

The following is an account of how one young man, born with a disability, took control over his own health care decision making.

Paradigms, Disabilities and Ethics

Russell Ohan has a disability. As the result of temporal lobe damage, he has epilepsy and a type of obsessive behavior known as perseveration. Some consequences of Russell's perseveration are that he is literal, concrete and suspicious. Subtlety and nuance do not make his world seem more orderly; he constantly tests for congruence between the talk and the action of the people with whom he interacts.

Russell and I are colleagues. We both served on the task force that Midwest Bioethics Center and the University of Missouri - Kansas City's Institute for Human Development formed to consider issues raised by the prospect of adults with disabilities participating in their health care decisions — the group which authored the guidelines document in this issue of *Bioethics Forum*. We also serve together on the Heart of America United Way's task force for volunteers with disabilities.

Since my best understandings about ethics have been distilled from the stories people tell me, it is fair to say that Russell is my teacher.

Recently I was introduced to the Prader-Willi Syndrome, a disability that has as its primary characteristic an insatiable appetite, which results in obesity. The perseverative aspects of Russell's disability and of Prader-Willi Syndrome are very similar. However, Russell and the people who have Prader-Willi Syndrome have been armed with different ways to understand their disabilities. Since adolescence, Russell's health care providers have encouraged him to aggressively participate in the management of his disability. Adults with Prader-Willi Syndrome are told they cannot survive on the frontier, that they are among society's most vulnerable members — unable to independently manage their disability but deserving of protection from its effects.

Russell received two messages from his health care providers. Neurologists told him his epilepsy is evidence of unusual electrical activity in his brain and that, while we know a lot about seizure disorders, there is also much that we don't know. He was told that his assistance was crucial to controlling his seizure disorder and that he should look for patterns that might explain when or why his seizures occur. Mental health providers told him to show his anger and to give straight answers. Since we met in 1993, Russell has favored me with a string of autobiographical writings. In the first of these, Russell wrote, "Epilepsy is what I have Lived With, NOT What I am."

Providers of care to people with the Prader-Willi Syndrome give a different message: "Your disability is the result of a blemish on your 15th Chromosome. You did not inherit the Prader-Willi Syndrome. Although the syndrome's

effects vary from person to person, the variations among people who have the syndrome are less important than the differences between you and the people who do not have the syndrome. Though we can't explain why you have it, we know, and we want you to know, that it is the defining part of who you are. And even though the syndrome is a life-threatening disability, we will save your life."

If his perseveration had been accompanied by an insatiable appetite as in Prader-Willi Syndrome, health care providers would have assumed responsibility for creating the best possible Russell. But, since his perseveration is accompanied by a seizure disorder, his providers told him that whether the best possible Russell emerges is largely up to Russell. Russell, therefore, dedicated himself to observing and reporting things that might bear on his disorder. The following excerpts from Russell's written record of his observations demonstrate his involvement in his health care.

—Russell's Notes —

The FACT(s) is/are:

During November '86, a co-worker informed Russell to NOT consume Cold Cuts, Canned Fruits. Russell Stopped Consuming Cold Cuts, Canned Fruits.

Russell ate basically ZERO food April 8, '87 thru May 16, '87. Russell consumed water in excess, remaining SEIZURE FREE, without feeling a sign of HUNGER, NOR an aura.

During both May 17, '87 and May 18, '87, Russell consumed ONLY Cheddar Cheese, Crackers, and Water. During both May 17, 18, '87, Russell experienced seizures.

During May 18, '87, Russell stated to himself I have lived this long eating ZERO food, taking all this medicine on an empty stomach, Without feeling a sign of hunger, Without having an aura, and experiencing ZERO SEIZURES while NOT eating. Maybe I am allergic to dairy products like Dr. [name] stated. I WILL continue drinking water daily and find out if I can live longer than three consecutive months without having a seizure, If I can live this long without eating, I will be able to live four consecutive months without eating.

During May 19 '87 thru September 14 '87 Russell consumed water in excess daily at the same time Russell consumed ZERO food four consecutive months, Russell lost thirty-nine pounds without feeling a sign of hunger, without experiencing an aura, experiencing ZERO SEIZURES.

During January '88, Russell informed [name] I have

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consumed steak for supper each of the past fourteen days. [name] informed Russell Stay away from fried foods, bake your meats.

Dating back to January '88 Russell has cooked zero fried foods at home. Russell has consumed fried foods ONLY when Russell has eaten in restaurants, fast food.

During 1988, Russell was transported to [hospital] from [hospital]. At the same time Dr. [name] stated Your sodium level is at 124, that's way too low, and hospitalized Russell. Russell did not understand Russell's sodium level being what is TOO LOW.

SIDE NOTE: Russell consumed fourteen ounces of chips. Russell traveled to (location), testing [emergency service provider]. Russell experienced one seizure at [location] two different times.

During 1988 thru 1993, Russell put himself to the TEST by TESTING Dr. [name's] stating Dairy products will give you constipation. Russell consumed as many as twelve slices of cheese with fourteen ounces of chips a number of times. Russell experienced both bowel movements and seizures after Russell consumed cheese and chips.

During seven consecutive days of December 1993, regardless of what food(s) Russell consumed, Russell's body increased in temperature immediately after Russell finished consuming breakfast. Russell questioned Dr. [name] of Russell's body increasing in temperature. Dr. [name] stated Cut Down On Your Salt.

Before Russell informed Dr. [name] of his Indigestion Russell put himself to the TEST by TESTING himself. In testing himself, Russell consumed a full bag of chips with thoughts: Perhaps eating chips will help my bowels move. After Russell consumed a full bag of chips, Russell experienced a seizure.

During February 1994, Russell consumed four pieces of a small size Meat Pizza from [restaurant]. Russell experienced a seizure inside (restaurant). Russell was transported to (hospital) by ambulance.

During February 1994, at the same time Russell was placed in [hospital], a dietitian visited Russell. UNLIKE Dr. [name], the dietitian Explained (NOT state, She made it plain) to Russell: Cut Down On Your Salt, INFORMING Russell Cheese is High in Salt. What helped Russell misunderstand [doctor] is the fact, Russell uses Table Salt heavily.

Clearly, when his health care providers told him to look for the patterns that might explain seizures, Russell thought they meant it. During 1994, Russell reported his observations to the Mayo Clinic. On September 1, 1994, the clinic admitted him to its neurology program and on September 12th a surgery (temporal lobectomy) was performed to reduce his seizures. Russell has been seizure free since the surgery.

Russell's story supports the proposition that, if listened to, adults with disabilities can be essential participants in their health care. While seeming to tip the scales in opposite directions, I believe that both the model which Russell embraces and the alternative that the provider of care to people with the Prader-Willi Syndrome frame, are similarly afflicted. Both support the notion that persons who have disabilities are "others"; both excuse our inability to fix their disability.

How ought we explain to a person who thinks concretely and who constantly tests the congruity of what others say and do, that our straightforward explanation of how his disability establishes his relationship to the world is actually complex and self-serving? If we do not disclose to Russell our beneficial stake in the paradigm we have offered to him, how can we be faithful with him if he takes us at our word?

The task force that wrote the Midwest Bioethics Center - Institute for Human Development guidelines document responded to these issues with an alternative vision of the relationship between health care and disability. On one panel it painted a decision-making collage in which neither patients with disabilities nor physicians dominate. The second panel is a graphic, two texts. One is the rights of an adult with incomplete decisional capacity to participate in her health care. Alongside are those rights for an adult with decisional capacity. The two texts are identical. The third panel includes a critical open process for confirming the absence of decisional capacity, sketched against the background presumption that everyone has decisional capacity. The three-part process promotes making the least necessary accommodations to an individual's disability.

Vanity may propel me to understand Russell's disability as marginalizing. Vanity may push Russell to see himself as hero. Is he a scout, alone on the frontier or is he a victim, vulnerable at the margin? According to the guidelines document, we're both wrong. In this, as otherwise, Russell and I are more alike than unlike, and there is no *other*.