



WISPEL

Wisdom of Special PEople



Aarhus Social and
Health Care College



INTRODUCTION

About WISPEL

When we have started the **WISPEL** (**WIS**dome of **SP**eciAl **PE**ople), we were thinking about those people and families of people with disabilities who have come to that point in life when they can say they are no longer suffering because of the disability. Not mentally. Not in their heart. They feel accomplished. They feel that their life is good. They are serene and content.

We knew there are such people! We just needed to find them. And to ask them about things that could help other people like them, who have themselves a disability or have some child or relative with disabilities. Tell them simple things, like where to look for support, how to deal with problems, what could make them happy or motivate them.

At that time, we have thought this could be a great example of peer-to-peer learning and passing knowledge, even wisdom. And we were right!

We have found amazing people, in every country! We have learned life stories that changed us for good! We have seen how the stories told by the very disabled persons are more powerful than so many books and lectures!...



During these two years of the project, we have been to multiple events and experiences: we have participated in national and international conferences; we have visited education, rehabilitation, living and training facilities for people with special needs (or without); we have talked to fantastic persons, who got above the disabilities and suffering, building a decent or sometimes brilliant life; we have seen shows of people with disabilities, and we have laughed, we have been impressed and we have cried...



It took us 7 project meetings, endless hours of talks and interviews, hundreds of e-mails, few Facebook pages, blogs, web sites, countless phone calls, paper, posters, flyers, time, heart and soul, spirit and focus...

After we have found the right people, asking in the communities and nationwide in each partner's country, we have applied a questionnaire. Only five questions. Asking, if necessary, for more information, more content for those who will receive the messages at the end of the project. Because we didn't want to have just a product, at the end of the project. We wanted to have an inspirational instrument, which could be accessed and used every day by those who are still looking for support and answers about their disability or the one of their son or relative! So we have insisted in having real, powerful, meaningful answers.

All these wouldn't have been possible without the network we have created from seven European countries (Romania, Spain, Italy, Turkey, Latvia, Portugal, Denmark). Only these kind of diversity of cultures, ways of life, social

environments, disability approach etc. could have brought us to such a broad view on life and how you can live beautiful, no matter the disability.

It is the great merit of the European Commission Programme, which allows organizations of all sizes, types, backgrounds etc. to participate in such projects, to be equals, to bring their input and contribution and to benefit from the results. It is a unique opportunity for most of the participants, and it was appreciated throughout the entire project.

So, what have we done, after all? Well, basically, apart from the rest of the work and things we have done during the project, we came out with two main products:

- a book
- a website

They contain the wisdom we have gathered from the people we were talking about at the beginning - those who have overcome not necessarily the disability, but the suffering and the distress and depressive thoughts about it. Advice, suggestions, positive experiences, guidance.



That is what you can find in here.

Hopefully, all these things and pages and pieces of soul and spirit from all over Europe will lead to a better life for the other people with disabilities or families of people with disabilities. We are convinced the products have the power to increase their knowledge and basic, social and life competencies and skills.

Have we achieved our objectives? Let's see what we intended when we started the project:

1. To form a network of organizations working/ in contact with disabled people
2. To gather advises and experiences from the people with special needs and their families for their peers.
3. To provide the structured information to other people with special needs and families of such, in the countries of the network members and across Europe/ worldwide.

So, what do you think? We say we have done all that with great success! And more: we have made good friends, enriched our lives and improved our work!

We have always wanted a life without barriers for the individuals who have disabilities or the families who have members with disabilities. This book you are reading (on paper or on an electronic device) is another step towards this life.

A life with purpose, filled with joy and happiness...



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ROMANIA

Esperando Association

Founded in 2001 by parents of disabled children, Esperando Association became one of the best-known organizations working in the field in Maramures County, and also in Romania. In October 2001 Baia Mare Day Care Recuperation Centre for Disabled Children and Youth was opened, further on developing a network of services in Botiza and Cavnic.

Esperando assists disabled children and adults who either attend the activities in its day care centre or get home care services (rehabilitation and support for patients that can't move or walk).

The activities in the Day Care Rehabilitation Centre are complex and consist in recuperation, physical therapy, physiotherapy, therapy with games, music and arts therapies, therapies with animals, special education, speech therapy, development of independent life skills, psychological counseling for children and parents, parents support groups, practical activities and handworks, socializing and inclusion activities etc. We personalize the interventions for each kid or adult.

We also try to have activities with our clients as much as possible in the community: we organize selling, shows, we go to museums, shops, trips, summer camps and so on. Our members have lots of interactions and exchanges with community schools, kindergartens, high-schools, organizations, volunteers etc. This way, the people with disabilities learn to leave inside the community, to communicate, interact and relate. They make friends and show their work and abilities/ capacities. On the other hand, the students from public schools and the

other partners we have get acquainted with disability and learn about diversity, special needs, generosity, love and friendship.

Esperando is member in all the national umbrella organizations in Romania in the area of disability and child protection.

Since 2011, Esperando Association is an accredited provider of vocational trainings and support for employment. We have organized numerous trainings and provided recognized qualification certificates. As a result, more than 90 persons could get a job and improve their life.

The Association provides education also to parents/ members and to staff. We offer support, information and help to families, disabled adults and people in need.

To support the social activities, Esperando has developed a number of social economy activities. We have dozens of clients and partners. Most of these collaborations are long term relations built on trust and reliability. Apart of the exclusiev use of the funds from the economic activities for supporting the social services, we have 6 employees with disabilities.

At European level, Esperando became a very active organization, involved in many projects, some of them as coordinating partner. As a result of the work in these projects, the activities have developed and improved in Esperando Rehabilitation Centre and in the organization. As a recognition for the good work in these European projects, the Association was invited to represent Romania in several European and Romanian Conferences regarding European projects.

We have also received awards and other recognitions for our work in Europe.



DENMARK

Aarhus Social and Health Care College

Aarhus Social and Health Care College is a non-profit vocational educational school and the second largest in the country.

The college provides different educational programs and supplementary trainings of educated staff members varying from child care, social and health care institutions for elderly to hospitals and psychiatry. The college offers special educational introductory programs for immigrants and refugees.

The college employs more than 130 people including around 90 educators and offers basic education as well as refresher courses and in-service training.

The college cooperates with more than 100 partners in 30 countries all over the world - and have learned how much there is to learn from international cooperation.

Employees and management have a common responsibility to create a good and attractive workplace with ambitious goals and results.

The college works purposeful towards a strengthening of professionalism and inclusiveness by focusing on the development of the school's learning environment.

The college is one of few Danish Social- and Health care colleges with its own multimedia production unit and is one of the leading developers of interactive web based pedagogical and learning materials.

ITALY

Coordinamento Nazionale Insegnanti Specializzati

The Association CNIS is on the list of qualified associations (MIUR) and the list of accredited associations for staff training of the MPI School.

Its main features are distinguished by efforts to update teachers, with a close link with university researchers in the field of disability. The President is a Professor and pro-Chancellor at the University of Padua. C.N.I.S. promotes teacher training through a variety of activities with the following aims:

- promoting studies and research in the field of psychopathology, learning, psychology of disability situations and individual educational intervention;
- encouraging the widespread of information, of scientific and technical knowledge among those who work in these areas of research, teacher training, teaching.

The association aims at:

- contributing to study programmes and research carried out by scientific institutes;
- carrying out surveys, studies and research directly;
- publishing or divulge monographs, documents, papers;
- organizing congresses and meetings, carrying out training and cultural courses,

-participating in congresses, conferences and meetings on topics relevant to the aims of the Association;

-maintaining contacts with the Italian and foreign operators in this field.

On a national level congresses are organized which are attended by well-known international scholars. On a decentralized level it is represented by Local Branches (on a regional, inter-provincial, inter-municipal or municipal level). Locally, the Branches operate with different types of proposals.

We organize high level trainings, seminars, workshops on specific topics, laboratories, specific training to draw up learning material. We have a long experience in pedagogic and reading tools and strategies to improve the processes of education, in training the teachers and parents., so we can have an important role of training in this project, spreading our long experience on partners. With this project CNIS aims to widen the European dimension of the Association through the contribution of the participants, to overcome the actual diversity problems in the cross-cultural dimension of lifelong learning programme.





LATVIA

Cerību Spārni (Wings of Hope)

Union Cerību spārni was established in 2003 and united families with disabled children, their supporters and specialists. The main activity of union is oriented on persons with functional disorders and their family members integration in society, protecting their rights and interests, organizing their free time, education and rehabilitation, promoting their employment.

Social rehabilitation services beneficiaries:

- Children - 80 (active cases);
- Adults - 18.

Core activities of Union:

- Rehabilitation services to persons with disabilities and development of new services for families in needs;
- Support program development and implementation;
- Development and implementation of social projects;
- Participation in national and local working groups of various documents, development of plans and guidelines;
- Organizing various trainings for Union audience and the public;
- Promoting and providing volunteering;
- Working with local governments, businesses and other NGOs.

Charity trade centre Pogotava in Sigulda:

- Various handicraft technique training;
- Handicraft sale (custom-made toys, knits, crochets, embroidery, etc), diverting income for community project Cerību sēta ("Yard of hope") development;

FUTURE PROJECT: COMMUNITY CERĪBU SĒTA (YARD OF HOPE) FOR PEOPLE WITH MENTAL DISORDERS:

Offered activities in the community:

- Living environment (at houses);
- Specialized workshops;
- Social enterprise, alternative forms of employment;
- Family environment;
- Self-care and participation in daily activities;
- Ability to live according to age group needs.



PORTUGAL

Associação de Paralisia Cerebral de Coimbra

Associação de Paralisia Cerebral de Coimbra - APCC is a private institution of social solidarity and a non-profit organization in Portugal, created in 1975. Everything it does is reflected in its mission statement and values.

Mission: Promoting social inclusion of people at a disadvantage, with special focus on people with disabilities.

Vision: Being a reference organization, nationally and internationally, in enabling full integration of people with disabilities and other disadvantaged individuals.

At APCC people's with disabilities have the opportunity to develop their skills through areas of Rehabilitation, Vocational Training and Employment, Youth, Volunteering and Adult Education.

The APCC works with multidisciplinary teams. The methodology is regarding the quality of life in the whole life cycle perspective according the approach of World Health Organisations - WHOQOL.

APCC is integrated in a National Federation and its geographical scope of intervention is all the centre region of Portugal.

APCC has considerable expertise and competence in the delivery of its

i) Centre for Qualification - CQEP with the aims to information , Guidance and Recognition and Validation of Competences in the ambit of Vocational Education

and Training , ii) Local Resources Centre, recognized by the Labour Ministry assuring all the socio-professional integration process of disadvantage groups,

iii) 3 Residential Units , iv) Support Unit Transport network, v) Horse Riding School specialized in Hipotherapy , vi) Toy Library/ Resource Centre, vii) Home support services, viii) Sports and Recreation, ix) Music Therapy , x) Drama & Arts , xi) Volunteering Department and xii) Office of projects innovation with more 21 years of experience.





SPAIN

Asociación Profesional de Orientadores en Castilla - La Mancha

The Professional Association of psychologists in Castilla-La Mancha (APOCLAM) is a non-profit association that is composed by more than 400 professionals dedicated to the school guidance in the region of Castilla-La Mancha. We are psychologists, secondary school teachers and therapists who freely and independently organize ourselves to improve our work for the benefit of the students with specific needs, teachers and families.

Among our main activities we highlights the organization of courses for guidance educational advisers to treat with different problems and issues like social integration, disabailities, giving them lots of resources and tools to face these particular problems. Periodical meetings, publications with news for being updated, workshops, conferences, etc. are some of these activities. Furthermore, we are in close contact with Regional University as for the next coming teachers training is referred.

Consequently our main goals are:

- • To improve education in those areas that we are working, especially, the school at both public and private sector.
- • To establish a to facilitate the communication of all the members, to share experiences and materials and to promote initiatives.
- • To contribute to the training of their partners, teachers in general and families by means of the organization of congresses, courses, seminars, workshops, conferences, etc.
- • To promote collaboration with the University of Castile-La Mancha, and other institutions in a local, regional and national scope
- • To make possible a contribution, with all the actions of our institution, to achieve the goal of a quality educational system for all.

The intention of taking part in this european cooperative work is to take to exchange practices and good experiences on family educational field and to learn how to integrate into our work new methodological approaches.



TURKEY

Şile IMKB Halk Eğitim Merkezi

Our center opened for education in 1965 in the building of Local Special Administration and later has moved to the current building which was once a secondary school. The building was ruined by the earthquake in 1999 and our center temporarily had to move to Balibey Primary School building in Hacıkasım District. Upon that the central building was completed by the contribution of İstanbul Stock Exchange Market, our center has been moved to its new building in May 2003. The Public Education center is one of the best educational institutions in our district with its new building sufficient to meet all the needs, its 50-year corporate culture and its activities and disciplined corporate structure. Common goal of all the staff who has adopted and shared the corporate values is to make our public education center well-known beyond the borders of Şile District and to improve the current corporate values.



WISPEL

Setting the Scene

The WISPEL Project it was designed having in mind the persons and the families who are living with a disability and is aimed at promoting peer-to-peer sharing of life wisdom and experience.

Notwithstanding the relative pertinence of more traditional approaches to the understanding and intervention on disability, a social model of disability was clearly preferred in the context of the present project and its program initiative. Within this theoretical and operational framework, disability is defined as the consequence from the insufficient adaptation of the environment to the needs and characteristics of the individual (Fauconnier et al., 2009). Therefore, despite the merits of the contemporary terminology in the expression “people with disabilities”, for its focus on the person to a greater extent than his/her disability, some authors have claimed their preference for the phrase “disabled people”, in order to emphasize the idea that those people are in fact disabled by society or the environment (Colver, 2005). Given the fact that environmental factors can act as potent facilitators or barriers for the adaptation, development and quality of life of people with disabilities (Mihaylov, Jarvis, Colver, & Beresford, 2004), the contribution brought by the present project is best understood as an peer-to-peer education informal learning approach to the quality of life of every person who has a disability and family of such a person can be significantly improved and enriched in the sense that it objectifies an inspiring practice cases-based namely in terms of the enhancement of the most general quality of life facets, such as their work capacity, learning abilities, self-esteem, social support, opportunities to acquire new

information and develop skills (The WHOQOL Group, 1995), as well as the most specific quality of life facets for people with disabilities, which include their future prospects, control, choice, advocacy, social inclusion and social network (Power et al., 2010).

The main outcome from the WISPEL Project is a tool that use the wisdom of life and experience of the disabled people and their families as an opportunity to improve their competencies and knowledge benefiting from the experience of their peers.

In agreement with the aforementioned theoretical approach to quality of life conceptualization, it is noteworthy that the empowerment of people with disabilities may be described as a dynamic, interactive process between the individual and his/her environment, which covers the dimensions of access to information and resources, availability of options for decision-making, assertiveness, introducing change in personal and community settings, acknowledging the importance of learning skills, and changing others' and self's perceptions towards one's abilities and skills (Chamberlin, 1997). According to this operational definition of empowerment the WISPEL final product may thus be considered as a practical contribution for the continuing empowerment of disabled people and their relatives.

In fact, even if the target-group of disabled people poses specific challenges, the vision shared by this project's European team is that people with disabilities need essentially the same things as other people in general, even though they may require significant environmental adaptation and additional attention to their learning and functioning specificities.

The WISPEL tool is tailored to the most general learning characteristics for people with disability and their families.

For more information on the WISPEL cases and best practices for peer to peer adult education informal learning , please visit the project's website: <http://wispel.europole.org/>

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The red line of happiness

Being happy is not easy and for a disabled person it can be even more difficult.

Nonetheless the interviews gathered for this project demonstrate that it isn't impossible. But how is it possible? What is the red line common to all the people with disability looking for happiness even if they are living different lives, in different places?

The first condition is that the person with disability need to be at the centre, not his/her disability.

All people have a name and we all would like to be identified through that name, not through the type of disability.

What we have learnt from our interviewees is that family is important as it is one of the worlds full of love around us.

A family that can/must build up a net of positive alliances with associations and residences for people with special needs: school, rehabilitation centres, job places, local authorities, etc.

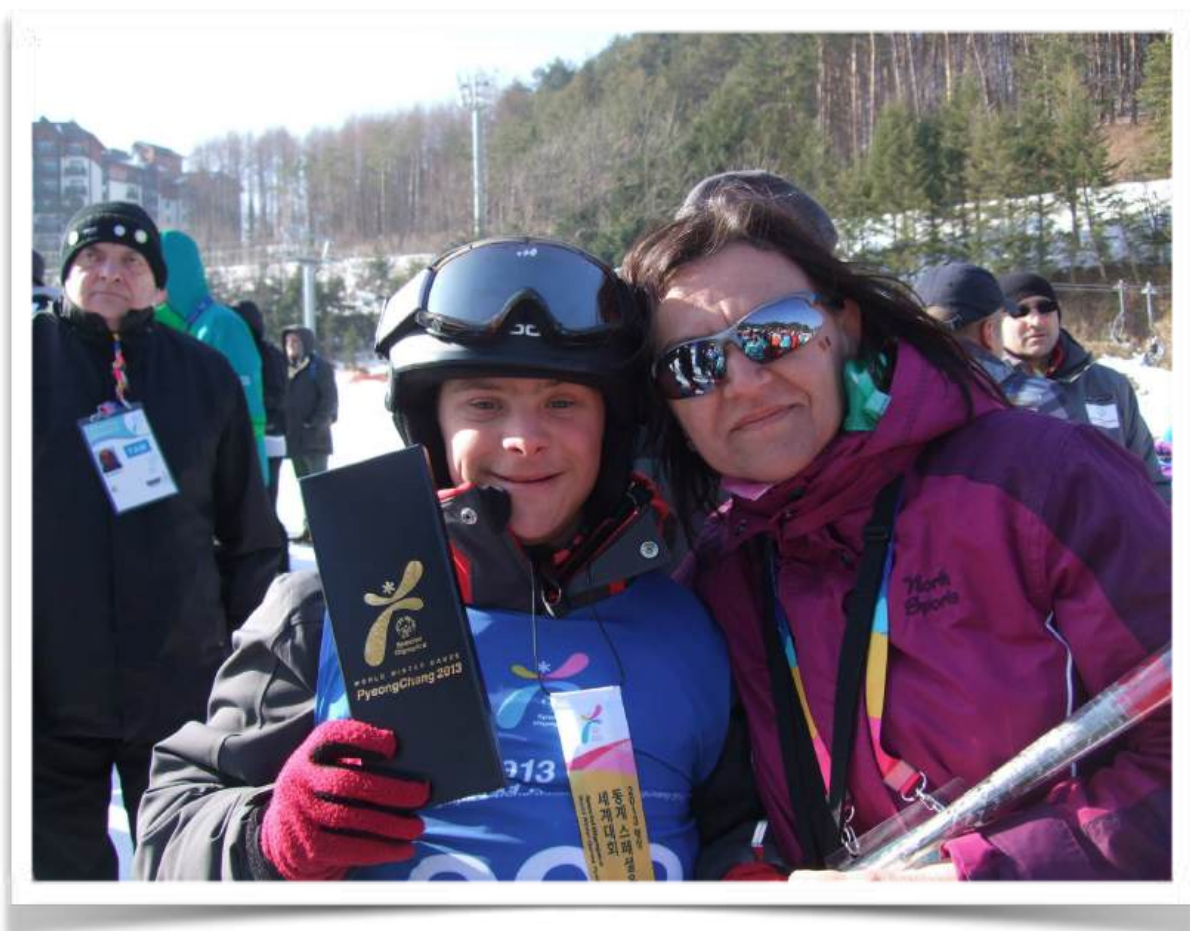
We don't have to forget that these places are home of professionals: teachers, doctors, social workers, educators, all people that can make a positive difference in the quality of life of the person with disability and his/her family.

Finally, through this kind of righteous sympathetic net, the person with disability can face the challenges of life improving and becoming, step after step, protagonist of his/her own life, finding "keys of reading" but also practical and proactive supports which consent to take advantage of all the chances to be herself/himself.



INTERVIEWS

About Andrei Cupsa (son of Liliana Cupsa)



Andrei, who has Langdon Down Syndrome and is now 20 years old, started sports at 9. He started with swimming, in a group with 20 children who were having no disabilities or problems. There were no integration issues, he went with pleasure at every practice, and he managed to somehow float!

In time, with the help of the trainer and with a lot of work, he got to swimming by himself, in a pool, a lake or a sea. Since 2010 he is participating in Special Olympics competitions, and at the same time more serious trainings. During the years he have won medals in regional, national and international competitions. Last year he won a silver medal in Monaco, competing with athletes from 15 countries.

About the same age (9-10), he started to ski. He loved it and love it a lot, even better then swimming! In 2010 he also participated in ski camps and national and international competitions. Now he is the best ski athlete in the country among people with intellectual disabilities.

In 2013 he represented Romania at the winter Special Olympic Games in South Correa, where he got a silver medal in slalom and two other 7th places.

Sport had a major contribution in Andrei's integration and even more in his self confidence building. Due to his sport results, the local community, and not only, realized that it is important to appreciate somebody for his abilities (even when it's a person with intellectual disabilities).

Written by Liliana Cupsa, Andrei's mother

Answers to our Questionnaire

1. What exactly brings happiness into your life?

Happiness for me represents the fact that I am healthy, that I have a healthy child who is satisfied with his life. Each accomplishment from his part is an acknowledgement of the work that I have carried through all these years.

2. Where have you found support and assistance/ counseling when you confronted yourself with difficulties?

I found the support I needed in my friends and in my family. The professionals (teachers, psychologist and speech therapist) provided counseling. I did some research of my own and I tried as well to be a “professional” in all the aspects that concerned my child.

3. How did you handle the new challenges?

A challenge represents all those 19 years that have passed since I had Andrei. There were situations when I needed help (I asked for it and I received it) and there were challenges that have stimulated both of us and we managed to get through them. A challenge was the enrolment into the community and each passage from one school programme to another. A challenge for us was to grant Andrei the independence that he longed for (friends, school trips, go out for a movie with the mates etc.). A challenge was when he took up different sports and he participated to competitions.

Each summer before changing a school programme we read the law, we went to school and we discussed it with the teachers (we presented the reality related to Andrei). We had meetings with teachers and with the parents of the children who were to be his mates. After having received the approval from the school, we knocked at the doors of the county board of education, after having studied well the law, and we received the distribution to the related school with the promise of having a support teacher (if the school had money to pay him). There were times when I had to pay the support teacher. I did homework, at home, every day, for every subject. Since Andrei started going to school I have been involved in all the school and extracurricular school activities, trying to sensitize the school and the society in general regarding the disabilities. Why have all these things been a challenge? Because I was a sort of “pioneer” and because I did not imagine I could fight against so many preconceived ideas and against such a lack of information.

A challenge has also been Andrei's participation to competitions and sport camps. I had to let him go for 7-10 days, I had to deal with him handling luggage, dealing with a daily schedule, with trainings, without me helping him. He proved to me that he could deal with all this and that he could apply everything that I have taught him.

I believe I did well and that Andrei is today a worthy example of a disabled person who is able to do everything he desires (in his own rhythm and at his own level). He is also aware of his limits, but this does not prevent him from desiring the same things as any other young person.

4. What was the motivation to always move on?

The motivation? That is easy: my child had to reach his full potential, he had to be happy and satisfied of what he CAN do and he had to live a normal life (as normal as possible considering the society we are living in).

5. What sort of advice would you give to someone who is now dealing with a disability or to someone who has difficulties?

My advice concerns parents who have disabled children!

We are not aware of what a child can do unless we put him in a certain situation. Try to discover and develop the abilities of the child (surely, there must be things he can do) and do not insist on the disability. Work constantly with the child, praise him for every good thing he did, let him take chances (I know it is very hard and there is a tendency of protecting them more than necessary). Try to do things as if you do not have this "problem" and try to live, as well, for yourselves. Having a disabled child does not imply that you cannot have a normal life. It involves more work, but also greater satisfactions and a great deal of love.

Liliana Cupsa (Mother of Andrei, a young man with Down Syndrome, Special Olympics medalist) - Baia Mare - Romania



About Gheorghe Petreus



Ghita (that is how everybody is calling Gheorghe) is a unique man. After a quiet childhood, he got to be flat in a bed for the rest of his life. Still, he lives life at it's full and he enjoys every moment!

"I am a happy man and I live in harmony with everything that surrounds me" says Ghita.

Laying on his back, and moving only his fingers, Ghita wrote a book! All by himself! With a rod bended as a claw with a long arm, which his friends put in his palm, he is hitting the keys of a laptop one letter at a time.

And so we have a beautiful book filled with the wisdom of a man who have got closer to God in his suffering and who have come to appreciate and to enjoy every thing he has or he sees; a flower, the forest, the rain.

Ghita has fulfilled his dream - to see the Sea! As any special man, Ghita has fantastic friends who are by his side and help him with the daily life, and also to pass through the loss of his dearest persons - his parents.

Not only he is optimistic and grateful for life's gifts, but he is also encouraging other people who are in difficulty - friends who have disabilities or who find themselves in tough times in their lives, with problems, depressions, sadness...

Ghita has always a nice word for them, an encouragement when its needs, a rebuke when they let themselves taken down too easy...

This is Ghita, the man who, leaving his life laying on his back, sees more of the sky then we do...

Answers to our Questionnaire

- 1. What brings happiness to/ into your life?**
- 2. Where did you find support and assistance/ advice/ counsel when you faced difficulties?**
- 3. How did you cope with new challenges?**
- 4. What was your motivation to always go on?**

No matter of the situation of each and every one of us, no matter of the way we look, of who we are or what we have, I personally reached the conclusion that without God we are dust in the wind, and sooner or later we go back to being dust. I say this as I have understood the depth and the value of the man facing God. Everything comes from Him, and everything will go back where it came from. The Holy Bible says... What would be the use of winning the entire world, but losing our soul? Or, what would man give in return for his soul? This shows one more time, how sick is a person who allows himself to be overwhelmed by the passions and misdemeanors of this world and in the end becoming their slave, searching for his personal interests, without any consideration to the ones around him. This is how the envy, the selfishness, the malice, the deceit and all the other sins come to light, things that only cloud the judgment and the soul of the human being and drift him away from God and from a moral life.

I am happy and satisfied with myself and with God. I cannot walk and physically speaking I am the prisoner of this bed, but spiritually speaking I am FREE. Yes, I am free to look at the marvels around me, at the nature with all its beauties, to smell the flowers and to admire their gentleness, to listen to the songs of the birds and when the night comes to look at brightness of the stars and at the mysterious

universe while listening to the wonderful song of the crickets... I am happy that I exist and that I have the face and the image of God. For this and for many other things I cannot and I lack the words to properly thank to God.

I do not consider myself sick or a marginalized person, even though I have sometimes encountered many difficulties due to my situation.

5. What advice would you give to somebody who now faces disability or who has difficulties?

My advice for other disabled people is to never stop fighting for every sunrise and sunset, for this magnificent and unique gift that we have from God, called LIFE. We have to rejoice and to be united in this fight and never forget to thank God for all these trials. The food is for the stomach, and the stomach is for the food, and both shall perish, but the soul is for God and it is immortal... Let's live in dignity, with our heads up, no matter what those around us say. Let's always try and be beautiful inside of us and let's show to others our true face, just as we were created by God, beautiful and carrying a noble soul.

Gheorghe (Ghita) Petreus – Botiza - Romania

(47 years old, paralyzed since he was 16 years old, only moving one hand and the head)



About Crina Pop

Mrs. Crina Pop is a success woman. Despite her disability from early childhood, she got herself through school, established a family, raised a child and became a respected professional. She is leading a very good organization of people with physical disabilities in the North-West of Romania, in Satu Mare. She is the president for many years, and she succeeded not only keeping the organization afloat, but also making it visible, having lots of activities and getting a lot of support.

She shows not only character, but also strength and determination and she lives a happy and full life.

She is for sure one excellent example of how you can live a good life even if your disability is not at all easy.

Answers to our Questionnaire

1. What exactly brings happiness into your life?

The fact that I have come to this world represents the greatest gift God gave me. This could be enough to declare myself happy, but I have so many other reasons to consider myself happy: I had the chance to study, to have a job, to work, to receive a pension after my work, to get married, to be a reliable wife, to have my own child, to raise the child of another mother, to make my children special people who are useful to this society, to find resources to still have to this day a job, to help my peers, to be a trustworthy friend, to be appreciated by the people I meet... And to do all these things while having a serious disability (first degree disability with

personal assistant), acquired at the age of one year and four months, after getting sick with poliomyelitis.

2) Where did you find support and assistance/advice/counsel when you faced difficulties

I come from a poor family and I am the youngest of the four children. I left home once I got sick and I actually grew up in hospitals, sanatoriums, homes, special schools. I think this was my chance. I grew up only among intellectual people (doctors, nurses, educators, teachers). Nobody pampered me, but I felt that everywhere, the people who contributed to my raising and education did all this with a great deal of dedication. The fact that I grew up in communities with children having the same disability as mine helped me a lot. We used to copy one another and do the same things when dealing with certain situations. If I saw a child who managed to stand up using his crutches, I did it myself, being convinced that if he was able to do it, I would as well. At school I did not miss any laboratory or practice using the excuse that I could not go up the stairs. We were a great number of children who used to crawl up the stairs in order to get to the chemistry, physics or biology laboratories. Nobody laughed at me, we were all the same, and there was some sort of competition in our studies.

There, I have learned to communicate in a civilized manner, to ask someone to help me and to thank for the favour I received. There, I have learned that God only helps us through people and that the greatest assistance or counseling is received from that person who is near you and who is just like you. In my childhood, I only met psychologists when groups of psychologists came from Bucharest, from Pantelimon Hospital, to evaluate us and to establish the intelligence quotient of each child. Because the only way to remain in the school of Cravoia was to be able to study. I remember even now, with amusement, of the group counseling sessions, where we managed to counsel them instead of having them counseling us.

Where I found support and counseling during difficult times???... Yes, we also had the adults near us who got irreversibly fond of us. Even now, I am still in touch with my teachers, the ones who are still alive.

3) How did you handle the new challenges?

Ohhhh.... It wasn't easy, but it wasn't extremely hard, either! People say one thing but feel another. If you ask a person what he's thinking about a person with a disability, he will tell you a "mushy" story, but he will never attach his life to such a person without having a specific interest. Nobody will give up his work place in favour of the one he "admires" for his strength to carry on, while carrying the burden of a disability. I will go back to the first question: "What exactly brings happiness into your life?"... Them and this: God gave me the gift of discerning. After leaving the special schools, as a bird leaves its cage (the curriculum was similar to the one used in the mass education, I used to participate in school competitions along with children from all the schools in Craiova), I would see so many people moving around chaotically, without any thinking.

I quickly realized that God put in us, people, gifts, but that He also took some away from us. I realized that inside us there is a perfect balance. I weighed the things I had and the things that I missed and I decided to use what I had. This helped me a lot. I am a brave, optimistic person and I have accepted my disability. By accepting my condition, it became easy to me to handle new challenges. I am a disabled person, but I am not a dead person. So, I have no reason to feel sorry for myself, I have no reason to fight for a health that I will never have, or even if I had it, it would be too late and I would lose precious years. Life is short and deserves to be lived to the fullest.

4) What was the motivation to always move on?

When my daughter was a baby, in order to discard any fear that death would take me away from her (when she realized that there is death in the world she would fear of this), I used to tell her that people die once they have finished their job here.

I was always busy, doing a lot of things to earn a living, and she would always complain that I did not spend enough time with her. I barely finished a job and I started another. Seeing this, she was sure that I would never die because I always had something to do. I have to say in this case as well, that I would create my own motivations to carry on: to raise my children, to provide them with everything, to never make them feel that they have disabled parents, to have a cozy house, to enroll them to the highest schools, to offer them brand clothes, to have time to read a book, to make myself beautiful in the parts where I can improve things, to have a car, to know my country, to travel abroad etc... And to do so that I would grow old nicely.

5. What sort of advice would you give to someone who is now dealing with a disability or to someone who has difficulties?

First of all, I would tell them to accept their disability, to raise their heads and face their destiny. I would tell them not to put a sign of equality between "to walk" and "to be able to do". I would tell them to love their family, who is their shield and shelter, but to decide their own fate alone. I would tell them not to stay small, because they have the right to be exceptional people. I would tell them not let society hide them, and never forget that a person is persecuted as long as he allows to be persecuted.

Crina Pop - Romania



About Mihaela Constantinescu



Mihaela is the kind of person who can change the way you see life. Instead of pitying herself or being depressed because she is in a wheelchair, Mihaela lives every moment with joy and thanking God for everything.

As any woman, Mihaela dreamed to be bride, with a white dress and a handsome husband in a nice costume by her side. And she fulfilled this dream! She have met her husband on Internet - which is, so many times, the best support for people with severe physical disabilities or limitations.

The couple made a bank credit for this wedding, and they pay the installments from the small income they have. With dignity! They manage their household together, and they rented a studio to leave together.

In order to manage the living costs, Mihaela looks for small business she can do from her home, on Internet: selling earrings, kitchenware or anything that is decent and can help them.

On Easter night, her husband pushed her in her wheelchair for more then 3 km, from her parent's house to the church, for the Resurrection ceremony, and the same back home! All that on a cold weather which left a mark on Mihaela's health. But with an open heart and with joy!

Things seem to become nicer every day for Mihaela and her husband: he's got a job with flexible hours, so he can by her side when she needs help. Friends are by their side, too, and all the ones who know them appreciate them for their beauty and for the sensible life they leave.

And not few are those who are changing the way they see life after knowing them...

Answers to our Questionnaire

1) What brings happiness to your life?

My name is Constantinescu Mihaela, I am 43 years old and I have been suffering from progressive muscular dystrophy my entire life. I want you to know that I am

happy and that I enjoy life as it is, and that I reached the peak of happiness in 2011 when I got married.

2) Where did you find support and assistance/ advice/ counsel when you faced difficulties?

I can say that I have received and that I still receive support and assistance, firstly from my family and my dear husband. But I also receive a lot of support and counseling from my second family which is Esperando. And I say *family* because the staff from Esperando has always been and they still are close to me, in my fortunate times, as well as in my unfortunate times.

3) How did you cope with new challenges?

I dealt and I am still dealing pretty easily with the great challenges of life, as I have had and still have by my side those who are dear to me and who support me in every moment.

4) What was your motivation to always go on?

My motivation to carry on is Life. I have learned that every joy or sadness is a motivation to carry on, because if God gave us this gift, He knows why He did it, and we have to thank Him for giving life to us.

I have lots of motivations, the fact that I am alive, that I have a family who is close to me, that I have a wonderful husband, that I have the Esperando family very close to me, that I have friends. And I could continue listing my motivations. But the first and most important of them is Life. Life is beautiful the way God gave it to us.

5) What advice would you give to somebody who now faces disability or who has difficulties?

Dear friends, I advise you to raise your heads and walk the road of life as any other

healthy person does. Do not think that it can't be done. You only have to want it, to be ambitious and to really desire it. Then, your life will change completely and you will be happy.

Dear parents who already have a disabled child, or who have just found out that your child will suffer from a disability, I advise you not to lose faith! You will harm your child if you do! Help him live like any other child! Help him become as independent as he can be! Help him to be like any other normal person, as we are normal as well!

I wish to end this by telling you that I know cases where family and friends pull away and you cannot find understanding with them, but in the Esperando family you will always find the warmth and understanding that you need.



Constantinescu Mihaela– Baia Mare - Romania

About Sine Marie

Sine Marie - Age 22 - Born with a spastic paralysis on her right side - Dyslectic

Answers to our Questionnaire

1) What brings happiness to your life?

- Happiness to me is to be able to do the work that I love, which is working with kids..
- Fill up my life with happiness and hope..
- Friends and family supporting me and believing in the things I do

2) Where did you find support and assistance/advice/counsel when you faced difficulties

- I've had a lot of support from friends and family..
- I've received a computer at my school, where the books we are reading is recorded so that I can listen to them..
- I have an assistant teacher, who help me for a couple of hours a week, doing assignments ect..

- Im getting better at asking for help at work when I need it

3) How did you Cope with New challenges?

- Im learning how much my hand can endure, and knowing when my it needs rest. I can use my full potential..
- Until now I haven't really needed any help at my new job, I've just found other ways of doing the same things that the others do

4) What advice Would you give to somebody who now faces dissabilities or who has difficulties?

- I will tell them 'don't give up and believe in yourself'..
- Say yes when people offer your help, then you can make your dreams come true..
- Go against those who says you cant...

5) What was your motivation to always go on?

- I am a strong person, and therefor I'm not one to give up.
- I always tell myself, when things get though, that I will do my very best and then thats fine..

About John D Band (a Punk band with handicapped band members from the institution Snåstrup Vestergaard)

Answers to our Questionnaire

Two of the band members are interviewed, for us to get inside information on what having a good life with a mental handicap and diagnosis means.



My name is Thomas Jørgensen and I am 25 years old. I have a mental handicap, ADHD, and I also have autism in a mild form.



I hate school stuff like math, Danish and sports. What I love to do is play music, make music, paint, watch movies. I also like to play around with my computer. I make all the bands music videos and put them on YouTube

My name is Daniel Hyttel and I also have mental disorders. I am Schizophrenic. It is difficult for me to learn normal things like math, English, and so on, but I am good at music, drawing, and fixing cars. I am really good at fixingcars.



We live with 14 other mentally handicapped at a place called Snåstrup Vestergaard, witch is a housing and activity center for adults between the age of 18 and 65 who have some form of learning disabilities and complex personality issues.

We live in our own apartments and take care of ourselves, but there's always 3-5 staff members in the house to give us a hand when we need it.

We go to work everyday and have different tasks from day to day. In the summer we are mowing lawns for different companies and do other gardening jobs. In the winter we are mostly inside doing all sorts of things.

In the evening we play in a band called John D Band, named after a tractor (John Deer) we have here at Snåstrup Vestergaard. We make our own music and play concerts all over the country. We have even been to Germany to play at a handicap festival, which was pretty cool.

1) What brings happiness to your life?

Thomas: My girlfriend who is always there for me. I need to have something to wake up to in the morning, in order to have purpose in my life. To be real happy I need my job, my music and the band from whom I get so many fantastic moments and of course my family and friends.

Daniel: My family always comes first. My cat who is my guardian angel is second. My car which can't drive I rather fantastic, but I'm building it from scratch. The band of cause. It's giving me so much happiness to play with my friends, and all



the great memories we have shared together.

2) Where did you find support and assistance/ advice/counsel when you faced difficulties

Thomas: My family, the staff at Snåstrup Vestergaard, my friends and the social workers here.

Daniel: The same really. If I'm really sad, it also helps to cuddle with my cat.

3) How do you cope with new challenges?

Thomas: Biding my time. Trying to do things right, instead of stressing myself. I also get a lot of help from the staff here.

Daniel: I don't have that much trouble with new challenges. I take it at my own pace and deal with it. But I don't like being stressed.

4) What advice Would you give to somebody who now faces disabilities or who has difficulties?

Daniel and Thomas: Try to find something you love doing and never give up, always tell yourself "I can do it".

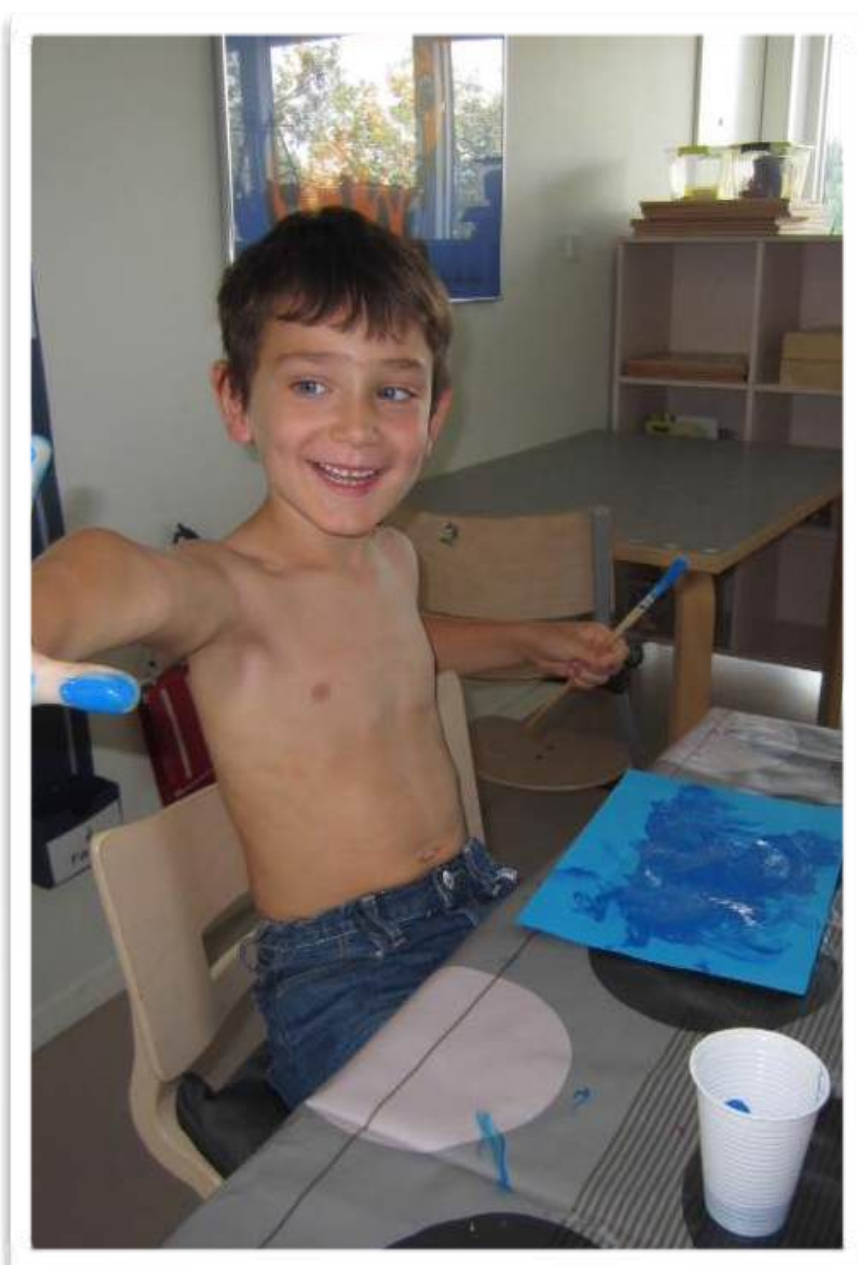
Stay strong. Never be afraid to ask someone you trust to help you and when you wake up in the morning say to yourself; "it's going to be a good day".

5) What motivates you to always go on?

Thomas: My girlfriend and of course the band.

Daniel: Despite my handicap, I want to have a good life.

About Stina (mother to Zack)



My name is Stina, and I am 30 years old and a single mom to Zack, 6 years old. Zack has ADHD, a developmental delay and specific developmental disorders like cognitive and social problems..”

Answers to our Questionnaire

1)What brings happiness into your life as a mom to at handicap child?

- The little things, like when he made his first real drawing at the age of six.
- When he meets new kids and actually plays with them.
- Just to see my son grow and have a happy life. ...It might not be the life, I first thought it would be, but as long as he is happy, nothing else matters.

2) Where do you find support and assistance / advice / council when you face difficulties?

- I get support from my family and the people are around my son -his teachers and educators, the psychologist who is provided to him from the municipality.
- Especially my mom who often takes care of him.

3) How do you cope with new challengers with you child?

- I take it step by step. When you have a kid, who doesn't think like the majority, you have to take it slow. New things can be scary or he might not understand them. If I introduce these tings to him several times, it gets a little better every time..

4) What advice would you give to somebody who now faces a child with disabilities or difficulties?

- To listen to your child's signals and your own gut feeling. There might be many smart people, who wants to tell you, what to do, and a lot of these advice are of course wise words, but the one who knows you child the best is YOU..

**5) “What motivates me to always
THE LAUGHTER OF MY CHILD go on..??”.**

About Claudio Imprudente

Interview to Claudio Imprudente by Giancarlo Onger and Mary Santillo



BACKGROUND

Short presentation by the interviewee

Claudio Imprudente is one of the founders of Maranà-tha, a community of host families, and president of the Documentation Centre of Bologna Handicap.

He created, along with his team of specialized trainers, the "Project Inkwell", which offers training programs on diversity and on the new culture of disability in the world of school and work. Through it, he realized, since 1986, more than five meetings with the Italian school children.

As a trainer, he has been invited to numerous conferences.

He is also a writer, journalist and editor of the magazine "Hp-Accaparlante" and author of books; among the last: "Stories of Calamai and Extraordinary Creatures", "There is still ink in the Ink well", "One Life imprudent" and "The Prince of the lake," a fairy tale for children, published by the Publishing House Erickson, "Letters imprudent on diversity. Conversations with readers' Messenger of Saint Anthony", "Effatà 2009.

He collaborates to the Inail social information portal, www.superabile.it and writes a column entitled "Differently" on the Messenger of Saint Anthony of Padua.

He likes to call himself not "disabled" but "diversity able."

Answers to our Questionnaire

1) What makes you happy?

It makes me happy the Inkwell Group, the serenity in my family, the Milan football team, reviewing 82 Tardelli's scream, the music ... so many things! My dream, however, is not to hear the word integration. As the word peace. As long we talk

about it means that there is too little. When you do not feel more will mean that the process will be ended!

2) Who has supported, advised, assisted, included, comforted, when you found yourself in trouble?

My friends, my colleagues ... especially the trust received from my family ... The relationship with my mother was important..I want to mention here an episode of our summer vacations ...

"Dear Mom,

Do you remember when the man rested for the first time his foot on the Moon and Tito Stagno was the commentary? Then you brought me with you on the beach in Misano Adriatico, and there I also placed for the first time my feet, or rather my wheels, facing the sea ... On that beach we spent many summers, the same beach and sea for the same several years. I remember how, every morning, your watchful eye was traveling fast, scanning the beach and finding out the first swarm of children playing with sand, building castles. Immediately, quietly, you put me next to them.

In general, it was all for the better as long as my playmates were not called by their parents, a little for need , a little because frightened by my presence. Times were different but you certainly were not afraid of fear and you were insisting to take me there in the middle, until I became "the guardian of the castles of sand" and even

the lifeguard marine were the protagonist of my holidays on the Adriatic coast, who answered to those who complained that I was a child like everyone else and that I'd been there.

But why now do you remember all this? The beach and the shore, at the end, what are they? A boundary between land and sea, a boundary between my limits and those of the people. With the limits and boundaries you made me play, putting me at the center, teaching me how to overturn them , so overturning in the other eyes

and perspectives, to bridge distances through the communication. And I found out just living ...

Thank you, your guardian of castles. "

3-4) What reasons did you find to go on?

I go back with my mind and briefly I tell my story, as I did during the Lectio Magistralis ... We must take a step back fifty years. As you know "at that time" (it seems to refer to other eras and to use an evangelical formula) disability was really an "handicap".

If you want to use a synthetic formula, if to have a disable child is today seen as a misfortune, at that time it was a real curse: personal, familiar, etc.. Let's say that, in the scale of negativity, we have moved away from the latest positions. There is a big difference between misfortune and curse, The course seems to be falling from above and leaves no way out or escape routes, usually it has divine or demonic origin ...

The famous phrase of the doctor who, after having visited me at the age of two, he shook his head, "There is nothing to do, it will be a vegetable", was accepted by my parents just like a curse . From that moment , hearing those words, they started a lonely path in the dark. Or rather, they had to imagine an alternate route to that of their expectations. Trust mixed with complicity. This, and it's a very vivid memory, resulted in the creation of gears, with perfect and functional mechanics and timing, for example for carrying out domestic daily activities .

Trust and complicity as a first solid brick to build the rest. And, at a more intimate level, to give me the feeling of not being an obstacle, not to "interfere" too much in the lives of my parents.

The humus that has enabled my growth is, in many aspects, the same that has led to the birth and development of the "forest" Documentation Centre Handicap / Project Inkwell and the plants and animals that inhabit and animate it.

Trust and complicity, so I have taught by my parents, and so, once I lost them, I continued to face my challenges, so I learned to move forward.

5) What advice would you give to someone who now is facing the problem of disability and having difficulties?

On this topic I recently wrote a letter to a hypothetical my nephew with disabilities, along the lines of the one published by Umberto Eco to his nephew. I think it is useful reading it in full, because it's a kind of my will, the advices that I would leave: "A few days ago I was fascinated by a reading. An open letter from Umberto Eco, pointing to his little grandson on the time to come. A letter, many of you will have read it, who wants to communicate with a generation that is growing up with rhythms and cultural tools very fast and frantic, certainly different from ours. This is under the eyes of all. If you think about the habits of our children, our grandchildren " stuck" to the pc and bombarded with constant information ... it is difficult to recognize ourselves, so much has changed the society in recent years.

I would, therefore, my dear nephew, just to you that have a disability, give you some advice, from my experience, from my real life, so you can do the same and more.

I go back to my classroom, in the days when I attended special schools. Do you know what they were? Imagine schools built and designed exclusively for people with disabilities, where the teacher is the only " able-bodied", divided between skill and deficits extremely different from each other ... Maybe today your classmate helps you to do homework together with your teacher support and then takes you to play football, basketball or what you like ... All of this is not obvious. And it is the result of years of failure, realizations, reflections, struggles and achievements that have brought us here, to an image of disability capable of contamination, meetings, discussions with other disciplines and experiences.

If today there is still something to be done is mainly to retrieve that desire, the desire that we have not to take anything for granted and that we have always to go beyond, to finally arrive at no longer having to talk about integration but simply to live.

Knowing what there was before you is important. The historical memory, as reminds us of a famous personality, Umberto Eco, is crucial for your future and maybe even for my own, because I like to think that, what I did, might continue with you in your battles and in your goals.

Of course you will not lack the tools, today innovation is just a click away. I would, however, tell you that this is not enough, because it is not on facebook that you will meet the gaze of others and above all that will not be there that you will assess the importance of the gazes

Remember that if someone looks you in the eyes and you look down, you've lost, but if you return his gaze... then you will win. And on this, believe me, there is no tool or technology that helps you.

Do not be afraid of your body, even if it is deformed, use it, be an artist of yourself and put it at the center of the others.

Do not be ashamed of your desires. Remember that you are a whole person, you may even fall in love and to be loved.

The world that we leave in your hands is certainly not "the best of all possible worlds." But it is useful to remember how it was a few years ago, because without knowing our past we cannot change our present. "

About Laura Davo (mother of a disabled child)

Interview by Giancarlo Onger and Mary Santillo



After living 17 years with a disabled child, there would be lots of things to say.. My way of living has changed a lot during these years..

I wouldn't have given the same answers 15 years ago. I am firmly convinced that, in the experience of being Federico's mum, I get more than what I give.

Answers to our Questionnaire

1) What makes you happy?

To see my son in peace/serene/quiet, sharing life with the other people (both positive and negative things), accepting life with everything it offers and looking for beautiful things in every day's life.

2) Who has supported, advised, assisted, included, comforted, when you found yourself in trouble?

At first my family, but as time went by and being a pain for them too, their support wasn't enough anymore. I then found a lot of help and support in other parents who were living the same experience. I also found support in some therapists who have always tried to help me, in a delicate way, looking for strategies, without giving up hope.

3) How did you face the new challenges?

Trying to be always positive and not losing sight of the main aim: to improve our life's quality because in a family with a disabled person, you tend to focus about his/her wellbeing while it's important that all the family members are well. It's

important to appreciate every single progress (it isn't always easy: I can assure you!) and relying even on the other people's help without any prejudice like "they can't understand what I am living" or "I'm ashamed" or "they are not prepared" because nobody is never trained enough, not even myself, as Federico's mother.

4) What motivations did you find to go on?

Many years have passed and looking back in time at the beginning my motivations were trying to raise my son's competences. I looked for every kind of information, therapy, different stimulation, medical specialist (sometimes very questionable) because only getting knowledge you can have the chance to choose. Not everything was good of course but as my son's psychomotor development is very serious, my motivation today is to improve his life's quality, trying to make it as normal and serene as possible.

5) What advice would you give to someone who now is facing the problem of disability and having difficulties?

My advice is not to withdraw into one's sufferings, but talk about your feelings and mood with people who are available to listen (as I said before, it is difficult to find support in the other members of the family because they are living the same problem and so they feel the same). There will always be difficulties but it's fundamental to live with composure our "new life" and choose to be as happy as possible!

About Luca Carrara (Miriam's father)

Interview by Giancarlo Onger and Mary Santillo

My name's Luca and I have been married with Monica for 22 years. We've got three children: Isacco (16), Emma (6) and Miriam (13), the one who made our life more special.

She is our second daughter but we chose her twice: firstly when we decided to have her, secondly when we found out that she suffered from heart disease and Down syndrome. Doctors asked us if we wanted to have her. We said yes and our adventure started full of happy moments but even difficult ones for example when Miriam had to undergo two heart surgery..

Answers to our Questionnaire

1) What makes you happy?

What is making us happy now on a daily basis, is the fact that we have a leading role in our life expectations; and we always have our dreams on which we invest our enthusiasm, energy and a lot of passion, sharing it with those who live by our side, and turning every single fact of life in an opportunity to grow - regardless of any other consideration.

2) Who has supported, advised, assisted, included, comforted, when you found yourself in trouble?

When times are hard, our family (whose roots are quite peculiar) has a fundamental supporting role; nonetheless, our friends have always been up to it, the network of social relationships having been an important earthwork to sustain our uncertain steps in the course of the daily toil of life. Our family, as unprepared as it was, disoriented and with little resources, nonetheless still remains the only reality ready to fill the gaps, the dysfunctions, the deficiencies; in this regard, more often than not, parents are phenomenal in making the impossible happen. As a family, finding skills, expertise and support in the institutions is a breath of fresh air feeding the hope that you are never alone; on the contrary, when you are confronted with a shortage of it, for lack or malfunctioning, the family feels helpless and defeated: one instance is school, where this happens too often.

3) How did you face the new challenges?

As a family, we managed to go on with the new course, with the help of those who stayed on our side or supported us from a distance; their presence in every single step since the very beginning, let us share everything. The social fabric of the environment where you live is essential: the smaller the community, the better the relationships. Friends have been fundamental!!!

4) What motivations did you find to go on?

As a family we believe in the one gift in our lives that is Love. The rest - all that happens to you, is a part of the facts of life. That is what our daughter is. When you

fully realize your situation, there are two options: live with it, creating a balance that will not exceedingly destabilize, avoiding to question yourself all the time (*why us?*); or you can choose to completely adjust your life moulding the experience called “handicap” into a new vision, an alternative perspective, a new name for 5 things, weighing them differently!

5) What advice would you give to someone who is now facing the problem of disability and is having difficulty?

In our experience, we can say that, as much as we were prepared - thanks to the lifestyle our families gave us as an imprint, in terms of personal commitment and community work – you are never really ready to face an event like the birth of a so called “special” or “different” child. You just can't, because what radically differs is the perception of things, being the experience so unique. We believe that what really counts is to avoid keeping it all inside; to turn it into a shared vision; to never ask yourself all the questions at the same time, because you will always get only one answer at a time and even then, this answer will come with a time that will seem endless. After a while, we can say that it is alright, because the vision of things must be full and complete, and that in every single experience lies a privileged way that will allow growth as human beings and as a family. If we could choose freely, we would never pick an experience like this; we would have felt not ready and not up to it; we would have found a thousand contraindications: most of all, we would have been scared. But today, we can claim that this was, and is, the most exciting experience that we have ever lived, as human beings and as a family.

About Paul Griffin (a newzealander rugby player who lives in Italy now. His son is autistic)

by Maria Chiara Riviera, Mary Santillo and Giancarlo Onger

Answers to our Questionnaire

1) What brings happiness to your life?

I'm happy when I see Jackson who is succeeding in doing something he couldn't do before or in which he was not very good at. I understand it from his gestures, movements or from his beautiful smile or his eyes more brilliant than usual.. These are the things which make me happy..

2) Who has supported, advised, assisted, included, comforted, when you found yourself in trouble?

Doctors from NPI (neuropsychiatric doctors for children) helped me a lot.. in particular doctor Trebeschi.

A very important person has been the teacher Carmen Clerici: she helped us very much.. We would have been lost without her..

3) How did you face the new challenges?

I have never refused a challenge in my life.. so **this** challenge has been accepted from the very first day. We first have accepted this new family situation and then we have gone on asking, reading and above all.. living this experience.

4) What motivations did you find to go on?

The key for us is motivation, emotion and the will to do the best for Jackson. Our motivation is to see Jackson smiling and very happy..

If he doesn't feel well we want to understand why and help him to live that moment as a growth experience not as a sad moment. While if he is ill, we try to understand what is the process which has created this moment of happiness.

5) What advice would you give to someone who is now facing the problem of disability and is having difficulty?

Enjoy the happy moments and learn from the difficult ones..

There are a lot of difficult moments but it's important to understand the reason **behind it** then we try to recreate it in order to let the child understand that it's not so dramatic, terrible or sad.. This is what works for us..

About Rossana Bresciani (mother of a student with cri du chat syndrome)

by Mary Santillo and Giancarlo Onger



Presentation

She is 48. She got divorced soon after her disabled child was born. Today she lives with her daughter. Her older daughter works and lives on her own. Rossana is a worker now but she hasn't worked for a long time to look after her daughter.

Answers to our Questionnaire

1) What makes you happy?

First of all you have to accept your daughter's disability. Then a black world opens in front of you and you have to conquer it.

Every single new step is happiness but behind it there's a huge work. When my daughter's happy, I'm happy too.

2) Who has supported, advised, assisted, included, comforted, when you found yourself in trouble?

You need a lot of time to start this progress and you need a lot of time to get in touch with the right people. I looked for specific doctors but nobody helped me. I had to do everything on my own like for example starting a gym for Gloria inside my house.

Behind every single step there's a long work but when you reach every single autonomy, a great joy waits for you. I think of the Maslow scale: eating, drinking, breathing, washing one's self, walking..

Life is centred on autonomy. For a family in which there's a disability this is not always true. It is lifelong aim

3 - 4) What motivations did you find to go on?

To go on you need to trust in your child possibilities, you have to believe in him/her. And appreciate him/her for every reached aim.

5) What advice would you give to someone who is now facing the problem of disability and is having difficulty?

You need a lot of love, organization, observation and understand your child's skills, tastes and qualities reminding yourself that they want to live their own life.

They need to learn how to behave well because this is important to be accepted by the others and, if they are sociable, better!

They are children and they need to put themselves at stake. For example, if they have to learn how to wash themselves, it's normal to have a lot of water on the floor in the bathroom..

For children's future we try to do the best: more autonomies they gain, better will be their future. We need to think at the future even "after us". You need to refer to specific associations and to a medical group.

About Tatiana Vitali

by Giancarlo Onger and Mary Santillo



Short presentation

I'm Tatiana Vitali and I live in Castel Maggiore near Bologna. I graduated in 2004 in Education Science and I have a master university degree entitled "Technologies for the quality of life."

My expertise is in fact on Assistive Technology.

I am a woman with physical disabilities, my deficit is a cerebral palsy resulting in a spastic tetra paresis. I move with a wheelchair pushed by others, I'm visually impaired and I also have speech difficulties.

I live with my family. I have a very active social life: both work and interpersonal relationships. I have many friends with whom I share thoughts, emotions, joys, laughs and travels.

I work within the Project Inkwell at the CDH (Documentation Centre Handicap) of Bologna with a internship and I collaborate with the University of Bologna in co-leading workshops.

My favourite sport is horse riding. I have a very strong passion for horses and they are my favorite animals.

Answers to our Questionnaire

1) What makes you happy?

The word happiness is a very nice term. It's a positive emotion that everybody feel and I live these emotions, too. In my life there are many things that make me happy. First of all, thanks to my stubborn and determined character, I reached the beneficial objectives for my life project and surely my positivity in looking to the future, makes me happy.

Today, to be aware of my disability and what I am and what I can do is increasing my self-esteem and confidence in myself, making me stronger and allowing me to have a possible autonomy. I like to share the situations, both good and bad, with my family with whom I often put myself in listening and also under discussion.

A key thing that makes me feel good both emotionally and physically is to have every week a special relationship with the horse and with instructors who support me. This is "my space" and I dedicate it to myself, I ride for my own pleasure and enjoyment.

It makes me happy to have friends with whom I can share situations, confidences, and to feel that the relationship is true, honest, non-judgmental. It helps me to control my anxiety to know that in case of emergency a phone call is enough and immediately I receive comfort and help.

The studies that I have done so far, have given me the opportunity to enrich my knowledge, giving me tools, so my actual job is in the helping relationship and I feel fulfilled. I work only on my disability and everything allows me to relate to other people feeling myself on an equal level..... this makes me feel very good and I am satisfied.

2) Who has supported, advised, assisted, included, comforted, when you got into trouble?

I was supported by my family and the network of people that they have built around me. I had the good luck to be born into a family that after the initial shock of the diagnosis, did not give up, but tried to start to overcome this phase walking towards the acceptance phase. My family, through the "doing", found that I was a little girl who could "give" if stimulated and helped.

My parents believed in me, and created a network of services, institutions and schools to share ideas and suggestions with me, so, when I grew up step by step, we've built my life project.

In the most difficult moments of my life, such as during adolescence, I went through a critical period regarding the acceptance of my disability but I found a great support in my family and in my educator, Rita Mastellari.

At that time, as a family, we understood to be in difficulty in the management of intra-family relationships and we contacted a neuropsychiatric doctor.

This professional has regularly supported us through psychological support to overcome these moments, pushing us to look to the future.

Yes, life is made of difficult times, but it is also full of joy and satisfaction. I have met some friends when I was a high school student. They were always present in the “critical moments” making me feel their presence, comforting me, supporting me, and I must say that these friends are still present today and we do share happy moments together. All people need in everyday life to have “a vent hole” and I found it in horse riding. These are my moments of fun, sharing and entertainment. I have been horse riding for 20 years and on Tuesday no one can take me away my “ride hour”. It makes me feel good to attend the environment of the stables, to relate myself with the instructors, to be in contact with the animal and to mount the horse walking in nature. I can recharge the batteries to deal with possible difficulties of everyday life.

3) How did you face the new challenges?

Since I was a child, I have always been a little curious, determined, tireless, even a little bit stubborn and all this still characterizes me today. Surely the context of the family in which I grew up has helped to shape this personality. My parents were a great example: very fighters and confident. They have rarely surrendered and have always found alternative solutions in order to overcome the difficulties.

I also recognize myself as a person like them and , if I start a project, I do everything to carry out the commitment, I rarely leave unfinished things.

The advice to attend University came from my teachers and educators...it was one

of the many challenges that I have faced in my life. I do not hide the fear that initially pervaded me because I was afraid of not being able to deal with this new step, with new subjects. I had no support teachers or educators, and this alarmed me. I would have to be accompanied by my mother, let her to take notes, to read my texts ; I had to pass a lot of exams and my mother had the same fear as me, too. Spurred on by my teachers to continue, I made a bit 'timid first step. Coming from a commercial language institute, I went to an interview in the faculty of languages and I came out very disappointed, because I was told that the faculty was not ready to welcome people with disabilities like mine.. there were too many barriers and no technological tools as support.

My Educator Rita Mastellari was enrolled in the faculty of pedagogy and she asked me to do an interview with Professor Andrea Canevaro, before taking a decision. During the interview I felt an open mind in accepting my difficulties, I understood that, with that degree, I could never handle alone a class of kids jumping, but I could pursue a profession of help and support in the classes of each level of education if I were accompanied by an educational figure. I could have an active role in many areas of education. From that moment, my challenge started.. I had taken a spring ..and with enthusiasm I started my trip. I saw great openness and acceptance in many teachers, but not in all of them.. some showed indifference towards me.. they didn't speak with me.. they avoided me. This made me feel very bad. Initially it was not easy to be in the classroom next to the chair and to have my teammates on the steps in front of me with their eyes on me; this put me anxiety. Some group work gave me the opportunity to let me know. I tried a verbal contact with them and they slowly learnt to know me, to talk to me even without the figure of a mediator (who was in that moment my mother). After that many other colleagues approached me and my real participation at university started.

4) What motivations did you find to go on?

Even as a child I have always been afraid to face the new things I did not know; growing up I gained more confidence, but even today improvisation is not my speciality... but I have understood how to overcome this limit.

Certainly my will, my character fundamentally positive and resolute, helped me to face the emergencies and problems of life.

I like to feel myself useful as an active citizen and when I have the chance to show my character, I always try to show as I am, as a person, and through my actions ... or at least I try. To perform well in a job, to do what for which I have studied and make a mark in my step...all this gratifies me.

As a child I was terrified of the blind, the physical disabled people, especially those who walk with a wheelchair. All this led me to avoid situations where I could have met these people as I was involved with inconsolable crying spells and absolute panic. I believe that the motivation of this behaviour was because I had not yet accepted myself and I saw myself in them.

Today I know that to work on visibility has helped me to overcome my difficulties . People with disabilities must not think that everything is due, so each of us needs to find and open a passage in our lives..

When I have the opportunity to participate in meetings or comparisons in different contexts, I never refuse. The architectural barriers are more easily overcome with simple measures and aid, but cultural barriers are an obstacle on which we still have to work a lot, although much has been done, but we have to continue. This is the reason for my involvement in this field, too.

5) What advice would you give to someone who is now facing the problem of disability and is having difficulty?

Every person is different, each of us has different needs and desires.. so this is a question that embarrasses me because I wonder if what was useful for me, could be useful for others too. I take courage and I feel that perhaps my advice could help, “turning on a light bulb “ to someone else.

Initially I did not accept myself as a person, I did not understand the essence of my person... I saw only the limits. My family helped me, pushing me to do a psychological journey ; at the end , after a long time, I was able to face the mirror and to accept me .

In my life, it was essential to look for a network of institutions and services that helped me to find the most suitable routes to my skills.

My family have given me the confidence in others and the need of the other people, so when I had to choose and to start a school curriculum , or in front of any change in school, or in other areas, the choice always took into account the advice of the professionals close to us.

Also if it was easier to isolate myself socially, I never did it even though my body gave me signals that could isolate me.

Not even my family has surrendered to the social difficulties of “being” special” parents: they chose to stay in contact with other families, to enjoy holidays together, to invite them to our house and move when asked.

Sometimes there was shame, I recognized her, but I've understood that shame is useless. It has been useful the comparison with the others instead.. I stopped to wait that “the other” approached me and I started to be the one who reached out to others, asking for what I needed.

My way of life has sent me very positive feedback from the outside regarding the decisions taken and these responses from the outside world have helped me to move forward and to continue on this road.



About Alla



Background: She is a mother of 3 kids and all 3 of them have some kind of disability. The youngest and oldest boys have mental disabilities and autism. The oldest boy is 16 and attends special school, youngest boy is 5 and he attends special kindergarten. The girl has cleft lip and attends first class in ordinary school. She raises her kids alone and studies pedagogy.

Answers to our Questionnaire

1) What brings happiness in your life?

My kids and my mom. Notwithstanding that my kids are with special needs, they are the best and the loveliest to me.

2) Where did you find support?

I get support from my relatives, doctors and employees of union Ceribu sparni, and also the teachers at school and kindergarten where my kids are learning.

3) How did you manage the new challenges?

I rely on my strength and, of course, on advices I get from various organizations and people. Without support and professional consulting it is very difficult to solve the problems you have as mother with disabled children.

4) What motivates you to keep moving?

I motivate myself, because I am worried about the future of my children. When you have disabled child in your family, the most painful issue is - what will happen when he will grow up? That's why I really support and hope for project Ceribu seta.

5) What advice would you give to others in similar situations?

Don't live only in your own world! There are a lot of people outside your home and you can find the solution by sharing the problem. During last years the situation with attitude of society has dramatically improved and a lot of persons feel compassion to the ones, who can't protect and take care of themselves.



About Alona (37 years old)

Background: She is social worker at union Ceribu spāni and is mother of two kids. She has birth trauma and disability for her right hand. She has graduated special integration school and now also teaches sewing to disabled youngsters.

Answers to our Questionnaire

1) What brings happiness in your life?

I can assure that I am a happy person. Besides all the difficulties and restrictions, I have achieved all that I have ever wanted in my life. My family is the most important thing for me. When I am feeling bad or lose the hope, my husband and children are the ones, who support me and cheer me up. My husband is my strong support and my children are the biggest joy in my life. Happiness can not exist without understanding and supportive friends, without work you like and it gives you satisfaction.

2) Where did you find the support?

First support and help I got from my mother, who taught me not to give up, not complain, but just DO. Now very big emotional support I got from my own family. My colleagues also are people, from which I can get advises in professional issues and also assistance in difficult situations.

3) How did you manage the new challenges?

Every one of us gets new opportunities in life, whose also are new challenges for us. My motto is – don't say no, but try to make it work. I always depend on the person if he is passive and helpless, or uses any opportunity he gets to survive in the fight called life.

4) What motivates you to keep going?

My children – this is my largest motivation no to give up. I am also thankful to my colleagues, whose always says appreciative things about my work. This acknowledgement gives me power and energy to keep moving.

5) What advice would you give to others?

In difficult moments, it is extremely important not to give up and seek for people, who has similar problems and find out how they have managed to overpower them. The main thing – don't stuck in passive action. Be active, get involved, gain knowledge and explore the unknown.



About Lolita



Background: She is mother of two disabled children – 7 and 13 years old. Oldest one has Duchenne-Becker syndrome and the youngest girl got brain damage (spent some days in coma) during drowning when she was 1,5 years old. Doctors told the mother to give up, but now the girl attends kindergarten and can talk and move. She raises her kids alone.

Answers to our Questionnaire

1) What brings happiness in your life?

My happiness is my family. I am proud to be with them. Notwithstanding the difficulties, I can live wholesome life and enjoy it. I can be sure that always there is somebody next to me to support me.

2) Where did you find the support?

The biggest support for me was the family again. When I realized the seriousness of the situation, I also needed help from healthcare professionals. I also found out about community Ceribu sparni and they become my second family.

3) How did you manage the new challenges?

By not giving up, by support of family, by help of Ceribu sparni – all of this gave me understanding that I am not the only one with such problems and I am definitely not alone.

4) What motivates you to keep going?

By visiting the specialists of Ceribu sparni, I saw other kids and their development and that gave me strength not to give up. When I understood that the situation of my daughter is hopeless, any smallest improvement gave me hope and reason to think that I have been lucky in my life.

5) What advice would you give to others?

I always tell my story to people, who have faced the similar difficulties as I. I tell them about the people, who supported and helped me, and where I have found this help. Notwithstanding the problems, we still are able to find happiness and sense in our lives. The feeling that you are not alone gives, does miracles!



About Olegs (33 years old)



Background: works as accountant in Ceribu sparni and studies master degree in economics. He has a birth trauma – deformation of backbone and thorax. Grown up in orphanage and was regarded as unteachable. One social worker noticed his ability to understand and organized a learning program for him. Hi has been awarded as „Pride of Latvia” in year 2011.

Answers to our Questionnaire

1) What brings happiness in your life?

Faith that God exists.

2) Where did you find the support?

Do everything by myself, ask help to professionals.

3) How did you manage the new challenges?

Life would be boring without challenges.

4) What motivates you to keep going?

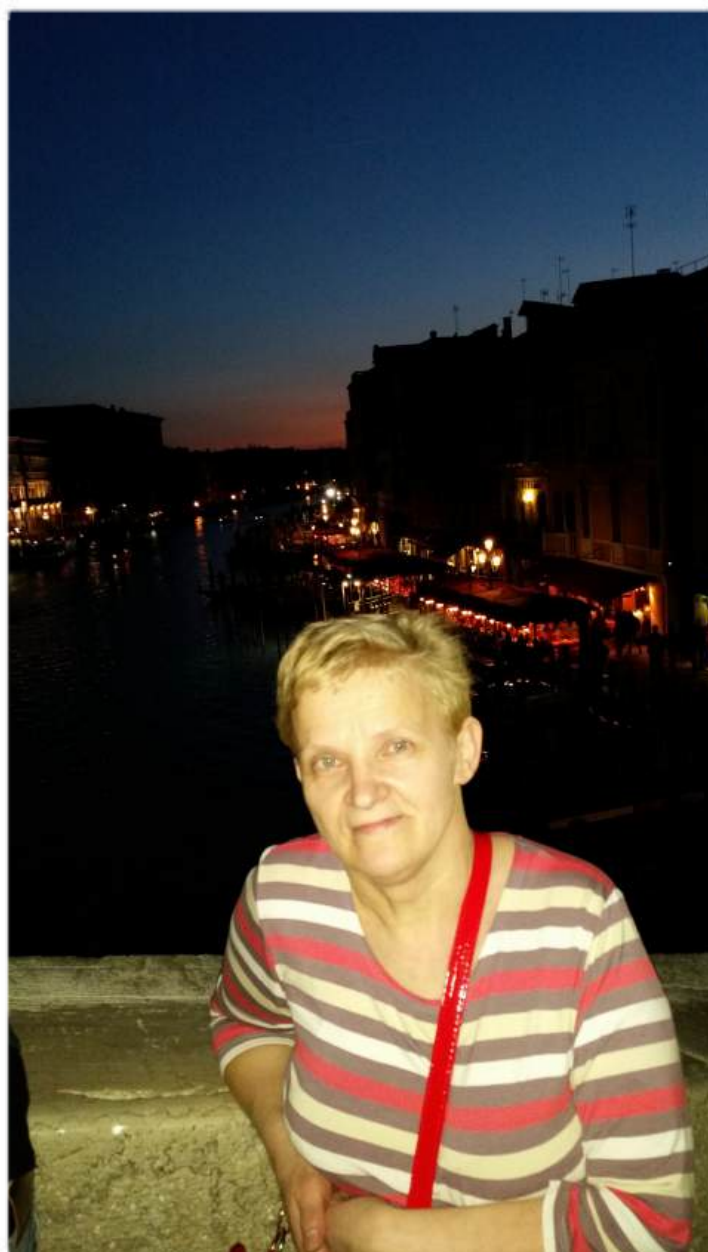
Willingness to achieve more and learn new things.

5) What advice would you give to others?

There are difficulties in your life, just don't be afraid of them. There are trouble only with the ones, who can handle it – so you can. Cheer up and move on!



About Liga (52 years old)



Background: She has cerebral palsy when she was a kid, when she got disability of movement in left leg and hand. She works as accountant in Ceribu sparni and has two children and also two grandchildren. Doctors has been slighting to her ability to have kids and also granted her group of disability only when she was 25 years old.

Answers to our Questionnaire

1) What brings happiness in your life?

Actually I haven't found out what is the meaning of the word "happiness". Possibility to walk, see, hear, and work, and to be myself – that is probably the happiness in my life!

2) Where did you find the support?

I have gain support from peers, which has been next to me in various moments of my life. I found support also in my perseverance and willingness to be active and to be present everywhere.

3) How did you manage the new challenges?

If this question is about my disability, then I get on by telling myself that I have to deal with my situation by myself. I have willingness to make others understand that one of the most important aspects of your life is that you are PARTICIPATING IN CREATING of your life. It is also the hardest thing – self engagement.

4) What motivates you to keep going?

I get motivation from desire to live; desire to be master of my own life.

5) What advice would you give to others?

Meet clever and skilled specialists, peers with similar problems, to share the experience of their paths. Believe in yourself!

About Vanessa Ana (11.03.2015)



PRESENTATION

My name is Ana Vanessa I'm 27 years old and I suffer from a neuromuscular pathology, degenerative, called Sarcoglicanopathy . This disease first occurred when I was 7 years old. It's a progressive disease that affects all the muscles. Currently, I use an electric wheelchair and I am highly dependent to accomplish the daily-life activities.

I've always had the philosophy of ceasing each day as it was the last. I've never tried to question why it had happened to me, I've never let myself be beaten by obstacles or by the difficulties of life. I've done everything I can to live with what life has given to me.

With the valuable support of my family, of friends and of the Associação de Paralisia Cerebral de Coimbra, I've managed to get one of my main goals: to live the most normal life as possible. Therefore, I've followed the regular schooling path and I took a master degree in Forensics Psychology. I've always tried to live an active social life and feel active and alive. As a child I became famous as a singer, after I took part on a TV show; I was a member of a political party that had a seat in my borough. I had the opportunity to spread my example through media, and now I know what the world of work means and also that I am able to have a job.

Therefore, never stop yourselves from following your dreams and the best ways to accomplish them. We must bear in mind that we are presented with many obstacles throughout life, and that we need many adaptations, but that the fact that we are different doesn't necessarily mean that we have to live a worse life. Above all **DON'T STOP BELIVING!**

Answers to our Questionnaire

1) What exactly brings happiness into your life?

Well ... it's not easy to answer this question, but I will try to be as objective as possible.

I find happiness in the little details, the small achievements or moments, whether a week in holidays with the all family together, the accomplishment of small personal goals, for instance being able to go alone to the shopping center to solve my own problems, to an appointment with someone, or to charge my transport card every month. I refer to issues related to my independence and autonomy, which make me feel normal.

In a general way, those goals that I decided to achieve and which don't let me give up, for instance: having completed my psychology course, having managed to find work experience in order to exercise the profession and, with some adjustments, to be able to follow the normal life stages of someone without any disability.

Having a disability or not, happiness is something very particular that varies from person to person and that everybody wants to achieve. Honestly, I do not seek happiness, but I try to enjoy the most from every day, from every small moment that I know is important to make me feel good. Nothing and no one is eternal, so I try not to look for what I know that I can't reach, or to have what is not mine (ou... what I know is impossible for me to have). In some way, I think this reduces the feeling of sadness and incapacity and increases happiness in every achievement.

Thus, I can identify three areas in my life that are a source of happiness: my family, my personal and professional fulfillment and my personality, the way I am and I live.

2) Where have you found support and assistance /counseling when you confronted yourself with difficulties?

In what concerns this question, I consider it is important to explain that I always wanted to know all the important information about my disease. So, I always found a lot of support and help from doctors, who talked with me about my doubts and explained me how I could try to manage certain situations.

Whenever I find a difficulty or limitation, I do not give up until I find an alternative solution for that situation.

I generally try not to think too much about the difficulties that my disability imposes. I try to integrate them as quickly as possible and share those situations, my fears and concerns with my parents, friends, health professionals and other persons who help me in everyday life.

On this subject, my life slogan is: things we want don't fall from the sky neither come knocking on our door. If I can't do something or if I have a problem, I must try to solve it, looking for help, sharing it with someone; I shall not stand quiet, waiting that it solves by itself or passes by. As I have a degenerative disease, I know that I will not get better and, on the contrary, I shall expect to get worse; so, I feel that I shall not take my time and that I can't delay or postpone, because I don't have "all the time in the world".

3) How did you handle the new challenges?

Difficulties are and will always be an important part in my life. So, whenever possible, I try to convert all my difficulties in challenges, in opportunities to overcome me or to test my abilities and to turn it up.

This doesn't mean that I never feel discouraged, cry or get angry with life and those around me, but I think it is natural. We all have bad periods in our lives and, in those moments, what makes the difference is the way we deal with those difficulties.

I have physical and organic difficulties that I am not able to solve alone and that tend to get worse. However, I try to do what I can and what I need, to have a life as normal as possible, knowing that I need adjustments, more time, help from other people, fundamental help of association of cerebral paralysis of Coimbra in all AVDs and accommodation, devices and technical aids.

I always try to get over difficulties and challenges, so that people can say I have made mistakes or bad choices, but shall not accuse me of not having tried or of giving up.

4) What was the motivation to always move on?

Will of living. I know I'm different, that I will not have the same life of my colleagues and school friends, but that's life. We all are unique and have different lives.

I probably will not have my own family and children however, I have already lived and I will certainly live moments that no one else will live.

People usually tell me, when I look back in my life, that I already achieved many things, however, I always want to do more and better, and I believe I will be able to do it..

Besides myself, there are people who always expect more from me and I don't want to disappoint anyone. As a friend told me recently, my life will last for as long as I

want. Thus, I must venture myself out of my comfort zone, not allowing disability and all the difficulties to be stronger than me.

5) What sort of advice would you give to someone who is now dealing with a disability or to someone who has difficulties?

There are not two similar persons. No one is better or worse than the other because we are all different. And within those differences, we must take risks, we shall try to achieve our objectives, not being afraid of knowing and accepting what may happen.

We shall be aware that things will not be easy, that we will have moments of deep sadness, a great desire to give up, to blame everyone, to pretend it is not real, to leave it to others to do and to decide, to cry and scream, hoping that destiny dictates what will come, but the choice is always ours.

I don't want to be an example for anyone else, only for me.

We all had, have or will have difficulties and health problems in some moment of our life.

Of course some people are not disabled, but disability doesn't make us necessarily incapable, unable of doing everything. We must find out what we are able to do and how we can reach it in our own way.

About Alda Matos (15.01.2015)



My name is Alda Matos , I am 42 years old and I suffer from cerebral palsy, diplegia. The injury was cause by premature delivery. It happened before the 28 weeks of the gestation period. This was in 1972! Therefore, the doctors considered that there weren't many chances for me to survive. But I have!

I was born in inner Portugal, where I lived until I was 18 years old. My parents struggled for me to have the best medical and technical care possible. Once a year I started to have the care of the Associação de Paralisia Cerebral de Coimbra from 6 years old on. From 12 to 18 years old I had this care at the Associação de Paralisia Cerebral de Viseu.

At the age of 18, I attended higher education in Coimbra, I took a degree in psychology and, then, a master's degree in Education Sciences. For 14 years I've been working as a teacher at the Escola Superior de Educação de Coimbra, and now I am about to finish a PhD in Psychology of Motivation and Personality.

I consider myself a happy person, although I believe that happiness must be built; it's not something you can get without a job!

Thanks to the help of my family, of the personnel from the Palsy Associations of Coimbra and Viseu, and many friends, I've learnt that we are much more capable than we usually think we are. Just like Célestin Freinet said:

"Failure, whatever type it is, should not compromise our will to overcome it. Here's the meaning of life!"

This is the message I'd like to pass on to everyone.

Answers to our Questionnaire

1) What exactly brings happiness into your life?

I think that what makes me happy are the small autonomy achievements for which I fight for every day. In fact, apart from the Cerebral Palsy I also have to deal with diabetes type I on a daily basis and also with joint problems. Notwithstanding all the sacrifices it all implies, I am a teacher in a higher education institution and I perform my tasks just like any other colleague. I am also about to finish my PhD.

2) Where have you found support and assistance /counseling when you confronted yourself with difficulties?

I started facing difficulties underlying disability when I started elementary school. At the beginning I found the help of the Centro de Paralisia Cerebral de Coimbra and, then, of the Centro de Paralisia Cerebral de Viseu.

3) How did you handle the new challenges?

I must say that sometimes it wasn't easy to deal with all the challenges and difficulties. The help of professionals at the centres mentioned above was essential. They taught me how to fight for my autonomy, helping me to believe I would be able to achieve it. E.g., they taught me that I should only ask for help if I realized that I couldn't by all means undertake a task on my own.

4) What was the motivation to always move on?

I believe that the main motivation to move on was the desire to conquer enough autonomy to live my life without being a burden to other people. As my mother would say: "Every person must be their own help".

5) What sort of advice would you give to someone who is now dealing with a disability or to someone who has difficulties?

I would say to that person: "You are worthy!", "You can do it!", "Do not quit!"

About Paulo Antonio (29.03.2015)



I am Paulo António and I am 47 years old. I suffer from Cerebral Palsy. In October 1974 I started my studies at the primary school of Pousafoles (Miranda do Corvo), and on 30th July 1992, I graduated as a Bachelor in Accountancy and Administration by the Instituto Superior de Contabilidade e Administração de Coimbra.

I am a chartered accountant. I am married and I have an 11-year old girl. Although I have a handicap, I managed to have a normal life path, similar to everyone else, only with a few extra difficulties. Without the support of the Centro de Paralisia Cerebral, and of God, i wouldn't have been able to be so successful.

Answers to our Questionnaire

1) What exactly brings happiness into your life?

Just like anyone else, my happiness is determined by the people around me. First my parents, my brother and the rest of the family, and currently my wife, my daughter and the family resulting from my marriage.

Friends deserve a bold place when I mention my happiness as I have people who have always been there for me, who have been my friends for 40 years.

2) Where have you found support and assistance /counseling when you confronted yourself with difficulties?

On the first years of life my parents, as usual, specially my mum. And then the doctors, who followed me during my early ages (I only started walking at 7 years and a half of age).

Later on, from 1974 on, when I was 7 years old, at the institutional level I got help from the Centro da Paralisia Cerebral, first in Lisbon, where I went a few times with my parents, and then in Coimbra.

Considering the time when I started getting the support of the Centro da Paralisia Cerebral, in which Portugal had come from a political regime to which some honesty may be considered, but that limited people's points of view regarding their

ideals, the support by this centre was essential not only by the support in terms of motor and psychological rehabilitation, but also civilizational, in the sense that it made clear to me and to my family that the fact that the fact of having a disability is a disadvantage, but does not prejudice my future rehabilitation, which would happen with great achievements.

Of course that when I think about tackling obstacles underlying my disability, and without undermining any of the help mentioned, I feel that in my whole life there has always been an indispensable help, God's help. I am a Christian.

3) How did you handle the new challenges?

Some times with perplexity but always recognizing that difficulties are inherent to everyone, should they have a disability or not.

My perplexity lessens when I realize that around me there are people who do not have a disability but who also face difficulties, and although very different from mine they sometimes are not able to overcome them.

Disabled people (disabilities) should try to organize their lives (obstacles, challenges and opportunities) in the way that society does not feel obliged to address them in a differentiated way, within the functional and operational limits, because if that happens they may contribute to self-exclusion.

4) What was the motivation to always move on?

My main motivation is driven by my belief in someone above us who commands our life, who for me is Jesus Christ. Then my family who passes on the motivation to move on.

My other motivation is music.

When I feel a certain lack of motivation, I listen to music, to my favourite band, Pink Floyd. I like most of their songs, specially “Shine on you crazy Diamond” which is one of the songs of my life. It seems quite strange and incomprehensible, but sometimes it gives me the necessary motivation to move on.

5) What sort of advice would you give to someone who is now dealing with a disability or to someone who has difficulties?

That people never quit and look for help among the right people and institutions, and that they should never forget that the insight for problem’s solutions appears when and where you least expect it.

About Susana Lindim



I am Susana Lindim , I am 29 years old, I was born in Coimbra and I suffer from Cerebral Palsy. This condition has caused hydrocephaly, which in turn has caused hemiparesis on the right of my body. This affected my balance, walking and hand sensibility.

I was born in the 80s, and medicine was developing, and as a newborn everything seemed to be fine. But my faith was not exactly what was expected and I ended up going through a big journey. Thanks to a phone call made by the maternity hospital, I was received by a family who started loving me right from when they saw me for the first time, when I was only 3 days, and today I know that was a reciprocal love... A LOVE THAT WAS BORN FROM THE HEART.

I remember that during my childhood I was a happy girl, joyful, who would play on the street with friends, taking part on every game and play. As an adolescent I had my complexes, just like any other girl, and I dated boys, like any other girl, but it has been a difficult time, and I counted on the support on my family and friends, and the big support of APCC.

I've never been a good student, I would have a lot of trouble to pass the subjects, and when I got to the 12th grade I was about to fail the school year. With the support of my family and of the APCC, I decided to enroll in a 4-year vocational training for IT.

My self-esteem was very low and thanks to those 4 years and the support of all the technicians, I managed to get back on track and become a positive person, joyful and in good terms with life. I made a lot of friends and met my boyfriend. We both suffer from Cerebral Palsy.

The time I spent I APCC has given me the strength to get other victories in my life, namely, the successful conclusion of the 12th grade, also in the IT area and in Escola Avelar Brotero, as I enrolled for an evening course. I also enrolled on an English language course at the Wall Street Institute, and with my father's help, I also graduated in insurance intermediary, and the biggest of my achievements was being able to get a driving license.

At the moment, I have a work placement as an administrator at the swimming pool back office. I direct children to the shower rooms, and sometimes I help my colleagues to blow-dry the children's hair, and guide the older kids so that they don't take too much time to get dressed.

My dreams aren't over yet. I want to get married and have children.

I hope that this testimony contributes for you to achieve all your personal goals, and overcome all obstacles that come up in life. Do not forget that a smile is the best weapon for everything.

Answers to our Questionnaire

1) What exactly brings happiness into your life?

To read a book, to be with the family, friends and boyfriend.

2) Where have you found support and assistance /counseling when you confronted yourself with difficulties?

First, as a child, in the Children's Hospital of Coimbra and then, as a teenager at APCC.

3) How did you handle the new challenges?

My childhood wasn't easy, and I overcame this phase as i grew up.

4) What was the motivation to always move on?

To look face thinks as they are and always think positive.

5) What sort of advice would you give to someone who is now dealing with a disability or to someone who has difficulties?

To have a positive attitude, always with a smile and above all, to accept ourselves just like we are.

About Teresa Vendeiro (29.01.2015)



PRESENTATION

My name is Teresa Vendeiro, I am 44 years old and I suffer from cerebral palsy. The injury was caused on delivery, at the central nervous system and I became affected in the motor level. I am quadriplegic and I walk with the help of a crouch.

In Portugal by the time I was born, in 1970, the future didn't seem to be very enticing. The "roads were winding" and there weren't many goals to be attained. In fact, the fact that I was born within a humble family, and the fact that I has a motor deficiency, didn't leave me many options. I was confined to my house and to playing by myself in my childhood; I lived no adolescence and I had no hopes for the future, and I used to count every day I lived until I would get to the blighted fate of all of us, death.

Despite all setbacks in life, I consider myself to be some kind of "force of nature", an "untamed spirit" and I've taken the opportunity that life has given to me with all my strength! With my family's support, friends and APCC, I have evolved greatly, not only at the motor level, but also in other aspects of my daily life: I no longer use a wheelchair, I started moving with the help of two crouches, and today I only use one of them to help me walking! In 1988, I took the podium to receive the gold medal at the Paralympic Games of Seoul for the modality of Boccia! In 1990, I got married, and then I gave birth to a healthy and perfect boy. That was the happiest day of my life!

Some years later, I got divorced and I took over my son's education on a full time basis. Meanwhile I graduated in Art and History at the Faculty of Humanities, in the University of Coimbra. I persisted, I struggled, I cried tears of blood as I was looking for a job; but I've never hesitated; I only wanted a "place under the sun". I worked in the Museu Monográfico de Conímbriga, and I currently work in my "second home", a dream of a lifetime, that I embrace with love, care and professionalism: APCC.

To those who are reading this testimony, I leave you a word of comfort and fight. Go for your dreams and never quit! Establish your life goals and go on!

“Stones in the road? I save every single one, one day I’ll build a castle.” (Fernando Pessoa)

Answers to our Questionnaire

1) What exactly brings happiness into your life?

Waking up in the morning and realize I am ALIVE and that I have much to live ahead; many projects and emotions to enjoy!! I am the happiest woman in the world when my son is with me (he currently lives in Lyon), and I can enjoy his smell, listen to his voice, see the sparkle in his eyes and his unique smile. I am happy because I have a partner, a stable emotional life with someone who understands and fulfils me. I am happy because I have a job and because I really like what I do, as I work for an institution that gives meaning to my existence. Then, although I have an handicap, I am healthy enough, and this allows me to dream and make short-term plans, such as to travel, something that I love to do. I am happy to be able to enjoy the sea and all its greatness. I am also happy because I am a mother and because I have the best mother in the world!

2) Where have you found support and assistance /counseling when you confronted yourself with difficulties?

I found help within my family, there’s no doubt about it. Family has been the most powerful foundation, where I have found safety and reliability. Then, also with the rehabilitation technicians, first in Alcoitão and the (up until today) in APCC, including board members. I must also acknowledge the important role of my friends who have always supported me throughout my life.

3) How did you handle the new challenges?

It hasn't been easy at all to deal with difficulties and challenges, but I've always been quite stubborn and determined; I've never been a quitter. Actually, the more challenges I have, the more I want to move forward, and sometimes I 'crawl' but I never quit. I owe to my personality the determined way I've been dealing with all the challenges (my untamed spirit in the words of Daniel Cruzeiro), and also to the education I got from my godmother, my grandmother, my mother and from my aunt Soledade, people with a strong personality and a unique sensibility.

4) What was the motivation to always move on?

My motivation has had four different phases: as a child I would never miss a session of physiotherapy because I wanted so much to get better in terms of my motor abilities. As a teenager I was the best student and at the honours level. I've always been a perfectionist. Then from the moment on that I was a mother, my motivation consisted of giving the best possible to my son, not only at the level of material goods, but also at the level of human values. Nowadays, my motivation is about maintaining the quality of life, maintaining what I attained in terms of physical abilities, and continue to work towards a life with dignity; to be healthy; visit my son whenever I can; to have people I love beside me, and in the short term to write a book.

5) What sort of advice would you give to someone who is now dealing with a disability or to someone who has difficulties?

First of all that you do not hide, do not get into a "shell". I know that sometimes we do have the desire "to quit", of "leaving everything behind", and stay at home, where everything seems to be easier. But move on, go out, let everyone look at you. People will look at you, but they will become used to it (if they want to)! We have

the right to live and be recognized. To be handicapped is not amazing, but it's not the end. We have to adapt ourselves, to learn how to like ourselves just like we are, and to have self-esteem. If we like ourselves and accept ourselves just like we are, everything becomes easier.

With a smile we face problems, make friendships; we attain our success at school, in university, at work... TO QUIT is a verb that cannot exist in our vocabulary! "Life is short!" we have to make the most out of it while we can.



About José Luis García Martínez

Presentation

José Luis García Martínez is 71 years old, retired, a native of Albalate de las Nogueras in Cuenca Province, Spain. He is handicapped by polio that affects his lower limbs and therefore his locomotor skills. He is able to walk with the aid of a cane.

Answers to our Questionnaire

1) What makes you happy in life?

The concept of happiness is subjective and very personal. You could say that happiness, even if it's not full happiness, is achieved when you're satisfied in your state of mind. From my perspective I can say that, given the ups and downs that any human experiences, I'm relatively happy because I feel fulfilled, serene and stable. And, when you're born with a serious physical disability in a rural environment to a meager peasant family, it's not easy to find the security necessary to succeed and achieve your goals. Society, and even your closest

relatives, are sometimes overly protective and on occasion, perhaps unintentionally, somewhat harsh.

That poor boy! What's he supposed to do in his situation? How will he defend himself in life? Those are the kinds of things you hear in your childhood, and if they don't make you withdraw or give you an inferiority complex it's because there's a special light inside of you that enlightens you and lets you come into your own when faced with the black situation before you. You work hard and study by your own means, without access to schools or academies, you learn and grow, and manage to find your first job at the early age of fifteen.

That's a good start, I thought then, and with energy and luck (yes, because you do have to get lucky), you make your way, you shed your fears, you overcome challenges and manage to achieve important goals. Then one day you say proudly, "I'm no less than anybody else. I'm doing meaningful things that other, 'normal, nonhandicapped' people would like to do for themselves."

That's basically how I feel at the ripe old age of 70, and I felt the same during my long period in the workforce.

2) Where did you turn to for support and advice when faced with problems or responsibilities?

The model of an industrious mother at home, the example of a hardworking, caring, selfless father, the whole family, are always bastions of support. Nor can I forget the only teacher I ever had. Much of what I've learned, and indeed the basis of what I am, I owe to him.

3) How do you cope with new challenges?

At my age, it's time to rest. There aren't many challenges left that don't have to do with leisure or entertainment. My physical state has worsened over the years and hardly allows me to walk, but you have to keep at it. Nowadays, I manage to stay informed, I use new technology and I get on the internet. I also write. I've

finished a novel, still unpublished, and I have a multitude of stories and tales, some of which have won competitions and contests.

4) What was your motivation to keep going?

The most important thing for a person is to maintain your lucidity and reason, and I tried to cultivate my intellect by reading, traveling and learning. Unlike before, I can't travel anymore, but I use my memories to travel back to the places I went. Books and television programs help me get closer to the places I used to travel. Living with the family members I have and remembering those who have passed, living a new day, trying my hand at emulating certain writers and essayists, maintaining friendships, riding through the streets of Cuenca on my electric scooter, going to the marvelous Hoz in my town and being able to admire its natural splendor, are all sufficient motives to keep going.

5) What advice do you have for someone who currently has a disability or problems caused by their disability?

Confront your challenges with vigor, have confidence in yourself and, above all, don't shy away from anything because of your physical impediments. Be tough, fight, prepare yourself to compete in a world that is hostile, but not impossible to overcome, and demand the right to work. You might have physical limitations, but I assure you that your obvious, visible restrictions are no greater than those that some people have, even if their restrictions cannot be seen with the eye. You must understand that in the end, even though your life won't be easy (nor is it easy for many who don't have physical limitations), it is no less true that no one is bigger than anyone else and that with the will and the effort you can take more steps forward than backward, minimize uncertainties, participate in the working world and live with dignity.



About Mari Ros Rosado, mother of Sergio Aznárez (young man with blindness and autism)



<http://www.lasonrisaverdadera.org/video/entrevista-madre>

Answers to our Questionnaire

1) What makes you happy?

I am a mother of a blind and autistic boy, and I feel happy feeling the care of the people I love. Being able of seeing my sons healthy and happy. And also I feel happy when I feel I am doing the right thing.

2) Who has supported, advised, assisted, included, comforted, when you got into trouble?

I found support in my family, and also in a nice doctor who oriented me about my son's disability. And also I founded supported by myself, having an optimistic and positive opinion toward a different reality, but also a very nice reality.

3) How did you face the new challenges?

With interest towards the life, and, even, thinking that everything which would make your life harder, can also make it beautiful.

4) What motivations did you find to go on?

The wish of helping my son, of making his life a nice experience, a nice place, where he can develop and expand himself. This is what make me go on.

5) What advice would you give to someone who is now facing the problem of disability and is having difficulty?

I would advice that problems aren't laid on the grade of difficulty they have, but in the way we face them, we manage them. Life can be even more beautiful when things are hard. When we have problems is when we give our best of ourselves. Then, I think that always life is beautiful, this is my message.



About Mónica Patón Ormeño



Presentation

Mónica Patón Ormeño is a woman with Down syndrome. She studied in a special education school in Ciudad Real until 21 years. Then she kept her studies in a occupational center called “Caminar” learning to be concierge. Currently she has two jobs as concierge since eight years ago and the other in early care with children. Both of them in a organization called Lavorvalía.

Besides, she is the radio presenter of the program “To be able”. In that program they talk about special people with a lot of topics.

Answers to our Questionnaire

1) What makes you happy?

Mónica says several things that make her life happy.

Firstly the people in her life like family and boyfriend, because Mónica says that love makes her life happier.

Besides she tell us that also another social structures are very important such as schools, or social entities like Lavorvalia. Also in the encourage of the people, for example sometimes mothers of special children ask Monica for advice o say to her “you are very pretty”.

Mónica tells us that work is very important in her life y. She feels herself very proud of working with other disability people and has the possibility of helping others.

Finally Mónica says that it is also very important to have goals and hopes and try to reach them. But over all the independence, because to feel free and equal is fundamental for her.

2) Who has supported, advised, assisted, included, comforted, when you got into trouble?

Family is the more important thing in her life, although she had to fight against the protection families make on her. Monica says that her family supports her always; but sometimes is not the better way, as in all the families.

She has couple since years ago, and he is an important person in her life.

3) How did you face the new challenges?

She likes have challenges in life, and thinks, I can do it, why not, there are not barriers. It's a question of having willpower and being perseverance. She believes in the personal effort and forever **onwards**. For Monica her next challenge is to live in a **flat** with her boyfriend. Also that there aren't more **discrimination** of the special people in the world.

4) What motivations did you find to go on?

Her personal motivation always has been to be independence, because when she was a child, people doesn't leave her to do a lot of thinks, because they were afraid or didn't see her able. So she has fought to do everything by herself.

5) What advice would you give to someone who is now facing the problem of disability and is having difficulty?

Be independent and autonomous and if we need help, ask for it. You have to fight, you have to believe in yourself, and you can to get everything that you wan. And if you don't get it, don't worry, at least you have tried it, and have learned.



About Antonio Hermoso



Presentation

Antonio Hermoso is 58 years old. He is from Córdoba where he studied Law. He has a physical disability: poliomyelitis 70%. He can't walk and he managed with a wheelchair. He has always worked in FEPAMIC (Cordovan Federation of physical disabilities) as office administrative. During many years he has been the President of FEPAMIC. Nowadays, he is retired although he works in FEPAMIC as volunteer.

Answers to our Questionnaire

1)What makes you happy?

Work is very important in his life and makes life happy. He feels himself very proud of working with other disability people and have the possibility of helping others. Even though he studied Law he has focused all his life in helping people with disabilities.

Another thing that makes life happy is family, he is married and have two children.

It is also very important to have goals and hopes/ dreams and try to reach them

2)Who has supported, advised, assisted, included, comforted, when you got into trouble?

Family, they are the more important people in his life, although he recognizes that it's very difficult to find the balance between protecting disability people and give them autonomy.

There are also another social structures very important such as schools, or social entities like FEPAMIC that they are involved in working and helping disability people.

3) How did you face the new challenges

Usually, it depends on the challenge, but always he faces to them with hope and willpower. He accepts it knowing that it's something important in his life and doing it with effort and determination.

4) What motivations did you find to go on?

Life's need, being alive is having wishes and try to get them. He has always wanted to overtake difficulties

5) What advice would you give to someone who is now facing the problem of disability and is having difficulty?

React, we have to take on ourself commitment. Always go on. Everybody needs an opportunity and feel we can do whatever we want. Be independent and autonomous and if we need help, ask for it. Maybe we cna need others support but your own commitment is indispensable.



About Sergio



Presentation

- Sergio is a young man of 26 years: he is blind and has therefore never seen a smile. Additionally, he is autistic. He does, however, give everybody a sincere smile every day; his purity, dedication and his inner peace with his life make his story of self-improvement even more unbelievable. It is a gift to all of us around him.
- Sergio faces many difficulties in life, yet this does not impede his cheerful disposition and he projects this deep, sincere happiness to others. Life is challenging yet straightforward for him at the same time. He moves at his own pace; he enjoys both the bigger and smaller pleasures of life in a very intimate and personal way.
- Sergio is a determined fighter who is capable of achieving every goal he sets himself. He plays the piano as well as some other percussion instruments, does tap dancing, sings in a choir, practises yoga, swims, rides horses and a tandem bike alongside his brother. All these experiences are relayed and recorded onto a Dictaphone. He is a great adventurer: an excellent travel companion and always ready to face up to a challenge.



Sergio, what makes you happy?

I really enjoy playing the piano, and singing, but, what I most like is travelling. Two years ago I went to Morocco, in tandem bike, with my brother. We get at the Gorge of Todra, we get at the town of Tinerhir. An the last year we went to, my brother and me, France, also in

tandem bike and we toured the route of the Loire Castles. And, this year I want to make a trip to the beach. I feel very happy.



About Sergio Vera Valencia



Presentation

Sergio Vera Valencia, disability visual (blindness). Degree in Educational Psychology. English Teacher. Research Fellow FPU Ministry of Education and PhD Center for the Promotion of Children's Literature (CEPLI) at the University of Castilla-La Mancha.

Passionate about reading and founder and coordinator club.

Answers to our Questionnaire

1) What makes your life happy?

When I lost the vision, the studies became my whole life during a long time. I only wanted to do my best, and to obtain the best marks I could get. I hardly ever went out and I studied from Monday to Sunday from the early morning to the late evening. However, I couldn't say I was happy. I felt satisfied, proud of myself, but I wasn't happy. The best mark wasn't enough for me; in some occasions I have complained when I got a 10 because I wanted an honor.

Sometime later, Reading started to be a very important part of my life. I spent (and I already spend) a lot of time Reading and I coordinate a Reading club for four years in the Public library. Although I consider Reading something necessary to be happy, it is not enough for me.

The same happens with my job, in spite of being the one I dreamt with. Only since the last year (March 2nd), I have been able to know what happiness means. It hasn't been for being the best student of my degree nor obtaining a grant from the Ministry for writing my thesis; it has been because I started a relationship with my girlfriend. I know it sounds like a topic, but it is true; only when I am with her I feel happiness.

2) Where did you find support/advice when you faced up to responsibilities/problems?

This question is easier: in my family. Always. It doesn't matter what people say but the only support disabled people can count on every day (seven days a week, 24 hours a day, 52 weeks a year) is the family. The rest are cheap rubbish. I don't want to say I have only received advice and support from my parents, but they have been, especially my father, the ones who have made me be here. It is sad, very sad, but it is true.

3) How do you meet new challenges?

I don't know. Honestly, I don't know. Before I realized, I am in a new business, involved up to my neck. Sometimes because I want to, some others because I have to, but I am very good at doing my life more complicated, I am addicted to the challenges. I even have a special folder for new projects in my desktop...

4) What was your personal motivation to keep going?

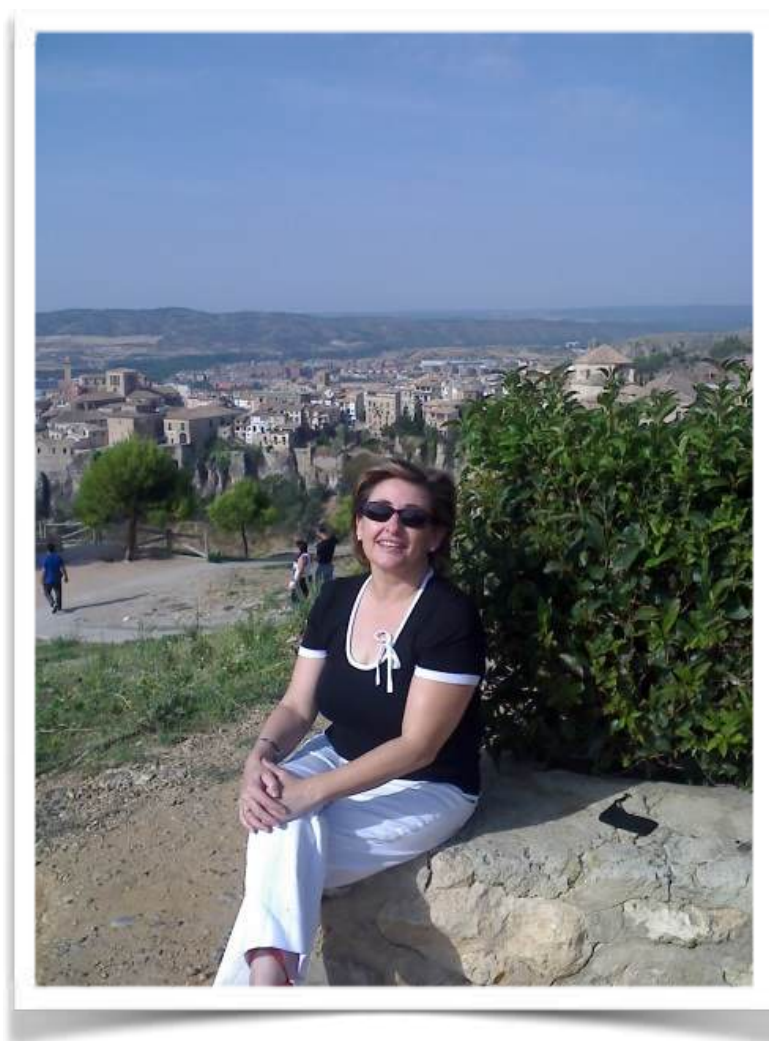
My father was. He told me: Nothing can be solved crying. Stand up and be brave. So easy. So hard.

5) What advice would you give to someone who is now facing the problem of disability and is having difficulty?

The same my father gave me. Having a disability is very hard, very, very hard, but you can't get anything only regretting. Your relatives can help you but it is you the only one who have to save your bacon. Nobody has said it is easy. You are going to hurt yourself, a lot, many times. You are going to cry, a lot, many times. But these are the cards which you have been dealt and you have no option, you have to play. And sometimes, very rarely, you win.



About Rosa María Pardo (57 years old - 30 years teaching)



Rosa has a physical disability in her two legs caused by the polio. A non-effective vaccine brought it on.

At that time, her mother had to fight, opening paths that were closed. We are talking about the 60s. The main institutions which should attend her (Health and Education), did not help much.

Joining the school was very complicated, because society was not ready for this kind of children. They weren't admitted in public school, so they were referred to Special Education Centers.

She completed university studies of Teaching. From this moment she got a job as a teacher and this is in what she has spent all his working life, working in different schools and high schools.

Regarding his private life, she is a married person and has two grown daughters. One is studying in Madrid, and the other remains at home as she is studying Baccalaureate.

Answers to our Questionnaire

1) What makes you happy?

That's a good question! And the answer is many things! Seeing the happiness as a transitory feeling or mood, I have many good things in my life for being taken into account. Very often I feel happy, and when it happens, I have free time for appreciating them. To see how my daughters are growing, to walk around my city, to do a normal life, it's more than a reward for me. I still remember the first day in my life when I was able to brush my teeth, stand without help after being two

months in bed. Enjoying the sun or the breeze, when it's so hard to go out... For me all those things are very valued, the small things make me happy.

2) Who has supported, advised, assisted, included, comforted, when you got into trouble?

Absolutely, my family. And, years after, not only them but also my friends and workmates, who are helping me very much. Of course, I have lived difficult situations, specially getting to a new work place, with accessibility problems. But, I have always counted on my people, my friends and my family, and I have also helped others. I have felt myself useful and I have always asked for help if I have needed it.

3) How did you face the new challenges?

Actually, you are never ready for whatever comes to your life, but, when you meet the difficulties more than once and twice, you also train your forbearance, you learn how to keep the illusion for getting new targets, because, when you get small new targets, and you gave your best in that, and all your time, this makes you stronger and you learn how to wait, how to try. Then, patience and illusion help me to face the new challenges.

4) What motivations did you find to go on?

Life in itself, and all I have got. To value what I have. I feel lucky because I can count on many people around me who light my life making it an easier place. They also give me their illusion and I feel responsible for responding to them, due to the fact that they make me very happy.

My daughters also motivate me every day. My life is so full of love and good things, that I feel really boosted to keep on trying, keep on moving, keep on living. I

cannot afford the luxury of being static, and this is my challenge, my each day renewed challenge.

5) What advice would you give to someone who is now facing the problem of disability and is having difficulty?

I would start with a word with is nowadays almost a trending topic, but is also full of meaning: resilience. Sometimes, life kicks you. Life kicks everybody, but, maybe specially, kicks stronger to the people with disability, because they are maybe weaker. Then, the resilience is the key for keeping harder and harder, the key which helps you.

Another important thing is being very optimistic. In life, we always face good and bad things and here, the psychology, our attitude, is very important: because is not the same to state: 'I cannot, this is impossible' than to state: 'I am going to try it'.

However, it is necessary to keep your feet on the ground, being realistic and noticing your limitations, because we all have limitations. But this cannot stop you. We have to set targets, to set on reachable targets.

It is not necessary to prove how much you worth. I am only a person, with my pros and my cons. So, from this idea, we have to face any challenge, from this normality. Being patient and keeping the strength to keep fighting.



About Cuma

Interview with Cuma a counsellor teacher working in Şile Turkish National Education Directorate Counselling and Research Center.

by Sibel Uğurlu and Alpaslan İpek

Presentation

Cuma is 38 years old. He was born blind. He is single. He lives alone. He went to visually impaired primary and secondary school then he went to a normal high school. He won the university. After graduation from university, He became a special education teacher. Now he works in the Family and Social Policy Ministry.

Answers to our Questionnaire

1) What makes you happy?

Every beauty makes me happy. I feel happy when I can't survive without discluded from the social life. When you are disabled person you always want that people behave you like they behave to normal people. You want your disabilities to be invisible.

2) Who has supported, advised, assisted, included, comforted, when you got into trouble?

I always try to solve my problems on my own. Thanks to my friends, they always became the biggest support in my life. But when I faced with a difficulty, the best way to solve it is communicating with other people. I think this is the way what normal people do as well.

3) How did you face the new challenges?

It's important to be decided. I like to search and find things on my own. Things are more valuable when I manage to find them myself.

4) What motivations did you find to go on?

I feel motivated when people respect me. And I feel motivated when people admire the work I achieve.

5) What advice would you give to someone who is now facing the problem of disability and is having difficulty?

I advise them to try to be educated. I don't only mean the university education, I mean courses on different subjects.

In addition that, people from the government generally build and create something without asking to the disabled people and so what they built or create are not so much appropriate for the needs of disabled people. I would be better if they ask things or decisions whatever it is thought to be realized, to the people who will use it. I mean disabled lifts, parks, common area arrangements etc.



About Fırat

Interview with Fırat, a counsellor teacher working in Şile Turkish National Education Directorate Counselling and Research Center.

by Sibel Uğurlu and Alpaslan İpek

Presentation

He is 38. He was born blind and as his other brother. He graduated from the visually impaired school in primary school. After that he went to a normal high school. He went to a university and became a counsellor teacher in Turkish National Education Directorate. Now he has been working in Şile Counselling and Research Centre and helping children with problems. He was married for 12 years and got divorced recently. He has been living alone and can look after himself.

Answers to our Questionnaire

1) What makes you happy?

What mostly brings me happiness in my life is to be admitted as an individual and to get the rights and acceptances that a normal healthy person gets. It makes me disappointed when we are distinguished and separated to be treated specially. I

mean differently from a normal person. In fact what really brings me happiness is to be seen as "normal" and to live in a world in which we are not being differentiated.

I feel happy for the things that I healthy person feel. I feel happy when I can survive in the society. I feel happy when I produce something.

When I was at the beginning of everything, I had no choice to get education. My dream come true was to be a public prosecutor. I couldn't realize it but I'm now happy in my profession as counsellor teacher.

2) Who has supported, advised, assisted, included, comforted, when you got into trouble?

Unfortunately there was nobody except God:) I didn't get any financial support from the government and what I advise for disabled people is the same. In other words I never expect to get help from the government, institutions and private associations. I didn't want to be a burden to the people. I wanted to survive with my own efforts. I can solve my own problems on my own.

3) How did you face the new challenges?

When I was trying to survive or cope with the new challenges, mostly technological innovations helped me like talking mobile phones and computers. In addition, I can't deny the help of sensible people.

4) What motivations did you find to go on?

What motivates normal people motivates me. I feel humiliated by these questions because I'm a normal person and I want to be included not discluded. If you ask me what motivates me, I can tell you that being admired, being happy with your wife and children, being loved etc.

5) What advice would you give to someone who is now facing the problem of disability and is having difficulty?

I advise them to try all the time not to give up. They had better try to be productive and creative to improve themselves. Some disabled people depend on very little financial support provided by the government and they give up producing something, adding their own values to the lives of other people; in a way they admit to be a "disabled" person. I always think that, whoever you are, disabled or not, you should always try to create something new. No use of feeling upset and closing your doors to the life.

IMPACT

For each partner, the project brought significant benefits. Some are related to the work with the people with special needs. Some are about the organizations themselves. Sometimes it is about the people involved.

We have asked each partner, at the end of the project, what impact had, in their opinion, should be mentioned here.

MESSAGES

We have talked, during the project, with hundreds of persons. Some having disabilities. Some parents of someone with some disabilities. Some working with people with special needs.

This book is about the persons who are at a certain point of fulfillment and tranquility in life, despite the disability they are facing every day.

Yet, there are so many others who have disabilities, who have wonderful stories, and who were involved and or impacted by the project.

From some of them, we have asked to send a message to everybody who is facing disability in Europe or in the world, and who is going to read this book.

You can find partners' opinions, messages of hope, love and encouragement on the following pages.



Impact on Esperando

For Esperando, WISPEL project had multiple impacts.

Being a project we have dreamed and created, we are first delighted to have so wonderful experiences from all the partners and all the countries.

We have learned again lots of things that are already improving our work for the better life of the people with special needs/ disabilities.

Looking for good examples, we have found again amazing people with inspiring stories and lives and we are grateful for that, too.

And we have had the chance to make new friends among our partners, people who have become so dear to our soul...

Thank you, Grundtvig! Thank you, European Commission!



Messages from Romania

I am also a person with "special needs" - I have spastic tetra-paresis with extra-pyramidal syndrome, so I'm in a wheelchair. But despite this I strongly believe that life deserves to be fully lived, to enjoy everything nice life is offering us. Never give up!!! You have to be strong and show you, your family, your friends and especially the society that you can overcome obstacles, life tough moments! Even we have a disability, life is well worth living utterly!

Suman Judita-Eva

I'm struggling with disability for 28 years now. I had moments when I said I give up in front it and I don't care about anything anymore. And I am sure I will have more of such moments. But life has taught me that it's well worth to fight disability and that I am strong enough to overcome any difficulty. My request for all those who have a disability - no matter which one - is to believe in themselves and in their strengths and they will outstep everything. And when they feel they have no more powers, say a prayer from all your heart and God will give you the power you need!

Dana Bonte



No matter how hard it is for you,
Fight in your life, to show to yourself
That you are strong, and so you will give also strength
To those close to you.
Because they are also giving you, at their turn,
The purest thing they have - their love for you,
The hope and the faith they have taught you
From your early childhood, to be always with you.
Even if you are in a wheelchair
Or you walk with ease, or hardly,
You want to go on...

Mariana Omota

In life there will be good days and bad days. Some things are meant to happen.
May God help us overcome them all!

Calina Vlasin

Impact on CNIS

This project experience has been really important for our association. We have had the chance to visit schools, associations, residences and talk to people with disabilities living in different countries.

We have had the opportunity to enrich our knowledge about how the other countries work with disabled people and share our 40 years experience of school inclusion.

It is interesting to read the interviews and find out how different the keys to happiness are even if they all share a red line.

Messages from Italy

What makes you happy?

...looking for beautiful things in everyday's life. **Laura**

Enjoy the happy moments and learn from the difficult ones.. **Paul**

Every single new step is happiness. **Rossana**

... we always have our dreams on which we invest our enthusiasm, energy and a lot of passion, sharing it with those who live by our side, and turning every single fact of life in an opportunity to grow - regardless of any other consideration. **Luca**

It makes me happy to have friends with whom I can share situations, confidences, and to feel that the relationship is true, honest, non-judgmental. **Tatiana**

It makes me happy the Inkwell Group, the serenity in my family, the Milan football team , reviewing 82 Tardelli's scream, the music ... so many things! **Claudio**



Impact on Ceribu Sparni

We gained international experience and saw what others are doing. We found out about social support system in each partner country. We met fantastic project team and we all are interested in the same target - how to make life of disabled people better.

Inspiring message from one person we interviewed

Olegs: You must see opportunities and bright sides of every thing in your life. You can't just sit there and be weak - you are too strong to afford that! Life is too short for being helpless.

Impact on APCC - Associação de Paralisia Cerebral de Coimbra

In the setting the scene we referred the empowerment of people with disabilities as an approach to quality of life , a dynamic and interactive process between the individual and the environment, which covers several dimensions. The WISPEL project and the experiences shared using the wisdom of people with disabilities have confirmed it as a contribution for the continuing progress of their life's.

They include :

- People who have reached success in life can inspire others to improve the competencies and the knowledge of other people who are now facing similar difficulties related to it and can benefiting from the experience of their peers;
- Effective strategies of empowerment can be developed by peers. People who participate in WISPEL and so many times felt that were left behind to waste away believe that they can give the type of support that can help people live full and productive lives.
- To set goals is part of life. Goals can be related to work, athletic endeavours, learning a new skill, gardening, resolving a contentious relationship, or finding a way to more effectively manage activities of everyday living. Unfortunately, you can't achieve goals when barriers prevent you from getting in the door. Worse than that, certain barriers prevent people with disabilities from even setting goals in the first place. However, there are many people who, despite their disability, achieved

much success. Stairway to happiness implies will, obstinacy and work. The sentence *“never give up”* was every time present in the testimonies.

- *“It’s better to teach people to fish than to just give them a fish.”* People with disabilities that are well with life have shown that in such a way as to help them sustain their independence, we create a happier, more connected and inclusive society.

APCC recognised active participation of people with disabilities in the project. Participants in the visits were women and all of them felt like a “princess”. They felt having inspiring stories making power, helping others seeing things differently, treated fairly, and as an equal, by others.



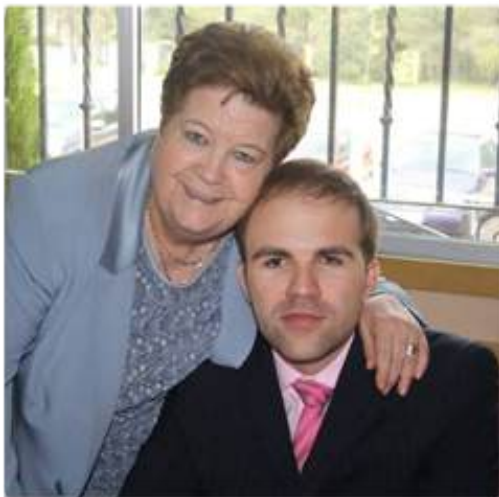
Impacts in the form of messages

İSTANBUL ŞİLE HALK EĞİTİM MERKEZİ - Şile Public Education Center

- Enable your minds and hearts before building disabled lifts.
- In fact, what really brings me happiness is to be seen as "normal" and to live in a world in which we are not being differentiated.
- I want to be included not discluded.
- If you are a disabled person, you always want that people behave you like they behave to normal people. You want your disabilities to be invisible.

IMPACT AND MESSAGES: SELECTED PHRASES IN INTERVIEWS

Sergio Vera Valencia, disability visual (blindness)



el único apoyo incondicional (24 horas al día, 7 días a la semana, 52 semanas al año) con que a día de hoy contamos las personas con discapacidad **es la familia.**

the only unconditional support (24 hours a day, 7 days a week , 52 weeks a year) we have people with disabilities : the family.

Sergio is a young man of 26 years: he is blind and has therefore never seen a smile. Additionally, he is autistic.



*Lo que más me gusta es la música ,
tocar el piano y viajar. Soy feliz.*

What I like most is the music,
playing the piano and traveling. I'm
happy.

Mari Ros Rosado, mother Sergio Aznárez (young man with blindness and autism)



Comprendí que tenía que ver las cosas con
una mirada positiva y diferente de las
cosas, sin dar pena.

I realized that as a parent of a person
special (my son), is that I had to see things
with a positive, things look different ,
without penalty .



Antonio Hermoso is 58 years old. He is from Córdoba where he studied Law. He has a physical disability: poliomyelitis 70%. *It is very important to have goals and hopes/dreams and try to reach them*

Family is the most important for me.

Being alive is having wishes and try to get them.

React, we have to take on ourself commitment.

Always go on.

Mónica Patón Ormeño is a woman with Down syndrome. She studied in a special education school in Ciudad Real until 21 years.

Love makes my life happier.

Working is very important in my life.

I can do it, why not, there are not barriers

You have to fight, you have to believe in yourself, and you will get everything you want.



José Luis García Martínez is 71 years old, retired, a native of Albalate de las Nogueras in Cuenca Province, Spain. He is handicapped by polio that affects his lower limbs and therefore his locomotor skills.

"With determination and effort, you can add more to subtract"

"I am no less than anyone else"

Rosa María Pardo, 57 years old

Rosa has a physical disability in her two legs caused by the polio. A non-effective vaccine brought it on.

"Everything is becoming in life has its rewards"

"I have been always helpful"

"I never lost hope to get new things"

Messages from Denmark

- Never give up
- Always look on the bright side of life
- You can do it
- Flight
- You are a gift to the world
- Room for everybody

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Disclaimer

This project has educational and charitable purpose.

The project has no commercial purpose whatsoever.

The seven project partners, each and every one with contributions and cooperation, realized the project. Every partner participated on its own free will and good intentions.

The persons interviewed in the project participated also on their own free will and they also shared their stories and/ or their photos voluntarily and without any financial or other type claims.

The partners are not exploiting in any way the image and/ or stories of the participants and interviewed persons for any financial or material benefit.

Each partner can use the results of the project as they wish, always with the concern not to harm in any way the interests and image of the other parts involved.

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