DOWN SYNDROME INTERNATIONAL (DSi)



DSi COVID-19 RESPONSE
TOOLKIT – Advocating for COVID-19 Vaccination Prioritisation for People with Down Syndrome

AIM

The aim of this toolkit is to outline advocacy measures that people with Down syndrome, families, advocates and organisations can take to promote prioritisation, accessibility and inclusion of people with Down syndrome in vaccination programmes around the world.

In a recent survey, DSi's national member organisations have told us they would like support, information and guidance to assist them with in their advocacy activities.

To support your advocacy campaign, this document provides details of potential advocacy activities, how you can go about doing these and who can be involved. This is followed by evidence and information to support your campaign, details about what other organisations are doing and tools you can use in your campaigns.

A UNITED GLOBAL VOICE

We need to work together to ensure that:

- The lives of people with Down syndrome are valued on an equal basis with others when accessing healthcare in line with the basic rights for persons with disabilities.

- Policy makers and health care planners are:

    - aware of and understand the additional risks of COVID-19 for persons with Down syndrome
    - including people with Down syndrome (and their support networks) in a priority group to receive vaccinations
    - involving people with Down syndrome and their representative organisations in planning distribution of COVID-19 vaccinations and related processes

- People with Down syndrome:

    - have the necessary resources in terms of transport, finance and personal support to accessing a vaccination
    - can access information about the vaccine and the process in formats they can understand (please see link to our website)
    - have the support required to enable them to make an informed decision, if they have capacity to do so, about whether to have the vaccination (vaccination should only be performed after receiving the full and informed consent of persons with Down syndrome)

By working together, we hope to enable an increasing number of people with Down syndrome to have access to and are included and prioritised in COVID-19 vaccination programmes around the world.

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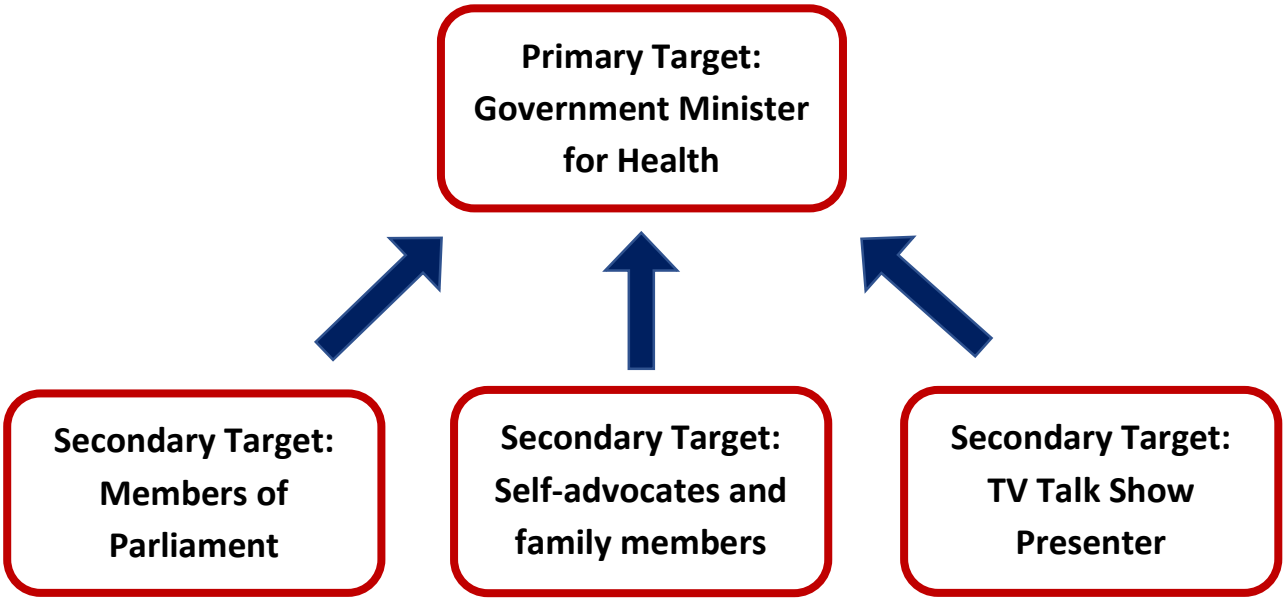
POTENTIAL ADVOCACY ACTIVITIES

Below are some potential advocacy activities that could be used to campaign for the prioritisation, inclusion and accessibility of COVID-19 vaccination for people with Down syndrome.

It is important when planning advocacy to be clear who you are targeting with each activity and distinguish between primary and secondary targets for advocacy:

- **Primary targets** are people who can directly influence the change you are advocating for.
- **Secondary targets** are people or groups who can influence or put pressure on the primary target.

See Diagram below for example **primary** and **secondary** targets in a health campaign:



The potential advocacy activities are grouped into Lobbying, Mobilising People and Media Campaigns:

Lobbying	
This involves direct contact with decision-makers aimed at influencing them to bring about changes in laws, policies and practices. Often successful lobbying involves building relationships with decision-makers across multiple meetings and interactions. Lobbying is often aimed at the primary target for advocacy (for example the Minister for Health), although can also be aimed at secondary targets who may be able to influence the primary target (for example a member of parliament with a link to the Minister for Health). **Here are some activities that can be used to lobby decision makers:**	
• Writing a letter • Producing a statement or position paper (see DSi statement in Supporting Materials section for an example) • Making a phone call	• Meetings and visits • Arranging for decision-makers to visit your community

Mobilising People	
Mobilising people involves organising and supporting people to take action to put pressure and on decision makers. It is generally aimed at secondary targets for advocacy and is open to anyone who wants to support the campaign. The people that are mobilised may include people that are directly affected by the issue (for example self-advocates with Down syndrome and their families) or people that are not directly affected but care about the issue. **Here are some activities that can be used to mobilise people to support a campaign:**	
• Public meetings and discussions • Demonstrations, marches, or protests • Group meetings with decision-makers • Stunts or flash mobs	• Petitions (see example petitions here) • Letters to decision makers • Sharing internet campaigns and messages

Media Campaigns	
Using media for advocacy campaigns is a powerful way to mobilise people and put pressure on decision makers. Media campaigns can take place in many formats including radio, TV, newspapers, emails, blogs and social media. **Here are some activities that can be used for media campaigns:**	
• Press releases, articles and letters to the editor (see template press release in Supporting Materials section) • Blogs • Factsheets, fliers or posters	• Radio and TV interviews • Video campaigns • Social media campaigns (see example social media here)

THE EVIDENCE

Research has shown that:

1. People with Down syndrome (particularly those over the age of 40, and younger individuals with significant comorbidities) are at a higher risk of severe outcomes from COVID-19 than the general population.

Trisomy 21 Research Society Statement – Vaccination for people with Down syndrome during the COVID-19 pandemic

Trisomy 21 Research Society Video - supporting prioritisation for COVID-19 vaccination of people with Down syndrome

Further evidence:

Hüls et al. Science Direct Medical vulnerability of individuals with Down syndrome to severe COVID-19 - data from the Trisomy 21 Research Society and the UK ISARIC4C survey – March 2021

DSMIG - COVID-19 and Down Syndrome – January 2021

Clift, et al. COVID-19 Mortality Risk in Down Syndrome: Results from a Cohort Study of 8 Million Adults – October 2020

Constantino, et al - People with intellectual and developmental disabilities disproportionately affected by COVID-19 – August 2020

Hüls, et al - An international survey on the impact of COVID-19 in individuals with Down syndrome – November 2020

DSMIG - COVID-19 and Down syndrome – January 2021

The **World Health Organization**'s Values Framework identifies the higher rates of COVID-19-related severe illness and mortality among systematically disadvantaged or marginalized groups as a key principle when prioritising groups for COVID-19 vaccination – November 2020

2. People with disabilities and particularly people with intellectual disabilities face enhanced risk of contracting and of severe outcomes from COVID-19.

   This may be due to a number of factors including:

   - existing health conditions and inequities in health and social care;
   - inability to observe recommended physical distancing, wearing a face mask or personal hygiene measures;
   - lack of accessible information about COVID-19;
   - inability to access timely and equal medical attention due to inaccessible health systems, inaccessible transportation, lack of required financial resources or lack of adequate personal assistance or support;
   - de-prioritisation when reaching critical stages of COVID-19 based on judgement about quality and value of their lives.



WHAT HEALTH AND RESEARCH ORGANISATIONS ARE DOING

Health and research organisations are continuing to collect data about all aspects of COVID-19, disability and Down syndrome to advance understanding, consolidate and update evidence and provide recommendations for governments, policy makers and all stakeholders.

Views from such organisations are often highly influential in developing standards and improving policies and practice on matters of health, including the COVID-19 vaccination programmes.

The World Health Organization (WHO) and UNICEF – Policy Brief on Disability considerations for COVID-19 vaccination – April 2021

WHO and UNICEF published a policy brief recommending actions to governments, policy makers, DPOs and all stakeholders to ensure equity in access to vaccination against COVID-19 for persons with disabilities.

They recommend that governments "c***onsider persons with disabilities according to WHO guidance when prioritizing sociodemographic groups for initial phases of immunization. Prioritize older persons with disabilities and persons with disabilities with relevant underlying health conditions according to WHO guidance. Consider staff working for disability support services when prioritizing frontline workers in health and social care settings in the initial phases of immunization"*** (April 2021)

The document recognises that persons with disabilities are disproportionately impacted by COVID-19, and recommends that governments consult with persons with disabilities, their support networks, and representative organisations when implementing vaccination programmes. There is CRPD-consistent language on accessibility, data collection, training of staff, and on recruiting persons with disabilities as staff for vaccination programmes. There is a section on free and informed consent, which explains how health workers should ensure they have full and informed consent from a person with disability prior to providing the vaccination.

Trisomy 21 Research Society (T21RS)

The T21RS has launched several initiatives to better understand the risk and to inform appropriate recommendations to protect individuals with Down syndrome against COVID-19, and to understand vaccination side effects and immune response.

T21RS – Dedicated COVID-19 section on website

The Trisomy 21 Research Society is collecting information from countries around the world about the roll out of vaccinations for people with Down syndrome.

T21RS – COVID-19 vaccination roll-out information

If you would like to add information about the situation in your country – please contact helen.powell@ds-int.org

WHAT DISABILITY AND ADVOCACY ORGANISATIONS ARE DOING

International, regional and national disability organisations are initiating advocacy at global, regional and national levels to maximise prioritisation, inclusion and accessibility of people with disabilities and Down syndrome in the roll out and distribution of COVID-19 vaccinations.

International Disability Alliance (IDA) – Statement: Reach the furthest behind first: Persons with disabilities must be prioritized in accessing COVID-19 vaccinations

International Disability Alliance (IDA) and International Disability and Development Consortium (IDDC) - Call to Action: Priority, Accessibility and Inclusion for Persons with Disabilities in COVID-19 Vaccination Rollout

Light for the World – Policy Statement: Front row for the most vulnerable. A call for equitable and inclusive COVID-19 vaccination roll-outs

International Disability Alliance (IDA) and International Disability and Development Consortium (IDDC) - Toolkit for National COVID-19 Vaccination Campaign for Persons with Disabilities

International Disability Alliance (IDA) - Resources and Tools for Action



Many national Down syndrome organisations have or are advocating for prioritisation for vaccination of people with Down syndrome.

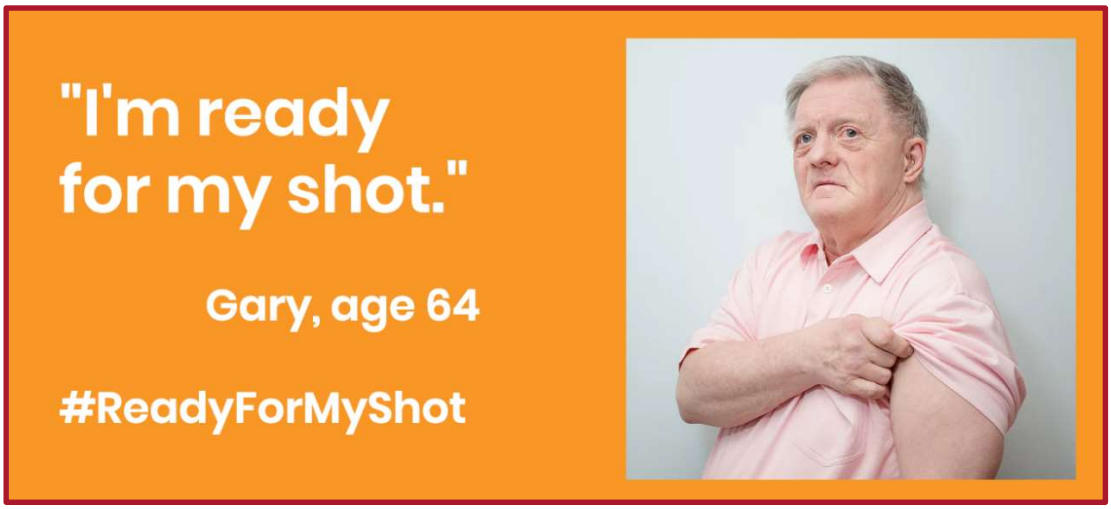
The Down's Syndrome Association (England, Wales and Northern Ireland)

Put pressure on relevant governmental and health bodies in the United Kingdom to add adults (18 and over) who have Down syndrome to the group of people who are classed as clinically extremely vulnerable and classed as at higher risk from coronavirus. The decision was agreed across all four nations of the UK by their Chief Medical Officers – November 2020

Evidenced and comprehensive grassroots advocacy campaigns are being established (grassroots advocacy is the process of communicating with the general public and asking them to contact local and national officials and policy makers regarding a certain issue).

Ready For My Shot – Canadian grassroots campaign for vaccination prioritisation

Campanella et al. - Including People with Developmental Disabilities as a Priority Group in Canada's COVID-19 Vaccination Program: Key Considerations – January 2021



IF YOU HAVE ANY QUESTIONS ABOUT THE INFORMATION IN THIS TOOLKIT PLEASE CONTACT helen.powell@ds-int.org

SUPPORTING MATERIALS

STATEMENT FROM DOWN SYNDROME INTERNATIONAL

COVID-19 Vaccination - Priority, Accessibility and Inclusion Of People With Down Syndrome

The COVID-19 pandemic constitutes a serious challenge in the implementation of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD) and the realisation of the Sustainable Development Goals in respect of people with Down syndrome.

People with Down syndrome are being left behind in the COVID-19 response around the world. COVID-19 has exposed inequalities, deepening existing discrimination and marginalisation.

This must not happen in the roll out of COVID-19 vaccinations, particularly in light of the current limitations of vaccine supply.

Furthermore, despite growing evidence that they are at greater risk of death from infection and severe outcomes from specific issues associated with the syndrome, not all countries have policies in place to vaccinate people with Down syndrome against COVID-19 as a priority.

We call on national governments and UN agencies to:

- recognise people with Down syndrome as a **priority group**;
- make COVID-19 **information campaigns and vaccination sites inclusive and accessible** to people with Down syndrome;
- ensure that organisations of persons with disabilities (OPDs) are **actively involved in the development of COVID-19 related planning and policy making** and that vaccinations must only happen with **free and informed consent** and
- **collate data** on the vaccination of people with Down syndrome, disaggregated by age and sex and shared this in accessible formats.

TEMPLATE PRESS RELEASE

This is a template press release letter which organisations can adapt (by inserting the relevant information where it is highlighted in yellow) and use in their advocacy campaigns.

PRESS RELEASE FOR IMMEDIATE RELEASE: [INSERT TODAY'S DATE]

Persons with Down syndrome must be prioritised in COVID-19 vaccination programmes, says [insert name]

[Insert organisation] is calling on the government of [insert country] to ensure persons with Down syndrome are prioritised in the country's vaccination rollout.

The call comes amid growing evidence that persons with disabilities, and particularly persons with Down syndrome, are at greater risk of death from infection and severe outcomes from COVID-19 than the general population.

The World Health Organization identified persons with disabilities as a priority group for vaccination. Evidence shows the majority of COVID-19 deaths have been persons with disabilities. Persons with disabilities are particularly exposed to the risks of COVID-19 and require specific measures to mitigate these risks and their impact. Persons with intellectual disabilities have been up to six times more likely to die than others.

Furthermore, research has shown that persons with Down syndrome (particularly those over the age of 40, and younger individuals with significant comorbidities) are at a higher risk of severe outcomes from COVID-19 than the general population and should therefore be given top priority in national vaccination programmes.

[Insert name], [insert job title] of [insert organisation] says "With the rollout of COVID-19 vaccination programmes, and with limited vaccine supplies, it is vital that persons with Down syndrome are not left behind. We are campaigning to ensure vaccination plans and pandemic recovery strategies involve them, are accessible to them and reach them." "We are calling for the prioritisation of persons with Down syndrome in [insert country]'s vaccination programme in accordance with growing evidence that persons with Down syndrome are at greater risk of severe outcomes than the general population".

[Insert name], [insert job title] of [insert organisation] says "Since the World Health Organization declared COVID-19 a pandemic, persons with disabilities including persons with Down syndrome have had to shoulder some of the worst effects of this disease in [insert country] and around the world." "For example, we are seeing [insert what you are seeing persons with Down syndrome go through right now and the impact of COVID-19, any national survey results or studies and current steps the government may be taking with regards to persons with Down syndrome and with other disabilities].

Down syndrome organisations and advocates, alongside the disability rights movement, are calling for prioritisation of persons with Down syndrome in vaccine programmes around the world. This is of extreme

urgency. We are in an international crisis and there are up to 1 billion persons with disabilities, including persons with Down syndrome, who are trying to survive without the recognition or support they need.

For further details, interviews, and case studies contact [insert name], [job title] at [insert organisation] on [email] / [phone number].

Notes to Editor About [insert organisation name]

NATIONAL LETTER TEMPLATE

Dear [please insert name of minister/policy maker],

We are writing on behalf of [please insert name or organisation/OPD]

As the world faces a historic moment to test existing commitments to equity, equality and universal health care, we call on you for political leadership to ensure that the needs of persons with Down syndrome, are fully considered and prioritised in the development of your national COVID-19 vaccination program and pandemic recovery strategy.

[Please insert here a brief paragraph on the impact of COVID-19 on persons with Down syndrome in your country and include any national survey results or studies. Please also include here any positive steps the government may have taken with regards to people with disabilities in response to the pandemic]

As you will know, the World Health Organization identified persons with disabilities as a priority group for vaccination. Evidence shows the majority of COVID-19 deaths have been persons with disabilities. Persons with disabilities are particularly exposed to the risks of COVID-19 and require specific measures to mitigate these risks and their impact. Persons with intellectual disabilities have been up to six times more likely to die than others.

Furthermore, research has shown that persons with Down syndrome (particularly those over the age of 40, and younger individuals with significant comorbidities) are at a higher risk of severe outcomes from COVID-19 than the general population and should therefore be given top priority in national vaccination programmes.

We are aware that each government is responsible for the COVID-19 vaccinations at national level. We would like to urge you to ensure that persons Down syndrome are included in your plans, and to guarantee that:

• The national vaccination plan of [please insert country] will prioritise reaching persons with Down syndrome.

• Health information campaigns and vaccination delivery sites will be inclusive and accessible to all persons with disabilities including persons with Down syndrome and intellectual disabilities. For example, information related to vaccination must be provided in accessible formats including captioning, sign language, audio formats, and plain language.

• Organisations of persons with Down syndrome will be meaningfully involved in the development of COVID-19-related planning and policymaking, and vaccinations will only happen with the free and informed consent of persons with Down syndrome and their families.

• Data collected on vaccination programs will be disaggregated by age, gender and disability using internationally comparable tools and shared in accessible formats.

We would welcome a meeting with you to discuss the above, including any ways in which we can support you to ensure that persons with Down syndrome are prioritised according to their proven needs.

Sincerely,

[insert name]

[job title]

[insert organisation]