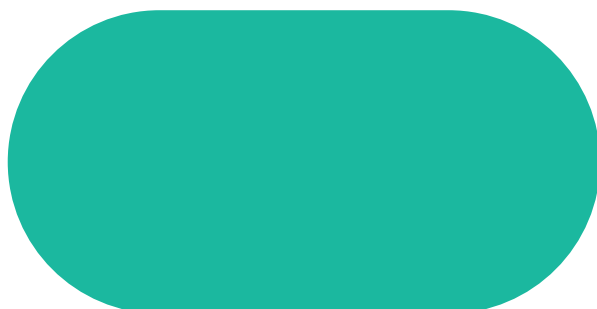
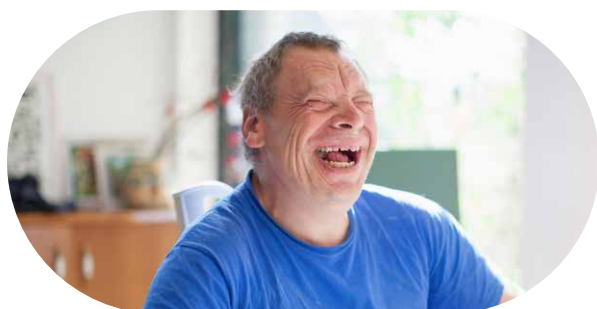


**Unity 26–30**

# One Purpose, One Standard. Everywhere.





Down  
Syndrome  
Ireland

National Leadership Local Support



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**Easy Read strategy**  
also available

# Message from Our President

## Martina Kelly

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As President of Down Syndrome Ireland, and as a parent of Nathan, I understand both the personal and collective responsibility we carry. I see every day the determination of families, the commitment of volunteers and the resilience of people with Down syndrome who continue to advocate for inclusion, dignity and opportunity.



Unity 26–30 reflects that lived experience. It recognises what has been achieved through decades of goodwill and advocacy, while also acknowledging that the environment around us has changed. Governance expectations are stronger. Systems are more complex. Families are carrying too much responsibility. If we are to protect the future of DSI and the people we serve, we must strengthen how we operate.

As President, I hold overall governance and strategic oversight responsibility alongside the Board. This strategy has been carefully considered at Board level. We are clear that structure, accountability and sustainability are not administrative exercises; they are essential to protecting people, safeguarding our charity and ensuring public trust.

Unity 26–30 is ambitious, but it is grounded in reality. It seeks fairness, consistency and long-term sustainability. It honours the work of those who built this organisation while ensuring that the next generation inherits something stronger, clearer and more secure.

Most importantly, this strategy is about people. It is about ensuring that every person with Down syndrome, wherever they live, can rely on safe, equitable and consistent support across their lifetime.

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**Martina Kelly**  
President

# Message from Our CEO

## Aidan Stacey

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Unity 26–30 marks an important moment in the evolution of Down Syndrome Ireland. It is the result of listening carefully to members, families, volunteers, staff and partners across the country.



The message was consistent: families are tired of fighting systems. Members want to be heard and respected. Volunteers want clarity and support. And people expect DSI to be professional, reliable and consistent wherever they live.

This strategy responds directly to that feedback.

We are strengthening information pathways from pre-natal diagnosis through to ageing. We are building clearer transition supports from early years to primary, post-primary and adulthood. We are expanding employment supports through structured Employment Support Specialist roles. We are elevating housing, ageing and transport as strategic priorities. And we are reforming our structure to ensure consistency, accountability and sustainability nationwide.

Implementation will require discipline. It will require clear communication, strong governance and a willingness to change how we work. But it will also allow us to reduce duplication, strengthen equity and protect public trust.

Unity 26–30 is not about centralisation for its own sake. It is about creating a stronger, safer and more sustainable organisation capable of delivering consistent standards for people with Down syndrome across Ireland.

Our ambition is simple: one purpose, one standard, everywhere.

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**Aidan Stacey**  
Chief Executive Officer



# Our Plan

## You asked. We will act.

People with Down syndrome, families and volunteers told us clearly what needs to change. Unity 26–30 is our plan for what we will do from 2026–2030. This strategy is built directly from what you told us matters most: fairness, clarity, independence and being listened to.



### Clear, trusted information

Finding reliable information can be confusing and stressful, especially at key life stages, from diagnosis through adulthood and ageing.

We're going to make it simpler. One clear whole-life pathway of information for every stage of life, so people know what support's available, how to get it, and what comes next. We'll share information when it's needed – from prenatal and early years through to adulthood – not just when it's asked for.



### Fair access nationwide

Support shouldn't depend on where you live, who you know, or luck.

We'll work towards consistent access to key supports across the country, including Speech and Language Therapy. We'll use evidence and data to challenge inequality wherever it exists.



### Support through change

Moving between school stages or into adult life can feel rushed and uncertain.

We'll act by supporting families with information to prepare for transitions, and by advocating for all post-primary schools to have staff training in transition planning 3 years before school leaving. We'll advocate for clear accessible options for after school and further education.



### Work and independence

Meaningful work, independence, and community involvement matter to everyone, but they look different for each person.

We'll expand work experience and Employment Support Specialist programmes, strengthen partnerships with employers, and support practical independence skills like travel, budgeting, and planning daily routines.



### Healthy, connected living

Health, housing, and transport all influence independence and quality of life, especially as people get older.

We'll work with health services, housing agencies, and Transport for Ireland to plan ahead, improve access in rural areas, and reduce last-minute, crisis-driven responses. We'll place greater focus on adult health pathways, ageing, and planning for housing earlier in life.



### Safe spaces to talk

Everyone needs safe and respectful places to talk about relationships, sexuality, wellbeing, and independence.

We'll create trusted, trauma-informed spaces with professional support, and make sure safeguarding is built into everything we do.



### Your voice matters

People with Down syndrome should help shape decisions, not just be consulted.

We'll make sure people with Down syndrome are directly involved in shaping, monitoring and reviewing this strategy through the NAC, RACs, and member-led engagement.



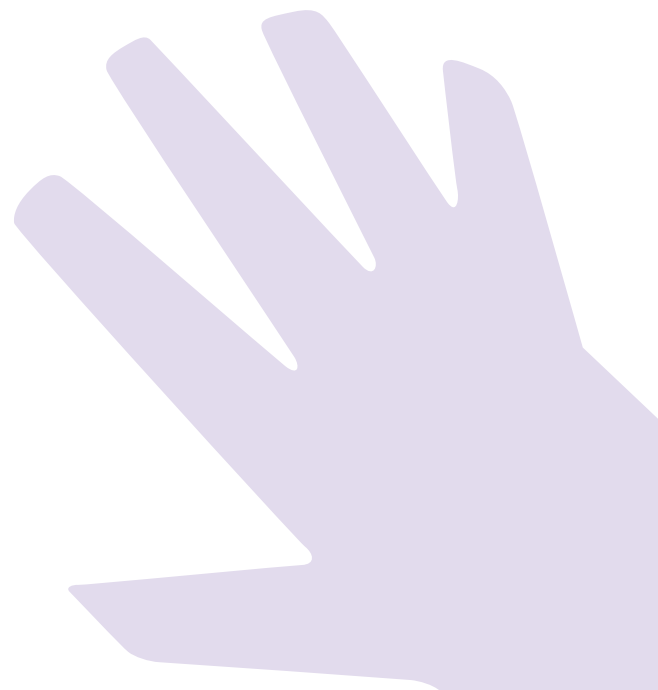
### One strong DSI

Families and volunteers often carry too much responsibility and uncertainty.

We'll build one clear, well-governed organisation with consistent standards, sustainable funding, and better use of data, so every member can depend on DSI. Strong structures protect people and dignity, not just systems.

## Our ongoing promise

This strategy is only the beginning. We'll report openly on progress, share what's working and what isn't, and keep listening as needs change. We're accountable to the people who matter most—our members.



# Strategy on a page

## Our Mission

Our mission is to support people with Down syndrome and their families by providing clear information, consistent services and strong advocacy, working in partnership to reduce inequality, strengthen independence and build inclusive communities.

## Our Purpose

To deliver and advocate for safe, equitable and consistent supports to people with Down syndrome through a clear and well-governed organisation.

## Our Values

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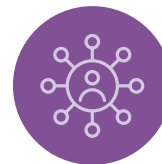
### Unity

We work as one organisation with a shared purpose and collective responsibility.



### Equity

The same high standard of support, everywhere.



### Partnership

We achieve more by working together with families, communities and the State.



### Evidence

We use data and lived experience to improve and advocate.



### Respect

Rights, dignity, choice and self-determination come first.



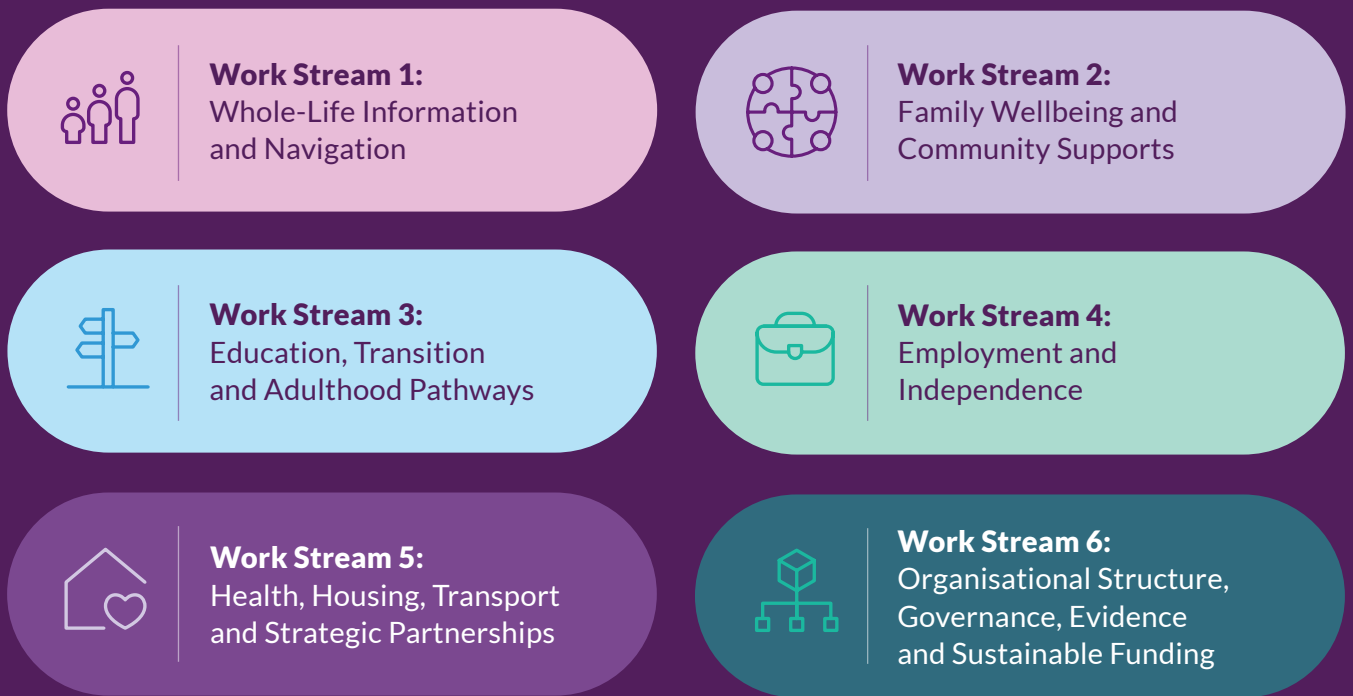
## Our Vision

From inclusion in policy to equality in life for people with Down syndrome.

## Strategic Pillars



## Strategic Workstreams



## Strategic Enablers



# Real Lives, Real Journeys

During our consultation process, we created a series of life-stage personas to help us think carefully about the real experiences of people with Down syndrome at different points in their lives. These personas are not real individuals, but they reflect the common challenges, hopes and needs shared by members and families across Ireland – from pre-natal diagnosis and early years through adult hood and ageing. They helped us test whether Unity 26-30 truly responds to lived experience and ensures that support is planned for every stage of life.

## Sarah

30, and daughter Katie



I'm Sarah. I'm in my 30s and a new mum to my daughter, Katie, who is six months old. I'm still learning about Down syndrome and what it means for Katie and our family. I want to make sure I'm doing everything I can to support her development and wellbeing.



### NOW:

#### Current Challenges

- New diagnosis & limited knowledge about Down syndrome
- Uncertainty about where to find clear, trusted information
- Adjusting to life as a new parent alongside additional needs
- Limited connection with other families on a similar journey
- Unclear pathways to early supports and services

### DSI STRATEGY:

#### Our Actions

- Early connection with families from diagnosis
- Clear, accessible information and guidance
- Peer connection with other parents and babies
- Person- and family-centred early planning
- Early intervention supports at the right time
- Coordinated pathways across health and community services

### FUTURE:

#### Our Outcomes

- Strong early development for Katie
- Confident, informed parent advocacy
- Connected and supported family network
- Timely access to the right supports as Katie grows
- Inclusion, wellbeing, and positive long-term outcomes

# Ben

10 years old



I'm Ben, I am in 4th class in school. I love school but I am struggling with some subjects. I am a member of Down Syndrome Ireland but I don't know what support is available to me or people in my age group.



## NOW:

### Current Challenges

- Enjoys school but finds some subjects challenging
- Learning needs are not always fully supported in class
- Limited awareness of supports available for his age group
- Inconsistent access to tailored learning supports
- Limited connection to peer or age-appropriate DSI activities

## DSI STRATEGY:

### Our Actions

- Early identification of learning support needs
- Child-centred education and learning pathways
- Clear information for families about available supports
- Collaboration with schools and families
- Skill-building and confidence development
- Age-appropriate programmes and peer connection opportunities

## FUTURE:

### Our Outcomes

- Improved learning and participation at school
- Increased confidence and independence
- Access to the right supports at the right time
- Strong peer connections and social inclusion
- Positive educational and developmental outcomes

# Amy

18 years old



I'm Amy, I'm 18. I've recently finished school and I'm excited to take the next steps into adult life. I'm motivated, friendly and keen to build my independence with the right support.



## NOW:

### Current Challenges

- Transition gaps after school
- Transport limits independence
- Unclear employment pathways
- Fragmented supports
- Late intervention

## DSI STRATEGY:

### Our Actions

- Early engagement before school exit
- Person-centred pathway planning
- Transport embedded across all supports
- Coordinated, joined-up services
- Early investment in independence
- Strong employer partnerships

## FUTURE:

### Our Outcomes

- Meaningful, sustained employment
- Greater transport independence
- Increased independent living
- Active community participation
- Reduced long-term support reliance

# Olivia

38 years old



I'm Olivia. I'm 38 years old and I'm interested in finding meaningful work that suits my strengths and interests. I would like to build my confidence, gain new skills, and become more independent through employment. I'm keen to explore the supports available through Down Syndrome Ireland's Employability services to help me prepare for work, connect with employers, and build a positive, fulfilling routine in my daily life.



## NOW:

### Current Challenges

- Not currently in paid employment or underemployed
- Unsure what employment supports are available through DSI
- Wants to build confidence, skills and social connections through work
- Needs support to understand her strengths, interests and work options
- Seeking greater independence and routine through meaningful employment

## DSI STRATEGY:

### Our Actions

- Clear pathways into DSI employment services
- Person-centred employment planning based on strengths and goals
- Skills development, CV support and job readiness training
- Employer engagement and supported work opportunities
- Ongoing coaching to build confidence and sustain employment
- Coordination with other DSI supports to enable success at work

## FUTURE:

### Our Outcomes

- Meaningful, paid employment aligned to her strengths
- Increased confidence, routine, and independence
- Expanded social networks through work
- Greater choice and control in daily life
- Improved wellbeing, purpose, and quality of life

# Sean

50 years old



I'm Sean. I'm 50 years old. I'm not currently a member of Down Syndrome Ireland and I haven't used DSI services before. As my parents get older, I'm starting to feel unsure about my future and what options are available to me.



## NOW:

### Current Challenges

- Living with ageing parents and uncertain future plans
- Not connected to Down Syndrome Ireland or other services
- Limited social connections and opportunities to meet peers
- Wants to work or join structured daytime activities but unsure how
- Needs support with health and wellbeing but doesn't know where to turn

## DSI STRATEGY:

### Our Actions

- Welcoming entry points for adults new to DSI
- Person-centred planning for adulthood and independence
- Employment exploration and meaningful daytime activities
- Social groups and peer connection opportunities
- Health and wellbeing guidance and referrals
- Confidence-building and independent living skills

## FUTURE:

### Our Outcomes

- Strong friendships and social inclusion
- Meaningful work or regular social engagement
- Greater independence and choice about living options
- Clear future planning and peace of mind
- Improved health, wellbeing, and quality of life



# Strategic environment

Down Syndrome Ireland operates in an environment that is becoming more complex, demanding and fast-moving. For more than 50 years, families—particularly parents—have shown extraordinary commitment, advocacy and goodwill, often stepping in to secure supports, create opportunities and fill gaps where systems fall short. Their resilience and determination have been central to the progress achieved to date. However, families are increasingly clear that the level of effort required to access basic supports has become unsustainable. The fight for early intervention, equitable access to therapies, inclusive education, smooth transitions into adulthood and meaningful employment too often rests with parents themselves.

As needs grow and become more complex over time, particularly around health, housing, transport and ageing, the demands placed on families intensify. Navigating fragmented systems, coordinating multiple agencies and repeatedly advocating for entitlements is now the norm rather than the exception. This is not only exhausting for families; it also creates inequity, as outcomes depend on personal capacity, time and resources rather than need.

Member voice and self-advocacy are central to this strategy. Feedback from people with Down syndrome through the National and Regional Advisory Councils has shaped our priorities, reinforcing the importance of independence, connection, communication and safety across the life course. Members consistently highlighted the value of opportunities to speak for themselves, to connect with peers through member-led and member-only events, and to access trusted, professional spaces where they can discuss topics that matter to them, including relationships, sexuality, independent living and future planning. This strategy commits to strengthening self-advocacy, expanding safe and inclusive member spaces, and ensuring that lived experience continues to inform delivery, accountability and improvement over the life of the strategy.

Externally, DSI is operating in a crowded and competitive voluntary sector, where disability funding is under sustained pressure and often fragmented. Economic conditions, including the cost-of-living crisis, have reduced household giving while increasing demand for support. Corporate and philanthropic partners expect professionalism, clear accountability and demonstrable impact. At a policy level, inclusion and rights are increasingly recognised, but delivery lags behind ambition, leaving families and voluntary organisations to carry responsibilities that should be system-led.

The regulatory and governance environment has also become more exacting. Compliance with the

Charities Regulator, safeguarding standards and accountability expectations is essential to protecting public trust and organisational credibility. As a registered charity and company limited by guarantee, DSI must demonstrate transparent financial management, clear reporting lines and disciplined governance oversight. These requirements are necessary and appropriate, but they add further complexity to an already demanding environment. Together, these pressures mean that reliance on parental goodwill and volunteer effort is no longer viable. The environment now demands clearer structures, stronger systems and more sustainable ways of working.

There is also a narrowing window of opportunity. Inclusion, disability rights and reform of health and disability services are firmly on the national agenda, but influence depends on credibility, coherence and readiness. Organisations that cannot demonstrate strong governance, consistent delivery and a clear operating model risk being left behind as systems evolve. For DSI, change is not about abandoning what has worked; it is about protecting it. Acting now allows the organisation to honour the commitment of families and volunteers, strengthen partnership with the State, and build a structure capable of delivering fair, safe and sustainable supports into the future. Delaying change would place greater strain on those least able to carry it—and that is a risk DSI cannot afford to take.

## Government partnership

The need for a clear and effective partnership with the State has never been greater. Families have long carried the burden of advocating for their children, often acting as coordinators, case managers and campaigners simply to access basic supports. While this advocacy has driven progress, it is neither fair nor sustainable for responsibility to continue to rest so heavily on parents and carers. Meeting the needs and upholding the rights of people with Down syndrome is ultimately a State responsibility.

DSI aims to work constructively with Government as a partner, bringing lived experience, trusted relationships and evidence from services on the ground. At the same time, we will advocate tirelessly for meaningful, sustained, multi-annual statutory investment that reflects this responsibility and reduces reliance on parental advocacy and short-term voluntary capacity. Effective partnership requires clarity of roles: where the State provides stable funding, joined-up systems and equitable access to services, and DSI contributes expertise, coordination, innovation and accountability.

Strengthening DSI's own structure is a necessary part of this shift. A clearer, more consistent organisational model improves our credibility as a partner, strengthens our ability to manage public funds responsibly and ensures that advocacy is grounded in evidence rather than exhaustion. Structural clarity enhances compliance with the Charities Regulator and strengthens confidence among statutory and philanthropic partners. Ultimately, a stronger State partnership and a stronger DSI serve the same goal: allowing families to focus on raising their children and planning for the future, rather than fighting systems that should work for them.



# By 2030



## Membership growth

We will have increased our membership. This growth will not be pursued as a numbers exercise but will be the natural consequence of becoming a trusted, whole-of-life organisation delivering equitable, consistent standards nationwide. As relevance, quality and clarity improve, membership will follow.



## +50% Employment

We will increase by 50% the number of people with Down syndrome supported into paid work through DSI pathways.



## 30% Stable Funding

30% of our core delivery will be supported by multi-annual statutory funding.





## Equitable access, everywhere

Access to information, navigation and core supports will no longer depend on postcode, personal networks or ability to pay.



## Independence that lasts

More people with Down syndrome will live, work and participate in their communities with the right supports that sustain independence and longevity, promoting wellbeing over time.



## One strong DSI

DSI will operate as one united, well-governed organisation delivering consistent standards nationwide



# Our four pillars

## Information



Clear, accessible information is foundational to good outcomes. Under this pillar, DSI will ensure that people with Down syndrome, families, volunteers and professionals can easily find reliable, accurate and consistent information at every stage of life, from pre-natal diagnosis through to ageing. Our focus is on replacing fragmented advice and informal knowledge-sharing with trusted, structured guidance that supports informed decision-making and reduces stress. By strengthening how information is created, shared and maintained, we will help families feel more confident and less alone as they navigate education, health, adulthood and ageing.

## Services



Services are where our strategy is experienced day to day. This pillar focuses on delivering supports that strengthen wellbeing, reduce isolation and support independence across the life course. We recognise that families' needs change over time and that emotional, social and practical supports are critical alongside formal services. Our services will be clinically informed, community-based and designed to support key transitions, including pre-natal to early years, early years to primary education, primary to post-primary education and the transition into adulthood. Consistency, equity, quality and sustainability will be central to how services are designed and delivered.

## Advocacy



Advocacy is central to DSI's role as a trusted national voice. Through this pillar, we will continue to influence the systems that shape daily life for people with Down syndrome, including health, education, employment, transport and housing. We will advocate clearly and consistently for a meaningful contribution from Government that recognises its responsibility to people with Down syndrome and their families. Our advocacy will be grounded in lived experience and strengthened by service evidence and research, enabling us to close the gap between policy intent and lived reality and to press for practical, sustainable change.

## Structure



Strong structure enables strong delivery. This pillar recognises that to deliver consistent, equitable and safe supports, DSI must operate as one clear, well-governed organisation. Our structure will reduce variation, support volunteers, embed safeguarding, and ensure accountability across National Office and regions. Clear roles, shared systems and consistent standards will allow the organisation to focus energy on people rather than process and remain sustainable into the future.

Structure is not an operational preference; it is a governance and safeguarding imperative. Clear employment lines, standardised financial controls, defined regional accountability and central oversight protect members, volunteers and the organisation itself. Structural clarity strengthens compliance with the Charities Regulator, enhances credibility with Government and funders, and ensures that public trust is maintained.

Most importantly, structure protects people and dignity, not just organisations.

# Our work streams



## Work Stream 1: Whole-Life Information and Navigation

Our members asked for information supports that include practical guidance on everyday independence and safety, such as planning routines, managing money, using transport, and knowing what to do in unfamiliar or stressful situations. They asked DSI for information on relationships, sexuality, consent and personal safety to be accessible, age-appropriate and delivered through trusted formats that support informed choice.

This work stream will deliver a single, coherent pathway of information and guidance from pre-natal diagnosis and early years through adulthood and ageing. We will publish a whole-life roadmap, available digitally and in print, setting out supports by life stage and county. Families will be proactively contacted at key milestones—including pre-natal to early years, early years to primary education, primary to post-primary education and transitions into adulthood—with clear next steps, reducing reliance on informal networks or crisis-driven decision-making. We will strengthen first-contact routes through hospitals and GPs, expand accessible formats such as webinars, podcasts and workshops, and equip schools with Down syndrome awareness, LAMH training and practical tools. Earlier and more structured transition planning will help smooth the move into adulthood, while clearer guidance on adult health and ageing pathways will support better long-term planning. Volunteers will be supported through standardised resources and training, reducing single points of failure and improving consistency.

### What will change:

Families will no longer need to piece together information from multiple sources or rely on who they happen to know. Instead, they will have a clear, trusted and accessible pathway that shows what supports exist, how to access them and what comes next. DSI will provide members with safe, structured spaces to discuss difficult topics, ensuring informed choices are age-appropriate and delivered through trusted formats across every stage of life.



## Work Stream 2: Family Wellbeing and Community Supports

Our members asked DSI to strengthen opportunities for self-advocacy and peer leadership, recognising the importance of people with Down syndrome speaking for themselves, shaping decisions and supporting others. We will expand member-only and member-led events, including social, learning and advocacy spaces, to reduce isolation and strengthen confidence, identity and belonging. Services will provide trusted, professional and therapeutically informed spaces where people can safely discuss sensitive and important topics such as relationships, sexuality, independent living, boundaries and personal safety, supported by appropriately trained staff and clear safeguarding practices.

This work stream focuses on strengthening resilience, connection and wellbeing for individuals and families. We will expand counselling and psychologically informed supports alongside peer connection opportunities, both online and locally. Working with partners, we will develop sibling supports and practical early guidance for families. Regional meetups will be expanded, with particular attention to reconnecting adults and older members who may have become disconnected over time.

### What will change:

Emotional wellbeing and community connection will become a consistent part of the DSI offer, reducing isolation and strengthening resilience for families across the country. The voice of our members and their ability to self-advocate will be central to this work stream, ensuring lived experience remains embedded in delivery and accountability.

# Our work streams (continued)



## Work Stream 3: Education, Transition and Adulthood Pathways

Members told us that school, college and the move into adulthood can feel uncertain and stressful, especially when supports change or stop. They asked for earlier and better transition planning, fair access to Speech and Language Therapy in every county, and consistent communication supports throughout childhood and adolescence. Members also said they want more help to prepare for adult life, including learning independence skills, understanding choices and having clear pathways into further education, work and community life.

This work stream will address key transition points that currently create stress and uncertainty. We will strengthen structured planning across all major transitions, including early years to primary education, primary to post-primary education and post-primary education to adulthood. We will support earlier transition planning during post-primary school, using a standard approach that links childhood, education, further education, employment and community participation.

Working in partnership with the HSE and other providers, DSI will help ensure equitable access to Speech and Language Therapy for people with Down syndrome in every county, combining DSI-delivered provision where funded, strong navigation and family support, and sustained advocacy for statutory delivery. We will work to ensure communication needs are identified early, supported consistently through childhood and adolescence, and planned for as part of transitions into adulthood. A structured 18–25 bridge offer will further support life skills, social connection, FE/ETB engagement and employment pathways.

### What will change:

Children and young people with Down syndrome will experience more consistent and equitable access to Speech and Language Therapy and communication supports, regardless of where they live. Transitions through primary, post-primary education, further education and into adulthood will be planned earlier and more clearly, reducing uncertainty and stress for families. Young people will be better supported to build communication, confidence and independence so they can take part in education, work and community life with greater choice and continuity.



## Work Stream 4: Employment and Independence

Members told us that having the chance to work, volunteer and be active in their communities is central to independence and confidence. They asked for more opportunities to gain work experience, stronger employment support and assistance that continues after a job starts, not just at the point of placement. Members were clear that meaningful employment looks different for everyone, with some people wanting part-time work, flexible hours or gradual progression rather than a single definition of success. They also highlighted that everyday independence skills—such as managing money, planning routines and getting to and from work—are closely linked to employment outcomes. Transport was raised as a major factor in whether work is possible at all, particularly in rural areas. They asked for employment supports that recognise these realities and help people build sustainable independence over time.

Through this work stream, DSI will expand access to meaningful work and greater independence. We will grow work experience and Employment Support Specialist provision, with consistent follow-up to support job retention. Employment Support Specialists will provide structured employer engagement, job matching, onboarding support and post-placement retention guidance. Employer readiness will be strengthened through partnerships that promote inclusive workplaces. Transport skills and confidence will be supported in parallel with employment preparation, recognising mobility as a key enabler of independence.

### What will change:

More people with Down syndrome will access employment that reflects their individual goals, strengths and circumstances, supported by Employment Support Specialists and sustained follow-up to remain in work. Employment will be better connected to everyday independence skills such as planning, budgeting and transport, reducing drop-off and enabling sustained participation in working and community life.



## Work Stream 5: Health, Housing, Transport and Strategic Partnerships

Members told us that good health, safe housing and reliable transport are essential to living an independent and connected life. They asked for earlier and more consistent health supports, with better understanding of Down syndrome–associated health conditions across the lifespan and clearer adult health pathways, so that care is planned and coordinated rather than crisis-driven. Members also highlighted the need for long-term thinking about housing, including realistic options for independent or supported living in both urban and rural areas.

Ageing was raised as an area requiring stronger attention. People with Down syndrome experience a distinct ageing profile, including increased prevalence of early-onset dementia and Down Syndrome Regression Syndrome. Members and families emphasised that planning for ageing must begin in early adulthood, with clear pathways, accessible information and appropriate clinical awareness to avoid crisis-led interventions later in life.

Transport was raised repeatedly as a major barrier to everyday life. Members described how limited public transport, inaccessible taxis and lack of driver training restrict access to work, education, services and social activities, particularly outside cities. They asked for transport to be treated as a core enabler of independence and inclusion, and for DSI to work in partnership with health services, housing providers, Transport for Ireland and local authorities to address these barriers in a joined-up and practical way.

This work stream focuses on strengthening partnerships to improve long-term health, housing and mobility outcomes. DSI will deepen collaboration with statutory bodies, clinicians and aligned agencies to advocate for more joined-up, proactive pathways. A key priority will be strengthening clinical partnerships to promote greater awareness of Down syndrome–associated health conditions across the lifespan and to advocate for Down syndrome–specific specialist clinic models, particularly for adults. In parallel, we will collaborate with housing agencies that align with our values to support better planned, regionally delivered housing pathways, recognising that stable housing reduces long-term residential dependency and supports dignity and independence.

Transport will be treated as a critical enabler of independence and inclusion. DSI will work with Transport for Ireland (TFI), local authorities and partners to improve rural accessibility, expand travel training, and address transport barriers that limit access to services, employment and community life and contribute to isolation.

### What will change:

Health, housing and transport supports will be identified earlier and addressed in a more joined-up way, reducing crisis responses and reliance on informal workarounds. Improved clinical partnerships, clearer adult health and ageing pathways, better planned housing options and strengthened access to transport—including in rural areas—will enable greater independence, social connection and confidence in planning for the future.



# Our work streams (continued)



## Work Stream 6: Organisational Structure, Governance, Evidence and Sustainable Funding

Members told us they want to be listened to, respected and taken seriously, not consulted as a formality. They asked for clear roles for people with Down syndrome in shaping decisions and holding DSI to account, including through the NAC and RACs. Members also spoke about the importance of consistency, professionalism and trust, so that the quality of support does not depend on where someone lives or who happens to be involved locally.

They were clear that families and volunteers already carry too much responsibility and that DSI needs to be strong, organised and sustainable. Members asked for clearer structures, better use of information and stable funding so that people can rely on DSI without having to fight for basic supports. For them, strong governance and structure are not abstract ideas—they are what make fairness, safety and dignity possible in everyday life.

*This work stream underpins the entire strategy.*

We will move from branch-by-branch variation to consistent regional delivery through shared intake, coordinated routing and better use of data to identify gaps and inequities. Strategy implementation will be led by the CEO, supported by a strong performance and impact rhythm. Leadership will be streamlined through a single Directorate of Income, Influence and Communications and a single Directorate of Services and Engagement responsible for the national service model and member journey. Regional branches will operate a consistent staffing model, supported by volunteers and governance structures and enabled by national systems, training and standards.

As some branches have grown to operate at a scale comparable to SME's, governance structures must evolve accordingly. Volunteer committees remain central to representation, community and local engagement, but operational, financial and employment responsibilities must sit within clear professional structures to ensure continuity, reduce personal liability and protect service stability over time.

The regional model establishes a minimum staffing baseline to guarantee core service access nationwide. Regions with greater service demand, staffing scale or programme complexity will operate proportionately larger teams within the same governance and reporting framework.

National Advisory Council and Regional Advisory Council members will continue to play a formal role in strategy implementation and review, providing ongoing lived-experience challenge and accountability to ensure services remain relevant, respectful and grounded in real life.

Central to this work stream is advocating for meaningful, multi-annual statutory funding that reflects the State's responsibility to people with Down syndrome and supports consistent delivery of agreed priorities. Alongside this, we will continue to strengthen fundraising, governance, digital systems, people capability and safeguarding assurance so that impact, quality and compliance are evidenced—not assumed. Compliance with the Charities Regulator and safeguarding standards will remain central to protecting public trust and organisational credibility.

Local fundraising will remain a vital and valued part of DSI's model, sustaining community activity and enhancing services beyond core provision. National oversight will ensure equitable distribution of core supports so that access does not depend solely on local fundraising capacity. This approach protects stronger branches while ensuring that members in less resourced areas are not disadvantaged. Service continuity should not depend solely on the strength of a particular committee at a particular time, national systems should provide stability and protection across the organisation.

### What will change:

**DSI will operate as a stronger, more consistent and more reliable organisation nationwide. Clear structures, sustainable funding and stronger evidence will reduce the burden on families and volunteers to repeatedly advocate for basic supports, while ensuring people with Down syndrome can trust that services are safe, professional and equitable wherever they live.**

# Strategic enablers

Delivering this strategy depends not only on what DSI does, but on how the organisation is enabled to do it. The following strategic enablers provide the foundations that allow ambition to translate into consistent, safe and sustainable impact. Without them, delivery would remain uneven, overly reliant on goodwill, and difficult to evidence or scale. These enablers ensure that Unity 26–30 is implemented with discipline, accountability and measurable outcomes.

## Data reform and evidence-led delivery

Reliable data and evidence are essential to delivering fair, effective supports and to advocating credibly for change. DSI will reform how data is collected, managed and reported so that it consistently captures who we support, what supports are delivered, where gaps exist and what outcomes are achieved. This will allow the organisation to map need more accurately across regions, identify inequities, plan services proactively and demonstrate impact with confidence.

Robust data will also strengthen DSI's advocacy, enabling evidence-based engagement with Government, funders and partners, and reducing reliance on anecdote or crisis-driven narratives. A defined performance framework, overseen at Board level, will monitor equity of access, transition outcomes, employment participation, safeguarding assurance and member satisfaction. Data will therefore not only inform services but also underpin accountability and credibility.

## Organisational restructure

A clear and fit-for-purpose structure is critical to delivering consistency, accountability and regulatory compliance. DSI will continue to move from a branch-by-branch model with wide variation to a joined-up regional delivery model supported by strong national coordination. Clear roles, defined responsibilities and streamlined leadership will reduce duplication, strengthen decision-making and ensure that services are not dependent on individual capacity or goodwill alone.

This restructure is not about centralisation for its own sake; it is about creating a sustainable organisation where families receive a comparable standard of support regardless of where they live. Structural clarity strengthens safeguarding, financial oversight and compliance with the Charities Regulator. Most importantly, structure protects people and dignity by ensuring that standards do not vary according to geography or local capacity.

## Finance and sustainability

Financial sustainability underpins everything DSI seeks to achieve. The organisation will strengthen financial planning, controls and transparency to ensure resources are used effectively and aligned with strategic priorities. Alongside diversified fundraising, DSI will continue to advocate for meaningful, multi-annual statutory funding that reflects the State's responsibility to people with Down syndrome.

Strong financial foundations will enable longer-term planning, investment in quality and people, and reduced exposure to short-term funding shocks. Central oversight of significant funding applications and disciplined financial governance will further protect organisational stability and public trust.

## People and culture

DSI's impact depends on its people—staff, volunteers and leaders. As demands increase, the organisation must ensure that people are supported, skilled and able to work within clear systems. DSI will invest in a culture that values clarity, collaboration and accountability alongside compassion and lived experience.

This includes supporting volunteers so they are not overburdened, building staff capability, improving retention and fostering a shared understanding of roles, standards and purpose across the organisation. A healthy organisational culture is essential to sustaining energy, retaining talent and delivering consistently for families.

## Governance and assurance

Strong governance is a strategic enabler, not an administrative burden. DSI will continue to strengthen governance, safeguarding and compliance to meet regulatory expectations and protect public trust. Clear oversight, disciplined reporting, defined risk management processes and compliance with the Charities Regulator ensure that decisions are fair, evidence-based and in the best interests of the people we support.

Strong governance enhances credibility with Government, funders and partners, reinforcing DSI's role as a responsible and trusted national organisation. Governance and assurance provide the stability upon which innovation and service expansion can safely occur.



National Leadership Local Support

**Down Syndrome Ireland**  
Unit 3, Parkway House  
Western Parkway Business Park  
Ballymount Drive  
Dublin 12  
D12 HP70

T 01 426 6500

W [www.downsyndrome.ie](http://www.downsyndrome.ie)