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21ST OF MARCH 2015 – EDSA EVENT

The group of the board that is organizing the event in Bruxelles is still waiting for an answer from the European Disability intergroup. As Edsa board members think that, without such a meeting, the event would not have almost any external visibility, they have decided to wait for the Disability Intergroup and, just in case of positive response, a delegation will be set up with the people that it will be available at that moment.

On the other hand, having a joint event it's a sign for the members of EDSA to consider our organisation as a European organisation. This is the reason why they propose to organize a virtual flash mob, on the 21st of March.

The idea is to have an agreed text to be sent by mail (in all EDSA members' languages) to the President of the EU Commission as a reminder of the existence of DS people in Europe and of the enforcement of their rights.

The text could be spread also through Facebook by each EDSA organisation. It should also be asked to send many messages to the President of the EU Commission from different parts of Europe in this day.

You will receive the text to be translated and all the details to take part in this virtual flash-mob by mail.

In the meanwhile, Edsa board will proceed organizing a meeting with the Disability Intergroup and a delegation of Edsa with people with DS to meet the group will be set up as soon as possible.



OPPORTUNITIES FOR PARTNER COUNTRIES

As a general rule, participants in Erasmus+ must be established in a Programme Country (EU Member State or former Yugoslav Republic of Macedonia, Iceland, Liechtenstein, Norway or Turkey).

Some actions, notably in the fields of higher education and youth, are also open to Partner Countries (Armenia, Azerbaijan, Belarus, Georgia, Moldova, Ukraine, Algeria, Egypt, Israel, Jordan, Lebanon, Libya, Morocco, Palestine, Syria, Tunisia, Albania, Bosnia and Herzegovina, Kosovo, Montenegro, Serbia, Russian Federation).

The specific conditions for participating in an Erasmus+ project depend on the type of Action concerned.

For more details on the conditions for participation in each specific Action, please contact the National Erasmus+ agency in your Country.

List of National Erasmus+ Offices in Partner Countries:

https://eacea.ec.europa.eu/erasmus-plus/contacts/national-erasmus-plus-offices_en

WDSO 2015

21 March 2015 marks the 10th anniversary of World Down Syndrome Day (WDSO) and each year the voice of people with Down syndrome and those who live and work with them, grows louder.



Down Syndrome International (DSI) encourages associations to choose their own activities and events to help raise awareness of what Down syndrome is, what it means to have Down syndrome, and how people with Down syndrome play a vital role in our lives and communities.

Here are some ways to take part in WDSO 2015:

WEAR our WDSO Merchandise, available to buy online and delivered worldwide

<https://www.worlddownsyndromeday.org/wdsd-merchandise>

SHARE your WDSO World Events on our dedicated WDSO website in a single global meeting place

<https://www.worlddownsyndromeday.org/world-events>

JOIN DSi's 2015 focus on 'My Opportunities, My Choices' Enjoying Full and Equal Rights and the Role of Families

<https://www.worlddownsyndromeday.org/wdsd-2015>

WATCH and SHARE our WDSO Global Video Event, with a number of videos from countries around the world to be published on our YouTube Channel shortly before WDSO

<https://www.youtube.com/user/DSiWDSO>

REGISTER TO ATTEND, APPLY TO SPEAK AT or WATCH ONLINE our 4th Annual WDSO Conference at United Nations HQ in New York

<https://www.worlddownsyndromeday.org/wdsd-conference>

WEAR LOTS OF SOCKS to get people talking about WDSO

<https://www.worlddownsyndromeday.org/lots-of-socks>

SHARE the announcement of the 2015 WDSO Awards, to be made shortly before WDSO

<https://www.ds-int.org/wdsd-awards>

PARTICIPATE through our various WDSO Social Media channels

[#WDSO15](https://www.ds-int.org/wdsd-social-media)

NEWS FROM THE PROJECTS WITH EDSA MEMBERS INVOLVED IN THE PARTNERSHIP

THE ESSENTIAL IS INVISIBLE TO THE EYE (INV)



This project, funded in the framework of the EU Lifelong Learning – Grundtvig programme (adult education), has involved three organisations (Associazione Italiana Persone Down – IT – leading partner -, Down Alapitvany - HU, Fundació Catalana Síndrome de Down - ES) that have cooperated in the implementation of the INV project, from October 2012 until January 2015.

The project was focused on staff working with /taking care of people with severe intellectual disabilities, defined as people “who need treatment and permanent support in their daily life and do not possess the basic competencies necessary to manage autonomously their personal relationships”.

The main purpose of the project was to increase the awareness of professionals involved in constant/periodical relationships with people with severe intellectual disabilities about new educational strategies, which could enhance their working conditions and, at the same time, ensure an increased respect of the rights of people with disabilities.

Thus the main result of the project is a pedagogical model which illustrates such relationship and provides a specific itinerary and training tools to enforce it.

The project is over now, but the handbook containing the pedagogical model and its accessory tools, which have been developed within INV, are still available for those who are going to learn more about the INV approach, methods and tools or would like to introduce the model in their organization or service.

These support-materials are available in four languages (EN,IT, HU, ES) and available on the web site, on CD and on paper copy.

If you are interested in consulting these materials you can:

- a) visit the project website <http://invllp.eu/inv/> and download them for free.
- b) Ask one of the partners to send you paper copies.

POLITICAL RECOMMENDATIONS FROM THE “what is essential is invisible to the eye” PROJECT

The new pedagogical model, as designed and tested within the INV project, is based on a new attitude of the support staff working with people with (severe) intellectual disabilities (ID).

The successful testing has proven the viability of the new model, which is focused on an equal and adult relationship between the supporting person and the ID person, and on the empowerment of the ID person.

The successful empowerment of ID persons and their development toward an independent and autonomous life is not only a model to be followed by professionals and social service providers, but, at the same time, a message to decision makers and legislators not to disempower intellectually disabled persons and to accept and commonly practice the new attitude by

- practicing individual, person - centred education and social support;
- turning guardianship to active support in decision making;
- ensuring free movement, free decision making on residential location and housing, as well as workplace of ID persons;
- fostering participation of ID persons in political decisions by not restricting them in exercising their political right to vote;
- acknowledging their right to have their own partner and family;
- ensuring a “mentally accessible environment”, primarily in governmental offices and community based services and enforcing it in personal services;
- opening a space for the participation of severe ID persons in „normal” life.

SCIENTIFIC NEWS

Quality of chest compressions by Down syndrome people: A pilot trial

A recent investigation paper authored by Servicio de Críticos y Urgencias Pediátricas, Hospital Clínico Universitario de Santiago de Compostela (ES) about training people to perform good quality cardiopulmonary resuscitation (CPR) is now available to be read.

Read the whole article [here](#)

NEWS FROM EDSA MEMBERS

ASSOCIATION LIFE WITH DOWN SYNDROME OF FEDERATION OF BOSNIA AND HERZEGOVINA



Main goals of the association

Promoting and protecting the rights of persons with Down syndrome and enforcing EDSA directions within the national legislation.
Supporting families and promoting a better understanding of persons with Down syndrome in society.

- Youth club -

Goals

promoting the right to work for youths with DS; increasing self-awareness of youths on their right to work; empowering families; increasing employers' awareness.

Actions

10 members of the Club worked in 5 different companies, one day in each company. Each participant had his/her own tutor, who was there to assist him/her in every moment, including the journey to/from work. They also went through 3 workshops with psychologists. 17 companies participated in the project. We had meetings with representatives of the Labour and Social Security Ministry, the Employment Agency, the Fund for Rehabilitation and Employment of Persons with Disabilities and the Pension Fund. These meetings helped us to identify many administrative and legislative obstacles

on the path to employment of persons with DS. One final round table gathered all these stakeholders, together with parents and employers (more than 60 participants). They all learned about the results of the project as well as about the identified obstacles.

Visibility

The round table was very successful. The project and round table got enormous media attention and coverage on TV, radio, newspapers, lifestyle magazines and the internet. 5 TV stations were present at the round table. We produced a short documentary about the project, which was broadcasted on many small, local TV stations around the country.

Comments

However, this is the top of the iceberg; the legislation is old, complex, cross-sectorial and discriminatory and it has a very discouraging effect on the employment of persons with DS. We are determined to continue our efforts in this area.

- Club of little actors - inclusive theater group

Activities

20 actors aged 9 - 19 worked intensively for 10 months with professional actors and professional dancers. The result is the drama "Stories from the meadow", which, apart from the premiere, had one more performance. Visibility Excellent coverage by the media.

Impact and comments

The actors improved their skills of presentation, with clear effects on their speech and collaboration with others. We will continue with performances as well as with widening the repertory in 2015.

Educational projects

- **Club of mathematicians** - improving math skills of children in pre-school and school age.
- Our association provides support of **speech therapist** for children with DS in mainstream schools and kinder gardens.
- Our association implemented an educational programme aimed at **improving motor skills** of children with DS, in 4 large cities in B & H, which also resulted in a book about the same topic
- Educational workshops to increase **empathy and peer-to-peer support** among students in mainstream schools, who have children with DS "Through play to my friend"
- Educational workshops for teachers to learn about methodologies and tools related to the creation of **Individualized curriculums**

Those EDSA members who would like to diffuse one or more of their activities or, however, to present their association, are kindly requested to send a text to the editorial committee (internazionale@aipd.it).

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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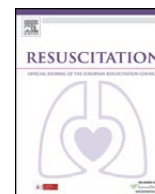
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NEWSLETTER BY



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Simulation and education

Quality of chest compressions by Down syndrome people: A pilot trial[☆]



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ABSTRACT

Introduction: Immediate bystander cardiopulmonary resuscitation (CPR) is essential for survival after out-of-hospital cardiac arrest. Down syndrome (DS) citizens have improved their active engagement in society. The objective of this pilot trial was to investigate if they are able to perform quality chest compression-only CPR after a brief training.

Methods: Nineteen DS young people (15–30 year old) and 20 University level subjects (18–29 year old) were trained by means of a short video and a brief hands-on session on manikins, to perform chest compression-only CPR. All participants were naïve in CPR. Chest compression (CC) quality (percentage of correct CC, CC rate and depth and chest complete release) was measured during a 2 min test. CPR quality goal was according to 2010 European Resuscitation Council guidelines.

Results: DS people had similar weight, lower height and a higher BMI than controls. They were able to deliver chest compression-only CPR but with higher mean CC rate (140 ± 30 vs 123 ± 12 CC/min, $p = 0.03$), less mean CC depth (35.4 ± 10.3 vs 47.2 ± 9.6 mm, $p = 0.03$) and lower % of full correct CC (13 ± 18 vs 39 ± 37 , $p = 0.02$) than controls. Differences were maintained when first and second minute of test were compared.

Conclusions: After a short instruction based on a brief video and hands-on session DS people were able to deliver CC but with poor quality.

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1. Introduction

In case of cardiac arrest, immediate initiation of cardiopulmonary resuscitation (CPR) by bystanders improves survival.^{1,2} However, the number of laypeople who deliver first aid after witnessing an accident remains to be poor.³ Everyone should be

informed and trained to detect a cardiac arrest victim and to immediately start good quality CPR as an essential link of the chain of survival.⁴

In recent years, many institutions have targeted efforts at training laypeople in compression-only CPR skills and have designed CPR training programs and resources to be applied in schools as well as in other settings.^{5–7} Brief videos have been used to train laypeople on the provision of compression-only CPR.⁵

Down syndrome (DS) is the most common genetic cause of intellectual disability. As a result of improvement in medicine, technology, and education, the life expectancy and quality of individuals with DS is nearly comparable to the general population in developed countries. Due to health and social policy strategies as well as multifaceted efforts DS citizens have increased their active

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presence in the society and try to gain integration. Offering DS individuals the same learning and training options as laypersons may be a good way of improving their self-esteem and active role in society.⁸

Due to the fact that we were not aware of prior experiences about CPR training of DS people we designed the “Yes, we also can!” pilot trial. We hypothesized that DS young persons were capable of learning and performing quality chest compressions (CC) similarly to laypeople. The aim of this study was to assess the ability of young people with DS to perform good quality compression-only CPR in a manikin after a brief training supported by a brief funny video in comparison with university students. Primary endpoint was CC depth, CC rate and composite CC quality.

2. Material and methods

2.1. Study design and selection of participants

This study was designed as a prospective investigation and it was conducted in April 2014 in Galicia, Spain. The study sample was divided into two groups: experimental (DS) and control.

DS subjects: The participants were recruited at the Down Compostela Foundation. This is a not-for-profit organization where DS and other disabled people go for training and education to live independently. Currently, a total of 68 DS persons aged from newborn to adulthood use the facility. All DS persons older than 15 years were invited to participate in the study.

Inclusion criteria were: age from 15 to 30 years, mild or moderate intellectual disability (estimated by the Foundation's psychology team),⁹ ability to understand the objective and methods of the study and signed informed consent (by the subject and a parent). **Exclusion criteria:** any physical disability that limits chest compressions. Of possible 20 candidates, one was excluded due to lack of cooperation during the learning/training process and the study was performed with the 19 remaining.

Controls: University students of the Social Sciences and Communication School at the University of Vigo (Spain), without physical or psychological disability, aged between 18 and 29 years were invited to participate in the trial by means of posters at the School entrance hall and cafeteria. Of a total of 220 potential participants, the first 20 who accepted and signed the informed consent were recruited. Three of them did not come to the test, resulting in a final inclusion of 17 participants.

None of the participants had received CPR training before the study. Participation was voluntary and no personal incentive for participation was given.

2.2. Curriculum content

In designing the training program we took into consideration the characteristics of the experimental group, who usually have some difficulties to maintain their attention span during instruction.¹⁰ We decided to use a short (3 min, 20 s) video that tells a story of a boy who suffers a sudden collapse while playing indoor football and is resuscitated by his coach; at the end of the video, an “expert” summarizes the essentials of bystander CPR. The video is available on the web: <https://www.youtube.com/watch?v=ZQdwoRf-TLg>.

The video was intended for a younger audience or people with learning difficulties as it is narrative with some comic elements.

Each group was split in two subgroups that viewed the video in separate rooms. After viewing the video, the instructor performed a real time chest compressions-only basic life support (BLS) sequence on a manikin (*Resusci Anne*, Laerdal, Norway) and was open to questions from participants for 15 min. After that, participants trained the CC hands-only sequence on manikins (*Resusci Anne* and *Mini Anne Plus*, Laerdal, Norway) (one manikin for each two of them)

with a 5/1 participant/instructor rate, during 45 min. Feedback was provided to subjects by the instructor in order to achieve the goal of 2010 European Resuscitation Council adult BLS guidelines.⁴ The four instructors and the course director (all co-authors of the study) were certified in basic and advanced life support and had a substantial experience as CPR instructors in courses for laypeople, lifeguards and health professionals.

2.3. Measurements

We documented age, gender, body weight, height and body mass index (BMI) of participants and previous BLS training.

CPR quality was assessed through the *Laerdal Resusci Anne* manikin connected to a *Laerdal PC SkillReporting* Software, version 2.4, which measures hands position, chest compression rate in CC per minute, depth in mm, detects leaning and hands-off time. It gives results for the individual CC quality components as well as a composite result of the combination of all of them that indicates full correct CC. Goals were set according to the 2010 quality standards established by the European Resuscitation Council: 2010: depth of 50–60 mm and rate of 100–120 compressions per minute.⁴ Complete release was defined as a leaning force between compressions of <0.5 kg.

During the challenge tests, participants were asked to deliver 2 min of continuous CC. Tests were done between half and one hour after the training. Subjects were tested individually; they were alone and without feedback or external references. CPR quality recorded variables were: total number of CC, CC rate (CC/min), CC depth in mm, and percentage of fully correct CC, correct CC rhythm, and chest complete release. Applied work was calculated as: CC rate × CC depth.¹¹ Analysis of the test total time (2 min) and an analysis segregated by time (first minute and second minute) were done.

2.4. Statistics

Categorical data are described by absolute numbers and percentages. Continuous data were described by average and standard deviation (SD). All *p* values are two-sided and *p* < 0.05 was considered to be statistically significant. The homogeneity between groups was assessed by Kolmogorov–Smirnov test. The equality of variances was determined using Levene's test. Correlations between continuous data were assessed using Student's *t*-test. SPSS Statistics 20.0 Software was used for statistical analysis.

2.5. Ethics

Participation was voluntary and no personal incentive for participation was given. Data were treated anonymously. The study respected the Helsinki Declaration and was approved by the local institutional review board (Research Ethics Committee of the School of Education and Sports Sciences, University of Vigo). Verbal and signed informed consent was obtained by the participants (in control group) and by participants and parents or guardians (in DS group).

3. Results

DS individuals had lower height and slightly higher BMI than controls (Table 1).

CC quality results are shown in Table 2. CC rate, percentage of shallow CC, and percentage of CC without complete release were significantly higher in DS subjects than in controls. Mean CC depth, percentage of CC delivered at recommended rate, and the percentage of the composite variable “full correct CC” were significantly lower in the experimental group than in controls. The applied work

Table 1
Age, sex and anthropometric data of subjects.

Group	Down syndrome (N = 19) 16 male/3 female		Control (N = 17) 7 male/10 female		p
	X ± SD or median	95% CI or IQR	X ± SD or median	95% CI or IQR	
Age (years)	23.3	21.6–24.9	22.3	20.7–24.0	0.40
Height (cm)	159 ± 4	155–163	170 ± 10	165–175	0.001
Weight (kg)	71.7 ± 14.8	64.8–78.7	71.8 ± 20.3	61.4–82.3	0.06
BMI (kg/m ²)	28.4 ± 4.7	26.2–30.6	24.5 ± 4.8	22.1–27.1	0.02

IQR: interquartile range.

Table 2
CPR quality variables in Down syndrome persons and controls (mean ± SD).

Group	Down syndrome (N = 19)	Control (N = 17)	p
Total CC (n) (goal range: 200–240)	279 ± 61	249 ± 25	0.06
Mean CC rate (bpm) (goal range: 100–120)	140 ± 30	123 ± 12	0.03
Number of subjects inside the goal range	2	7	
% of CC with a rate inside the goal range	20 ± 25	86 ± 9	0.008
Mean CC depth (mm) (goal range: 50–60)	35.4 ± 10.3	47.2 ± 9.6	0.001
Number of subjects inside goal range	2	9	
% of shallow CC	84 ± 31	46 ± 42	<0.001
% of CC with incomplete release	46 ± 42	21 ± 15	0.04
% of full correct CC	13 ± 18	39 ± 37	0.02
Number subjects reaching 70% of full correct CC	0	5	
Applied work (CC rate × depth)	4976 ± 1693	5805 ± 1359	0.1

measured as CC rate × CC depth was slightly higher (non-significant difference) in controls.

When performance during first minute was compared with second one, no significant intragroup differences were observed and the differences between groups persisted.

4. Discussion

Layperson information and training is essential to increase bystander CPR rates and out-of-hospital cardiac arrest outcome.³ Although several training methods and programs have been implemented, we lack evidences about the best in terms of feasibility, usefulness and cost-efficiency. Hands-only CC is a proposed alternative to standard CPR for laypeople in witnessed unexpected cardiac arrest, because it delivers substantially more compressions per minute and may be easier to remember and perform.^{12–15}

Our results obtained with a mixed method (relatively brief video and short instructor training), indicate that with a total of 1 h training, university level laypersons can achieve a relatively good quality of CC. However, with this training method DS people were able to perform CC but with poor quality.

In terms of CC rate, control subjects delivered CC in the high range of the ERC recommendations (123 ± 12 CC/min) and in terms of depth they performed in the lower range of recommended (47.2 ± 9.6 mm) limit/level{AQ}. Comparable results have been reported by Hirose et al.¹⁶ using a simplified 45-min CPR training program for non-medical staff working at a university hospital. On the other hand, Panchal et al.⁵ obtained worse results (median depth 37 mm and median CC rate of 106 comp/min) with an ultra-brief video viewing without hands-on training among bystanders in a shopping mall. These data support the use of

brief video + hands-on demonstration + hands-on practice as the CPR training methodology for laypersons with the aim of increasing as much as possible the number of people trained with the minimum amount of material, staff and time.

With this training methodology we have observed that DS young people performed worse than controls when CC rate and depth were considered. Our DS subjects obtained CC depths comparable to those reported in laypersons after viewing an ultra-brief video⁵ and to those reported in other settings by professional subjects.¹¹ Hong et al.¹⁷ in a crossover study comparing 100-cpm to *as-fast-as you can* observed that subjects from both groups achieved similar CC depth as our DS subjects (38 ± 8 in the 100-cpm group and 35.6 ± 12 mm in the push-fast group).

DS people delivered CC at a higher rate than that recommended by ERC⁴ but if we follow the AHA recommendation *push-as-fast-as you can*, instead of 100-cpm,¹⁸ they would have achieved the goal. In fact, in the Hong et al. study,¹⁸ the nonprofessional volunteers in the *as-fast-as you can* challenge delivered even higher rates (156 bpm) than our DS subjects.

We observed that the work applied (CC rate × CC depth) by DS was similar to controls but if we consider that prior studies have reported a link between excessive CC rate and insufficient CC depth,¹⁹ as it was the case with our DS participants, it seems clear that some additional advice and training should be needed in order to increase CC depth and avoid an excessive number of CC. Training aids like metronomes^{20,21} and popular songs,^{22,23} as well as repetitive retraining²⁴ might be helpful in this sense. Although no prior studies have been carried out to test this hypothesis, having in mind the psychological as well as the learning and training characteristics of DS people,²⁵ we consider that songs and other fun and focused strategies might improve CC quality and would be welcome by youngsters with DS.

Although the results of our pilot trial indicate that they need more training time or sessions than university laypeople, we consider DS people a good population target to train basic CPR. An increased risk of cardiac arrest due to their diseases may be a rationale to support this effort, but other reasons like their society-inclusion must be also considered. Our subjective opinion is that DS people and their support groups are willing to learn new abilities and to become more active in their social environment.

Our pilot trial opens some perspectives for future studies. It can be hypothesized that DS people may achieve similar performance as of University students if they are trained more intensively or with repetitive training sessions. Also, a similar training approach could be applied to other selected disabled people.

Limitations: Our samples were not equivalent in terms of anthropometry (although both groups had similar weight, DS subjects were 11 cm smaller and had 3 point higher BMI than controls). Some results bias could be attributed to this difference. It can be argued that controls were favored by their height but also that DS could have an advantage because of their higher BMI.²⁶ Although a possible selection bias could be present if the most well functioning DS people were volunteering, this is not probable because one inclusion criteria was to have mild or moderate intellectual disability and physical disability to perform CC was an exclusion criteria.

In this sense, our results only refer to well functioning DS subjects and not to those with severe disabilities. Our study was done in controlled situations, on manikins and just after the training; therefore direct extrapolations to real life cardiac arrest and CPR (occurring at random and in uncontrolled situations) cannot be made. Knowing that CPR performance decreases quickly with time, it would be interesting to test the ability of DS to deliver CC after 3 or 6 months and the potential effect of periodic rolling-refreshers on their CPR quality.²⁷ Also, our results may be biased by the innovative and non-validated training methodology applied; additional studies to investigate the effect of specific training programs on CC quality both in normal and DS people are needed.

5. Conclusions

After short instruction based on a brief video and hands-on session DS young people with mild or moderate intellectual disability and without physical disability were able to deliver CC but failed to achieve good CC quality.

Conflict of interest statement

The authors declare that they have no conflicts of interest related to the present study.

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