

EUROPEAN DOWN SYNDROME ASSOCIATION

September 2020

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News from EDSA members: Switzerland, again!

Summer camp inclusion: how? (Second episode)

Switzerland is complicated!!! Not only by languages, but each cantons/region has its own set of politics, laws, status on education, inclusion and institutions.

There are 3 Down Syndrome associations separated by language:

- Swiss-German Insieme 21
- French Association Romande Trisomie 21 (ART21)
- Italian Avventuno.

According to the websites:

"Insieme21" is the network providing support for persons, parents and relatives of people with trisomy 21 (Down syndrome) in German-speaking Switzerland.

Insieme21 also provides some educational training for families alongside specialists in the fields of medicine, therapy, early intervention or school who deal with people with trisomy 21 in their professional activities. Contact person: **Caryl Lüthy**

"ART 21" aims to inspire, promote and implement any action of information, training, research, exchange of contacts and experience. We wish to contribute to an improvement in the knowledge, development and living conditions of people with Down's syndrome. Contact persons: Ruth Lee Foley and Jillian Reichenbach Ott

"Avventuno" is the fusion of three concepts closely linked to Down syndrome: the future is full of opportunities and supporting children with Trisomy 21 in their growth can be a wonderful adventure. Thanks to the progress of medical, rehabilitative and educational research, people with Down's Syndrome today can achieve great results. Contact person: Monica Induni

These 3 associations are entirely run by volunteers/parents and try relentlessly to make Switzerland a better place for people with Down Syndrome.

Jillian Reichenbach Ott



Dear reader,

do you remember that Monica Induni wrote an article about summer camps on the last EDSA newsletter? (http://www.edsa.eu/wp-

content/uploads/2020/07/edsa_newsletter_July-2020.pdf).

A little debate has risen among EDSA Swiss members

Hallo Paola

Monica's article from Avventuno in this last EDSA June 2020 newsletter is great and the advocacy service for inclusion in holiday programs that Avventuno is providing is totally inspiring. It is a a great model for our and other associations to ideally follow. Although I am not sure if Insieme21 has the capacity. We have a part time administrator, then everyone else is in a voluntary capacity. It would be great to have a person on the committee with the role of family advocacy through community liaison and education.

On a personal note, our daughter was fully included in Pfadi (Scouts) from 10 years old without extra support and now at 17 she is a leader helper with the kindergarten children. Pfadi and Cevi are also totally inclusive in their holiday camps. They may also be a great source for inclusion in holiday camps around Switzerland.

Have a great summer and best regards

Caryl Earwaker Luethy

This is EXACTLY the model that I was just brainstorming about with the friend of mine.

I am lucky this summer to have found a regular camp for my 5 year old daughter that was willing to include her, and it is going well... but I still think they could have benefitted from some accompaniment (e.g. makaton for my little one as she does not have many words yet, but also to increase the capacity about inclusion in general so they be able to include others in the future too...)... ... and I know that in future years, it looks like it may get harder to find welcoming, inclusive camps... yet there are so many camps out there, but what they need is support to become inclusive... not the creation of additional special camps!..

I would really want to work on something like this... but, again, it is the capacity issue!

Ruth Lee Foley



From Inclusion Europe newsletter





UNFAIR SITUATIONS DURING QUARANTINE THAT SHOW THE WORLD IS NOT DESIGNED FOR PEOPLE WITH INTELLECTUAL DISABILITIES

It is clear: the world is not designed for people with intellectual disabilities. We already knew it, but we thought putting together several absurd situations that happened during quarantine would prove this even more.

Going outside

Facts: Perhaps this is the most common of all situations. The Government declared a state of emergency but did not consider that some people need to go out for a walk to calm down. After advocacy work from organisations, the government eased the lockdown measures to allow people who need it to go outside. Although most people have a good attitude towards people with disabilities going outside, some neighbours chided them and there were cases were police officer treated them disrespectfully. Because of that, some families avoid going for walks, which means they have fewer ways escaping anxiety crises.



Institutions

Facts: People who live in institutions are more vulnerable. This became very clear for residential homes for elderly people, as they are a high-risk group, but also for residential institutions for people with intellectual disabilities. In addition, in cases where someone might be infected, the Ministry of Health recommend that the person should remain isolated in a separate room. However, the model of residential institutions is generally designed so that 2 people live in each bedroom.

What does this show? It is necessary to work towards deinstitutionalisation, and towards a model where life and support are community-based.





Education

Facts: Schools have been closed for days now. Teachers send homework to students and have online classes. But have they thought about students who need support? Many people with intellectual disabilities have great difficulties accessing and understanding online environments, and they are not keeping up with the pace of online classes as their classmates are.

What does this show? The education system is not inclusive.



Accessibility

The Government and the media spread a great deal of information. But is it easy to understand? Have they thought about adapting the information for people who have difficulties in understanding? It is not about "lowering" the level of the message to make it understandable. The initiative of Televisión Española "La infancia pregunta", in English "Children ask", is in a clear and simple format, which shows that things can be explained in many different ways for all kinds of audiences. A similar format designed for adults would be useful to many elderly people and many migrants who do not fully understand the language. Also, many people with intellectual disabilities would have more access to information if there was more thought put into different ways to transmit it.



Technology

During quarantine, many people are using technology, even more than before. But there are people with intellectual disabilities and their families who are living in great poverty because of the extra costs they face. Many also need special support because technology is not accessible. From what organisations have been doing, there are two important lessons: a hopeful and a self-critical one.



The hopeful one: organisations will come out of the pandemic with many more technological skills.

The self-critical one: it has taken a pandemic for many organisations to make more effort in the use of technology.



Allied families

Facts: When people with intellectual disabilities stopped going to schools, to early intervention centres and to centres and services where they received specialised support, a curious thing happened. Families became teachers, therapists, playmates and creators of home activities that involve learning. Professional teams have discovered that families are much more expert than people thought, and that they are great allies in supporting their children's development. Families were also not aware of their great potential and how prepared they were to give support until they replaced the professionals.

What does this show? So far, families have not been trusted enough as having capacities and were seen as having minor roles. There will continue to be more complicated methodologies and support techniques that should always be done by professionals, but it is proven now that families should be equipped with more tools, so they can be autonomous.



Article by Sofía Reyes, Amalia San Román and Olga Berrios, who are part of <u>Plena Inclusión</u>, Spain.



Funding opportunities from the European Commission

Call for Proposals VP/2020/003: Establishing and testing integrated interventions aimed at supporting people in (the most) vulnerable situation

This call for proposals is financed under the European Programme for Employment and Social Innovation "EaSI" 2014-20201 which is a European-level financing instrument managed directly by the European Commission to contribute to the implementation of the Europe 2020 strategy, by providing financial support for the Union's objectives in terms of promoting a high level of quality and sustainable employment, guaranteeing adequate and decent social protection, combating social exclusion and poverty and improving the working conditions.

The target group of the call relates to people in vulnerable situations and those facing the greatest barriers to social and labour market integration.

Deadline for submitting proposals: 15/10/2020

The call

From Australia

Bus stop films

Watch the 13 minutes video: "The interviewer" (2012)

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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