RHODOPES CENTER for COMMUNITY DEVELOPMENT

LOOK WHO IS TALKING!

SHARING THE STORIES of EUROPEAN YOUNG WOMEN WITH DISABLITIES…

Directorate of Youth and Sport
Direction de la jeunesse et du sport

COUNCIL OF EUROPE CONSEIL DE L'EUROPE

The Disability Experience from the Inside Out

Young women with disabilities in Europe have a wealth of experience to share with those in society who are not disabled. It is only by sharing and giving out to other people that we can receive experiences and knowledge that will enlighten our thinking.

The disabled and the non-disabled young people in Europe would then perceive and see each other with the same eye. There would be no need to hold expertises to us as pinnacles on high, but rather, there would be an opportunity and need to give and gather ideas for improving and extending lives of all of us irrespective of disability or ability.

This will not be as difficult, as it first seems, if we can stop judging the interior to be what the exterior appears to be. This is a step towards letting go our perceptions and assumptions of each other and seeing, ourselves and others, with a new in-sight.

Each one of us needs to be recognised as human beings with intelligence, talents, and gifts to give and receive from others. If this recognition does not take place then our very state of being is invalidated.

We all need to be recognised as people.

We have to recognise humanness in ageing, disability colour or ethnic and religious difference.

And we need to start learning from each other... because there is so much waiting to be shared...

THE STORY OF DANIELA STOYANOVSKA, 26 years old, MACEDONIA:

"NO COMMENT AFTER THIS HONESTY"

The childish stories usually start with: 'once upon a time there was a girl from…', but it is sad when in the eyes of other people from the aspect of what is called 'public', even the stories about people with disability start in similar 'childish' way.

And even if the start of the story is not like that right after the contact with the girl with disability with any other character from the society, the conversation gets the tone of weakness in the voice and pitiful look, as if the speaker can really put himself in her shoes and lives through that 'heart-breaking story'. The first opinion and impression of the public of this marginalized group of citizens is identical for all people with disability.

The only thing left for a person with disability after that is to fight fiercely and to proof that doesn't want any pity, and that is a never-ending fight because there will always be someone to proof to. But I say different people different characters, but I don't feel any need to make physiological analysis and profiles to all people from the reason that I've proven myself as a girl with disability firstly to myself, and than to the public that I can life perfectly normal regardless of my disability.

I exempt myself completely from this category because I am absolutely realized and affirmed as a member of this society and in social acting and work, but I can be a good daughter and sister as well, a good partner for romance, and an excellent friend for those who had shown me sincere love and I love them back, but at the same time imperfect as any other person with all of our flaws characteristic for man and woman. But those who don't know me and constantly turn around on the street to satisfy their curiosity, because they are amused by the way I walk, because this is Macedonia, and it is still miracle to have twisted legs in the knees and to walk in hand with someone, and an even bigger tragedy is to hear a diagnosis by someone like this is cerebral paralysis and that there is no saving me, or that by default you are mentally retarded and it is a pity to life when you aren't good at anything.

But for this second group of people I wouldn't even bother, because this is a group of people that cast away people by default and wouldn't want tot have more information, fearing that would change their opinion and attitude about the 'miracle' and they wouldn't be able to feed their spirit on it later. They are shallow and empty people, for who the only field of interest is other people lives, and they interest about others to hide themselves.

There is a third category of people which will be mine field of interest and those are, professionals, experts, intellectuals, who by my opinion should provide necessary services to provide every segment of social life for us. For these professionals I already curse at their diplomas, their titles, and on everything else, because in my life of coarse there has passed the phase of detection, and diagnosis of my disease, which was accompanied by their statement that I wouldn't be able to walk, talk, and that I would have an IQ equal to a border case or maybe even small mental retardation.

But for their deep regret, and my endless happiness today I stand equal to these experts who had set this diagnosis for me, and as doctors I started to tear down their God complex, and their power suddenly goes to terrible weakness, thanks to my graduation as a defectologist. I say this for a simple but justified reason: 'My diploma is different from theirs, not only for the grades that have been put inside, but also for the color, the color of my life, a color that is a perfect mix of subjective experience and knowledge gathered through life but also with the process of learning. Many of them lack that and then it easy for them to put labels on the disease based on the discovery of the disease, well isn't that exactly their work, to do it the best?

But every work demands emotional involvement. The mustn't let themselves to look at the patient as an object, although in daily practice they meet different types of patients with different kind of retardation, but nonetheless they must keep in mind that they are mostly responsible for the success of the treatment, and the relations: doctor – patient, nurse – patient, medic – patient. Exactly for this number of relationships, I will publicly speak of as a girl with disability.

I was 23 years old when because of the diagnosis and with the purpose to improve my walking and finally to achieve balance in order to walk independently, I had to take another sixth in a row operations. The operation (just as the previous one) should have been made by a famous orthopedist surgeon, because this time also it was about relaxing a muscle on the top of my right leg, only inches away from the hip. When we finally managed to set the date for the operation, the doctor said to my mother:' Bring tomorrow the patient clean, and fresh and don't worry everything will be all right.' But those words didn't have the same meaning for us as they had for the doctor. Nor I as a young girl neither for my mother with great life experience didn't understand the doctor’s point. Under clean and fresh we understood that I’ve taken a bath and wore clean pajamas.

That morning was THE DAY which I will remember for the rest of my life for the shame I’ve felt that day. Before I’ve entered the operational room a nurse and a medic together with my mother took me in the preparation room, they made my lay and asked to take my clothes off. In the mean time there was the question ‘you are fully prepared, right?’ we confirmed in a single voice with my mother. But when I was left to lay completely naked there was a physiological stress, spirit ache, shame, humiliation and a big dose of hatred and anger for the people that stood in front of me. Even from my puberty, when my sexual organ had fully developed, I regularly remove the hair from the ties, with the purpose of removing the hair, and in the last few years I completely remove them.

That day I didn’t do it, considering that it wasn’t necessary since the muscle that should have been operated is located almost 10 cm. The nurse and the medic stunned by the view started criticizing and it all looked like forever to me. ‘Does hair grow to disabled people?’; ‘Look it is impossible that so much hair grows at a little girl.’ Sometimes the nature doesn’t know what she is doing.’ And than both spoke to me in a single voice with a dose of insolence: ‘Why haven’t you took care of yourself?’, ‘Would you like for us to take care of you, like we don’t have nothing else to do and this is the only thing left.’. My mother tried to settle the situation and decisively said: ‘Don’t worry at all we will take care of it in a spilt second and your presence is not necessary at the moment.’, but the angry nurse replied: ‘We don’t have time to wait for you to prepare, I will now go to inform the doctor that the operation will be postponed for 20 minutes, and in the meantime the medic will take care of the patient.’, and thane started the process of ‘butchering’, with an old razor and some water until all of the hair was removed, and in meantime the medic murmured during the whole time: ‘My God, this is incredible, could this people be same like us!!!’, when the process was over I ironically thanked the medic and I said to her: ‘I am sure that what you have seen today will significantly contribute to your professional experience.’

But I can’t fool myself, or the rest of you that this ungracious and unpleasant event hadn’t enriched my personal experience. I have realized that although I am a girl, barely anyone from the outside world perceives my femininity, and to be honest I didn’t perceive, and haven’t been aware of it until this unfortunate event. But one is sure; However people can’t perceive how old I am, by my outside appearance, it’s not normal that they constantly say and treat me as a child.

This provoked in my a desire to emphasize my femininity, of course firstly by the clothes I wear, because the first impression people get by visual perception, and than I started to emphasize my woman’s’ behavior and features, and strongly to defend the positions of a girl. Unfortunately this first facing with the reality of this sort proved that even the biggest experts, doctors and medical staff aren’t aware of the femininity or manliness within people with disability. Their thousands of pages, studied for the exams in anatomy are in obviously spent in vain, and so is their grade as a mark of their quantum of knowledge, when 'They judge the essence only by the surface'.

The anatomy of the human body precisely and clearly says: 'The formation and development of the sexual organs goes by the same way with women too, but do these doctors understand that the laws of the anatomy apply equally to people, women with disability as well. These treatments by these so called professionals started an eruption in me and a big desire and crave to declare war on them. The man started all wars for a woman, but I as a woman understood that my greatest motive and reason is my femininity and my sex appeal as a girl with disability. The biggest weapon in this 'THIRD WORLD WAR' is the word, the voice of a group of girls which will show to this society that the power of the woman with disability is as much as different, not by her special need, disability or something else, but by her femininity, sex appeal, which as a powerful individual, with strong attitude for self affirmation and self realization will succeed to satisfy her needs from the aspect of a human being and a woman, but in the frames of the society.

The woman that beautiful, gentle, human being will prove to the society how fragile and gentle she is, that much strong and unbreakable she is when justice is in question, justice should prove that the first and even the last impression about her is wrong and twisted up to complete blindness. Because blind is only the human who doesn't want to see. And if the public doesn't want to see and hear than that is their problem, although it will stay blind for one truth, and that is that disability is not a disease, and it doesn't have to become social handicap if the society provide conditions for normal life for the person creating all necessary pre-conditions and conditions for it. But the person with disability should also be enough human and character and to see at their disability as a state from which he can clearly see the dark and bright side of life, not only from the aspect of the disability, but also from the point of a human, because human sounds quite proud, but it is difficult to stay human, and very few will succeed to walk that difficult path.

That is why God hadn't planted roses without thorns; cry without tears, But God knew that life could reach perfect state only through suffering. If suffering for our disability concerns us all, we so bodily imperfect are closer to God in spiritual sense, and the fact that God created us as females, that means that our spiritual beauty is increased by our gentle woman's hearts, which with their eyes see light in darkness, peace in war.

That is why this war will be a war to create beauty which will rule this world.

THE STORY OF DESISLAVA, 26 years old, BULGARIA

"My angel does not dance.
She holds her cracked skull in her hands.
Her cement lips are parched, so parched.
She is cold, cold to my touch as a bone-yard stone."

I was born on 21 June 1982. In May 1983 I have become ill from infantile paralysis in K. where my father was working at that time.

I have been the first case in the town with such an insidious disease. It is caused by virus but the medicine at that time and place hasn't been developed a lot, so I and my mum have been put in an isolator for a month and a half to be diagnosed. During this time the disease has done its awful job – the whole my motive apparatus has been damaged and I became like "walking corpse". The diagnosis was terrifying for my parents.

And the nightmare has started for me and them – treatment from one hospital to another. In view of the increasing rate of children morbidity, a sanatorium was built for children sick of poliomyelitis.

Up to the age of 4 I have been there with my mum, then alone.
I remember my childhood as a real hell – operations, pain, a strict hospital regimen, and no parents beside me, having no right to complain – and thus, until finishing my basic education, 8th grade, I've been there for 6-9 months a year.

Everything was like in a military formation – marching to the canteen, to sanitary procedures, even at night, before going to bed, punishment of the naughty children or those with poor marks. We have been forced to eat up the served food, regardless of whether you like it or not. And procedures – everything had to be done before the eyes of the rehabilitation therapist who usually didn't have any pity for the suffering children.

My parents usually received a letter from the sanatorium where I had to be taken to, and I was crying the whole day long, begging them to leave me home. And when operations were made, oh, then only I know how I felt – a few children "packed" in plaster, absolutely helpless, without mums' caress...

And the school - children different ages study together in one room, often offended, upbraided and even spanked by teachers.

When I was at home most of the time I spent alone. Other children played outside, they didn't have the nowadays concept that the impaired children have the same rights as healthy ones. I cried so many times because the others laughed at me or imitated my walk. That's how my childhood passed.

The Medical Expert Board was the institution that determined my further education without taking in account my preferences and will – I was sent to study Economics in the town of Cherven bryag.

After 4 years in high school I graduated in 2004 with specialization on 'Financing the state economy'. My mum came with me to help me. When the weather was good, I was managing to walk to the school, but when it wasn't; my mum had to carry me on her back. I remember how ashamed was I! I couldn't look at my classmates and passers-by. This was the time when the first feelings of love were growing, my school-mates were talking about boys, boyfriends and dates...and I was always out of this, as if I didn't have the right of this... I felt so hurt and isolated...

Then in June 2004 I started work in Dolni Dubnik.
And again as during the youth years I was feeling different. It's not that my colleagues were rude with me, no. Just all of them were married and all the talks were about their families and children.

I lived like that till 1998 when I met S. who became my husband and 10 years now we are together, loving and helping each other. He is also disabled. During the national military service he lost his hearing. We lost our parents, too. We brought up a child who is 2 now. I have got 5 years of service as economist and also I worked at home – I was knitting baby clothes, making bride's bouquets, presents bags...

My condition is getting worse and worse now, and almost all of the housework is done by my husband. I can't go down the stairs any more and he carries me in his hands.

Now I work for an organization of disabled people.

Our life is hard because after the democratic changes everything is money but our disability pensions aren't enough to live better.

A great obstacle for us is an inaccessible environment – we can't go where we want to because there aren't platforms for wheelchairs, our homes also haven't got any facilities for normal movement inside.

Unfortunately people's negative attitude towards us didn't change a lot.
But each of us, disabled people, still has that thirst for contacts and freedom that lies in each human being.

THE STORY OF ANN, 18 years old, UKRAINE

My name is Ann. I'm 18 now and about 15 years I cannot hear.

When I was 2,5 years old I fell ill and stopped hearing since then.

At the age of three I went to the special kindergarten for deaf children. I'm very grateful to my teachers from the kindergarten, who taught me to talk and to perceive the world around with a help of hearing aids.

After finishing the primary school I was forced to study at special boarding school for deaf children in another region. It was very difficult to live and study there without my mother and my father. And when they took me home for week-ends, I didn't want to return back to school. So I studied at this school only for one year. Then my parents sent me to the usual secondary school in my native town.

I had individual study at home but I went to school as well. I was accepted by the teachers with understanding. I got accustomed to school very quickly. My classmates were disposed to me well.

My brother studied at the same class and he always helped me and defenses me in difficult situations. But among the pupils there were some who mocked or didn't pay any attention at me at all. It was very insulting.

So at school I almost didn't have any friends.

My friends are girls and boys with the same problems as I have. We meet and spend our free time together, write SMS to each other.

I'm finishing secondary school this year. And I'm facing a problem of my further education and choosing a profession. I like to draw and I think my future profession will be connected with this my passion. From my friends experience I know that it is possible to get such vocational training in our town and I hope my dream will come true.

I understand that my mother and my family are the closest people I have. They have done so much for me and without their support my life will not be easy. So, now I do not find my life hard and desperate. But I realize that not everything is accessible to the person with disability in the same degree as to the person without disability.

Nevertheless, I think that we must explore and possess the fullness of our life and richness of our age.

I hope that my further life will not prepare me a lot of obstacles and disappointments.

And I'll have a power to fight, to create change, to grow and to be strong.

THE STORY OF MARY-ANN, 30, BELGIAN

So each night, naked on my bed, my body

doesn't want repair, but longs for innocence.

If innocent, despite the flaws I wear, I am beautiful.

I am 30 and a year ago I had a tracheostomy.

The decision to undergo this procedure was a conscious choice because nasal ventilation had become extraordinarily problematic. I had tried what seemed like every masking system known to humankind since I began using a ventilator, even coming up with some of my own modifications (much to the frustration of staff with years of experience in this area).

I say "finally face my fate" because this tracheostomy thing was something with which I had first been confronted almost 18 months beforehand. The additional complication of bronchiectesis of my left lung, rendering my lung virtually useless except for producing constant and somewhat debilitating secretions and chest infections, prompted the medical staff to suggest tracheostomy as a way of managing my worsening ventilation and lung condition. The whole idea was totally abhorrent to me. There was no way I was even going to consider it as an option. Not that I was any stranger to progression. My major condition of muscular dystrophy had seen to that. Having been diagnosed with this as a 7 year old and now being 30, I had already experienced many facets of advancement of my muscle weakness throughout this time, including the prospect of death on occasion. In fact, when asleep during the many months before ventilation, I wonder how many deaths I had died, since my breathing was stopping for up to 5 minutes at a time several times a night so I eventually discovered. I wondered why I was so exhausted, still working and trying to do a Masters degree.

The condition has indeed taken me on journeys that I guess statistically not too many people get the opportunity to encounter. I cannot say, though, that I have ever been prepared for what those journeys have delivered to me because there has never been a prognosis, indeed when first it was diagnosed the condition was thought to remain static, affecting only the muscles in my face and shoulders. Celtic composer and song writer Loreena McKennitt reflects in the introduction of her album Book of Secrets, that it is the journey not the destination which is a 'source of wonder' in life. She speculates that ultimately a major step 'on our journey is the one in which we throw away the map'. I tend to agree with this philosophy and it is one like this based on a theory of risk-taking that encouraged me to jump in and go ahead with the procedure.

Despite this, it would be too easy to say that McKennitt's belief was all that got me there and it certainly did not always come to mind as I travelled through what was expected to be a relatively straight forward process - in and out of hospital within a month, continuance of nocturnal ventilation only, speech, no other particular complications. Not...! Naturally, the outcome of the process I was not to know, quite possibly just as well. Quite possibly, it would not have mattered whichever way it turned out.

The struggle I endured in making the decision to go ahead and have the tracheostomy involved walking down roads that were treacherous to say the least. Having a tube inserted in my neck, my throat cut, under circumstances like this (as opposed to undergoing the procedure in an emergency when the choice is taken away), threatened many aspects of my life and at the same time forced me to face my own mortality. The decision to do this, therefore, is not like making a decision to have your toenails cut.

A tracheostomy meant for me potential life extension but it also meant giving up the life I had made for myself because it meant looking straight into the eye of the place where my condition had brought me and accepting the dependent state that my body had afforded me. My belief system told me that dependency was not necessarily a good thing despite the fact that I had relied on attendant carers for several years already. In the eyes of the world, living "independently" as a person with a disability was a sign of strength and the implications of tracheostomy would, I felt, send me hurtling backwards fast. More specifically, I was bound to lose my space in the world and, even more fundamentally to me, my control of that space.

Issues of body image and how my being as a woman would be threatened also haunted me. I plainly did not want to parade around with a tube sticking out of my throat. I did not know how people would react.

Being single, I did not know how men would react. There was already enough to contend with.

I have always believed that one's value as human being is not determined by a socially defined structure of physical perfection nor that the ethic of physically being able "to do" makes one's life more important than one who is not able to do. I needed to apply this to my own life. So in the end, when it came to the crunch and it was time to decide (the bottom line being between life and death), though these physical, bodily concerns were driving me to sleep, to reject the tracheostomy, something inside me, my spirit or I know not what, would not have a bar of it. I still had life to live. And with the tracheostomy, it is an interesting experience.

And if, by facing the tracheostomy head on, I have grown in some small way as a person, then I count myself as certainly blessed.

The Story of IVANA, 24 years old, BULGARIA

Tonight, when I take off my shoes: three toes on each twisted foot.

I touch the rough skin. The holes where the pins
were. The scars.

If I touch them long enough will I find
Those who never touched me? Of those who did?

Freak, midget, three-toed
bastard. Words I've always heard.

Disabled, crippled, deformed…

Words I was given.

There were only 10 days left, before my entrance exam to University…

I realized that they weren't 10, but whole 8 years of my life! In the yard of the University of Architecture, Engineering and Geodesy there are special swallows with long wings, called swift-winged. There I saw them for the first time and they have engraved on my memory, as if they are my friends. At the same place is held the math's exam for the University of Sofia, so a lot of people gather in the yard. We had to pass through this thick crowd, me in a wheelchair and my relatives, who elbowed my way to the door and carried me up the stairs.

For eight years I have been "locked" and "hidden from view", and now I was among all these people…on the other hand, I had worked hard for the exam and I wanted to see the result of my work… Everything passed great – invigilators hadn't had a student in a wheelchair before, and there wasn't a desk or a table where I could write, so one of them pulled out a drawer, turned it upside down and I had a special table. But both, the wheelchair and the embarrassment I felt from the fact that I was with so many "normal" people disappeared, when it turned out that I could solve one of the most DIFFICULT problems, using one of my math's teacher's favorite theorems. At this very moment two of my too long kept dreads disappeared – the fear of the exam itself and the fear of the transition to outer world, among normal, healthy people.

I have had other moments in my life when I got free from a deep fear. In other words, such a way I was grown up a bit:-) We were swimming in the Vita River and I was about to get drowned. The river was unexpectedly high-watered. I was swimming and when I tried to reach the river bed it wasn't there! I panicked and started to swim upstream. If I thought a little bit and didn't panic, I would let the stream to push me to a swallow place. But no!

Fortunately, when I felt exhausted, there were people nearby, they took me out. That was an emotional shock but I understood this later :-).

One day I decided to swim across the local reservoir. I have seen people doing this and I've always been over them… As I was floating on my back, thought 'Let me see, can I swim on back but frog-like?' It appeared I could, even very well. With every stroke I was moving faster and faster and didn't feel tired at all. My ears were dipped in the water, so, the only sound I sensed was the soothing babbling of the water, my eyes were looking up in the sky, the water was holding me… I felt unbelievably peaceful and confident. After a while I was under the birches on the opposite shore. I stretched my legs wondering which way back to choose – walking or swimming. Soon I was swimming back and when reached the other side and climbed up the steps to the ground, suddenly remembered that day on the river. Obviously that fear of drowning had vanished.

From my childhood I've always been plump and not so fit. It wasn't quite a merry situation, especially at school in sports classes – ups –downs, presses, 600 meters dash… In compensation when I was in my ninth year I started the karate lessons. It was serious and heavy discipline – trainings include full body contact, well, real fight, concentration, etc. and my inner conviction that school exercises were tough just faded away. It was my decision to start such a sport and that's why I kept going to the club, but each lesson was so hard and scaring, that I still remember the feeling, the feeling that I'm not good enough, not fit enough…

After 3 months training I could perfectly make side- splits and in turn they help to perfect the kicking skills. Very surprisingly for me! A year later there was a summer camp with 2 trainings a day. It was Thursday, in the beginning of August, when our instructor had us run up the hill, a high and long one. We were sprinting, turning and running backwards, again sprinting and so on and so forth. When we reached the peak, most of us were worn out. But then a straight and even path followed and something happened to me.

Every muscle of mine started 'singing ', incredible strength came to me and I 'flew'. I was so wonder-struck by myself and everything happening…I was flying past the others and soon I was two positions behind the instructor. There was no trace of the fears that were holding me and especially my low self-confidence. This surge of energy is called "second wind" and happens sometimes.

And as to university exam, I enrolled for correspondence courses in Mathematics and IT Faculty and graduated from it successfully. And guess if I was embarrassed, when I had to pass through the crowd of graduates in a wheelchair in the diploma ceremony. Hmm, honestly, yes! Because everyone had to go three steps up to the stage and then, three steps down, but from the other side…
…. My relatives were already there, waiting, to carry me up and down the stage…

THE SORY OF A HUNGARIAN WOMAN, 32 years old

Underlying Expectations:

I am sure my personal experience is similar to many others. I'm sure that many Hungarian women with disabilities, coming from a Catholic background, where there in an underlying expectation of who they are and supposed to be, by the cultural standards and the traditional values of the community.

Yet the expectation of falling in love, getting married and having children is just really expected for women with disabilities. There are many taboos and fears and some of them still hunt us...

There is a British writer, Simon Brissenden, he envisaged for people with disabilities a true holistic independence, so he writes:

"The point is that independent
People who have control
Over their lives, not that they
Perform every task themselves.
Independence is not linked
To the physical or intellectual
Capacity to care for oneself
Without assistance; independence
Is created by having assistance
When and how one requires it."

I would like to share a part of me that illustrates my experience of being a young woman with a disability and how my parents coped with me falling in love and getting married.

I was born in a Hungarian village in 1976 in a family of devoted Catholic parents. I'm a middle child and quite balanced considering. I never really understood what it meant to be a woman with a disability until my mid 20's when I found it difficult accessing employment due to having a disability. Then my parent's had this high expectation of me to achieve beyond their dreams and yet often didn't expect me to do as well as I have.

My Catholic background is very important too be because of its caring, sharing giving nature and the extended family that I have grown up in and still cherish. I recently got married, which in it self should have been a very normal part of life, but not for me. One I married a man with a disability and two he wasn't a Catholic. Our courtship, if anything was a challenge. It tested all our boundaries and at one time I was even prepared to leave the home I was brought up in because of the differences.

It's difficult even today to understand why my parents couldn't understand my choice. My dad however had the most difficulty, followed by my mum. There was a year and a half of courtship in which he just wouldn't recognise my husband. He wouldn't remain in the same room yet in the same house.

However we knew that there would be difference and that I wasn't prepared to back down. They finally then accepted that my husband was going to be the one that I married and take me from them. I think they always assumed that I would remain at home. I'm not sure still today, if it was the disability that caused the inconceivable differences or the different cultures.

With sheer persistence and help from other family members who only wanted to see the peace again, our relationship was accepted. My husband's side was so different in their response. They were so accepting and couldn't understand what all the fuss was about. My brother and sister did not experience this situation. My brother was male, so he couldn't do anything wrong, as he carried the family name. Expectations placed on women were of marriage and children and this was true for my oldest sister. These expectations were not placed on me, and relationships of any sort were not expected.

There is one subject though, that I just don't mention to Mum, which is very taboo. That is, the idea of having children. You just don't mention it as there is this underlying fear that if we get pregnant, our child would have a disability, yet neither of our disability is genetic, so the chances of having a 'disabled' child is the same as it is, for anyone else. We are planning to have children one day soon, so I'm sure it will bring new issues and problems to deal with. We will take that day when it comes with calm and an understanding and it will be okay. My parents will just have to accept our choice. They need to let go and see me as a woman and not a child that they still would like to control.

I've illustrated briefly my experience to show how disability and culture work and what this all means when you are a woman.

The underlying expectation of what you are supposed to and yet not to do.

THE STORY of “B”, 28 years old, BULGARIA

Even blind girls get the blues,
I tell my mother when she wonders
why I expect to go to the senior prom
when no one would ask someone
like me, and why I can't be happy
spending Saturday evenings curled
up with a large print book

Hello, I’m B. and I’m from Varna.

When I was a baby, my parents noticed that I couldn’t see well. My mum realized that fact after I hadn’t been able to focus my sight on the handed over toy. Nobody told her that this is only a part of the pathological physiology of prematurely born children, and I, for sure, was such a child with my 850 grams weight, born like an abortion or mouse somewhat! After a lot of consultations with Bulgarian and foreign ophthalmologists, it was found out that I was going blind progressively and to the age of 20 I would be completely blind. But everyone thought that 20 was not so bad because you would have a chance to find a job, get married and have children… Alas, I totally lost my sight at 24, i.e. 3 years ago and although I’ve already known this will happen, I still refuse to accept the fact!

So, I could see passably, but when I was in the 3rd grade a snowball hit me and there was a bleeding in my eye. After they had discharged me from the hospital by mistake as I think, /the doctor claimed that such bleedings could be healed at home, and he knew me well from the birth with my eye problems/, my eye just ran out very painfully, with a high temperature. Then I was operated as an emergency case and doctors took out the remains of the eye but by sympathetic way the other eye, which was damaged by oxygen therapy after my birth, was affected, too.

I left the School for Visually Impaired Children in my hometown with highly reduced eyesight and started my studies in Psychology and in parallel the second training in Philosophy at University of Veliko Tarnovo and I graduated successfully but during that time my sight was getting worse and worse. Then I had three, four operations, hoping to improve my situation but all for nothing

– after each one, as more we paid, as fast I was going blind and that way I've been living in darkness for 3 years now.

My children keep me alive, I'm writing so disorderly and, of course, I apologize to the readers.... I have two children who are the most wonderful gift for me. They were born after two unsuccessful pregnancies, one of them 'in vitro', but both finished with miscarriages. I had a lot of physiological problems, doctors treated me a long time and finally, the children appeared after great concerns about holding the pregnancies. But as all things in life, it was too good to last. I started my attempts to find a suitable job and that's how I entered long law procedures. At one and the same time I brought a suit against Local Medical Expert Board, employers who haven't approved my job application because of the special working recommendations and institutions in charge of engaging people with permanently reduced working capacity. I won the suit but long legal proceedings were killing me. Sometimes I was thinking "That's enough" but only till the next day...

Since then I'm trying to understand how long this "hell" will continue to trouble people who want to be equivalent members of society, to work and pay taxes. And when will this stereotype change, the stereotype, viewing people according the medical model, not the social one, which tries to give more opportunities to people with special needs? Is that the way to treat people who want to study, to have a family and job? I don't want my presentation to sound like parody of tragedy but nothing to do – that's the reality.

Now I'm again jobless, my older child starts school, the younger – kindergarten. It happened that I look after them by myself, I'm divorced, my parents died. I've got only my children and an older brother who helps me within his means. And again I have to initiate legal proceedings in order to get a job. Getting a job is difficult for people like us, it never happens with the assistance of authorized Labour Offices or related to them employment programmes. So far I have worked for a private labour office, in a centre for people with sensor disabilities, in children protection department and for other employers without full labour rights.

Everyone has the right to have his chance in life; thanks to art, science, labour, people with problems like me, are able to change entirely their lives and live in their community just like normal people. The rights to desirable work, accessibility, education and social security are basic human rights and their violation is a shame and discrimination!

THE STORY OF ...., 23 years old, UKRAINE

Hello, everyone!

For my friends - I'm a Flower or a Seller of Emotions or a Collector of Instants. These are my pseudonyms. I live in Lutsk – the best and the dearest town in the world for me. It is in the western part of Ukraine. Now I'm 23 and I endured about 2 dozens of operations. Of course, it hardened me great. It taught me to be an optimist.

I was longing to become a journalist from the school years. I study intensified at school and at the courses. The years of hard studies gave the results – from the first attempt I became a student of the journalism faculty of Lviv National University. Now, I'm already a student of the 4th course.

I try to study hard and to get the honors- diploma. Some students try to get excellent marks for assessment record book not to aspire to get profound knowledge. I think that the substance is not in the marks and knowledge but in understanding what you've read, heard and seen!!! The term, which you've learned by rote, will not give you practical and positive results at the moment that you need. Frequently it works as a scheme-"learned, passed and forgot". It's sad.

The honors-diploma –is a characteristic of the seriousness of a person whom you can rely upon.

Once I asked my friends what is the word they associate me with – and the answer was one the same word - Life. Some of them refused to explain why they think so. But it is not the main point. The essence is that they think so. There are a lot of important words in my life – INDEPENDENCE, tolerance, HONESTY, TRUST, music, hospitality, positive, rain, friends and communication, love and GOD. Life is a constant movement.

People often asked why I didn't choose the profession of psychologist. It's probably not mine. Though without corresponding education I can help my friends any time they need – by advice, by conversation or embrace of support. Even if it is 3 o'clock at night. Of course, I try to fight with my physical defects, sometimes it seems I can cope with it. I'm grateful very much to those sincere and kind people who always are side by side in spite of nothing (for example my appearance or my walk with crutches). I'm convinced that a real friend - is that who knows everything about you and for all that stays with you.

Step by step, from session to session I go to my dream to be a reporter – to see the world and to open its beauty for myself and for other people. It's already about 10 years I have a dream to go to Taj Mahal (India). I was a schoolgirl when I heard the love story of two young people and I was charmed by creating of this architectural monument of the past.

About so much time (about 9 years) I'm writing a book. It's something like a romantic essay from the real life. This book will see the world very soon. Why I've been working at this book for so long time?

Because I need a real inspiration and I could not make it to come when I need it. I have already written 48 issues, 2 more are left. I decided just so. The time will put everything in its own places. The word "literature» and everything connected with it is holy for me. Because literature can teach us a lot, can open new world, which we've never seen before – world of feelings, emotions and pictures of nature.

Sometimes, I'm outraged by those, who ignore literature's laws and write the novels, which cannot teach anything but only accustom readers to use unprintable words. And every page of so called books is full of such vocabulary. I'll do all I can, not to replenish my book to this category of books.

I often think that my problems are not of great importance in compare with problems of physical and moral health of other people. I call everyone to see that the glass is half full but not half empty. And then you'll see that the world really smiled to you with all its colors. But when only sadness is a norm, then 7 colors of a rainbow are absolute hallucination and only one color exists then - grey. I adore rain and I wish you also to see in it all colors of inspiration, delight, positive, optimism and LIFE.

THE STORY OF ANETA, 21 years old, MACEDONIA

Life isn’t easy for a person with a disability.

I have a serious hearing damage, and this means that I can hear only with the help of a hearing device, and my life is unthinkable to me without them.

I got rehabilitation for ten years in the National Institute for hearing, speech and voice, together with my mother and the rest people from the institute who were experts for my problem, and they worked really hard with me, and they helped me to achieve verbal communication, I practiced proper pronunciation of words, and we worked on my hearing. It was arduous work, and without them I wouldn’t be what I am now.

Most of all, A BIG THANKS to all, who protected me from everything and furthermost made me a real person. One “thank you!” couldn’t be enough for everything that my mother has done for me, I can’t find words for her greatness and self-sacrifice she has done for me. She believed in me and she still does. She has protected me from all harm, and she wouldn’t let anything happen to me. She wanted and still wants for me to fit in the real world.

As a result I’ve finished primary and secondary school, and now I am enrolled to an University faculty.

In primary school I was well accepted from the pupils as well as the teachers. We were young than and didn’t understand all events. I’ve made a lot of friends with whom I still communicate. As children we all made jokes and as a result there were awkward moments as: ‘the one with the hearing device’ when I recall this moments even nowadays I laugh and say to myself: all right, we didn’t understand these things than, we were only children.

I was well accepted by the teachers, there were no problems on their as well as on my behalf. I want to congratulate them for that. I can openly say that they weren’t easy on me about grades, because they considered me as any other normal person, they didn’t feel sorry for me, as some would say: ‘Let’s be easy on her she is with serious problems.’ But it didn’t happen in any moment. I’ve earned all of my grades and I’ve worked hard. I’ve entered a biology contest on my free will, and I’ve signed with my mentor and class manager by myself. My problem wasn’t an obstacle for my wish to participate in the contest. I’ve made it to the state contest and won the first place. As a result I've won a scholarship. This was a big boost for my character and faith in me.

I wasn't too sensitive to my problem in my childhood. Every new enrollment was with fear weather I would succeed and how will I fit in the new environment. In high-school we were already more mature and in sensitive years, I was now more sensitive to my problem, but there I was accepted very well by teachers and students, with some inconveniences as casting up to me and making jokes.

There were also some misunderstandings from the type, I haven't heard something so I asked several times or requested to repeat in order to get the proper information. It happened to get a strange look or to turn their heads and making that they haven't heard me, or they would turn with their eyes and tell me with a dose of insolence. It discouraged me, I withdraw and I feel intense in these awkward moments. I have the impression that they are pretending that they don't know about my problem, and that I have perfect hearing.

The enrollment on faculty also represented a big stress for me, but I handle it quite good for now, I've explained my problem to some of the colleagues, although there is some of the type that wouldn't like to 'help me'.

I've managed with my average grades to win a scholarship. I got the advice from the closest to tell to the professors and assistants, but I am still on the opinion that they will get the wrong impression about me, that they will get easy with me, feel sorry for me or even that I am a liar.

I want to earn my grades with my personal effort, and I have a wish to improve my education in the future. Even today when I say about my problem to someone close, they don't believe me and say that I am great and noting can be noticed.

At the end I realized that without my mother and certain people, and without my persistence and fight I wouldn't be what be what I am today, and I try to understand all the problems and to function normally in this society. I know that I perceive life with an optimistic view, and I would give everything to point out my abilities and values.

All people with disability are normal persons, and we mustn't let that prevent us from living in the real world. On the contrary it should make us stronger and braver people, because nobody is perfect.

A. L.

THE STORY OF NATASHA, 26 years old, UKRAINE

Natasha was born in the family of military man in 1982. The news from the doctors that their daughter had a Down syndrome was a shock for the family; they could not cope with it for a long time. So, later on mother began to work. Natasha was 10 years old and she didn't visit any kindergarten. Her grandmother took care of her.

She began to study at the age of 10. She didn't visit regular school. She studied individually at home. The teacher said that Natasha was able to study.

There was not special school in their town, so the parents were forced to send her to a special boarding- school, which was situated in another place. Her mother was worried very much, because it meant to part with the daughter for a week. They took her home from school only for week-ends. But they didn't have a choice, the girl had to study. So at school Natasha learned to write, to read, to communicate with other children, to serve herself, to be disciplined, to behave herself with other people. At school she got skills of sewing and house holding. She got there incomplete secondary education.

After finishing school there were no attempts to find the job because Natasha had speech problems. But when her father died, the financial condition of the family became really bad.

So Natasha's mother tried to find a job for her daughter. And they were lucky enough. Natasha was employed as an office - cleaner in one of the banks. Mother thinks that this is because of the good will of the bank's director. He took their request about the job with understanding. But it isn't a rule that person with Down syndrome can have a job in Ukraine. It's more as the exception from the rules.

Now Natasha is 26. She has a job. Her mother supports her at the job. Her mother is a great optimist. She is a very beautiful women and she tries to implant the feeling that everything might be beautiful in the women to her daughter. Mother and daughter are real friends. They do all housework together; they enjoy gardening and having a rest out of the noisy town. Natasha has got two friends - girls 20 and 22 years old with whom she can communicate. In fact, these girls and a family is all Natasha's surroundings. Isolation affects not only Natasha but also her mother. But meeting with other families which have the same problems with children give the support to them. They learn a lot from each other, they spend free time together. That's of prime importance to them. They are no longer isolated and their struggle with internal and external prejudice is united.

Natasha's mother understands that her daughter is dependent on the family. And she cannot realize her position within the social environment as mother or wife (any other role is not even considered). And mother is worried what will happen with her daughter when she will not be able to assist her?

The story was told by Olena Melnik

THE STORY OF ANJA, 24 years old, Belgium

'Through sheer determination and willpower I'm where I am today, gradually reclaiming my life'

When I was 16 years old, my boyfriend bashed me almost to death. He beat me so badly I suffered a severe brain injury and was in a coma for four months. That evening when he bashed me he repeatedly stomped on and kicked my head.

While lying in my hospital bed my family and nursing staff could see the imprint of his shoe in my very swollen face. Intensive care nursing staff told my father they had never seen injuries like mine before, injuries that medical staff normally associated with road trauma cases.

I was 14 years old when I began my relationship with my moody, abusive, violent boyfriend – he was four years older than me and was controlling and possessive. I was a young stupid 14-year-old girl who thought she was in love. I thought everything was great at first ‘til he started the abuse. I thought it was my fault, so I made up excuses for his actions, but no-one deserves to be treated the way he treated me. I think I really thought he loved me.

Before my abusive relationship many people describe me as a very fit and healthy beautiful young girl in control of my own life, very athletic, a very strong netballer and a quick swimmer. I was pretty smart although I couldn’t see that staying in the relationship could put me in a wheel chair with a brain injury. I thought I was just living life to the fullest - not to know that really I lived it almost to the end.

I was a young girl, who foolishly believed she was in love. There are many things I am aware of now, which should have led me to end our relationship. Like when he would often verbally abuse me or when he became physically violent towards me. Like when he introduced me to drugs and supplied me with them. When he would make me stay back from girls’ days out and threaten violence if I left. When alone with him, he would gain control by breaking down. He would become very emotional, cry and carry on telling some story which was so often, if not always a big, fat horrible lie (he was a very, great actor).

Before the last attack my parents tried to get help from the police but the police explained their assistance required me charging my boyfriend with assault. The only other way was to have him charged with having sex with a minor but I wouldn’t cooperate. I didn’t want him to get into trouble with the police. He had already been in contact with the criminal justice system over the assault of another person. He had been to court and ordered to attend anger management classes. I didn’t want him to get into any more trouble.

My parents also made contact with a local youth outreach program who recommended a couple of things, which they found very helpful. That’s what my boyfriend used to tell me when he was in the right mood - that he loved me and that I was the only important person in his life.

I began seeing a psychologist and his support had a big impact on me. He diagnosed a hidden disability - dyslexia. I had always had problems reading. When I was in early primary school my mum spoke to my teachers who said I was fine because of my skills in story writing but mum had to read books to me because I wasn't very good. In year 9 I tried to put myself in the reading recovery program at school but the teachers thought I was just trying to get out of school work and sent me back to the classroom. My parents now wonder if my undiagnosed dyslexia had something to do with my low self-esteem as a teenager.

The psychologist convinced me to break it off with my boyfriend. I decided to focus on my studies and I was voted in to the girl leadership group as a leader. I had finally realised I would never be able to change him. We were not boyfriend and girlfriend for the 3 months leading up to the assault although we continued to see each other. I still wanted to be his friend. During this time he rang me and said that he had had my name tattooed on his stomach and that we would be friends for life.

My ex-boyfriend was charged with assault and on us appealing his sentence, received a 10 year gaol sentence with a minimum of 7 ½ years.

Despite the horrific injuries he inflicted on me, and all the medical team's belief that I wouldn't be able to improve any further, with a bit of strength and determination I have proved them wrong. I am gaining new skills all the time and have plans for the future. I now communicate through a text-to-voice machine and use a wheelchair to get around. I always try to keep moving forward, and with the help of my family and friends I've been able to keep soldiering on, though it hasn't been easy by any means.

There has been no real connection made between my disability and the fact it was caused through relationship abuse. The family's experience of me being in hospital directly after the assault was not a positive experience. The social work department offered no support around the assault, there was a long delay in my family receiving written information about what to expect in relation to the brain injury. This information is supposed to be given to families within 24 hours of their family member being admitted to hospital.

I'm really pissed off and angry about the past. I don't remember anything much about the last bashing, thank God, although I get small flash-backs occasionally of being bashed, but then they're gone.

When I'm in a bad mood and things are getting to me I write down on the computer how I'm feeling and it helps.

What I would say to the other young women?

Do not live your life in fear because it will consume if not kill you. The biggest thing about my relationship with my boyfriend was I wasn't a woman with any knowledge or wisdom. I was a child. People - young and old - should be aware, in control, and comfortable with their own lives and relationships, and not be afraid to get out of a relationship where you don't feel comfortable.

So if he threatens or demonstrates any physical violence get out. Realise it's not worth it, no matter what happiness he may bring on a good day. If he starts insulting your friends or if he becomes obsessive, by any means, like wanting you to start spending every second with him. If he starts deterring you from spending time with anyone else or doing the things you like. If anyone else considers his behaviour strange or aggressive, think about it.

We need to build young people's self-esteem, to stop them from thinking violent behaviour is acceptable and ending up in a viole17-Dec-2008t, sexy, cool and smart you all are and don't worry about whatever nonsense anyone else thinks! Just focus on your studies and getting the best job you can. Boys don't really matter at your age, they're just for fun on occasions, at the moment!

If I had my time again I would listen to everyone - my parents, my teachers, my friends, the counsellors. I would listen to what they were telling me. I should have turned my ears on and heard how foolishly hormonal I was being by continuing to return to such a violent, negative, and abusive relationship. I am now aware of what I should have done to end the relationship. Number one I should have done it in public vision so he couldn't hurt me. I shouldn't have ever listened to or taken anything he said so seriously, unless it was at face value to avoid a violent outburst.

Girls really need to open their eyes, accept information, and direction from all who love, respect and care for them. When you are in a relationship, no matter what your partner says, always remember you are number one. Without respect in a relationship it just won't ever work happily for you both.

Through sheer determination and willpower I'm where I am today, gradually reclaiming my life. Though I was only 16 when I was bashed, I now hope to keep others away from violent and controlling relationships. So you all need to begin to enjoy your lives. Stop taking it for granted. Be sure that you're the one in control of your life.

I wish to be seen as a strong, inspirational young lady and helping others is my will to achieve this. I just hope all the young women who hear my story take the right kind of power in their lives, keep it real and don't play the fool.

THE STORY OF ARIJETA AHMED, 26 YEARS OLD, MACEDONIA

I was born on 29.08.1981. I am a young girl with disability. I live in Skopje. I've finished primary school in 'Jane Sandanski' elementary, in the settlement Dukandzik. I live there as well, close to the school. Because I was a girl with disability I thought that I wouldn't be able to continue my education to high school. I thought that it would be difficult for my parents to carry me every single day, but they were so persistent and they considered that I had to finish high school, and they enrolled me in the trade high school 'Cvetan Dimov' in Skopje.

There I've lived my first big disappointment considering my body disability. Unaware that the school was completely inaccessible my hell started shortly. Architectural barriers given trough a pile of stairs, for me were identical like starring in the face of death. You wonder why? A young 15 years old girl on the way to become a graduate from secondary school, who should be constantly carried by someone, to lean on someone, to take her under the arm, that feeling made me feel different from the others, a lot different.

There was so difficult for me because despite the architectural barriers, the teaching was going on in cabinets, and going from one to another cabinet was extremely tiring. But every difficult has its benefit, because in the class I had a friend named Suzana who was the only one socializing with me, she cared for me, she took me under the arm.

To be honest the scariest part of the disability is to be taken under the arm like a small child. No one from my co-students talked with me, they all avoided me. On the major break all of the students went out to buy something to eat, and I was left alone in the cabinet, like forgotten from the rest of the world. Painful and difficult for a young girl, when everybody is leading carefree and normal, I was always lonely, and I felt on my back the difference and the discrimination accompanying that difference.
You know what?!
All these things I've written was all the negative things that happened to me, but when I lived the discrimination from the teachers I just couldn't believe it, I was hearing it from professionals and it hurt much more. A teacher once said to me: 'why have you enrolled at this school, you are disabled, you can't find a job, why would you need a diploma?!'

This was the thing that really made me down, to close for other people and to think that I don't deserve anything in this life.

But if you ask me now if I have the same opinion you would certainly get a negative answer. I will explain to you why I have this opinion. When I face a problem connected with my disability, which firstly seems unsolvable makes me think worst for myself. I am bothered by the dependence on other people, and that I am not completely independent and self-reliable, but from the other hand God gives me enough energy to perceive, although I don't have healthy and functional legs I have enough wit and sense, good parents and friends, whose support makes me, although only for a moment to think alive and full with myself. That support is a motive more to continue my education in a higher educational institution.

One more thing that makes me richer is the fact that I come from a multiethnic family, my mother is Albanian, and my father Turkish, from two ethnic groups were people with disability are even more protected, attitude that this category of people shouldn't be prevented from university education. But it is also important to say that girls don't always get proper education within the Albanian ethnic group, although they don't have disability.

I determined on 29.09.2003 to enroll to the faculty of philology 'Blaze Koneski' Turkish language and literature.

Before I enrolled I thought that the faculty would be a completely new life for me. But unfortunately it wasn't quite so. Maybe you wonder why? Because from my first day I saw that once again I will be haunted by architectural obstacles, and I wanted to quit studies the same day. I started even talking to myself: 'wherever you go to university, been it to Mars, you will always carry your disability with you, it is your biggest flaw with which you will have to face all the time.

I had a big pain in my soul that night, I cried all night long and I didn't sleep that night. I told my parents that I want to quit. They turned to me in this tone: 'As long as we are alive we will carry you and accompany you.'

We started to study as a family together. To tell you honestly it was quite difficult, for me to pass the best student years carried under the arm by my father, actually I was so different from other male or female students, that it would be difficult for anyone with a healthy sense, but what could I do, It was my destiny and I ha to accept it.

At the time of my studies I faced a lot of other difficulties, like administrative and bureaucratic obstacles; like enrolling for a new year, verification of a semester, checking a date for an examination... Al this important tasks are completed even now by my father, that is why it is difficult to study with a disability.

At the time of examination I faced the problem – Arabic language, I asked the professor to help me pass the last exam from second year in order not to lose a year, and he told me that it wasn't important that I had a disability and that he can give privileges to me: 'You alone decided to come to faculty, I didn't force you to.'. This however was one of the moments when I felt like everybody else, not discriminated.

I fight against all of this problems, but now when I am about to graduate I fear that I wouldn't be able to find a work place in this poor country.

All this said with the voice of a girl with disability means that education as an important segment of social life is in great deal determined by the difficult of the disability. The gender although for the Albanian population plays an important role, still I consider that obstacles and discrimination is a great deal stronger when there is a disability involved too, and the difficult is absolutely determined by the difficult of the disability the person has. Appreciating the social disability caused by the bodily one it is completely certain that when the first one takes place it closes the circle firstly within the person it self, and than the ability to build bonds and relations in a wider sense.

Written by Arijeta Ahmed

THE STORY of BORJANA ZLATANOVA, MACEDONIA:
Education and Society and their Relation with Women with Disability

The biggest gift and blessing to the being is the power in the world which is called FEMALE. He secretly gives to the man the taste created by sin.

The taste of irresistibility and sensuality at the same time, and to her it gave the gift to be fertile and to have an even bigger seductive power, the reason why men rule stupidity.

A ***POEM of Sheila Black:***

Crippled they called us when I was young
later the word was disabled *and then* differently abled,
but those were all names given by outsiders,
none of whom could imagine
that the crooked body they spoke of,
the body, which made walking difficult
and running practically impossible,
except as a kind of dance, a sideways looping
like someone about to fall
headlong down and hug the earth, that body
they tried so hard to fix, straighten was simply mine,
and I loved it as you love your own country
the familiar lay of the land, the unkempt trees,
the smell of mowed grass, down to the nameless
flowers at your feet—clover, asphodel,
and the blue flies that buzz over them

With a fine simplicity with all mankind rules tenderness and silky beauty of tenderness and softness. An example for this is the numerous stories which exist for centuries, for that how a woman can destroy or sweeten society. Consider the power of Cleopatra, or of fare Elena who trough the bed conceives the apple of discord. How beautiful this might sound fairytales have minuses too, maybe even more when you have a disability. You face differences between you and that other person. You are a target of ill treatment or the positivism in society in one way or another. And there is the question: “Am I truly a woman?” Because for a woman you rise and fall, fight and give all. And I haven’t heard that some woman with disability had put the world in front of her legs, but there is a first time for everything. I would be delighted if there were a girl like this some where in the world, even if she was at the other and of the world.

From that point of view the silence faced with the truth, we all stood silent or pretending that it doesn’t exist, with fear of being hurt and fail. I have the same needs you have, although I face many more challenges than other people. When I wanted an education I had to persuade the others that I can do it. After numerous attempts I had prevailed and got the attribute congratulation, although I didn’t have had any material benefit from it. But I didn’t felt different from the others because I thought others that disability was I life philosophy and not something to lament on.

That was my life motto: I have to be like the others, to adjust to their needs and demands, because I am an individual, and the majority always wins. I had to learn to love and not to let the pain prevail, because she doesn’t bring noting well, while she grows the labor achieved. As it is said: sadness is silent in front of the serenity.

Therefore I am grateful at those that thought me that equality lesson is not only for the healthy. She is inborn or learned.

And after all the end of my high school education is coming. There I succeeded that I can do it, and there starts the quest for the truth, to obtain a piece of paper called a diploma. For me this is the end of the world, because there is no possible way to realize my wish, and I am disappointed. But I was aware that it was going to happen, because it was inevitable. Physical barriers were stopping me to enroll to faculty. And in addition a gossiping column was being open in which everybody had their opinion; what good it will do for you when you can’t make it, and I thought why should I matter to all those people, when I don’t respect their opinion, because everybody has the right to think for himself. And I had a million questions to answer, but who am I to judge when the world should be equal for all of us.

In the moment when I thought that the grief has no end, not for being disabled but for being underprivileged, and they are the worst category being furious and angry, one encounter could change it all. The meeting with the wife of a former prime minister, with the Foundation “”Blagoslovie called like this than. After a day or two my dreams came true, it was unbelievable. The doors to the faculty were opened for me. Kalimero comes for the justice and I am once again alone and designated, I was thinking what now because I didn’t had time so far, but I decide to fight. I took my first exam with success, surprisingly strange I was accepted wonderfully. It was strange to me because I didn’t expect that sort of treatment.

That very same I met the woman to whom I awe it all; in her eyes I can see love and equality. Aunt Sika doesn't let to for me to fall short, she even argues with the professors, and I constantly torment her: 'Sikce this, Sikce that.' And I know that although I make her lose her temper, I make her scream and all that and the other way around too, but we make things for the time being. And after a big fight she knows I love her and that nothing I have done was with intention of hurting her. This can be applied only to situations when things get out of control.

Otherwise I lead a life like every other ordinary girl, starting from chatting and going to gossiping. I am bothered by the fact that sometimes some people are better although they are not, but you can't see that in them. I wouldn't like to speak for love at all, I am being judged for letting someone without disability enter my life, but mind can't control the heart, if I could I would protect myself from these pains. Although the others suggest that I should leave him and that I am too different, but I can't be different nor I can love a man with disability not because I underestimate people but because I can't give my soul to anybody, and that man probably would have skipped classes on love and wouldn't now how to start or how to finish. Wow, I shouldn't talk too much, because talking is affecting badly at the moment, it will affect my holy secret. And he could be reading this, so I wouldn't like to become a mere object in his hands, a sugar bar that will melt in his mouth, and like a small child which can't resist it. A human example that I wouldn't like to become true, but according to others it might with just one right or false move from him. And I wouldn't like to give material to the petty souls, gossiping and there is a little 'retarded Cinderella 'in each and every one of them. Here the question whether only my intelligence stops in front of reality that anyone could be called the real one, but the least that one that lost the compass to reality. It really goes centuries back, something appearing vulgar, somebody wasn't raised properly. It hurts when I need to stay silent because of this unrealized world in which nobody cares for nothing. I would rather stare in someone's appearance because he forgot what culture is and he didn't look at himself. I don't care for those people, and I don't plan to understand their feeble mind, not worth a single penny. But I don't consider that I have a big discrimination, because I rule the world and not the other way around.

Simply I feel good although I have a disability, nothing is short for me, and I just do things my way. I don't consider myself fro a person with special needs, because everyone has his special needs, and I frankly don't understand the meaning of the words 'special needs', and I consider something else as a need, a mean of being different at the time of speaking, when I think how to get to the way of doing it because by default the fingers on the hands are different by they have the same function and no one finds fault in them. From the other hand I can't understand those people with inborn disability which pity themselves and would like others to feel pity for them; they are convinced that those other people should do something for them. They should ask the question when they have done something for those other people.

Offense is best defense, and we have also forgotten about the thing we do ourselves. I do what I want, and I bear in mind to contribute to a better world and better future, and that prevents me from crating something that will make the world a better place, or will at least make life easier for some disabled person. This goes for me, but not for the others like me, because their world is packed in a small box which opens when there is need to. Maybe because my world has less people with disability and not with special needs. Because they don't accept me, I don't talk their language, of simple and dark, black and white, we are different although we are the same, and I put on the pink glasses when I feel good.

Although I senselessly judge the world sometimes, but the rage is for the whole curse because it destroys reality for me. I have my one world in which roses aren't blooming, but there are no thorns either, my real world. Let someone say that his world consists of roses alone and that he never tasted thorn, and he doesn't have a disability. That probably isn't possible. Aren't we all equal? And how should we be equal when with this attitude I am judged by those with disability, equality is achieved through battle and effort and not by lamenting when we have a bad reception by the doctor. I simply change the doctor and not lamenting, I leave in demonstration.

There are many doctors, there are a lot of café shops, and you can change your neighbors shop when you are not properly served. But not because I have a disability but because they are ill in the brain, or somebody stepped on their toe in the morning. Unhappiness doesn't choose religion, status, or political views. Unhappiness is for those without disability as well. Everybody knows that but they understand it how it is good for them. This is so because attitude is choice of taste. And to feel good you have to make it good.

Do the things you like, don't run from the attitude, and with that carry the desire, because it makes you better from the other no matter whether you have or don't have disability.

The disability doesn't prevent you from anything, and even from being full with tenderness, understanding, love, because only people who don't feel love are with disability.

Don't prevent yourself from getting pregnant, because you might be lucky in your life, because no disability should prevent you to enjoy in your sex life, of course that is my opinion and attitude, and even though someone might not like it, I don't care.

I just wait on the good moment. And once again disability is not a special need but only special circumstance in which we must try to fix things. And we will fix them if not all people with disability go to the heaven, put all people go to heaven or hell in difference with the character.

THE STORY of NADICA ANTIK, 26 years old, MACEDONIA:
Meaning of Life realized trough Optimism and Pessimism in Human Personality

Health care and it's role seen trough the life of a girl

Life is beautiful for the ones who know how to live it.

I used to observe people frequently and I think to myself that they aren't the ones who should change (and should change, but it should be myself). I am 26 years old, my disability is inborn, I have cerebral paralysis, with body disability to the right arm and keg with the later development.

However I am a person with a strong will and ambition to surpass all of that. There are people who were able to see this and they have accepted me for who I am, but unfortunately they few only few. I was exposed to mockery and rejection with malice attitude for me.

This story will be in most part for my later maturity and physical disability. I finished secondary and primary school with the 'normal' kids. I mention this because when I wanted to go to school doctors wanted to put me in a special school, considering that I am a person with easy mental retardation, but my father didn't allow it, because he chose not to believe them and he decided to enroll me in a school for 'normal' kids. It is easier for the doctors to ratify the false diagnosis, rather than the real one which was hurting for me and for my family, where further analysis were required in my later development, and not to conclude easy mental retardation, those are two different things, and in my opinion doctors should take bigger initiative in resolving this kind of problems.

But in difference from this problem body disability can be seen from a different perspective, thanks to the doctors that provided that for me through tree operations, two in Skopje and one in Ohrid, who gave their best for the operation of the leg to be successful, and with good exercises to improve my health condition. They gave me hope that with persistent exercises the disability with the leg could be about 80 % surpassed, but I have to admit that I was a bit lazy in exercising. Considering the disability of the arm only

exercises were required, because operation wouldn't have a considerable effect. After conducting the operations under the initiative of the doctors I was send to physical therapy. Their development showed good results, the therapists were kind with me and their most frequent words were: 'It can be better than this.' They were determined that the operation would give results. After completing the exercises I was sent for home treatment, and the last operation should have finished with finishing of my 18 year. In difference with the previous two operations this one was a bit more complicated because in the course of the operation my skin on the right leg burst, and instead of four days I've stayed a month. Here the doctors and nurses weren't so kind with me. I had stronger pains and I couldn't go to sleep, and they usually told me: 'go to sleep, there is nothing else that we can do for you. After one month spent in the hospital I was sent to home treatment. I didn't exercise after this new situation. I had a cast for a month on my leg, then they took out the cast and treated my leg, firstly the doctor who made the operation, and than my father after it was completely healed. I had a cyst on my head as a small girl, I go to radiography regularly, and I must say that this is a static problem; I have to live with it like everybody else.

This is just a confirmation that the part of the health protection in my life showed to be good and gave results because of the timely discovery of the disease and early rehabilitation, but stronger consistency was required on my behalf to continue with exercises on my own. Still I have to point out the moment of insufficient proficiency of the doctors simply to go through the started. I can understand the nurses, to whom the doctors give orders which medications should be given to which patient, brought from other places to ease the pains. I think that there isn't a good communication between doctors and patients that is necessary, a good knowledge of the patient's psychology is needed, and than they should also resolve problems among them which should improve their relations, all doctors are not alike but this is necessary for some.

Concerning the bad quality of care provided in our healthcare system, or to say it more exactly – the reckless behavior of many "medical professionals", it is needed to develop a bigger conscience with them and not to rush them, but to leave space and time to sort things out for themselves, but if they aren't prepared, or they simply don't want to do it properly, they shouldn't do it at all, then they should leave this problem to persons with higher levels of motivation, and with stronger optimism and prepared to give real help to those who need it.

The brave heart beats all barriers in education accessibility

Loneliness doesn't come from the lack of human company, but it comes from the failure to communicate about things important to him, or taking attitudes considered inadequate for other people.

Loneliness is a frequent phenomenon nowadays.

Some people leave, some people are left, get fired from their work position or non-governmental organization or they simply leave. I am one of those who had felt loneliness on their own back.

I was abandoned by my mother when I was a child and therefore I feel rejected even at the moment, and as a feeling caused a lot of conflicts in me, but I would like to present growing up as a theme in this conversation. My growing up was influenced by several factors: firstly I, than my family, here is my mother who would increase the process of my growing and finally the social surrounding. While from health reasons I missed all the child play and smile, and spent my childhood in hospitals, my friends without a disability had all that, which is why they saw mw with different eyes, to make an awkward situation for me.

Most inconveniences I've suffered in primary and secondary school were because my friends socialized with me superficially, I would give several examples: we have made plans for going out but they went out early without waiting for me, or while playing with rubber bands, they didn't include me in the game, but they only passed the band in order hold it for them, and while I was performing that task they insulted me wit words like 'crippled ugliness'.

From this sort of events in life I create a feeling that I bother people. But the hardest part is to take insults where you don't expect, and to be falsely accused.

After finishing high school, after a one year break, I got enrolled the University, at the Faculty of Philosophy – Department of History. At the Faculty still different from "the others", or still a child in other words, I managed to graduate with the wonderful help from my parents and my history professor's support.

In the course of my study I was always scared and getting petrified how wouldI be accepted. I was often worried that I would be probably rejected because I take those thing quite difficult, and that is due to my difficult childhood, and that anxiety is still here, I haven't surpassed it but there are the friend I have now to help me. They are few but still they give sincere support to me.

I finally managed to live trough this period much better than primary and secondary school. The professors had a lot of understanding for me, and I can even freely say that they were easy on me for some of the exams, while some professors imitated my behavior and acted childish towards me. I didn't have any problems with my colleagues; I had good relationship with them and with some of them I still communicate well. I once had an inner conflict when an opinion should be given and I had a different one, so that time I was completely separated.

We all make mistakes, [redacted] but it is important is to learn from them and not to repeat them. We make the most important decisions in our lives.

For easier confrontment with the disability, as well as surpassing it (bodily as well as physic) we should really confess to each other that we mustn't compare us with the people without disability, but we are able to do things they can't, and therefore we must accept ourselves for who we are. With the creation of a real image we successfully contributed in surpassing this problem in ourselves, and afterwards with the surrounding.

Actually with my late development saw things that the people who had helped me couldn't see, and seeing other children from my generation, I decided not to take any pity and not to make things even more difficult than they really are. And concerning the abuse of people with disability, which I was a part as well, certain people didn't let me in my ignorance to develop my vision, but on the contrary because of one unsuccessful work, they didn't permit to start in a different area, certain people do it from respect, considering that I shouldn't be in that area, and permitting to me to find myself in a different space and different area.

They are the so called humane humans and non-humane humans, filled with evil and making fun of other people's pain, but we should blame them but simply to make distance from them, there is a famous saying: ' the enemy can be made friend but you can't make friend from a false friend'. Inner beauty surpasses even the biggest disability.

From molestation we can learn how we can surpass them and make good deeds from them. If in history people fought for given territory, why shouldn't me or anybody who identifies with the story fight, and we need to fight till the end.

Life brings unpredictable things; we should enjoy and live every day like it is our last. When it's most difficult I try to keep it for myself, and not to shame myself with my late growth, because it will help me in the formation of my character, the character could be different analyzed from the other side and it want to judge the right characteristics with people. Physiological and emotional development is more stressed with girls with disability, and body disability presents a bigger barrier for boys. From this aspect as a girl with disability I consider that my late development seriously affected my since I am a member of the females, because I know that girls without disability show more emotions than boys.

According to Freud:' The childhood is the parent of the human personality'.

These words are written by a girl with big courage, pure heart, and strong will, and I am prepared to put behind molestations that happened to her, to put them in the past and to remember them like shadows in the past, and prepared to leave the presence in progress, and to have a bright future.

Written by : Antik Nadica

THE STORY OF KATHERINA, 27 years old: A GREEK WOMAN IN BELGIUM

Because I needed a father
more than myself,
because I cherished my father
I kept seeing things I could not say
I kept not saying
until it became only important
not to talk.

People can hear stories about disability being caused by road trauma or a long illness but not by being abused by a family member. People can handle it if you say your disability was the result of an assault on the street. I mean it’s getting into the area of ‘that’s not nice’ but people still react better than if they know the assault was from a family member.

My father had an awful temper and I think he would have had an awful temper regardless of the cultural background he came from. On the other hand, he had attitudes towards both my brother and I, or men and women, that were cultural - or stronger because they were cultural. Some men use their culture as an excuse for violence. However my father never actually gave me an explanation for his treatment of me other than it was always because of me, things that I did or didn’t do. It was always about me rather than about him but on the other hand I was always supposed to be a 'good Greek girl' and I am definitely not a good Greek girl.

So while my father never gave me reasons for his abuse other than it was all my fault and nothing to do with his behaviour, his cultural expectations of me were used to make me feel as if I was failing him. Those cultural expectations also had an impact on my brother. My father, like all Greek men, had served in the Greek army. I can vividly remember my brother being quite young, I don’t remember what he was doing, but I remember him getting Greek army discipline for it. My father thought this was a reasonable way of punishing a primary school-aged child because he was a Greek boy who needed to grow into a Greek man.

My father experienced a lot of conflict within his family because he fell in love with my mother who was German born so he married outside of the Greek community. My mother wasn’t accepted by my father’s family. The first acknowledgment of her was when she gave birth to my brother, a son, but she spoilt it in their eyes by refusing to follow Greek tradition when naming him. I think it was one of the very few times she put her foot down and my father did not want to go back to his family and tell them his son was not going to be named properly. My brother’s birth was registered at the last possible moment.

My father’s conflict with his family was just another reason for his temper. Being Greek influenced his expectations of what proper behaviour was. The fact is that I am not a ‘good Greek girl’ - so the further I drifted from his image of what I should be, the more I copped it. Mind you, I think if he wasn't Greek he would have still found fault in me and he had a rotten temper. There were less expectations of my mother than there were of me. I was the one that had to be the good Greek girl. My overwhelming memory of my mother is that she was in her bedroom with the door closed.

I remember at one point feeling very alone in having the sort of experience that I did and being quite desperate to find somebody else that had had a similar experience. Now fifteen years on from then I have met or know of an unfortunately large number of women and men too that have had those sorts of experiences but because most people out there in the community can't hear these stories there is this silence and it makes you feel quite alone.

Thinking of some of the reactions I had when I did talk with people it is hard to put into words how to respond because it's about how the response makes the person feel. The 'what not to do' stuff comes out as motherhood statements or the 'what to do' stuff also comes out as motherhood statements.

I remember once talking to my teacher about how I would be killed if I did something - now I didn't necessarily mean I would be killed but I did mean I was worried I would cop it from my father, and the reaction was 'it won't happen', but I was absolutely panicked and could not be reassured. I guess that's another example of asking the need to ask 'What is really behind this fear?' I know that some people's stories are difficult to listen to but if you can't hear the person's story it makes it even harder for them.

Women with disability don't get access to information about gender violence; everything is so bloody siloed. If you are a woman receiving disability services you receive information about your disability but almost no general community information. There are exceptions and some individual workers are great, but if you use a day program, work in a business service, or live in a shelter of special care institution the chances of you receiving information on family violence are minimal.

When thinking about broader community services it's better, but apart from the physical access issues, there are workers who don't think they have the skills to work with people with significant cognitive and communication difficulties. The issue of having to take longer to work with women with disabilities is a problem when you work for a service that is overstretched. Information in alternative formats is an issue - they do exist but how do you get your hands on them? There is still the 'It's too hard' thing and for example how many underfunded community organisations can pay for deaf interpreters?

The resource issue is a problem. I think there is greater awareness and greater willingness - that varies from worker to worker - but the resource barriers are there, like how many physically accessible refuges are there? And what the hell can they do about it?

THE STORY OF MARIANNA, 20 years old, UKRAINE

I'm 20 years old.

My mother said, when I was born everything was all right with my health - I began to walk as all healthy children.

And after one of the vaccination, which all children get in the childhood, I felt myself worse, and then I stopped to walk by myself. My parents tried to find the best treatment for me. I remember that we even went abroad to Hungary where I got a course of treatment and rehabilitation.

But I still had problems with walking and I need assistance in moving.

I finished secondary school, but I studied at home because of my limited mobility and need in assistance to use public transport and to move about a school. The school has not conditions for pupils on wheelchairs. In primary school my parents tried to take me to school for different holidays and parties but later on it became more complicated and the attitude of the classmates was different. I understand that they have their own life. I've not made a lot of friends at school. Best of all I liked languages and arts.

But I found real friends at the rehabilitation center, which was created by NGO of our parents. I learned there to sew, to weave, to make macramé. We show and sometimes sell all our manufactured wares at the exhibitions. At this center we have musical and other classes, interesting meetings and parties; we go together somewhere to the nature or on the excursions.

I think it's the only opportunity for young people with combined disability, who completed their school education but cannot start working, to leave their homes on regular, daily basis, meet their friends, spend their time in a sensible and pleasant manner. We are given an opportunity to actively participate in the life of community.

Another young boy appeared in our center later. We became friends. He has cerebral paralysis too but he can move by himself and he helped me a lot. He was keen on sport and he even played in football team.

We fell in love...

We decided to get married. First my mother was against it, she said that my difficulties will double if we marry. I realized that our mutual life would not be easy but I felt myself desirable and beloved in spite of the public view that woman with a disability is asexual and not able to have a sexual relationship that is satisfying to her partner.

So we married and I gave birth to our beautiful son.

Thanks to the God my son is a healthy boy.

My mother helps us to take care of our child. We also hired a nurse who helps us. But I think that not all young families like ours can pay for the service of a nurse so there must be some social child care services that can respond to the needs of the mothers with disabilities. And I think that our housing situation would be easier if we have specialized equipment to enable us to do the housework or take care of children.

Neither me, nor my husband cannot find any job so we just live on the state invalidity benefit, and this benefit is not at all adequate to the real life needs.

It is not easy to cope with all problems that our family happens to meet but I’m happy to take life with all its advantages and disadvantages.

THE STORY OF SVITLANA, 22 years old, UKRAINE

I'm Svitlana from Ukraine.

I was born on 11th of March, 1986 in the town of Lutsk, which I love very much. Almost at once after the birth, the doctors gave the diagnosis cerebral paralysis, so I was forced to learn to use the wheelchair.

First my parents and I tried to fight with it, we visited doctors, and received treatment in different health centers. It helped but not strongly. However, now I understand, that if we didn't do that then, may be I could not rise out of my wheelchair at all. I still can move a little without my wheelchair.

I began to study at school at the age of 8.
But teachers came to me and taught me at home. So, I didn't know what a real school life was. The walls of my flat were the only things I could see at that age. I was ashamed of the glances of people in the streets, who looked at me because I was not like others. So, I studied and tried not to think about it. I was successful at my study, but first it was not easy for me to learn to write because my right side was limited, so I learned to write with my left hand. I finished school with honors (decoration).

In 2002, by chance, I was invited to visit Youth Rehabilitation Center "The Source of Life" for young people with disability. Before, I thought that the word "disabled person" means something terrible and helpless.

After acquaintance with the team of the center I understood that the wheelchair is not the most terrible thing that can happen with the person. Even with the term "invalid" your life can be absolutely full of value. It means that you only have some physical defects but you are not different from the other people. I became the part of the team and try to do everything I can for further developing of the center. I try to spread information about our center among the youth, who still stay at home in full isolation. It just in the center I learned not to be ashamed of my disability, to perceive myself such as I am. I found there friends which understand me – Tanya who always helps me to be self-confident, and Sasha who taught me to look at my wheelchair in a different way (though his situation is complicated too, he takes with pleasure every moment of his life). And I met there many other young people who prove every day that they are not different than the other people.

In 2006 I learned that in Ukraine there is "The All-Ukrainian Center of Vocational Training of Invalids', where young people with the same problems get education.

My mother and I began preparation for entering to this center. The study means that I must live alone in the strange town, without my parents, whom I love very much and who brought me up as a personality. They helped me to cope with all living conditions. Nevertheless, I entered this center and was astonished by the quantity of young people with the same problems. We need only one day to get acquainted with each other and to understand each other. Then I have to learn how to go and to rise skillfully on my wheelchair, but also I learned to dance. We lived there as one family. I learned there for 6 months and got a diploma with a qualification of a "secretary'.

It's a pity I can't find a job according to my qualification, but the study at this center gave me a lot. When I returned home I became braver and more self-confident. Now I can walk with my friends along the streets of my town and enjoy every minutes of our life.

I would like to say everyone who will read my story – no matter whether you are on the wheelchair or not - you are the same as the other people and don't be afraid to live.

Just live-because we have only one life and we must love it.

GRACE AMONG THE WHEELS by DONA GRITZ

She walks as if favouring a sore foot and her one hand can’t distinguish coins from stones.

Mostly, she imagines, no one knows.

At last week’s dance, a boy with sleek hair kissed her in the corner.

Tonight, her youth group is doing a yearly good deed. Leaning on a wall, she watches guests crowd the gymnasium in wheelchairs.

Skewed legs wrack with sudden currents.

Arms lay folded and stiff like cooked wings.

Her friends hold the twisted hands in their own then sway,
grace among the wheels.

She’ll choose a partner among the palsied strangers when there’s a song she can get lost in.

It will be like dancing with her secret self.