

## **EUROPEAN DOWN SYNDROME ASSOCIATION**

**November 2020** 

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# **BREAKING NEWS: EU ROAD MAP**



# Disability rights strategy for 2021-30

The strategy aims to ensure that people with disabilities can experience full social and economic inclusion on an equal basis with others and live free from discrimination.

It will focus on implementing the UN Convention on the Rights of Persons with Disabilities and consolidating the EU's body of law in this field.

It will build on the 2010-20 strategy, both through targeted action and by ensuring disability rights are taken into account across all EU policies, programmes and instruments.

#### Type

Roadmap

More about roadmaps

#### Feedback period

15 October 2020 - 12 November 2020 (midnight Brussels time)

The Commission would like to hear your views.

This roadmap is open for feedback for **4 weeks**. Feedback will be taken into account for further development and fine tuning of the initiative. The Commission will summarise the input received in a synopsis report explaining how the input will be taken on board and, if applicable, why certain suggestions can't be taken up. Feedback received will be published on this site and therefore must adhere to the feedback rules.

Read more... <a href="https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12603-Union-of-Equality-European-Disability-Rights-Strategy">https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12603-Union-of-Equality-European-Disability-Rights-Strategy</a>

01



#### COVID-19 AND DOWN SYNDROME SURVEY



#### **COVID-19 and Down Syndrome on-line survey**

The Trisomy 21 Research Society published the research conducted to examine the risk of individuals with Down syndrome who have been diagnosed with COVID-19.

The preprint report is open access and available

here: https://www.medrxiv.org/content/10.1101/2020.11.03.20225359v1

This work has been developed and undertaken by the T21RS COVID-19 taskforce, and supported by many stakeholder groups. The report contains information on symptoms, risk factors and outcomes following a COVID-19 diagnosis in people with Down syndrome.

Key findings are that similar to the general population, the most frequent signs and symptoms of COVID-19 were fever, cough, and shortness of breath. Pain and nausea were reported less frequently (p<0.01), whereas altered consciousness/confusion were reported more frequently (p<0.01) than in the general population. Risk factors for hospitalization and mortality were similar to the general population (age, male gender, diabetes, obesity, dementia) with the addition of congenital heart defects as a risk factor for hospitalization. Mortality rates showed a rapid increase from age 40 and were approximately three times higher than for controls individuals without Down syndrome even after adjusting for known risk factors for COVID-19 mortality. The risk in those over age 40 was comparable to individuals in the general population aged 85 and older.

However, individuals with Down syndrome under age 40 were approximately 90% less likely to die than those over age 40. Furthermore, few children age 19 and younger were severely affected, suggesting that the risk in children and young people could be balanced against quality of life. We would recommend that extra care needs to be taken by adults over the age of 40, and that individuals with Down syndrome should be offered flu vaccinations, vitamin D supplementation, and the pneumococcus vaccine (particularly in those aged 40 and older) this winter, in addition to following other local guidance e.g. for hand-washing and using face masks.

The T21RS has developed a series of infographics highlighting key findings which will be updated today - https://www.t21rs.org/results-from-covid-19-and-downsyndrome-survey/



# NEWS FROM PROJECTS WITH EDSA MEMBERS IN THE CONSORTIUM





#### **ACTIVE AGEING APPROACH IN ADULTS WITH DOWN SYNDROME**

(From ALDO-CET Romania)

The fight for a long and healthy life can start with the DS-AGEING training program.



Many studies, starting in recent years try to solve the arithmetic of well ageing in individuals with Down syndrome especially that some of them reach age over 70. Physical health skills training and healthy ageing strategy should ideally start in childhood and take a lifelong perspective.

Babies born today with Down syndrome and their families can expect a life with many possibilities and opportunities that have been developed through such initiatives and knowledge transfer projects and completed by joint teams of beneficiaries, family, therapists and future therapists. Their fight for long and healthy life can start with a training program like DS-AGEING project proposes. This project aims to exceed the lack of an integrated and inclusive approach that takes into account the support that people with Down syndrome (family and community members) need.

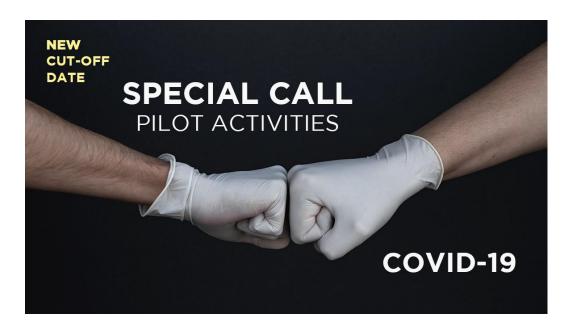


Ageing is the subject of concern for many families of adolescents and young people with Down syndrome (DS). The families and therapists that work with them know their needs and changes that appear after the age of 30-35 years (when the signs of getting old start to emerge), also the new problems that they struggle to exceed as they get older. The fight of a person with Down syndrome is also a fight of family and therapists. The scientific articles discuss about the changes and problems that emerge with aging. With the improvements of care and health treatments, today people with Down syndrome live until the age of 60-70, even 80 years old, a reality that was not possible decades ago. Read more......



# **EUROPEAN COMMISSION: Opportunities**

**European Youth Foundation** 



**14 December 2020** is the new cut-off date for <u>local</u> or <u>national</u> youth organisations that are looking for funding for pilot activities which respond to local needs arising from the COVID-19 crisis.

The European Youth Foundation will continue to give priority to projects that aim at demonstrating solidarity and support to all persons affected by the COVID-19 crisis, such as:

- Reaching out to and supporting particularly vulnerable groups of people, including homeless, refugees and asylum-seekers, people with disabilities, people living in isolation or in remote communities;
- Support to health, social and educational services;
- Education and awareness-raising of the importance of human rights in responses to COVID-19 crisis.

#### **Further conditions**

All pilot activities must respect the sanitary and safety measures put in place by the competent authorities at national and/or local level. Further, applicant youth organisations are strongly encouraged to co-ordinate their activities with the competent authorities and to indicate such in their project proposal.

#### Important!

The maximum EYF grant to a pilot activity is €10 000.



Youth organisations can submit applications only if they are registered with the EYF. The instructions and criteria for registration can be found <a href="here">here</a>.

Visit the EYF website and facebook page to stay up to date.

#### How to apply?

Information on the procedure and criteria for application can be found on the EYF website (What is a pilot activity).

If you decide to submit an application, please mention clearly at the top of the application: special call COVID-19.

Applications for Non-COVID-19 related Pilot Activities can be submitted at all times and will also be assessed and decided upon.

#### Please note:

The COVID-19 pandemic has negatively affected young people in many ways and the European Youth Foundation's special call for Pilot Activities is an opportunity to mitigate the consequences in an impactful and meaningful manner.

If you consider applying for an EYF pilot grant under the special COVID-19 call, please keep the following in mind:

- You are applying for a grant from a foundation that is part of the Council of Europe. Therefore, the EYF only awards grants to applications where proposed activities match with the tasks of the Council of Europe, and are in line with the specific <u>priorities</u> of its youth sector.
- Your project should have a non-formal education component, meaning that your activity is also designed to improve a range of skills and competencies of young people, outside the formal educational curriculum.
- Although the COVID19 call is a special call, it is not an urgent call, which means that the normal procedures apply. After the indicated cut-off date, your proposal will be assessed and presented to the Programming Committee on Youth, which decides whether a grant will be awarded. This procedure may take several weeks. Therefore, proposals should be submitted to the EYF at least 3 months before the intended starting date.
- Since launching the special call in April 2020, the EYF has received proposals aimed at relieving urgent needs, physical or psychological. Unfortunately, such proposals cannot be supported, as the Council of Europe is not an emergency aid organisation.



## **MAKE THIS NEWSLETTER REALLY YOURS!**

Have you got any news that we could publish in EDSA newsletter? Please send us any information you would like to announce and we shall be happy to disseminate it all over Europe!

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