

Submission 4.26 [Down Syndrome Ireland](#)

ABOUT DOWN SYNDROME IRELAND

Down Syndrome Ireland has worked on behalf of people with Down syndrome and their families since 1971. The year 2021 is the fiftieth anniversary of the establishment of the charity. We work with more than 3,500 people with Down syndrome and their families each year. In addition to a national office, we are made up of 25 local branches which provide a wide range of vital services including education, support and research that enhance the lives of thousands of children and adults with Down syndrome. Our branch network is primarily run on a voluntary basis by our members and offers a range of activities, outings, services and supports throughout the country.

We are dedicated to being the primary source of information and support to people with Down syndrome, their families, and the professional community, working towards an improved quality of life for our members along with a respect and acceptance of people with Down syndrome as valued members of society. We place the person with Down syndrome at the centre of everything we do. We recognise the value and uniqueness of every person with Down syndrome. The unique and diverse needs of people with Down syndrome and their families govern all our activities.

We are committed to working towards a society where people with Down syndrome have their human rights to healthcare, education, employment opportunities and decisionmaking upheld.

What should our overall vision for equity of access to higher education in Ireland be for 2022-2026?

Down Syndrome Ireland is delighted to have the opportunity to make a submission to the National Plan for Equity of Access to Higher Education. The 2015-2019 plan highlighted how we can improve society by increasing levels of participation in higher education among all Irish citizens. This was backed up by having targets to increase participation by underrepresented groups including people with disabilities, however there was little to no inclusion of people with intellectual disabilities in these targets. One of the biggest barriers to people with Down syndrome reaching their potential are low societal expectations. When Down Syndrome Ireland was founded fifty years ago, children with Down syndrome were not sent to school, in more recent years people with Down syndrome were not considered

capable of completing the leaving cert, yet every year students defy that expectation. In very simple terms, taking part in further and higher education is next. People with Down syndrome have high expectations and want the option to take part in lifelong learning, however for most once they leave school that will be the end of their formal education. Down Syndrome Ireland has been working to change this. Ten years ago, Latch On, a literacy and Technology course developed by the University of Queensland was introduced and has been delivered in branches of Down syndrome Ireland ever since. However, people should not have to rely on a charity for further education and it is the goal of Down syndrome Ireland that Latch On should be available in every ETB around the country.

Recently there has been progress in including people with Down syndrome in further education. SOLAS have developed a working relationship with Down syndrome Ireland and have funded the charity to employ people to work on progressing inclusion in adult education.

The ETBI and the individual ETBs generally have been receptive and open to working with Down syndrome Ireland. Galway Roscommon ETB and Donegal ETB piloted courses and in September 2021 City of Dublin plan to deliver Latch On in three locations. Crucially the CDETB have agreed to a co teaching model of delivering the course in order to maintain the optimum ration of 1:4 in the classroom. This change was necessary as the Teaching Assistant or Special Needs Assistant role is not utilised in the ETBs.

Down Syndrome Ireland view collaboration with the ETBs as a very positive step and appreciate that the ETBs are working towards greater participation of people with Down syndrome in the FE and Training sector.

Who are the target groups that should be specified in the next National Access Plan?

Down Syndrome Ireland would like to see adults with an intellectual disability prioritised as a target group in the National Access Plan.

Within that group we would like to see a renewed focus on functional literacy that sits alongside the QQI framework. For many adults with Down syndrome education is the key to interacting with the world, progressing up the QQI framework is a lower priority.

Adults with Down syndrome need to be able to interact with the world around them.

Functional literacy is a necessity in order to be independent and to navigate daily interactions successfully.

Functional literacy needs to be explicitly taught in the Further Education sector and guided concrete opportunities to practise this form of literacy needs to be made available.

Attaining and maintaining a level of functional literacy will greatly enhance the level at which an adult with Down syndrome can be independent, exert control over their own lives and to be a decision maker and active stakeholder when planning for their future.

Having a basic level of functional literacy enables adults to carry out simple tasks in their personal lives such as being equipped to write a shopping list, choose what to watch on television, catch a bus and have access to their own post. The effect of having this freedom has an enormous effect on the well-being of a person and increases the number of choices and opportunities to be independent daily.

Literacy and numeracy enable adults with Down syndrome to become more active members of society and enables them to engage in the political process and state systems that affect their daily lives. Registering to vote, having an opinion on social issues and having a voice in elections are essential if adults with an intellectual disability are to influence how society views and treats them. Without literacy, political involvement at any level is an enormous challenge.

As information systems increasingly move online, digital literacy is also essential. In today's world, we all need to be able to look up information online to find out about things like events, courses, jobs, transport, etc. It is now rare to find printed job adverts or printed train timetables, so people who have poor digital literacy may struggle to find the information in other forms. Poor access to information becomes another barrier to inclusion in society.

During the last year we have also seen social contact with friends and family move into the online space. It is important that people with intellectual disabilities are not excluded or just passive recipients at digital events, but the ability to initiate contact and organise events requires a level of digital literacy which needs to be actively taught.

For all adults, literacy is important in order to fully engage with the people, systems and information around them but for adults with an intellectual disability, if they do not have a level of functional literacy their pathways in life and daily interactions can be severely limited.

How can the goal of mainstreaming be further embedded within HEIs?

Examples of good practice are already established in Ireland. The Trinity Centre for People with Intellectual Disabilities is an excellent example, as is the Certificate in General Learning and Personal Development delivered in Mary Immaculate College in Limerick. These programmes offer students the opportunity to study in a mainstream setting.

However, places on the courses are limited and access is largely determined by where you live. More courses need to be run for students with an intellectual disability and every higher education campus should have a course for people with intellectual disabilities.

The next step is for students with an intellectual disability to study alongside students on a mainstream course. Part of a course or a module should be made available. Learnings from the Covid- 19 pandemic can support this such as recording lectures and having them available to be listened to more than once. Until this next step is achieved an element of segregation remains on campus.

How can pre-entry and post-entry activities be developed?

Students with Down syndrome often receive no career guidance at school as the assumption is that they will move straight from education into disability day care services. In a recent survey by Down syndrome Ireland only one in every four students received career guidance. This speaks to the expectation that they will not access further or higher education and that their path in life is already decided. Without appropriate guidance or digital literacy skills to find out about courses people may be unaware that further or higher education options exist.

Adults who wish to continue to study need to go against the trend and defy the expectation that a day centre is the only option for them. It is shocking that this outdated assumption is still there. Improved guidance, accessible information and clear pathways from school to further and higher education need to be established and maintained.

As well as ensuring that courses at the right level are available locally, change is needed in Post-Primary schools and Special education settings to ensure that people are aware of the courses.

According to a survey carried out in 2020 by Down Syndrome Ireland:

- ❖ 62% of post primary students would like to go to college.
- ❖ 71% of adults who have already left school would like to attend further education
- ❖ Before the pandemic, just 29% of adults were doing some kind of course, many of

which were delivered in a health setting by care staff.

- ❖ Only 16% of teenagers say they would like to attend a day service after leaving school.

- ❖ 71% of adults with Down syndrome are attending a HSE day service.

Families tell us that HSE day services are often the only option offered to school leavers.

Adults with Down syndrome need to have more choices when they leave school and suitable courses should be available in their community.

Families are also fearful that if they do not take up the offer of a HSE day service after leaving school they will be unable to access disability services later in life if their needs change. This is a real disincentive to continuing in education which will need a crossdepartmental

approach to resolve.

What are the barriers to accessing Further and Higher Education courses?

Adults with Down syndrome need access to appropriate post-school education in local mainstream settings, such as ETBs. Down Syndrome Ireland are currently running three courses in multiple locations through our branch network but we need to bridge the gap for school leavers by ensuring there are meaningful alternatives to the current system where people move directly from education into health/disability services. In order to make this work, structural change is needed. Courses at this level need to be taught by experienced qualified teachers. Further education teachers require specialised courses written to meet the needs of adults with an intellectual disability, along with training on how to teach people with intellectual disabilities effectively.

Students with Down syndrome in the further education sector have ability and ambition however, in order for them to succeed the inclusion of the following factors will enhance their learning experience:

Deliver materials at an appropriate language level

People with Down syndrome have language disorders in addition to intellectual disabilities, meaning that their level of ability is often underestimated, and teaching is not adapted to meet their needs.

Deliver materials at an appropriate maturity level

An added challenge is that even though the student may have the reading age of a primary

school student, the tone, content and materials need to be age appropriate for an adult student.

To use correct Teaching Methodologies

The course should be delivered by a qualified teacher who is trained in how to best teach an adult with intellectual disabilities in order to fulfil the students' potential.

To include basic concepts and vocabulary

Typical learners attain basic concepts about the world around them during childhood. It cannot be assumed that this is true for adults with Down syndrome. Teachers need to explicitly teach underlying concepts and vocabulary to ensure their students full understanding of topics.

Adults with Down syndrome are often excluded from further and higher education opportunities. Evidence based adult education programmes for people with intellectual disabilities need to form part of state funded further education. Suitable further education courses like the courses provided as part of Down Syndrome Ireland's Ability Programme need to be available locally beginning at QQI Level 1.

There are also financial barriers to accessing Further and Higher Education:

Further education students studying QQI Level 1-4 are not eligible to apply for a Susi grant which disadvantages students with an intellectual disability and can prevent them progressing from further to higher education. This pathway to higher education can be more achievable for adults with Down syndrome.

Access to individualised funding, structured so that there is flexibility to pay for further education courses and supports needed to attend (i.e. transport, Personal Assistant, etc.) would provide real choice. Many people with Down syndrome are funded for a full-time day service within a disability service, but they have no say in how this funding is used. If they choose to regularly engage with an alternative course or activity outside this service on some days, they have no entitlement to use a portion of the money provided to help fund any costs associated with those days. The disability service provider retains the funding for the full-time placement regardless of the number of days actually attended.

There are also concerns relating to some support schemes currently available to students with disabilities such as the Fund for Students with Disabilities and the DARE admissions scheme. Both schemes have a defined list of disabilities which excludes intellectual disability

yet no rationale for this is provided. This implies that these schemes are discriminatory in nature. This need to be rectified going forward if students with intellectual disabilities are to be given equal access to reasonable accommodation to attend higher education.

The Reasonable Accommodations at the Certificate Examinations scheme overseen by the State Examinations Commission is an example of this at second level education. The criteria for this scheme was initially limited to students with a 'Specific Learning Difficulty' but in recent years this has been broadened to include 'General Learning Difficulties'. Learners with Down syndrome often have complex learning needs due to intellectual disability, significant language disorders and a relatively high incidence of autism compared to the general population. However, they are also individuals with their own strengths, weaknesses and life experiences.

How do we ensure that vulnerable members of our society are included (e.g., learners currently in care or who have experience of being in care)?

In order for adults with Down syndrome to be able to fully take advantage of those educational opportunities, individualised funding should be widely available so that adults can make choices and pay for the supports they need.

It is important to note that there is also a medical imperative when discussing the importance of access to further and higher education for adults with Down syndrome. People with Down syndrome are living longer than ever before, life expectancy is now between 50-70 years compared to an average of 9 years around 1930. This marked improvement in life expectancy for people with Down syndrome means that issues relating to the condition and old age are only recently being researched and addressed. It is now well evidenced that people with Down syndrome experience accelerated aging, which can be seen medically, physically and functionally with associated illnesses such as dementia occurring 20-30 years before the general population. It is long established that people with Down syndrome have a greatly increased risk of developing dementia. Professor McCarron, Professor of Aging and Intellectual disability, Trinity College suggests however that up to 35% of dementia cases are preventable.

Lifelong learning and community engagement are known to be protective in the general population, but a recent DSI survey suggested that 80% of adults with Down syndrome are unable to find courses that are interesting and accessible in their local communities.

Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) outlines the obligation of the Irish government to recognise that people with disabilities 'have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability' this includes preventing further disabilities. People with Down syndrome represent the largest group of people with dementia under the age of 50, yet the needs of this group are not being met and investment is needed to prevent and slow down the progress of dementia and improve quality of life.

Current scientific evidence for reducing the risk of dementia includes mental stimulation and continued learning. For adults with Down syndrome, very often the opportunity for mental stimulation decreases as they age, as does their prospect of continued or lifelong learning.

In a recent study, adults with Down syndrome without dementia, who engaged in higher levels of cognitively stimulating and social leisure activity experienced less decline across three years in episodic memory. Another study has found that individuals who engage in more cognitively stimulating lifestyles better tolerate early Alzheimer disease symptoms. Such lifestyles enable an individual's neural networks to adapt and cope better with early symptoms of Alzheimer disease. Increased access to further and higher education will provide a more stimulating environment for adults with Down syndrome and will enable them to lead fuller lives with greater engagement with the world around them.

Thank you for the opportunity to contribute to the consultation on the National Plan for Equity of Access to Higher Education.

The key changes that Down Syndrome Ireland would like to see in Further and Higher education are:

- An increase in the number of adults with Down syndrome accessing Further and Higher Education courses.
- An increase in the number of teachers trained to deliver Further Education courses to adult learners with Intellectual Disability and Language Disorders.
- A decrease in the number of school leavers directly entering full time HSE day service provision following completion of secondary school.

- An increase in the number of locations where courses at QQI level 1 are delivered.
- An increase in the number of active engagements with post primary schools and special schools to inform school leavers about local further education options.