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## Book review

### **The Diving Bell and the Butterfly**

Jean-Dominique Bauby. New York: Knopf., 1997, pp. 132, hard cover, \$20.00.

#### **1. Preface**

I selected this book to share with the readers of this journal based on events I experienced in Illinois in 1993. During a consulting assignment in the northern part of Illinois I met with two parents of a teenage daughter who received services from the agency I was visiting. Their daughter's mobility had been impaired due to meningitis which left a condition referred to as Locked In Syndrome. Their daughter could move her eyes, but that was about it. Intellectually, her mind was functioning as before the onset of meningitis. I talked with the parents about what community presence and participation means to individuals with their daughter's capabilities. Two years later, a half world away in France, the editor of *Elle* magazine awoke from a coma with his life about to take a similar fate as a teenager in Illinois. *The Diving Bell and the Butterfly* contains the literary musings of this talented man.

#### *1.1. The general highlights of this book*

- The title of this book originates from the author's analogy of a person who puts on a diving bell for deep sea exploration. In such an apparatus his body is confined and his mobility extremely restricted but images can surface in his mind and float out like a butterfly.
- The author painstakingly relates vignettes typically of 1–3 pages each using an eye gaze

method of scanning an arrangement of letters to spell out the words he intends to use to convey his stories. This method of authorship reminds me of another book I read several years ago, *I Raise my Eyes to Say Yes* by Ruth Sienkowitz-Mercer.

- The relationships with people who knew the author prior to the onset of his disability and those who knew him only as he currently lived are contrasted. Bauby could predict when a person walked in his room the tone and quality of the ensuing conversation. Some former friends would approach his door, turn away and leave not knowing how to interact with someone with whom the burden of the conversation rested squarely on his or her own shoulders.
- The ability in his mind to fantasize and reinvent scenes from the past, both experienced and from history long ago, provided Bauby with a Director's chair perspective on a stage in which he engineered his own version of events. Smells, sounds and sights took on more significance as his daily rehearsal of memories circulated in his mind.
- Bauby's humor often surfaces in his insightful essays on an appreciation of what is common around us. He reminds us to be mindful of the patterns and subtleties of every day routines.

#### *1.2. Specific areas of excellence*

- *Crossword fans and Scrabble players have a head start* (p. 20). Bauby comments on people who decode the letters he scans with his eyes

to form the words of his communication. Individuals who can see patterns fill in letters of words to reduce the amount of effort he must expend in a conversation.

- In commenting about residents of the hospital in comas Bauby says *Yes, everyone knows they are there, and they weigh strangely on our collective awareness, almost like a guilty conscious* (p. 31). This is a sample of the similes the author uses to help the reader grasp the essence of his new living environment. In this same chapter he describes those patients who are there for only a brief rehabilitation stay to recuperate from an injury as *The Tourists*.
- *We are both locked-in cases, each in his own way: myself in my carcass, my father in his fourth floor apartment* (p. 45). Bauby's father is 92 years old and unable to walk down the long staircase of his apartment building. The author comments that his father is just as isolated as he is and relies on people to come to him if they want to experience his companionship.
- *And by a curious reversal, the people who focus most closely on these fundamental questions tend to be people I had known only superficially. Their small talk had masked hidden depths. Had I been blind and deaf, or does it take the harsh light of disaster to show a person's true nature?* (p. 83) In each community there are leaders who lead when events transpire in predictable ways. However, when emergencies and/or disasters strike, other people with unexpected valor step forth. Their abilities to lead were always there. Circumstances beyond their control allowed their inner strength to surface. I found Bauby cautioning us that the people who surround us now in times of health and prosperity may not be the allies we need in times of despair and adversity.
- *'Look out — here comes Fangio' I know who he is, but who is he really? I have no idea* (p. 87). Bauby describes a well-known character who is a hospital patient who, when lying flat on his stomach, manipulates a hospital bed around the hospital hallways. We know the people's names in our community with disabilities and we know some of the things they do. *But do we really know them?* Or, are they

personifications of who we would like them to be or what we think our lives must be like. There is a tendency for people to stereotype individuals with disabilities into people who we know on a superficial basis, but whose lives are much more complex — and very similar to our own routines and patterns of existence.

- *Mithra-Grandchamp* (a place where Bauby experienced a lost opportunity) *is the women we were unable to love, the chances we failed to seize, the moments of happiness we allowed to drift away* (p. 94). Bauby reflects upon lost opportunities and what might have been — if only he had seized the day. What could he have done differently? What opportunities did he let slip by? Who did he leave out of his life because he were afraid to ask?
- *August, mysterious paradox: time, motionless here, gallops out there. In my contracted world, the hours drag on but the months fly by* (p. 101). This passage represents Bauby's poetic flow of thoughts throughout his memoirs. Can we put ourselves in his position and wonder what different message time would have for each of us? In this same chapter titled *Sunday* Bauby continues. *A very black fly settles on my nose. I waggle my head to unseat him. He digs in. Olympic wrestling is child's play compared to this* (p. 102).

### 1.3. Areas in which this publication can be enhanced

- Often it is useful to put ourselves into the lives of the individuals we support and see the world from their perspectives. How would we see the world differently through another person's eyes who is experiencing a permanent disability. Reading a publication from a first person's perspective enhances the value of 'being in the presence of another person' and at times, that is enough. Its not what we do and its not necessarily what we say. Being there is enough.
- Some friends of mine read this book upon my recommendation while they were at an ocean front center preparing their presentations for an upcoming course. I believe this atmo-

sphere, which is a similar one described by Bauby in his hospital setting, enhances the images and visions he presents in his writing.

- I searched a web site search server and put in Bauby as a key word which resulted in 93 citations. I connected to some of the sites and read some other book reviews about this current book. It was interesting to read about the tributes to Bauby from a non-rehabilitative/medical perspective.

#### *1.4. Common threads throughout this publication*

- Bauby's inner voice is a constant throughout this book. He invents an imaginary world in which he is the conductor of the actions around him and the actors respond to him as an equal. However, in reality he endures the forced politeness of others to be in his presence and the awkward silence after the initial salutations.
- The reader gains an appreciation for the succinct way in which Bauby uses words to capture image-laden scenes. The chapters are brief, but you realize the length of time each sentence takes from the moment of conception to the final product.
- Finding beauty in ordinary moments and activities is a common theme. The subtle touch of a caring aid is a welcome anticipation as well

as being placed in the sun for an afternoon facing the lighthouse off in the distance.

#### *1.5. Recommendations of its utility to rehabilitation professionals*

- The ability to communicate one's thoughts requires the cooperation of people who take the time to listen to individuals and provide the output technology. Each of the people we support has stories to relate that reveal more of who they really are than their outward appearances may imply.
- I am beginning to read more thoroughly the accounts by family members who write to teachers, professionals and others to interact with their relative as an equal rather than a 'condition' or 'syndrome'.
- This book may be good, easy-to-read resource for family members to gain a better understanding of a loved one who had recently undergone a transformation to a life of greater dependency on others.

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