to present significant structural barriers autistic people's access and participation. Furthermore, autistic people and their families face substantial financial inequalities as a result of who they are.

Key examples include:

- The average cost to family budgets generally amounts to over €28,000 spent on private services per autistic child in their households.<sup>1</sup> These expenses largely arise from the State's failure to sufficiently invest in crucial services for families, many of which are forced to reduce their working hours or leave their jobs altogether just to care for their children;
- Despite having much to contribute, just 32% of autistic people are in some form of paid work (part-time as well as full-time)<sup>2</sup>. This in turn leads to poverty and social isolation;
- Due to the inaccessibility of public services, including many schools and mainstream health services, autistic people are frequently found to pay for services available for free to others.

The social and financial isolation of autistic people is not only devastating to the one in 65 people in Ireland who are autistic<sup>3</sup>, or their estimated 243,000 immediate family members. Exclusion presents an ever-growing cost to the taxpayer in terms of negative impacts on health, increasing reliance on welfare and a loss of talent and ability. We propose that the Government invest in the full participation and acceptance of autistic people in Irish society by:

- **Autism-proofing public services and ensuring parity of access;**
- **Building the capacity of the autism community through adequate State investment in services;**
- **Empowering autistic citizens and their families to exercise full choice over the supports and strategies that they feel best meet their needs.**

We have set out our specific proposals for investment along these lines in relevant Government Departments.

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<sup>1</sup> Roddy, Áine et al. (2018) 'The economic costs and its predictors for childhood autism spectrum disorders in Ireland: How is the burden distributed?' *SAGE Journals*. 23(5): pgs.1106-1118. Online. Accessed: July 2019. Available at: <https://journals.sagepub.com/doi/full/10.1177/1362361318801586>

<sup>2</sup> National Autistic Society. (2016) *Too Much Information: The Autism Employment Gap Report*. Pg.5.

<sup>3</sup> National Council for Special Education (NCSE). "Major education report finds 14,000 students have autism diagnosis." NCSE Press Release. 15th July 2016. Online. Accessed: July 2019. Available at: [https://ncse.ie/wp-content/uploads/2016/07/6\\_Press\\_release\\_ASD.pdf](https://ncse.ie/wp-content/uploads/2016/07/6_Press_release_ASD.pdf)

## Children & Youth Affairs

The professionalisation of the Early Year sector and the ECCE scheme provide unique opportunities to provide the right support at the right time to young children who may be on the autism spectrum. The Access and Inclusion Model (AIM) has great potential for providing this support to our community however it is presently under-resourced throughout the framework.

We therefore propose **an additional €20 million should be allocated this year to further develop the scheme.**

In addition, we propose **€500,000 be sanctioned for the development of an Autistic Youth Strategy** to address the social isolation of many autistic young people across the country.

## Education

Significant strides have been made in recent years towards autistic people's inclusion within mainstream education. Indeed, 86% of autistic children enrolled in Irish schools now attend a mainstream setting<sup>4</sup>.

Inclusion, however, is far more than buildings' accessibility – it is about being respected and empowered within the school environment.

A shift in culture within the education system is as important as a shift in policy. This reality is reflected in the large number of autistic students who still do not have access to a suitable school, are on reduced timetables<sup>5</sup> or who have had negative experiences throughout their schooling owing to a lack of trained staff.

We propose:

- **€10 million** – national training programme to be rolled-out for all mainstream teachers on inclusive education and best practices for engaging with autism within school settings (including primary, post-primary and special levels). We believe the LINC model<sup>6</sup> used in Early Childhood Settings could serve as a useful model in this regard;
- **€0.8 million** – An independent review of the availability and quality of autism class and special school placements and their appropriate resourcing;
- **€1.96 million** – The provision of a full-time dedicated support teacher in every College of Further Education in order to increase successful completion of further education by members of the autism community.

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<sup>4</sup> National Council for Special Education (NCSE). (2016) *NCSE Policy Advice: Supporting Students with Autism Spectrum Disorders in Schools*. Pg.5.

<sup>5</sup> AsIAM. (2019). *Invisible Children: Survey on School Absence and Withdrawal in Ireland's Autism Community*. Pg.2.

<sup>6</sup> Online. Accessed: July 2019. Available at: <https://lincprogramme.ie/about/programme-overview>

## Health

Autistic people presently not only struggle to access clinical supports for their condition but also, due to a lack of training, often cannot access mainstream health services. This is worrying in the context of research which suggests autistic people, for a wide variety of factors are more likely to require health care including:

- Autistic people are at a significantly heightened risk of developing mental health problems such as depression and anxiety<sup>7</sup>;
- Autistic people are dying on average 16 years younger than non-autistic people<sup>8</sup>;
- Significant correlations with co-occurring conditions, including physical disabilities and bowel disorders<sup>9</sup>;

It is imperative that autistic people access the clinical supports to understand their own condition and the healthcare they need to live healthy happy lives. We propose that:

- The HSE be allocated **€50 million for the development and roll-out of the promised HSE Autism Strategy**<sup>10</sup>;
- **€2 million be provided to the Child and Adolescent Mental Health Services (CAMHS)** to develop an appropriate, timely clinical pathway for young autistic people in mental health crises;
- **Funding be provided for a National Training Programme**, open to all HSE staff, on providing for the needs of autistic people in primary and acute clinical settings.

## Social Protection & Employment

Autistic people continue to face bureaucratic barriers to accessing the welfare system. The present application processes demonstrate a lack of understanding of the condition and are also counterproductive to many autistic adults' personal development.

Carers are a keystone support for many autistic people and yet they continue to be undervalued and under-supported.

<sup>7</sup> Simonoff, E. et al. (2008). 'Psychiatric disorders in children with ASD: prevalence, comorbidity and associated factors in a population-derived sample.' *Journal of the American Academy of CaAP*. 47(8): pgs.921-929. Online. Accessed: July 2019. Available at: [https://jaacap.org/article/S0890-8567\(08\)60059-3/fulltext](https://jaacap.org/article/S0890-8567(08)60059-3/fulltext)

<sup>8</sup> Hirvikoski, Tatja. et al. (2016). 'Premature mortality in autism spectrum disorder.' *The British Journal of Psychiatry*. 208(8): pgs.232-238. Online. Accessed: July 2019. Available at: <https://doi.org/10.1192/bjp.bp.114.160192>

<sup>9</sup> Ryzewska, Ewelina. et al. (2018). 'Prevalence of long-term health conditions in adults with autism: observational study of a whole country population.' *BMJ Open*. 8(8). Online. Accessed: August 2019. Available at: <https://bmjopen.bmj.com/content/8/8/e023945>

<sup>10</sup> Department of Health. 'Minister Harris announces first ever Autism Plan for 2019.' Department of Health Press Release, 5th December 2018. Accessed: August 2019. Available at: <https://health.gov.ie/blog/press-release/minister-harris-announces-first-ever-autism-plan-for-2019/>

We propose:

- An **additional €20 a week should be allocated to those in receipt of Disability Allowance;**
- **Domiciliary Care should be extended to 18 years of age** and paid at the rate of the present Disability Allowance;
- **Reversal of the cut to the Rehabilitative Training Allowance;**
- **Increase public awareness of current Workplace Supports available from the Department of Employment Affairs and Social Protection (DEASP),** including the Wage Subsidy Scheme, the Workplace Equipment Adaption Grant and the Reasonable Accommodation Fund;
- **Establish a disability-specific Access to Work Scheme within the DEASP,** similar to the model used in the United Kingdom<sup>11</sup>. This will combine existing supports available to jobseekers and employees with disabilities to secure and maintain employment;
- **Mandate all State bodies to work towards hiring more autistic employees,** in line with the incremental target of at least 6% by 2024 envisaged within the Comprehensive Employment Strategy<sup>12</sup>.

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<sup>11</sup> Government of the United Kingdom. Online. Accessed: August 2019. Available at: <https://www.gov.uk/access-to-work>

<sup>12</sup> Government of Ireland. (2015). *Comprehensive Employment Strategy for People with Disabilities 2015-2024*. Pg.22.