

## **EUROPEAN DOWN SYNDROME ASSOCIATION**

## SUMMARY

01 Coronavirus and Europeans with Down syndrome: news from EDSA members

03 Two recent European surveys

06 Funding opportunities from the European Commission

07 From the International Labour Organisation

## **Coronavirus and Europeans with Down syndrome:** news from EDSA members



# Lauren's experience of coronavirus (Covid-19)

Posted on: May 3, 2020 By Sarah, Lauren's Mum

In addition to having Down's syndrome, in her teens Lauren was diagnosed with severe verbal dyspraxia and ASD with significant oppositional behaviour and demand avoidance. These diagnoses removed the stigma from us of "failing parents" and opened doors to get the right level of support.

In August 2018 Lauren moved into a supported living placement close to home after six years in independent specialist colleges. Since then we have seen her blossom into a much more independent young adult.

Lockdown & illness

When the UK went into lockdown we brought Lauren back home to be with us. Shortly afterwards her Dad became unwell and a few days later Lauren started to complain of feeling tired and that her head/neck hurt.

Over the next week to ten days she started to sleep more and lost interest in her normal activities, including FaceTiming her boyfriend. On day ten Lauren's oxygen levels dipped and she was getting distressed saying her stomach really hurt.



EUROPEAN DOWN SYNDROME ASSOCIATION



Sarah in the PPE she was given on arrival at A&E.

#### Hospital

The paramedics were great and there was no problem with me going with Lauren in the ambulance. In A&E it was also accepted that I needed to be with Lauren and I was handed PPE gear to put on.

In the 18 minutes I had to pack whilst waiting for the ambulance I had printed a copy of Lauren's hospital passport which included the need for 24/7 care. When Lauren was transferred on to a ward I went with her. We were put in a side room with a bed for me and there we stayed 24/7 for the next seven days.

Shortly after arrival in A&E I was asked to complete a Respect form. Lauren has no underlying conditions and an excellent quality of life and it was agreed that, if necessary, she would receive full escalation including ITU, intubation/Ventilation & CPR.

Lauren's Covid-19 swab came back negative so a CT scan was arranged. Lauren was a star and pronounced the CT scanner "cool". The results showed severe Covid-19 changes throughout her lungs but the staff were quick to reassure me that they had spoken with ICU and had a plan in place just in case, and that there would be a ventilator for her should she need it. That was probably the most frightening moment but thankfully the next level of intervention wasn't required.

Without exception the staff were amazing. They listened to me and adapted their procedures accordingly.

For example Lauren hates blood pressure machines but we made a deal with the nurses that they could have one go to get it right, but if it didn't work, we would stop. Every time they came to do it she reminded them...just once



EUROPEAN DOWN SYNDROME ASSOCIATION

then stop. It definitely focused their minds and by the end of the week we had worked out the idiosyncrasies of the machine and how to fit the cuff to ensure they got a reading most of the time.

On the left, Lauren is in an oxygen mask in the earlier stages of her hospital stay. On the right, she just has just has nasal prongs, and she's eating the first meal in hospital where she was able to feed herself.

#### Recovery

It took until day six for Lauren's oxygen requirements to reach the point where she no longer needed supplementary oxygen and after 24 hours of observation we were finally allowed home.

Within a few days, although still tiring easily and slightly short of breath, she was kicking a ball around the garden. Two weeks post discharge she is almost back to her normal self, interested again in all her activities and (much to her boyfriend's relief) happy to FaceTime him again.





## **Two recent European surveys**

## DIVERSITY AND EQUALITY IN EUROPEAN COMPANIES

statista 🗹

A STATISTA DOSSIERPLUS ON DIVERSE AND INCLUSIVE WORKPLACES IN AUSTRIAN, BRITISH, FRENCH, GERMAN, AND SWISS COMPANIES

Studies have already shown the many benefits organizations embracing diversity can experience, including increased employee retention or even an increase in effectiveness and, thus, profitability. Companies, therefore, have been striving to improve inclusion and implement productive diversity strategies. But have they been successful in doing so?

Download our free DossierPlus for new data, among others, on:

- Employee satisfaction: How satisfied are employees with their employer in general and specifically with their diversity policy?
- Types of diversity: In what regard are companies most advanced, gender, ethnic, disability, age, or LGBTQ+ equality? What type of discrimination is most prevalent?
- **Demographic differences:** Do employees with different demographic characteristics have a different opinion on the matter?

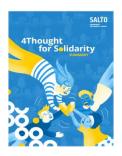
The answers to all these questions and more are just a click away. Download the DossierPlus <u>here!</u>

Look at the 4th chapter! It deals with "Disability equality"

TALKING ABOUT SOLIDARITY

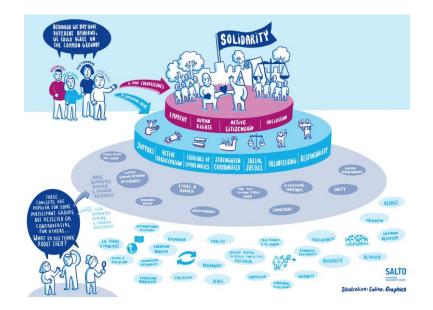
'4Thought: Finding a Common Narrative on the Concept of Solidarity from Research, Practice, Policy and Young people'





## **4Thought for Solidarity - Salto Youth**

By the end of 2016, building on the success and quality developments of the European Voluntary Service, a new programme, the 'European Solidarity Corps', was launched. In November 2018, the European Solidarity Corps Resource Centre was established. One of the first tasks of the Resource Centre was to commission a project, a study on the meaning of the concept of solidarity. This project was called '4Thought: Finding a Common Narrative on the Concept of Solidarity from Research, Practice, Policy and Young people'. Its main aim was to create a vision of what the concept of solidarity means to different people, all the while assisting in the implementation of the European Solidarity Corps by making clearer what is meant by a 'solidarity activity'.



https://www.salto-youth.net/downloads/4-17-4056/4TDS%20Summary.pdf



## **European Youth Together 2020**

### CALL FOR PROPOSALS – EACEA/10/2020

Erasmus+ Programme, Key Action 3 – Support for Policy Reform European Youth Together

https://eacea.ec.europa.eu/erasmus-plus/funding/european-youth-together-2020 en

**Specific Objectives**: The initiative seeks to specifically support:

• promotion and development of more structured cooperation, online and offline, between different youth organisations to build or strengthen partnerships focusing on solidarity and inclusive democratic participation of all against a backdrop of the backlashes on socio-economic structures and in line with youth goals numbers 3, 4 and 10;

• youth organisations involved in initiatives to encourage young people to participate in the democratic process and in society by organising trainings, showcase commonalities among young Europeans and encourage discussion and debate on their connection to the EU, its values and democratic foundations, including by providing a meaningful voice to youth in the framework of the Covid-19 recovery process;

• promote participation of under-represented groups of young people in politics, youth organisations and other civil society organisations by engaging vulnerable and socioeconomic disadvantaged youth; new ways to empower youth organisations in dealing with the Covid-19 crisis and its aftermath, by supporting innovative ways of cooperation and network creation, development and management. Indicatively, this could include enhancing collaboration between youth organisations in a digital context through and by non-formal learning and organisational models including alternative modes of exchanges and mutual aid.

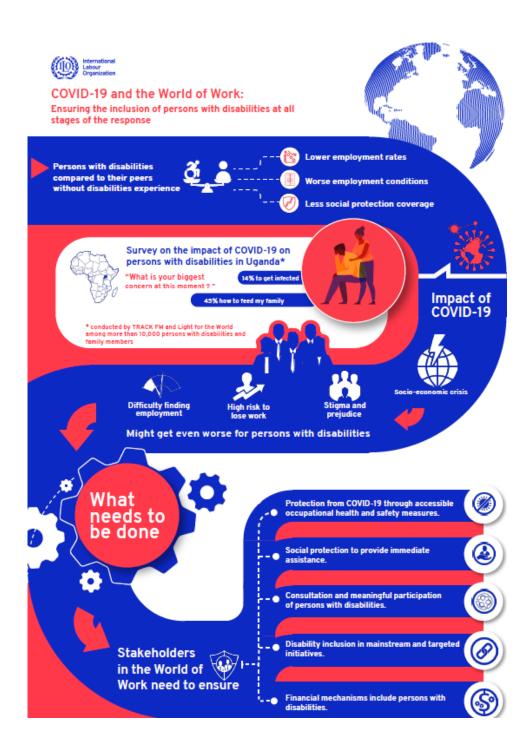
Deadline for submitting applications 28/07/2020 at 17:00

#### **Budget available**

The total budget earmarked for the co-financing of projects under this call for proposals/invitation to submit a proposal is estimated at EUR 5,000,000. The financial contribution from the EU is minimum EUR 100,000 and cannot exceed EUR 500,000. It is limited to a maximum co-financing rate of 80 % of the total eligible project costs. The Agency expects to fund 10 to 15 proposals. The Agency reserves the right not to distribute all the funds available



## From the International Labour 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!

CONTACTS phone: 0039 06 3723909 e-mail: internazionale@aipd.it

#### THE STAFF

Carlotta Leonori Paola Vulterini

