

### **EUROPEAN DOWN SYNDROME ASSOCIATION**

July - August 2019

**SUMMARY** 

01

NEWS FROM THE PROJECT WITH EDSA MEMBERS IN THE CONSORTIUM – ALDOCET (ROMANIA)

08

**BOOK REVIEW** 

10

**NEWS FROM** 

**EDSA MEMBERS** 

# NEWS FROM THE PROJECT WITH EDSA MEMBERS IN THE CONSORTIUM – ALDOCET (ROMANIA)

### MAKING VIRTUAL JOBS REAL FOR PEOPLE WITH DOWN SYNDROME

#### **PREFACE**

Asociatia Langdon Down Oltenia Centrul Educational Teodora (ALDO-CET) from Romania, participates in the VIRTUAL DS project, which is a training program that aims to improve access, participation and learning performance among people with Down syndrome regarding employment competences, reducing differences in learning outcomes through the use of virtual reality. www.virtualds.eu



The Consortium is formed by four NGO working in the field of Down Syndrome: FUNDACION ASINDOWN (Spain) - the project coordinator, DRUŠTVO DOWNOV SINDROM SLOVENIJA, DDSS (Slovenia), ASSOCIAÇÃO PORTUGUESA PORTADORES DE TRISSOMIA 21. APPT21 (Portugal), ALDO-CET (Romania); and STATUS EMPLOYMENT (Great Britain), a non-governmental organization specialized in supported employment, and IMAGINA RV (Spain), a private company specialized in the development of Virtual Reality training contents.

VIRTUAL DS is funded by the European Commission within the ERASMUS+ 2017 Programme.

#### **INTRODUCTION**

The VIRTUAL DS program is intended for

people with intellectual disabilities and the communities to which they belong. Using this program, people with Down syndrome or other intellectual disabilities can learn how to correctly perform a series of 5 specific work tasks for certain jobs in the free labour market.

The design and development of the program is done between 2017 and 2019.



The VIRTUAL DS program aims to:

- training people with Down syndrome and other intellectual disabilities, poorly qualified,
- promoting on-the-job training,
- providing efficient and integrated professional guidance services.

#### THE PROBLEM

According to the statistical data provided by the National Authority for People with Disabilities (www.anpd.gov.ro), in January 2018, 4537 persons with Down syndrome are registered in Romania, among them being 1776 children and 2761 adults. 145 people with Down syndrome are institutionalized and 4392 are in the family's care.

According to the level of education, from the total number, only 1071 people with Down syndrome are enrolled or have graduated various forms of education, as follows:

- 22 graduated from vocational schools.
- 56 graduated high school
- 3 graduated a college
- 756 people are uneducated
- 2710 people did not report the level of education.

### CLASSIFICATION OF ADULTS WITH DOWN SYNDROME BY AGE CATEGORIES

- 18 -25 years = 809 people
- 26 45 years = 1468 persons
- 46 65 years = 469 people
- Over 66 years = 15 people

#### **ANALYSIS**

According to the national research conducted by ALDO-CET with the support of the employment agencies and Social Assistance Directorates (100 invited institutions, 57 respondents) in the country, in January 2018, there were no persons with Down syndrome employed with a labour contract on the labour market or registered as unemployed.

The results of the study show that the employment and training agencies in Romania:

- do not offer vocational training courses adapted to people with Down syndrome, but allows them to access the regular courses;
- do not identify jobs relevant for people with Down syndrome, but believes that people with intellectual disabilities can work as unskilled workers in agriculture, construction, textile and household;
- there are no job trainers nor career guidance counsellors specialized in working with people with Down syndrome or other intellectual disabilities;



 if a person with intellectual disabilities is placed in a job, the average duration of employment is between three months and a maximum of one year.

#### THE BARRIERS

The economic sector does not know the typology of people with Down syndrome and does not know how to manage their inclusion in the labour market.

There are no job trainers nor training agencies that provide training for supported employment and seek for jobs for this population.

Specific recruitment processes are not defined and regulated, so people with Down syndrome have to deal with the classic processes that apply to the typical population:

- CV analysis,
- the career guidance counsellor selects from the database, only the persons who meet the requirements of the employer,
- the employment interview held in front of the employer.

A person with Down syndrome cannot successfully go through such a process, so they are not interested in employment on the labour market.

#### THE ACTIONS

All responsibility is placed on the parents. Parents are afraid of the free labour market, for various reasons:

- people with Down syndrome are rejected by employers if the family address directly to them;
- the state does not have specialized structures to provide specific training, search and placement in the workplace according to the wishes, abilities and potential of the person, neither support in the workplace and nor tracking the evolution in the workplace;
- people with Down syndrome are not understood in the workplace, even if they know what they have to do and can adapt to the work environment;



- the people they interact with in the work environment do not have the patience to understand them nor to adapt to their rhythm;
- the short term on which the employment is maintained;
- the loss of social facilities that provide stability in the person's life;
- the difficult and traumatic process through which the person with Down syndrome must go through to regain the social facilities in the situation in which he/she becomes unemployed;
- the general tendency of the expert commissions to analyse the aspect and the communication skills of the person with Down syndrome, without taking into account its functionality, the learned clichés and the lack of social inclusion facilities offered by the state and the community in which the person lives.



#### THE EFFECT

People with Down syndrome over 23 years of age spend their time at home, watching TV or listening music, alone or with family members.



In a small number, residents in urban areas are enrolled in day care centers or occupational services for people with disabilities. The residents in rural areas have no occupational or employment

alternatives.

The family does not know how to deal with the situation, consequently the family accommodation. offers adult the meals and personal The Social Assistance Directorates monitor the care provided by the family, without offering alternatives for social inclusion or placement in a workplace. In Romania, there is no cost-benefit analysis of supported employment of people with Down svndrome or other intellectual disabilities. In Romania, in terms of costs, the responsible authorities and institutions do not publish annual reports on the efficiency of the support provided for employment with disabilities.

#### **VIRTUAL DS SOLUTIONS**

After identifying the state-of-art of adults with Down syndrome, ALDO-CET, like all the other partners, organized a workshop, in which adults with Down syndrome together with parents, representatives of the institutions responsible for training and representatives of the free labour market in Craiova participated.

Based on the conclusions and identified needs, the VIRTUAL DS Consortium



produced a set of training materials to prepare and support the employment of people with Down syndrome for five jobs:

- HOTEL ROOMS HOUSEKEEPING
- WAITER ASSISTANT
- SHOP ASSISTANT
- WAREHOUSE ASSISTANT



#### CASHIER ASSISTANT

#### The VIRTUAL DS training program trains:

- Vocational profile of the candidate the guide presents the views of the European Union of Supported Employment, regarding the elaboration of the vocational profile for supported employment and encourages all of us to adhere to the strengths and values of the supported employment model. A vocational profile template developed by the National Development Team (NDT) in the United Kingdom is presented for learners with learning disabilities. It is designed to be completed together with the person and is more accessible to people with learning difficulties than the standard vocational profile, being easier to understand for candidates.
- Emotional intelligence of people with Down syndrome the workbooks provides guidance for training social skills, politeness, listening, subordination and solving unforeseen situations, through face-to-face sessions and role-playing games; and work forms and ICT tools to verify acquired knowledge.
- the candidate's abilities to perform certain work tasks specific to the five jobs concerned - each guide describes the job, the necessary professional competences and social skills, five actions at the workplace, the work tasks in each action, work forms and possible unforeseen situations, all being supported by icons, pictures, videos and virtual reality scenarios.

These training materials can be a resource for job trainers and companies in order to facilitate the employment of people with Down syndrome in the labour market. https://virtualds.eu/?page id=1092

#### **VALIDATION OF TRAINING MATERIALS IN ROMANIA**

During February and June 2019, 13 people with Down syndrome from Băilești and Craiova, Romania, were enrolled in the VIRTUAL DS training program. The VIRTUAL DS training program has three dimensions: face-to-face sessions, e-learning and on-the-job training.

In the class, the trainees trained their work competences, soft skills and elearning abilities; watched videos and simulated the work tasks with the support of virtual reality scenarios.

8 trainees with Down syndrome, participated on-the-job training in units on the free labour market. The internship lasted 5 days, as follows:





how to interact, how to motivate each other. On the last day of practice, the team decided that is ready to serve the students at the table. The interaction with the other students was very interesting when they came to lunch.

Our trainees only served at a table with 4 students. The cheerful and relieved students came and suddenly they woke up in front of an unforeseen situation: three ladies serving at the table and politely asking them if they wanted something else, or if they are allowed to pick up the plate, etc. The students didn't know how to react, they inhibited themselves and they enjoyed the lunch in a quiet way. In

3 trainees completed the internship in the Canteen of a high school in Bailesti having the support of 2 volunteer students and a cook. In the beginning, the volunteer students didn't know how to interact with our young ladies, how to deal with countless questions or blockages or the slow pace of execution. At the end of the 5 days of practice, a team had already been consolidated, which not only experienced the five work tasks of the guide, but learned together how to execute them correctly,



other words, they have felt what a person with Down Syndrome is experiencing almost every day when meets new people and situations; and has to cope with them with desirable behaviour.

The principal of the high school was very happy with the educational and inclusion components of our training program and is waiting for the girls with Down syndrome to continue the training when the new school year begins.





5 trainees completed the internship in Ramada Plaza Craiova. They practiced during five consecutive days, 2 hours per day, 3 in the restaurant and 2 in the hotel rooms. Each of them had a volunteer coworker from the regular staff of the company, and experienced all the 5 work tasks presented in the training manual. They did the internship in shifts, 3 in the morning, in the breakfast section of the restaurant, after its closing time, and 2 in the afternoon, in the hotel rooms, after check-out time.

At the end of the internship period, the general manager congratulated them personally and proposed them to continue this collaboration. Starting with

October, the young men are invited to come one by one, by rotation, two hours once per week, in order to acquire all the skills necessary for employment.

The on-the-job training was carried out one by one by the economic agent.

All the training materials, products and results of VIRTUAL DS are available on the electronic platform of the project.

#### www.virtualds.eu

Promoting the employment potential of people with Down syndrome in the labour market, ALDO-CET organized and participated in a series of events aimed to the dissemination of the VIRTUAL DS training package.

With the objective of raising awareness of the greatest number of parents and specialists from various social and economic sectors, on the employability of people with Down syndrome, ALDO-CET has organized VIRTUAL DS

multiplier events at local, national and European level.



The VIRTUAL DS Consortium thanks all users and collaborators for their commitment and dedication!





#### **BOOK REVIEW**

## NEW CHILDREN'S BOOK HIGHLIGHTS THE GIFT OF PEOPLE WITH DOWN SYNDROME



There's a great family story behind 'Kelly and the Great Pinewood Derby,' as well as a message for today's culture.

My family has always known people with Down syndrome, so they're not unfamiliar to us, but with too few of these precious people allowed to be born today, many people are not familiar with them. Jordan Burk, the author of a new children's book called *Kelly and the Great Pinewood Derby*, wants to help change that.

Burk's main character is based on his favorite uncle, Kelly, who had Down syndrome. Urged by doctors to place him in an institution when he was born, Kelly's parents chose to raise him in their loving family, so Burk grew up with a special relationship with his uncle and even became his primary caregiver for 14 years.

Today, parents of babies aren't urged to institutionalize their babies with Down syndrome, but to end their lives before they're even born. This horrible trend is something Burk is aware of in his goal of writing about the love and joy of people with Down syndrome.

After losing his Uncle Kelly at age 64, three years ago, Burk was inspired to create a children's book series based on his uncle. With an illustrating background, he started to draw what he thought a children's book about Down syndrome should look like, saying he wanted Kelly to look different from the other characters so readers would be able to recognize the individuals in real life who may have Down syndrome and reach out to them.

Burk says his goal is to make folks aware that there can be happiness and life beyond a diagnosis:

Those around my grandparents constantly questioned their decision to keep Kelly. It was the 50's, and most children with Down syndrome were sent away to institutions. The doctors explained Kelly would be in a vegetative state, but to



everyone's surprise he flourished as he mimicked his sibling' movements, speech and social behavior.

Kelly was brought into this world to show love, kindness and share his contagious smile ... He brought fun and excitement to our entire family and made a huge impact on my life. He was joyful, curious, loving, and affectionate. Many things brought him happiness, especially, hamburgers, "I Love Lucy" reruns, game shows, dancing and family. His favorite restaurant quickly learned that he liked to say, "Hacky Birfday!," which was Kelly's way of reflecting a good time. The staff would then sing "Happy Birthday!" and bring him ice cream on every visit. He especially loved teasing his siblings and was guite the comedian.

The book's other characters include a Dalmatian named Tex, Professor Kelso a stuffed animal koala that teaches children about friendship (the real Kelly always carried a stuffed animal) — and Aaron, Kelly's friend, someone that Burk hopes the reader will want to be like. He also hopes kids will be able to relate to Kelly and see that they have far more in common with him than differences.

In the story, Kelly can't find his shoe. We're all frustrated when we lose something. Kelly gets anxious in big noisy crowds. Everyone has their idiosyncrasies. Kelly likes routines, and don't we all have certain routines we're comfortable with? Like most children, Kelly loves recess, and running around playing is something all children can share. Kelly also loves cheeseburgers and all readers have their favorite foods. "I want to break the barriers and tear down the walls and show them what they have in common with people like Kelly," Burk says. "But I also want to show them the things that make Kelly, Kelly."

Burk believes his life was changed for the better by someone whom "the world" would have locked away or even worse, given a death sentence by abortion. "I can't imagine who I would be if it wasn't for his example of love." And he hopes "that Kelly's story of love, acceptance and HOPE, could change a heart in such a way as to save the life of a baby with Down syndrome."

Burk says plans are in the works to make the first Kelly book into a series, and introduce a new character named Shannon, a girl who has Down syndrome. He wants the book series to proclaim, "The world needs who you were meant to be!"

Source: Patty Knapp, www.aleteia.org

**NEWS FROM EDSA MEMBERS** 



#### **DOWN SENDROMU DERNEGI (TURKEY)**





Down Sendromu Dernegi's self-advocacy group Söz +1 (Voice +1) began to work against poverty and social exclusion as a partner of a new Erasmus project called "Ideas against poverty". The project has 4 partners from Spain, Hungary, Poland and Turkey. Söz+1 is expected, first to learn about poverty & social inclusion and second to find activities to help people in their cities and build a network. The group will also visit other partners to meet people with intellectual disabilities and to share their experiences mutually. Söz +1 and representatives of our branches made their first meeting in İstanbul and discussed about poverty and social exclusion. The group members will begin to work in their cities with the cooperation of brach representatives.



The Network for the Rights of Children with Disabilities (EÇHA) was held on the 3rd & 4th August with the participation of yougsters with disabilities and with the support of Unicef. Down Sendromu Derneği is the cofounder of that network which has 73 member NGO's from all around Turkey. During the meeting next 4 years' activities were disccused and youngsters made a presentation about their expectations from EÇHA. Our association took part as a facilitater during the meeting.

**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 Claudia Galieti

