

# ***‘All to play for’***

***a strategic framework for  
Down’s Syndrome Scotland***

**2022-2025**



## Foreword

As we take our first cautious steps forward into a world where we are all learning to 'live with COVID', and everything that entails, it is imperative that we remain ambitious for people with Down's syndrome, their families and their carers.

Like many people who found themselves marginalised before the pandemic hit, our community experienced deepening levels of inequality and injustice throughout the COVID-19 crisis.

This strategic framework seeks to challenge that inequality by creating opportunities for people with Down's syndrome to fulfil their greatest potential.

Our framework seeks to partner with all those who share our values and ambition for everyone living with an extra chromosome.

We want to reach more people with Down's syndrome, more quickly and more often. We don't underestimate the scale of that ambition and we know we cannot do it alone.

We hope you share our ambition and that will join us in our plans.

You will not be disappointed.

## **Our Vision**

*A society that fully values and includes people with Down's syndrome.*

## **Our Purpose**

*To improve the quality of life of everyone with Down's syndrome living in Scotland.*

## **Our Mission**

*To support families and people with Down's syndrome to reach their full potential by providing a range of services, influencing public policy and by changing attitudes.*

## All to play for

When we talk strategy at Down's Syndrome Scotland, we talk about our 4-4-2 formation.

- We have **four** strategic goals (our players defending our core purpose, promoting the potential of everyone with Down's syndrome, supporting families, raising awareness and challenging perceptions).
- And then we have our **four** programmes for change (our players in the midfield demanding changes in health, employment, transition planning and community living).
- And finally, we have our **two** foundation blocks (our players up front, promoting human rights and demanding equality for everyone who has Down's syndrome).

These are the players on the pitch and it is vital that they are supported by a great team, off the pitch. Support that includes good governance, brilliant fundraising, excellent communications, digitally enabled systems and processes and inspiring volunteers and supporters.

Although this is a strategic framework for Down's Syndrome Scotland its ambition can only be realised by working in partnership with everyone who makes up the community of Down's syndrome **in** Scotland. Our local branches are key to the success of this framework, and we are excited also to work closely with other charities who share our passion for all things Down's syndrome.

It's all to play for.

## **Our four strategic goals:**

### **Support for Families**

Families are at the heart of our work. We will support the needs of the whole family - parents and carers, siblings and family members with Down's syndrome.

### **People of Potential**

Every individual with Down's syndrome is a person of immense potential. We will facilitate their personal development and champion their value and worth.

### **Policy and Research**

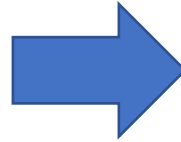
Advancing the inclusion of all people with Down's syndrome demands both system and society change. We will seek to influence policy and research that facilitates this change.

### **Awareness Raising**

We believe in people with Down's syndrome - they have so much to teach us. We will raise awareness about their potential and we will challenge out-dated negative perceptions.

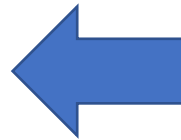
## Support for Families

Families are at the heart of our work. **We will support the needs of the whole family - parents and carers, siblings and family members with Down's syndrome.**



## How will we assess our impact?

- We will gather feedback from families who access our support and services.
- We will assess family wellbeing in terms of self-confidence, resilience and absence of crisis.
- We will reach more families, more often.
- We will have more professionals participating in our training.
- We will engage more people with Down's syndrome and increase the number of life members.
- More families will be claiming the benefits to which they are entitled.

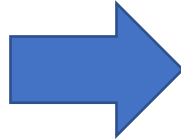


## How will we do that?

- Our Family Support Team will be available to support families at every stage of their journey with information, advice and support.
- We will host family workshops bringing parents together on a range of important and relevant topics.
- We will provide training and information to a wide range of professionals.
- We will support our local branches to create opportunities for families to connect and support each other.
- We will create opportunities for siblings to meet and connect.
- We will develop further our online community portal, Hub21, and bring Hub21 to adults with Down's syndrome.
- We will partner with other organisations who share our values to add value to our Family Support programme.
- We will partner with others to provide more welfare benefits advice to more families.

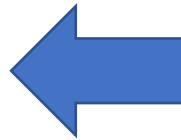
## People of Potential

Every individual with Down's syndrome is a person of immense potential. **We will facilitate their personal development and champion their value and worth.**



## How will we assess our impact?

- We will gather feedback from families who access our support and services.
- Parents and carers, who use ABC, will be more confident in supporting their child to develop their communication skills.
- ABC participant's communication skills and confidence will have improved.
- More schools will join our ABC programme and be recognised for their commitment.
- More people will be engaged in ABC, TeenZ and FriendZ.
- Our young people and adults with Down's syndrome will report increased confidence, friendship and connections.

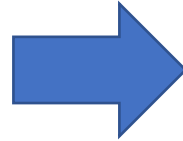


## How will we do that?

- Our Achieving Better Communication (ABC) programme will support and develop the communication skills of children and young people with Down's syndrome.
- We will develop ways to increase the number of children and young people accessing the ABC programme.
- We will extend ABC to include a specific provision for adults with Down's syndrome.
- We will work with schools to connect our work to the curriculum while providing support to teachers and school.
- We will run a series of Makaton and Signing workshops for families and for professionals.
- We will offer a series of flexible, added value opportunities to develop communication skills across our community.
- We will expand our FriendZ Space and TeenZ Space programmes.

## Awareness Raising

We believe in people with Down's syndrome - they have so much to teach us. **We will raise awareness about their value and potential and we will challenge unacceptable negative stereotypes.**

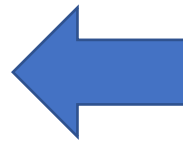


## How will we do that?

- We will celebrate the potential and the achievements of people with Down's syndrome across all media channels.
- We will campaign for their full inclusion in all aspects of Scottish society.
- We will promote the rights of our children and young people as afforded by the incorporation of the UNCRC in Scots Law and we will campaign for the incorporation of the UNCRPD.
- We will deliver awareness training sessions to a wide range of organisations and institutions.
- We will build the reach of Down's Syndrome Awareness Week in March and Down's Syndrome Awareness Month in October.
- We will challenge out-dated language and negative perceptions about people with Down's syndrome, wherever they exist.
- We will secure the involvement of people with Down's syndrome in places of influence and power.
- We will build a coalition of supporters and allies who support our cause.

## How will we assess our impact?

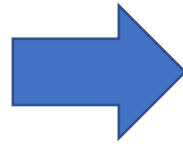
- We will gather feedback from people with Down's syndrome and their families.
- Our community will tell us that the public and professional's attitudes to people with Down's syndrome feels more positive and inclusive.
- We will have greater engagement and support for Down's Syndrome Awareness Week/Month.





## Policy and Research

Advancing the inclusion of all people with Down's syndrome demands both system and society change. **We will seek to influence policy and research that facilitates this change.**

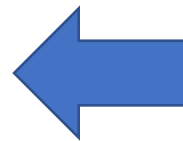


## How will we do that?

- We will work closely with the Scottish Government to inform and advance the full and visible inclusion of people with Down's syndrome in policy development and legislative change.
- We will support the implementation of the joint COSLA and Scottish Government Plan (Towards Transformation) for Learning Disability, Autism and Neurodiversity.
- We will participate in the work of the Scottish Parliament including attendance in a range of cross-party groups.
- We will enhance our involvement in research that impacts our community, and we will amplify all research findings that demand changes in policy, practice and provisions for people with Down's syndrome.
- We will support the development of the Learning Disability, Autism and Neurodiversity Bill in Scotland.

## How will we assess our impact?

- Policymakers and those responsible for policy development understand the needs, inequalities, and gaps that exist in relation to people with Down's syndrome in Scotland.
- Our community will tell us that we are campaigning on what matters to people with Down's syndrome and their families.
- Legislative changes will demonstrably include references to people with Down's syndrome.



## Our four programmes for change:

### **Better Health**

We have known that there is a pressing need to address health inequalities and improve health outcomes for people with Down's syndrome across Scotland. That need has become even more acute as our community was disproportionately impacted by the COVID-19 pandemic.

### **Transition Planning**

People with Down's syndrome and their families experience many key transition moments in the course of their lives. Leaving school and starting your young adult life can be a challenge for everyone but for people with Down's syndrome this key transition step is often fraught with additional hurdles and difficulties.

### **Employment**

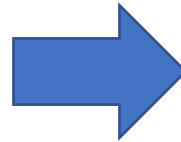
People with Down's syndrome have an immense range of qualities and skills. And yet, less than 7% of people with learning disabilities are in paid work. We know that lots of people with Down's syndrome who want to work, don't have a paid job.

### **Community Living**

People with Down's syndrome tell us they want to be active members of their communities, they want to be visible, valued and included. When we ask adults with Down's syndrome what would make their lives even better, they tell us they want to build friendships, have more opportunities to socialise and live in their own home.

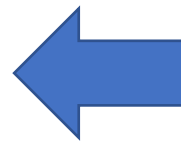
## Better Health

We have known that there is a pressing need to address health inequalities and improve health outcomes for people with Down's syndrome across Scotland. That need has become even more acute as our community was disproportionately impacted by the COVID-19 pandemic.



## How will we assess our impact?

- We will gather feedback from people with Down's syndrome and their families.
- Adults with Down's syndrome will consistently receive annual health checks.
- Fewer people with Down's syndrome will die prematurely from preventable deaths.
- GPs will be more informed about the needs of people with Down's syndrome and our community will report improved support.
- The introduction of NIPT will not negatively impact on the human rights and status of people with Down's syndrome.
- Health outcomes for people with Down's syndrome will improve.



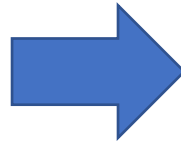
## How will we do that?

- We will work collaboratively with the Scottish Government, NHS Boards, Public Health Scotland and the Royal Colleges to ensure our entire community is properly protected from the ongoing effects of the pandemic.
- We will press for a full and transparent evaluation of the NIPT screening programme in Scotland.
- We will campaign for greater recognition and action to address the reduced life expectancy of people with Down's syndrome and the high number of preventable deaths among our children and young people.
- We will engage with the GP community in Scotland to develop greater understanding of the health needs of people with Down's syndrome.
- We will support the introduction of annual health checks for all adults with Down's syndrome.
- We will engage and support the work of the Down's Syndrome Medical Interest Group (DSMIG)
- We will work with others to identify action needed to address the prevalence of dementia in our community.
- We will create a wellbeing programme to promote positive good health approaches for our community and we will assess the impact of climate change on the health of people with Down's syndrome.

## Employment

People with Down's syndrome have an immense range of qualities and skills. And yet, less than 7% of people with learning disabilities are in paid work.

We know that lots of people with Down's syndrome who want to work, don't have a paid job.

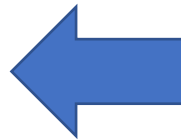


## How will we do that?

- We will establish an employment support programme in Scotland for adults with Down's syndrome seeking meaningful paid work.
- We will support employers with training and advice on employing people with Down's syndrome in their workforce.
- We will establish a bank of candidates seeking job opportunities across Scotland.
- We will engage with the Scottish Government's Fair Start programme, including its appointed providers, to lever more support for people with Down's syndrome to enter the world of work.
- We will promote and celebrate people with Down's syndrome who are successful in obtaining work and progressing their careers.
- We will develop a recognition of excellence scheme for employers who consistently provide work opportunities for our community.
- We will work with colleges and universities to understand their role in preparing young people with Down's syndrome for a career.

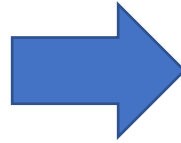
## How will we assess our impact?

- We will gather feedback from people with Down's syndrome and their families.
- More people with Down's syndrome will be in meaningful and paid employment.
- More employers will become aware of the potential and benefits of employing people with Down's syndrome and more opportunities for employment will arise.



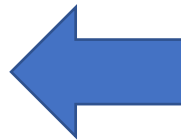
## Transition Planning

People with Down's syndrome and their families experience many transition moments in the course of their lives. Leaving school and starting your young adult life can be a challenge for everyone but for people with Down's syndrome this key transition step is often fraught with additional hurdles and difficulties.



## How will we assess our impact?

- We will gather feedback from people with Down's syndrome and their families on their experience of transitions.
- More families will have a plan in place to support good transition from school.
- Schools, colleges and social work will be more aware and engaged in delivering positive transitions for people with Down's syndrome.



## How will we do that?

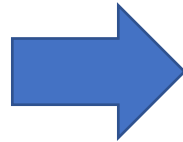
- We will support our families and our young people as they navigate transition planning processes with schools, social work, health professionals and others.
- We will continue to be involved with the 14-25 Pathway Group involving Scottish Government, health professionals, social work and education in developing clear advice and guidance for our families.
- We will reach out to the further and higher education sector to build stronger provision for young people with Down's syndrome.
- We will partner with others to amplify the voices of young people with Down's syndrome around transition planning.
- We will support legislative change that seeks to strengthen the current transition planning arrangements for children and young people with Down's syndrome.

## Community Living

People with Down's syndrome tell us they want to be active members of their communities, they want to be visible, valued and included. When we ask adults with Down's syndrome what would make their lives even better, they tell us they want to build friendships, have more opportunities to socialise and live in their own home.

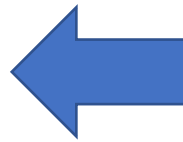
### How will we assess our impact?

- We will gather feedback from people with Down's syndrome and their family's experience of community life.
- There will be more local branches in more areas across Scotland.
- The impact of social isolation on people with Down's syndrome and their families will be reduced.
- Adults with Down's syndrome will have options about how and where they live.



## How will we do that?

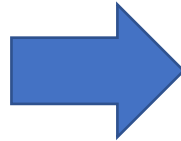
- We will develop an active citizenship programme for adults with Down's syndrome.
- We will develop a wellbeing programme for adults with Down's syndrome that supports positive social connection, friendships and relationships.
- We will support families and adults with Down's syndrome to find independent living options that best suit their needs.
- We will look for innovative models and approaches that support our adults to live their best lives in the community of their choice.
- We will expand our branch network across Scotland.
- We will partner with others who can accelerate ideas around living safe and well in your local community.
- We will better understand the role of technology and identify levels of digital exclusion across our community and seek to bridge any gaps.



## Our two foundation principles:

### **My Human Rights**

“Like everyone else in society, I have human rights too. I just want that to be respected and understood. I want people to see me first, a human being who just happens to have an extra chromosome.”

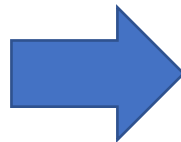


### **What will this involve?**

- We will work with advocates and self-advocates to promote the human rights of everyone living with Down’s syndrome.
- We will collaborate with the Scottish Commission for People with Learning Disabilities (SCLD) and others to secure the human rights of our community.
- We will support the calls for the full incorporation of the UNCRPD into Scots Law.

### **Equal and Included**

“I rarely feel equal and only occasionally do I feel included. I want to contribute my ideas and my thoughts. I am not less than everyone else just because I have Down’s syndrome. I want the prejudice and discrimination to stop.”



### **What will this involve?**

- We will call out inequality and exclusion when we see it.
- We will celebrate and applaud great examples of equality, diversity and inclusion that impact the lives of people with Down’s syndrome.
- We will ensure that people with Down’s syndrome have their voices heard.

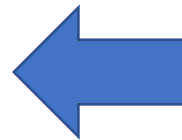
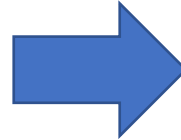
## Our team at the centre:

### Sustainable excellence

Down's Syndrome Scotland will be fit for purpose, by being compliant with legislation, striving for continuous improvement and demonstrating best practice.

### How will we assess our impact?

- We will gather feedback from people with Down's syndrome and their families.
- Our financial position remains strong and our reserves remain compliant with our operating requirements.
- Achieve EFQM accreditation.
- Achieve Cyber Essentials accreditation.
- Increase our reach and engagement on social media.
- Increase our DSS membership and our followers on social media.
- Increase the number of volunteers and supporters.
- Increased online participation by our community.



### How will we do that?

- We will generate increasing and more dependable levels of income to fund future growth and ensure financial sustainability.
- We will become an employer of choice by building an engaged workforce, with the right skills, in the right roles to deliver the highest standards of service.
- We will establish a fit for purpose infrastructure (systems, processes and policies) that encompasses best practice and continuous improvement.
- We will embed our digital approach and explore future models for blended service delivery.
- We will review the impact of home working to support future working arrangements.
- We will explore additional methods of communication such as podcasts and augmented reality.
- We will enhance communication with families and members.
- We will explore how our community uses our website and use this to inform its re-development.
- We will develop a programme to recruit and sustain an engaged and valued volunteer workforce.
- We will enhance membership development and experience.



# Back cover

## **Down's Syndrome Scotland**

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