

# KALEIDOSCOPE

EXPLORING THE EXPERIENCE OF DISABILITY THROUGH LITERATURE AND THE FINE ARTS

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## THE EVOLUTION OF INCLUSION

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*"The Devil's Grip" by Casey Robb*

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*"The Lost Year" by Grace Lapointe*

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*"Everyone Deserves a Turn" by Bert Edens*

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*"Chromosome 17 and the State of Mutual Trust" by Alisa A. Gaston*

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# THE LOST YEAR

GRACE LAPOINTE

Olivia always had her long blond hair in a ponytail. Even though we all wore the same uniform at my new school, I thought her shoes and hair barrettes seemed like the right ones to have. She rolled up her skirt above her knees and always looked right at the boys and made weird faces while she put on her ChapStick.

Mrs. Renault, the principal, had assigned her to guide me around. That was exactly how she'd said it: "Olivia will guide you around and help you get acclimated." Mrs. Renault always wore colorful sweaters and a lot of makeup and called everyone "kiddo."

"So, do I have to carry your books?" Olivia asked me.

"No, I can do it myself." I didn't want anyone to act like my servant.

She didn't really have to do anything, just walk to class with me and make sure I didn't fall. I'm not sure what she would have done if I'd actually fallen, though. Most of the classes were on the same floor, except history, which was in the basement. There were no elevators, but the staircase was narrow, so I could grab onto both railings at the same time. It took me a long time to climb stairs, but I could manage. I could do anything if I put my mind to it.

I was never sure what to say to Olivia. She'd ask me things like, "Do you know what a hickey is? Do you know what oral sex is?"

"No," I'd answer. She'd start explaining, but I thought she must have been getting some of the details confused. I started asking her questions about sex that I'd never ask my mom or look up on the Internet.

One day Olivia said, "There was a girl who died here, back in 1962. Before Father Duggan was here, when all the teachers were nuns. She fell into the water bubbler and

drowned."

I laughed. "That's impossible. You can't drown in a bubbler."

"Of course you can. You just stop breathing."

Besides Olivia, I didn't really know any other girls in my class yet. The boys always said "hi" to me, though. Rob held the door for me and sat with me at lunch. He liked to mix different kinds of soda together until it made a disgusting concoction. If he thought that would impress me, he was wrong. I noticed he never offered to hold the door for Olivia.

"Don't talk to Rob," she whispered. "He touches himself."

On my first Thursday at St. Agnes', I noticed all the other sixth-grade girls were wearing white polo shirts and navy sweatpants instead of their pleated skirts. I hadn't even known that was an option. At the end of math class, the bell rang, and everyone else stood up and started marching out the doors. They moved in unison, like the cars on a train. I couldn't even see where they were going. Where was Olivia? How did they all know exactly what to do? I felt almost queasy when I realized that the runaway train was leaving me behind.

"Excuse me," I asked the math teacher. "Where are we going?"

She looked up from her correcting. "Oh. Outside."

"OUTSIDE???" I repeated.

"Yes, dear. It's gym day," she said calmly, as if I already knew this. On the tour, I thought Mrs. Renault had told Mom and me that gym was always in the auditorium.

I tried to follow the rest of my class, but I couldn't even see where they'd gone. I wandered around the corridors, which all looked exactly the same and were painted blinding white. Every once in a while, there was a painting of Jesus, but even those looked almost identical. I started to feel dizzy, like I was walking in a maze.

I finally found the back door and realized that I was sweating and out of breath. In the distance, I could see everyone running around in a park across the street. I stepped outside, my legs shaking a little. I usually needed someone to walk with me when I was outside and never crossed streets alone.

Then I noticed someone coming towards me. I hoped it was Rob, but as the person got closer, I could see that it was a girl—Olivia. Had she wanted to go and find me, or had the teacher sent her?

When Olivia walked across the street with me, I tried to grip her arm for support. At least that was less awkward than holding hands. My fingers felt clammy. I was trying not to put too much pressure on her, but I felt her flinching away, like she thought I was contagious. *Dear God, send a BOY next time!* I thought.

"What's wrong with you? What are you doing?" she almost screeched, trying to run away from me.

"Sorry Olivia, I know it's weird, but I kinda need to hang on," I explained.

"But you can walk OK when we're inside!"

"Yeah, I know. It's hard to explain. I have trouble with coordination and long distances."

"Maybe Father will let you skip gym."

"I don't want to stay inside though. I'd become a pariah."

"A what?"

"You know, like an outcast."

She looked at me like I was some exotic animal with two heads.

I stared straight ahead, not looking at her, like I was wearing blinders. I tried to block out the noise of cars roaring by and the feeling that gravity was pulling me down towards the hard cement. I couldn't stop imagining being swallowed

up in the concrete and run over by cars. The image kept repeating itself in my brain, like someone was rewinding a videotape.

The rest of the class was playing soccer in a little grassy area. There were no benches in this park, just a white-washed statue of some saint or bishop.

"Well, what am I supposed to do?" I asked the gym teacher, Mr. Richards. He was tall, kind of young, and had spiked hair.

He looked surprised that I could talk. He smiled at me, talking very slowly, like he thought I had a mental disability in addition to a physical one. "Hi there. You can sit down in the shade over there, OK?" He pointed to a tree.

It was hard for me to get down onto the ground, so I leaned against the tree, trying not to get dirt on my clothes. Why hadn't I brought a book with me? I was so bored that I became fascinated watching a little boy and his mother walking their hyperactive Jack Russell terrier down the street. They stared back at me.

When we got back to the classroom, Olivia said to me in a flat tone, "You're a lesbian." It wasn't a question.

"Huh? No I'm not."

"Yeah, right. You were, like, grabbing me."

"I just needed to hold onto something! It has nothing to do with who I like."

"Look at your hands."

"What about my hands?" Did they look like a boy's? Had I bitten a hangnail?

"They say if your ring finger's longer than your index finger, it makes you a lesbian. It's because of your hormones."

"That's stupid." I kept checking my index finger just to make sure it was longer.

Olivia wouldn't speak to me after that. She turned away when I said "hi" to her. I overheard her telling the other girls that I was a lesbian who'd tried to molest her. From then on, only the boys would eat with me at lunch.

I wondered if Olivia was the person who'd stolen my jacket the first week of school. I asked Mrs. Renault to tell Father Duggan, but they never figured out who took it.

"We can work this out, kiddo. You should probably go talk to Father," Mrs. Renault said, with a big smile.

I was tired by the time we got across the street to the rectory. The secretary met us at the door and told us Father would be in momentarily. While I waited, I looked around his office. There was an icon of Jesus, holding open his cloak to reveal his Sacred Heart, which was bleeding and surrounded by a crown of thorns. I could see the nail marks in his hands and feet. I shivered. I'd seen icons like this at my grandparents' parish, but the art at my church wasn't quite this graphic.

Right then, Father Duggan walked in. I'd only seen him from a distance before. He had glasses and gray hair, and he was much shorter and thinner than I'd expected. He was wearing regular clothes ("civilian clothes," as Mom would say), with his white collar poking out from his sweater. I thought it looked out of place, like the time I saw my physical therapist at a fancy restaurant, wearing a dress, makeup, and high heels instead of a T-shirt and sweatpants. Father wasn't making eye contact with me, just looking past me like I was invisible. I kept staring at the icon with its big, mournful eyes instead of at him.

He said in a deep, musical voice, "Good afternoon, TalEETHa. What a beautiful name." I'd never heard anyone pronounce my name that way. It sounded so threatening—like "lethal."

"Actually, it's TALitha," I corrected.

He smiled. "Ah, Talitha. I used the Aramaic pronunciation. You know the story behind your name?"

"Yes."

"In the Book of Mark, there was a little girl around your age who was very sick. Her father, Jairus, approached Jesus in the synagogue and begged him to heal her. But by the time Jesus reached the house, the child was already dead." Even though I knew this story backwards and forwards, I felt like I was hearing it for the first time. He sounded like a radio announcer. "Jesus took her by the hand and said, 'TALITHA CUMI! LITTLE GIRL, ARISE!'"

I jumped. Father Duggan was practically shouting. It was like he was acting in a play, or like his words were a magical spell that could actually raise people from the dead. By then, I'd almost forgotten why I'd come to see him in the first place.

"So, how's everything working out so far? Can you get to and from class?"

"Yes."

"I'm told you're very bright and you're doing well."

I almost said yes to that, too. "Thank you."

"We'll find something else for you to do during gym. OK, Talitha?"

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**. . . "Good afternoon, TalEETHa. What a beautiful name." I'd never heard anyone pronounce my name that way. It sounded so threatening—like "lethal."**

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"Thanks. At my old school, the gym teacher adapted all the exercises for me. And could you put me on the schedule for the readings? I always read in my church at home. The priest usually just carries the book himself. They set up a chair so I don't have to climb the steps, or someone helps me. It wouldn't be difficult at all."

"Of course." He was looking down at paperwork on his desk, like I was already gone. I'd planned to ask him to meet with my parents, but I decided that I could handle this by myself. After I left, I realized that I'd forgotten to ask him about my coat.

After that, I got to stay inside during recess and gym. It gave me more time to read anyway.

No one had ever mentioned God at my public elementary school. But every Friday at St. Agnes', we had a prayer service with readings and a sermon, plus Masses on holy days. Father always picked students to be the readers. While he processed down the aisle, the reader marched up the stairs to the altar, carrying a heavy missal. During the "Our Father," I once held hands with the girl next to me, like we did at my church at home. She let go, like I'd given her an electric shock.

I kept asking Father Duggan to put me on the schedule, but he never did. Every other kid in my class got at least one turn. Sometimes they made hilarious mistakes, like: “He *prosted* himself before the king.” I didn’t usually think other people’s mistakes were funny, but soon, I started laughing at them.

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**At first, I thought she was pretending to be drunk for some reason. Then I noticed that she was dragging her left leg and shouting long, nonsensical words in a snobby voice.**

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Father Duggan always used a lot of incense, which the priest at my church only used on Good Friday and at funerals. When I opened my mouth to sing, the bitter-smelling incense hit the back of my throat and made my eyes water. I usually sang along anyway, until I realized no one else was singing except Father. He sang every part of the Mass, even the readings. Sometimes it sounded ridiculous when he tried to cram in all the words. His voice was so low that it blended in with the organ. Even when he was giving a sermon, it sort of sounded like he was chanting. I usually didn’t pay attention to what he was saying, just the mesmerizing rhythm of his voice.

On the first day of religion class, Father walked into the classroom and said in his booming voice: “Boys and girls, some people try to take every word from the Bible literally. But listen to Psalm 14: ‘There is no God.’” He closed the Bible and smiled at us. *That can’t be in the Bible*, I thought. He said, “Now let me read the whole thing: ‘The FOOL says in his HEART, *There is no God . . .*’” I couldn’t decide whether he was a brilliant speaker or he’d tricked us somehow.

“What’s the last book of the Bible?” he asked us the next week. Most of the other kids were staring out the windows in a daze. He looked around the room. “Anyone? Miss Dias?”

“Revelation,” I whispered, staring at my fingernails.

“Yes, exactly!” he said excitedly. “Protestants call it *Revelations*, as if there are all sorts of juicy secrets in there.” After that, he always called on me, even when I wasn’t raising my hand, and seemed amazed when I knew the answer. When-

ever I got a question right, Olivia would snicker. Sometimes one of the boys hissed, “Yessss, Miss Diassss!” One day, someone stole my homework from my backpack. I thought I saw Olivia and her friends passing it around and copying it.

Father talked about abortion a lot in religion class. On the anniversary of *Roe v. Wade*, he told us that 30 million babies had been aborted since then, which seemed like an unimaginable number. I wondered how many parents chose an abortion because the baby would have had a disability. I couldn’t stop thinking about it. It made me feel almost like part of an endangered species.

After Father’s dramatic sermons, even Communion seemed anticlimactic. He rushed through the prayers of the Consecration. He’d shifted the focus of the Mass off of Jesus and onto himself. The altar was his stage, and we were his audience. Late one night, when I was watching TV, I saw a few minutes of *Rosemary’s Baby*. I had a nightmare about a strange cult with bizarre rituals, like a backwards version of the Mass. Father Duggan was their leader. I couldn’t tell whether they were Satanists or worshipped him instead of God.

While I was walking to class one morning, I saw Olivia stumbling around in the hallway. At first, I thought she was pretending to be drunk for some reason. Then I noticed that she was dragging her left leg and shouting long, nonsensical words in a snobby voice. A bunch of other girls were watching her and laughing.

I thought my heart had dropped into my stomach. Is that what I look like? I wondered. I wanted to ignore them and just concentrate on walking to class. My eyelids felt weirdly heavy, like I wanted to cry but couldn’t.

Ever since that meeting in Father Duggan’s office, I’d never complained to an adult at school. But Mrs. Renault was just walking by. “Hey, girls!” she called cheerfully. “No one’s in trouble. Let’s just chat.” She asked us to gather around her in a circle, like she was our buddy, not the principal. “I know these years can be tough, but they’re wonderful too. Believe me, someday you’re going to want these days back. So let’s all try to be nicer to each other, OK? Remember, Father and myself are always here if you need to talk.” Then she walked back to her office, without looking at any of us.

In April, Mrs. Renault announced that the sixth grade was going on a field trip to New York City. “I think it would be too tiring for you, kiddo,” she told me. I’d gone on lots of field trips in elementary school and had never had any problems getting around. I almost told her that nothing was too tiring for me, but it’s not like I wanted to go with them.

“Of course you can go!” Mom said. “Do they need any more chaperones?”

On the day of the field trip, we all had to be on the bus by 6:00 a.m. I grabbed both railings at once and tried to climb up the high stairs, but other kids kept pushing around me and saying I was holding up the line. I hoped no one noticed that Mom had to help me a little. I sat down in the first row, relieved that I’d made it. When the other girls walked onto the bus, Olivia looked very carefully at me and then averted her eyes, like I was repulsive. Her friends copied her exactly. They walked past me and chose seats near the back of the bus, as far away from me as possible. Even the boys followed them. The only kid sitting anywhere near me was Rob, a couple of rows over.

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## **I’d never told my parents about the gym teacher making me sit under a tree, Father not letting me be a lector, or anyone else excluding me at school.**

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Mom was sitting with the other parents and teachers, but she immediately walked over and sat next to me. I almost said, “Please don’t, Mom.” Sitting with your mom on a field trip wasn’t just mortifying—it was social suicide. But they already hated me, so I had nothing to lose.

Mom looked exhausted. She had puffy, dark circles under her eyes and her long hair was disheveled. She’d started working second shift at the hospital a few months ago, and Dad drove me to and from school on his way to work. If she got home at midnight, she’d probably gotten about five hours of sleep. It made me feel guilty that she had to get up so early and take a day off from work.

The inside of the coach bus didn’t look anything like a regular school bus. There was a TV screen in every other row, and the seats were covered in what looked like a carpet. I had closed my eyes and leaned against the headrest when I heard Mrs. Renault shouting over the traffic.

“Good morning, kiddos! Some public school kids don’t learn anything on field trips. So we’re doing something fun AND educational. We’re going to have a scavenger hunt. For a grade.” I heard people grumbling. She passed out disposable Polaroid cameras and sheets with trivia questions.

Then she put a video in the VCR, a Biblical miniseries with cheesy music and special effects.

“This is absurd,” Mom said.

“Seriously! The Israelites didn’t have blond hair and blue eyes.”

“No, look at this. You all have to go up to the top of the Statue of Liberty, the Twin Towers, the Empire State Building—and it’s all part of your grade.”

I looked at the long list of landmarks. We had to visit each of them and “collect” an interesting fact or take a picture. “I know a lot of things about those places anyway. I can just make something up.”

“But you shouldn’t have to do that, honey!”

I shrugged.

“I thought she said they made sure the trip would be totally accessible for you! Do they do this a lot? Leave you out of things?”

I’d never told my parents about the gym teacher making me sit under a tree, Father not letting me be a lector, or anyone else excluding me at school. Each of these things seemed unimportant when they happened, and I thought it was better if I dealt with them by myself. I’d usually just nod when my parents asked me if I’d had a nice day at school. Sometimes I lied: “I had lunch with my friend Olivia.” I was afraid that if I told them one little thing, the rest would come out like a flood, and I’d never be able to stop talking about it. But now I finally told Mom everything. We were almost whispering, but I didn’t even care if someone overheard us. I thought it might take the whole five-hour bus ride to explain everything.

I kept my voice calm, but Mom sounded like she was going to cry. “This is all my fault, honey. I wish I’d been home after school so you could’ve told me right away. But you can talk to me any time, even in the middle of the night! We could have found another school back in October.”

I wasn’t even sure whether I wanted to transfer in the middle of the school year. Somehow it seemed like failing or at least surrendering and letting people like Olivia win. I was used to being able to handle new things, even really uncomfortable ones like different kinds of physical therapy. I couldn’t let it get to me.

The bus finally stopped near Battery Park. It was one of those cloudy, depressing days when the sky is more white than gray. The sky reflected in the water, making it look creepy, almost silver. I stared across the harbor at the Statue of Liberty raising her torch into the fog. Rob smiled at me and held up his arm at a weird angle, so it looked like he was carrying the torch. I can't remember whether I smiled back.

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**Most of them had shopping bags or those silly green foam hats that looked like Statue of Liberty crowns. No one even asked me where I'd been.**

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Mom and I waited while everyone else stampeded out of the bus. A man in a lime green shirt ran over to the bus, gesturing wildly. By the time Mom and I got off of the bus, the tour had started without us. Mom took my hand and ran after the group, shouting that she wanted to give Mrs. Renault a piece of her mind. But they were already gone, following the guide at a much faster pace than I could walk.

"I guess we're our own tour group now, honey," Mom said, trying to sound cheerful. We didn't exactly have a choice. The bus driver had said he was coming back to Battery Park at 5:00, so at least we'd be able to find them at the end of the day.

I noticed a sign outside the visitors' center describing all the handicapped accommodations. You could read brochures in Braille or even rent a wheelchair for the day, as long as you called in advance.

"So they paid for a guided tour but didn't care whether it would be accessible," she said. "Unbelievable! You're all supposed to go to the top of the Statue's crown, but there's no elevator up there. What the hell is wrong with this school?"

"It's OK, Mom," I said, but that's not even what I meant. I just wished she wasn't so upset.

I realized that we couldn't even get in because Mrs. Renault had everyone's tickets. Mom and I spent most of the day waiting in an enormous line that twisted around the buildings. The visitors' center had a video about immigration

playing on a loop, and I'd almost memorized the whole thing by the time we got our tickets. We took the ferry to Ellis Island because it was more accessible than the one to Liberty Island.

Then Mom and I went back to Battery Park to wait for our bus. When the rest of the class arrived, they were all talking excitedly. Most of them had shopping bags or those silly green foam hats that looked like Statue of Liberty crowns. No one even asked me where I'd been. Apparently they didn't notice. Or maybe they thought I'd planned to spend the whole day with my mom in the first place.

Rob sat near me again on the way back. He tried to show me how to make origami, but I was terrible at it. He wrote down his phone number on a piece of paper, but I lost it by the end of the day.

From the back of the bus, I could hear the other girls playing those clapping games that seemed like a secret code. When someone messed up, Olivia would laugh and say, "Gay!" or "You're retarded." Without looking up from her novel, Mrs. Renault said, "Ladies, language."

Mom said we'd come back to New York by ourselves someday and see the Empire State Building and the Twin Towers. But first, we had to find another school. Before I transferred, Mom wanted to have a meeting with Father Duggan and Mrs. Renault. I thought that would be what Dad called a "moot point."

\* \* \*

The only public middle school in my city had six floors, a thousand students, and security guards with metal detectors. It was constantly in the news because kids were beating each other up and joining gangs. The other Catholic schools were decrepit and over a hundred years old. They had steep staircases and uneven floors. When Mom and I looked around at other schools, we remembered why we'd picked St. Agnes' in the first place. At least it had a much newer and more accessible building than all the others.

That summer, after we'd finally found an accessible private school in another town, it seemed like every story on the local and national news was about pedophile priests. Dad stopped watching the news at dinner, but it's not like I didn't realize what was happening. It was everywhere. The papers included all the gross details. Even when they tried to imply things, I could figure it out.

One afternoon, I had the TV on, but I was only half-watching. Then I heard a voice say: "After over thirty years as pastor at St. Agnes' Parish and School, Father James Duggan has resigned following an accusation of sexual abuse."



I put down my book and stared at the TV. The report said that a woman had accused him of molesting her back in the '70s, when she was twelve. The statute of limitations had expired, so they couldn't arrest him. I wondered if he'd get defrocked. I imagined him giving a long, eloquent speech saying he was innocent, and Mrs. Renault telling the reporters that he was so holy. But the reporter just said, "Duggan could not be reached for comment," and moved on to another story.

Mom came running into the room. "Honey, did he just say Father Duggan?" Her voice was shaky. She hugged me and stroked my hair.

"I'm fine, Mom. Nothing happened. I don't know whether it's true or not."

"Oh, thank God, Tallie. You'd tell me, right?" She turned the TV off.

"I tell you everything. Nothing happened," I repeated.

When I went back to my room, I thought about that day near the end of Lent when Father Duggan had held a Reconciliation service. He told us to remember that Jesus had died for each and every one of our sins. That made me feel guilty because it sounded like Jesus was still dying right now, and my actions were killing him. We all lined up in front of the confessional, fidgeting nervously. I wished I could have gone to some random priest I'd never met before—anyone but him.

There were two booths set up in the chapel: one with two chairs facing each other, and one with a screen and a place to kneel. I'd never seen a confessional like that before, and I don't kneel, because it's uncomfortable. But I chose the confessional with the screen just so I wouldn't have to talk to him face-to-face. It was dark and cramped, with a stale,

musty smell. I could barely see Father silhouetted through the screen. I recited the Act of Contrition and mumbled a few boring things. The priest stands in for God, so just imagine you're talking directly to Jesus, I reminded myself. But I couldn't—not when I heard Father's booming voice.

"My child, that was a *lovely* confession." I had been going to confession for four years, and no priest had ever said anything like that to me before. "You are *so* spiritual. That's a gift, you know. You're very conscientious. Do you know what that means—conscientious?"

I nodded, like he could see me. For some reason, my tongue felt frozen. I wondered if he talked to everyone like this. *Do you even know who I am?* I thought. I was waiting for him to give me my penance, but he just kept talking: "Now I'm going to have to ask you to forgive me. Remember when you came to my office? You were so quiet. Before I had a conversation with you, I'd always assumed—" His voice trailed off. "Well. Our Lord thinks people like you are very special, you know."

*Oh God, he knew who I was.* I wasn't anonymous behind the curtain.

When he finished the prayers of absolution, I asked, "Can I go now?" My knees felt glued to the carpet. I got up, my legs feeling tight and unsteady, and left the confessional as fast as I could.

Of course I knew Jesus cured disabled people, but I'd never wondered whether they wanted him to. I probably used to have an answer for that too, but it was gone. That was the day I realized that I couldn't sing anymore, even when I was alone at home. Whenever I tried to sing, my throat would close up, and no sound would come out. ♦