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### NEWS FROM EDSA MEMBERS

#### "I'm a piece of art too" - Down Syndrome Albania Foundation (DSA)



Albanian photographer Soela Zani, in collaboration with DSA – Down Syndrome Albania and its director Emanuela Zaimi, recreated 18 famous paintings with children with Ds. Zani is specialized in family photography, but she has always been drawn to classic works. So the project "I'm a piece of art too" was the perfect combination for her. The purpose of this project is to represent the disability with a smiling and optimistic outlook, and to appreciate the differences, showing how each human being is a work of art. To appreciate these works of art:

<http://soelazani.com/exhibition/>

<https://www.facebook.com/media/set/?set=a.939303459456177.1073742002.177492705637260&type=3>

#### APPT21 – 25th anniversary of the association

The Portuguese Down Syndrome Association celebrates, this year, their 25th anniversary. It was founded in October 1990 and its first aim was to develop an intervention methodology for children with Down Syndrome. With the passing of time, they began to expand their work to other impairments in child development. Today, there are a set of different professionals dedicated to diverse areas of development. This year the Portuguese Down Syndrome Association celebrates



25 years and 25 actions were developed to raise awareness among professionals and the community about some problematic issues and with regard to new developments in education and health. The actions were diverse, such as the “Count Down Conference” and development of workshops in schools or other education institutions. The conference was the main action since under discussion there were, equal opportunities, approaches and the latest methodologies for the promotion of academic and vocational progress of people with Down Syndrome. It was also a space to share the successful experiences between different realities in Europe. For the first time in Portugal, this action promoted self-advocacy and civic participation of people with DS through a set of testimonials.

### The Hungarian Down Foundation introduces itself



The aim of the Hungarian Down Foundation is to ensure for children with intellectual disabilities to be brought up within their own families and live an autonomous life as adults. To fulfil this purpose, the Down Foundation provides a wide range of support services for parents in order to encourage them to bring up their children within the family rather than sending them to care institutions. In addition to family support and consultancy, our services cover (i) childhood by early development and health care; (ii) adulthood through supported living, supported employment and supported decision making in order to establish – as far as possible – an autonomous life for intellectually disabled persons. All of our activities and projects during the past 25 years have been in pursuit of these goals based on the normalisation and integration principle. Our holistic approach integrates services from birth until the old age, in the fields of social and health care, education, employment, recreational and sports activities. Several innovative methods and tools, and practical knowledge have been developed and a person-centred service-system maintained, where empowering and coaching of intellectually disabled individuals are the focus. These are complemented with intensive awareness raising, education



for professionals and parents, dissemination of our experiences, advocacy, collaboration with NGOs, fund raising and efficient managerial issues, e.g. the developing a specific on-line management system. To ensure stability in addition to maximum professional and financial efficacy and quality, our main tool has been increase in the number of services and activities, so Down Foundation has become the largest self-made, organically developing NGO in Hungary, with 350 employee (150 of which intellectually disabled persons), 400 daily clients (150 of which in supported living), in 20 locations.



Short list of our main activities:

- Sustaining and supporting parents' groups and clubs by training and education;
- Maintaining advisory service and education for parents and professionals;
- Cooperating with higher education institutions by giving lectures and practical courses;
- Managing a nation-wide, parents-to-parents first aid network – Down Dada – embracing new parents after the birth of a Down-

syndrome baby;

- Two non-stop running Respite-Care Homes each for 30 people;
- Day-Care Centres at 5 locations for 100 people;
- Early Development Centre for 120 children between the ages of 0–6 years;
- Out-patient-clinic for 150–200 Down-syndrome children/year – in cooperation with Hospital Bethesda;
- Out-patient-clinic for disabled adults in cooperation with the Hospitaller Order of Buda: 16 different specialists, plus neurology, psychiatry and psychotherapy in 120 hours/week);
- Supported living in 4 family houses and 7 flats for 90 persons, dispersed in Budapest;
- A special home for elderly intellectually disabled persons;
- Alternative education, vocational training, job training, labour market services, support in integrated employment;
- Sheltered workplaces for 150 intellectually disabled people and for another 150 persons with changed abilities to work;
- Adult education: seven accredited courses, workshops, conferences;
- Leisure time programmes: creative studio, theatre, orchestra, sports programmes and sports education, holidays. Sustaining an integrated Sports-centre with programmes and services.
- Down Foundation Publishing: books, booklets, calendars, posters, online publications.
- Supporting talented disabled persons in the fields of music, theatre, arts and sports.
- Our 'Mental accessibility' project enforces the full extent of accessibility and universal design, also for intellectually disabled persons: both in the physical environment and in the mind. The slogan of this project is "Convenient for all".

In terms of the history of the Hungarian Down Foundation, I have to mention, that the driving force behind the establishment of the above-described activities and the whole system is primarily the commitment of a small group of people who are involved as parents or highly emphatic professionals, including myself. I am the mother of a 36 years old daughter Cecilia, who made me reactivate myself and I collected information around the world in the 1980's, and in those days Hungary was not fully open and services (out of the state-owned institutions) were not available at all. Therefore, I went around Europe and the US to see what was going on in the rest of the World, and met many people, parents and professionals who helped me to understand what is necessary and what is possible with regard to intellectual disabilities. Among the hundreds of names, I would like to mention Cora Halder, whom I met on a training course (organized by Etta Wilken) for parents at the end of the 1980's and received a lot of useful information personally and via the newsletter edited by her. I have exported the methodology of the Down-clinic from Wolfgang Storm, parent and director of a clinic especially for DS in Paderborn, and the music education method of Ulvilla colour-notes from Heinrich Ullrich, music teacher and conductor of the Ulvilla-orchestra which is well known all over Europe. Professionals

from England, Scotland, Sweden and Spain could provide plenty of new things and new approaches for me, such as the Australian Moira Pieterse, the 'grandmother' of the 'small steps' in early development from Macquarie University. Later on I learned the basics of advocacy and human rights from Judy Klein a teammate of MDAC and as 'private student' gleaned as much knowledge as possible from Bengt Nirje, the 'father of normalization'. The acquired information was a great help in the creation of my dreams and my engineering capacities were needed in the realization of these dreams. I hope that the Hungarian Down Foundation's demonstration project with its innovative service-systems – in spite of the every-day difficulties – will remain faithful to these ideals. *(Katalin Gruiz, president)*

## MY OPINION MY VOTE: THE PROJECT CONTINUES Down Syndrome Ireland



Political decisions influence the lives of people with learning disabilities in the same way as they influence the lives of the general population. Nevertheless, people with learning disabilities represent a group in society who are most frequently excluded from the political process. The MOTE Project - My Opinion My Vote - ([www.myopinionmyvote.eu](http://www.myopinionmyvote.eu)) was established to address this gap and attempt to educate and encourage those with learning disabilities to become active within their countries political systems. The project was completed over a two-year period (2008-2010). An education programme comprising of ten training units was designed, tested and published as a result and is available to download [here](#) .

This political education programme continues to go from strength to strength with nine classes currently running in every province in Ireland. The MOTE programme supports people with Down syndrome to learn about decision-making and how to make informed choices through the use of multi-storey teaching techniques such as role-play, audio-visual materials, discussion groups, facilitation groups, reflective practice, visual scaffolds and alternative augmentative communicative supports.

January 2016 will mark a historic landmark for people with intellectual disability in Ireland when the enactment of the Assisted Decision-Making (Capacity) Bill 2013 will repeal the existing Lunacy Act 1987

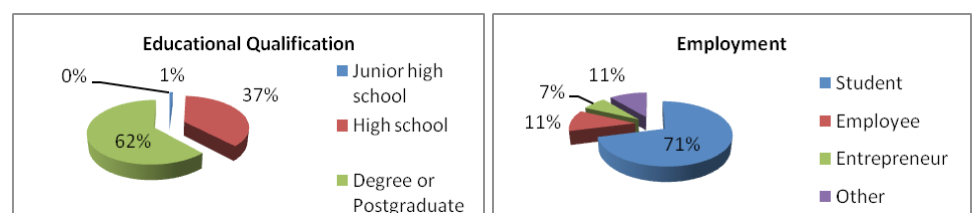
which terms people with an intellectual disability, those with mental health problems and older people with dementia, as ‘lunatics’ and facilitates a system that takes away a person’s right to make their own decisions about their lives. The enactment of the new legislation marks a significant shift from the paternalistic stance of looking after what others decide is a person with intellectual disability’s ‘best interests’, towards recognising a person with intellectual disability’s right to make decisions about his/her own life, and to enable them to be supported in making such decisions. It is reported that the enactment of the Assisted Decision-Making (Capacity) Bill 2013 would remove the final impediment the present Irish Government (2015) pronounces exists to ratification of the UN Convention on the Rights of Persons with Disabilities (CRPD), (Oireachtas Debates, 2015).

## SURVEY ON THE INTENTION TO STAY AT HOTELS EMPLOYING PEOPLE WITH DOWN SYNDROME

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The tourism industry and organizations operating in the hospitality business seem to be particularly suitable to employ people with intellectual disabilities. Scheduled tasks (housekeeping, breakfast preparation, check-in and -out procedures) can be learned and achieved relatively easily by a person with Down syndrome (Ds). This is why the EU has financed a three-year project (OMO, On My Own ... at work) led by the Italian Association Down Syndrome, program Erasmus +, KA2 – Cooperation and Innovation for Good Practices, aimed at creating a European network of “disability-friendly” hotels willing to host for an internship/hire people with Down syndrome. The survey has been designed to investigate the intention of young adults to stay at hotels where people with Ds work in the front office while travelling.

A total of 284 respondents (176 female; 108 male), aged 18-35, returned the completed questionnaire that has been submitted online.



### *The outcomes of the survey*

**General results:** respondents show general positive attitudes towards workers with Ds and a generalized predisposition to stay at hotels where people with Ds work. 63% of the sample answered that if they stayed in a hotel with employees with Ds, they would experience a pleasant and comfortable environment.

The outcome suggest that far from being the result of a merely cognitive process, staying at hotels where people with Ds work are greatly affected by further components. First, intentions are strongly

influenced by their moral norms, i.e. the sense of duty that people perceive to engage in behaviour that they consider right or wrong. In other words, they seem to be strongly spurred by their personal standards of conduct. Second, they are also strongly influenced by the emotional aspects related to their actions, that is the feelings that individuals would experience performing the investigated behaviour (staying at hotels where people with Ds work in the front office). 40% of the respondents claim that staying at a hotel employing workers with Ds could be useful for society.

Risks: findings also reveal that people might be possibly worried about the increasing complexity and slowness of service provision processes if they were performed by workers with Ds. Around 45% of them claim that they would be more willing to stay at hotels employing disabled workers if these latter were monitored and supported by a tutor.

Stereotypes and subjective knowledge: positive stereotypes seem to be more diffused than negative ones. In fact, while almost all respondents basically disagree on the fact that people with Ds are able to achieve only repetitive activities and are unaware of their handicap, almost 52% of them believe/strongly believe that people with Ds are always affective and tender. Furthermore, investigated individuals think they know people with Ds quite well, given that those who claim to have a medium, high or extremely high knowledge of this type of disabled people represent more than 59% of the total sample. It is interesting to notice that respondents who state to have a higher knowledge are also those who hold higher positive stereotypes. This means that there might be a significant gap between perceived subjective knowledge and “real” knowledge, which could potentially give rise to wrong beliefs and biased attitudes.

The investigated sample, limited at the moment, is going to be enlarged also in terms of socio-demographic and geographical characteristics of the respondents in order to obtain more reliable outcomes.

## 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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European Down Syndrome Association

