



JOY VAN DER STEL

The

POWER
of my DISABILITY

THE LIFE STORY
OF AN INSPIRING WOMAN

INSPIRATION

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of my **DISABILITY**

THE LIFE STORY
OF AN INSPIRING WOMAN



The power of my disability
Joy van der Stel

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Thanks to

Preface

This book disseminates my view on life. Very often this will differ to yours at the time you are reading this. Each chapter includes a personal awareness which – once, I was able to capture it in words – opened doors like a *key* to new insights and opportunities.

Try to keep these in the back of your head whilst you read. I hope that, if you can project them onto your own life that they will serve you the way they served me and still do so today.

I hope you will find the reading inspiring.

Joy van der Stel

Chapter 1

Joy, pleased to meet you



When I was born, I was as big and as heavy as a pack of sugar. It was in the year 1975. My parents were still very young and my grandparents had decided that the delivery should take place in the local village convent infirmary.

They already had a healthy two year-old boy. Another child was expected around Christmas. However, this child couldn't wait that long and already wanted to enter the world at the end of October. The delivery took ninety-two hours.

By the time I was born, I had every color under the sun. I had suffered a lack of oxygen. My mother's greatest fear became reality: 'There is something wrong with my baby!' My father just stood there staring. The doctors said: 'We advise you to wait with the birth announcements. She won't make it through the night.'

The next morning, I was lying in an incubator attached to all sorts of tubes and looked around with my tiny eyes.

Everything begins and ends with you.

You are the center of your own life.

You are born and you die. In between things happen. That it all happens is a fact.

How you deal with it all is up to you.

‘Doctors are only human too’, my father realized. ‘My little girl has long decided to stay in this world otherwise she would have left it already.’ Mom told him to go and register my birth and he decided to follow his heart. When he came back he announced with a smile: ‘Her name is Joy instead of Linda.’

The nuns kept me alive to their own astonishment. Mom came to visit me every day. She cycled for one hour there and another one back. A clear diagnosis wasn’t made. The doctors were not able to tell my parents much more than that I had difficulties to move and that any day could be my last.

After spending six months in an incubator, my weight was normal and I was able to move to a regular bed. Finally, mom could bath me, dress me and cuddle me.

‘Look at you, young lady, what a lovely dress you’re wearing’, she beamed.

Her chance to breast-feed me had long passed and what’s more, I neither had the strength nor the control to do that. All my feeding went through a small tube, through my nose right into my stomach. Whenever my parents weren’t there, I was lying in a stiff and cramped position, separated from the rest in a small glass room.

I was the only child in the whole hospital. The matron was the only one who would get me out of bed sometimes in order to sit with me in the rocking chair. ‘Little Joy, what are we going to do with you?’ she whispered as she rocked me gently.

When I was eighteen months old, I uttered my first

‘Dada’, clearly to my mother’s sadness. ‘I am also your Dada,’ she smiled kindly, as she took me from the matron’s arms, ‘say it again, da-da.’

I didn’t say a thing.

My father also wanted to hold me, and gave me his tickling cuddle. I lay there giggling in his lap and babbled loud and clear: ‘Dada!’

‘Dada?’ said my dad, ‘I’m your daddy. Come on, say it, Da-dy.’ ‘Can’t you just be happy with what she can do?’ my mom snapped.

‘I am happy, but it’s simply not right’, my dad returned drily.

When I was two and a half years old, every now and then I was allowed to go home for the afternoon. My parents were given a large syringe and liquid food to take home with them.

‘Simply connect the syringe to the tube in her nose and gently squirt the liquid into her stomach’, said the nursing personnel. With an expression that spoke for itself, the doctor said: ‘Enjoy your little girl as much as you can.’

After four years of shuttling back and forth without any clarity or perspective, my parents decided on their own initiative to take me to a rehabilitation center in the big city of Rotterdam. There, they were hoping to get answers to their questions ‘What is the matter with her?’, ‘What does this mean in future?’

After a brief examination, they were told: ‘Your daughter has encephalopathia infantilis...’

‘My daughter is not infantile!’ my mother interrupted, as if stung by a bee.

‘Sorry, I mean spastic. Your daughter is for eighty percent spastic. It means that some muscles are continuously stimulated and any additional stimulus will cause them to contract involuntarily. Her muscles have enough strength, but the uncontrollable spasms make it very hard for her to do anything voluntarily. There are some movements that she will only be able to make with great difficulty or not at all. The right side is worse than the left.’

My arms were usually bent towards the upper part of my body and my legs were in a cramped position against each other. With a lot of effort I was able to separate them a few inches. When I moved them I had no control over them.

‘Joy will never be able to lead an independent life. We can’t detect a mental disorder, however, due to her disability she will most likely also fall behind in her behavior’, the doctors continued. ‘That’s unfortunately the way it is. We are sorry but it is probably the best if you accept this fact. We advise you to leave her with us.’

My mother’s last hope for a normal life for her child faded. Her idea of a mother-and-daughter-relationship vanished before her eyes: no first food, no first step, no playing together with building blocks, no bed-time story, no shopping and chatting together, no boyfriends, no wedding, and certainly no chance of ever becoming a grandmother to her daughter’s children.

On the contrary, my father became somewhat quar-

relsome. He had no intention of ‘accepting this fact’. He looked at me and knew that, somewhere deep inside, there was much more in his little girl than was visible now.

He didn’t know yet how to reveal it but he was determined to concentrate on my possibilities instead of my impossibilities. That was indisputable.



During the week, I stayed in the rehabilitation center and during the weekends and holidays I went home to our flat on the first floor, also in Rotterdam. In order to be closer to me, my parents had given up their farmhouse. My grandmother had also moved to live nearby.

To begin with, the center set up a medical report in the form of a list of possibilities and impossibilities. At the top of the list stood: ‘Eat solid food’. According to the doctors and statistics my feeding tube could be removed.

For the first time I was supposed to take in food through my mouth instead of my nose. They put me in a chair to which they tied me because I couldn’t sit by myself.

Bib on and – oh, I was so excited – there came the first spoon with nice green stuff. I could hardly talk but I understood that I had to open my mouth. That was something I could do!

In great anticipation I opened my mouth and the spoon went into my mouth. Unfortunately, I didn’t know

what do to with it so after keeping it in my mouth for some time I simply spat it out. I was given a new spoonful which, after a while, I spat out again. And again I was fed and spat it out just the same.

It was a game which I simply didn't understand. 'You have to eat, Joy, try to do better. Swallow!'

What did these people want from me? I had learnt something new: put something in my mouth and I will throw it out again. I started to cry bitterly because I didn't understand why they started to get angry with me.

This started a whole discussion. Someone thought that I didn't want to do it, another thought that I couldn't do it and the third was in doubt. They asked specialists to come in and after two weeks of trying all sorts of methods on me and my eating disorder my parents were asked to come in for a talk.

'Your daughter has quite a will of her own, Mr. Van der Stel', the doctor fired away.

'That's great! And what's the problem?'

'She doesn't want to eat. We have tried everything. We tried it playfully: Joy gets a toy if she eats something. Normally, this works very well. Also, the hard way does, a day without food. But she only takes food in through the tube. We would now like to try a combination and give her more solid food through the tube.'

The look on my father's face was enough to end this conversation.

A few days later, my father took a day off to try and find out what the real problem was. Again he put on my bib,

the spoon came, I opened my mouth and kept the food in there for a while and then... my father stroked me along my neck and taught me what it meant to swallow. I didn't have a swallow reflex. After all, I had received my food through a small tube for four years.

'We didn't think of that, Mr. Van der Stel.'



Every rehabilitation center sets up a treatment plan with goals and therapies. There are three types of therapies in order to get the body into good shape. I was given all three, almost every day: physiotherapy to keep my muscles supple and to improve my posture; ergo therapy to fight the hindrances I encountered performing daily routines; and speech therapy to try to learn to speak. After six months of speech therapy, I was talking nineteen to the dozen and sometimes even more.

A wheelchair was the next step on the ergo therapist's list. I was four and a half and the wheelchair had to be designed to grow with me. In order for me to sit upright, the back of the wheelchair had to be identical to the shape of my back. The hip belt and the tray, which, for more support, was fixed under my armrests with tubes, had to fit me perfectly.

Because my legs mostly stuck out straight very inconveniently like two little sticks, tailor-made crossing straps were made to hold them back on the foot rests. To keep them apart, a special wedge was made which was attached to the seat. The team treating me was

convinced that I would not be able to move on my own and therefore recommended an electrical wheelchair. My parents refused categorically: 'First we want to try whether she is capable of doing it.'

Additionally, a normal wheelchair – one with small wheels in the front, and big ones at the back to push me around easily – would not be a problem to carry up and down the stairs at home. An electrical one would. The treating team agreed.

While the wheelchair was fitted it was as if I was getting a pair of wings, and I felt like a princess receiving her little crown. I realized that I would be able to move around with this thing. I could already see myself racing through the hallways of the building.

All I needed to do now was figure out how I was going to do that, because my control over my arms was still hopeless. I could barely hold large objects and only if they were handed to me first. And because, statistically, that was about the maximum of what I could do, the therapists didn't try to teach me anymore.

The maker of the wheelchair showed me how to use it: 'If you turn the big wheels forward at the same time, you are moving forward. If you turn them backwards at the same time, you are moving backwards. If you want to turn, you need to turn one wheel slightly faster than the other one.'

It was going to take four months after the fitting of the wheelchair before it was delivered. The team still had their doubts about this wheelchair but I was busy with just one thought: moving around on my own!



The longer I was in the rehabilitation center the less my parents liked how they were treating me. They felt that they were not doing enough with me. Of course I had my therapies, my nutrition and care but there was so much more. Things that only parents can give their child.

Especially my father was convinced that they should take a different route with their daughter. Mom did agree with him but was very hesitant in disobeying the doctor's instructions. 'The doctors said...' she would start.

'The doctors said that Joy would die', my father would interrupt her, 'but she didn't, did she?'

I celebrated my fifth birthday at home and my present was that I would go home every night from then on and only go to the rehabilitation center for school. How they were going to do it all they weren't sure yet. But one thing they knew for sure: 'It is our duty to give you a place in this world where you are happy. Until now we have only heard what you won't be able to do and every time their future prospects are gloomy. From now on we are going to find out together what you can do and we will make sure that you and we will be happy. Yes, you have a handicap but in the first place you are a human being.'

My parents believe in the tough manner of dealing with things: the world is a tough place and you have to learn to deal with it. Their vision of the reality was a rather confrontational one to me when I was young but already

taught me as a little girl to deal with reality. My reality: I have a body that works differently to that of others but that doesn't mean that I am different.

I wanted the same things that other children want: to play with dolls, be a princess, do somersaults. And when I saw a couple of children playing in the sandbox, I wanted that too.

'You can't sit up by yourself,' my father said, 'you will fall over.'

'I want to play in the sandbox! I want to play in the sandbox!' I screamed.

He frowned, got up and got our coats. Mom watched from the window as dad and I went to the sandbox. I had a feeling of victory until we arrived there. Dad opened the straps and freed my feet. I began to realize that he was really going to put me in the sandbox.

Resolutely, he put me down in the sand: 'Okay sweetheart, have fun!'

He simply let go of me and I just barely saw dad go away before my upper body decided to tumble over into the sand.

There I was, my face in the sand and all alone. I hadn't seen that dad was behind a tree watching it all anxiously. Mom bit her lip. With my face flat in the sand, I racked my brains. Everyone says that I can't sit by myself, I thought, mom and dad say it, everyone at school says it but I want to sit upright!

I was thinking of just one thing, I want to show dad that I can play in the sandbox! And – yes – my body went up two inches. My body was shaking but I continued. When

I managed to rise another two inches trembling all over, I felt my father's hand saving me from tumbling down. Even if he was proud of what had just happened, I didn't notice any of it. He buckled me up in my wheelchair and looked rather confused.

'So you can do it but as long as I have to tie you up with these belts you will not get a chance to learn to sit upright.'

As we entered the house my mother quickly hid a tissue. She had seen my victory but also my struggle and she suffered from her own feelings of being helpless. For my part, I wasn't sure whether to be happy or sad. We were all impressed by what had happened. For a moment the earth stopped turning. Until my brother came home and everything went back to normal.



Every day I felt how "different" I was to my brother. Dad or mom took him to school and I was picked up in a small bus with my wheelchair and everything by two paramedics dressed in white uniforms. In the afternoon, I was brought home by them in the same bus, whereas my brother was dropped off by the mother of one of his friends. Very often this friend would stay over to play.

No one ever came home with me. I only had girlfriends at school and they too were all picked up and dropped off or they lived there. We didn't live close to each other. I had no contact with normal children.

I played by myself or with adults, did my exercise

assignments for my father and watched loads of TV. I often felt very lonely.

And then there were the practical things. My brother ate with a knife and fork whereas I couldn't even eat with a spoon. And I was already five! My brother got dressed by himself, I had help. Why didn't he?

Then, whenever my father saw me frowning, he said: 'If you really want something, then you can do it. You too.'

What had happened in the sandbox was proof to him that I was capable of incredible things if you just put me on the spot.

My parents taught me to use my left arm and hand more and more by letting me try and grasp things constantly. Rather impatient and very ambitious my father initially gave me a ping-pong ball to practice with. To everyone's frustration, I permanently let that ball bounce through the room. My mom then turned up with a sponge but that was almost too easy.

My right arm was still useless whilst in my left arm I had quite some strength. It stayed cramped but with all the training I was able to lift it up on the armrest quite well. Dad, mom and my brother had all stimulated me in their own personal way.

'That looks rather ridiculous, your arm against your body that way, sweetie', dad said. Mom could then see my sweater better. 'At home it doesn't matter so much but if you could try it when we are with other people...' she began.

'It will make you look a bit more normal', my brother added.

If I wanted to be like my brother, my father used to say, I would at least need to be able to get in and out of my wheelchair by myself. Therefore, I was thinking very hard until I came up with a way of doing it. How do I have to move, what's keeping me from doing it and how do I solve this problem? After weeks of theory it was time for practice. I generally only put an idea into practice if I was certain that I could do it. Then I choose the right day: 'Dad, I want to play in my room.'

He put me down on the floor and as soon as he had left the action began. Some hours later, covered in bruises, I had reached my goal: I sat in my chair! Completely out of breath I called my father. Mom and my grandma also came. I gasped triumphantly: 'I made it!' I thought I was going to be rewarded with applause and cheering but nothing. 'That's good,' my father said coolly, as mom and my grandmother wiped tears from their eyes, 'but if you want to play on the floor again, you're going to have to get out again.' And off he went.

Mom gave me a meaningful look and grandma gave me a kiss on my forehead before they both rushed after my father.

I could hear them arguing from my room: 'You can't do this! The girl does her very best and all you can come up with is "Now you're going to have to get out again!"'

I didn't understand what the fuss was all about. Dad meant it well after all? Dad always meant it well, didn't he? Despite the disunity between my parents as far as

the approach was concerned, I learnt a lot. My brother was my big model. For example did I watch him when he put on his coat: one arm into the sleeve, the other arm behind his back reaching for the coat which dangled behind his back, hand into the sleeve and then by straightening his arm the coat was on. With a bit of fiddling, my brother also managed to get his zip closed. Watching him in admiration, I memorized every movement, so that I would be able to try it out myself later.

We are just about to leave the house. 'Hurry up,' mom says to my brother, 'and help Joy into her coat.'

'Hello... I have to do it by myself too', my brother moans.

'I'll do it myself', I say. Quickly my brother throws me my coat.

'Go for it, sis!'

Okay, here we go then, I thought. With my left hand I lift my right arm and push it into the left sleeve opening. After a few attempts this works and I can push up the sleeve over my arm. My coat is now dangling next to my wheelchair. I have to try and get the coat to the other side but the back of the wheelchair is in the way... Let's see, I need to pick up the coat with my left hand and throw it backwards... the coat is stuck somewhere on the back of the wheelchair.

After rambling around I manage to free it and it is now hanging next to the wheelchair again. Let's try again. Lean forward as much as possible... perfect! Now I need to find the coat with my left hand somewhere behind

me. Got it! Where's the opening? Straighten that arm and yes, I am wearing my coat! Next, all I need to do is straighten it out a bit, because the back is all double-folded. Mom breathes a deep sigh of relief, gets up and closes my zipper.

'Practice makes perfect', says dad.

'Can we finally go now?', my brother asked.

Of course I was helped with a lot of things, especially by mom and grandma when my father wasn't around. Or simply because we didn't know yet how I was to accomplish something or how I could learn it. I still peed in a diaper for example. How do you teach a child that can't stand up to go to the toilet? My family was my example but who did they learn from themselves?

'We are thinking with you but we can't do it for you. There is no such thing as "I can't" but there is "I don't want to" which will get you wet pants', my father said. 'If you need to pee what do you need to do? You need to sit on the toilet. It doesn't matter how you do it as long as you do it.'

A high toilet seat with handles on either side seemed enough. After that it was simply a matter of a lot of practice. 'Every time you make it to the toilet on your own, we will help you the next time', my mother promised. My diapers were banished forever.

Slowly but surely, I learned the most important things you need to know to get through the day: eating with a special fork en knife, spreading and cutting a slice of bread, drinking from a mug, putting on and taking off my sweater.

And, moving around in my wheelchair. Initially with only one hand. I turned in circles and was deliriously happy. It wasn't like I was flying but it was a start! Mom was delighted but the men in the house said: 'Nice but riding around in circles won't get you anywhere.'

I knew they were right. It wasn't good enough yet. I practiced and practiced until I could steer with my right hand. I was going in a straight line if you ignored the slight deviation to the left.

That's how things went at our house: just do it. Everyone puts a coat on to go outside, hence me too. I did it slightly differently to the others, so what. It cost more effort and took way longer than it did for Dad, Mom and my brother but it worked. It was terribly difficult but yet, I felt like an equal part of the family. I was happy.



The difference between home and the rehabilitation center was as night and day. The people at school and therapy treated me as if I couldn't do anything. I wasn't challenged; everything was done for me. On the one hand that was rather nice. The pampering was a nice change to the tougher "do-it-yourself" approach at home.

On the other hand, the feeling that I was "different" was intensified a lot with all the help when I explicitly wanted to be "normal".

I lived in two worlds: the closed little world at school amongst only other disabled children, and the everyday world amongst the normal people at home. I didn't want

to be out of tune at neither place. I used school as a place of rest. Nobody there realized that the other Joy existed. Why swim against the stream and tell them that I could do much more by myself? I was busy enough at home.

I also wasn't challenged mentally. We didn't have to do any Math or learn words, all we did was play or we had therapy. If by accident we learnt something it was so much the better. I asked my brother why he learned all sorts of things in school and I didn't.

'Because they think you're crazy', he said without even looking up.

My father nodded to confirm. My mother gave my brother a good punch.

Hey, finally we are going to learn something, I thought, when we learned how to tie our shoelaces at school. However, only the children who could use both hands were given the small board with the two laces attached. I was only able to hold onto small things with one hand, just like another girl.

'If you can't do it, you don't have to learn it and we will do it for you'. My classmate and I just sat there staring, too young and too flabbergasted to react.

I also want to learn this, teach me! I also want to be able to tie my own shoes. By myself. And not that somebody else does it for me. If I can't do it with two hands, teach me a different way then.

That's what we did at home: If it didn't work going to the left, you went to the right and if that didn't work you

could still try backwards. But school, the place to learn things, just let me down?

‘What are they thinking? I’ll call them tomorrow?’ my mother scolded at the dinner table. My father did not say anything.

At bedtime he tucked me in. I was still angry.

‘Yes, sweetie, the world is a tough place. And you are stuck in a “Small World” with only disabled children. If you want to be part of the “Big World” with normal people, you need to show everyone that you can do it.’ He kissed me good-night. At that moment his words meant little to me but subconsciously they were engraved on my memory: “...you need to show everyone that you can do it.”



Despite or possibly thanks to all their efforts the bickering between my parents got worse. They argued about everything.

The truth is that a disabled child puts a great deal of pressure on a family and my little accomplishments in independence were too small to really make a difference. A few months before my seventh birthday the decision was made: I was to stay at the school again during the school week. At school too, they questioned whether the decision was purely based on the extra pressure of taking care of me.

Mom longed for more rest and space for the family.

She also wanted her daughter to be treated with a milder approach for the moment. ‘During the weekends and on holidays you will come home. Five days just fly by’, she said laconically. I knew she was acting.

Dad stayed dad and said nothing. I saw him frown in a way that was new to me. He didn’t think that this was a good move for me. Not good for my independence, my self-image, my future. He held his breath at the thought that this would change his daughter. However, at the same time he knew that this was the better choice of the two bad ones: losing his marriage – wife and son – or his daughter. The preference went to sending the daughter to the rehabilitation center.

‘That way you can spend the whole day playing with your boyfriends and girlfriends’, my grandmother said. No one asked my brother of what he thought, but I could see that he was going to miss me.

As for myself, when I saw mom, dad and grandma walk out of my little room in the rehabilitation center the first evening, I could almost see the door to the “Big World” slam shut on me and then disappear. There I was boarding with five other children, all boys between the ages of eight and eleven. What was I to do?

Boyfriends and girlfriends? They were all so different. And the caretakers! They treated me like a disabled person, it was awful. Everything came down to me being spastic and how incredibly terrible that was. Good-bye independence, equality and self-esteem. Everyone focused on what I couldn’t do and what made me so different from the people in the “Big World”.

My feeling of helplessness was overwhelming. Nothing was discussed, decisions were announced. They talked about me, never with me. I had nowhere to turn. Obviously, it was easier having help with getting undressed and going to the toilet but the real things like grocery shopping, playing outside and getting dirty were gone. They belonged to the “Big World”.

I shared my room with another spastic. Then there was a boy with a muscle disorder, one who was paralyzed, one with spina bifida and a third spastic. And yet did I feel like the biggest outsider. They really believed that this was it: getting dressed by strangers in the morning, going to school in the same building you lived in, getting your warm lunch out of a trolley and getting tucked in without a kiss.

In between those rituals nothing much else happened. There is so much more outside these walls, I thought, how can they think that this is it? This is what dad had meant with the “Small World”: none of the five had lived anywhere else before. I simply wanted a kiss when I went to bed. I never got a kiss from the caretakers and actually I didn’t want that either. Not from them. I wanted one from mom and dad.

I was profoundly miserable.



The fact that I had seen more of the world had not escaped the attention of the group instructors. I didn’t let them make me out and played games with what I could

do and couldn’t. I set the table without letting the ugly “I can’t do this”, which was often used in the rehabilitation center, raise its ugly head. But in front of the group instructors who treated me like a little disabled girl, that was incapable of doing anything, I acted like one.

I knew what I was able to do and that was enough at the time. There was only one group instructor who acknowledged what I could do and then I did more.

Of course I made things more difficult for myself this way. Although, at first glance, I may have appeared to fit in well with the other children in my group, in reality we were completely different. Many of the group instructors considered me a “dreamer”.

What hurt me most was to see how they were able to go home and therefore went from one world to the other. Take me with you! I screamed silently. I felt like a bird in a cage. More and more I turned into a loner and my best friend was my “tricycle”.

It came with a backrest with a belt and had special foot rests to which my feet could be strapped. I had had this tricycle at home already but could only use it outside there and that was too difficult with all the holes and bumps. However, in the smooth hallways of the rehabilitation center it was a piece of cake.

My tricycle gave me freedom. After school, I asked someone to strap me up and then went to the assembly hall, which was deserted after school. I followed the patterns on the ground. Then I would ride to the physiotherapy department where I would receive compliments for my hard work: ‘You’re always moving around – even out-

side physiotherapy time!’ After that, I would get a glass of lemonade from the kind lady in the nurse’s room.

At the end, I would ride down to the corridors where the administration sat, the only halls with carpet. I stopped by the typing room. Here, the typing for all doctors was done, wow, this was important. In the next room sat the fanciest lady. Then I gave way to my fantasy: She is typing for the Director and probably earns a fortune. I want that too. Then I can buy a big house with all kinds of gadgets in order to be able to live by myself!

When I then returned to my group, still beaming from my future dreams, you could feel the difference ever so strongly. ‘Joy thinks that she is different’ they joked, ‘she thinks she is “normal” but no way, Jose, she isn’t and we aren’t and never will be. That’s why we are stuck here.’

‘When I am out of here, I will live normally, amongst normal people!’ I screamed.

‘Do you really think that? Dream on.’ I did, every day.



Living at home again apparently wasn’t an option. ‘You are just going to have to make the best of it’, my father said, seeing how difficult it all was for me. I would have appreciated a bit more explanation but as usual I had to figure out the “how” by myself.

It started to annoy me more and more. My group mates only had to give a little cry and their parents came into action: ‘My son wants this, my son thinks that, will

you please make sure that my son...’ It was easy to get jealous. My parents kept out of it most of the time. ‘If you want things to change, you need to open your mouth yourself.’

I did that but usually with a rather clumsy and blunt approach. I was extremely outspoken for a little girl of eight. Most of the group instructors and teachers considered me “cheeky”, and only the odd one saw this as a “talent” and viewed me as “a rough diamond that only needed a bit of polishing”.

Correcting me was preferred over stimulating me. Whenever I cut up rough, I was cut off immediately.

My message mostly came across in the wrong way. They would say something like ‘You know Joy, it’s as if you are trying to tell the story you briefly heard from someone but you don’t know the details.’

‘Then tell me the details!’

‘Joy, go to your room! If you can tell us what you did wrong you can come back’, it was always the same old story.

They wanted an apology but since I didn’t understand what I had done wrong they didn’t get their “sorry”. Explain it, I was thinking, but they didn’t. Consequently, I often stayed in my room until they would get me for dinner without ever resolving the “problem”.

Very rarely one of the “talent hunters” would take the time to explain things.

‘Look Joy, if you tell somebody to swallow because the drooling out of their mouth is disgusting, then that hurts their feelings.’

‘Why, that’s the way it is.’

‘Yes but still you are hurting people.’

‘What should I say then? Nothing?’

‘Maybe.’

‘Maybe, maybe, what am I to think now? You are just like my father,’ and I turned around angrily.

My relation with the group instructors worsened more and more. The growing distance and the cooling down were visible in every move. My group mates yelled ‘Chat, chat, chat, Miss Chatterbox’.

But they also realized that Miss Chatterbox sometimes spoke the downright truth and had her heart on the right spot – I poured a drink when someone was thirsty and if someone dropped something I picked it up – but I had a love-hate relationship with more or less everyone.

Nobody knew how to deal with this contradiction. After a long discussion the treating team unanimously decided to send me to a psychologist. Dad was against this decision, mom was in favor. Something was wrong but what exactly?

Through the leaded window with red flowers, separating the school from the rehabilitation center, the late afternoon sun cast a fantastic glow over me. I let my first session pass before my eyes and rebelliously thought: this is really too silly for words. At the same time I had to laugh: I found it rather exciting that a stranger would tell me who I was.

I am hesitant in front of the door on which you can

read “psychologist” and then knock. A chubby, rather unfashionable woman opens: ‘Hi Joy, how nice of you to come.’

I nod and enter her room which is identical to all the rooms in the building. Due to the look in her eye, my curiosity changes to suspicion. You want to know something about me? Then you can do all the work, good luck!

‘How are you?’

‘Good.’

A meaningful silence falls. Not talkative and without initiative doesn’t match her information on me. She moves her chair in order to sit right across from me.

While she is reaching for a box with blocks I am studying the ceiling. How did that brown ring get there?

‘Can you make some figures with these blocks for me, please?’

The blocks have four colors: red, yellow, green and blue and four shapes: round, square, triangular and rectangular. There are sixteen blocks in total.

‘Put four blocks in a row.’

I reach for four random blocks and am setting them next to each other.

‘Good, now a square one.’

I am wondering what she is noting down. After another round in which I take all the triangles I can’t stop from bursting into laughter. What on earth am I doing?

She reaches for a box with cards. ‘Can you tell me what you see here, Joy?’

On the card is a large blotch of ink with spatters around it. Okay, so we are not going to have a real conversation. I am trying to keep a straight face. 'A painter that messed up', I try to say seriously. Obviously, this is the wrong answer.

'This is not funny, Joy', she grumbles and puts down the next card: a diagonal stripe.

I pick up the card and pretend to study it. 'Oh, here's my letter. I wanted to write something but I got scared by something and got the shock movement you then get as a spastic.'

She blushes while I put on an innocent air: what did you want to hear then? Again she moves her pen across the paper and suddenly surprises me with a final verdict: 'you should be happy with what you have, Joy.'

With a diminishing movement she nonchalantly wipes away all of my dreams – which in my eyes are realistic goals.

Happy with what I have? My anger was just as red as the flowers put on fire by the sun in the leaded window. What have I got, then? I have nothing! I am living with people I haven't chosen to live with, there is nothing to experience, in school we don't do a darn thing, and nobody ever explains anything to me. I only get told off all day. And she says that I should be happy with that?

Shaking my head I returned to reality. Playing with blocks and looking at blotches! As if I was a toddler!

I started to move my wheelchair, took a last look at the

flowers and sighed deeply. Who is the crazy one here? At any rate, their opinion after this first session was crystal-clear.

I was hesitant. What now? From my own experience I knew that there was more than just what happened in this building but if I wanted to have fun here then I had to stop thinking, feeling and seeing it. My surrounding seemed to have an even greater problem with my "vision" than I did myself, so I had to come up with something. At the moment I couldn't think of anything smarter than to keep my ideas and goals for myself.

To say "yes" when they wanted to hear that and "no" when it was expected. And naturally only doing the right things without them having to ask for it because of course I knew very well what that was.

It worked. The looks changed. 'You see, we knew it. That's how it's supposed to be', the group instructor approved. My way of making up to everybody thawed them. To live up their expectations turned into my new game and I got better at it daily. I even started to enjoy it.

Do you want a disabled girl? Then you will get a disabled girl! It was written across my face. However, nobody took the time to actually read these words. The few group instructors that found that more could be done with me stayed in the minority and therefore couldn't do much but run with the crowd.



My new approach to life had one big disadvantage: I really got disabled. My physical skills deteriorated quickly because I did very little myself. I had everything done for me and therefore mingled with my group mates much better.

The sentences 'I can't do that... can't you see that... can you do that... because I am disabled', could also be heard from my mouth more often. I started to believe it myself. How horrible, I thought from time to time but nobody contradicted me. Sharp remarks did not come from my mouth anymore because they suddenly fitted me just the same and then I suddenly thought that they were quite hurtful.

In school – more of an occupational therapy as far as I was concerned – I kept quiet and showed no more ambition. I blended in with the crowd and didn't hear anybody complain anymore.

My dreams vanished, the psychologist had succeeded. Everyone was happy. Or not?

One person in particular was very unhappy with the changed me: my father. He saw how I lost touch with the "Big World" more and more. He knew that it was due to where I was staying. In the end, there I was trained to feel at home in the "Small World". If he wanted to change that back, he needed to get me out of there. If he was honest he even knew how and where to go, after all, he had taught me that: if you want to change something you have to do it yourself.

Mom on the other hand was really happy with the place her daughter stayed at. She detested the way I was

put on the stand by my father and brother during the weekends and preferred to keep it cozy.

Just like me, my father managed to keep his mouth shut from time to time. No matter how much it annoyed him, he had to wait for the right moment and until it came he concentrated on the weekends. As downright intensive training coaches he and my brother confronted me constantly with mental and physical challenges.

Whereas I seemed to be at a summer camp during the week, from Friday to Sunday I literally sat in *Boot Camp*. The rehabilitation center saw my disability and forgot about the person in me. At home I was a person but they forgot about the disability. The honorable task to match these two up well went beyond my capability at that moment. The transfer was more and more difficult for me. Even the simplest acts became difficult. It was so horrible I wanted to run away from myself. But realistic or not, my dad had me floundering until I fell: "I can't do this" wasn't an option.

Whenever I asked: can somebody cut my meat? Pour me something to drink? Close my button or open a bag of chips for me? it stayed horribly still. Whilst I kept trying in rage, I quivered: 'I can't do this! Can't you see that?' No reaction. I gave it another desperate try. If in vain, I peeped with a red face: 'See?'

It only made my "attackers" laugh very hard which drove me into an even bigger sense of losing control. Thank God mom always eventually did what I had asked for.

'Whenever you want something you can do it. It doesn't

matter how you do it – on your nose, turned around, inside out – as long as you do it. We have nothing with all those disabled people you play theater with during the week. We have something with you. You can do so much more than what you are doing now but you don't want to. If you have to you can do it. I know that for sure.' All the time my father repeated the same story.

I began to see his preaching as a sort of bullying. Also, it got me more and more confused: deep inside I assumed that he was right but why did everything go wrong all the time then? I felt more and more disabled with a body that didn't do what I wanted.

Not wanting to... he is crazy! I don't want anything as badly as this. Not wanting enough... I simply can't.

Every weekend it was war between me and my father. To tease me seemed to be my brother's biggest hobby.

And my mom tried her very best to keep it cozy.

Chapter 2

Under the knife



The world around you will always reinforce your convictions.

When you start out by assuming the good you will encounter good people and good situations. The contrary is equally true.

There are intense spasms and supple spasms. I have the first. During childhood the tension of the muscles fluctuates a great deal and the ability to move my legs apart changed from day to day. Putting on a pair of pants was a huge task. Even my dad wasn't able to change this and as far as training was concerned, I had my hands full with dealing with my arms.

The standard procedure is to release the tension operatively by cutting through the muscles in your groin and hereby enabling your legs to move apart. In passing, the rehabilitation doctor said that walking was forever impossible after that. This made my parents doubt it all.

While their decision was pending the rehabilitation team suggested giving me muscle relaxants: 'That will reduce her muscle tension just the same and we can treat her much easier. And for Joy it is more pleasant as well.'

My parents looked at each other 'I don't know why but