

**WRITTEN QUESTION TO THE MINISTER FOR HEALTH AND SOCIAL SERVICES
BY DEPUTY C.S. ALVES OF ST. HELIER
ANSWER TO BE TABLED ON TUESDAY 18th JUNE 2019**

Question

Will the Minister provide a breakdown of the number of adults and children currently diagnosed with autism, indicating their ages; the level of severity; whether they are living independently; the level of care / intervention that is currently in place; whether they are being cared for by family or carers or neither; and will the Minister explain what support services are provided for them and their carers?

Answer

The provision of support to children with Autism and their families

There are two main pathways through which a **child** in Jersey would receive a diagnosis of Autism. These are the Autism and Social Communication (ASC) Clinic for children aged 5 to 18 and the Early Years Social Communication (EYSC) pathway for pre-school children.

The total number of children that received a diagnosis of Autism via ASC (since 2009) and EYSC (since 2014) is 191.

The breakdown of this across each calendar year is as follows:

2019 to the present date = 18
2018 = 30
2017 = 32
2016 = 25
2015 = 21
2014 = 10
2013 = 11
2012 = 14
2011 = 16
2010 = 7
2009 = 7

Total = 191

The age of each of these children at the time they were diagnosed can be provided if this is required and the Education Department's inclusion register may provide a further source of information. There is, however, no database held by Health and Community Services which documents the total number of autistic children in the island and their current age. There is also no available information on the level of support all autistic children on the island are receiving. We do know the number of children with Autism who are in the Government of Jersey's care but the low number means it is not appropriate to report back on this as it could make individual children and their families identifiable. The number is less than 5.

The Government of Jersey launched the Children with Disabilities Register in 2017, which is voluntary. Families who sign up receive a Max Card which offers discounts with several local organisations and 3,000 UK organisations. A newsletter is also sent to families which contains information about activities and events. A Children with Disabilities Directory is available for families to download from gov.je in addition to the Jersey Online Directory. The following link can be copied and pasted into a search engine in order to access a leaflet for this service:

<https://soj/depts/HSS/Registered%20Documents/ID%20Children%20with%20Disabilities%20Register.pdf#search=children%20with%20disabilities%20register>

The concept of “*severity*” is difficult to define, quantify and therefore to report upon. As an example of this, an autistic child may be very academically able but may have their quality of life much more significantly impaired (possibly by higher levels of social anxiety) than an academically less able peer. Different ways of defining the term could therefore see either child as being more *severely* affected by their diagnosis of Autism. In terms of the most recent diagnostic criteria, it should be highlighted that the single diagnostic term of Autism is now used. Other previously used terms such as Aspergers are no longer recommended as distinct criteria of Autism when establishing a diagnosis.

Modern services such as those provided on-island involve individualised care packages that look to assess and meet the needs of a particular child and their family. This is often built around Team Around the Child (TAC) principles that involve deciding which key professionals are needed to work alongside parents/carers as the members of an individual child’s TAC. Support for pre-school children is co-ordinated through the Child Development and Therapy Centre’s Early Years Pathway. For school age children, support may be co-ordinated by school, an Early Help assessment and plan or a Social Work assessment and plan according to the complexity of need. In addition to the aforementioned short breaks (respite), this could include (but wouldn’t be limited to) support with a child’s communication, feeding, behaviour, sensory needs, education or social inclusion. Provision in these important areas could be through working with a child and whoever is supporting them in whichever settings they access (i.e. home, nursery/school or the community). Evidence-based training programs are also provided for some parents.

Adults with autism

The number of adults currently with a diagnosis of Autism is 88. We have not at this point got details on age, although individuals are between 18 and 60 years. When the question is asked about severity it is irrelevant as the diagnostic assessment focuses on whether the person has Autism or not.

While our diagnostic process concentrates on one question only – do they or don’t they have Autism – it would, however, be quite common in our recommendations to signpost people onto social work for an assessment of need. This assessment would then source information relevant to their living arrangements family input etc.

Support that we offer for individuals that receive a diagnosis is as follows:

1. A six-week course for anyone that receives a diagnosis (there is a focus on what the diagnosis means for them, exploring the disorder further, and meeting others with the diagnosis etc.)
2. A drop-in advice service every Tuesday afternoon. This consists of an organised schedule of groups targeted at common challenges for individuals with Autism. There is also a service for parents and carers who can pop in for advice regarding personal situations.
3. As a consultative service, we offer advice to parents and carers in relation to Autism.