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Title: What it is like to have a cognitive disability and the implications for computer program design and WEB site design.

Talk written for John Slatin's class on Accessibility, the WEB and the Virtual Body at the University of Texas, April 12, 2001

John asked me to talk to you today about what it is like to have my disability—a cognitive disability—and to briefly discuss what the implications are for computer use and WEB site design

(First section)
a. (Disability)

Disability is defined as a problem that makes one unable to work or perform the functions of daily living.

A cognitive disability means that there are problems with thinking processes that limit functioning. Cognitive disabilities can either be developmental or "acquired" –which means that they happen later in life either because of a fall, a beating, or a motor vehicle accident. I have an "acquired" cognitive disability. I was injured in a car accident in June, 1997 – almost 4 years ago. My diagnosis is a mild traumatic brain injury.

As a result of my injury, it is impossible for me to work—in my previous occupation, or even, at McDonalds. I can perform minimum requirements of daily living such as feeding and dressing myself which means that I can live independently. For brain injury, I am relatively lucky.

However, simple tasks of feeding and dressing are much more complicated for me to perform now, and take more energy. The basics are tough and thus more complex functioning is even more problematic.

My disability affects every aspect of my life. I cannot drive. Absorbing what I read is tough. Simple mathematics are tough. I do not remember things. I could not watch a movie for the first two years. I could not use the computer for about the first three. And walking is the only form of exercise I can do now.

Contrast this to prior to my injury when I functioned at quite a high level. I have a Phd in economics. I worked as a research economist at a nonprofit institute in Washington, DC. I drove and loved to drive. I played competitive volleyball and coached youth soccer. I knew how to sail. I was very computer literate. I had an active social life.

I used to be able to give a talk like this extemporaneously, so ...please bear with me as I give this one in a more structured way. I am going to have to read it, and I have never had to read a talk before. Also, this talk is more personal than those I was used to giving.

b (consequences)

The consequences of the injury have had a dramatic change in my life because the injury has changed my ability to function in all areas—at work, at home, vis-a-vis myself, and in my social life. This is worth saying more about since these changes are not obvious.

Not being able to work has been frustrating and very hard for me. Work was what I wanted to do with my life and I worked hard in graduate school to be able to do what I was doing. I liked to work and I loved my job. Instead of advancing in my career, I am relearning things I already knew.

Working was also a source of self-esteem—a way I experienced myself as being valuable in this society. So, not working is a huge loss in terms of everyday accomplishment, and in terms of my sense of myself. Not to mention that work was the source of my income, and hence my livelihood. I am much poorer than I was when I was when I was able to work.

But losses from this injury go far beyond the loss of the ability to work, and the ability to make money. I have had to learn to adjust to being a different person—I cannot be who I used to be because having a well-functioning brain was a central part of who I was. I have had to find--and am still trying to find--a different me, based on other facets of myself other than my ability to work.

I cannot do most of the other things that I enjoyed pre-accident, either. Being occupied with productive things is fundamental to living a meaningful life. I have had to find new interests. And I have had to figure out how to occupy myself and remain hopeful during those at-least-three-times-daily "down-times" when my brain cannot handle taking on anything more.

Much of coping is also about avoiding getting too frustrated, and avoiding getting worse, or getting into a downward cycle. As my neurologist explained, anxiety, comes with the territory of an injured brain, the inability to do what one used to be able to do, inevitably makes one anxious. While anxiety is natural, anxiety only makes poor cognitive processing worse, not better, so I have to work to moderate that alot. Depression, too, is natural because of all the losses, but it is not one's friend if it sets in for too long. One would be a robot if did not experience both of these, but it is important not to let these feelings take over and stand in the way of recovery.

c (My Deficits)

Every head injury is different. So I want to tell you more about the specific cognitive, visual and balance deficits that I have that, together, make up my disability.

A deficit is relative to a function that the brain performs---hence it is important to briefly understand what our brains do. There are three categories of functions that the brain does—it takes in information, it processes it, and it makes decision as to what to do with the information. It is useful to compare the brain to a computer, although scientists know that it is much more plastic, and more elaborate in terms of its abilities to formulate and solve problems.

Since the accident, my brain has had problems with knowing:
--what information to take in,
--where to store it,
--how to remember what it has taken in,
--where to find it,
--how to determine what information is useful versus what is not relevant in making a decision, or what to pay attention to in reading,
--recognizing and learning from feedback
--diagnosing what is not working,
--finding words and concepts,
--putting together thoughts,
--learning,
--planning,
--thinking abstractly,
--analyzing,
--sequencing,
--knowing how long things are taking,
--mult-itasking.

Just to name a few.

I also have visual deficits:

--my brain does not know where things are like it did, and
--my eyes do not track movement of objects smoothly or easily.

And I also have a balance problem caused by increased pressure in the inner ear.

Both the visual and inner ear problems contribute to the cognitive deficits.

Although my injury may not be apparent to you as I give this speech, my deficits are observable and can be measured objectively by the doctors using tests of cognitive functioning called neuropsychological tests.

The eye doctor can measure my visual deficits with standard equipment, as can the ear, nose, and throat doctor measure the damage to the vestibular system.

d. (more texture to brain injury)

How does something like this happen? Structural damage to the brain occurred during the accident. Connections in the neurons that make up my brain, were injured—either broken or stretched--during the movement of my head. The electrical impulses do not fire in some areas as they used too.

(***Talk about picture of electrical impulses around the head that can be seen using qualitative EEG technology for normal person vs. brain injured)

There is not a second my brain is functioning how it used to—I am now very aware of the malfunctioning even if I do not know what is actually going wrong at any particular time.

That is to say that for the first roughly two years, I was aware of the malfunctioning, but I could not understand why I could not work, and why I could not function better. I have moved past that stage to a different stage of awareness of my injury. I know why I cannot function better which is, believe it or not, an improvement.

At the same time, it is also important for you to understand that my entire brain is not malfunctioning:

--I don't have paralysis, and
--I have good control of my limbs.

And, some areas of my cognition--such as long term memory--work just as they did before. Everything I knew well before the accident is preserved.

Back to the computer analogy of the brain as an information processor, relative to before the accident, the input into the computer is often faulty. (primarily the input from ears and eyes) The RAM space of my computer is diminished, and corroded. Many of the functions that performed fine before, cannot be found, or perform faultily, and sometimes perform faulty, randomly.. Other functions work fine.

To help you imagine the disconnects and discontinuities that an injury to ones brain causes.... My boyfriend always uses the example of a photo-journal display in Life Magazine a couple of years ago –and one picture in particular--a list of things that one does in the shower, hanging in the shower of a brain injured person.

The list is on the wall at eye level behind the shower nozzle and it says: wash arms, wash torso, wash face, wash genitals, wash legs.

A person with a brain injury may get to the shower and not know what he/she is doing there. So lists and cues are needed.

But also notice the specificity of the directions—this person would not remember to wash legs, just because he was told to wash arms. A reminder to Wash would not be sufficient.

That's the basics of my injury

8 minutes?

2nd section

There is a second component of the injury that is also very important. That is that my deficits are changing (although not as fast as I would like.)

While the brain learns more slowly with a cognitive disability, it does learn (especially through repetition and more repetition) so the injury is not a static one.

The reasons why my deficits are changing are:

--because the brain compensates instinctually,

--because I am doing rehabilation to get better at a faster rate,

--because I am working very hard to get back to a more tolerable life. Living with a brain injury is not enjoyable. I am determined to get better.

--And finally because I am learning new compensation habits and eventually those compensation patterns will be how I function, and, who I am.

Coping, and doing rehab is how I spend my day, so it is my "work" right now. Its very hard work, and I can tell you it doesn't pay well, or stop at 5:00, or 6:00 or 7:00.

Rehab is made harder in that the very thing I need most to help me in rehab, my brain, is what is malfunctioning. A huge irony of the injury

My "work" is satisfying as I am improving. But it is also not the work I expected to be doing at mid-career. I expected to be advancing in my career, not relearning things I learned in elementary school

And, my work is not very well regarded. Most people (those who are not close to me and see my struggles) do not understand my injury and therefore underestimate the work it takes just to live my life in a meaningful way, much less to recover.

So I want to talk alittle about my day, what rehab is about, and how it changes the nature of my injury.

Let me tell you what it feels like from the inside to be me.

If you ever hurt an arm or leg you know that you are suddenly aware of all the things your arm or leg did that you did not know, never fathomed that the limb did. You know now because doing those things you never thought the limb did, are suddenly painful or uncomfortable. And you also find out how limited your movement is suddenly when the arm or leg does not work.

Similiarly, I have a distanced relationship to my brain and I am aware of all kinds of things that it does, that you completely take for granted, fortunately. Let me tell you I take none of them for granted anymore.

I talk about my relationship to my brain (post-accident) as that of a pilot looking at the gas gauge, oil lights and warning lights in a plane. Pre-accident, reading these gauges was automatic, I never had to think about it. I had my breakfast, went to work, sat down at the computer and worked. I got in the car and drove.

Post accident, my life is about being constantly aware of my brain functioning, and knowing that I am very dependant on figuring out what is going on with all these gauges, for my very survival.

I am also aware that I get very different feedback from my various senses, then what I previously did. For example, the oil lights are constantly flashing "warning" and many of the other levels of the gauges don't "look" or "feel" right. This is sort of a permanent state.

What changes when I go out to do my daily life is that the signals in some of the gauges change and I may be aware that something is different or wrong but not know which of these functioning or mal-functioning signals can help diagnose what is actually wrong.

Recovery from injury is learning not to pay as much attention to the feedback to the permanently flashing signals, or the feedback from temporary flashing of some signals. Signals that once meant danger, are haywire, and don't necessarily mean danger anymore.

For me, I have learned not to rely on information from my eyes, because it is often wrong. I have to pay more attention to touch and smell because they are correct. Hearing is better than sight for comprehending a news report, but not trouble free.

Recovery is learning not to be concerned if I get dizzy because it will not create too many problems as long as I am not in a busy intersection. It is figuring out what situations to avoid, what not to avoid, what is safe.

1) Section a (Natural compensation)

The brain naturally works to compensate around the injury. Its instinctual. The brain knows that it is not working, and "knows" that its malfunction compromises its very survival. So the brain figures out how to optimize as best it can given the parts that are working the best. The brighter you are the more your brain will figure out better means of compensation.

Some compensation is pure avoidance, some compensation is figuring out a different way to do something, or a different part of the brain to use to accomplish a given task.

Some compensation is unconscious, some is more conscious.

An example of the unconscious:

After the accident, I was very scared of heights.... Brain was saying stay away from places were balance is important.

Of course, I did not know my balance was bad, but I did know that my brain was saying that it did not want to go near heights.

An example of the conscious:

If someone asks me an economics question, I cannot "think" through the answer right now.

But I can consciously go to the long term memory part of my brain to find an answer I used to know.

Sometimes the "recalled" answer is a good one. Often it does not quite fit the situation at hand. It feels better to be working the brain, then to be silent. And an old answer is a good place to start in getting the conversation going.

Here are the primary factors that make compensation tough.

2) Post-accident—My brain has had difficulty filtering out information. Its as if information would come at me all at once, as if its all important. Background noise would come in as loud and meaningful as what's going on next to you. This is Very Overwhelming. There is no room in your brain to figure out other things—because it is so overwhelmed by information it cannot sort or process.
3) Awareness is one of the deficits I have. I might be unaware I had a headache, even though I had one. I would realize it if someone asked me—providing an external cue. Or I might realize on my own after several hours of pain.
4) These disconnects make it hard to figure out what to do about a problem also. I could go hours, knowing I had a headache, without knowing that I should take an aspirin to moderate it.
5) Often the negative consequences of an action are delayed for me. Some activities cause my brain to "wake up" and then I cannot sleep at night. If I do not sleep well then more problems will occur because my brain works less well the next day. One can get into a bad cycle downward this way. I only know that I did too much way later when I try to go to sleep and cannot. I do not know I am doing too much while I am doing it, so I cannot stop doing it in time.

6)The injured brains make the same mistakes repeatedly, because it doesn't learn quickly.

b. Formal rehab.

So having a trained therapist to work with makes a huge difference towards learning new things, learning to stop nonfunctional behaviors, to move things forward, faster.

I started doing formal rehab for my eyes early on. I have done formal cognitive rehabilitation about National Rehabilitation Hospital in DC, and know am working with a speech and language therapist at St Davids Rehab. .

The goal of rehabilitation is to get me better by teaching me functional strategies for the tasks that are now difficult. This often means reteaching me things I used to be able to do. The hope is by using the brain in specific ways, and practice, the brain will either find the old connections of the neurons, or it will build new ones.

Rehab is also a retraining so that one learns to understand the signals that come into ones head—which to pay attention to now, and which not to. And, how to function in the face of signals that do not make sense.

There are 2 approaches to the rehab—

1) One is to teach me to use the non-injured parts of my brain that I may not know to use. Working the non-injured parts of the brain will also rehab the injured parts, because the brain uses many different parts and paths in doing a specific function.

****Doing jigsaw puzzles would be an example.

2)
The other is to teach more functional compensation strategies in the damaged areas that I tend to want to avoid, or where I get really frustrated that I cannot do what I used to be able to do, or where figuring them out on my own goes nowhere .

An example is reteaching me elementary school mathematics. Simple division is very hard for me now, but with the therapist I can learn functional strategies that are more concrete than what I used to know. I then practice these and build up from there

Section c (unobservability and compensation)

One other thing to know about mild traumatic brain injury and rehab is that, ironically,

the better I am at rehab and doing things using compensatory strategies, the less you will observe my deficits.

Two reasons why difficult to observe my deficits—

One,

I do not do what I cannot do.
I constantly compensate.
So for example I do not drive because I cannot.
At first I took taxis, and now I take the bus. (Taking the bus was a huge challenge for me at first.) I am good at taking the bus now because I have practice.

You cannot observe me doing what I cannot do. You observe my compensation, and think my life is not diminished.

Second,

I can, eventually, do some of the few things that are very hard for me.
I can do them, but it takes me a lot longer, its takes a lot more energy to figure out compensation, and I have to make big choices because doing one thing means that I am not able to do many other things—a tradeoff much bigger than the ones I faced prior to the accident. To use an economics phrase-- the opportunity cost-- is huge in terms of what I do not do in order to do what I am able to do.

The fact that you cannot observe the injury actually increases the burden to the person with a brain injury. Since you cannot observe the injury, you cannot help with the problem, and it puts an extra burden on the injured person because they must find the energy to articulate the problem and educate the other person to get the help they need.

This is at the same time when the person with the injured brain is needing to work on very important other things—like single minded attention to doing the task at hand.

Third section;

Implications for the computer and WEB design for others with cognitive disabilities.

-Every head injury is different so designing for this group is difficult. One would need to find out which deficits are most debilitating, or most constraining, or most common by looking at information on patient population, market research, and interviews.

My experience is that my visual disabilities were the most constraining for computer use the first three years. I could not look at the computer screen for longer than a minute or so—it hurt my eyes, and if I got past that, it would put my brain into over-stimulated, wake up mode, and I could not sleep hours later. I could not overcome the visual problems by using a talking program like Jaws, or a speaking program like Dragon Speak, because of my cognitive disabilities which prevented me from learning something that was not already familiar..

About 3 years after my injury, I was able to learn severe behavioral restrictions (no longer than 20 minutes... and don't look at the screen while you type... use the printer to read text on paper rather than looking at the screen). These restrictions allowed me to have some computer usage, and email. (An LCD monitor would have helped but the cost was too high at the time given my needs)

Now I can look at the screen, and I can handle about an hour at a time of computer work. However, I am still limited by my cognitive disabilities in that all I do is open a word processing file and save it, and leave formatting to someone else. I also use the WEB, but someone else helps me if I have use a credit card or learn anything about how to use the site. I don't understand the logic of what I am doing like I used to, nor can I figure it out. I just try things until something works or until I get too frustrated.

-Although every injury is different, there are some basic features that could be incorporated in a computer program designed for someone with a cognitive disability. Some ideas are:

--prompting for time and attention cues,

--automatic filing,

--offering choices, but a limited number,

--help with planning, like a datebook

--memory cues hooked to the datebook,

--visual simplicity

--a program that could help diagnose what the difficulties are.

--a program that is capable of changing or learning as the patient does would also be useful.

--or one that the therapist could interface with the user.

- Using the computer is NOT available as a standard part of rehabilitation. I have not seen it being used with patients in the rehab hospitals I have been in. Furthermore, therapists and doctors seem to be one of the last-adopter groups. My friends and computer friends have helped me the most with the computer.

-For someone like me with a cognitive disability and no paralysis, using the Mouse is better than a DOS environment, where I would have to remember exact words. However, the mouse presents other problems for those with paralysis or movement difficulties which are often present in the brain-injured population.

-The fact that my injury is acquired, and not developmental, means that I have a series of skills or resources pre-injury (my long term memory) that have helped me with the computer post-injury to draw on. I am not scared of computer, and I am not scared of trying things until something works. Programs for head injured with developmental brain injury would be different.

-With regard to the WEB, simplicity and consistency on a WEB site are best for me. No movement on the screen, no flashing icons make a site much more tolerable and understandable. Bells and whistles are confusing at best. Site design that is well done for non-disabled people would probably overlap with my needs also.