

Religion and Natasha McDonald

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I AM NATASHA McDONALD. THIS IS MY MOM AND DAD. I HAVE CEREBRAL PALSY. I THINK AND FEEL LIKE YOU DO BUT THE PART OF MY BRAIN THAT CONTROLS MY PHYSICAL SELF WAS DAMAGED WHEN I WAS BORN. MY VOICE IS A COMPUTER VOICE. I CAN PRODUCE WORDS MYSELF.

THIS IS THE INTRODUCTION Natasha activated by repeatedly pressing the right side of her head against a switch when I interviewed her with a professional videographer in July 2004 in her home in Alberta where I grew up and had returned for a visit. Twenty-four years old and completely dependent on others for all physical care, Natasha weighed sixty-seven pounds.

Later in the interview, I ask, "How do you expect Heavenly Father to be when you meet him again?" She thinks, adjusts her computer screen, activates the switch nine times, her face serious, then increasingly happy, arms askew, then spread wide, and answers "LOVING."

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With this essay, *Dialogue* begins a series of pieces about the relationship between persons with disabilities and the LDS church. Please see the call for papers in this issue.

And later, "If you had to describe your Dad in one word, what would it be?" She breaks into glee, directs the computer switch through another nine steps, laughing in her own way throughout the process, and answers, "CRAZY!"

No one has expected this answer, not her parents, not the professional videographer, not I; and we are all laughing together.

The computer software with which Natasha writes and speaks is called MINSPEAK, meaning "minimum-effort speech." It is designed to require the least possible amount of physical effort, based on the idea of hieroglyphics in which one picture can be used to represent many ideas. For example, a shark could mean fish, teeth, gray, water, danger, big, fast, mean, wild, strong, etc. MINSPEAK is a language of categorization, association, and sometimes sound-alikes.

One day Natasha wanted to say "orangutan." She had been at a zoo, and while she was looking at an orangutan, it came up, pressed its face against the glass wall separating them, and stayed there, staring at Natasha who was staring at it. To say "orangutan," Natasha first needs to activate the icon ZEBRA, because all animals are represented by that icon. To activate the icon, Natasha pushes her switch to start a search. Each quadrant of the 128-icon keyboard is highlighted in turn till Natasha signals when the right one is reached. Then each line in the quadrant is highlighted, then each icon in the right line. With the three selections, she chooses the icon ZEBRA.

Next, she must go through the same three steps, highlighting and choosing, to identify the icon for the sub-category "wild animals", which again is ZEBRA. Finally, she goes through the same three steps to identify the particular icon that she has chosen to represent, in this particular context, ORANGUTAN.

To say, "I don't know," Natasha first chooses an icon for SENTENCE, then an icon for THINK, then an icon with a knotted rope, KNOT. The computer translates SENTENCE THINK KNOT into "I don't know."

Natasha must take nine steps to produce any single word or simple sentence. Because the system includes thousands of choices of categories and icons, including customized ones specifically for Natasha that have been recorded in a three-inch binder with Susan's help, sometimes only Susan can translate the full meaning of a word or sentence from Natasha.

"But she can spell with the alphabet, so why doesn't she just use it in-

stead of icons?" I wonder. "Spelling out words would give her more flexibility and fluidity."

But using letters on a standard computer keyboard to spell a five-letter word, or a sentence like "I don't know", would require more steps and, therefore, significantly more energy. I tried spelling out "IDONTKNOW" on my own computer keyboard as though I were Natasha highlighting and choosing from only the letter lines and keys, with no punctuation or spacing. I would need to push my head against the switch eighteen times, twice the number and therefore twice the energy Minspeak requires.

Natasha's cumbersome computer speech frees her from silence and isolation but also prevents the ease and complexity of language most of us enjoy. Her process requires a period of silence interrupted only by computer beeps before she responds to a question.

For the first fifteen minutes of her life, Natasha did not breathe. The lack of oxygen destroyed brain cells for intentional control of her body but did not destroy major autonomic processes or capacity for thought and emotion. In Lethbridge, Alberta, Canada, in 1979, her teenaged parents were not yet married and not prepared to take care of any baby—but especially this baby—so her grandmother took her.

With severe athetoid cerebral palsy caused by the brain damage at birth, Natasha would be completely dependent on other persons all her life. She would never roll over, sit without support, walk, talk, control elimination, or eat solid food. She would control only some face and head muscles, could respond to stress or express emotion only with facial expressions and altered range and tempo of body activity. Though alert and eager to learn, and loving play and humor, she would have no freedom to explore, experiment, or question in ways that most children do. She needed instruction to discover spatial relationships, identify cause and effect, learn how to swallow blender-mixed food, and identify a comfortable position.

When Natasha was more than a year old, my niece Marsha Edmunds, an occupational therapist, was assigned to go to the home and help Natasha discover her abilities. Marsha found Natasha so joyous in learning and playing that Marsha invited her own sister, Susan McDonald, to come and meet Natasha. Susan fell in love with her.

"Why? How did you know her, if she couldn't move or speak?" I ask. "How could you fall in love with her?"

"We saw the light in her eyes," answers Susan. "Look," pointing at a

picture of young Natasha. "Who could resist?" Susan and Marsha saw Natasha through Natasha's eyes.

Susan and her husband George had three children: Laura-Lynne, aged nine, David, seven, and Chantelle, six. One evening when the family had just arrived home from a camping trip, Marsha came by: Natasha's grandmother had a health problem and could no longer care for Natasha. Would Susan and George like to adopt her? If so, they needed to go to the grandmother's home that night.

"I don't know," Susan hesitated, "if I could really love someone else's child as much as I love my own." "Yes, you'll be able to," said George, and it was so. They went to see Natasha and, the next morning, brought her home. Laura-Lynne had been praying for a little sister and thought Natasha was an answer to her prayer.

Natasha was twenty-two months old. Before they officially adopted her, Susan and George took Natasha to the Diagnostic, Assessment, and Treatment Center in Calgary (the DAT). Professionals there advised them not to go through with the adoption. "She'll never be anything but a vegetable," they said, knowing the enormity of the task of caring for her but perhaps not knowing what Susan and George and their family would give to it.

They took Natasha home and adopted her.

She and the other McDonald children gladly bonded with each other. Susan recalls one occasion when the family ate at a fast food restaurant, and people stared at Natasha. Laura-Lynne, David, and Chantelle pointedly stared right back at them.

A photo shows little Natasha, grinning with delight, perched securely on George's shoulders and backpack and leaning her head against his on a family hike. On bicycle trips, Natasha rolled along in a bike trailer behind George. Securely wrapped in a pulk, an adaptation of the traditional Lapland pulka pulled by a reindeer, Natasha went skimming across the snow pulled by George or one of her siblings as they skied. Natasha loved family music: Laura-Lynne's viola, David's cello, Chantelle's violin, Susan's piano, George's singing. While Susan fixed meals, Natasha in her wheelchair was with her in the kitchen where, after Natasha mastered her computer, Susan taught her to ask questions, for questions had not come naturally or easily to Natasha.

When the strain of lifting Natasha began affecting Susan's back, David and George knocked out a wall in their small home between Natasha's bedroom and the bathroom. They installed a ceiling track and pulley with

a sling that could go under Natasha for moving her from bed to bathtub, and then to a fold-up changing table they had made and installed at Susan's hip level. In a junkyard they found a long bathtub in which Natasha could lie. They installed it and the plumbing on a platform so that Susan could bathe Natasha at hip level. They took out a wall between the living room and kitchen to make wheelchair movement easier, and the house more pleasant and light.

An aide, Darlene, is now with Natasha a few hours on weekdays to visit, watch Natasha's favorite TV show with her, play games, and engage in various other activities. Natasha's favorite game is "Memory," at which she is very good. She likes videos, especially, according to George, "chick flicks," romances in which a woman gets what Natasha wants.

Natasha can read but, even with support, cannot hold her head still enough long enough to do it without strain and great fatigue, so every day Susan reads to her.

"What kinds of books?" I ask.

"Every kind," says Susan. In June it was a mystery, in July a novel, Lloyd C. Douglas's *The Robe*.

Natasha's health is now fragile. She cannot handle heat or cold. Two years ago, doctors said she would not survive a nine-month bout with, among other illnesses, flu, pneumonia, a bowel blockage and consequent surgery, hip displacement and tight hamstrings and consequent surgery, asthma that made breathing difficult, severe reflux exacerbated by Natasha's swallowing problems, and long heavy pain. Susan spent months "sleeping" in her hospital room.

Reflux became such a problem that Natasha now receives only liquid nutrition, throughout much of the day and night, through a tube from a backpack to a permanent opening in her abdomen. This nutritional system is working well. Natasha herself chose tube-feeding over regular blender food (including her favorites: pizza and ice cream). Because timing the feedings is essential to controlling the reflux, Susan gets up at midnight to start a feeding, then is up to check Natasha two or three times a night.

And Natasha, like Susan, thinks, and feels.

As is customary for disabled children in Alberta, Natasha started school at age four so she would have two years of kindergarten before grade one. David and Chantelle were in a school near by, and sometimes in good weather they pushed Natasha home in her wheelchair. One such

day when they got home, David told his mother that they had met a grade three classmate of Chantelle's on the street.

"Oooh," he said, "is that your *sister*? Is she *retarded*?"

"No," shot back Chantelle, "but *you* are. She has ears, too, you know."

Natasha still calls Chantelle her best friend.

Natasha entered a regular grade one class with a government-provided aide and an Apple IIe computer with special software and an on/off switch Natasha could operate with her head, but she did not yet have a computer voice. Teaching and learning proceeded as usual for the rest of the class, but Natasha had never spoken and could not copy, imitate, converse, or use a letter or number except by translating it into computer language she did not yet know. The aide helped, but the process was slow.

At the end of grade one, Natasha had not completed learning the alphabet. Susan met with the teacher and told her Natasha would need another year of first grade to finish learning her letters.

"What's the point?" said the teacher. "She'll never learn them anyway."

But she did. In grade two she was producing short sentences with her computer. The first, to Susan, was, "I LOVE YOU."

Another, about her brother whose endless teasing she liked, was, "DAVID CRAZY."

In grade seven she got a computer voice and for the first time could answer a question vocally if the asker were willing to wait through the cumbersome computer process and try to understand her abbreviated response.

One junior high school educator was perplexed about how to assess Natasha's learning, because she could not take the usual exams.

"Assessment isn't the point of her education," said Susan. "We just want her to learn all she can."

When I asked Natasha what she thinks is the purpose of life, her reply was "GROW." She did not say, "To be tested."

In high school she got an electric wheelchair and, for the first time, once strapped in, could move herself. While Natasha was learning to "drive" the chair, George and Susan took her out in the driveway to practice maneuvering it with her head switch. Cloth in hand, David was there, proudly polishing the final coat of finish on the old car he and George had spent months lovingly restoring. After practicing a little, Natasha

took aim at the beautiful shiny classic car and rammed straight into the bumper at full speed. Finally an active teaser like her beloved brother, she laughed and laughed. So did everyone else, except David.

When she finished high school at age twenty, Natasha wrote a short valedictory address. Here are a few sentences from an edited copy of her computer talk:

My favorite part of school was that I learned lots. The next best part was getting to know my teachers and aides. . . .

In high school I drove my electric wheel chair. My favorite subject was psychology.

The things I learned that are most helpful to me are writing and reading. These will help me in working toward my second goal which is to become a writer. My first goal is to get healthy.

I am happy when I am with my family and friends and when I go to church. I also especially like walking, singing, and flowers.

I think the most important part of life is to learn. I am very excited to be able to continue to do this in college with Ronda's help.

Although Natasha attended one or two classes per semester with her aide for a couple of years, Natasha found college unmanageable.

Now Natasha is invited back into public schools to help students and teachers recognize persons like themselves in disabled bodies. She introduces herself and answers questions with her computer voice. At the end of an hour last May, a fifth grade student said, "Natasha, I didn't know you'd be so *cool!*"

Natasha has experienced most LDS activities and rituals, including meetings, activities, baptism, temple endowment, and work for the dead. Some adaptations have been necessary. For example, because Natasha has never been able to swallow solid food, sacrament bread is only a small crumb or two, and water a touch on her lips.

I asked Susan if Natasha was afraid to be put under water when she was baptized.

"No," said Susan, "because her father did it. She trusts her father."

When she was eleven, in a Primary talk about "What I Am Thankful For," Natasha named family members and friends, her teddy bear, telephone, cookie monster book, doll, bed, and more significantly, "TALK FRIENDS," and most significantly, "NATASHA ME," and "MY COME ME." With follow-up questions, Susan was able to translate this as, "I am thankful I came to earth as ME."

During Natasha's teens, Susan taught her seminary lessons at home.

One day she found Natasha teaching her doll Jennifer, as she often did with what she was learning at school.

“What are you teaching about?” Susan asked.

Natasha answered, “LEARNING ABOUT SCRIPTURE BEHOLD I WILL GIVE YOU GREAT JOY THAT ME AND MY HOUSE WE WILL SERVE LORD.”

Another day when Susan found Natasha teaching seminary to Jennifer, the lesson was:

GETTING KNOW JESUS
 LOVING NICE
 WEARING WHITE CLOTHES
 LIVE WITH HEAVENLY FATHER
 BORN DECEMBER 25
 KEEP COMMANDMENTS
 KEEP SUNDAY HOLY
 I WAS NEED A PLACE TO LIVE
 I WAS SICK TAKE CARE

Here are some excerpts from an October 2000 dialogue between Natasha and her parents about Natasha’s temple experiences. The first time she had gone to the temple was at age three to be sealed to her family. Natasha did not remember this first visit.

“How old were you the next time you went to the temple?”

FOURTEEN

“Why did you go?”

YOUNG WOMEN’S BAPTISMS FOR THE DEAD

“Why did you do this?”

THEY CAN’T DO IT THEMSELVES

“How did it make you feel to do this?”

GREAT

“How many times were you able to go?”

THREE OR FOUR

“Is there anything special you remember about your endowment?”

FAMILY THERE

“How did you get around in the temple?”

DAVID AND DAD [There are steps between rooms in the

Cardston Alberta Temple. Natasha and her bulky wheelchair had to be lifted up them.]

“Why was it important to you to take out your endowment?”

HEAVENLY FATHER WANT US TO RETURN

“Have you gone to the temple since then?”

YES

“Why?”

WORK FOR THE DEAD

“Why does work have to be done for the dead?”

SO THEY CAN BE WITH HEAVENLY FATHER AGAIN

At this point, Susan thought the conversation was over, but Natasha was excitedly writing something else: “CHANTELLE HAD WEDDING IN TEMPLE.” This was very special to Natasha because the wedding was four months after she was endowed, and she was able to attend.

When the bishop recently asked Natasha to bear her testimony during a talk he was giving at a joint priesthood and Relief Society meeting, this is what she wrote, one sentence a day over a two-week period, with no help:

THANK YOU EVERYONE HELP ME GET BETTER.

HEAVENLY FATHER IS LOVING.

HOLY GHOST LISTENS TO PEOPLE.

JESUS DIED FOR US.

HEAVENLY FATHER MAKE US FEEL BETTER.

HEAVENLY FATHER GIVE US FRIEND.

HEAVENLY FATHER GIVE US WONDERFUL SISTERS AND BROTHERS.

JESUS LET US CELEBRATE HIS BIRTHDAY.

HEAVENLY FATHER TEACH US HOW PRAY.

JESUS TAUGHT US HOW LOVE.

JESUS TEACH US HOW GIVE.

When Susan asked Natasha some questions I had mailed for her, Natasha was so excited that she answered them all at one sitting, then added more responses and wanted more questions. Here are some of them:

When you pray to Heavenly Father, what do you pray about?

HEALTHY, GOOD FAMILY

How does Heavenly Father make you feel better?

MEDICINE [With follow-up responses, she explained that God helps people know how to make it.]

What do you think is the most important thing people can give to each other?

LOVE

What do you think is the purpose of life?

GROW

What is the hardest thing about life?

SICK

What is the best thing about life?

FAMILY

What do you want to do in heaven?

TALK, FALL IN LOVE, WORK, FAMILY [meaning a husband and children of her own]

Is there anyone you feel sorry for?

JOY

Why?

SHE HASN'T LOVE

Why do you think Jesus died?

LOVE US [Not justice, mercy, blood sacrifice, or atonement. Just love.]

When do you feel closest to God?

SICK

Why?

HELP

Is there anything you wish were different than it is?

FAMILY [of her own]

I asked Natasha what she likes best at church. After thinking for a while, she slowly activated the computer and replied, "I DON'T KNOW."

I asked if she could tell me one thing she likes about church. Her answer was "FRIENDS."

There was a period, Susan says, when Natasha was lonely, "dying for friends." Susan arranged for a girl from church to come over to visit and, in time, others also, taking care that Natasha not be a charity case and the visits not be gold-star-earning service projects but just plain acts of friend-

ship. Natasha gained friends and delights in visits with them. (There is little joy in being at best an object of kind, tolerant pity. Natasha yearned for friends and knows one when she sees one.)

When the ward chapel was being remodeled, two men thought, "If we cut off the bench by the organ, Natasha can sit in her wheelchair next to the organ while her mother plays for choir practice and sacrament meeting." They got permission and did cut off the bench for Natasha.

George sings in the choir and Susan is the accompanist. They began taking Natasha with them in her wheelchair in the van. Natasha loved the choir and loves "singing" hymns with the congregation. At choir practice, she began making noises as the choir sang: Susan says she "Let it all out" and "sang" though without controllable pitch, melody, or rhythm. Choir members and director smiled, and some told Natasha what a happy thing it is to have her making music with them. Natasha understands that she remains silent during performances. In the medieval Catholic Church, only unison singing was allowed—no diversity of voices, no harmonies from diverse pitches. I prefer the harmony in Natasha's ward.

Natasha's computer is too cumbersome to be taken to church. She does not verbalize questions there or make comments. Some teachers would consider her the perfect listener, attentive and silent.

Unless they ask Natasha later, no one knows what she thinks of a teacher, a talk, or an idea. If she does have a question or new idea, she can think about it but her disabilities prevent her from searching the scriptures, wandering into a library or bookstore, scanning the internet, or exploring the idea with diverse persons. Her computer language makes quick dialogue impossible.

Utterly dependent upon her family for life and language, Natasha has also been dependent on them for religious experience, if indeed religion can be considered a category separate from all else in the McDonald family.

"Susan," I asked one day, "you didn't grow up with seminary or regular church meetings. As a child and teenager, how did you develop your understanding of the religious concepts you've taught Natasha?"

"By watching my parents," said Susan. "Both of them."

A relative has asked what I think Natasha's I.Q. might be, a question impossible to answer. "I.Q." is an arbitrary measurement of selected skills representing norms for a specific group. Neither Natasha's remarkable memory nor her thinking skills could be demonstrated on standard I.Q. tests that require verbal ease and the capacity to copy or rearrange pat-

terns. To assess her intelligence would require finding 10,000 persons like her to create a standardized test, and what would be the point anyway?

More productive questions might be, "How can Natasha and I know each other and enjoy each other? What do we have in common? How are we different? What might we give to each other?" Such questions might be explored by talking to Natasha as to any person ("she has *ears*, you know"), and seeing through her eyes, and listening to her even if it requires more time, patience, and attention than is usual in casual conversation. It might mean asking follow-up questions rather than hurrying to talk over her or answer the questions for her. This may take practice.

When I called Susan to ask whether she and Natasha would participate in preparing for this discussion, we agreed that she should talk it over with Natasha, which she did.

"Natasha wants to know what the purpose is," she said, "and so do I. We agreed that if it is to glorify someone, no, but if it is to help anyone understand that the disabled are persons like themselves, we will do anything we can."

Experience with Natasha, Susan, and Aunt Marsha has evoked for me many considerations, some of which I'd like to suggest here:

1. According to Deuteronomy, for at least two reasons Natasha could not have joined the religious community in ancient Israel: she is an illegitimate child, and her body is frightfully flawed beyond the norm. There is a third reason not included in Deuteronomy: Anciently she would not have survived her birth, not breathed a breath, not been deemed worth saving. Among many peoples of scarcity, resources are not "wasted" upon so needy a person. But in our own time and place, medical personnel do all they can to enhance the life of a Natasha, and the Alberta government does all it can afford. Shall religious persons today do less?

2. Our church says that little children do not need baptism or other rituals, because they are not accountable and do not comprehend profound solemnities. Should we say, then, that rituals don't matter to Natasha—she is as a child who cannot sin or comprehend?

Her one-word categorical answers and helpless body do not make Natasha a twenty-four-year-old child.

What has she gained from the rituals, and what would she miss without them? They have given her a sense of formalized community with the living and dead, as well as with God, which is especially precious to one who has known isolation and loneliness. Rituals have affirmed for her

transcendent reality beyond present experience. She feels she has made necessary preparation for heaven where she can move, talk, and marry. She has helped others who could not act for themselves. In rituals she has done what is right and good, which matters to her, and she has made her family happy, which matters greatly to her. Most especially, she considers herself a normal person and would not understand why she could not be baptized and endowed like everyone else.

3. Persons have questioned for millennia why an all-powerful benevolent God allows unearned suffering, loss, or disability, and many have written contradictory conclusions as though they come either from God or from irrefutable logic based on unquestioned assumptions. In the dark of the night, with excruciating muscle spasms, or struggling to breathe or swallow, or laboring to express herself in language like and different from that of those around her, Natasha might have believed in a distant God, unapproachable without an intermediary, a God judging her for the very limitations he is inflicting upon her, but instead she knows, as I do, a God who is a helper and close comforter as we struggle to grow with a degree of agency on a globe with inherent material laws, among fellow humans who also have much growing to do.

4. Lenin called religion the opiate of the people, and often it is so. But opium dulls not only pain but also the soul. Natasha's religion enlivens her.

5. When my husband Bob came out of anesthesia from open-heart surgery, all yellow, puffy, tongue hanging out, tubes down his throat and in his nose and arms, unable to move or talk, he motioned to the nurse for pen and paper, and wrote, "Life is good." At age eleven in her Primary talk about what she is thankful for, Natasha said, "MY COME ME" ("I am thankful I came to earth as me.") When low functioning autistic Tito Mukhopadhyay was asked, "Would you like to be normal?" he scrawled in rough but legible script, "Why should I be Dick and not Tito?"¹

6. I'm remembering a comment of John Gardner, a now-retired BYU physics professor who said to me one evening long ago, "I've been pondering how to be the best Mormon I can, and think it might be by being the best physicist I can." Can George and David's hip-high changing table, ceiling trolley, and platform tub, and Susan's use of them to keep

1. Madhusree Mukerjee, "A Transparent Enigma," *Scientific American* 290 (June 2004): 49.

Natasha clean and comfortable, be separated from their religion? Can Natasha's doctors, or inventors of medicines, tubes, surgical instruments, computers, wheels under her chair, or legislators who enable the handicapped be separated from the history of western religion? Can religion ever be a separate category, even for atheists?

7. For millennia, many have said that only fear of detection and punishment, or hope of reward, deters able persons from the evil they would otherwise do. I do not believe this. Have they never known persons in whom fear of punishment and hope of arbitrary reward are absent, people who move on love, or on what is quite simply a good thing to do?