

**Images of Ourselves: women with disabilities talking, edited by Jo Campling
(pages 1-15 in the original text)**

SARAH

Sarah, who is 17, lives with her parents in Surrey. She is hemiplegic with restricted movement on one side. She has two brothers and one sister, all older and able-bodied. Originally she attended an ordinary school but, at her own request, transferred to the Thomas Delarue Spastic School at Tonbridge. She has 3 '0' levels and has been accepted at Queen Elizabeth College at Leatherhead to do a course in business studies. She is a very able swimmer and has won several medals and certificates.

As the youngest child, born with a disability, I am very lucky to have a caring family. I have a particularly good relationship with the younger of my two brothers. He helped me to become more independent by fighting with me so I had to defend myself and become stronger. I always felt that my sister and brothers were more intelligent than I was. I worked hard at school but never seemed to achieve their standards and this began to undermine my confidence. My disability restricts me only to the extent that if I want to achieve something, I have to work twice as hard as an able-bodied person. Then what I do achieve may not be perfect but I persist and do not give up. There are some things that I just cannot do like gymnastics and ballet dancing. I can sew but so slowly that it bores me to do it.

When I was at junior school I never had nasty comments about my disability. It was probably because when children are very young they don't notice that a disabled person is any different from anyone else. The local integrated comprehensive school was a different matter altogether. I felt very self-conscious about my disability because both the other girls and the teachers made it difficult for me. The students did not treat me as a girl with a slight handicap but as a person set apart. I felt that I was worthless and very vulnerable every time someone made a personal remark to me or about me. They used to ask questions like 'Why can't you go to the disco?' (It was four miles away.) I would say that I didn't want to go and they would whisper and giggle. Then I would remain quiet and hurt inside. I did have a sort of friend there but I would not call her a friend now because she had a bad reputation with the rest of the class and was very unpopular. I felt we were in the same situation in different ways. She used to make me do errands for her, like carrying her bag up four flights of stairs as some sort of threat that if I did not she would not be my friend. Once she made me kiss the toilet floor and then told everyone that I had done it voluntarily and I was very embarrassed. She used to tell me that she had a new boyfriend every week. I went along with these stories until she made up false telephone numbers and pretended to talk to them. I knew they were false because when I asked to listen she said they were cut off. I didn't have any boyfriends and used to wait hours for her and then get home very late. The other girls just ignored me and I felt very isolated. They didn't want to be seen with a handicapped girl especially when their boyfriends were around. It was not only the girls who gave me a tough time but the teachers as well. They were not sure how to treat me, particularly in the sporting activities. And most of them did not give me much encouragement academically. I began to lose all confidence in myself and became very unhappy and depressed. I wanted to be a part of the group but I

could not see how to join in. I used to feel that no one else could be as isolated I was in that huge school.

I wondered what it would be like to be in a school for handicapped people. I felt that a special school might be my only escape. No one suggested this solution to me as everyone thought that I could manage perfectly well in an ordinary school. I had a long talk with my father and he understood. For two years he tried to get me into a special school. When the other girls found out what was happening they teased me and said I would be a moron if I went to a handicapped school. Eventually I got a place at the Thomas Delarue School in Kent, which was a boarding school for disabled children. I can remember my last night at home very clearly. I had a terrifying nightmare of lots of very severely handicapped people (more handicapped than I had ever seen or imagined) crowding round me in a circle, telling me that I did not belong to them. Then they tried to bury me with all their strange aids and appliances. It was very frightening and I did not know what to expect. I need not have worried at all because I found out that I could get on with them much better. Although on the first night, when I was put into a dormitory with three girls, one of whom was very severely handicapped, I thought that my nightmare was coming true. She has now become my friend.

It was a vastly different world at Thomas Delarue. It was much easier to make friends and I didn't feel an outsider any more. Everyone had a disability and no one was self-conscious about it. They treated each other as human beings and you could be friends with anyone. Some of the pupils had very restricted speech. It was like learning a new, strange language but when I got used to it I was patient enough to understand them. With them I did not ask long questions but ones which had multiple choice answers so that they could reply and we got along fine. I now have a few special friends who are so close that they are like sisters to me. My best friend is more disabled than I am and she is in a wheelchair, but she helps me just as much as I help her but in different ways. I have now lost touch with the people from the other school and even the girls at the Guides. I am rather sad about this as it means I have no contact with the outside world. I sometimes think now that if I met someone from the old days I would be happy and overwhelmed to see them whatever response they gave me in return. I have the feeling that I shall always be lonely inside.

LISA

Lisa, who is 18, was born with bilateral myelodysplasia and can only walk with crutches. She is studying for 'A' levels at the Lord Mayor Treloar College in Hampshire and from there goes out daily to courses at the local sixth form college. During vacations she lives at home with her parents in Middlesex. Lisa hopes to go on to university to do business or computer studies. She took part in the BBC TV series 'The Handicapped Family'.

In this world in which physical perfection is sought by the majority of women, and which is given so much publicity in many circles of society, it is obvious that those who are, in one way or another, physically disabled will often be regarded as 'different', and will have many difficulties in making those around them aware that in fact they are the same in most other aspects as other women. One of my greatest

problems is in making people accept me for what I am - an individual, to make them realise that although I am disabled, I am capable of leading a 'normal' life and doing exactly the same things as I would have done otherwise.

In my opinion one of the most important facts that some people seem to disregard is that although physically different, mentally I am not disabled. I share the same hopes, anxieties, fears and general emotions with women the world over. Many people have supposed that because I am obviously disabled I am mentally sub-normal and have therefore treated me as they would someone of low intelligence or as a child. When I was young this did not upset me much, but to treat an eighteen-year-old as a young child is not only degrading and upsetting but deeply embarrassing. It therefore becomes more important for me to be able to show people that I am capable of living a 'normal' life by mixing with them in the same social places and by competing with them in every aspect of it, socially, academically and in leisure pursuits.

At first the actual meeting with people who were not disabled was difficult. I attend a boarding college for handicapped students where I lead a varied social life but the main difficulties arise during the holidays when I find that I know very few people of my own age in the locality and find it extremely hard to socialise because of this. I am just getting over feelings of shyness, inferiority and insecurity which have, in the past, made it even harder for me to go out and meet people. Now I am realising that if I am to go out and lead a fulfilling life I must have personal confidence, for it is only through self-confidence you can make others around you relax in your company and come to accept you as a friend.

Quite often I find that there is the added problem of the wheelchair or crutches becoming a psychological barrier between the outside world and the disabled person. They are obvious and the user is quickly registered as 'a disabled person'. This barrier is often difficult to break down and it usually takes time and patience before you are accepted as a normal human being and the disability disregarded. Some people say that 'you can't tell a book by its cover'; this is a very nice ideal, but in reality the cover - the person's physical appearance - is always judged before their personality, and first impressions are formed on the information that the senses send to the brain. It is therefore more important that I create a good impression not only visually but personality-wise if I am to compensate for any flaws there may be physically.

Some people have been surprised at the varied social life that I lead, but like any other person of my age this is a very important aspect of my life. The theatre, cinema and many other places hold the same interest for me as they do for others. They also provide a means by which I am able to come into contact with 'the outside world' and to integrate in it. Here, however, there are also problems with access in many buildings. It is true that all modern buildings are being designed to cater for the disabled but many, particularly older ones, are totally inaccessible, or, for reasons concerned with fire precautions, we are not admitted. In many theatres and cinemas the disabled are seen as acute fire risks, they would apparently be too slow to vacate the building in the event of fire, or would need such help that they would be endangering the lives of others, yet many people I know, including myself, would be capable of leaving a burning building under their own steam, perhaps faster than some able-bodied people could. In some theatres that I have visited, I have been provided

with my own personal 'companion' who has insisted on pushing me to my seat and creating such a fuss that my presence in the theatre has become too obvious and rather embarrassing. I am in no way saying that their help should not be provided for those who need it, but that it should be provided on asking and not automatically because you are disabled. Many disabled people handle their wheelchairs better than anyone else, so the helper can become more of a hindrance than a help.

I am very interested in sport, including canoeing, swimming, archery and various others. In my opinion not enough handicapped people know about the facilities that there are, or could be, for this type of activity. Some people think that there is too much risk involved in such sports as canoeing and swimming, but providing that the disability is not too severe and correct coaching can be obtained there is no more risk for the disabled person than for the non-disabled.

The college that I attend gives a lot of encouragement to those who compete in any sports. It is a pity that more schools and colleges do not follow their example. I am also very lucky in having parents who have always encouraged me to compete in new sports and who have seen that the risks involved are no greater because I am disabled. Not only do sports provide exercise, but also another way in which I can meet and compete with people as an equal. In canoeing I have the same advantages as able-bodied people as I only have to use my body above the waist and in some respects I have the added advantage of strength in my arms due to the continued use of crutches and wheelchairs. I now attend an ordinary canoe club where I find that my disability does not limit me at all. It becomes more of a challenge for me to do ambitious things. For example I canoed with a party of equally disabled girls down a French river with fast moving water, rapids and waterfalls, which probably had I not been disabled I would never have done.

All disabled people must be able to mix freely with able-bodied people if they are to become as independent as possible but there is always the added problem of transportation from place to place. This has to be overcome before a disabled person can be employed as usually there are distances between home and work. Up to a certain point one can rely upon others for transportation but I find this very limiting as you can only go out when others are free to take you, therefore your independence is being cut. At one time, because I find using public transport difficult, I had to rely upon taxi services when away from home and upon my parents when I was at home - the former became very expensive and although I am very grateful to my parents, there will be a time in the future when I will not have them to rely upon. I have now solved my problems by learning to drive my own second-hand car which I run using my 'mobility allowance'. I could have used the 'mutability scheme' which meant giving up my mobility allowance, but by either method some form of personal transport must be obtained if full independence is to be reached.

I try to live a normal active life. I am lucky in a way that I was born disabled and so have not had to adjust to a new way of life, just to overcome any problems that the disability has caused naturally. The greatest help which can be given to disabled people, like myself, is a greater public awareness of our needs in access, transport, and other aspects of daily living. With this is needed the realisation not only of the disability but of the capabilities of the individual, and an acceptance that there are no

disabled people. We are just people who happen to use crutches or wheelchairs but we are otherwise no different to the rest of society.

ANGIE

Angie, who is 21, lived in residential care for fifteen years, but two years ago moved to an adapted flat with her husband. She has cerebral palsy, which means she is unable to walk and gets around in an electric wheelchair. She works as a clerical assistant for the Department of the Environment. She wants to travel to as many places as possible and in a few years would like to have children.

From the age of six years old I attended a residential school for disabled children. The school was very poor on education, so much so that at the age of sixteen I was only at the level of a nine-year-old. I used to go home at weekends and talk to the able-bodied kids about what they were doing at school. I had never even heard of some of the subjects they studied. I felt so ashamed that they knew more than I did and I was a lot older. I decided to ask my teacher why I did not do the same things as my friends did at their school. She told me it was because I was disabled and that there wasn't much point in educating me to 'O' and 'A' level as I would never get a job. I told her I was not prepared to spend my life in a workshop making baskets. I was going to improve my education and get a job in open employment no matter how long it took. Since the age of twelve I had been very bored with school life and started to become rebellious. I felt frustrated and couldn't explain why. Most of the other children were not very intelligent and this made me feel very alone. I could not talk to them as friends. I tried to talk to some of the staff about how I felt, but in their eyes we were all the same whatever disability we had. I was told to go and play and stop bothering them. This was quite common amongst the staff, never explaining what their ideas meant. One idea which most of the staff held was explained to me quite clearly. I was about fourteen years old and had just finished preparing a salad in the cookery class. The teacher came over and said, 'What a good job you have made of that. You would have made someone a good wife.' 'What do you mean, I would have?' I asked. 'Well', she replied, 'What I meant to say was if you marry a disabled man, you would make him a good wife.' The school had really strange ideas on marriage and the disabled. They believed that if a disabled person got married it should be to another disabled person as it would not be fair on an able-bodied person to burden them with a handicapped partner. Anyway an able-bodied person would not fancy a disabled person. I didn't go along with this idea at all. I knew for a fact that able-bodied boys fancied me. I had proved that when I went home for weekends.

They also seemed to think that disabled people did not have any feelings. Well, that was how it seemed to me. I remember a humiliating experience I had when I was twelve. It was in the physiotherapy room. I was seeing the doctor who came from the local hospital on weekly visits. On this particular day he had brought five male student doctors with him, and I was made to walk naked in front of them and then lie on a mat while in turn they examined my body, opening and closing my legs, poking and prodding here and there and making comments. I was at the age when I was developing from a child into a woman and they made me feel so embarrassed. I used to cry on these visits. Then I started to lose respect for my body but it wasn't so embarrassing for me. There was no one I could talk to mainly because I was too young

to understand what was happening. I had learned how to defend myself from an early age. I had to be strong minded and strong willed and by the age of fourteen I started to respect my body again. It took a long time and even today I sometimes find it difficult.

I left school when I was sixteen and went to live at a centre for adults. At the centre I tried to improve my education but this was very difficult. The other people at the centre were of normal intelligence and I easily made friends. When I'd been living there for a year I met and fell in love with a member of staff, a care assistant. His name was Tony and he came from my home county. We found we had quite a lot in common and enjoyed each other's company. Before Tony and I got together some of the staff tried to discourage me from going out with him. In the centre, such relationships were frowned upon because most of the staff did not approve of them. However, after a while our relationship developed and each day Tony was doing more things for me. Then he moved into my room and we started living together. This was made easy for us because firstly, as we were living away from home we didn't have any parental pressure and also we did not have the problem of finding somewhere to live. Secondly, the Principal, unlike most of the staff, realised that disabled people had the same feelings as anyone else so he allowed us to be together. Tony had looked after handicapped people for some time so he knew what was involved and anyway we loved each other so we found it easy to adapt.

We lived at the centre for fifteen months and then got married. We lived a further four months there and then we moved to our flat. It is a ground-floor flat which has been adapted to my needs. Tony got a new job and I stayed at home alone. At first I was very lonely as I had never been without people, having always lived in residential establishments. I spent most of my time trying to become more independent and on one occasion I sat on the loo for three hours until Tony came home from work. I just could not get off and I felt so angry with myself but there was nothing I could do. When Tony came home he was worried when I told him how long I had been sitting there. When he realised that I was OK we started to laugh as it was quite funny. At first Tony had wanted to give up his job and stay at home to look after me but he knew it was better for us if he could work and if I could be as independent as possible. Nowadays he doesn't worry because I am really quite independent.

When we had been living in our flat for some weeks, my Mum rang and told me she had met the headmaster of my old school, who had asked about me. She told him that I was now married and living in a flat. He asked what handicap my husband had. When my Mum told him Tony was able-bodied he was quite surprised and didn't know what to say. I have met a number of people who seemed surprised when they find out Tony is not disabled. It is as if they cannot understand how an able-bodied man can marry a disabled girl. One day while Tony was at work the gas man came to read the meter. I showed him where it was and waited in the doorway for him to finish. I always sit with the door open when anyone I don't know comes to the flat, in case they try anything, so I can shout to my neighbour who lives upstairs. As he was leaving the flat he turned and asked if I was married? I told him I was, then a funny look came into his eyes and he asked if I had sex? I was shocked at his question and at first was stuck for words. Then I was angry and said the first thing that came into my head. 'Yes, do you?' He looked embarrassed and hurried away. During the rest of the day I kept thinking what a cheek he had asking me such a question. Since then I have

been asked that question several times in different ways, most often by men, and I answer them in the same way. But some people do seem genuinely concerned. For instance, I had some builders in doing some adaptations. One of them was very fatherly and friendly and we had long chats over cups of tea. He was about forty and was married with five children. One day he tried to ask me if I had sex but couldn't find the right words. I knew what he was getting at so I told him not to worry as everything was all right and we were very happy that way. For the rest of the day he never stopped apologising for asking such a personal question. Somehow I did not mind him asking as I felt he was not just curious but anxious about us.

Tony and I are often asked if we are brother and sister. The first time we were asked this was while we were buying some fruit and the shop assistant asked Tony. He replied, 'No, Angie is my wife.' The man seemed really surprised and stared long and hard at me. We left him thinking it over! The next occasion stands out clearly in my mind because of the fuss leading up to it. We were in a restaurant enjoying our meal when we noticed all the waiters watching us. We ignored them hoping they would lose interest but they didn't. Eventually one came over and whispered to Tony, 'Is she your sister?' When Tony said I was his wife, he looked quite incredulous and went off to tell the others. We couldn't help laughing, to think that was why they were standing watching us trying to find the courage to ask us.

Questions like these used to bother us but after a while we learned how to handle them. It would be better though if people would stop and think before they spoke and try and put themselves in our place. How would they feel if someone asked them if they had sex? Or if the person with them is their sister or brother? Why shouldn't disabled and able-bodied people be lovers and marry?

EDWINA

Edwina, who is 24 years old, has cerebral palsy. Her speech is restricted and she is in a wheelchair. She has a younger brother and sister who live at home with her parents. She met Derek, who is able-bodied and works as an assistant cost surveyor with a building firm. They have been married for a year and live in a flat in South London. She belongs to the Support Group for People with Disabilities and is a Council Member of GLAID.

Edwina's contribution was dictated to Micheline.

When I was born the doctors thought I would die because I was so small and I stopped breathing at the time of birth. The consequences were that the lack of oxygen caused cerebral palsy which, at the time, no one knew. About six months later when babies are starting to co-ordinate their hands and sitting up, I didn't. My parents took me to our GP and he sent us to Great Ormond Street to see a paediatrician and he said that I had brain damage which causes cerebral palsy. It must have been a great shock to both parents that their pretty little girl was going to be different and this had a bad effect on their marriage. They divorced. My mother wanted me to be put into a home, but my father and family wouldn't have this, so we went to live with my grandparents. My father heard of the hospital in Cheyne Walk in Chelsea so off we went to see what could be done. I can remember being pulled about by the physiotherapist and being

filmed with nothing on. This ritual went on for the next few years then one day I realised I didn't want to be filmed in this way. It was as if I had no sex. So I progressed at Cheyne Walk, my co-ordination improving and my family and father becoming more protective. It was decided that while my Dad and his fiancée got to know each other I should stay in the hostel from Monday to Friday. I didn't like this because I wanted to be at home and I used to kick up quite a fuss. But when they got married my stepmother had me home. I remember at that time that I dribbled a lot and my mother tried to dress me up. I was so nervous about spoiling the clothes that it became worse. As a little girl I remember that I thought to myself that when I grew up I wouldn't dribble, I wouldn't make a mess when I fed myself and my speech would be perfect. I went to a day school in Kingston for five years where I was taught to walk with callipers. I hated those callipers because my dresses never covered them up. I had this craze that every time I dribbled I wanted to change my dress but my mother kept saying, 'You can't because of the washing.' I remember the headmaster saying to visitors that it's such a pity that she's bright because not a lot of people can understand her.

I went to boarding school and because there were people there who had faith in me, they pushed me to do my best. This sowed the seed of bloody-mindedness. If someone said I couldn't do something I would go all out to prove them wrong. I made up my mind then that I wanted an operation to stop me dribbling. I bullied the doctors until they gave me the operation I wanted. I felt a lot more confident after this. I was quite popular at school because I helped them make fun of me. Because I was jolly. This was what I call a put-at-ease theory, i.e. I used to put people at their ease at my own cost. This is best explained in my college and later days. If I wanted a particular guy to like me I would put him at his ease by letting him think that I was a bubbling, noisy, don't-worry-nothing-hurts-me person. It was like saying 'treat me like one of the boys.' At that time I had a lot of confidence as a person, but not much as a woman. I thought that I was not very attractive because of my speech, and I couldn't get witty remarks out at the right time. When I went to parties where I didn't know anyone, I would sit in an ordinary chair and not move or speak and men would come and chat me up, but as soon as I spoke they would often turn away or go and get a drink and not come back. When I went with some man that I knew, I felt protected and, if I could get away with it, I wouldn't talk too much.

I went to live back with my parents and got a volunteer job with a charity. My theory was still in practice and I was very nervous and up-tight because my father and my family were very protective and wouldn't let me do anything in the house. I had this feeling of being trapped and relationships outside the home began to suffer. The volunteer job stopped and under great pressure from my parents and social services, I went to a work centre run by the Spastics Society. I felt it was very degrading putting things into bags, and my fellow workers and I seemed to have nothing in common. At that time I decided to get a flat, to my parents' horror. Once I made up my mind I was given a flat with a warden to call if I needed help. So I moved. I felt very scared because I had never cooked before for myself and I thought, 'What if I burn myself?' I was very lonely at first but enjoyed finding out what I could do. Every day I accomplished something new. Such a lot happened in that time. Derek crashed into my life and I didn't use my theory because I think he would have seen through it. Our relationship seemed to escalate. In no time we were thinking about getting married.

Our friends were not surprised but both sets of parents were horrified. My father said that we could get engaged but not married and Derek's mother said, 'Why do you want to marry her, she's in a wheelchair?' I was angry. They were both trying to take my rights as a woman away from me. Luckily Derek didn't listen to them and after a lot of hassle all round we married. So far it's working out just fine.