

# Working Together for a Brighter Future

Strategy 2022 - 2025



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Down  
Syndrome  
Ireland

Sinéad Friel

# Introductions

## Introduction from the NAC

My name is Sinéad Friel and I am the Chairperson of the NAC – the National Advisory Council. The NAC is the voice of adults with Down syndrome in Down Syndrome Ireland, so we are delighted to have a voice in the DSI Strategic Plan.

There are six adults on the NAC – Claire, Orla, Chrissie, Ross, Conor and me. We give our opinions as part of the decisions that affect us. We are included in these decisions. We have a say in what Down Syndrome Ireland does.

The Strategic Plan is important for us and for all DSI members. Adults with Down syndrome want to lead full lives. We want to reach our full potential and this is what we want for all people with Down syndrome. We have shared our opinions with DSI and are very happy these opinions are included in the Strategic Plan.

We are interested in self-advocacy, adult education, employment and much more. We would like more opportunities in these areas. A lot of work has been done to help people with Down syndrome reach their potential and we know there is a lot left to do. We think the Strategic Plan will help achieve this.

We are excited for the future, working with DSI and continuing to be the voice of adults with Down syndrome.

Sinéad Friel  
Chairperson of the National Advisory Council  
Down Syndrome Ireland



Just because  
we've got Down Syndrome  
doesn't mean we won't  
use our **VOTE**

## Introduction from the President

As President of DSI, I would like to welcome you to our new Strategy Document, Working Together for a Brighter Future. The world has changed dramatically during the past three years and we too must evolve to ensure that we have the best structures, systems and processes in place to deliver on our ambition.

Regardless of the remit and focus of any organisation, there is a responsibility to step back on occasion to evaluate the work achieved to date; to reaffirm the vision, mission, purpose and values; to analyse the changing landscape and to ensure that the organisation remains fit for purpose and structured in the best way to deliver for its members. Down Syndrome Ireland is no different and I am delighted on behalf of the Board to present to you the outputs of the review process and the new three year strategic plan.

Working Together for a Brighter Future will guide us to deliver on the ambition that is set out below. It is important to recognise that this document doesn't belong to the Board or National Office, it belongs to all of us, starting with our members. It reflects our shared and collective ambition.

We are nothing without you and the outputs in the following pages reflect the views, passion, feedback and insights of so many people who are directly involved and actively engaged in and with Down Syndrome Ireland.

I am deeply appreciative of all who contributed to the process especially those who provided much valued critical feedback

in a candid and cogent manner in relation to how Down Syndrome Ireland can grow.

This strategy will result in change, but change as evolution rather than revolution. I have no doubt that in three years time we will reflect on a different working environment, a revived engagement between the National Office and the branch network and most importantly a stronger level of support provided to people with Down syndrome.

We cannot shy away from the challenges that affect our members on a day to day basis and this is a source of continual frustration but if we commit our collective focus to improving the lives of people with Down syndrome we can continue to make real difference and change.

Last year's Upside campaign provides a framework to structure our activity across four key areas that impact our members and their families the most - health, education, employment and life in the community.

I encourage everyone to make the time to read this document in its entirety. I hope you find it reassuring and the recommendations outlined will help us to improve on the delivery of our goals.

Liam McLoughlin  
President  
Down Syndrome Ireland



# Introductions

## Introduction from the CEO

When appointed back in 2021, one of the key initiatives that the board tasked me with as part of my remit was to deliver a new three year strategy. This document is the culmination of a very thorough process that commenced at the start of this year. It has taken most of this year and that duration reflects the scale of the input that has been captured and is reflected in the coming pages.

I want to reassure everyone that at all times, we have listened and taken on board all of the feedback. The passion and insight shared with us has been most welcome. It gives us a clear direction in what needs to be done.

One recurring theme which emerged in the process is connectedness. There is a clear need for the organisation to strengthen connections: between the branches and the National Office, between branches themselves, and between the members and the wider organisation.

It is our firm belief that by evolving our structures to strengthen our branch network we will become a more efficient, responsive and impactful organisation both at local and regional level, but also providing stronger feedback and stronger connection to our national level. This improved information flow will help us to affect real and sustained change not just at policy level but for all of our members.

Society is constantly evolving. The improved level of understanding of inclusion is encouraging, but we know that significant gaps in services to people with Down syndrome and their families remain.

Throughout this journey, we must be transparent, compliant and agile. We are an entirely different organisation than the one that was founded 51 years ago, and yet our focus remains resolute. We need a robust framework so that we can achieve more than the minimum standards. We want to be ready to confidently step forward to achieve our goals.

I am committed that my team and I will ensure that we communicate and update you regularly not just with the issues and challenges that we face, but also with the progress that we are making.

I hope that you share my enthusiasm for the future and possibilities of what can be achieved together.

Barry Sheridan  
CEO  
Down Syndrome Ireland



## WHO WE ARE



### **How this strategy was assembled**

This Strategy is informed by a substantial listening exercise which we carried out over the spring and summer of 2022. This work involved listening, engaging, and debating our mission, our purpose, our structures, and how we do what we do. We spoke to our members, branch volunteers, committee members, adults with Down syndrome, parents of children with Down syndrome, our employees, Board, and national office management team.

We want to thank the people who took the time to speak with us, to fill out the survey, or to give feedback along the way for their engagement and passion in doing so. Each of the strategic objectives set out here are in response to what was raised, and we have done our best to make sure that this strategy is a shared one for the whole organisation, and which sets us on a common path for the next three years, to build a brighter future.

A detailed summary of how the strategy was assembled is available in the appendix.

### **Vision**

We work towards a society that enables all people with Down syndrome to participate to their fullest potential, as equal members with full entitlement as Irish citizens.

### **Mission**

Down Syndrome Ireland supports people with Down syndrome and their families in their communities. We strive to provide consistent, high-quality advice, support and information to every person with Down syndrome to ensure that whatever their stage of life they have a network to support them.

### **Purpose**

Our purpose is to create the environment for people with Down syndrome to achieve their potential, with a particular focus on health, education, employment, and life in the community. Down Syndrome Ireland is a confederation of local branches, who work together to ensure consistency, quality and a common approach which celebrates, supports, and advocates for people with Down syndrome.

# Who we are

## Our Values

- ✓ **Inclusivity:**  
We strive to create a society where people with Down syndrome are supported, valued and integral members of their communities and we demonstrate that inclusivity in our own work.
- ✓ **Passion:**  
We will fight tirelessly to enrich the lives of people with Down syndrome and their families through our work and support Nationwide.
- ✓ **Integrity:**  
We will act with honesty, accountability, and professionalism at all levels of the organisation.
- ✓ **Respect:**  
Everyone should be supported to live a meaningful, rewarding, healthy, and happy life.
- ✓ **Collaborative:**  
Together we are stronger. Sharing information, knowledge and expertise improves outcomes for everyone both locally and nationally.



# OUR ORGANISATION





Down  
Syndrome  
Ireland

# Our Organisation – Fit and ready for the task at hand

Down Syndrome Ireland is first and foremost a local organisation, driven by passionate and hard-working volunteers who share a common vision of building a brighter future for the person with Down syndrome in their life.

Whilst we are focused on delivering locally, we should also work together and share knowledge to make it easier to achieve our shared mission. To do that, we need to have a solid foundation in place, by making sure that our organisation is healthy, accountable, responsive, and focused.

A strong desire was evident amongst our members to grow the connectedness of our organisation structurally between our branches and national office, and between the branches themselves.



**OUR STRATEGIES**



Down  
Syndrome  
Ireland

# Where we are going – Our 2025 Strategic Priorities

## **We will be local-led and local-first.**

We will embark on a structural reform which creates a stronger network of branches, supported by a national office through a regional structure which ensures that all branches and sections of Down Syndrome Ireland are working together toward the agenda set by our members.

## **How will this make a difference?**

Through talking to our members across the country during this strategy development process, the strongest finding we have made is the need to have sound structures in place to pull every part of our organisation closer together. Having staff located across the country supporting and coordinating branch activity will close the gaps between our branches, and between the branches and national office. This will improve all aspects of our service delivery and create meaningful value to our members.

## **How will we know if we have succeeded?**

We will recruit, employ, train, and deploy a new staff division, based regionally and with a broad remit to work with and support branches. This team will coordinate branch work, streamline fundraising and campaigning, and ensure that branches are getting access to the right resources to make their work simpler, reduce the administrative burden. With such a major change it will be necessary for National Office to work with the branches to create this structure, and to agree how it will be implemented.





### **We will become a more efficient organisation.**

We will foster the development of centres of excellence across the country where we can be most effective at delivering the most effective and targeted supports. We will carry out a review of our structures to make sure that we are working towards providing consistently high-quality supports across the country.

#### **How will this make a difference?**

This structural reform will assist our branches in the consistent delivery of supports appropriate to the areas they serve. This will reduce the challenges posed by geography and will create critical mass to ensure coherence and longevity across the organisation. A review of our structures will also improve our accountability and attractiveness to funders and partner organisations.

#### **How will we know if we have succeeded?**

Our branch network will have a clear geographic remit, covering the country, with a clear plan for growth and to eliminate the missed areas in our current coverage. Every person with Down syndrome in the country should have easy access to their local branch. Our democratic structures will be evaluated to ensure that our organisation is truly local-led and responsive to the needs of the branches.

### **We will be responsive to our members.**

By continual engagement with members using different forums and regular topic-based surveys we will ensure that we have up to the minute information to represent members. We will also develop and roll out annual surveys, which we will use to make annual plans to help us deliver the supports our members need, where and when they need them.

#### **How will this make a difference?**

Having a suite of formalised feedback mechanisms will give members, branches, and national office an unparalleled ability to understand what our members need, what supports our branches need, and what direction the organisation should take on a nationally level. We will also be able to regularly update our database on members' contact information, life-stage, and appropriate supports and events.

#### **How will we know if we have succeeded?**

These surveys, working groups, regional meetings, and other engagements will be carried out regularly, with reports on their findings and outcomes disseminated, alongside action points arising from their findings. Members and branch representatives will be empowered to hold the organisation to account to ensure that Down Syndrome Ireland at every level is responding to the real needs and demands of its members.

# Our 2022-2025 Strategic Priorities

## **We will be transparent, compliant, and strategic.**

We will collaboratively develop and deploy a new governance framework for all levels of the organisation, to include guidelines and practical advice to assist branches and members to deliver the supports that are needed in their area, and to spend less time on administrative tasks.

### **How will this make a difference?**

We need to be fully compliant with all our governance obligations, including to the Charities regulator and more amenable to receiving funding from other State and private partners. Ensuring we are local led will ensure that our branches and volunteers are the guiding force of the organisation nationally. Our branch volunteers will have clear guidelines and training regularly to ensure the considerable administrative burden of running a branch is lifted and lightened.

### **How will we know if we have succeeded?**

We will be locally led. We will respond to the identified needs of our members through our branch network of volunteers who will lead the organisation locally and nationally to achieve our common objectives. We will hold regular and relevant governance support training branches and volunteers to reduce the burden of administrative work undertaken and to ensure simpler compliance with our obligations. We will be in full compliance with the Charities Governance Code, and all other applicable regulatory and legislative obligations. Finally, we will have a revised Constitution or Memorandum and Articles of Association for the organisation, which will support our members, volunteers, branches, partners, funders, employees, and most of all support the needs of people with Down syndrome.

## **We will become a more sustainably funded organisation.**

We will work towards reducing our dependence on public fundraising and build sustainable partnerships with the State and other partners at the national and local level.

### **How will this make a difference?**

By reducing our reliance on private donations, we will be free to shift our focus to improving the other things we do, and which are set out in this strategy. This will need to be carried out with a regional focus to ensure consistency, and a clear funding plan will be developed to support this strategic objective. By strategically engaging with State funding bodies, we can address the postcode lottery limiting the accessibility of supports and be more influential in the rollout of the right supports in the right areas. Our locally delivered supports can be tailored to the needs of our members and provided according to our common approach.

### **How will we know if we have succeeded?**

We will be regularly reporting on how we have supported fundraising initiatives to ensure local branches and the national organisation have the necessary means to set and achieve ambitious goals and strategic objectives. We will develop a multi-annual fundraising and financing plan which will be backed up by annual plans and reports informed by need and resource availability. We will report regularly on the decisions underlying our fundraising and financing strategy and longer-term prospects to build sustainable funding streams and lasting partnerships which provide benefits to Down Syndrome Ireland and our partners.

# OUR GOALS



## The Next Three Years: Putting our Vision to Work.

We will work to ensure that that the necessary supports and services are available through the appropriate service providers and *work towards an Ireland where people with Down syndrome are recognised as equal members of society, with access to the supports required locally to lead healthy, happy, and fulfilled lives.*

Over the next three years, our focus to realise this vision will be on **Health, Education, Employment, and Life in the Community.**

To achieve the ambitious goals we need to make sure Our Organisation is fit and ready to do this.

This strategy sets out what we plan to achieve by 2025, and how we are going to do it.

Health

Education

Employment

Life in the  
Community

GOAL

1

# Health

**Living Longer,  
Healthier,  
and Happier.**

Down Syndrome Ireland branches advocate tirelessly for better access and a consistent level of therapy across all areas of the country, with every person with Down syndrome getting the services they need to thrive.

While calling for the State to provide increasing levels of services to match the needs of the population, we will continue to provide peer-support programmes, therapy supports, information, and advice for people with Down syndrome and their families where and when they need them.

Down Syndrome Ireland will be the one stop shop for State and non-state bodies who need to know more about Down syndrome and how to support people with Down syndrome.



# We will:

- 1.1 We will demand adequate health services in the community.** We will campaign to double the number of Speech and Language Therapists in community healthcare, for at least one Clinical Nurse Specialist post for Down syndrome per Community Health Organisation and demand adequate allied health professionals to ensure quality access to physiotherapy, occupational therapy, and general practitioners for people with Down syndrome, including sufficient cover arrangements to ensure continuity of service.
- 1.2 We will provide a consistent, efficient suite of supports for people with Down syndrome, responsive to their needs where they are not accessible otherwise.** Our branches are most equipped to deliver the supports that are needed in the communities they are based in. We will work together to ensure that branch supports are delivered where they are needed, and that families of people with Down syndrome are well informed about what is available.
- 1.3 We will develop and deliver a new medical training campaign** to ensure that medical staff are effectively trained to provide support and guidance to families of people with Down syndrome, with a particular focus on birth and the conditions that tend to arise in the first few years of a person with Down syndrome's life. We will develop a programme of regular online and in-person events to help new parents get to know the community support network available through Down Syndrome Ireland.
- 1.4 We will support the research into early onset dementia for people with Down syndrome.** We will advocate for, support, and disseminate research into the changing nature of health issues that arise as people with Down syndrome age, with a particular focus on dementia prevention.
- 1.5 We will use the available information on dementia prevention to develop, pilot and evaluate evidence based healthy ageing programmes** with and for adults with Down syndrome
- 1.6 We will support research into health issues particularly affecting people with Down syndrome.** We will support the building of a stronger understanding of the particular health challenges faced by people with Down syndrome and support the dissemination of up-to-date knowledge and understanding throughout the healthcare sector helping to ensure that information, services, and advice are based on best available evidence.
- 1.7 We will campaign for individualised funding.** Ending the 'all or nothing' approach to disability services will provide pathways to accessing further supports as an individual's needs change, and funds can be used for personal assistance or transport so that as people grow, they will have more options to pursue to the care and opportunities that suit them.



## GOAL

# 1

# Health

## How we will know if we have succeeded:

- ✓ We will be reporting annually on how we are using our collective means to ensure that each branch is offering the suite of supports that are needed and appropriate in their community.
- ✓ We will have initiated training agreements with every Irish medical, midwifery, and nursing university to ensure the next generation of healthcare professionals are able to provide the right support and care for families and people with Down syndrome from the moment of birth.
- ✓ We will have run annual advocacy campaigns where families and people with Down syndrome will have been able to speak directly to decision makers, politicians, and the relevant Ministers and spokespeople to ensure our demands are heard and acted upon. We will publish annual updates to highlight where our members are not able to access the services they are entitled to.
- ✓ We will have supported research into health issues for older people with Down syndrome, especially dementia, and disseminated the findings among our members and the broader healthcare community.
- ✓ We will have developed a draft healthy ageing programme together with people who have Down syndrome and delivered at least one pilot programme.
- ✓ We will have campaigned across the country in advance of the next general election to bring about the full implementation of individualised funding.



OUR GOALS



GOAL

2

# Education

## Building the Foundations for Future Success

Every person with Down syndrome is entitled to an appropriate education that sets them up for a fulfilling and happy life.

Our branches provide the glue that bridges the gap between that aspiration and what schools and educational institutions can provide, which is all too often lacking.

We will make sure our members are supported in the entire education system with a particular focus on transition points, making sure families and people with Down syndrome are supported and prepared for the months and years ahead.





## We will:

- 2.1 We will campaign locally to address unmet educational need.** Education, particularly in early years is local. Every pre-school, school and further and higher education institution should be given the opportunities to address the issues faced by students with Down syndrome. Every branch of Down Syndrome Ireland will carry out an education campaign to identify and provide guidance to help address local unmet need for students with Down syndrome.
- 2.2 Our members will be supported and prepared for educational transitions.** As children with Down syndrome move through the educational system, we will support our families to support each other with information and resources to be prepared for the difficulties in transition.
- 2.3 We will demand inclusive early years education.** We will campaign for an inclusive early years' education system where children with Down syndrome learn and play with their peers in mainstream schools, is maintained and supported and that programmes are differentiated to ensure accessibility. AIM supports should be available at all levels in advance of the child arriving, and every preschool where a child with Down syndrome is enrolled should deliver the See and Learn Programme.
- 2.4 We will provide information and support to parents and teachers** of children with Down syndrome at primary and post-primary school, working with teacher education and CPD providers so that teachers are better prepared. We will also work on holding schools to account on reduced timetables, and on provision of adequate additional support and intensive behavioural interventions.
- 2.5 We will support and grow adult, further, and higher education.** We will continue to develop a broad and diverse adult education curriculum while also supporting other providers, in particular Education and Training Boards, by providing support and expertise in delivering further education for people with intellectual disabilities in a wide variety of fields of study.
- 2.6 We will advocate for increased pathways to further and higher education.** We will work with guidance counsellors, school leaders, educational institutions, and Education and Training Boards to ensure that the people who advise students with Down syndrome are aware of what further education and training courses are available, so that we can raise society's expectations for what our members with Down syndrome can achieve.

## GOAL

# 2

# Education

## How we will know if we have succeeded:

- ✓ By 2025, every branch will have been supported to create and deliver a local education campaign, specifying the local unmet need for students with Down syndrome and a local action plan will be developed.
- ✓ Every preschool with a child with Down syndrome will have staff trained in See and Learn, and we will have researched the scope, and real day-to-day effects of reduced timetables and behavioural interventions for primary school pupils with Down syndrome.
- ✓ Every post-primary school with a student with Down syndrome will have at least one staff member who has training in further education options for students with Down syndrome.
- ✓ We will have developed and published a resource bank for parents of students with Down syndrome at every age, and for adults with Down syndrome, with a particular focus on support for transition points in the education system.
- ✓ Our advocacy will ensure that all Education and Training Boards will either already offer or have committed to offer at least one DSI adult education course, with the option of progression to either a second DSI course or an alternative ETB course. Further and Higher education institutions will have been consulted on their plans for provision for people with Down syndrome.



# OUR GOALS



GOAL

3

# Employment

## Meaningful and Rewarding Work

The opportunity to take up meaningful and rewarding work in the local community is a prerequisite for people to live independently throughout their life. We want to support our members, for whom it is appropriate, to obtain employment that interests them and matches their capabilities close to home.

We will ensure that every branch is supported to provide guidance to adults with Down syndrome to access employment, and to help local employers create opportunities for people with Down syndrome to work.

We will launch a new National Employment Programme to build on the success of the Ability Programme which will set new expectations for employment for our members and industry.

Employment is not appropriate for everyone with Down syndrome, and we will continue to celebrate the achievements of those who choose to take other routes and provide a strong support net to help ensure that a fulfilling and happy life is available to every adult with Down syndrome, whether in employment or not.





## We will:

### **3.1 We will develop local employment programmes across the country.**

These programmes will support branches to employ regional employment support specialists and develop employment committees, while every branch will be equipped with specialised employment-based training.

### **3.2 We will deliver an ambitious national employment strategy over the next three years.**

We believe that many people with Down syndrome are capable of meaningful and rewarding work, but employers require support and examples before taking the step to hire. We will continue to develop and build a national model where employers can see the benefits to them of providing employment for people with Down syndrome and provide recognition to these employers.

### **3.3 We will build our expertise as trainers for specific sectors.**

We will build on international best practice and the work that is already being done across the country to deliver work/training programmes and apprenticeships in industries including horticulture, beauty, retail, office, hospitality, and catering etc.

### **3.5 We will connect our employment and education work together.**

We will work with Education and Training Boards to develop skills-based training, and to ensure training is available and accessible to all adults with Down syndrome in their communities. We will work with families to facilitate appropriate work experience and training options for teenagers and young adults, in preparation for the transition to post-school employment or further education.

### **3.5 We will share best practice and set new standards.**

Advocating for new employment opportunities should be matched by a commitment to showing the positive effects of our work. We will run annual research seminars with key stakeholders from advocacy and employer groups to demonstrate the good work that is going on and how we can continue to grow.



GOAL

3

# Employment

## How we will know if we have succeeded:

- ✓ We will launch our National Employment Programme in 2023 and will have welcomed 100 new employers into the scheme by 2025, delivering 200 jobs for people with Down syndrome.
- ✓ We will have national coverage of training options available across the country, including local and national plans to ensure equitable access to employment for people with Down syndrome to local work placement, training and employment.
- ✓ We will have campaigned for the Comprehensive Employment Strategy for People with Disabilities target of 6% to have been exceeded, and the 2025 – 2034 targets will be much more ambitious and will include targets for the private sector.



OUR GOALS



GOAL

4

# Life in the Community

## Full and Equal Citizens

People with Down syndrome and their families are frustrated and tired of demanding the same basic supports, resources, and accommodations over and over again. People with Down syndrome are entitled to be fully equal participants in society.

National policy and legislation are far behind where they should be to ensure people with Down syndrome are supported to be included fully in everyday decisions and in advocating for their rights.

Across the country, we will insist that the voice of people with Down syndrome is heard and acted upon by decision makers and insist on the issues that matter to us being at the top of the political agenda.



# OUR GOALS



## We will:

- 4.1 We will be the leading advocacy group of and for people with Down syndrome.** People with Down syndrome are their own best advocates, and our local volunteers will support them to be heard clearly on the issues that matter to them. We will build the structures and supports necessary for people with Down syndrome, their families, and supporters to influence the decisions that have an impact on their lives. Our own National and Regional Advisory Councils will inform our work and be at the forefront of our lobbying work, being trained and supported to do so. In addition to carrying out focused local campaigns, national advocacy events will give a platform for people with Down syndrome and their families to meet decision makers face-to-face to influence the HSE, education and training bodies, politicians, and local authorities.
- 4.2 We will provide a social outlet and community for our members with Down syndrome.** A lot of our work is serious, but we believe that one of the most important things about our organisation is the social side of our work. We will support and provide for community events for people with Down syndrome and their families, and provide funding and support for dance classes, music, sports, and fun activities across the country.
- 4.3 We will collaborate with other charities that work for people with disabilities. The political goals we have are ambitious and difficult.** They will only be achieved if we work with our allies across the charity sector. We will be a leader in the shared campaigns to ratify the Optional Protocol to the United Nations Convention on the Rights of Persons with a Disability (UNCRPD), to fully implement the Assisted Decision Making (Capacity) Act 2015, and to highlight and combat the unmet needs throughout the health, education, and social protection systems for people with disabilities

GOAL

4

# Life in the Community

## How we will know if we have succeeded:

- ✓ Every candidate at the next general election will be invited to meet voters with Down syndrome in their constituency who will tell them first-hand what they need, and that they are ready, willing, and able to use their vote.
- ✓ We will have additional Regional Advisory Councils to ensure that members all around the country can help direct the organisation and become effective self-advocates.
- ✓ By 2025 we will have carried out regular member surveys and published their results, showing that we are meeting the needs of members for social and informal activities, as well as health, education, and employment supports.
- ✓ We will have employed a dedicated public affairs staff member to work with branches and national office to coordinate and hone our lobbying activities to better promote our members' interests.
- ✓ We will have campaigned to ensure that Ireland ratifies the Optional Protocol of the UNCRPD and that the Assisted Decision Making (Capacity) Act is brought into force, confining the 19th Century Lunacy Regulation Act to history.



# Appendix: Strategy Development Process

## This strategy was developed by undertaking three major activities:

- A review of Down Syndrome Ireland's operating context, structures, processes and culture, including an analysis of Down Syndrome Ireland's previous strategy and planning procedures.
- A wide-ranging engagement with members and stakeholders across the country through surveys, one-to-one discussions, focus groups, and targeted feedback sessions.
- Visioning workshops with the Board and National Office Management Team.

The process was managed by a team of consultants from Crowe Ireland who provided insight and guidance to a team from our board and senior management who were instrumental in guiding the project.

## Member consultation

Consultation took place through various means throughout this project, and we are extremely grateful to everyone who took the time to engage with us.

A short strategy survey was developed using an online survey tool which was then disseminated to the entire membership of DSI with a generous timeline to return completed answers. A total of 446 responses were received, including a small number of surveys completed by people with Down Syndrome.

Survey respondents who indicated they were a family member, carer, or support person of a person with Down syndrome were asked the age of the person with Down syndrome in their life. Almost half reported that the person was of school age (between 6 and 17 years), with a significant percentage younger (16%), and a smaller cohort of older people (22% aged 18 – 25 years, 16% older than 26 years). Of the people with Down

syndrome who returned the survey, the mean age was 29.

Geographically, the survey reflected the membership makeup of the organisation, with the largest group of respondents being based in Munster, followed by Leinster excluding Dublin.

Based on the demographic data, and the relatively high number of responses, we were satisfied that the survey presented a representative reflection of the members' opinions on the organisation's strategic direction. A separate survey was carried out among the staff of the organisation.

To support the survey's findings and to enable us to probe deeper into certain findings we arranged a series of focus groups. These included two sessions with adults with Down syndrome, one of which was made up of members of the national and regional advisory groups, and another which was made up of volunteers from the survey. The discussions with adults with Down syndrome were facilitated by members of Down Syndrome Ireland staff after discussion on the form and topics of discussion with our consultants.

Additionally, focus group and interview-type discussions were held with a number of parents of people with Down syndrome, who volunteered to be contacted through the survey. These conversations were held confidentially, and participants were assured of the private nature of these discussions. While their insights were included in the consultants' reports to Down Syndrome Ireland, they were anonymised to ensure no possibility of attribution.

In parallel to this larger scale consultation project, there were targeted discussions with certain key stakeholders in the organisation. This included in-depth discussions with board members and senior managers, as well as inviting the leadership of DSI's branches to submit detailed responses to

questions similar to those in the survey, but with more opportunity for depth in their responses. This feedback was invaluable in collating and ensuring the quality of our findings, which have all fed in to the final strategy document.

## Consultation Outcomes

On completion of the consultation phase, a detailed insights document was prepared for DSI which set out the key themes and findings of the consultation. Several workshops were held with the Board and senior management team to develop, refine, and hone the strategic plan that makes up this document in response to the issues raised by the membership.

It was clear from these consultations that DSI is an organisation at a crossroads, where fifty years of successful cooperation and achievement of some remarkable milestones has led to an organisation in need of modernisation. To that end it was decided early in the process that this strategic plan was a necessary tool to set the agenda for the coming years, but that a timescale longer than 3 years would be unhelpful. As such the document sets out a limited but ambitious set of goals which are necessary, achievable, and focused to ensure feasibility and coherence, and also to allow for oversight by the membership of DSI, its ultimate 'owners'.

Among the themes which arose from the consultation, and which are addressed in the strategy are the following:

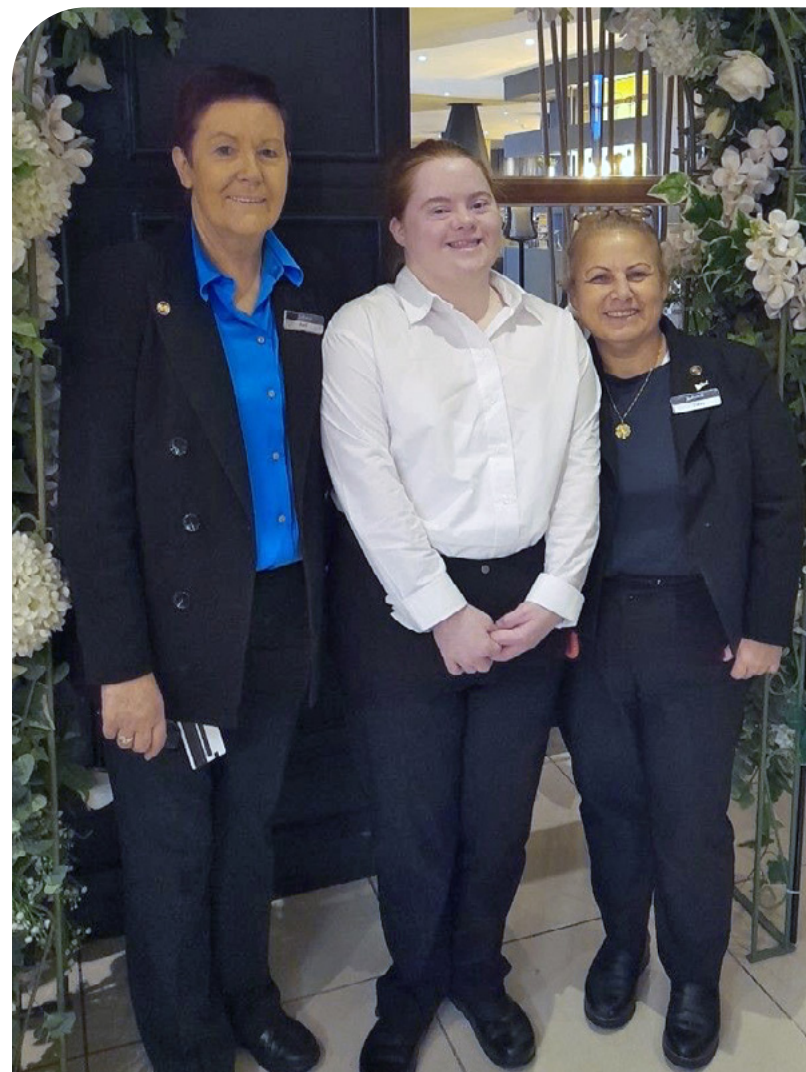
- Governance,
- Structures,
- Communication and engagement,
- Resources,
- Advocacy,
- Member support, and
- Volunteer support.

Each of these issues presents complexities and challenges, which underline a

fundamental need to align Down Syndrome Ireland's overall mission, vision, values, and purpose across the organisation, and to allow the strategic direction of DSI to become something which may be discussed and planned openly and democratically.

## Next steps

It is important to recognise that this plan is a product of the moment, reflecting the choices made in 2022. Like any plan it will become dated soon after completion and the context which is envisioned today may change, necessitating some changes to the plan. To that extent this plan is an enabling document which should assist us in navigating the next three years, with room to flex and reprioritise if necessary. Any such changes in direction should be reasoned and clearly communicated to the membership and be taken note of in three years' time when the next plan like this is put together.





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