

EUROPEAN DOWN SYNDROME ASSOCIATION

March 2015

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COORDOWN

THE SPECIAL PROPOSAL: COORDOWN CELEBRATES WORLD DOWN SYNDROME DAY



The new international communication campaign for CoorDown, once again created with Saatchi & Saatchi, is online https://youtu.be/InaajSxOsWI. It is about the rights of people with Down syndrome having housing autonomy and conducting an independent life.

Moving into your own house is a common dream among couples. Even people with Down syndrome have the same desire. They have the right to live a relationship, to conduct an independent life and to build a family. Same opportunities and same choice range: this is the focus of the tenth edition of the World Down Syndrome Day, scheduled for Saturday, March 21, 2015.

"For people with Down syndrome, independence means a brighter future". The campaign "The Special Proposal" has been produced with the help of Down Syndrome Australia and Down Madrid and the participation of Down Syndrome Development Trust (UK), Movimento Down (Brazil), Saving Downs (New Zealand), National Down Syndrome Society (US) and Japan Down Syndrome Society.

DOWN ESPAÑA

"Life is not about chromosomes", the new campaign of DOWN ESPAÑA for this year's World Down Syndrome Day.

Its protagonists are 10 mothers and their 10 children, and it's purpose is to demonstrate that there are no differences between children with and without this intellectual disability.

"Life is not about chromosomes". Is about enjoying the company of those you love, squeezing good times, being happy,...



That's the reason why this year's campaign highlights the happiness that children and mothers feel about the relationship that binds them. A relationship in which disability makes no difference.

To produce it, DOWN ESPAÑA has had the testimony of 10 mothers of children with and without Down syndrome, and has asked them how they viewed their role as mothers. Later we showed them what their children thought of them. The result is a video that strikes directly into the core of the heart.

https://www.youtube.com/watch?v=26Tr1J6Dqlw#t=128

AFRT

On the occasion of World Day of the person with Down Syndrome the French association AFRT organized three days of meetings entitled: Symposium trisomy 21: New Horizons.

The topics discussed were:

- progress to ensure better health
- Evolution of ideas and practices to move towards a better inclusion
- scientific and medical advances : ethical experience and clinical research, short presentations from 4 clinical trials

For any further information please check on www.afrt.fr

NEWS FROM THE PROJECTS WITH EDSA MEMBERS INVOLVED IN THE PARTNERSHIP

OMO, ON MY OWN... AT WORK, STARTS

Rome, March 16, 2015 - The first experimental phase of the international project OMO starts today in Portugal: four youngsters with Down syndrome (DS) begin an internship at the all'Axis Hotéis & Golfe in Porto. In Italy, another group of persons, aged between 21 and 23, have started the same experience on March the 9th at the Hotel Melià Aurelia Antica, Rome. This first operative step is part of the "OMO – On My Own ... at work" project funded by the European Commission, program Erasmus + Key Action 2 (Cooperation



for innovation and the exchange of good practices - Strategic Partnerships). Officially launched in September 2014, the project will last 36 months. The partners of OMO are AIPD – Associazione Italiana Persone Down (leading organization), EDSA – Euopean Down Syndrome Association, Fondazione Adecco Italy, Fundacion Adecco Spain, APPT21 – Associação Portuguesa de Portadores de Trissomia 21, Axis Hotéis & Golfe Group, Sol Melià Italia, Alma Mater Bologna University, Roma Tre University.



The Omo project aims to break barriers and open doors for an accessible and inclusive society for people with Down syndrome. The project aims at designing, developing, testing, delivering, as well as diffusing a training method with the goal of enhancing the learning process of people with Down syndrome willing to work in the hospitality business. The project provides the development of advanced educational tools specifically designed for hotel tutors (videos on ways to improve the tutor-trainee with DS relationship) and innovative learning materials (pocket interactive resources) for youngsters with DS who will achieve an internship at a hotel and gain knowledge, skills, and competencies to perform the tasks of selected iob positions.

It will be created a European network of "friendly hotels", which – in agreement with Vocational Education and Training (VET) providers – will host internships/placements of people with Down syndrome, according to quality process rules and adopting the tools developed within the project. Hotels participating in the network and willing to systematically provide work opportunities to persons with Down syndrome implementing the established code of conduct will be awarded with a label. Through these activities, the Omo project will contribute to facilitate access of European people with Down syndrome to VET in the hotel sector, enhancing the creation of long-lasting collaborative partnerships between VET agencies (mainstream schools and disability associations) and hotel employers.

According to the United Nations, over one billion people, approximately 15% of the world's population, live with some form of disability. Everywhere, persons with disabilities face physical, social, economic, and attitudinal barriers that exclude them from partaking fully and



effectively as equal members of society. They lack equivalent access to vital resources, such as healthcare, education, employment, social and legal supports, as well as have a higher rate of mortality. Despite this situation, disability remains largely invisible in the mainstream development agendas of all countries around the world.

For any further information please write to AIPD c/o omoaipd@gmail.com



NEWS FROM EACEA

Joint Programmes from A to Z. A reference guide for practitioners

This guide published by Joint Degrees from A to Z (JDAZ) project aims to provide a comprehensive, practical reference guide on all aspects that need to be taken into account when developing and managing joint programmes.

There is a lot of information available in this field, but these data have so far not been available in a central place and in an integrated form. This guide is aimed at four target groups:

- 1. The National Agencies for Erasmus+.
- 2. Higher education institutions and coordinators interested in setting up or maintaining joint programmes.
- 3. Current coordinators of joint programmes (e.g. Erasmus Mundus, Erasmus+, Atlantis, EU-Canada, ECP-ICI, Joint Nordic Masters) who are working to improve their current practice.
- 4. National research academies in their advisory role on joint doctoral programmes.

To read the guide:

http://www.nuffic.nl/en/library/joint-programmes-from-a-to-z-a-reference-guide-for-practitioners.pdf

NEWS FROM EDSA MEMBERS

DDSS DRUŠTO DOWNOW SINDROM SLOVENIJA

Present situation in Slovenia for persons with DS

General Information

In Slovenia, a country of 2 million inhabitants, 15 - 17 babies with Downs syndrome (DS) are born every year; this means that one baby with DS is born in every 1245 births.

The average life expectancy of persons with DS in Slovenia is over



60 years.

Maternity leave in Slovenia is 12 months and in cases where a child with special needs is born it can be prolonged for 60 more days.

Preschool Children

Preschool children with DS are mostly included in kindergartens; either in groups of children with typical development or in (smaller) groups of children with special needs.

In Slovenia's public health system at present early intervention programmes are carried out in a very unstructured way by special developmental teams including a paediatrician, physiotherapist, and special pedagogue, but the services they are able to deliver are often inadequate, infrequent and at lengthy intervals - generally once a month at best. In an effort to provide better services to those in need, DS Slovenia developed an early intervention programme in three cities. In 2013, the programme was taken over by the Union of "Sožitje", an NGO with more than 50 local associations in the country and there are plans underway to further develop this early intervention programme on a national scale.

Primary School and Early Adulthood

The system of special schools being very well developed in Slovenia, most school children with DS enter these schools. Their inclusion in mainstream schools is very rare. Elementary schooling takes nine years; secondary schooling is almost non-existent. DS Slovenia is trying to improve this situation.

Adulthood

After they reach 18 years of age, young persons with DS usually join "protective working" centres where they work under supervision, learn some skills, and participate in various educational, cultural and other activities. Some adults with DS reside in institutions; others stay at home with their families. Recently, some new forms of employment have been developed and a restaurant employing persons with special needs (persons with DS among them) has been opened.

Some persons with DS can also be employed under special conditions in some forms of supportive employment (e.g. enterprises for handicapped). DS Slovenia are now pursuing other employment avenues and opportunities.

Legal Position of Persons with DS

As a rule a child with DS is declared (by a state agency) to have a certain level of mental retardation before his/her 18th birthday This entitles him/her to certain social care services including health care, financial support and some others.

Some of persons with DS have some political rights, e.g. the right to vote. Efforts have been made – for all persons with intellectual handicap – to limit some parts of their legal capacity only and not to take them legal capacity as a whole.



DS SLOVENIA ACTIVITIES

DS Slovenia has been active in Slovenia since 1997 – at first, as a section of one of the local associations "Sožitje"- an NGO devoted to work for all persons with intellectual handicap. Since 2013 DS Slovenia has been organized and operates as an independent NGO. It carries out numerous activities aiming at improving the quality of life for persons with DS. Among them:

- 1. Teaching help and gymnastic support programmes: these two programmes, being carried out in Kranj and Ptuj at present, are aimed at providing tutoring to school children and teaching their parents what methods they should employ while helping their children with school work. Gymnastic support is a programme specially developed by a gym-teacher.
- 2. Five day camps for pre-teens and teenagers 10 18 years of age at the River Kolpa. Participants get to taste the experience of life in the open air, living in a small comunity and sharing their duties.
- 3. Week-end seminars for families with children with DS in one of Slovenian spa. Seminars have a structured programme: there are three lectures for parents with a workshop following the lecture while children participate in their own activities specially designed and adapted for them and organized and supervised by volunteer carers.
- 4. One-day workshops to designed to teach parents and professionals how to carry out early speech support for children with DS
- 5. One-day workshops for families with children with DS, focused on one selected topic being of interest to the families. During the workshop volunteer carers take care of the children.
- 6. Saturday workshops for children and teen-agers with DS with creative activities for them in which to participate and learn.
- 7. Scheduled lectures with different topics (e.g. sexual life and DS, mathematics for pupils with DS, healthy diet, legal questions referring to families with a member with DS etc.) take place in different cities of the country.
- 8. An annual conference, each focussing on specific aspects and relevant topics connected with the life of persons with DS. So far, five conferences have been held and their proceedings published.
- 9. Marking the World DS Day with different activities aimed at informing the general public about DS and promoting their issues.
- 10. Publication of different materials in order to provide important information and increase knowledge about DS among professionals, parents and the general public. DS Slovenia has so far published and made available around 20 different publications on various issues concerning and referring to DS.

For any further information please visit the association's website: www.downov-sindrom.si

NEWSLETTER EVOLUTION: TOPIC OF THE MONTH

We would like to start a new section of the newsletter.

The idea is to choose a topic that is of common interest and try to develop it recommending useful links.

In this issue we have explored the theme: "people with intellectual disabilities: safety at work".

If you think that this new section might be interesting, please point



out areas/topics for investigation and we will try to develop them . "People with intellectual disability, safety at work"

http://www.tn.gov/didd/civil_rights/ada/intellectual.pdf

http://www.hsa.ie/eng/employees_with_disabilities.pdf

https://osha.europa.eu/en/publications/factsheets/53

http://www.ucl.ac.uk/estates/maintenance/fire/documents/ UCLFire_TN_012.pdf

http://www.napier.ac.uk/policies/equality-diversity/Documents/Risk-assessments-and-disabled-people.pdf

http://lohp.org/wp-content/uploads/2012/07/staying_safe.pdf

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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