**WWW.Welcoming.Wide.World**  
Internet and Mobility Impairments

**Introduction**

This report describes the everyday use of computers by two women and five men with significant mobility impairments. The seven people range in age from 25 to 54. They are all experienced in using computers and the Internet for personal purposes and their everyday work. All of the people in the study require a personal assistant (PA) from seven to 24 hours a day. Pseudonyms have been used to ensure anonymity.

This specially selected group of users is not statistically representative of Internet users with disabilities. Their reflections and answers to questions presented here are based on extensive and rather specialized experience, and hence do not include aspects related to inexperience and/or poor adaptations of the user interfaces.

In qualitative research, content validity is based on an existing, extensive and open knowledge about the subject under study. My knowledge comes from 20 years as a computer user, 15 years as a wheelchair and personal assistance user, more than 10 years as an Internet user, and more than five years of postgraduate studies the area of disability studies and independent living theory. The basis of the latter is that disability is situated and relative, which has greatly influenced and guided my work. This blend of experience and knowledge is the most important cornerstone of my career as a researcher in the field of rehabilitation engineering.

**The Case Study Tool**

The seven case studies have been chosen because they represent different, relevant aspects of the study. A case study is an empirical investigation into a complex phenomenon. It aims to create a basis for analysis and description (Yin, 1994; Miles & Huberman, 1994; Patton, 1990). Miles and Huberman (1994) describe one aim of multiple case studies as an attempt to increase the ability to generalize from the phenomenon under study. However, there is also a deeper level: it becomes easier to see the underlying causes and processes and thus easier to be able to “develop more sophisticated descriptions and more powerful explanations” (p. 172).

Multiple cases provide an opportunity to illustrate and elucidate several aspects of a phenomenon and to show complex dependencies between several parameters in a study by painting a composite picture. In addition, instead of generalizing from the cases in a multiple case study, the distinctive character of every case helps to construct the descriptive space where the analysis and description are made.

Furthermore, case studies should not be considered merely as pathfinders for subsequent statistically based studies (Ramachandran and Blakeslee, 1998). Case studies have significant advantages that are not found in statistical studies and vice versa.

The field of rehabilitation engineering and design is mainly case study based. This is not only because of the difficulties in finding enough subjects in the same “category.” It also has to do with a strong connection to the situated: the focal point is one individual together with others in the individual’s environment. Pretending that an individual’s everyday environment can be
replaced with a laboratory environment without considerably influencing usability tests, for instance, would not only be naïve, but unethical as well (Jönsson, et al.).

**Seven Experienced Internet Users**

This report presents descriptions of the situations of seven experienced Internet users: Charles, Beatrice, Adam, Karl, Ivan, Dora and Eric. An interview and brief discussion is included for each case, followed by concluding comments.

**Charles**

Very soon after his injury, Charles recognized the possibilities new technology presented. He actively looks for and quickly acquires the latest technology to improve his functioning.

Charles: I learned early on that the only way to improve my situation is to use the technology available and I try to acquire new technology as soon as possible. When the healthcare system started giving me new wheelchairs to try out, I realized right away that the system would not supply me with an abundance of assistive technology. It is up to me to make sure I get what I want. So that is why, from the beginning, I took the initiative to get a motorized wheelchair and protested when the healthcare professionals said something couldn't be done. I have been relatively lucky in this regard because some of my occupational therapists have been problem solvers not problem creators.

Charles has actively embraced new technology and has purchased many items without exactly knowing what to use them for. He felt, rather, that they could improve his functioning.

Charles has been impaired long enough to remember the time before home computers and the Internet were available and can compare his situation now to his situation then. When asked what kind of assistive technology he had to use, communicate and work with before he had a computer, he answered:

Peter: Before you used a computer, what kind of assistive technology did you use to help you communicate?

Charles: For text, the technical aid I used was an electric typewriter with a postsum system. In 1976-77, I learned to use it to write letters. But that technology is extremely limited compared to a computer since it cannot be used for word processing. It was just a simple electric typewriter.

Peter: And you still needed help to put paper in the machine and take it out?

Charles: I needed help with almost everything: to put the letter in the envelope, to write the address and so on. And the person helping me was able to read what I had written.

Charles does not consider being able to write on his own as the most desirable function; for him it is the ability to communicate independently of others help. While the typewriter technology provided a writing function, because it was limited to the physical world (versus the virtual), it provided no actual independence and did not improve Charles’ integrity in any important way.

Charles: I have never been able to sit and turn pages and read an ordinary paper-based newspaper. And my eyes are so bad that I cannot read black text on a white background. On the computer, I can invert the screen so there is white text on a black background. Then my
eyes can handle it.

Computer technology improves the effect of functions by acting as a user interface to the surrounding world. All the virtual environments that the computer is linked are readily available. In comparison, a robot that can turn the pages of a newspaper in the physical world but cannot invert the text to white on a black background is of no use for Charles, even though with the page turning function. Further, as in the case of the typewriter, no increased independence and integrity is possible since somebody else must buy the newspaper and place it in the machine. Many times it is not only the actual enabling of the function that is important; the control and the context in which the function is performed are equally so. However, in virtual environments the increased functioning provides increased independence and integrity.

Charles: Another thing is that now I can communicate with others without letting the people around me know about it. Before, I was forced to get help when I wanted to send a letter and sometimes they read the letter just to see that I hadn’t made any spelling mistakes. Even my mother-in-law started checking my writing. It is an enormous freedom, with e-mail for example, to have a dialogue with anyone I choose without the people around me interfering or even knowing who I’m communicating with.

Peter: What you're describing is that in such an environment your disability is filtered out.

Charles: Yes it is. When I’m at the computer, I have the same possibilities as everyone else. Nobody has any control or knowledge of my financial situation and nobody knows who I am e-mailing.

Peter: You can control your own world without unwanted interference?

Charles: When you are such a high quad as I am, you are always dependent on others, on their benevolence, willingness or unwillingness. But now, I don’t need to negotiate about which channel I want to listen to. I can read what I want to or look at or communicate with whom I want. It is a freedom I never had before.

Peter: Are you able to compare it with how it was before you began using computers and the Internet?

Charles: Yes. I am old enough to have experienced how it was before the Internet.

Charles is speaking about absolute dependency. In the physical realm, he is almost always dependent on another person to perform various functions, such as writing, sending, receiving and reading a letter. Charles said that asking a personal assistant for help can feel like a negotiation about what he wants to do. He used the words “interference” and “dependence” to describe his pre-computer and pre-Internet situation.

His current situation, as he described it, includes being able to transfer certain functions to the virtual realm. Thus, he now has access to functions that were previously impossible for him to perform by himself.

It is important to note that the functions created by information and communication technologies (ICTs) are only present in virtual environments. The arenas and affordances available in virtual environments are sometimes only complementary. Charles still cannot read a printed newspaper, but he can read the ones that are available online. Nonetheless, Charles strongly feels that his functions are increasing as more and more material becomes
available on the Internet.

Charles is still completely dependent on assistance in the physical realm, but no longer in all areas of his life. Different parts of his identity exist in the online and offline worlds, and there is a flow of experience between them as well.

Charles is very interested in trading stocks and today carries out his transactions completely over the Internet, which is becoming the norm for many traders. With his computer connected to the Internet, he can manage all phases of his businesses and does not have to let a personal assistant or anyone else have access to his business and financial information. He can thus act on the same terms as non-disabled people. Charles experiences the same aspects and advantages that exist for non-disabled people, for example, more control. For Charles there is not only a quantitative difference in function, but a qualitative difference in integrity and independence as well. Since it would be impossible for Charles to perform these functions on his own in the physical environment, being able to carry them out online is both quantitatively and qualitatively immensely important to him.

Another example of independence from the physical environment is the ability to exchange an unsuitable one for one more favorable. For many people with various impairments, the winter and cold pose significant problems. Charles leaves Sweden during the winter and moves to a warmer climate where his disability is easier to deal with. It is easier to be geographically independent when functions are available over the Internet. Charles can move more easily from one physical location to another and continue to live his life in much the same way. This is possible because the functions available online are independent of the physical location of the user.

Carrying out a function in the virtual environment is not dependent on a fully physically able body. In a physically adapted environment (e.g. at home with a high level of adaptation), functions are available in the virtual realm that do not exist at all in the physical realm, or are difficult to achieve.

Peter: You also have a business enterprise and you publish a newspaper.

Charles. Yes, I've been doing that for seven years. And the computer is my tool there as well. It would be impossible without the Internet.

Peter: Do you produce the newspaper using your computer? For example, gather information via the Internet and use e-mail for all your contacts, etc.

Charles: Yes I do. And it just wouldn't be possible without a computer and the Internet.

People’s prejudice and bias, and their lack of experience in meeting a person with an impairment can create problems. Through his work, Charles has contact with many people. Most are made over the Internet and many are later followed by meeting IRL (In Real Life). Charles experiences the differences between meeting people online and offline as follows:

Charles: Well, the advantage for me of meeting people online is that there are a lot of people who have prejudices or are insecure when they meet a person in my situation, so it is possible that it is easier to get through to and communicate with someone when they can’t see I’m in a wheelchair and how I look. Maybe they wouldn't want to meet me if they knew that in advance. It sometimes happens that people I meet over the Internet become a bit disconcerted and say, “Do you look like that?!”
Charles’ experience is that the reaction he encounters when he meets people IRL is often due to insecurity or prejudice. By not having his body with him when he meets people online, he does not have to deal with these reactions. He feels that it is easier to “get through” and “communicate” when a person cannot see him, when he can be bodiless.

The opportunity to obtain additional fuel for one’s thoughts in the form of facts and knowledge is another feature of the online environment. It is possible to quickly follow lines of reasoning and receive immediate feedback on a thought or point of discussion.

Charles: One thing that I find amazing is being able to access an encyclopedia. That also gives me enormous freedom. There are a lot of things I just couldn’t do before. I’ve never been able to take a book off the shelf and look through it.

For people with mobility impairments, computers and online systems provide access to information and knowledge sources previously unavailable or difficult to come into contact with. To a great extent, this makes it possible or easier for this group of people to engage in study or work that was previously out of reach.

**Beatrice**

Beatrice uses personal assistants 24 hours a day. She is somewhat ambivalent about this. She described how the contact with her personal assistants is sometimes difficult and how she is troubled by being confronted with the mood of another person when she is focused on her own needs.

Beatrice: I have a rather ambivalent relationship to my assistants. I can’t manage without them so I am very glad to have them. But everything I can do without them is a bonus.

Peter: It sounds like you would rather have a robot.

Beatrice: Yes definitely. And I would settle for one who could do half of what an assistant can do.

Peter: You wouldn’t miss the human contact?

Beatrice: No not at all. Imagine not having to explain why you want to do something, never having to deal with an assistant in a bad mood or with a hangover, and not being irritated when you want something done exactly in a certain way. Imagine having a robot that just did what you wanted all the time.

Peter: Like a computer?

Beatrice: Yes. That’s one of the things I love about computers. It’s a pity they can’t help me get out of bed or to the bathroom.

Beatrice sees the technology as a neutral extension of her functions, and experiences total control over those functions. Thus, the technology removes the special type of filter that exists with a human assistant.
Beatrice often comes back to the fact that a computer makes it possible for her to liberate herself from dependence on a personal assistant. This liberation comes from being able to start and control specific functions and categories of functions without involving a personal assistant.

During a discussion about virtual communities and chat rooms she made the following observation about meeting people in online discussion forums.

Beatrice: It is so nice not having an assistant around when I am meeting people.

Peter: Do you mean they interfere?

Beatrice: Not directly. I usually hold them on a short leash. An assistant is always with me when I go out, so even if I send them away people think we are out together. At work, my colleagues freak out when the PAs have to sit in another room. But it feels good when they don't know everything I do. Otherwise they get too close.

Beatrice: I can't manage without assistance so the more things I can do myself with a computer, the better I feel. The computer never complains or gets sick.

Beatrice: But there is another kind of dependence. I can't manage without my mother and sister. Yesterday my morning assistant was sick and my night assistant had to go home to her children so my mother came over to help me out. Without her filling in, I couldn't cope. That is rather tiresome. My mother has a job to think of. Still, I can work from home so things work out anyway, and I don't lose money because my assistant is sick.

Beatrice talked about two types of independence a computer and the Internet provide her as a personal assistance user. The first is the opportunity to meet people without having a personal assistant with her as an unwanted filter, as well as not having to confront other people’s attitudes about how she treats her personal assistants when she’s trying to claim her independence by sending them away. In the online environment she can directly meet other people without these problems, i.e. without human filters or additional interfering factors.

The second type of independence is from an assistant who you cannot always depend on. People get sick, including personal assistants, and this affects Beatrice. When an assistant does not show up, Beatrice is unable go to work, even though it is not her fault. However, the ability to work online makes the consequences less problematic. Beatrice can temporarily reduce her need for hired help by having her mother come over on her way to work, and Beatrice can also meet her own responsibilities from the accommodating environment of her home.

Beatrice: Seriously, I'm very happy to have personal assistants. They are a prerequisite for my being able to live as independently as I do, but it is very tiresome having people around all the time and being dependent on them. If you do something to annoy or aggravate them, they can just get up and leave.

Peter: Has that ever happened?

Beatrice: No. Because I would not let it go that far. But for example, I have an assistant at the moment who is very depressed because her boyfriend left her. She is quit listless and I have to tell her to do everything. And then she just sighs and says that I don't have any understanding or sympathy for how she feels. That kind of thing gets me down as well. Before that, I had a girl working for me who had a hangover almost every day she came to work. I think she saw her work here as an opportunity to get some rest before the next night out. At the time, I had
another personal assistant who was on maternity leave so I couldn’t let her go either. I had to cope.

Peter: Is the computer a free zone, a possibility to function without the assistants, to get away from them for a while?

Beatrice: Definitely. I can enter that world and shut out the PAs. They can help me get to the bathroom but I don’t need to socialize with somebody who is in a bad mood.

Beatrice says that she is used to participating in different chat rooms and meeting new people all the time, but that she has become more selective and visits chat rooms more sporadically. Her focus has been on virtual communities where she has gotten to know a few people better. She has never met anyone IRL that she met online.

Peter: Do you ever tell anybody in a chat room that you have a disability?

Beatrice: No.

Peter: Why not?

Beatrice: Because I don’t want to meet anyone in person. I only want to relax and chat for a while.

Peter: And not be “disabled”?

Beatrice: Yes.

Peter: Do you like that?

Beatrice: Yes. It’s unbelievably nice to be normal for a while.

Peter: Aren’t you normal otherwise?

Beatrice: No, not in the eyes of others. Most people only see an invalid, but there are always exceptions.

Peter: Over the Internet no one can see your disability.

Beatrice: That’s right. You’re just one in the crowd, just like anyone else.

Beatrice uses the fact that there are no visual indicators of her impairments when she meets people in the online setting. In the virtual environment she can construct an identity without impairments. Beatrice often comes back to the fact that she thinks it is nice to be “normal” for a while and to be like everyone else and not have to deal with other’s perceptions about being disabled.

She is not anonymous in these online communities in the sense that no one knows who she is. However, she reconstructs her identity without including her impairments and the disabling consequences. With this alternative identity, or part of her full identity, she has many online friends. Beatrice feels she is trying out different aspects of her identity and that she is always herself, but without her impairments. In addition, she does not intend to have any contact outside the online setting. When we talked about the problems that can arise from having two different identities, she perceived this as a problem only if she wanted to meet people IRL that she met online.
Beatrice: If you become really interested in someone, I think it's a good idea to tell them as soon as possible. Otherwise, there could be problems.

Peter: What kind of problems?

Beatrice: If you start to like each other I think is best to be honest. It could be a bit embarrassing otherwise. Offline, you may be completely different than the person the online acquaintance is interested in. I think it's best to be as honest as possible.

This discrepancy between the different aspects of an online and offline identity can also arise when a person’s bodiless, non-disabled online identity confronts a discourse that has no relevance for their bodily identity.

Beatrice: I was at a wedding site once and then I thought about using my true identity because otherwise I couldn't ask some of the questions that were most interesting to me.

Peter: What do you mean?

Beatrice: Well, there are a lot of things I wonder about. For example, how to manage with a wedding dress when you’re in a wheelchair and things like that.

Peter: And there was no thread for questions about wheelchair dresses I guess?

Beatrice: No.

Peter: So you didn’t fit in there either?

Beatrice: No. But there were a lot of other things that were interesting.

Peter: But the consequence is that you have to tell them that you’re in a wheelchair if you’re going to be able to ask some things.

Beatrice: Yes, but you cannot always count on everything working out. It’s still nice to get some time off from your disability. Even if you’re just pretending.

Beatrice has provided examples of how her non-disabled identity is at times problematic. Sometimes she has to choose between keeping her non-disabled online identity and asking a question that is important to her. This problem can, however, be easily overcome by using a new identity constructed for the occasion. The lack of visual mechanisms for recognition lets Beatrice experiment with different online identities. She can choose to reconstruct her identity and not include her impairment, to take a break from what she sees as the disabling perceptions of others. This has positive consequences for her as she has an opportunity to develop other aspects of her identity with no regard to her impairment. This is an example of the very interesting issue of the flow of experiences and knowledge between the online and offline environments.
Adam

Adam has a slightly different perception of his assistants than Charles and Beatrice. Just like them, he is in need of 24-hour assistance. However, unlike them he does not express such irritation about having other people around him so much. He described his relationship to his personal assistants as “almost like a family.” He also described an interesting view of the difference between personal and technological assistance.

Adam: I have assistance on a 24-hour basis and am very limited without it. My motorized wheelchair gives me a certain independence. I’ve used a motorized wheelchair at work for one year now. Before, I used a manual wheelchair all the time. The manual wheelchair provided a certain amount of freedom as I could take the subway, escalators and so on, and when I visited China, I even made it up onto The Great Wall. I know I can go almost anywhere with my manual wheelchair. It is small and with good assistance I can do almost anything. Still, I’m aware that this freedom is dependent on personal assistance.

Adam cannot operate his manual wheelchair himself. Thus, from the perspective of control, he is able to function more independently with an electric wheelchair. However, from a perspective of enabling, the manual wheelchair together with an assistant makes it possible for him to function better in all physical environments that are unadapted for electric wheelchair use. An electric wheelchair cannot get up onto The Great Wall of China or climb any significant unramped difference in height. Unadapted environments reduce Adam’s functioning from a control perspective rather than from an enabling perspective. The limiting factor is the inaccessibility of the surrounding environment.

Even if Adam has a rather unproblematic relationship to his assistants, he still sees his access to the online environment as a factor that makes this relationship easier.

Adam: Living with personal assistants, with people around me all the time, there is a constant flow of words and opinions that I need to filter out and live with. Some people find that extremely hard, but I like social contact, I like relationships, and I like to develop as a person in these relationships. So for me it’s okay, even if it’s easier sometimes than others. But when I got a computer and online access, it became much easier because I had access to a secluded area where I can act and grow. It has become a sort of safety valve.

At the end of the interview he returned to this issue. He changed his way of expressing himself by using words like “irritating” and “frustrating” to describe his need for assistance.

Adam: But I just want to say that it is hard to have any integrity when you have personal assistance. The assistant is a filter. Before I had my computer, the PAs knew everything I did. I couldn’t write a word without them knowing it. It was very annoying and frustrating.

Peter: And there was no alternative before?

Adam: Exactly. When I first got a computer I never saw it as a remedy for that. But when incidents occurred I started to understand a bit more but still not fully. It was when I started to use e-mail that I really understood that this could be the thing for me. And when I decided to take over full responsibility for my personal assistants and become an employer, I was already doing my banking over the Internet. I understood that I could do all my own banking and have much more integrity when it came to my financial situation. I then got new administration software to carry out all salary payments myself.

Peter: So gradually the assistants did not have access to your financial situation?
Adam: That’s right, and after that I started to take over more and more functions, paying my taxes and doing my tax return directly at the tax department’s website. I have much more integrity now. I can still talk to my assistants about financial matters, but as their employer, I can show them what I want and hide what I want.

One of the big advantages of the online environment is not having to move physically between locations in order to carry out various functions and thus saving both time and effort. If most of the functions needed to perform a job are available online, it is possible to work anywhere there is an Internet connection. As most Internet services are available around the clock, being able to choose when and at what pace to carry out a task is another important function made possible by the asynchronous nature of the Internet. Adam sometimes gets sores from sitting that prevent him from getting out of bed for a while and sometimes he has to lie down in order to avoid getting sores from sitting. This makes it difficult for him to have a regular work schedule. However, since he can control both when and where he works, the negative consequences of his disability are less severe.

Adam: There are economic factors that are very important. Not having to be on sick leave has economic as well as human consequences. Being able to control my work hours myself instead of having to be at work between eight and five is essential in order for me to be able to work at all. Instead of me adapting to my workplace, my workplace adapts to me.

From the beginning, Adam saw the computer as a tool for his creativity. He had painted pictures by holding a brush with his mouth and saw the computer as a tool for developing his creativity and acquiring new functions independent of the motoric capability of part of his body. In Adam’s case, his artistic expression moved from the physical realm to the computer realm where the possibilities for controlling the actual artistic processes are much greater. He is still able to produce a physical piece of art even though the artwork is designed using a computer.

Karl

Being able to decide what newspaper to read and when to read it can be seen as a question of personal integrity and independence. The only way Charles can read newspapers by himself is online. Karl can read newspapers offline, but reading online is by far the easiest. Offline reading is time consuming, which keeps him from doing it. When many small chores and tasks are connected in long chains, as commonly occurs in the course of a day, and each little thing takes an disproportionate amount of time, it is often easier to skip it or just leave it to somebody else do. This creates an unnecessary dependency and makes learning and knowledge creation difficult. Use of computers, both offline and online, provides a platform for achieving the chains of functions that make up an ordinary day.

Peter: How much do you use your computer every day?

Karl: Well, I go to my computer in the morning directly after breakfast. And if there is nothing special to do that day, if I’m not going anywhere, then I stay at the computer for a normal workday. I work mostly with my music and different texts and such. But I also read newspapers, pay my bills, and take care of other things. In the evening, I put my work aside and spend more time playing games and having fun with my NHL and rally software.

Karl has created an ordinary day from various functions available using his computer online and offline. All of these functions create a structure in his life that he controls himself. To be able to create things and to test one’s limits by challenging them in various ways are
important human activities. It is important to be able to find areas where one can compete with others and participate on equal terms in games and challenges. For people with mobility impairments it is often hard to find ways to channel such needs. Playing different computer, network and online games fulfils many of these needs for Karl.

Karl: I get a lot from playing games. All of these games require a certain amount of motor activity and alertness. You need to be perceptive and quick otherwise you drive off the track or if you play hockey, you are beaten badly. There is a kind of training or practice in the midst of all the fun. You simply need to be alert. You have to make quick decisions and everything moves fast in the games. Everything else in my life is very slow.

Karl has many games installed on his computer. When he talks about his game playing, he often comes back to the feeling of being one with the computer; that he must concentrate and be alert to manage what he is doing.

Karl: It is really wonderful; you really become free and unconstrained. Your wheelchair ceases to exist, your weak arms cease to exist, you just act.

Karl described another kind of “time off” from his impairments. While Beatrice viewed socializing online as an opportunity to get away from the disabling perceptions of others, Karl’s use of the computer has to do with using the visual impressions and the feedback from what happens on the screen to experience playing hockey or driving a racecar. The opportunity to seek challenges in games and sports in the virtual realm also makes it possible to challenge other people including non-disabled people. It is possible to compete on the same level and win.

Karl: What is really fun is that after playing a new game for a while I always get a lot better. In the beginning, I think there must be something wrong with the new game because I am so bad at it. But then I discover that I get better and better and finally I master it. And it is important when you are disabled like I am to see that you can assert yourself. I have played online games against people without disabilities and we are on the same level. In real life, there are no games in which I could play against someone without being badly beaten, so it is also a type of “equalizer” that evens out the different conditions that exist.

Karl described how in the virtual gaming arena his disabilities disappear and he can compete on equal terms. Karl feels it is “for real,” referring of course to the challenge, not the actual car driving, and no less a challenge for him than if he had played for real.

Karl: When you are sitting there, it’s for real; you are entirely into it. It’s as if you were sitting in a car or really playing hockey and you can tackle, which you can’t do in real life. You can even tackle so you get a penalty and that is really a boost for your confidence, that you can be...

Peter: ...a bit bad?

Karl: Yeah, exactly. You don’t always have to be nice and apologize and be careful with your fragile body.

This gives Karl an opportunity to let out and channel feelings that he otherwise would have had to suppress or expresses other ways.

Karl distinguishes between recreation (playing games) and work (creating music). He has always composed and played music. When his decreasing muscular strength made it
impossible for him to play instruments, he transferred these functions to a computer. He uses something called “Band-in-a-Box” where he can program different styles and download music files from the Internet. This enables him to continue his creative work.

Peter: How do you create and play music using a computer?

Karl: I use something called a “Band-in-a-Box.” It sounds like a whole band in your computer. You configure a loop of chords and the style of music you want. And then you can test different ideas. It is very simple and clever. And very good for disabled people who cannot physically play. I can no longer play on my synthesizer keyboard but I can still use it as a source of sound. Band-in-a-Box is the professional. I let it play all the instruments. I just tell it what to do and it plays.

Peter: You liberate yourself from the actual physical playing but can still let the music you create in your brain emerge?

Karl: That is what is fantastic. A person doesn’t have to stop playing or creating music just because their arms grow weaker and they lose some of their functional abilities. There are things today that allow a person to play music as long as they can tell a computer what to do.

The computer does not merely replace the physical function of playing music, but also a function that has to do with the consequences of not being able to play. As mentioned before, with mobility impairment, various simple functions often take a very long time. Even if it is possible to perform them, the extra time required makes a person refrain from doing so. Furthermore, in some cases the alternative of performing certain functions with the help of a personal assistant is not an alternative, since the direct control of functions is a prerequisite for some. Anyone who has ever tried to get another person to do something exactly the way he/she wants it done knows that it is hard, to say the least. However, for a person who wants to compose and play music, doing it through somebody else is hardly an option. That is why being able to create and play music on his computer is so great for Karl. If he could not do it himself, he would not do it at all. Having only secondary control of functions makes skill acquisition difficult as well. The knowledge of “the hand” is neither established, challenged nor increased if it does not itself act, control and receive feedback directly. Technology, in this case computers and the Internet, is a neutral and impersonal tool that enables direct control of a function and removes unwanted filters.

Ivan

Ivan provides another example of the problem of direct control of functions and feedback. When he is filling in a pool betting coupon, for example, he wants to be able to switch between looking at the tables and statistics, and filling in the coupon. This is difficult if you have to ask somebody else to do it for you; it is hard to explain exactly what you want when the next step depends on impressions from the current one. A time delay is likely to make this feedback more difficult.

Ivan: When you have personal assistants around you all the time, you stop doing things that you actually could do yourself, but which take too much time and are too awkward to do yourself. But with the computer you can do those things as well.

Peter: Can you give an example?

Ivan: There are actually a lot of examples; playing the horses and the pools is one. It’s brilliant. You can do everything yourself online.
Peter: Filling in the coupon and turning it in and so on?

Ivan: Everything. I can transfer money from my Internet bank or credit card to my gaming account. Then, I can fill in the coupon and submit it in over the Internet.

Peter: Sounds perfect. I wasn't aware you could do that. Can you do it entirely by yourself? Would it be more difficult for you to do it in the physical world?

Ivan: It wouldn't be possible, but I couldn't fill in the coupon and turn it in and so on by myself. The boxes are too small. Online there is absolutely no problem. I can pay, fill out the coupons, take them to the checkout, cash in any winnings, etc. Also, on the Internet the coupons look exactly like ordinary pools coupons. There is access to all the tables and so on there too. It's perfect if you can't turn the pages of a newspaper.

Apart from being spared the “repetitive asking,” Ivan is fully independent in this function because he can perform the whole chain of integrated stages in the function. This is possible because the functions available online in this case do not have any connection to any activity in the physical world. If Ivan had to print out and snail-mail the coupons, the independence would be lost.

Ivan describes another advantage of online computer use which Beatrice and Charles also mentioned. When people meet for the first time in a text-based, digital environment, there are no visual disability indicators available; an impairment does not become a hampering factor.

Ivan: If I come to a meeting and have to be carried up the stairs, then the others immediately have an unconscious, negative impression of me. Or at least a condescending impression. It doesn't matter what they think or what they say. And even if they really don't care, I do. On the Internet that doesn't happen. There, I'm like everybody else.

Peter: Do you become “normal”?

Ivan: I am not too conspicuous anyway.

Peter: How does that feel?

Ivan: It feels really good.

Peter: Do the same or new problems arise when you finally meet them IRL?

Ivan: No. Then I have already had a chance to show people who I am.

Ivan is referring to a situation in the physical world where he experienced that other people had a negative or condescending impression of him when they saw his physical inabilities. It is of course his own interpretation of the situation but nevertheless it has a strong influence on how he experiences his disability and on his functioning in that situation. He thinks that other people have a negative impression of him and internalizes this view. Obviously, he feels that this has a strong negative impact on his functions in the situation.

He becomes “normal” online in the sense that he does not stand out, i.e. he has no visually perceptible characteristics in an online meeting and does not have to confront the prejudicial perceptions of others and his own internalizations of these. In this case, online normality means that there are no distinguishing special solutions.
The opportunity to increase the geographic area in which to see contact with other people with disabilities is another function of the digital environment. It is not necessarily so that a person wants to socialize with others who have a similar disability, but if that is the case, many people are not usually available. The digital environment provides arenas where it is possible to get in touch with people who have similar experiences, and to increase the number of people to socialize with.

Ivan: IRL I don’t feel like hanging out with other disabled people. They mostly complain and whine about everything. The local disability organization is only for seniors. On the Internet, I find disabled people who are more enterprising and that can be fun. There you can choose and don’t have to be packed together with a lot of other people just because they are in wheelchairs and who otherwise have nothing else in common.

Peter: Online, can you decide for yourself who you want to hang out with?

Ivan: Yes, and if I don’t like it I just leave. You can’t do that if you have to wait for the transportation service to arrive.

Due to the nature of his impairments, Ivan can no longer travel. However, he has found a way to experience the world around him over the Internet. By finding web cameras, pictures and texts, he can visit places he will never be able to travel to physically.

Ivan: I found one of those virtual reality things where you can travel around up in Machu Pichu. It was awesome!

Peter: Maybe it would be difficult to really travel there?

Ivan: I couldn’t of course. Some things are just impossible.

Ivan’s impairment was the result of a traumatic spinal injury. He started to use a computer very soon after he was injured. He does not play games to any great extent at present because he feels it takes too much time away from other things, and he is concerned about getting stuck in the gaming world if he took it up again. He used to play many games “when things calmed down after the injury” and soon it took up most of his time; he felt that he was missing out on “real life.”

Peter: What did you play?

Ivan: I hardly remember. Car driving, golf, and the usual shoot-them-down games. The quality of the games was not as good then.

Peter: Do you think that you lost yourself in those games as some sort of compensation for not being able to do those things IRL, not including the shoot-them-down games, of course?

Ivan: Well yes. I’ve thought about that. Maybe it was a way to express my competitive instinct. I have always been a very competitive person and always wanted to be the best. I don’t think I saw it like that then, but of course, it was in a way.

Peter: An opportunity to compete on equal terms?

Ivan: Yes. My little brother and I are almost the same age and we used to compete in everything. After my injury that wasn’t possible. When I got the computer, we continued to compete and I could still beat him.

Peter: Did that feel good?
Ivan: It felt good to be able to beat him sometimes. Even though it wasn't the same thing.

Peter: What do you mean?

Ivan: It isn't the same, doing it on a computer. It is something else. You do not have to make a physical effort in the same way.

Peter: So the challenge and the sense of winning were there, but the physical challenge wasn't?

Ivan: Yes, and of course the games weren't as good back then. They are much better now. But it is still not the same.

Dora

In online environments, desired functions can be performed independently of the body. You can remain in a physically adapted environment where no unnecessary constraints are put on your body and you have access to environments and functions that are not physically possible for you to reach, or can only be reached with difficulty. The ease and lack of friction with which the functions are performed in online environments sometimes makes it difficult to leave them. The discrepancy between what is available in the online world and the difficulties met in the physical world becomes apparent.

Dora: In the beginning, I was quite taken by the charm of novelty and almost forgot that I had a life outside the online environment.

Peter: Tell me.

Dora: My real friends, the ones who didn't have Internet, told me I was becoming more and more distant. I was really addicted. My first thought when I woke up in the morning was if I had received any e-mail, and checking it almost became a compulsion. I couldn't even make a date with any of my friends IRL, because I had to check if somebody logged into the chat room just then. It was hopeless.

Peter: Do you think it has something to do with how easy things can be done in the online world?

Dora: Yes. Everything is available at home. It's so easy. You don't having to leave your home when it's winter and cold, and you don't have to move yourself physically!

Several of the people interviewed also found that the Internet provides an environment where it feels safe enough to open up and discuss their disability. People sometimes react with curiosity if information is disclosed about an impairment or disability. Since the disability is not apparent online, the discussion becomes only indirectly and abstractly connected to a person. People you meet in online environments dare to ask things they would not ask IRL. It is also easier to answer these kinds of questions over the Internet and there is the opportunity to refute prejudices and misconceptions.

Dora: When you finally tell them about your disability an incredible number of curious questions are asked right away that people never would have dared to ask IRL.

Peter: Is it easier for them to ask and explore your disability and who you really are and is it easier for you to tell them?

Dora: Yes.
Peter: When you decide to tell them, do you also give them the opportunity to ask and yourself a chance to defuse the issue?

Dora: Yes, absolutely. I’m positively sure about that. If they had seen me in the streets they would, of course, never have asked all those questions, and I wouldn’t have felt comfortable answering them. And then they would never have gotten to know who I really am.

A person decides for him or herself how to paint the picture of their disability as it exists in the physical realm. They also have full control over the situation where the questions are asked. They can break up the discussion and pull back any time they like and decide when and if to mention their disability at all. They have complete control over how they choose to describe themselves/their identity.

Dora: The Internet is unique. It is the only time I choose for myself. I can make anything up and pose as a marathon runner if I want to.

Peter: Do you ever make things up?

Dora: I haven’t really done that very much. The closest I came to lying was leaving out part of the truth, and that really isn’t lying.

An important part of building an identity is receiving visual feedback on one’s creations and seeing one’s thoughts materialize so they can be shared with others. In the virtual environment, a person has full control over the creative process, and access to an interactive process with direct feedback promotes and supports both learning and creativity.

Peter: You have a very elaborate website. Why?

Dora: Well, you can really wonder because it is a very egotistical site.

Peter: Is that what you are aiming for?

Dora: Yes, but it is strange because I started four or five years ago and it looked different in the beginning. It started out as a novelty. When I was out chatting it was fun to say I had my own website and refer to it. Then it became more and more elaborate, I started to keep a diary on the Internet, sharing many of my thoughts and other things. People were really interested. They get a total insight into my life and that seems to interest a lot of people. In my diary, I only write about the things I do and what I think. The rest of the website is only a presentation of myself.

Peter: Is it presentation that you want to make? To show yourself?

Dora: Yes.

Peter: Do you like the creative part of designing and building the website?

Dora: No, I’m not so good at that. I think it is the chance to show myself and to be personal that is the driving force, to give a different picture. In newspapers, for example, disabled people are either heroes or objects of pity. I am neither, and I want people to see that.

As mentioned before, an obvious advantage of the Internet for disabled people is to use online information to get a better picture of what the wider world looks like. For Ivan, it was the opportunity to “travel” over the Internet and visit locations that were unavailable for him in the physical world. Dora has used the Internet to expand her sources of information about
places she wants to or intends to go to, and to increase her knowledge about places she has no 
personal experience of before going there. This use of the Internet can solve the problem that 
many people with mobility impairments have who are very dependent on the organization of 
the physical space: nondisabled persons are often unreliable sources when it comes to 
assessing accessibility. This sometimes creates a lot of insecurity and makes people refrain 
from some travel and excursions. Increasing the variation and number of information sources 
can reduce this insecurity.

Dora: I usually send an e-mail and ask about accessibility at the place I want to go to.

Peter: When you plan to go out or to travel?

Dora: Yes, for example, when I go to a museum, new restaurant or cinema, I always check the 
Internet to find out if I can get in with a wheelchair and if it is otherwise accessible. If I don't 
find anything, I can always send an e-mail. Written information is often more reliable than 
information obtained over the phone.

As is the case with Ivan, Dora makes use of the opportunities available online to expand the 
geographic area in which she seeks contacts amongst other people with disabilities. Her 
search efforts differ somewhat from Ivan’s however, as she has tried to find rather than avoid 
certain people. Dora has had her muscular disease her entire life and never actively looked for 
people with the same kind of disabilities until she began using the Internet.

Dora: Actually, in a virtual community I belong to, I met two women who have the same 
diagnoses as I have. I have visited them and we get along very well.

Peter: What does it mean to you to find people in the same situation?

Dora: One of the women in particular has had experiences just like mine and is familiar with 
every little problem that I have. The other woman has a much milder version of my condition. 
She had never met anyone with my diagnosis, so for her it was quite an experience. 
Nonetheless, we get along.

Eric

The great majority of the people interviewed have experienced meeting other people over the 
Internet and in most cases these experiences were positive. Many of the people interviewed 
told stories about how they met people in online communities, and how a close relationship 
that was established (both friendship and love) in the online environment often became an 
IRL relationship. Still, most people interviewed were aware of the difficulties involved in 
presenting one’s self and one’s disability in a way that does not evoke prejudice.

The choice of disclosure when socializing in an online setting has given new freedom and 
new tools to many people. The people interviewed frequently expressed appreciation for the 
opportunity available in the online setting to choose if and when, how much and what to tell 
about themselves. When Eric began hanging out in online communities he always wanted to 
tell people about his disabilities at an early stage. He felt that he had nothing to hide and that 
in any case, he did not want to have contact with people who could not accept his disability. 
However, after a while he stopped telling people about his disabilities as it had some 
consequences he found unpleasant.
Peter: So you noticed a difference between how people responded to you when you told them almost at once and when you didn’t?

Eric: Yes that’s right.

Peter: Can you describe the difference?

Eric: Well, some people didn’t care and quite a few just disappeared.

Peter: By disappeared do you mean stopped chatting?

Eric: Exactly. It was very hard, and when I didn’t tell them, they were more interested in finding out who I was. When I finally told them after they had gotten to know me, they were a bit surprised, but they didn’t walk out on me and it then became much easier.

Dora told about how some people became curious and started asking questions about the disability. What Eric describes is the other end of the spectrum — people who immediately pull back or change their way of treating a person when the disability is introduced. This is, of course, a very difficult rejection as it is directly connected to a part of Eric’s identity, his disability. Repeated rejections of this type can be very trying. A direct consequence is that Eric withholds information about his disability until he feels he wants to continue with a certain contact.

Eric works at an online help desk for a big company. His job is one example of how the creation of new types of online work that are independent of the physical environment have made it possible for some disabled people to find appropriate work.

Eric: I work at the help desk for a big company and help customers who call in with a wide variety of computer and software problems. To help, I use a remote tool.

Peter: Is it software that lets you have total control over their computer?

Eric: Yes exactly. The client just answers “yes” to a question about giving me access to their computer that appears on their computer screen. It is perfect for me. If we cannot solve the problem, there are technicians that can be sent out.

Peter: It must be very convenient for you to be able to handle the whole situation from your computer.

Eric: Yes, it is very good not having to move around.

The system Eric uses makes it easier for all involved, but for Eric, it is absolutely necessary in order for him to be able to work. Without it, he would not be able to do it at all.

Comments

For individuals, to varying degrees, the Internet is a technology that improves functions, is (re)habilitating and easily eliminates some disabilities. In most other cases where technology is used to improve functions, there is an intervention in the individual’s immediate environment to increase functioning there. Such interventions can, to varying degrees, restore or create functioning for a person in the environment where the adaptation is made. In the virtual environment, the impairment is attended to by adapting the user interface between the individual and the computer. This is, of course, also an intervention with the individual, but the difference is that once this adaptation is made, full functioning is awarded in the virtual
environment and participation in all areas is possible. Functions are moved from the physical to the online world and thus change the conditions for how the body functions. This adaptation is invisible in the online environment. Internet technology does not mediate the impairment, which can have far reaching consequences for participation possibilities.

From a social model perspective, the physical environment and the social organization of the physical environment create disabilities. Online environments are at least free from these barriers. After an initial period of great hope and expectations about what computers and the Internet could do for people with disabilities, there followed a period of more sober description and analysis of the new and remaining obstacles and shortcomings created by ICTs. There is no doubt that many problems can be found when analyzing the large and rather indistinct area of “computer use by people with disabilities.” However, a closer look at particular groups or individuals reveals a pattern of strong and important effects. This report has tried to describe the everyday actions and interactions of computer-savvy research persons with significant mobility impairments. It shows that the opportunities afforded by computers and the Internet have resulted in not only improvements, but also in first time occurrences of great personal magnitude, where functions previously unavailable or impossible became readily available. These first time occurrences, when compared to what is possible IRL, do not seem to lose their outstanding importance even as they evolve into experiences on an everyday and taken-for-granted basis.

The overall picture is that computers and the Internet can have an even greater impact on the lives of people with mobility impairments than most of the initial predictions foresaw. Ideas without experience to back them up lack validity, but now there is a body of basic, lived and pondered experience that can be used as food for thought. The hope is that this information about both people and situations will inspire people with mobility impairments, further emphasizing the importance of the computer and Internet as a technical aid. It is neither fair nor reasonable for the life changing positive effects described here to remain invisible and hidden because of prejudice and bias, beginner’s problems, lack of proper technical aid or just sweeping generalizations about the failure of computer use for people with disabilities.

The many concerns about the creation of a new arena where inaccessibility, marginalization and discrimination of people with disabilities occurs because of the invisibility of impairments online should be taken seriously. But it is not fruitful to do this without making a connection to another interesting question, i.e. how does the flow of experience and personal growth between the digital and the physical environment look for the individual? Many of the people interviewed experienced consequences IRL from their Internet life experiences.

It will be interesting to see what happens as the mobility of the Internet increases. What results will ensue from being able to access and having a portable Internet identity while moving about in the physical world? What effects will emerge when 3D environments fully emulate the real world?

Along with increasing bandwidth and storage possibilities, communication using Internet will gradually become more graphics and sound based. How will this influence the opportunity for people with disabilities to be Cyborgs that have equal opportunities despite their disabilities?
References


This report describes the everyday use of computers by two women and five men with significant mobility impairments. The seven people range in age from 25 to 54. They are all experienced in using computers and the Internet for personal purposes and their everyday work. All of the people in the study require a personal assistant (PA) from seven to 24 hours a day. Pseudonyms have been used to ensure anonymity.

This specially selected group of users is not statistically representative of Internet users with disabilities. Their reflections and answers to questions presented here are based on extensive and rather specialized experience, and hence do not include aspects related to inexperience and/or poor adaptations of the user interfaces.

In qualitative research, content validity is based on an existing, extensive and open knowledge about the subject under study. My knowledge comes from 20 years as a computer user, 15 years as a wheelchair and personal assistance user, more than 10 years as an Internet user, and more than five years of postgraduate studies the area of disability studies and independent living theory. The basis of the latter is that disability is situated and relative, which has greatly influenced and guided my work. This blend of experience and knowledge is the most important cornerstone of my career as a researcher in the field of rehabilitation engineering.

www.certec.lth.se/doc/welcomingwideworld