

# Every Child Counts

A REPORT INTO AUTISTIC CHILDREN'S ACCESS TO HEALTHCARE IN IRELAND

MAY 2021



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## Foreword

Dear Reader,

Thank you for taking the time to read and consider the findings of our *Every Child Counts* report; a quantitative analysis capturing the experiences and opinions of the many families in Ireland who have an autistic child. The report's exclusive focus on healthcare is a first for AsIAM's Community Support Team, as we seek to capture the voices of our community with regards to accessing support and services from the Health Service Executive.

Our report is comprehensive in its remit, with several underlying issues and themes captured ranging from the perennial struggles in accessing an autism diagnosis, to the lack of assistance provided in the days after receiving a diagnosis for a child. Whilst there are a number of issues raised within this study highlighting the disconnection that exists between families and service providers, there is one consistent theme permeating its findings – namely the widespread fatigue felt by huge swathes of parents and guardians in attempting to secure adequate care for their children. It is evinced throughout our study the struggles families must endure to access basic yet *essential* services for their autistic child – or indeed, their autistic *children*.

*Every Child Counts*, we hope, will shed light on the numerous obstacles that members of Ireland's autistic community face whilst engaging with one of the most crucial public services. Many of these are systemic in nature, made manifest through, *inter alia*, lengthy waiting periods for assessments, navigating layers of red tape, and a fundamental lack of understanding about autism as a spectrum. A major culture shift is required within the HSE and its assorted agencies to ensure that every autistic child is counted, and their rights vindicated under the United Nations Convention on the Rights of Persons with Disabilities to grow and flourish within society.

Whilst this report is detailed, it merely serves as a small insight into the intrinsic brokenness of Ireland's public health service. The testimonies provided by respondent families give testament to this brokenness, and elucidate the need for urgent change so as to reduce the numbers waiting on assessment, and indeed

the numbers waiting on essential therapies and services. This brokenness has been compounded by the COVID-19 pandemic, which has seen a widespread and sudden denial of regular support for autistic children around the country. The recent HSE dossier issue has also damaged the trust between parents and service providers. A cultural change and a willingness to work in partnership with families is needed.

One of the few positives of the pandemic is that it has provided an opportunity to pause and reflect on the system and how primary care services are delivered. The time has now come for that pausing and reflecting to be turned into actions.

We would urge that equitable access to healthcare be prioritised as part of the HSE's Autism Action Plan's agenda, and that this urgency is similarly reflected in the work of the upcoming Autism Innovation Strategy initiated by the Department of Children, Equality, Disability, Integration, and Youth.

A handwritten signature in black ink, appearing to read 'Adam Harris', is centered within a white rectangular box.

Adam Harris

**Chief Executive Officer**

### **Research Team**

- Michael O'Flanagan - **Head of Community Support**
- Gáibhín McGranaghan - **Policy Officer**
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- Grace Lehane - **Policy Intern**

## Executive Summary

- **43%** of respondents' children were aged between six and ten years of age, with **16%** reporting having another child on the spectrum.
- **34%** of families stated that they were based in Co. Dublin; Leinster (excl. Co. Dublin) was the largest province of respondents at **31%**, followed by **25%** in Munster, and the remaining **10%** living in Connacht-Ulster.
- **42%** of parents and guardians have had to wait over two years to receive an autism diagnosis for their child.
- **54%** felt very dissatisfied with the support services from the HSE for their autistic children, with as many as **65%** of respondents going on to express dissatisfaction with broader Disability Services.
- **79%** said that they were not in receipt of any support from either the Early Intervention or School Age Going Teams.
- **70%** felt broadly dissatisfied with the HSE's support in helping them better understand their child's autism diagnosis.
- **76%** said that their autistic children were not receiving any support from the Child and Adolescent Mental Health Services (CAMHS).
- **40%** of respondents' autistic children have regressed during the COVID-19 pandemic, whether that be in their educational or interpersonal skills.
- **80%** of respondents who confirmed they were in receipt of Carers Allowance claimed it was insufficient; **61%** of those on Domiciliary Care Allowance echoed similar feelings about its capacity to cover costs.
- Only **7%** of families were in receipt of respite services and **less than 1%** were using residential services.

## Common Challenges Encountered

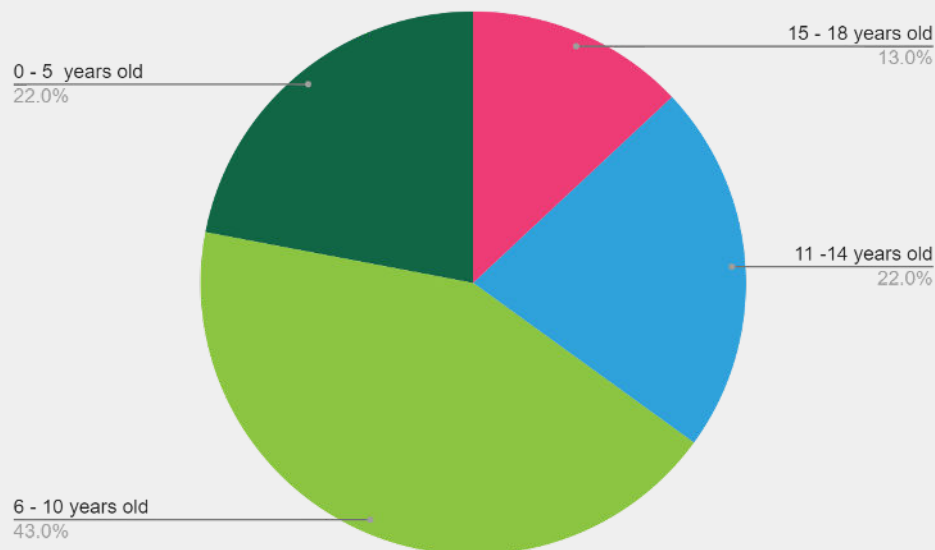
- Families are provided with very little information upon receiving a diagnosis for their child, as a result families often struggle to find supports post-diagnosis due to the lack of support and signposting from the HSE.
- Widespread dissatisfaction persists over the HSE's role in helping parents and guardians understand autism as a neurodevelopmental condition during the diagnostic process and afterwards.

- Inconsistent engagement between healthcare professionals and families on how to support their children on the spectrum is common, and has worsened during the pandemic.
- Inaccessibility to regular supports has contributed to the occurrence of significant regression in autistic children's interpersonal and educational skills during the pandemic.
- Financial pressure is acutely felt by families who assume full-time caring roles for their autistic children, reporting that existing social welfare payments are insufficient to cover the costs of therapy and additional support.

## Profile of Respondents

There were two types of respondents to this survey - **families of diagnosed autistic children** and **families awaiting an autism assessment**. **94%** of respondents were from families of autistic children, whilst **6%** were from families awaiting an autism diagnosis for their child.

A wide range of affected age groups were reported, with the majority of respondents' autistic children being aged 6-10 years of age (**43%**), followed jointly by those aged 0-5 years and children aged 11-14 years at **21%** each, and young people aged 15-18 years featuring as the smallest group at **13%**.



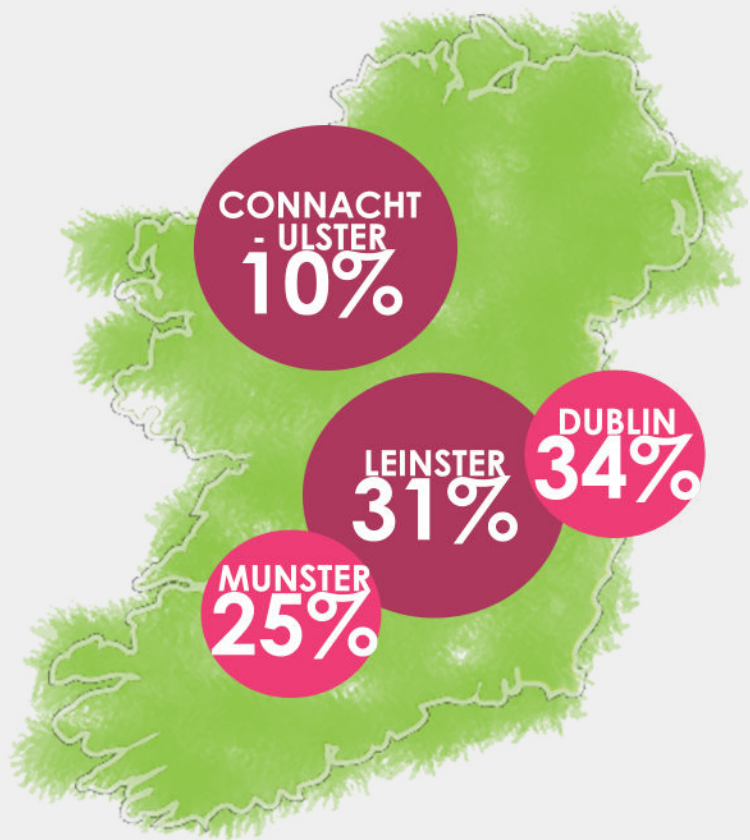
The majority of respondents' children were male at **72%**, compared to **27%** who were female and **1%** who were non-binary. This gender disparity, similar to that between age groups, is a common aspect of autistic profiling; AsIAm would nevertheless caveat that as the understanding of how autism develops and manifests between individuals grows, increasing numbers of girls and women are being diagnosed as on the spectrum<sup>1</sup>. This historic gap is set to steadily narrow over the coming decades. **We would therefore caution against viewing the reports' statistics, and indeed autism as a whole, along a gendered binary.**

A varied profile of co-occurring diagnoses was gathered during the study. A majority of respondents' children (**42%**) had neither an intellectual disability nor a

<sup>1</sup> Ratto, A.B., Kenworthy, L., Yerys, B.E., *et al.* (2018). 'What About the Girls? Sex-Based Differences in Autistic Traits and Adaptive Skills', *Autism*, 48, pgs.1698-1711. Online. Available at: <https://doi.org/10.1007/s10803-017-3413-9>

co-occurring condition (e.g., dyslexia, dyspraxia, or a mental health diagnosis). This is interestingly juxtaposed with just **8%** reporting that their autistic child had both an intellectual disability *and* a co-occurring condition. **28%** were reported as living with a co-occurring condition to their autism but not an intellectual disability, whereas **22%** said their autistic child had an intellectual disability but not any other conditions.

Geographically, a considerable concentration of respondents were based in Co. Dublin at **34%**. This is of little surprise, given that up to two fifths of the country's population is thought to reside in the Greater Dublin Area<sup>2</sup>, yet it also speaks to the rural-urban divide between accessing services. This is corroborated by Co. Cork being reported as the second-largest base of respondents at **10.5%**, followed by Co. Kildare at **6%**. Leinster (excluding Co. Dublin) was by far the largest province of respondents at **31%**, then Munster at **25%**, with the remaining **10%** living in Connacht-Ulster.



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<sup>2</sup> As many as 44% of Ireland's urban population are estimated to live in Dublin, whilst 40% of the State's total population reside in the Greater Dublin Area (understood as including Counties Dublin, Kildare, Meath, and Wicklow), according to the Central Statistics Office (2016). Online. Available at: <https://www.cso.ie/en/releasesandpublications/ep/p-cp2tc/cp2pdm/pd/>



## Methodology and Survey Analysis

Our survey was disseminated to the autism community on 8th February 2021 for four weeks, ending on 7th March, with a total of **454 completed responses** to an online questionnaire via SurveyMonkey.

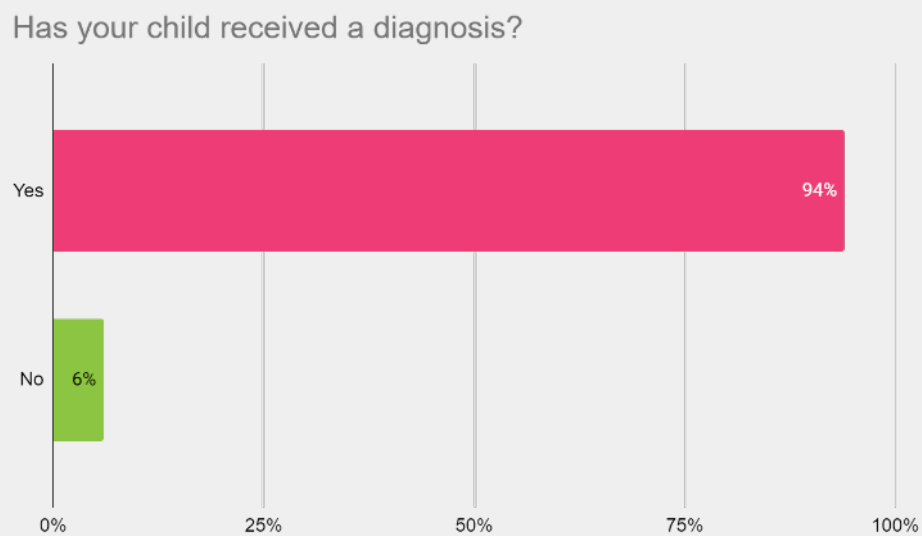
Whilst AsIAM received considerable engagement with this study, we would nevertheless qualify, from the outset, that these findings are only a snapshot of a problem with a much larger scale. Since our founding in 2014, our organisation has corresponded with thousands of families across Ireland in need of better access to better health services for their autistic children, particularly those of a *diagnostic* nature. Despite the levels of information available to the public through the HSE and its online platforms, far too many parents and children struggle to make sense of where to start their autism journey. Even upon entering the system, lengthy waiting lists for assessments and contending with a labyrinthian bureaucracy are two of the most immediate and persistent challenges families face, pre- *and* post-diagnosis.

AsIAM structured this study in such a way that we could gauge the experiences of autistic families throughout their engagement with the HSE, from applying for their first autism assessment to accessing follow-up services. To that end, we examined several areas of interest to members of the autism community under key headings. These include **Assessment and Diagnostics, Accessing Services, the Impact of COVID-19 on Supports and Services, Carers' Allowance and Domiciliary Carers Allowance**, and **Case Studies**.

## Accessing Services and Professionals

### Assessment and Diagnosis

The graph below indicates the percentage of families who had received a diagnosis of autism for their child, whilst the remaining percentage shows the numbers awaiting an autism assessment. **94%** of respondents were from families of autistic children, whilst **6%** were from families awaiting an autism diagnosis for their child.



We asked the parents/guardians of those children who had *not* received an assessment how long they had been waiting for one. The results were as follows:

- **42%** were waiting more than 2 years.
- **24%** were waiting 1 year.
- **14%** were waiting 2 years.
- **12%** were waiting 0-6 months.
- **8%** were waiting 7-12 months.

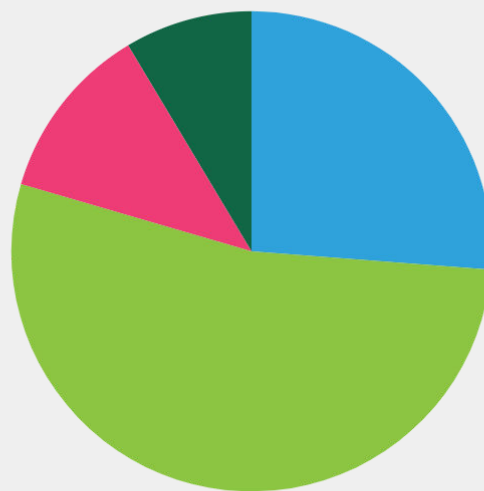
It is not uncommon for families to have more than one child undergo an autism assessment, often simultaneously with their siblings. We asked respondents whether this scenario applied to them during our questionnaire. At the time of this survey, as many as **16% of families had a second child waiting for an autism assessment**. Recent events have evince the lengths some parents/guardians have to undertake in order to ensure the HSE is compliant with its statutory

requirements, by taking legal action against the HSE. It is important to note the HSE has a statutory duty to ensure Assessments of Needs are carried out within a particular time frame. The Disability Act 2005 in particular Part 2 of the Act as well as the Disability (Assessment of Needs, Service Statements and Redress) Regulations 2007, set down the timeframe upon which an Assessment of Need must be provided to a child where an application has been made. When a dispute arises it is incumbent on the HSE to allow for a solution that is child focused rather than intimidating and costly litigation.

## Early Intervention and School Age Going Teams

Upon receiving a diagnosis, an autistic child may be referred to certain service divisions within the HSE, namely Early Intervention Teams who work with children aged 0-5 years of age, or the School Age Going Team who work with those aged 6-18. We asked families to identify which service provision their child had been assigned to, if any.

Which of the following has your child been assigned to, if any?



- Early Intervention Services (i.e., Occupational Therapy, Speech and Language, Psyc...
- School Age Team (i.e., Occupational Therapy, Speech and Language, Psychological...
- Currently awaiting assignment
- Not applicable to my child

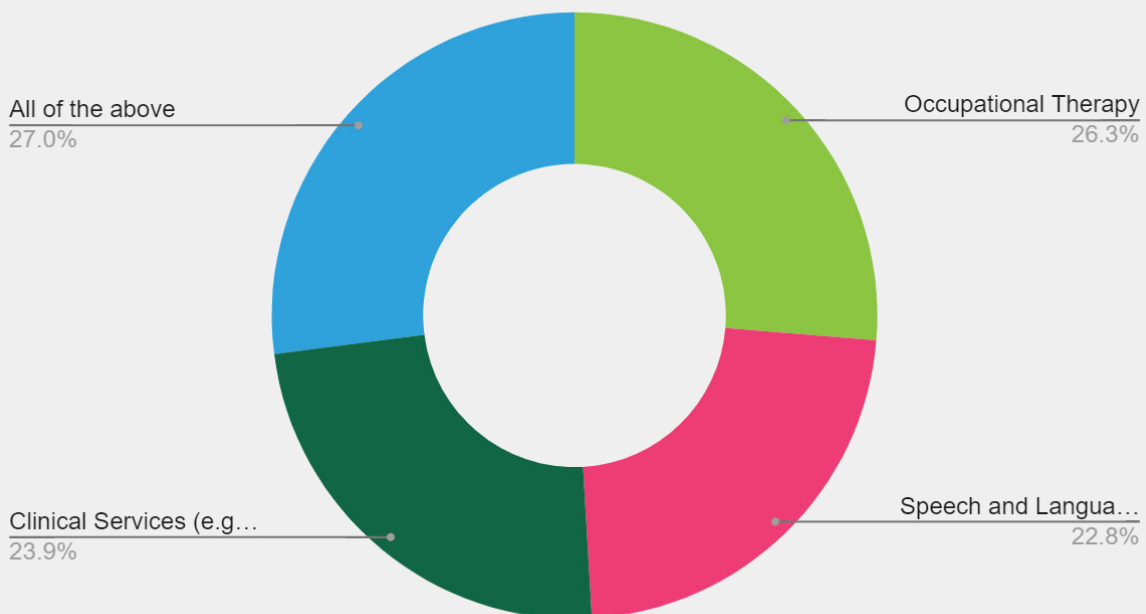
Of those who have been assigned to either the Early Intervention Services or the School Age Going Team, our findings showed that a number of families are still waiting on services for their child post-diagnosis.

- **79%** are not receiving any support from either Early Intervention or the School Age Going Teams.
- **16%** are receiving support from either an Early Intervention or a School Age Going Team.
- **5%** stated 'Not Applicable.'

## Waiting Times

We went on to ask about the services that are currently available from either the Early Intervention or School Age Teams, and which supports respondents' children were awaiting.

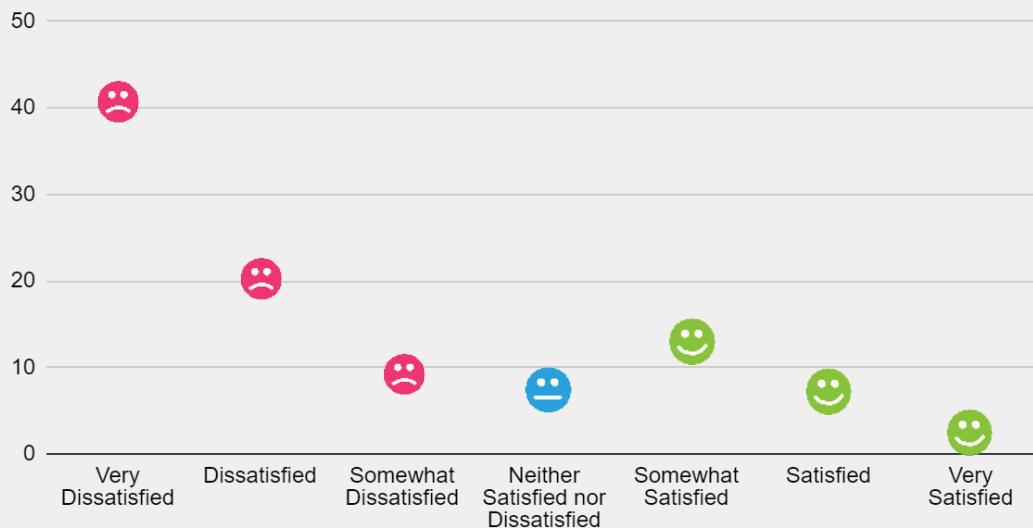
Which type of service is your child waiting on?



The above graph shows the reality for many families in accessing services for their child through the HSE. **49% of respondents are still waiting for access to Speech and Language, Occupational Therapy and other clinical supports for their autistic child.** The number of these children waiting on such essential services is reflected in the levels of satisfaction families have with public services.

## Satisfaction with the HSE Provision of Services

How would you rate your engagement with your child's support services?



The diagnostic process for a potentially autistic child is an overwhelming experience for so many families across the country. There are so many unknowns about what the process specifically entails, for both the parents and guardians and the child themselves, about which professionals are involved and what follow-up services are available post-diagnosis. Autism is a complex condition and for many families their child's diagnosis will present a plethora of questions on topics they may have never encountered before. Indeed, for those families who are on low- and middle-incomes, the prospect of follow-up services is an especially important one, as accessing reliable information on their autistic children's needs is so often dependent on these services' affordability and accessibility through the HSE.

We asked respondents about how satisfied they were with support received from the HSE in understanding their child's autism diagnosis. The results indicate that a significant majority felt broadly dissatisfied (**70%** in total) with the level of HSE support in helping them understand their child's condition.

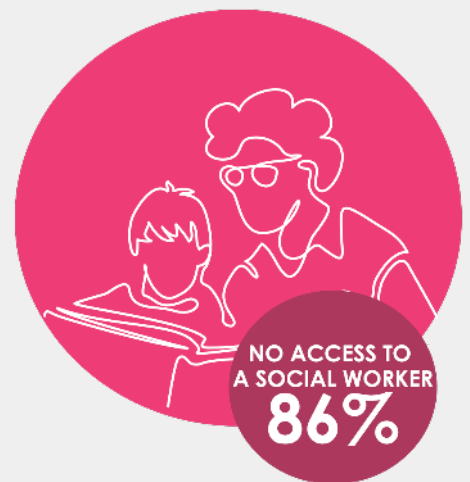
- **41%** stated they felt 'very dissatisfied'.
- **20%** stated they felt 'dissatisfied'.
- **9%** stated they felt 'somewhat dissatisfied'.

- **8%** stated they felt 'neither satisfied nor dissatisfied'.
- **13%** stated they felt 'somewhat satisfied'.
- **7%** stated they felt 'satisfied'.
- **2%** stated they felt 'very satisfied'.

These statistics are a stark reminder of the serious gaps existing within the health service - not just of the regular links between various services and their necessary funding, but also in a working knowledge of autism as a complex and invisible disability amongst clinical professionals. Addressing such gaps in service provision and professional development must be a targeted focus of the HSE and its Autism Action Plan going forward; particularly during the diagnostic stage where many families are on the cusp of starting a journey into a new world.

### Access to Social Workers

We found that as many as **86% of those who took part in our study said they did not have access to a social worker for their autistic child**. Whilst not each and every child on the autism spectrum will *necessarily* require a social worker, such a significant number of those families without one raises several concerns from AsIAM's perspective. Primarily the role of a Social Worker is to help families learn about the condition, acquire access to support and navigate complex challenges as they arise. Navigating the system is particularly important to families as they start out on their autism journey.



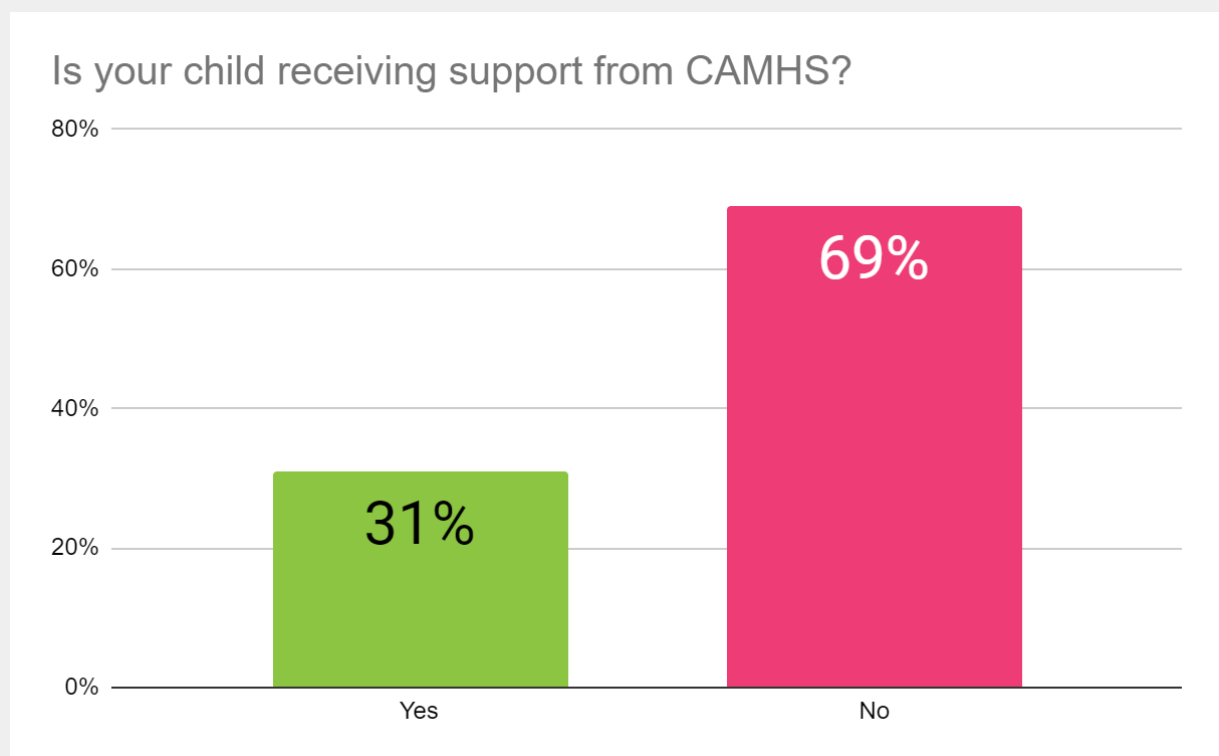
In the first instance, we are conscious that many autistic children are at a greater risk of developing behavioural, emotional and psychiatric problems than their neurotypical peers<sup>3</sup>. Addressing these difficulties will require a social worker's sustained and timely involvement as part of an autistic child's broader care team, so as to ensure better outcomes for their wellbeing in both the short- and long-term. Secondly, AsIAM are mindful of the heightened risks of abuse and

<sup>3</sup> Simonoff, et al. (2020). 'Trajectories of emotional and behavioral problems from childhood to early adult life', *Autism*, 24 (4), pgs.1011-1024. Online. Available at: <https://doi.org/10.1177%2F1362361320908972>

neglect that autistic children face<sup>4</sup>. This is a lifelong challenge for so many on the spectrum, but it is during childhood and adolescence, which coincides with the majority of autism diagnoses<sup>5</sup>, where individuals are especially vulnerable. Ready and seamless access to a social worker, AsIAM believes, is a vital lifeline for autistic children and their families to safeguard against these incidents from further developing and occurring altogether. Finally, we would add to this the precarious position of autistic girls and young women, for whom accessing diagnostic and follow-up services can be especially challenging.

### Child and Adolescent Mental Health Services (CAMHS)

Of those who indicated they were waiting on Clinical supports (such as psychology and psychiatry). 31% said they were receiving these supports, whilst 69% said they were not.



AsIAM has consistently raised this issue during our engagements with policymakers of the lack of engagement autistic families have with CAMHS.

<sup>4</sup> Fisher, Marisa H, *et al.* (2018). 'A population-based examination of maltreatment referrals and substantiation for children with autism spectrum disorder', *Autism*, 23 (5), pgs.1335-1340. Online. Available at: <https://doi.org/10.1177%2F1362361318813998>

<sup>5</sup> Daniels, Amy M. and Mandell, David S. (2013). 'Explaining differences in age at autism spectrum disorder diagnosis: A critical review', *Autism*, 18 (5), pgs.583-597. Online. Available at: <https://doi.org/10.1177%2F1362361313480277>

Hundreds of families have contacted us over the years regarding their inability to access support through CAMHS for a range of reasons, including a lack of awareness of how to apply and what precise services CAMHS can provide. The chief obstacle, however, often comes down to how autism is viewed by professionals as a separate diagnosis to any possible mental health condition. Upon disclosing to or receiving a diagnosis from a clinician or therapist that they were on the autism spectrum, numerous children have been referred from CAMHS to Disability Services, whereupon they are re-referred when they disclose a mental health condition. A vicious cycle thus ensues, whilst the autistic child in question is trapped in limbo without any professional support.

Accessing appropriate mental health services involves numerous hidden barriers for autistic people of all ages, yet it is the importance of securing early interventions which so often complicates the process for children and young people on the spectrum. Indeed, autistic children are four times likelier to develop a mental health condition like clinical depression than their neurotypical peers<sup>6</sup>; without appropriate professional intervention, the prognosis is often poor, resulting in likelier co-occurring diagnoses of significantly complex and chronic conditions later in life, such as anxiety, suicidal ideation<sup>7</sup>, and emotional dysregulation<sup>8</sup>.

Going forward, AsIAM would urge the HSE to prioritise greater accessibility to CAMHS for autistic children. This would involve greater investment to provide additional therapists, better training on best practices for engaging with autistic patients, and instilling a culture of renewed understanding of autism as a complex developmental condition, not as an illness or solely as a disability.

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<sup>6</sup> Hudson CC, Hall L, Harkness KL.(2019). 'Prevalence of Depressive Disorders in Individuals with Autism Spectrum Disorder: a Meta-Analysis', *Journal of Abnormal Child Psychology*, 47(1), pgs.65-175. Online. Available at: <https://doi.org/10.1007/s10803-018-3542-9>

<sup>7</sup> Masi, G., Scullin, S., Narzisi, A., Muratori, P., Paciello, M., Fabiani, D., Lenzi, F., Mucci, M., & D'Acunto, G. (2020). 'Suicidal Ideation and Suicidal Attempts in Referred Adolescents with High Functioning Autism Spectrum Disorder and Comorbid Bipolar Disorder: A Pilot Study', *Brain Sciences*, 10(10). Online. Available at: <https://doi.org/10.3390/brainsci10100750>

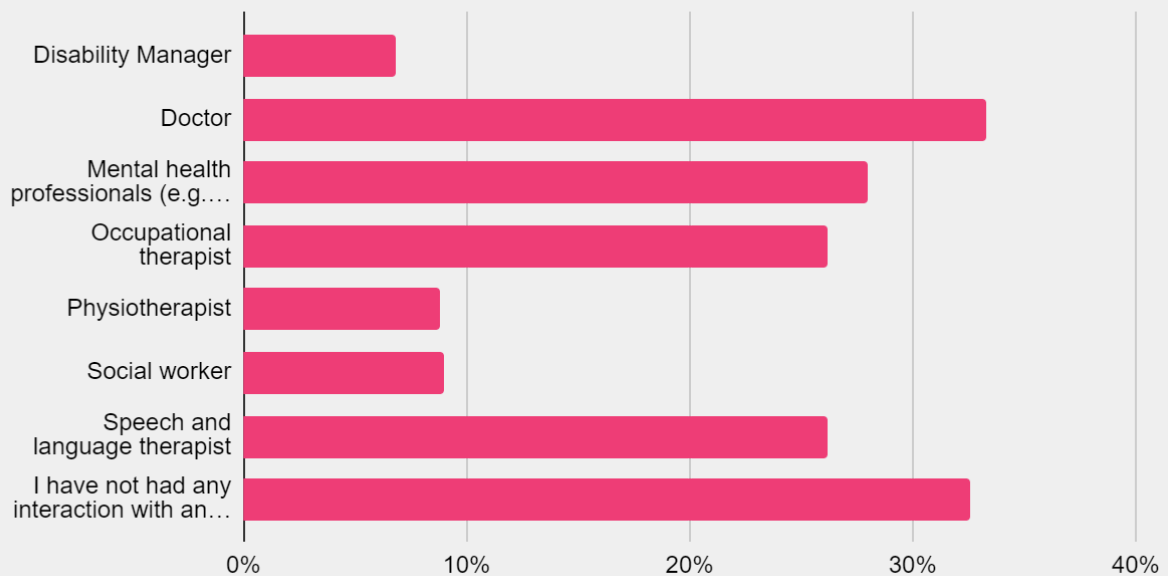
<sup>8</sup> Joshi, G., Wozniak, J., Fitzgerald, M. *et al.* (2020). 'High Risk for Severe Emotional Dysregulation in Psychiatrically Referred Youth with Autism Spectrum Disorder: A Controlled Study', *Autism*, 48, pgs.3101–3115. Online. Available at: <https://doi.org/10.1007/s10803-018-3542-9>



## Accessing Professionals

It is difficult to overstate how challenging the past twelve months have been for autistic children's families when accessing critical supports from the HSE. Chronic under-resourcing of Primary Care services over the years<sup>9</sup> has shed light on the fundamental shatterpoints within the wider system on several levels. It has, in the first instance, significantly stymied disability services' accessibility, and secondly, complicated families engaging with Primary Care workers. As part of our study, AsIAM asked respondents to gauge the frequency of their interactions with Primary Care professionals over the past year.

### Have you had any interactions with the following service professionals in the last 12 months?



That as many as a full third of our total respondents reported no engagement whatsoever with any professional in the past year indicates a serious disjuncture within the HSE's continuum of provision for autistic children. It is all the more incredulous to consider that this non-engagement persisted throughout a national health emergency, wherein these children and their families required targeted support like never before. Whilst we did not compare waiting times

<sup>9</sup> Cullen, Paul. (2019). 'HSE figures show 166 job cuts in primary care.' *The Irish Times*. 4th September. Available at: <https://www.irishtimes.com/news/health/hse-figures-show-166-job-cuts-in-primary-care-1.4006762>

between present and pre-pandemic levels, going forward it would be a useful exercise to include in any subsequent reviews into reforming HSE services.

Following on from the previous engagement, we asked respondents to assess the quality of their local Disability Services. A vast majority of respondents were very dissatisfied with the level of service they were receiving from their Disability Service. It is evident from this report that a change is needed in how service providers interact and engage with families. But also it is vital that the government provide service providers with the resources they need to ensure families and individuals needs are met.

### How would you rate the overall disability services in your community?



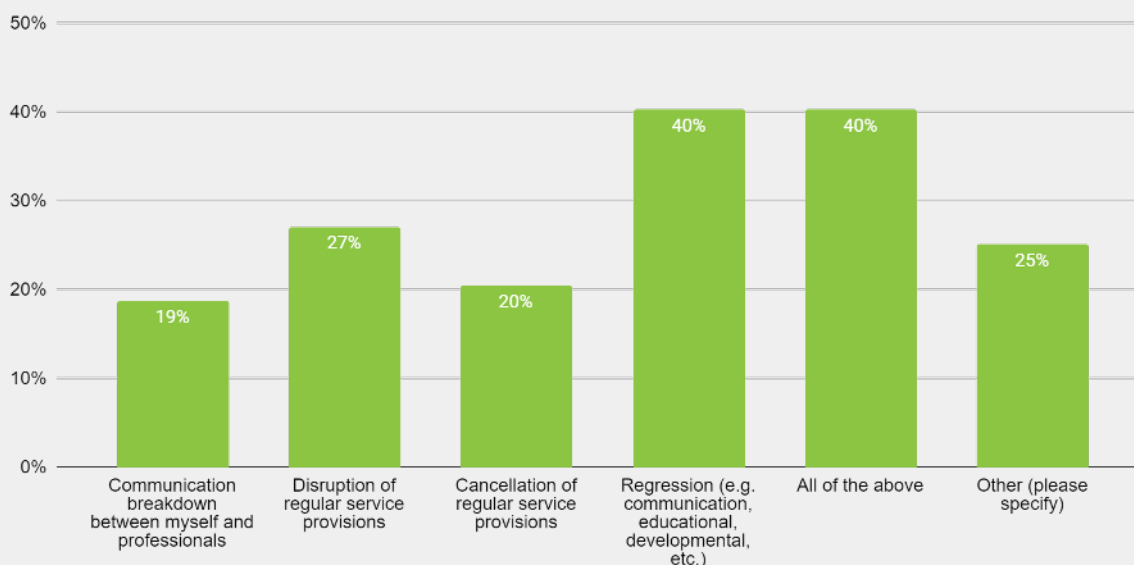
## Impact of COVID-19 on HSE Service Provision

The ongoing COVID-19 pandemic has impacted autistic people’s lives in ways few could have imagined from the crisis’ outset. Fewer cohorts within our community however, as our study’s findings bear out, have been as adversely impacted as autistic children and young people.

As many as **40% of respondents reported that their child had regressed in the past year**, ranging from relapses in their communication and interpersonal skills to their educational development. This figure corroborates with similarly stark

statistics gathered from our earlier collaborative research with DSI and Inclusion Ireland, whereby it showed that the absence of consistent routine and targeted support from schools contributed to widespread regression amongst school children with disabilities<sup>10</sup>. This is but one of many factors arising from the pandemic impacting autistic children’s quality of life and care, as the graph below indicates, where we asked how COVID-19 impacted children’s services.

How has COVID-19 impacted your child's services?



**19%** of respondents stated there were **communication difficulties with healthcare professionals**; **27%** experienced disruption to essential services for their children, and **20%** of respondents’ children had their regular support cancelled altogether.

Families have expressed their frustrations with the alternative methods of service provisions that have been put in place by certain providers. Whilst some families find accessing services through telehealth a useful accommodation which reduces the need for travel, sensory overload or a loss of routine, the testimonies gathered towards the end of this report show that these measures fell short or were inappropriate for many families’ autistic children. Indeed, a sizable cohort

<sup>10</sup> AslAm, et al. (2020). *Educational Supports on the Re-Opening of Schools: A Report by AslAm, Down Syndrome Ireland and Inclusion Ireland on Educational Supports on the Return to School in September 2020*. Pg.12.

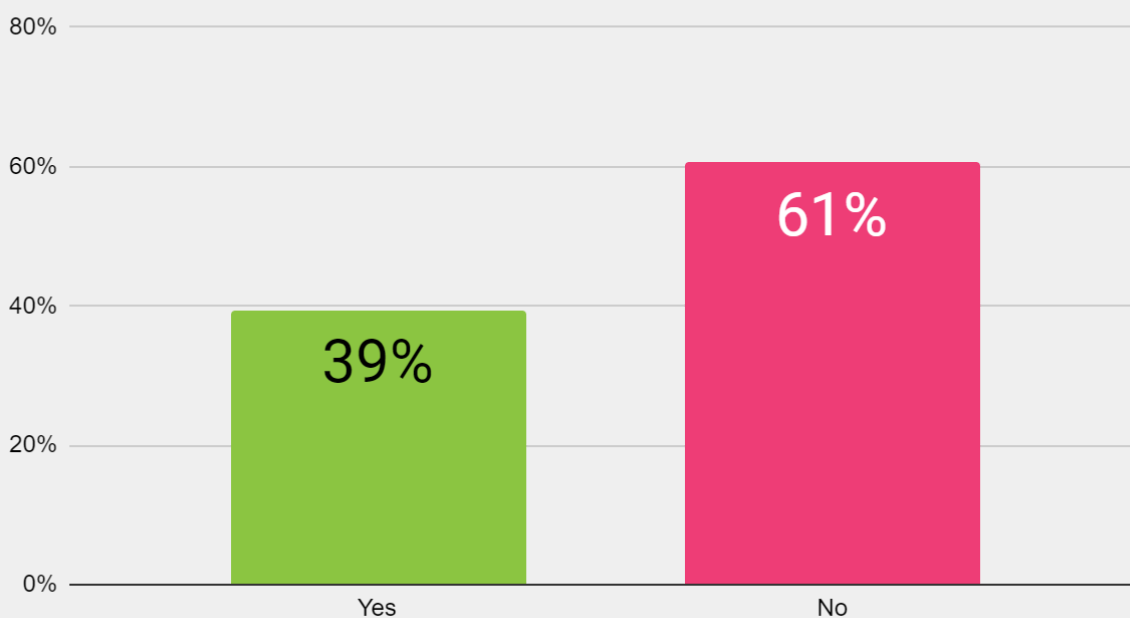
indicated they felt let down and even abandoned by Primary Care professionals over the past twelve months, further adding to the pressures of family life.

More information on the direct impact COVID-19 has had on autistic children and their families can be found in the *Lived Experiences* section (pg.20).

## Financial Supports

Many families with autistic children make the difficult decision to give up their jobs and become full-time carers for their children. This presents a plethora of challenges with regards to living on a viable income, whilst also accounting for the additional costs of living with a disability, wherein Ireland the risk of people with disabilities falling into poverty is almost 10% higher than the European average<sup>11</sup>. A sizable cohort of families in this position with whom AsIAM has engaged are reliant on social welfare payments to meet basic living costs, as well as helping towards accessing crucial services for these families' autistic children; affordable private support is simply out of the question.

### Are you currently in receipt of Carers Allowance for your child?



<sup>11</sup> Disability Federation of Ireland. (2020). *Pre-Budget Submission to the Department of Employment Affairs and Social Protection*. Pg.3. Online. Available at: [https://www.disability-federation.ie/assets/files/pdf/dfi\\_deasp\\_pre\\_budget\\_submission\\_for\\_2021\\_-\\_final\\_200720\\_2.pdf](https://www.disability-federation.ie/assets/files/pdf/dfi_deasp_pre_budget_submission_for_2021_-_final_200720_2.pdf)

Almost **40% of families who participated in our survey were in receipt of Carer's Allowance**, a welfare payment for carers on low incomes. Due to the means testing of this Allowance, many families and carers do not qualify, many of whom are experiencing strenuous financial hardship. AsIAM has heard from numerous individuals that are just *marginally* over the threshold to qualify for this payment, yet cannot fully avail of it. Of the **60.5%** of respondents who confirmed they were in receipt of Carer's Allowance, a staggering **80% believed that the payment was not sufficient enough** to meet their needs.

**80% of respondents confirmed they were in receipt of Domiciliary Care Allowance (DCA)**. This is a payment similar to Carer's Allowance, paid out on a monthly basis for a child under 16 years of age who has a severe disability with significant care needs. This figure shows how people rely on this financial support for the care and support of their child. From our survey, we have heard from families saying they use their child's DCA to finance different therapies from private providers and for educational purposes. This highlights many issues around public service provision for families with autistic children. The majority of respondents, **61%, do not think that the Domiciliary Care Allowance is sufficient**, compared to the 39% that believe it is.

## Lived Experiences

*"I am a full-time carer who gets no allowance because my husband is working. I do the same work as other carers and I cannot work due to having to give this care to my child. I feel carers should get payment that is not means-tested."*

*"The lack of services and support for my child is a disgrace. We have had to go privately for all services from diagnosis to therapy. It is a huge expense but without it, my son would not be able to go to the school he needs and would not get the support he needs. I flagged at 18 months there was an issue and I have had one half assessment since. He is now over five years old. It is unacceptable."*

*"We had to go to court to get services for [my daughter] and they were just about to start after a three year fight when COVID hit. I did get a phone call from Children's Disabilities services apologising as their team had redeployed and she wouldn't be starting this March either. I have had to pay for everything myself, even the diagnosis she was never assessed [for] by the HSE. Our system is broken beyond belief and I fear for the mental health repercussions for our children . . . there just isn't enough care or effort put into real change in my opinion."*

*"Support provided to children on the spectrum is very much dependent on the child's school. I feel that schools have become the primary source of support & in our case the only support that my child gets. He is with East Limerick who are under- resourced and not providing the same high level of meaningful support similar to Middletown, for example. Their approach to upskilling and educating parents is outdated, and provided by staff who have been providing the same slides in the same training for years."*

*"We as parents decided to have our son diagnosed privately as the waiting list was over two years. He was already six years old. In receiving his diagnosis, this was then sent to the autism team, and in return we were offered no help, as parents, for him, and that is because he does not have an intellectual disability. I understand resources are stretched, but just because my son's autism is 'mild' does not mean his daily struggles are not real. We were told our names would be put forward for the early bird course, we got nothing and he's now nine and a half."*

*"DCA stops at 16, autism does not stop at 16 and support is still required."*

*"I have six children, four are on the spectrum, as am I. I have received no services or help for any of them . . . [I have] had to hire a solicitor to access all of their assessments. I don't receive Carers Allowance as I am €22 above the means limit."*

*"My child was diagnosed at six. The process started and ended in thirteen months (no complaints with time frame), but was told what he had and that was it - no advice on where to go [or] where to look for support. For over a year I was left with nothing but a verbal diagnosis. My son is now twelve (thirteen this September) and we have seen no one apart from private sessions."*

*"My son was rejected from primary care speech and language therapy because they felt that his needs were too great before even meeting him! It took over a year to be accepted on the waiting list for early intervention and he will be waiting years before he is even seen by them! We received absolutely no services or support following his ASD diagnosis. I got his diagnosis over the phone following his AON assessment last year. We have been offered zero support."*

*"The means test for Carers Allowance needs to be removed. My income for caring for two children with disabilities should not be reduced because of my husband's income. I gave up full time employment to care for the children."*

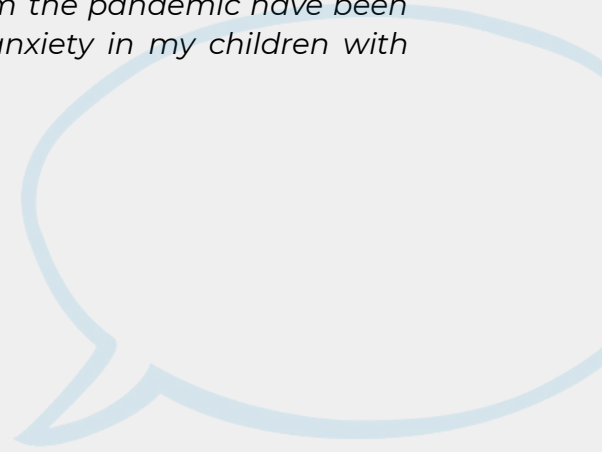
*"It has taken me four and a half years to get a diagnosis of autism. We were referred to a Primary Care physiologist who then referred us to CAMHS where a diagnosis of ADHD was given, and then we were sent for assessment of need which was not completed on time and in the end, we were sent by the HSE for a private diagnosis. I then received a letter to say he is on the list for services but wait time prior to COVID was 36 months for most. He will be thirteen years old before he gets the help he badly needs, after starting the process when he was four going on five. I feel the system is wrong . . . it should all be merged together into one, so you don't get passed all around each department. I am just starting the journey of seeking diagnosis for my second son, but at least I know what I am in for! It is not easy and a shame that it is not more streamlined. Eight years before he has any help is unbelievable."*

*"The majority of my son's additional care needs are met by myself at home through my own research and understanding of him. I have been disappointed by the outdated 'understanding' of autism shown by professionals in the Early Intervention services which often place my child under more stress and anxiety."*

*"There are huge pitfalls in the transition from the EIT to the School age team, I naively assumed it would be a natural progression after two and a half years waiting for an AON, at which point my son aged out of the EIT. The day we were given his diagnosis was the same day we were discharged and told we would have to wait another two years to be seen by the school age team! It just defies belief."*

*"The waiting lists and lack of communication with the Assessment of Needs process is unacceptable and has been practically non-existent during COVID-19"*

*pandemic. Children with extra needs have been lacking appropriate services during this time. All care and difficulties arising from the pandemic have been solely left to parents and guardians. The levels of anxiety in my children with extra needs have increased significantly.”*





## Key Recommendations

### The Department of Health should . . .

- Invest €5 million for HSE Autism Action Plan to accelerate its delivery, with particular focus on developing clear and accessible pathways for service delivery.
- Invest €5 million towards CAMHS to develop an accessible and timely clinical pathway for young autistic people in mental health crises.
- Invest €2.8 million to hire 100 additional caseworkers to support Early Intervention Teams for autistic children's referrals.
- Ensure that the Department and its agencies are compliant with their obligations as specified under the Education for Persons with Special Educational Needs Act 2004 and the Disability Act 2005.

### The Health Service Executive should . . .

- Fully engage with the upcoming Autism Innovation Strategy as a matter of urgency, with a particular view to improve accessibility to diagnostic pathways and follow-up services for newly diagnosed autistic children and their families.
- Accelerate the work of its Autism Action Plan so as to urgently identify and address accessibility barriers, both long-term and those arising from the COVID-19 pandemic.
- Instill a new culture of regular workplace auditing for developing better service delivery and engagement with users, and working with reviews' recommendations if and where dissatisfaction with services arises.
- Prioritise developing pathways for timely access to diagnostic assessments of children whom their families feel may be on the autism spectrum.
- Commit to reconfiguring CPD courses for healthcare professionals to include building greater awareness of autism and other invisible disabilities.
- Commence a formal process of collection, analysis and regular publication of data relating to autism diagnoses, the demographics of those seeking an AON, waiting times, and follow-up engagement of families post-diagnosis. AsIAM would echo similar calls from the Children's

Ombudsman for a central database of AON data's creation, accessible to all therapists, clinicians and administrators involved in the AON process<sup>12</sup>.

- Coordinate with the Child and Family Agency to identify care needs arising from a child's assessment which may require a dedicated social worker's allocation.
- Avoid engaging or escalating any legal action with families pertaining to any assessment of needs disputes.
- Ensure that an accessible and function complaints mechanism, as identified by the Children's Ombudsman<sup>13</sup>, remains open for autistic children and their families to seek timely and satisfactory redress.

## The Department of Employment Affairs and Social Protection should ...

- Introduce a cost of disability payment.
- Provide an additional €20 to the existing rate of Disability Allowance, with a view to increase it by €10 per annum throughout the course of this Government's lifetime.
- Domiciliary Care should be extended to 18 years of age and increase the rate of allowance by €20.
- Increase the rate of Carer's Allowance by €20, and remove the means testing for present and future applicants.
- Fund 100 additional caseworkers within the National Advocacy Service.

## The Department of Children, Equality, Disability, Integration and Youth should ...

- Invest €100 million in Tusla's services and programmes, joining in the Children's Rights Alliance's calls for similar levels of investment<sup>14</sup> to safeguard against vulnerable children's exploitation.

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<sup>12</sup> Ombudsman for Children's Office. (2020). *Unmet Needs: A Report by the Ombudsman for Children's Office on the challenges faced by children in Ireland who require an assessment of their needs*. Pg.31.

<sup>13</sup> *Ibid.*

<sup>14</sup> Children's Rights Alliance. (2020). *Pre-Budget Submission 2021*. Pg.8.

## The Houses of the Oireachtas should . . .

- Initiate a full legislative review of the Disability Act 2005 under the auspices of the two Joint Committees on Health and Disabilities, with a view to reform the Act's provision of services along a child-centred approach - one that is in full compliance with Ireland's obligations under the European Social Charter and the UN Convention on the Rights of Persons with Disabilities.
- Establish a Special Joint Committee on Autism, pursuant to the Private Members Motion successfully passed on a cross-party basis in April 2019<sup>15</sup>. This Committee would be mandated to hear directly from autistic people and their families in a consultative capacity, complimenting the work being undertaken by the Autism Innovation Strategy.

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<sup>15</sup> Dáil Éireann. (2nd April 2019). Autism Support Services: Motion [Private Members]. Online. Available at: <https://www.oireachtas.ie/en/debates/debate/dail/2019-04-02/30/>