

Annual Report

2020



Down
Syndrome
Ireland



#ShareTheJourney



“ We work to ensure that people with Down syndrome can lead the lives they want, how they want, where they want at whatever stage of life. ”

CONTENTS

About us	5
Our vision, mission and ethos	5
Our national team	6
Our 25 branches	6
Our objectives	7
Message from President Kevin Griffin	9
The voice of people with Down syndrome	11
Our work in 2020	13
Early years	13
School – aged years	19
Adult years	23
Health	35
Raising awareness	37
National Office fundraising	47
Financial tables	51
Our branches	55

Pictured on our front cover are beautiful Offaly branch members and sisters Sarah and Chloe, who has Down syndrome. They also featured in The Sunday Times, Ireland edition on World Down Syndrome Day 2020.

Here they are rocking #LotsOfSocks to celebrate World Down Syndrome Day with a little spring lamb. These beautiful pictures were captured by their proud Dad James Crombie.



“Down Syndrome Ireland offers support and services to people with Down syndrome and their families throughout Ireland.”

ABOUT US

Down Syndrome Ireland offers support and services to people with Down syndrome and their families throughout Ireland.

We have over 3,500 members with 25 branches nationwide. We provide ‘all-through-life’ supports and services with specialists in the areas of health, speech and language, early development, education and adult training and education, employment and independence that enhance the lives of thousands of children and adults with Down syndrome across the country.

We work to ensure that people with Down syndrome can lead the lives they want, how they want, where they want at whatever stage of life.

We also provide information and advice, influence policy, raise public awareness and work towards the improvement of services and supports for children and adults with Down syndrome.

Our vision

All people are valued, fully participating citizens.

Our mission

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.

Our ethos

- 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 of our activities.
- We are parent led – we promote our parents as well as our members with Down syndrome to get involved by encouraging support and collaboration as we all work together in working for a bright future for our members.
- We are committed to working towards a society where people with Down syndrome have the same basic human rights to healthcare, education, employment opportunities and decision-making as all other citizens.

- We believe in the right of parents to choose services for their child with Down syndrome and will continue to work with and lobby Government departments to make this right a reality for all members.
- We are also committed to changing the traditional society's traditional view of a person with Down syndrome as an 'eternal child'.
- We undertake to ensure that people with Down syndrome are treated with the same dignity and respect as all other citizens.



Our national team

Our national office is run by a small team dedicated to supporting people with Down syndrome and their families across Ireland.

We provide specialist consultancy services and supports around the country in health, speech and language, early development, education, adult training and education, employment and advocacy and independence.

The team comprises of a member support team, a communications and public affairs team, HR and finance support and a fundraising team.

Added to this, our organisation is governed by a Board of Directors – all of whom are parents of children and adults with Down syndrome.

The Board also consults with a National Advisory Council, which represents the opinions of adults with Down syndrome within our organisation.

Our 25 Branches

We have twenty-five branches across the country.

Our branches are run almost exclusively by volunteer parents working in committees, providing children and adults with Down syndrome with a wide range of services and social opportunities.

All the services provided at branch level are funded through donations and fundraising by the members of those branches and their families and friends.

The services and opportunities offered to members vary with each branch, but among them are:



Our Objectives

We aim to facilitate and optimise service delivery and supports in the country by:

- Raising awareness of people with Down syndrome as valued members of the community
- Working towards the development of essential supports and services to best support people with Down syndrome through the various life stages
- Working closely with our branches, service providers and community groups to ensure integrated analysis, planning and provision of services
- Being an efficient provider of high-quality evidence-based supports and services
- Lobbying for better supports and resources for people with Down syndrome through the various life stages.



150 Every year, around 150 babies in Ireland are born with Down syndrome

25 DSI branches around the country

3,500 Members of Down Syndrome Ireland

Marie Brennan with twins Conn (left) who has Down Syndrome and Ruairí. Baby Conn was our Woodies Heroes campaign ambassador in 2020.

Image Michael Donnelly

MESSAGE FROM PRESIDENT KEVIN GRIFFIN

The defining feature of 2020 was undoubtedly the COVID-19 pandemic. What was initially a two week lockdown became something that changed everyone's world.

Our work practices changed almost overnight. However, right across the organisation, we faced this challenge with strength and resilience. The enterprising spirit of our staff, branch officers, volunteers, charity partners and fundraisers meant we were able to respond and innovate to continue to meet the needs of people with Down syndrome and their families and I am extremely proud of this.

In the initial stages of the pandemic, new information was being produced and published rapidly and we needed to stay up to date as research emerged about the possible impact of the new virus on people with Down syndrome worldwide. We linked with the HSE to help communicate risks and responsibilities in Ireland, and to ensure equality of access to healthcare if the situation in Ireland worsened. We kept branches informed about their responsibilities to employees, volunteers and members, and how to make sure people were as safe as possible when they returned to in-person activities.

All the while, we focused on providing information, resources and reassurance for our members while, like the rest of society, exploring different ways to engage online with people with Down syndrome and their families across Ireland.

Looking to the future

I would very much like to thank my fellow Board members, our staff team, branch officers, volunteers, funders and charity partners, who together worked so hard to support people with Down syndrome and



their families. The generosity of the general public who supported Down Syndrome Ireland during this unprecedented year will never be forgotten. Thank you.

A core part of the work of the Board is to serve as guardians of the trust placed in DSI by our members and we are firmly committed to ensuring the highest standards of transparency and accountability in all that the organisation does. As we move beyond the crisis, I am confident that we are in a strong position to adapt to meet the changing needs of our members, and to help them navigate an external environment that may well be uncertain.

We appointed a new CEO Barry Sheridan, who took up his post in January 2021, and we look forward to working with him. Over the coming year, we look forward to continuing to give a voice to people with Down syndrome and their families as we emerge from this crisis.

In the months ahead, as the full extent of the repercussions of COVID-19 become clear, we will continue to work with Government, policy makers and our members to ensure that people with Down syndrome are supported to lead the lives they want, where they want and how they want. Indeed, this is at the heart of everything Down Syndrome Ireland does.

Kevin Griffin

President - Down Syndrome Ireland



NAC member
Ross O'Neill

THE VOICE OF PEOPLE WITH DOWN SYNDROME

Our National Advisory Council (NAC) represents the opinions of adults with Down syndrome within our organisation. The Council comprises of adults with Down syndrome from across Ireland.

As an organisation we need to hear the voices of people with Down syndrome, and after a short break, our interim National Advisory Committee and our Regional Advisory Committee were facilitated to continue their meetings online, ensuring the continuity of this valuable programme.

Here, one of our NAC members Ross O'Neill tells us about his experience on the council:

“ It was great in 2020 I got to be part of the NAC for Down Syndrome Ireland. During the Pandemic I was able to work on the NAC and on zoom. I appreciate that I was working with DSI's Adult Advocacy Officer Helena Connors on this and on zoom as well and I got the opportunity to meet new friends and I hope to stay on the National Advisory Council.

Even when it was a difficult time during Covid, I really enjoyed working with them and I hope to stay on it. I am proud to be on this council it was great experience as I am also part of the staff in Down Syndrome Ireland. I would like to say thanks to my work friends for putting me forward for this achievement to be on the National Advisory council. I love working on this council. I'm proud to have Down syndrome and to be part of Down Syndrome Ireland and the National Advisory council.

Thank you.



OUR WORK IN 2020

Down Syndrome Ireland provides supports and services across the life stage in early years, education, further education, training and employment and adult life.

In 2020, we needed new ways to engage with our members all around Ireland during lockdown.

Our Member Support Team (MST) continued to deliver services across their specialist areas in challenging times.

Changed circumstances due to the pandemic meant that from April 2020 the team were working reduced hours in uncertain conditions. However, remote working practices pre-pandemic meant that our MST were well set up to continue to work to support members remotely, transitioning from live conferences and meetings to online provisions to continue to support children and adults with Down syndrome.

Early Years

We work with children and families to support them throughout their early years up to and including their transition to primary school.

Our Early Years Specialist is available to provide advice and support to parents from early development, early intervention services and early childhood care and education. We are also involved in the development and delivery of conferences, workshops and training at regional and national level

Since the beginning of the pandemic, a massive 400 Zoom parent and toddler groups were facilitated by Olive, our Early Years Specialist. Having a child who may be medically vulnerable is an enormous strain on families at the best of times, but during a pandemic this was magnified considerably.



DSI needed new ways to engage with our members all around Ireland during lockdown.





Olive Buckeridge,
Early Years Specialist

Olive is an experienced speech and language therapist with a particular interest in early year's development. She has worked in a variety of clinical settings who before joining the national team, worked in our Limerick branch where she developed and provided specific intervention programmes.



400 parent and toddler groups
run by DSI

Lessons with Olive



We also developed a series of videos covering a number of vital learning outcomes for young children with Down syndrome.

“ During lockdown, having no contact with the outside world, the online SLT with Olive was great interaction for Jaime. She really enjoyed it and it definitely helped develop her love of singing and music and use of Lámh.”

- Jaime's Mum Andrea Bracken.



Jaime

“ Frankie and myself availed of the recorded SLT with Olive during Covid and it was invaluable to us, just to put aside the half hour just to sit and enjoy each other's company just the two of us and of course a little learning, it was great to keep us going on practicing our Lámh also. Frankie is nearly a professional at this stage on his Lámh!”

- Frankie's Mum Tina Hamilton.



Frankie

“ For the preschoolers during lockdown a ‘must see’ was Olive Buckeridge’s session every Tuesday. Tots of all ages from up and down the country were lined up in front of screens to see what Olive was going to do. Joanie was no exception. Netflix & CBeebies couldn’t compete with Olive. Joanie, like all her friends, was won over by Olive. For 20 minutes every week Joanie was totally engrossed as Olive introduced a collection of puppet friends, sang lots of songs (some became real crowd pleasers!), practiced using Lámh and encouraged some ‘good talking’. Thanks Olive.”

– Joanie’s Mum Andrea McArdle.



Additional Early Intervention Groups run by our Early Years Specialist gave families access to advice and information from specialists on feeding, health issues, physiotherapy and occupational therapy, and we’d like to give a big thank you to all the professionals who gave their time to facilitate those sessions.

See and Learn

Learning to talk is a particular challenge for most children with Down syndrome. Difficulties with understanding and using language present obstacles in daily life and can be a major source of frustration.

See and Learn is an evidence-based, structured teaching programme which teaches speech, language and reading skills in small steps for children with Down syndrome up to 6 years of age. The programme is designed to help educators and parents provide young children with additional support and practice they need to learn language.

In 2020, we developed an online See and Learn training video which is available for parents and early years educators. We plan to supply a starter set of See and Learn kits to each of our branches early next year, and continue lobbying government to make these resources available to every child with Down syndrome in early years education. Every child deserves the best start we can give them, and this means providing specific, evidence-led resources to meet the specific learning needs of children with Down syndrome.

Parents supporting parents

Our Parentlink programme is a support service for new parents, which is run through our branches. Our amazing volunteer Parentlink parents receive training from Down Syndrome Ireland. They will provide new parents with time, understanding, confidentiality and a listening ear.

Like all of our other programme, our Parentlink training also moved online and we hope to run another online training event early next year. When families have a baby who has Down syndrome, they don’t always want to see medical professionals. Many want to talk to another family nearby who understand how this feels. This is an important programme which provides training and information to help parents to support each other. All of the parents involved would recommend the training:

“ I felt we got a great foundation for going forward into this new role and am delighted with the support that will continue to be available to me should the need arise. The exercise around listening both surprised and challenged me. It made me aware of a need within myself to fill in silences or lead conversations, and how I need to learn to sit back a little and allow the other person to take the lead in the conversation.”

Feedback from parents who took part in the training.



“Going back to school in the autumn was always going to be a challenge after the abrupt closure of schools in March.”



Dr Fidelma Brady
Head of Education

Fidelma Brady is our Head of Education and is available to support you and your child in their journey through school from primary, post primary and special school. She will also provide advice and information at each stage of educational transition and when difficulties arise.



School – aged years

In education, DSI provides services and supports to parents, schools, teachers and SNAs directly through the provision of training and assistance with individual queries and cases

Going back to school in the autumn was always going to be a challenge after the abrupt closure of schools in March. In addition to a pre-recorded online seminar on the transition from preschool to primary school, 30 live webinars were provided to branches to help support children with Down syndrome who were making the transition to ‘big school’.

3,500 the number of calls and emails from parents and professionals about education in 2020

We also worked on online resources including a pre-recorded seminar and a downloadable booklet & workbook, which were provided for teachers, parents and students to support the transition to post-primary school.



Having used this time to make online resources will change the way we work in the future, making information more easily available to families and schools across Ireland. In addition to developing online resources, telephone and email support for parents and schools continued as normal, with approximately 3000 emails and 500 phone calls both to and from parents and teachers recorded over the course of 2020.

As the world has moved online, we spent a huge amount of time transferring content we would usually present in regional conferences into short online information seminars covering topics such as:

Videos for supporting communication development at preschool

Strategies and supports for children transitioning to Mainstream Primary School

Understanding the Specific Learning Needs of Students with Down Syndrome

Understanding Language & Communication issues

Understanding Common Vision & Hearing Issues

Introduction to Behaviour

Supporting Literacy & Numeracy at Primary School

Numeracy: Acquiring Basic Maths Skills

Using Numicon as a Resource in Teaching Numeracy

In-Class Behaviour Management

Managing the Transition from Primary to Post Primary School

Accessing the Curriculum – Differentiation of Work

Pathway through Junior Cycle

Mental Well Being

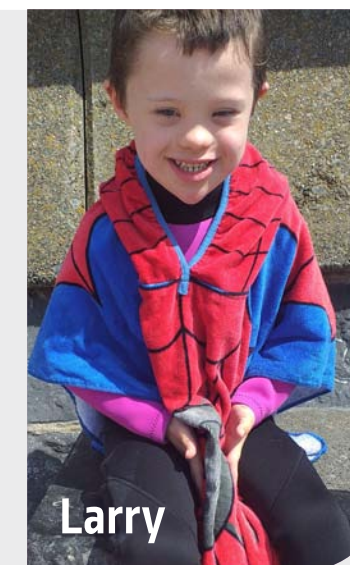
Introduction to Dual Diagnosis of Down syndrome and Autism

Access to the Extended School Year

During the summer, we finally achieved access to the extended school year (July Provision) for all children with Down syndrome, following months of consultations with members and with the Department of Education and Skills.

“My son Larry started in St. Martin’s special school in September 2020. We were thrilled when he qualified for July provision as it had been a long year of isolating and keeping safe which meant Larry couldn’t visit some of his favourite places. July Provision was solace in a tough year. To see our little boy come to life again and witness his confidence soar as the days went on was food for the soul. It made our families Summer the best one yet. They say a picture says a thousand words; I’ll let you decide what this picture says about his experience of July Provision.”

– Mum Greta O Sullivan.



Larry

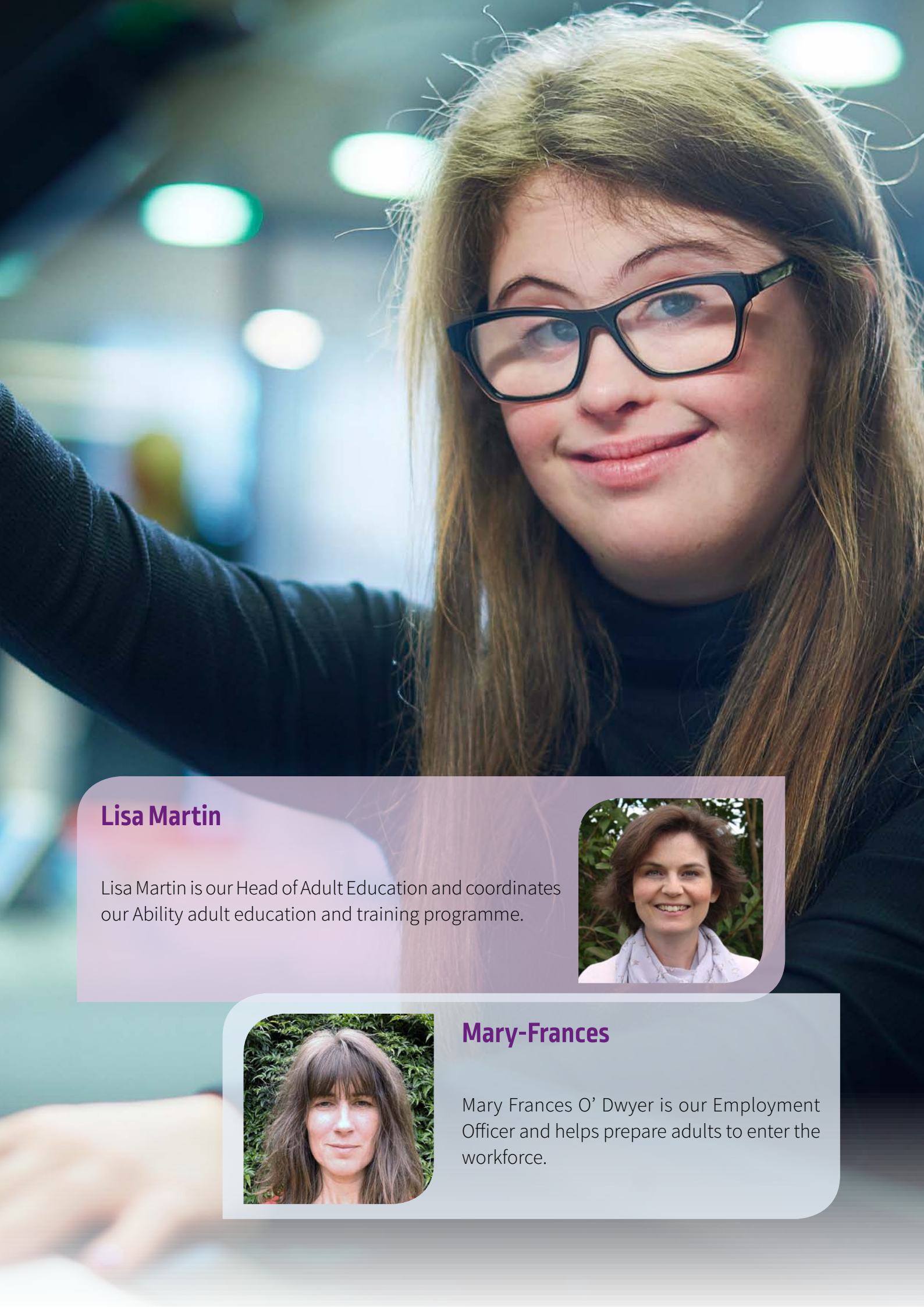
“Louise took part in the July provision programme over the summer. Her SEN teacher took her over 4 weeks in the summer. She came to the house and did some teaching and also brought her out on trips that corresponded to what they were learning that day. I took this opportunity to spend time with my other children and do things we couldn’t do with Louise. Louise enjoyed her time learning and benefited from the one-on-one teaching and attention. Also it was good to have continuity of learning to maintain focus and skills learnt.”

– Mum Cassie Ryan



Louise

We would like to thank all of the parents who also lobbied tirelessly to ensure their children could access this vital educational resource.



Adult Years

Life changed so quickly that it was hard for many to understand during the lockdown

Boredom and isolation was difficult for us all, and adults with Down syndrome saw their employment, education and day services badly affected by the pandemic. We created a resource page on our website for adult members so that they could keep active and engaged while at home.

2,400 users who visited our dedicated Covid-19 resource area of website

Life changed so quickly that it was hard for many to understand. During the initial lockdown, our team prepared easy read information about the pandemic so that our members could stay informed. This was shared by other Down syndrome associations as far away as America, Australia and New Zealand!

Ability Programme

People with Down syndrome want to work and represent a substantial source of untapped commitment and talent. In Ireland, less than 5% of adults with Down syndrome secure meaningful employment and we in Down Syndrome Ireland are working to change that.

Our Ability Programme breaks down barriers and provides people with Down syndrome access to meaningful employment opportunities.



Ireland's European Structural and Investment Funds Programmes 2014-2020
Co-funded by the Irish Government and the European Union



EUROPEAN UNION
Investing in your Future
European Social Fund



An Roinn Gnóthaí Fostaíochta agus Coimirce Sóisialaí
Department of Employment Affairs and Social Protection



pobal
government supporting communities



Ag tacú le daoine óga atá faoi mhíchumas barr n gcomais a bhaint amach
Supporting young people with disabilities reach their potential
Ability

We developed a new ten-week course, Ability Online, which was launched in October.

Lisa Martin

Lisa Martin is our Head of Adult Education and coordinates our Ability adult education and training programme.



Mary-Frances

Mary Frances O' Dwyer is our Employment Officer and helps prepare adults to enter the workforce.



Aimed at all school leavers and adults with Down syndrome across the country, the approach of the programme is two-pronged:

- We offer a bespoke person-centred education and training programme which prepares adults with Down syndrome for employment.
- We also develop direct links with employers around the country through a programme of partnership initiatives aimed at securing long-term employment for adults with Down syndrome across a broad range of sectors.

Here are details of the core adult education courses that are part of the Ability Programme:

LATCH-ON: Adult Literacy & Technology Programme

MY OPINION MY VOTE - Political Education Programme

WORK SKILLS - Pre-Employment Programme

ABILITY ONLINE - short topic-based modules used as an introduction or continuation of the programmes above.

Literacy & Technology programme - (Latch-On)

The Literacy & Technology programme (Latch-On) is two-year literacy programme developed specifically for adults with an intellectual disability. Latch-On was initiated and developed at the School of Education at the University of Queensland. Ireland is the first European country to acquire a licence to deliver the Latch-On programme. There are no academic prerequisites for studying Latch-On, as the course content is differentiated to suit the needs of individuals. This course provides a good foundation for adult learners, whether they are aiming for further education, employment or simply maintaining and improving their literacy skills.

MY OPINION MY VOTE (MOTE) - Political Education Programme

MOTE is a political education programme which was produced following an extensive pan European research project including Down Syndrome Ireland. As well as political awareness, MOTE encourages independent decision making and responsibility. MOTE aims to empower students through active citizenship and participation in the political process. This course teaches students about forming opinions and making choices. It encourages self-advocacy and a broad awareness of the social and political landscape, locally, nationally and at a European level.

Work Skills

Our Work Skills course was developed by Down Syndrome Ireland and is based on a project by Accenture called the Skills to Succeed Academy. This two-year part-time course is designed to prepare adults with Down syndrome to take up meaningful employment and to equip them with the skills to navigate the world of work. Students explore their own strengths and interests, and discuss how these could be useful in the workplace, as well as learning about how to find and keep a job. The students' study four modules over two years including a module based on interpersonal skills.

In 2020, due to the pandemic all of our in-person training was curtailed due to the pandemic. Likewise, many of adults with Down syndrome who were in paid employment as a result of our Ability programme were furloughed.

In Galway and Donegal, we partnered with the ETBI to deliver our adult education courses.

Unfortunately, the closure of adult education campuses in March 2020 led to the suspension of the courses. The pandemic had an enormous effect on the Ability Programme, but our branches responded well to the demands of teaching online.

As with all of our programmes, we had to learn new ways of training and engaging with adults with Down syndrome during the pandemic.

By September 2020, all sites with the exception of DCU moved to online teaching.

Our adult education committees and teachers rose to the challenge of delivering education to 151 students studying across 11 sites. Despite interruptions to study, courses resumed, either

with full protective measures on site, or delivering the courses online. We helped the teachers' transition to online teaching, providing resources and training, and exploring new platforms to meet the learning needs of our students.

95% of students said they feel good about themselves after taking part in our Online Ability Course

Ability Online

We developed a new ten-week course, Ability Online, which was launched in October. This course is taught remotely and gave students a taster of the adult education programme along with teaching personal skills such as independence, mental health and resilience. The first group of 24 students graduated before Christmas. The course has been a huge success and will continue into 2021.

Students surveyed said they feel good about themselves

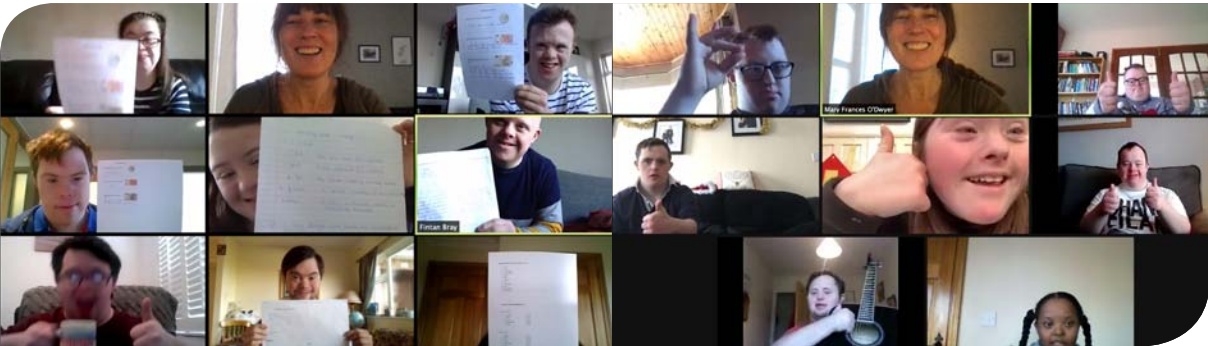
After taking part in our Online Ability Course

95% of students surveyed said they feel good about themselves
(up from 89% before commencing the course).

84% (up from 74%) of students surveyed said that
they can make new friends and 89% (up from 84%) said they can take part in
conversations with family and friends.

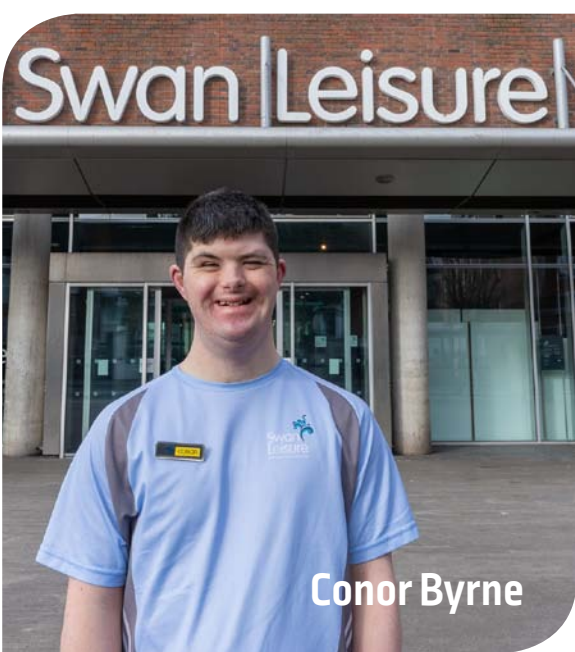
100% (up from 95%) said that they feel happy most of the time.

Our Ability Online students were surveyed before and after participating in the course. Before the pandemic, 64 of our Ability Programme participants had moved into paid employment, and while many of these jobs were in fields that have been badly impacted by the restrictions, we hope that most people will resume their jobs when it is safe to do so. Some are already back in work, working remotely or back on site, and are valued employees.



“ I am so delighted to be a part of the Ability online group. I look forward to our Zoom sessions every week and now even more so as I am off work due to level 5 restrictions. I would highly recommend this programme to all young adults as it is a very different experience and there is so much to learn from the course but also from other likeminded people. It most definitely improves our skills in the areas of conversation, listening and IT. Well done Down Syndrome Ireland.” – Conor Griffin, Kerry

What our employees & employers have to say:



Conor Byrne has been working as a Leisure Centre Assistant at Swan Leisure since July 2018. Here’s what Operations Manager Gregg Gannon had to say about Conor at work:

“ Conor is an inspiration to both members and guests. He is a fulfilment of our philosophy at Swan Leisure of inclusion and breaking down barriers to participation.”

And here’s what Conor had to say about his job:

“ I love the company and having work buddies to chat to. Everyone in the swan centre is nice and friendly and they look out for me. I think I do a very good job - I keep the pool deck cleaned and I clean the gym. I would advise someone with Down syndrome to get a job because you will learn new skills and responsibilities and you will achieve.”



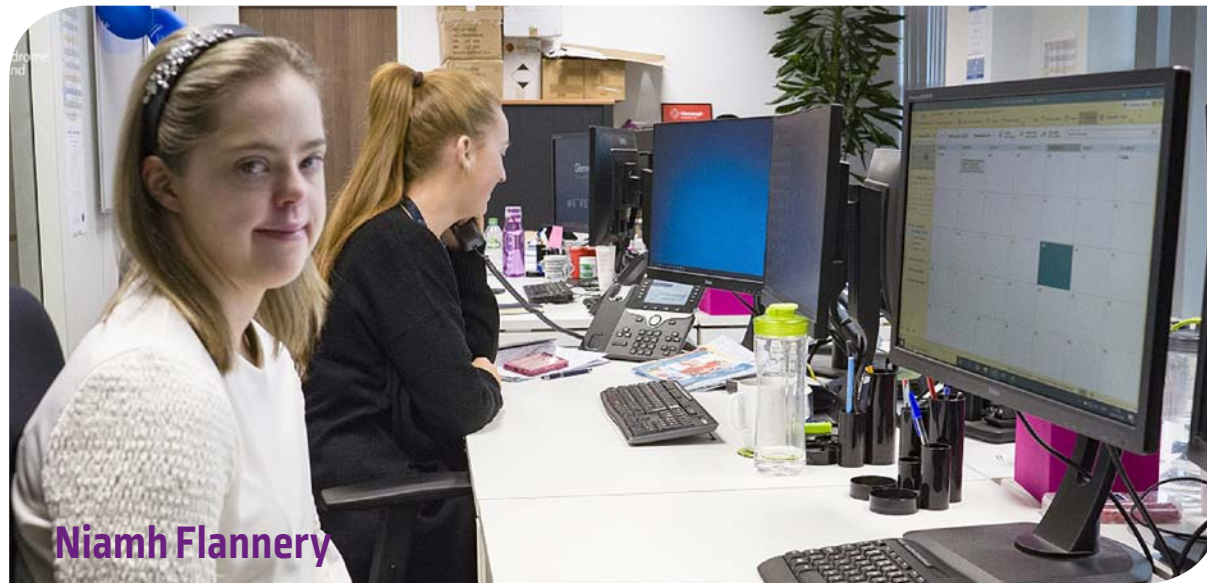
Through our Ability Programme, **Linda Dunphy** secured a job in Walkers Global Law Firm as part of the Mailroom & Facilities Team. Here’s what Linda’s Supervisor Richard Murphy had to say about Linda at work:

“ Linda is a valued member of the Mailroom and Facilities team and she always has a positive outlook with no task being too great or too small. Linda’s energy and commitment is admirable.”

And here’s what Linda had to say about her job:

“ Walkers is absolutely brilliant and I love it! The staff are so nice. I really have found my dream job!”

What our employees & employers have to say:



Niamh Flannery started working at Glenveagh in July 2018.

Here's what her manager had to say:

“Niamh is very much part of our HR team here at Glenveagh since joining us in July 2018. She has excellent initiative, is a strong team player and we look forward to the days that she's in work. Niamh has educated us in a lot of ways and is a great ambassador for the Ability programme.”

And here's what Niamh had to say about her job:

“I enjoyed my interview and appreciated the opportunity to work for a big company. I am learning a lot here. It's different to the jobs I had before and I like learning new things like Excel and using the scanner. Sure I am part of the furniture now!”

Chloe McEvoy works as a waitress at Lilly's Bar, Portlaoise, which is part of our partnership with Nolaclan Social Spaces.

Here's what Chloe had to say about her job:

“I love working in Lily's bar in Portlaoise. I serve people, I use the till to take money when they pay. I'm happy I have my job.”



In 2020, we continued our partnership with Accenture which aimed to improve our working practices and to sharing the DSI story.

The team facilitated a series of workshops across key areas of ways of working, branding, media training, data analysis, project management and maximising the use of Microsoft Teams as a collaboration tool.

In addition, the Accenture team supported on branding alignment and the production of key documents including the The Upside – Life with Down syndrome, adult education prospectus and employment information packs.

The team also created short animated videos providing an overview of the life of a person with Down syndrome and the different challenges that come with each life stage, which we used for awareness and lobbying purposes when we meet Government officials and Ministers.

accenture

New Employer Pack

During 2020, we also developed a 'welcome pack' for anyone who is interested in employing one of our Ability Programme graduates.

It includes sample easy read contracts and task lists to help people understand their responsibilities and succeed at work. This will be very useful when employment opportunities begin to arise when society opens up and employment opportunities once again become available for people with Down syndrome.



Síle Maguire at The Oak Bar, Dublin, which forms part of the Nolaclan Group. Síle was furloughed from her job at the Oak Bar during the pandemic but is hoping to return to work.



Helena Connors
Adult Advocacy Officer

Helena supports adults with Down syndrome and their families to have their voices heard and to act as a voice for people who don't yet have the skills to do so.



“ As well as supporting individuals and families in challenging situations, we created a bank of online resources for adults who were cocooning at home. ”

Adult Advocacy

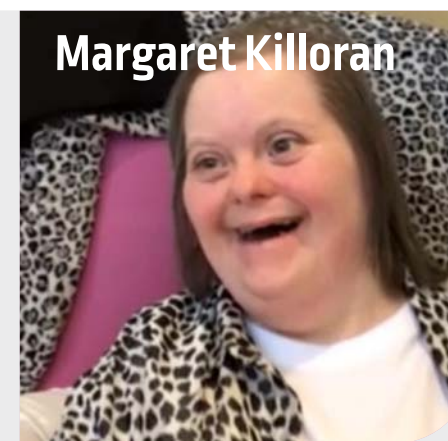
Among the advocacy cases in 2020, there were a number of complex situations. One example of a complex case involved supporting a family of a person with Down syndrome and dementia who was unable to leave hospital due to lack of an appropriate service, then placed in a nursing home during the height of the first wave of Covid-19, to eventually getting an appropriate residential placement.

We supported other families of older people with Down syndrome as they fought for home care services, adequate day services, avoiding placement in nursing homes, etc. We supported families unable to accompany family members to hospital and those unable to visit family members in residential services. We kept members informed around the closure of day services and advocated for additional supports for families and for safe reopening.

We continued to link with Government Ministers and Departments to lobby for our members on topics linked to health, education and human rights.

We surveyed members in July to gauge the full extent of the impact of day service closure and communicated the results of the survey to Minister of State at the Department of Children, Equality, Disability, Integration and Youth at the Department of Health Anne Rabbitte as part of our advocacy for resumption of services.

Margaret Killoran's sister Annie, first contacted us in early 2020 when Margaret was in hospital as they were finding it difficult to get appropriate supports for Margaret. Prior to the pandemic, Margaret was placed in a local nursing home with the agreement that it was a short-term placement. Unfortunately, she contracted Covid-19 and ended up back in hospital. Thankfully she made a full recovery. Margaret's family were anxious for Margaret to return to her local community. They were also anxious that Margaret was not placed long term in a Nursing home as it would be inappropriate for someone so young and the increased risk of contracting Covid-19 again. Margaret's family had to battle for many months to get an appropriate residential service for Margaret in her own community. They organised an online petition calling on the HSE to ensure Margaret received a service in Tubbercurry which attracted more than 1,500 signatures. DSI offered support and advice throughout this trying time and advocated on behalf of Margaret where possible. Margaret is now back living in Tubbercurry in a residential service for people with intellectual disabilities, where she is regularly visited by family when Covid-19 related restrictions allow.



Margaret Killoran

All the while we continued in our work to advocate and be the voice of people with Down syndrome. We contributed to the important Ombudsman Report **Wasted Lives: Time for a Better Future for Younger People in Nursing Homes** through attendance at a workshop and a submission on our experiences of members being inappropriately placed in nursing homes due to lack of suitable options.

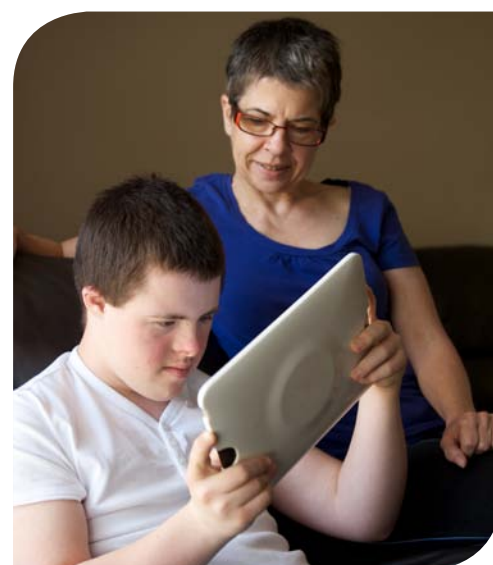
Submissions were made to the **Joint Oireachtas Joint Committee on Disability Matters** and to the Department of Children, Equality, Disability, Integration and Youth on their **Statement of Strategy 2021-2023**.

Plus Pilot Special Needs Programme

We delivered the **Parents Plus Pilot Special Needs Programme** in Limerick



branch through January – March, though unfortunately, the final session was cancelled due to lockdown. This is a group programme for parents to help them navigate the challenges of parenting an adolescent or young adult with additional needs and was very well received by the parents who participated. Parents Plus programmes are well developed evidence-based, solution-focused group programmes, which are successfully used with other groups, including parents of young children, and parents who are separated. We were invited to become involved at the research stage of this new programme, and data collected from our sessions supported its development and progression. Feedback from participants was very positive despite not getting to finish the programme. In particular, participants reported it was very beneficial to talk to other parents who were going through similar experiences and to practice self-care. They also reported that they found the resources provided by Parents Plus very helpful.



Lobbying

We continued to link with Government Ministers and Departments to lobby for our members on topics linked to health, education and human rights.

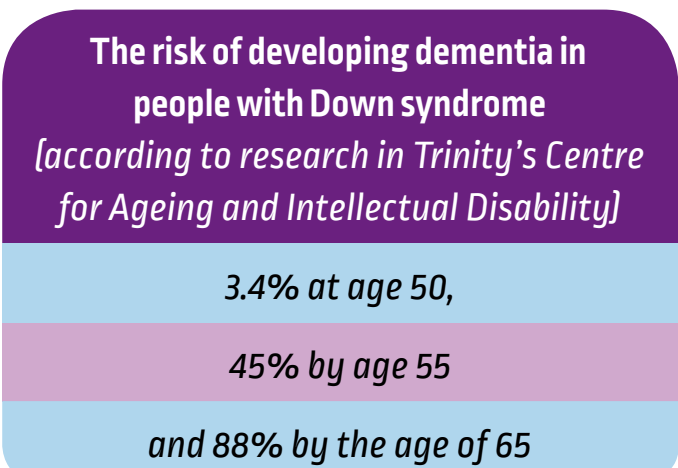
Throughout the year, we ensured that we were in touch with international research on the implications of Covid 19 for people with Down syndrome and engaged with the government and the HSE as it became clear that they faced significant additional risks should they contract the virus. We worked to ensure that adults with Down syndrome were prioritised for vaccination as soon as supplies allowed, to help them stay safe and well and enable them to resume activities as soon as possible.

Supporting adults

As the year progressed, the mental and physical health impacts of prolonged anxiety, isolation and reduced activities during the pandemic on many of us have been recognised. We are aware that adults with Down syndrome, who already have a heightened risk of early onset dementia, could potentially be badly affected by isolation and changes in routine in the longer term. As well as supporting individuals and families in challenging situations, we created a bank of online resources for adults who were cocooning at home. The activities were hosted on a dedicated page on the website for members to access and focused on four areas: Reading, Writing, Wellness and Alleviating Boredom.

PREVENT dementia-DS project

Research into the development of dementia in people with Down syndrome is still very limited, however this is changing. We have been working together with Dr McGlinchey and her team in the Trinity Centre for Intellectual Disability and Ageing on the PREVENT dementia-DS project, although the start has been delayed until 2021 due to the pandemic. The PREVENT dementia-DS project is an addition to the wider PREVENT study, which aims to establish novel and clinically applicable early biomarkers of Alzheimer's disease 20 to 40 years prior to its clinical diagnosis. TUD are part of a large-scale multi-centre study carried out in collaboration with Cambridge, Oxford, Edinburgh universities, Imperial College London in the UK and the INSERM Neuroscience, in France.



People with Down syndrome are at considerably higher risk of developing dementia at an earlier age than the typical population, so we are supporting the research team in sharing information and recruiting participants. In 2019 Dr McGlinchey gave a series of talks in several Down Syndrome Ireland branches on the importance of good brain health and lifestyle factors that help maintain good brain health throughout life. She spoke about the PREVENT dementia-DS, then due to begin in 2020 and invited expressions of interest from members. While we remained in contact with Dr McGlinchey throughout 2020, recruitment for the study did not begin until 2021 due to the pandemic.



“ We continue to lobby the Government for 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. Down syndrome affects all the cells in the body. Along with Down syndrome come many specific health implications and these are best dealt with clinical specialists who have an overview of the multiple health needs of children and adults with Down syndrome. ”

Health

Fiona McGrane

Clinical Nurse Specialist in Down syndrome

Fiona McGrane (CNM11, RNID, RCN) was appointed as research nurse in Down Syndrome Ireland in July 2010. She is based at Trinity College Dublin, Department of Paediatrics National Children's Hospital Tallaght. This post is supported by Down Syndrome Ireland.



Fiona's main role is to support parents and their families by giving a clear understanding of the healthcare issues that may affect children with Down syndrome and the treatment and care options that are available as their child grows and develops, but she is also here to:

- Play an active role in educating people with Down syndrome and their families in health and wellbeing
- Assist individuals and parents in availing of health services
- Act as an advocate for individuals and their families
- Communicate with patients, their families and fellow healthcare professionals and helping to identify issues and provide advice
- Promote individual and family participation in care
- Identify and meet the needs of children with Down syndrome through childhood and adolescence and their family's needs
- Provide a communication link between parents and allied health professionals within hospitals and community services locally and nationally
- Provide support and aftercare to individuals and their parents when they attend the hospital for procedures and give feedback to community services
- Educate parents/service providers on entitlements
- Educate parents regarding health issues that may occur
- Take referrals from maternity/GP and community services
- Carry out research within the area of Down syndrome in partnership with The Department of Paediatrics, Trinity College Dublin
- Support and provide education sessions to the branches of Down Syndrome Ireland
- Provide education sessions to student doctors/nurses and midwives throughout Ireland

During the pandemic, demand for the services provided by the clinic was extremely high and continues to grow everyday.

2,500 calls received

270 children attend the Down syndrome clinic

300 attendees attend other medical clinics as a result



RAISING AWARENESS

Lobbying for rights and supports is an important part of what we do. We campaign for the rights of people with Down syndrome and try to ensure that their voices are heard.

Down Syndrome Ireland continued to promote the unique and individual nature of people with Down syndrome and their positive contribution to society. We have continued to challenge societal views and perceptions of the condition of Down syndrome. We continue to produce and update new awareness materials and continue to distribute them. Initially during the pandemic, we focused on the needs of people with Down syndrome to understand the changing world around them and produced information which was shared by other Down syndrome groups internationally.



 **World
Down
Syndrome
Day**
21 March 2020

World Down Syndrome Day

World Down Syndrome Day was a challenge in 2020, coming so soon after the lockdown announcement. Planned events needed to be cancelled. An online 'Lots of socks' celebration replaced in person events, and the focus was on helping people to stay positive and safe.

DSI in the media

We continued to raise awareness through national and local media. In 2020, DSI delivered a total news volume of 1.65K. The advertising value equivalent of the coverage was almost €3million in 2020. Down Syndrome Ireland members and their families appeared across broadcast and print media both nationally and locally.

Pictured are the **Smyth family** from Dublin – Mum and Dad Rebecca and Damien with their beautiful children Georgina and Simon, who has Down syndrome, who featured on RTÉ News at 6 o'clock news on World Down Syndrome Day. They are rocking their **#LotsOfSocks4DSI** with RTÉ Social Affairs and Religion Correspondent Ailbhe Conneely and RTE cameraman Owen Corcoran.

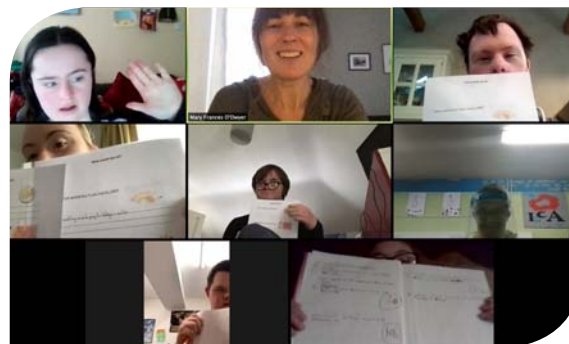


7million the number of people who saw our social media content in 2020

Social Media

We continued to have a huge impact on online, especially in 2020 when all of our courses, programmes, services and supports were delivered online given the pandemic.

In total, our reach across social media reach was 7,091,333. There were a total of 119,306 website hits, with 258,157 page views.

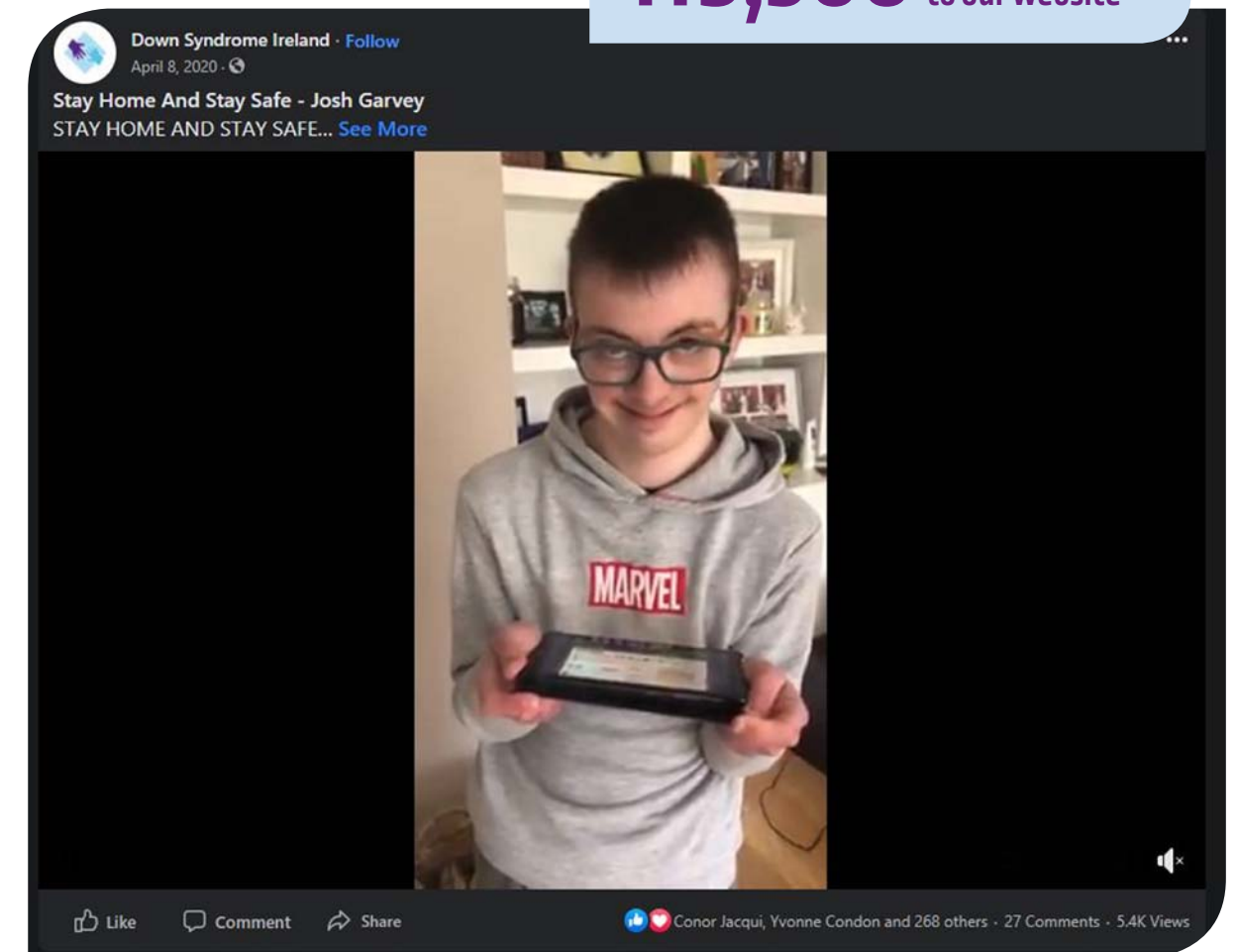


Internal Communications

We issued a total of 27 member email Digests containing useful DSI news, information, links and supports to all of our 3,500 members. During 2020, members contacted DSI to express their thanks and appreciation of all of the team's efforts to keep people with Down syndrome and their families informed and supported during what was an unprecedented year.



119,306 number of 'hits' to our website



International Day of Persons with Disabilities



In celebration of this important day, meet Wayne Kenny, who works as an IT Assistant in the National Treasury Management Agency (NTMA) as a result of our Ability Programme. Our programme, aimed at equipping adults with Down syndrome with the necessary skills to access meaningful employment offers a range of adult education & training courses.

We filmed this wonderful piece prior to Covid restrictions – though Wayne continues to work remotely for the NTMA, through the supportive partnership between DSI & the NTMA.

[Watch the video here...](#)

27 number of email Digest issued to members

Useful education activities and apps for learning



Your child's school may have sent homework to continue while the schools are closed. Your SLT may have provided ideas and activities to work on. You may be continuing with the See and Learn Programme. Continue with this work if you have it but if you do not have work from the school or a therapist, remember that most everyday activities are educational. Not all learning comes from books. Talking, listening, singing, dancing are all great things to do, with many positive effects.

It is also important for your child to continue developing attention and concentration skills. While at school, children need to be able to sit and work on an activity for a period of time. This should be continued at home so that the child can continue to develop their ability to concentrate. The activity does not have to be academic, but one that requires the child's attention and participation. Ensure that 'turn-taking' is practiced at home as this would be a very important part of school life and needs to be continued while the child is out of school.

Similarly, continue to work on developing your child's independence. Working on areas such as putting on their own coat, hanging up their coat, putting on their shoes will be very helpful. Other ideas include encouraging your child to help around the house: setting the table, clearing the table, tidying away their books, toys, games, etc.

We've developed some useful education activities for parents and teachers to help their children continue learning as well as outlined some useful apps for learning too...



Advocacy and Lobbying

Down Syndrome Ireland continues to focus on the needs of our members and seek to improve the services available through the different life stages.

Speech and Language and other therapies

Effective early intervention including speech & language therapy and occupational therapy significantly improves progress for children with Down syndrome.

Down Syndrome Ireland believe that these services are inadequate and inconsistent across the country, and many branches focus their fundraising efforts towards filling these gaps. Lack of HSE therapy was exacerbated by the pandemic, which saw therapists redeployed into COVID-19 related activity. This issue continued through 2020 and beyond. DSI will continue to lobby for additional resources from the Health Service Executive (HSE) to ensure that therapy is available at meaningful levels to people with Down syndrome of all ages.

We have long campaigned for Speech and Language Therapy to be provided within schools and to be fully integrated into the child's education.

The Government ran a pilot scheme to introduce speech and language therapy and occupational therapy services over the 2018-2019 school year in Health Service Executive Community Healthcare Organisation (HSE CHO) Region 7 which includes West Dublin, Kildare, and West Wicklow. Phase one of the project, a joint initiative between the Department of Education and the HSE, saw 150 schools and pre-schools receive in-house speech and language and occupational therapy services.

See and Learn Project

The See and Learn project, which was intended to run for the 2019/20 academic year, was affected by the overnight closure of schools and preschools in March 2020.

The primary goal of this project was to provide universal access to a structured language programme for all preschool children with Down syndrome, ideally delivered in an early education setting to reduce demands on families. We also wanted to monitor outcomes in order to lobby for state provision of structured preschool educational programmes for children with Down syndrome.

After the onset of the pandemic, many of the kits remained locked in preschools for an extended period, preventing them from being used. In other cases, families continued with the programme at home. The changed circumstances meant that it was more difficult to gather data on outcomes, however the extensive training and use of the programmes has led to an increase in interest from families and education professionals, who have seen the benefits of using a structured visual programme to support language development.



“ We have long campaigned for Speech and Language Therapy to be provided within schools and to be fully integrated into the child's education. ”

Early Childhood Care and Education (ECCE)

Despite our best efforts, our lobbying for flexibility and parental choice to be reintroduced to the Early Childhood Care and Education (ECCE) scheme has been largely unsuccessful. The situation remains largely unchanged, with little additional flexibility in the system (there have been a small number of exceptions for younger children). The position of the DES remains that schools need to be ready to receive children whenever they complete their early years education, however young they are, and that children who are not yet ready for mainstream have the option of specialised provision. This contradicts their stated aim of promoting inclusive education whenever possible.

We engaged with officials from the Department of Education and with other groups to assist schools and parents to plan for the safe return of their children to school.

Education

The July Provision scheme provides funding for an extended school year for children with a severe or profound general learning disability or children with autism. In 2020, after much negotiation with the Department of Education, the scheme was offered to children with Down syndrome. However, the administration of the scheme meant that many students were still left without access, as individual schools can decide not to participate, and the alternative of home-based provision relies on families being able to source a tutor. Children starting primary school in September 2020 were also included in the July provision scheme to help compensate for some of the early years education time missed due to the pandemic.

In 2020, after much negotiation with the Department of Education, the scheme was offered to children with Down syndrome.

The impact of the pandemic resulted in schools being closed from March. Much preparation and planning was necessary to ensure the safe reopening of schools for the 2020-2021 school year. To this end, we engaged with officials from the Department of Education and with other groups (i.e. AsIAM and Inclusion Ireland) to assist schools and parents to plan for the safe return of their children to school.

Further and Higher Education

Down Syndrome Ireland would like more options for students when they leave secondary school and greater inclusion in the further education sector. In our last survey only one in four students with Down syndrome received career guidance in secondary school.

In October 2020, we met with Minister for Further and Higher Education, Research, Innovation and Science Simon Harris and briefed him about the adult education



programmes we run. We explained the burden of fundraising for adult education puts on branches and how adults are excluded from a mainstream adult education setting.

Following the meeting, we were invited to meet with SOLAS and members of the ETBI. Down Syndrome Ireland were also invited to apply for funding from SOLAS and to work with SOLAS in an advisory capacity.

Personalised Budgets

We have been campaigning for some time for supports for adults with Down syndrome to be person centred and for personalised budgets to be made available to those people who want to manage their own supports.

The long-delayed position paper on Personalised Budgets (Individualised Funding) was launched in 2018, and pilot projects were due to start in 2019. These were delayed into 2020, where the impact of the pandemic created further delays. Despite calls for a clear timeline on the evaluation process and when personalised budgets will be available more widely as an option, this information is still not publicly available.

The reduction in services due to the pandemic illustrated the inability of services to respond to individual needs, highlighting the need for more individualised provision.

The reduction in services due to the pandemic illustrated the inability of services to respond to individual needs, highlighting the need for more individualised provision. Even when day services resumed, people were offered an extremely reduced service, as pandemic control measures required a reduction of the numbers of people meeting in the same space. The small number of people who are in receipt of a personalised budget were able to use the funds creatively and adapt to the challenging circumstances much more readily than any form of group provision.

Employment

Our campaign calling on the Government to introduce meaningful reforms to make it financially viable for a person with a disability to take up employment continues. We are calling for the decoupling of the disability allowance from unemployment assistance and benefits.

We have asked for three-year protection of benefits. We have also highlighted that the wage subsidy scheme, which applies only to employment of 21 hours or more a week, often excludes people with Down syndrome. Many entry level jobs are physically demanding, and some people with Down syndrome, who often have additional health issues, will struggle to maintain activities for more than 3-4 hours a day and may prefer part time employment with fewer hours.

This is particularly important as the country reopens after the pandemic. Many businesses have been badly affected and a subsidy scheme for people working fewer than 21 hours would be a welcome step to ensure that people with Down syndrome can return to employment.

Respite

The reduction in the availability of respite services continued, and was exacerbated by the pandemic restrictions. This left families under considerable strain, with both day services and respite services largely unavailable from March to September 2020, and the impact on these services continuing throughout 2020. This was not acceptable to our members and we will continue to work with the HSE to restore respite and day services to the levels required.

We are experiencing a significant increase in individual advocacy cases as our older members cannot rely on the support of aging parents. We need a clear pathway for our members to ensure that they receive the services required at this particular life stage.

We will continue to work with the HSE to restore respite and day services to the levels required.

Assisted Decision Making (Legal Capacity) Act 2015

The Assisted Decision Making (Legal Capacity) Act 2015 has been signed into law but we await an effective roll out of the provisions of this legislation. The Decision Support Service (DSS) will be key to this enactment, and the set-up of this has been delayed due to insufficient resources and outstanding actions which need to be dealt with by government. The DSS is due to be operational by June 2022. We continue to cooperate with other groups and lobby to make sure this happens along with the full implementation of the Act.

Health

In 2020, we continued our campaign for 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. Down syndrome affects all the cells in the body. Along with Down syndrome come many specific health implications and these are best dealt with clinical specialists who have an overview of the multiple health needs of children and adults with Down syndrome.

At the moment, there is one clinical nurse specialist post based at Trinity College Dublin, Department of Paediatrics in the National Children's Hospital, Tallaght. The post is supported by Down Syndrome Ireland. Demand for the service is huge and continues to grow everyday. For this reason, we are calling for additional resources to fund clinical nurse specialist-led clinics across Ireland for both children and adults with Down syndrome.

Along with Inclusion Ireland and the Disability Federation of Ireland, we made and will continue to make Pre-Budget Submissions. Collaboration with these organisations and other relevant organisations will continue in our efforts to ensure a better future for our members.

The poster is titled 'PRE-BUDGET SUBMISSION 2021' and 'A BRIGHTER FUTURE NEEDS ACTION NOW'. It features the Down Syndrome Ireland logo and the hashtag #ShareTheJourney. The main text asks 'CAN YOU AFFORD TO IGNORE DISABILITY ISSUES?' and states that Ireland is currently the worst country in western Europe to have a disability. It calls on the Government to commit to improving the lives of people with Down syndrome and their families. A map of Ireland shows that 7,000 people have Down syndrome in Ireland, and each of these people has friends and family. The poster also highlights the need to improve access to critical speech and language therapy and programmes, and lists specific needs such as funding state SLT properly, funding DSI's See and Learn programme at preschools, and funding DSI's See and Learn programme for young children aged 3-6 in pre-school. The website www.downsyndrome.ie is listed at the bottom.

In 2020, we continued our campaign for the creation of 9 additional Clinical Nurse Specialist posts within the major regional hospitals.

Internationally, we are working as part of Down Syndrome Medical Interest Group, Down Syndrome International, and the European Down Syndrome Association.



Actor Mark Smith [39], who has Down syndrome, was an ambassador for our HB Ice Cream Sunday.

NATIONAL OFFICE FUNDRAISING

Down Syndrome Ireland is dependent on the generosity of the general public for its annual fundraising income, as only an average of only 18% of income is received through State funding.

2020 was dominated by the COVID-19 pandemic and its dramatic impact was felt throughout the charity sector in Ireland, particularly through the loss of fundraising income. Down Syndrome Ireland's income was down by approximately a third for the year. This significant reduction in fundraising income can largely be attributed to the two factors, namely, the closure of our six charity shops for a total of seven months, and the postponement of our annual HB Fundays campaign, historically Down Syndrome Ireland's largest annual fundraising campaign. A HB Ice Cream Sunday fundraiser was held virtually in September, with 10 cent from every multipack sold being donated to DSI.

When COVID-19 hit in March and Ireland went into its first lockdown, a number of planned fundraising events for 2020 were either postponed or cancelled. These events included the annual Purple Run celebration in Dublin's Phoenix Park for World Down Syndrome Day on March 21st, the planned Abseil 4 DSI in Croke Park and the Climb Kilimanjaro 4 DSI which was planned for August.



Prior to the pandemic Down Syndrome Ireland had already seen the move away from more traditional fundraising activities such as bucket collections and bag packs etc. to more cashless and digital fundraising activities such as donations and challenges through online platforms. We already had established a good fundraising presence online with the increased use of platforms such as iDonate and Facebook fundraisers etc. This, combined with the user-friendly donation page on our website which is integrated into our CRM system, meant that Down Syndrome Ireland was in a good position to accelerate our digital fundraising presence and activities.



We launched our 21 Day Challenge online during lockdown, and with the support of Irish rugby star and Down Syndrome Ireland Ambassador, Conor Murray, it was a great success, with individuals taking on various challenges throughout the country and raising much-needed funds in the process.

During the summer of 2020 Down Syndrome Ireland was very fortunate to be chosen by the wonderful staff at Woodies as one of four charities to benefit from their annual Woodies Heroes fundraising campaign. Undeterred by the on-going pandemic, the campaign was an overwhelming success due to the fantastic fundraising by the Woodies staff in each store and the generosity of the public.



Other key corporate partnerships with Unilever, MACE, Mondelez, iNUA, Credit Suisse and Kaefer etc. helped sustain us during the year through their fundraising initiatives. We really do appreciate the continued support of all the teams involved.

Despite the fear, uncertainty, hardship and heartbreak that COVID-19 brought with it, we were constantly amazed and so very grateful for the support that Down Syndrome Ireland continued to receive from countless individuals, communities and companies all over Ireland. Their support through donations and fundraising activities meant that, despite a most difficult year, we could continue our vital work with children and adults with Down syndrome and their families.





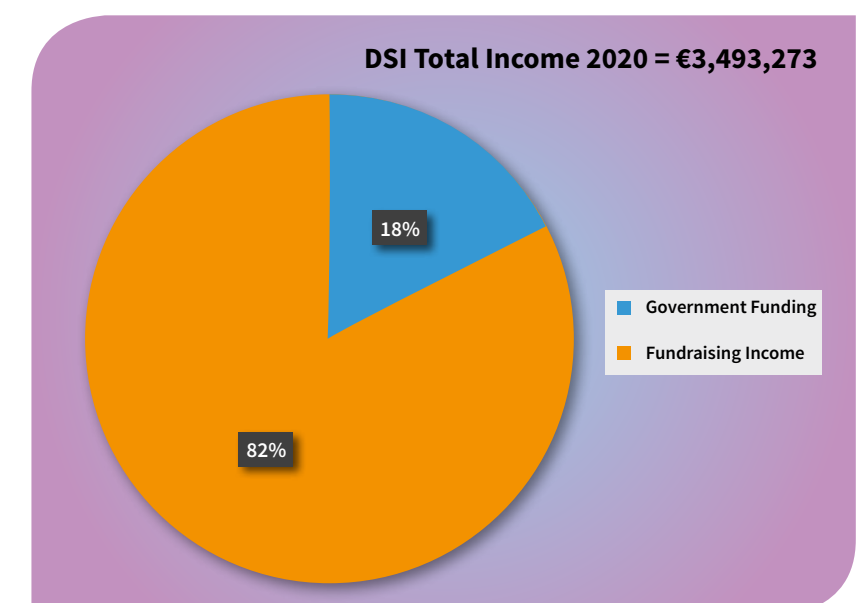
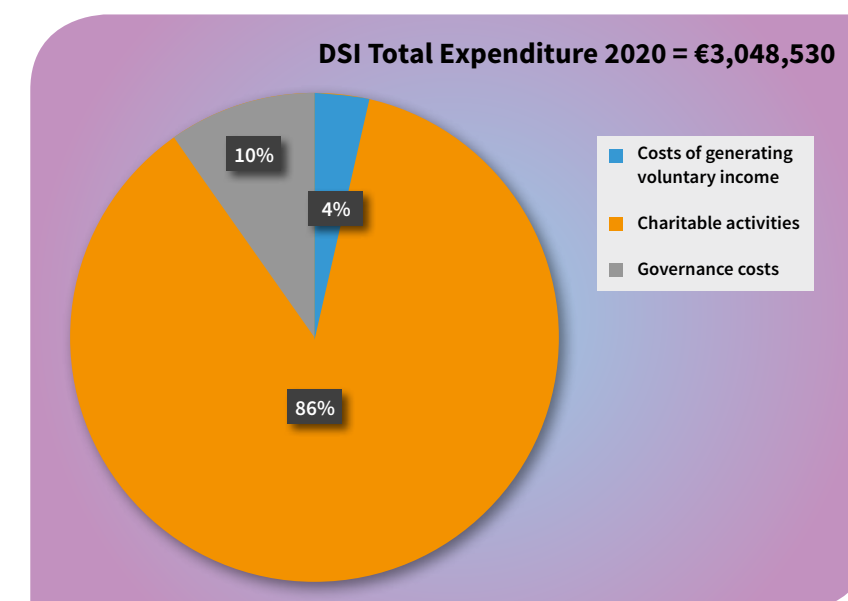
FINANCIAL TABLES

In 2020 Down Syndrome Ireland spent over €3 million on the provision of services and the achievement of the organisation's objectives.

The main sources of revenue for Down Syndrome Ireland continue to be donations and fundraising which accounted for 82% of the organisations's revenue in 2020.

The year was an exceptionally challenging year with the onset of the Covid-19 pandemic resulting in a significant impact on our fundraising income.

The work of the organisation would not be possible without the tremendous efforts of the members, supporters and the public in the generation of funds.



DOWN SYNDROME IRELAND
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING SHARE CAPITAL)

STATEMENT OF FINANCIAL ACTIVITIES
FINANCIAL YEAR ENDED 31 DECEMBER 2020

	Note		2020	2019
Incoming resources	4	Unrestricted Funds €	Restricted Funds €	Total €
Incoming resources from general funds:				
- Voluntary Income		680,460	446,830	1,127,289
- Grant Income		-	656,294	656,294
- Activities for generating funds		89,286	895,513	984,799
- Investment income		14	161	175
Incoming resources from charitable activities		271,025	416,748	687,773
Other Income		9,578	27,365	36,943
Total Incoming Resources		1,050,363	2,442,911	3,493,273
Resources expended				
Costs of generating voluntary income		24,807	84,903	109,710
Charitable activities		744,157	1,895,486	2,639,643
Governance costs		76,672	222,506	299,177
Total Resources Expended		845,636	2,202,895	4,813,173
Resources surplus / (deficit)	6	204,727	240,016	444,743
Retained earnings at the start of the financial year (as previously reported)		8,767	5,264,451	5,273,218
Re-alignment of Unrestricted Reserves		163,980	(163,980)	-
Retained surplus at the end of the financial year		377,474	5,340,487	5,717,961

All the activities of the company are from continuing operations.

The company has no other recognised items of income and expenses other than the results for the financial year as set out above.

DOWN SYNDROME IRELAND
(A COMPANY LIMITED BY GUARANTEE AND NOT HAVING SHARE CAPITAL)

BALANCE SHEET
AS AT 31 DECEMBER 2020

	Note	2020 €	2019 €
Fixed assets			
Intangible assets	10	-	6,758
Tangible assets	11	1,769,610	1,760,911
Financial assets	12	100	100
		1,769,710	1,767,769
Current assets			
Debtors	13	149,271	259,702
Cash at bank and in hand		5,087,460	4,283,734
		5,236,731	4,543,436
Creditors: amounts falling due within one year	15	(811,402)	(548,303)
Net current assets		4,425,329	3,995,133
Total assets less current liabilities		6,195,039	5,762,902
Creditors: amounts falling due after more than one year	16	(221,097)	(233,703)
Net assets		5,973,942	5,529,199
The funds of the charity			
Revaluation reserve	18	255,981	255,981
Restricted income funds	18	5,340,487	5,264,451
Unrestricted income funds	18	377,474	8,767
Total charity funds		5,973,942	5,529,199



Dublin Branch
Fun With Numbers Zoom Session

*Zig and Zag gave our
Dublin branch members a
Christmas message!*



**Leitrim West
Cavan branch
photography
group's 'Picture Me
Project'.**

Offaly
*Ailis Malone and
Offaly Hurlers*



OUR BRANCHES

Down Syndrome Ireland has twenty-five branches nationwide. These branches are run almost exclusively by volunteer parents working in committees and providing their members with a wide range of services and social opportunities.

Dublin

In March 2020, what we thought would be a two-week lockdown became something that changed the world.

First hit were our two adult education groups - we kept them going as best we online.

We had to cancel our planned WDSO party – in fact all our celebrations moved online and our members celebrated WDSO, as well as St Patrick's Day, Easter, Halloween, Christmas – and the All-Ireland finals! – through our various competitions on Facebook, and through the fantastic photos and videos they sent us throughout the year. At Christmas we were able to share video greetings to members from celebrities ranging from Brian Fenton to Nicky Byrne to Zig and Zag!

Zoom became our way of keeping in touch. Our baby and toddler group kept going, with help from Rainbow Phil. We ran an adult Halloween disco, which was a huge success. We started new weekly Fun with Numbers classes with members ranging from 5 to 16. The fantastic Evelyn kept us moving with her Hip Hop classes, which were attended by around 40 members every week.

And as a result of a request from a member at our AGM we started a brand-new adult Ballroom Dancing Class, which has been very popular!

The loosening of restrictions in summer meant that we were able to organise some kayaking sessions with help from Dublin City Sport and Wellbeing, which was great fun, but by necessity our main way of keeping in contact with members in 2020 was online – and we managed to increase our membership in doing so!

The world changed in 2020, but the Dublin branch found new ways of coming together as a community, maintaining a social contact that was hugely important to our members in difficult times.

Kerry

Down Syndrome Kerry has a membership of approximately 230 members and families ranging from infants to adults.

Covid-19 has had a significant impact on our branch and members. As a consequence to the lockdowns, we have lost our ability to host our sign language (Lámh) classes, our parent and toddler groups have had to stop meeting which is such a loss for our younger members. We currently have no date for resumption of face to face meetings.

Physiotherapy and occupational therapy can be scheduled and the majority of our Speech and Language tuition has had to go online. Despite Covid - 19, we have had a successful response to our online therapies with the majority of the members engaging. We have also been lucky enough to continue running our Ability programme for our adult members. We have nearly 100% attendance online.

While the online therapies are proving successful, they are not a replacement for face to face meetings.

Our Charity Shop, 321 which relies on public donations alone has had to close on more than one occasion due to lockdown.

Kildare

Branch Members: 234

Social Media Campaigns to promote community – Easter and Christmas 2020 – Sought messages of Positivity and Support.

Celebrations – Support from AN POST

- Virtual Adult Ed Graduation June 2020 balloons/certificates delivered;
- Mothers Days Baskets delivered to all new mums.

Services Maintained:

Online Classes

Adult:-

- Literacy Skills and Workskills;
- Dance;
- Horticulture/Art;
- Summercamp (Quizzes, fun facts...);
- Summer Social Chats;

Teen:-

- Junior Teen, Teen Youth Club;
- Make-up Zoom;
- Dance;

General:-

- Speech & Language Therapy;
- Webinar: Wills and Special Needs Planning;
- Adult Ed Open Night;
- Branch AGM.

Face-To-Face Classes

- Horticulture Summer Camp, 18 students, July;
- Speech Therapy open air on the Curragh;
- Sept-Dec 2020 and Mar-June 2020 - Adult Ed Classes returned in smaller pods - 3 Literacy & 2 Hort.

Branch led Fundraiser: Croagh Patrick Climb.



Covid in Review:- Branch community participation in Aontas/KWetb Adult Learners Festival - showcased **“Our Story through Covid.”** Through video; our community spoke:-

- “Covid 19 is like a big black cloud that slipped down over the mountain as we try to make our way up on the journey of life.”
- “Our greatest fear is that when we are hidden behind this big black cloud
- “We will be forgotten”
- “We fear that people may lose heart and never reach the potential that should be theirs”
- “We must stay Strong, We must stay Connected”
- “And when the big black Covid cloud has lifted”
- “We will have endured”
- “We will be Visible”

Leitrim West Cavan

In Spring 2020, our branch commenced working in partnership with the Docks Arts Centre, Carrick on Shannon with the support of Creative Ireland and Leitrim County Council to develop our ‘Picture Me’ project. This project is a photography group for our members aged from 10 – 25 years (see picture on page 54).

The vision for the project originally involved face to face workshops, but Covid-19 restrictions meant our members with the exceptional support from artist Anna Leask, who led the project, had to adapt to online workshops. Anna understood that our members were visual learners and conducted the workshops through Zoom supported by tutorial documents and videos which she created.

The ‘Picture Me’ project allows our members to use photography as an artistic format to learn and express themselves. This project was and continues to be a resounding success that produces some excellent photographs whilst providing social and creative support to our young members.

Limerick

DSL has 200 members

Services maintained:

Speech Therapy 1:1 and Group, Occupational Therapy 1:1 & Group, Youth Club, Drama Club and Adult Ed (Latch On Practice for Graduation), Parentlink (support offered via phone/text), Counselling service offered via phone, Transition Talks, Training online, including Covid 19 training, Fundraising online (great effort went into finding new and imaginative ways to engage with members and the community and the response was very heart warming and supportive), cycle lessons 6 hours outside and within Covid guidelines, Halloween & Christmas Parties and of course the committee, our therapists and office was available to provide help and support.

“ **My son Mikie was a Lockdown victim: stuck at home, missing daily stimulation and interaction of Day Service. He was regressing and reluctant to communicate.**

The option of Speech sessions via Zoom presented a most welcome, innovative, beneficial chance for Mikie.

Initially he was apprehensive and somewhat sceptical. However, patience and persistence by all resulted in most enjoyable and worthwhile sessions. I look forward to continuing via Zoom.

Benefits as I see them: Exposure to and familiarity with Technology (the way of the future.) Familiar home setting. No need to travel. Masks not required. Familiar face on screen.

While face to face Speech sessions are the preferred option, the current uncertainty could mean we have to rely on the Digital Option. Mikie says he would prefer to continue the Digital route. We are delighted that we had a Digital option and we hope we can continue with this program.” - Mum Marian Lynch and [‘the bossman’] Mikie Dore.



Virtual services:

SLT, OT, Youth Club, Drama Club, Adult Ed, Talks and information evenings, training including Covid 19 training, Fundraising (great effort went into finding new and imaginative ways to engage with members and the community and the response was very heart warming and supportive) & Halloween/Christmas Party

OT: 18 families received 5 hours of group sessions of OT (under 5 years) and members offered 11 (1:1) sessions of online OT plus 28 standard face to face sessions

SLT: 6 families received 6 hours of group sessions in SLT/communication (under 5 years) and members offered 68 (1:1) online sessions plus 401 standard face to face sessions

Youth Club: 15 hours of youth club activities were delivered to members aged 12 to 18 online including baking, singing, dancing, chat, quizzes, games and more

Drama Club: 38 hours of Drama club activities were delivered to our adult members online including newstime, quizzes, singing, afternoon tea, dancing, cooking and baking and art

Adult Ed: 9 hours of adult ed was held online this included continued preparation for graduation (2020 Year) and a look back at what was learned during the year and of course newstime and chat and singing!

Transition Talks: 5.5 hours of talks were held, 2 online and 1 in person, socially distanced to parents of both members moving from pre-school to primary school and those moving from primary to second level education.

Information Evening: 1.5 hours online on advocating for your child at school with Inclusion Ireland to parents

Parties: 8 hours of parties to members online from ages 0 to 40+ various ages for both Halloween and Christmas

Louth Meath Branch

Down Syndrome Louth / Meath, provides support and information to over 250 families with a family member with Down syndrome in Counties Louth & Meath.

During the early part of the Pandemic, Branch services were severely hit with most services shut down until we could come to terms with the Virus and assess what we needed to do. At our first Committee meeting after the outbreak, we agreed to continue with our Regional Resource Officer Service. Our Regional Resource Officer Mike Egan provides vital support and a point of contact for new parents as well as families who need help and support at local level at every life stage.

Gradually we reintroduced services that could be run online as well as introducing some new services:

Early intervention Programme was suspended in March but resumed in September with new Protocols, Risk Assessments and Procedures in place.

Work Skills Programme classes for our Ability programme students moved online from July to December 2020 and we provided 150 hours of online classes with 15 students attending 50 hours each.



Regional Advisory Council is an independent self-advocacy group for adults with Down syndrome. The 14-member council successfully moved online in May 2020.

Community Education for Adults in conjunction with the LMETB was started up in June 2020. 4 separate courses have taken place in Arts & Crafts, Computers and Cooking.

Sibling Workshops: A pilot Virtual Sibshop for 6 Siblings in June and 2 Virtual Sibshops for 16 Siblings in December 2020.

Speech and Drama club resumed online for Adults in June 2020.

An activity pack was sent to all children on the Early Intervention Home Teaching Programme.

Sourced and distributed Masks and Sanitiser to our members in the early stage of the Pandemic.

Funding scheme continued in 2020 which financially supports families financially to cover therapies, and sports / recreational activities that will benefit members with Down syndrome.

Fun with Numbers is a fun way of working with numbers through games and creative learning aids was organised on-line in November for 2 Groups for a total of 20 students.

Committee monthly meetings continued virtually throughout, and our branch AGM was moved from April to August and was held virtually.

Offaly

When Covid 19 hit us in the early days of 2020, it changed the way that Offaly Down Syndrome Association had to continue providing the services that we offered to our members with as little disruption as possible.

With more than 51 families in our association, we needed to make sure that we kept our members engaged, entertained, and educated.

One of the first things we did was ensure that all of our parents would be able to contact us if they needed support or help in any way. We gave each of our families a €50.00 One4All gift card that they could use on groceries if needed. Our Members WhatsApp group was active every day with light hearted fun, quiz questions, and suggestions of ways to keep the family entertained whilst locked down in our houses.

Once Zoom was introduced and became the norm, we moved our Music Therapy to an online programme of which at least 20 of our families signed up for. We also introduced an online play therapist for teenagers to help them socialise with their own friends online, virtual birthday parties, quiz nights and the Offaly Seniors Hurling Team organised a virtual variety show and solo relay challenge which brought in a staggering €30,000 (see picture on page 54)!

For Offaly Down Syndrome Association, living virtually during Covid 19 in 2020 really did challenge us, but in a way that has changed the way we do things from now on.



Here are our cover stars and Down Syndrome Offaly branch members and sisters Sarah and Chloe, who has Down syndrome featured in The Sunday Times, Ireland edition on World Down Syndrome Day 2020.



Sligo

When all activities ceased in March 2020 the decision was made to move activities online. The primary objective of these activities was to re-connect members with their peers and address some of the isolation that has been forced on us due to Covid-19.

Technology anxiety, rural Wi-Fi and having to communicate in such a different way were a challenge but support was given to ensure everyone could participate. We are now in our second year of providing online activities and supports.

Each online activity is moderated to ensure safety online and to deal with any technical issues. This allows the facilitator to concentrate fully on the group.

The added advantage of these online activities is that it has enabled members to up skill, firstly in the use of technology, and also skills such as yoga, singing and photography.

All activities were evaluated through simple online surveys and feedback was extremely positive.

Through 2020 and 2021 we have provided various online activities

including: **ZoomRoom** – (Social Group - Adults), **Teen ZoomRoom** – (Social Group), **Zoom Yoga** – (All age groups), **Photography Workshop** – (Teenagers and Adults), **‘Time To Shine’ Choir Camp** – (5 – 17 years)

We also joined with Down Syndrome Mayo and Down Syndrome Leitrim/West Cavan for some of the activities and we hope to continue to work with our neighbouring branches into the future.

Though we are looking forward to meeting up again, Zoom is a tool we can use to overcome geographical barriers, especially for members living in rural locations.

Wexford

We currently have 63 members comprising 22 adults, 16 secondary school, 17 primary school and 9 preschoolers (which includes 2 boys born during lockdown).

Unfortunately, all our in-person activities had to go on hold, with the exception of our Latch-On programme, which successfully made the transition to Zoom and we were delighted to see our 10 students graduate (in a socially distanced way!) recently. We hope that some of these members will continue on to MOTE and Life Skills later this year.

Some members were able to continue with speech therapy, whether in-person or online, and others were lucky enough to be able to avail of some respite.



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