Writing Our Journey:
Poems and Essays by Family Caregivers

Each meeting has a suggested prompt, or idea, for people to write about. Everyone is free to interpret that prompt however they’d like. Below is one of the prompts, followed by a sampling of what was written in response.

Please remember that each piece of writing belongs to the writer and, if quoted, must be credited to that writer.

**First person you remember meeting with a developmental disability**

Think about the first person you remember seeing or interacting with who had a developmental disability. How old were you? Where were you? What did you think? What did you feel? Were there other people around? What did you pick up on from them? If you’d like, you can write about how having a child with a disability has changed some of those earlier impressions.

- “What’s wrong with him?”, by Lisa N.
- “The Closed Door”, by Dorothy Ryan
What’s wrong with him?

Red squinting eyes
Blinking blinking

Wide gaping mouth
Mumbling mumbling

Weight shifting now
Rocking rocking

Small bloated hands
Throwing catching

Brown rubber ball
Bouncing bouncing

What’s wrong with him?
Nothing nothing

That’s just David
David David

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The Closed Door

The mother was adamant. “DO NOT go upstairs. She’s been changed and fed. She’s fine in the crib. I’ll be back in an hour.”

It was spring, 1955. I was 10-years-old, in the house of a neighbor I’d never met. My first babysitting job. 50¢ for the hour.

Magazines on the coffee table held no interest—Ladies’ Home Journal, Saturday Evening Post. No comics. I looked out the living room window, wandered through the dining room to the kitchen. Checked the clock on the wall by the refrigerator. Ten minute since the mother had left. Fifty minutes more.

I went to the bottom of the stairs. Looked up at the landing. Recalled my mother asking me to say “Yes.” My mother had explained, “The baby’s handicapped. Her mother needs help. It’s just an hour.”

Just an hour. To an active, curious, outdoorsy 10-year-old, spending an hour alone in a stranger’s house with a mysterious baby hidden behind a closed door was a lot to ask.

“No one will know,” I thought, lifting my right foot and placing it softly on the first stair. Then my left foot on the second. At the top of the stairs I paused and listened. Heard grunts and moans coming through the door facing me. The only door not open.

I put my hand on the doorknob slowly, cautiously. Glanced back at the stairs. Listened for the mother’s key in the lock. All was quiet. Except for the weird sounds coming from behind this door.

Quickly, before I lost my nerve, I pushed it open. There was a crib ahead of me, against a wall. A dresser and a changing table. The baby sitting up in the crib was about a year old. Curly brown hair. She wasn’t looking at me. And she was covered in poo—Her sleeper, her hands, her nose, her cheeks. Even her crib was smeared with poo. And it looked like she’d thrown poo at the wall behind the crib.

YECH! What was wrong with this baby? I moved closer. She started to scream. “It’s okay,” I said. She screamed louder. I tiptoed a little closer. She still wouldn’t look at me. Suddenly, I knew why. Her eyes weren’t brown, like her hair. Or blue like mine. Her eyes were milky white. They rolled in the sockets like marbles.

“She’s blind!!” I backed out of the room, closed the door and raced downstairs, the baby’s cries following mine. “I shouldn’t have looked, I shouldn’t have looked.” I sat down on the sofa. Tried to calm down. Tried not to see the baby covered in poo, her eyes…. She was still crying. What if her mother came home now! I was almost crying, too. But after ten or fifteen minutes, the baby was quiet again.

I spent the rest of the hour on the sofa, willing the time to fly. When her mother finally came home, I lied. Said I hadn’t gone upstairs, the baby had slept the whole time. “What’s her name,”? I asked, realizing her mother had never told me. “Carole,” she said. “That’s pretty,” I murmured, taking my 50¢ and running for home.

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