

# The Upside – 21 Demands

**In the past 5 years, Down Syndrome Ireland has submitted over 20 submissions to a wide and varied range of Government consultations. We have participated in numerous pilot programmes. The following 21 Demands relate to issues, services, therapies, programmes and policies. The time for discussion has passed. Now it is time for action.**

**1** Fully implement the 2015 Assisted Decision-Making (Capacity) Act immediately to replace the 1871 Lunacy Act, already 150 years old. The Decision Support Service is due to be operational by June 2022. It is vital this is not delayed again, all outstanding measures required to make this happen need to be dealt with quickly. 2021 is the 150th birthday of the 1871 Lunacy Regulation Act. Let's make sure it's the last.

**2** Make a real commitment by signing the Optional Protocol to the United Nations Convention on the Rights of Persons with a Disability (UNCRPD) to meet Ireland's obligations under the UNCRPD. This is an important mechanism which enables people with disabilities to make a complaint directly to the UN Committee on the Rights of Persons with Disabilities if they feel the State has violated their rights

**3** Double the number of Speech and Language Therapists and increase numbers of occupational therapists in HSE Network Disability Teams so that frequent direct therapies can be provided at a meaningful level.

**4** Create new and improved guidelines for GPs and Paediatricians to help pick up early signs and refer children promptly. Employ more specialist Paediatric Rheumatologists to diagnose and help people with Down syndrome manage their condition.

**5** Ensure that funding is provided to cover HSE therapy posts where therapists are on maternity leave or other long-term absences. Caseloads can't be put on hold until the therapist returns. Currently Down Syndrome Ireland helps by providing supplementary supports at local branch level. This intervention is paid for from public fundraising and donations.

**6** Provide at least one Clinical Nurse Specialist post for Down syndrome in every Community Health Organisation (CHO). In Ireland there is only one dedicated nurse, focused on 0 – 18s only, who specialises in Down syndrome. The post is based in HSE CHO7 which serves Dublin West, Dublin South City, Dublin South West, Kildare/West Wicklow. The post is supported by Down Syndrome Ireland.

**7** Provide increased research funding to gain greater understanding how to delay and prevent dementia in people with Down syndrome.

**8** Ensure that State-funded disability services for people with Down syndrome are proactive about lifestyle approaches to dementia prevention. This means services provide opportunities for physical activities, mental stimulation and support people to learn how to optimise their own mental and physical health.

**9** Review, fully resource and implement the EPSEN Act now. It's been 17 years. We know it needs updating, but we need a rights-based system now.

The EPSEN Act 2004 was a ground-breaking piece of legislation that sought to put the provision of education for people with special educational needs on a new footing. It required considerable changes to be made to the existing educational regime, and the legislature has recognised that time will be needed to meet the requirements necessary for full implementation of the Act. For this reason, provision was made for the phased implementation of the Act over a five-year period, beginning in October 2005. 17 years later, the EPSEN Act has still not been fully enacted.

**10** No more reduced timetables, suspensions and expulsions. Provide rapid access to additional support and intensive behavioural interventions to ensure that this doesn't happen. We've had the consultations, now we need action.

**11** Introduce the See and Learn Programme into every preschool where there is a child with Down syndrome.

The See and Learn Programmes are evidence based programmes using a structured, visual approach to help children with Down syndrome develop speech, language and early literacy skills.

**12** Ensure that every student that wants to continue in education is given the chance, by providing career guidance. 75% of adults with Down syndrome had no career guidance at school.

**13** End the 'all or nothing' approach to disability services by giving access to individualised funding. This will provide pathways to accessing further supports as an individual's needs change, and funds can be used for personal assistance or transport so that teenagers have more options than just adult day services when they leave school. The consultations and pilots need to lead to real change in people's lives.

**14** Ensure measures are in place to meet the 6% employment target for 2024 under the Comprehensive Employment Strategy for People with Disabilities (2015-2024). The current target for public sector employees with disabilities is 3% and the latest published figure from 2019 is 3.1%.

**15** Increase the Comprehensive Employment Strategy target beyond 6% and introduce similar targets in the private sector.

**16** Expand the wage subsidy scheme, where private sector employers are given financial incentives to employ people with a disability. Currently this only applies if the person is working 21 hours a week or more. Many people with Down syndrome work fewer hours, and finding part-time jobs would be easier if this support was extended.

**17** Oblige the Government to make annual statements in the Dáil on Ireland's progress on implementing the UNCRPD starting this year. This call has been led by the Irish Human Rights and Equality Commission.

**18** The Government needs to honour its commitment in Sláintecare's Action Plan to introduce a statutory right to homecare in 2021.

**19** Access to respite and appropriate residential care when required.

**20** Now that the Capacity Review of Disability Services has finally been published, highlighting the high level of unmet needs of many people with disabilities, government must commit to multi-annual planning supported by multi-annual budgets. Individualised and person-centred supports need to be at the heart of the Disability Action Plan 2022-2025.

**21** Publish and act on the report The Department of Social Protection commissioned from Indecon in 2019 on the cost of disability in Ireland.