



Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

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Deputy Peadar Tóibín
Dail Eireann,
Leinster House,
Kildare Street,
Dublin 2.
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Dear Deputy Tóibín,

The Health Service Executive has been requested to reply directly to you in the context of the following parliamentary question, which was submitted to this department for response.

PQ 41160/19

To ask the Minister for Health the level of funding provided for children with autism over six years of age to cater for their needs in each of the past five years; the number of children with autism on waiting lists for supports from the HSE; the average waiting time for those on waiting lists; and the longest waiting time for a child with autism over six years of age seeking supports from the HSE by county.

HSE Response

An extremely wide range of individual differences is represented within the Autistic Spectrum Disorder categorization, from individuals who also have a severe learning disability to those with average and above average intelligence. All share the triad of difficulties in reciprocal social interaction, communication, and a lack of flexible thinking. ASDs impact on all areas of functioning and have enormous implications throughout the lives of those affected across the entire ability range. Disability services are provided based on the presenting needs of an individual rather than by the diagnosis of the individual or the actual type of disability or service required. Services are provided following individual assessment according to the person's individual requirements and care needs. Care and/or services provided are tailored to the individual needs and requirements of the child/adult with ASD.

The HSE does not gather information routinely on the basis of diagnosis. So, while we know from previous studies that approximately 70% of those with Severe /Profound Intellectual Disability will also have Autism, although many will not have been formally diagnosed, we are not currently able to provide detailed information on the number of children and adults with autism. Similarly, in relation to the number of applications for residential care for children and adults with autism, while each Community Health Organisation Area would be aware of the presenting needs within each of the geographic areas, the HSE does not maintain a central list on the basis of diagnosis.

Hence, it is difficult to isolate and determine the exact level of funding provided for children with autism.

Children who may be presenting with a possible Autistic Spectrum Disorder, can present either through; the Assessment of Need process under the Disability Act, 2005, through Child and Adolescent Mental Health Services (CAMHS), or through Community Services.

For those children and young people with non-complex presentations, therapy services are provided through Primary Care Teams in Community Healthcare Organisations. For those with complex presentations (i.e. two or more disabilities), Therapy Services are provided by either Children's Disability Network Teams and/or Child and Adolescent Mental Health Teams (e.g., where a person with ASD also has a co-morbid mental health disorder).

Services and funding

HSE Disability Services has been allocated c. €1.9 billion in 2019. This funding is providing Disability Services throughout the country to children and adults with physical, sensory, intellectual disability and autism, including Residential, Day and Respite Services; Home Support & Personal Assistant Services; Early Intervention Services and Multidisciplinary supports for children and adults, including children with ASD.

Many children with autism due to the complexity of their presentation may have a primary diagnosis of intellectual disability or a co-morbid mental health component. In this context, it is important to note that the provision of supports and services for children presenting with ASD crosses a range of supports including Residential care, Respite Services and Day Services.

In addition, it is important to note that there are approximately 199 individual Service Arrangements in place between the HSE and voluntary groups who have a specific focus on Autism and Autism Spectrum Disorders. These include Grant Aid agreements and S39 Services Arrangements with funding being provided in the main by the Disability Sector (see Appendix 1 for further details-including funding provided by the disability service to those agencies over the past five years). Some funding is being provided by Mental Health and Primary Care. In addition, some agencies have received funding from the National Lottery. However, many more agencies provide Autism Spectrum Disorder services and supports to people and families without distinguishing these supports from their general support services being provided. These include for example – the COPE Foundation, Daughters of Charity Services, St. Michael's House, Brothers of Charity Services etc..

Residential Services

Residential services make up the largest part of the Disability funding disbursed by the HSE - €1.1b of the total budget of €1,817,004,322 in 2018, or 61%. Approximately 90 service providers provide residential services to over 8,000 individuals throughout the country. The bulk of these are provided by the 50 highest funded agencies (comprising both Section 38 & Section 39 organisations) – some 6,300 places, or 75%. The HSE itself provides 1,300 or 16% of the places.

Day Services

Day Services are a key component of support services that enable people to live within the community. Currently day services are transitioning to a new approach outlined in the policy *New Directions*. This policy is underpinned by the values of Person Centredness, Community Inclusion, Active Citizenship and Quality.

Similar to Residential Services, Day Care Services are based on presenting need rather than diagnosis and therefore, it is difficult to provide information on numbers of day care places available to children and adults with autism. For that reason it is difficult to provide information on the day services funding provided for children with autism.

Respite care

The HSE and its funded Agencies provide respite care to children and adults with disabilities including children presenting with ASD. Respite can occur in a variety of settings for various lengths of time, depending on the needs of the individual service user, the family and according to available resources. Respite is not always centre-based and can be provided in a number of ways, e.g. Centre based; In-Home; Home-to-Home; Family Support, etc. As a vital part of the continuum of services for families, respite potentially helps prevent out-of-home full-time residential placements, preserves the family unit, and supports family stability with the service users at the centre.

The HSE is very much aware of the importance of respite service provision for the families of both children and adults with disabilities, including the impact the absence of respite service provision can have on other services.

Targeted actions to improve supply

In 2018, the Minister for Health announced an additional €10 million for the HSE, specifically to enhance respite care in the disability sector. In accordance with the National Service Plan for 2018, the HSE committed to providing:

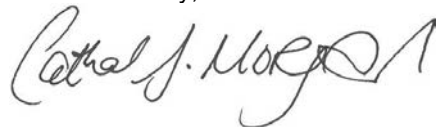
- An additional respite house in each of the nine CHO areas which will support 450 individuals in a full year and 251 in 2018 (€5m).
- Three additional respite houses in the greater Dublin areas (CHOs 7, 8 and 9) to support a further 225 individuals in a full year and 143 in 2018 (€3m).
- Alternative models of respite to support 250 individuals with disability (€2m)

The funding provided for the equivalent of 12 new houses, 1 in each CHO, and 3 in the Greater Dublin area. Twelve new or additional centre-based respite centres have opened to date, resulting in an additional 6,455 bed nights delivered to 763 people.

Community-Based, alternative respite projects, including Summer Camps, evening and Saturday clubs, also took place in 2018, delivering 15,144 'in home' Respite Hours, to 400 users and 1,296 Saturday/Evening/Holiday Club 'sessions' to 1,500 people.

The HSE is fully committed to maintaining the same level of service this year as in 2018. The programme to deliver on the €10 million additional funding will continue in 2019 and remains a high priority for the HSE.

Yours sincerely,



Dr. Cathal Morgan,
Head of Operations - Disability Services,
Community Operations

Appendix 1

ASD Service Providers

Please see below details for some of the larger Service Providers contracted to provide Autism specific services:

Autism Initiatives Ireland

Autism Initiatives began services in Ireland in November 2004 and has a range of services in Wicklow, Stillorgan and Dun Laoghaire (Baker's Corner), including residential respite, day and outreach services. In 2015, Autism Initiatives was asked to develop services for a range of young people with autism who required an immediate day service. The HSE gave over a former Health Centre, located in Glasnevin, to Autism Initiatives and funded the Service to remodel it for service users to meet their very particular needs. It is now called Botanic Horizons. The Service welcomed a number of service users in 2016 and currently has 14 service users, including those having a day service and those on an outreach service. The HSE allocates funding to this agency under S39 of the Health Act 2004. Funding allocated to date is as follows:

| Year | Funding |
|------|------------|
| 2015 | €5,468,978 |
| 2016 | €5,737,852 |
| 2017 | €6,943,431 |
| 2018 | €7,227,188 |
| 2019 | €8,411,286 |

An Tuath Nua

An Tuath Nua is an adult day service for 17 young people with autism ranging in age from 17 to 22. The majority present with challenging behaviour and there are 12 support staff employed in the centre. The attendees are graduates of Scoil Aislínn.

Scoil Aislínn was initially formed as the Cork Applied Behaviour Analysis School (CABAS). The school was established by parents and funded by the Department of Education. Subsequently, the school was established as a permanent primary school called Scoil Aislínn under the patronage of Cope Foundation. This was achieved with the agreement of the Department of Education and Science. Funding provided to the COPE Foundation from the HSE is as follows:

| Year | Funding |
|------|-------------|
| 2015 | €47,390,633 |
| 2016 | €44,331,970 |
| 2017 | €53,137,109 |
| 2018 | €55,679,963 |
| 2019 | €56,071,939 |

Cork Association for Autism

The Cork Association for Autism (CAA) was founded in 1978 by a group of parents in Cork with autistic children. The CAA provides residential, day and outreach supports to adults with autism and asperger syndrome across Cork and Kerry. It also provides respite services at its Crowbally facility in Mogeely.

CAA also provides a Home Support Service, either in an individual's own family home or within the wider community and often times during the evenings or at weekends for short periods or as a more long term solution.

The HSE allocates funding to the CAA under S39 of the Health Act, 2004. Services are provided through a Service Agreement which is reviewed on an annual basis. The agency received funding from the HSE as follows:

| Year | Funding |
|------|------------|
| 2015 | €4,677,494 |
| 2016 | €4,416,193 |
| 2017 | €4,416,193 |
| 2018 | €5,405,078 |
| 2019 | €5,743,746 |

Praxis Care

Praxis Care provides day services to service users on the Autistic Spectrum. Their mission is to provide their service users with individualised programmes of day activity that promote social inclusion and service user choice and control. Praxis Care opened their Clongriffin Hub in 2017. The HSE has allocated funding to Praxis Care as follows;

| Year | Funding |
|------|---|
| 2015 | €5,756,100 |
| 2016 | €6,693,530 |
| 2017 | €7,077,834 |
| 2018 | €10,000,386 Nth Ireland €706,280 Republic of Ireland |
| 2019 | €17,035,815 €706,280. (Northern Ireland) |

Gheel Autism Services

Gheel Autism Services (formally Gheel Training Group) was founded in 1971 by parents of people with autism. The agency provides Day, Residential, Respite and Outreach services for adults with Autism.

The HSE allocates funding to Gheel Services under Section 39 of the Health Act, 2004. This funding is governed by a Service Arrangement, which identifies service delivery provided by the agency in return for the money being provided to them. The Service Arrangement is reviewed on an annual basis. Funding provided to Gheel Autism Services from the HSE is as follows:

| Year | Funding |
|------|-------------|
| 2015 | €7,006,837 |
| 2016 | €7,370,173 |
| 2017 | €8,760,925 |
| 2018 | €11,377,366 |
| 2019 | €11,560,870 |

Irish Society for Autism (ISA)

Irish Society for Autism previously provided services at three sites nationally for people with Autism and this organisation was in receipt of substantial funding from the HSE (approximately €4.5 m in 2016). These services have now been transferred to three agencies as follows:

- Inspire Wellbeing which is receiving funding of €6,352,184.36 in 2019 (includes small amount from MHS)
- Positive Futures which is receiving funding of €5,066,029 in 2019 (includes small amount from MHS)
- Praxis Care funding received as outlined above.

Middletown North/South Centre for Autism

Middletown is a North/South government education initiative which aims to improve the quality of life for children and young people with autism and their families through the promotion of quality teaching and learning strategies. The service aims to achieve this through working collaboratively and with

families to meet the needs of children and young people with autism who are experiencing difficulties within their educational setting. This initiative receives funding from the Department of Education.

CoAction

CoAction was founded by parents and friends in Bantry in 1974 to ensure that children with an intellectual disability who were travelling to Cork for their education could receive the same in their own community. Local branches of volunteers were established in Castletownbere, Clonakilty, Dunmanway and Skibbereen, in addition to the original branch in Bantry. For many years local fundraising funded the services provided by the organisation but eventually HSE funding was accessed and now CoAction is the HSE designated service provider for intellectual disability services for children and adults in West Cork and has developed services for both children and adults with an intellectual disability and autism in the West Cork area and now provides services for 460 children and 130 adults. The HSE allocates funding to CoAction West Cork under Section 39 of the Health Act, 2004. Services are provided through a Service Agreement which is reviewed on an annual basis. The agency received funding from the HSE as follows:

| Year | Funding |
|-------------|----------------|
| 2015 | €6,832,145 |
| 2016 | €6,391,064 |
| 2017 | €6,391,064 |
| 2018 | €7,225,291 |
| 2019 | €7,337,016 |