

Bioethics Book Club



Left Neglected – A Novel

By Lisa Genova

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Summary¹

Sarah Nickerson is a career driven woman, working as the Vice President of Human Resources at Berkley Consulting. She is married to Bob, who is equally career driven. Together they live a hectic life with their three kids in the Boston suburbs. Sarah is exhausted, but miraculously still manages every minute of her busy life.

One day, when she is driving to work, she looks for her phone, and turns the focus away from the road for a short moment. She loses control of the car, which continues full speed over the side of the road. Sarah survives the accident, but ends up with a traumatic brain injury. This leaves her with a neurological condition, ‘neglect’, which involves not recognizing or being able to control the left side of her body. With the help from her family – including her previously absent mother – Sarah slowly starts to regain her independence but in this process she finds herself searching for answers about the past and about her uncertain future.

Ethical Issues:

Resource allocation

ADHD diagnosis and treatment

Stigma and disability

Dignity

Communication with patients

Patient expectations

Discussion questions:

- Was Sarah’s mother’s reaction to Sarah’s brother’s death understandable or unreasonable?

¹ Adapted from publisher’s summary.

- Sarah is adamant about not wanting a ‘disabled’ sign in the car so she can use the dedicated parking lots. She doesn’t want to think of herself as disabled (p. 188). Discuss her reasoning and what it reveals about conceptions of disability.
- When Charlie gets medication for ADHD, Sarah and Bob refer to it as ‘vitamins’. Their reasoning is that they want to avoid Charlie thinking of himself as “sick or disabled or broken” (p. 180). Do you agree with their decision? Why or why not?
- Do you think Sarah would have gone back to her old job if she had recovered completely?
- For a long time Sarah refuses to visit The New England Handicapped Sports Association’s (NEHSA) office at Vermont. She does not want to depend on someone to help her when she is skiing. In your opinion, is her determination to not be viewed as disabled an advantage or a disadvantage for her healing process?
- Do you think the health care providers’ expectations and Sarah’s own expectations to her recovery were aligned?
- Sarah’s insurance coverage for rehabilitation is used up and she is sent home without feeling physically or mentally prepared for it. She describes how the coverage is assessed based on progress by a certain number of weeks (see page 148-149). Do you think this type of resource allocation is just?
- After Sarah’s accident, her husband, Bob, uses his cell phone while driving with her and the kids in the car. What was your reaction to this?

Discuss the following passages from the book:

- (P. 110). “They don’t want me back at all unless I’ve recovered 100 percent. I chew on this piece of information as I chew the piece of fudge. *What if I don’t recover 100 percent?* I stuff another piece of fudge into my mouth. *What if I don’t recover 100 percent?* I eat another cube. I keep eating until I feel sick, but I still can’t manage to answer the question, and I can’t stop asking it, so I finish the box. Only the box still feels heavy. I shake it and hear and feel fudge bump against the side of the box. The left side. The side I have no awareness of. I shake the box again, this time like I’m trying to murder it, and a few squares stumble into view. I eat them. *What if I don’t recover 100 percent?*”
- (P. 57). “Doctors give kids with ADD Ritalin. That’s an amphetamine, isn’t it? We’re going to drug our seven-year-old son so he doesn’t fall behind in school. The thought flushes the blood out of my brain, as if my circulation won’t support the idea, and my head and fingers go numb. Ms Gaving keeps talking, but she sounds muffled and far away. I don’t want this problem or its solution.”
- (P. 57) “I remember when Charlie was born, checking him for all ten fingers and toes, studying his delicate pink lips and the conch-shell curviness of his ears. *He’s perfect*, I thought, amazed and grateful for his perfection. Now my perfect boy might have

Attention Deficit Disorder. The two thoughts refuse to hold hands. Kids are going to label him. His teachers are going to label him.”

- (P. 242) “See that person out there skiing sitting down? Did that person rent that equipment here?’ ‘Yes, it’s from NEHSA, New England Handicapped Sports,’ she says. She glances over at my granny cane. ‘it’s in the building next door. I can take you over if you want.’ ‘No thanks,’ I say before my mother has a chance to start packing up our things. ‘Just curious, thanks.’[...]
“I think we should check it out,’ says my mother.
‘I don’t want to.’
‘But you’ve been dying to ski.’
‘That’s not skiing, it’s sitting.’
‘It’s more like skiing than sitting in this booth. It’s outside. It’s a way down the mountain.’
‘No thanks.’
‘Why not just give it a try?’
‘I don’t want to.’”