



Down Syndrome Ireland Pre-budget submission 2019

Down Syndrome Ireland agree with many of the points raised by the Disability Federation of Ireland, and would like to add Down Syndrome Ireland's support for the measures they suggest to overcome poverty and increase independence and inclusion for people with disabilities. Ensuring that we have a disability friendly society which includes access to support and inclusive design of transport and infrastructure will improve inclusion across the board.

However, there are some things which affect people who have Down syndrome disproportionately, and we would like to highlight the following additional supports that would improve quality of life for our members:

1. Medical cards based on need

- DSI agree with DFI that the Disability Allowance needs to be increased by €20 a week to provide an adequate minimum income to guard against poverty. However, medical cards need to be unaffected by this increase.
- Medical cards should be based on need rather than means tested for people with a lifelong condition. DSI is calling for automatic allocation of medical cards for people with Down syndrome, based on the understanding that they will have additional medical needs across the lifespan.

2. Additional funding for direct Speech and Language Therapy (SLT), Occupational Therapy (OT) and Physiotherapy for people who have Down syndrome.

-Doubling the numbers of SLTs in HSE Network Disability Teams and ensuring maternity leave is covered in order to reduce caseload numbers and increase access to therapy services.

-Provision of a meaningful level of SLT support in preschool, school, further education and adult settings.

- Developmental Language Disorder is a predictable element of the profile of people who have Down syndrome, and access to frequent specialised SLT services enable people to maximise their communication skills.
- AIM preschool supports at level 6 require the support of SLTs, OTs and other therapists to support inclusion. Our members tell us that this level is currently not functioning well, due to lack of available therapists.
- The Assisted Decision Making (Capacity) Act 2015 will require people to understand options and make informed decisions. People who have Down syndrome are likely to need SLT support to develop these skills.

3. Additional funding for July Provision for children with Down syndrome.

- July provision, either school or home based, must be provided for all children with Down syndrome, regardless of their level of GLD. This will ensure their continued successful inclusion and educational development in a mainstream setting.

4. Additional funding for further and higher education for adults who have Down syndrome.

- Adults who have Down syndrome need additional education options after post-primary school in order to continue their learning. DSI is developing and running courses, but funding to cover running costs is needed in order to keep direct student fees manageable.

5. A clear pathway for funding for services and access into HSE disability services for older adults with Down syndrome who need support.

- It is currently difficult for people to get funding for a day or residential place unless they enter HSE services at 18. People are taking this route just to ensure supports are there in later life. It will save HSE funds if people are able to delay entry until it is needed (often either because of age related deterioration of skills or ageing carers), but there needs to be a straightforward route to access services.

6. Funding for intensive home supports for older people with Down syndrome.

- People with Down syndrome have a higher risk of developing Alzheimer's disease at an earlier age than the rest of the population. The average age of clinical onset is 55, but it can be as early as 35. People with Down syndrome are also less likely to be married, so the burden of care in many cases is falling on parents who may themselves be elderly and vulnerable. Commitment is needed to adequately fund services which enable people to continue living in their own homes.

7. The creation of 9 additional Clinical Nurse Specialist posts within the major regional hospitals with access to specialist consultants for all Down syndrome-related conditions.

- In Ireland, there is only one dedicated nurse who specialises in Down syndrome. The post is based in Tallaght University Hospital and is supported by Down Syndrome Ireland.
- The Paediatric Down Syndrome Clinical Nurse Specialist post has been used to good effect in Tallaght University Hospital - ensuring joined-up services for families and promoting research. This clinic is now at maximum capacity and the model needs to be extended out to other regions and into adult services.
- Down syndrome affects every cell in the body, which means that people who have Down syndrome need additional health checks and are likely to be seeing doctors in various disciplines such as endocrinology, respiratory medicine, orthopaedics, ENT, audiology, oncology, ophthalmology, etc. It is in the best interests of the person who has Down syndrome and their family and also the health service, that there is coordination of appointments, blood tests, etc. For the family, this minimises travel, time missed from school or preschool and time off work for parents. It also makes good use of resources for the health service as tests required can be coordinated.

8. Additional resources allocated for the diagnosis and treatment of sleep apnoea.

- Current research suggests that sleep apnoea is extremely common in people who have Down syndrome (estimated prevalence between 50% and 80%). Sleep impacts on cognitive functioning, memory, behaviour, mental health, response to therapy, etc. which impact on quality of life and developmental progress.
- Sleep apnoea has been linked with dementia in the typical population, so a very high rate of sleep apnoea in a population with the highest incidence of early onset dementia cannot be ignored. Investing heavily in proactive diagnosis and treatment may improve outcomes in many areas and reduce health costs in the long term.

While DSI's list of requests will cost in the short term, they have the potential to reduce some costs in the longer term:

- Specialised, coordinated, readily accessible health services will reduce stress on families and increase attendance in preschool and school.
- Early diagnosis and treatment of related conditions such as sleep apnoea will improve physical well-being and increase the ability to learn.
- Increased access to Speech and Language Therapy will help communication and enable the child to access education.
- Supported access to mainstream education and continuing education after 18 will help people find work, reducing the cost of providing HSE-led 'rehabilitative training' or day services.
- Access to employment will promote social inclusion and well-being and reduce reliance on disability income.
- Physical and mental well-being is known to help delay the onset of dementia, and the associated costs.
- Supporting people to stay at home for as long as possible reduces the need for expensive residential care.



**Unit 3, Park Way House, Western Parkway Business Park,
Ballymount Drive, Dublin D12HP70**

Ph: (01) 4266500

Email: info@downsyndrome.ie

Web: www.downsyndrome.ie