

My brother John McCoy is 66 years old and has lived at Polk Center for 48 years. He lived for his first 17 years with his family on a dairy farm near Emlenton, PA.

John has Downs Syndrome, is deaf, and doesn't speak. He is mostly passive and sits quietly dangling strings in front of his face. He tears his socks or shirts to get the strings and usually has several extra strings stuffed inside the front of his shirt.

He has a psychiatric diagnosis of Pervasive Development Disorder, not otherwise specified, with Obsessive Compulsive Spectrum. This causes him to be very ritualistic in his behavior and want his surroundings "just so". He may lick his shoes or remove his clothing. He does not want his daily routine or habits changed.

John can be very stubborn. If he does not like what is happening to him he may refuse to move, stomp his feet, or just sit down. He will not tolerate any band aids , IV's, or other medical devises on him. He may rip them off and throw them.

John has had failed surgery for Atlanto Axial Subluxation and cervical stenosis. He is at great risk of severing his spinal cord if he should fall or otherwise injure his cervical spine. He is not permitted to climb stairs or play sports.

John has a history of passing out, thought to be a seizure or heart problem. He has refused to allow hospital personnel to do diagnostic medical tests. He often requires Ativan to be given to calm him for medical appointments.

He has a swallowing problem and no teeth. He does feed himself but his solid foods must be puréed and his liquids must be thickened. A sip of unthickened soda pop can cause him to have aspiration pneumonia.

John has bronchial asthma and allergies that cause him to have a constant runny nose. He must be reminded by staff to wipe his nose.

John does not communicate or initiate interaction with others. He is totally dependent on staff to recognize when he is not feeling well or in pain.

He does not recognize safety hazards and has no fear of danger. He does not understand the consequences of his actions. He is dependent on staff to protect him from such things as fire or traffic.

John has a history of wandering off by himself if someone leaves a door unlocked and he can get outside. This puts him at risk of traffic, hypothermia, falling and many other things. He would not hear a car horn or understand that he is in danger.

He does not recognize the necessity of wearing seasonally appropriate clothing.

John has hypothyroidism and osteoporosis.

His feet are deformed and he must wear special shoes.

Staff must use gestural prompts to encourage him to bathe and otherwise care for himself.

John is at great risk for financial or physical exploitation

John spent his first 17 years living in the Emlenton community on a dairy farm. He has an older sister and an older brother. He lived with his family, attending church, going to family functions, shopping, visiting grandparents, playing with his siblings, and throwing things at cats. He often went to the barn with his parents when farm work was being done, or stayed in the house with his sister while she did homework and watched him. He learned to walk at age 3. He learned

to feed himself at age 10. He loved to tear Kleenex into strips and tuck them into the edge of the heaters. He would watch them flutter in the breeze when the furnace turned on.

All four of us loved John, cared for him, watched him, and tried to keep him safe. He had 24 hour care. My parents put locks on all the outside doors. In spite of all this John managed to not be safe and even put us all at risk. One time he caught a throw rug on fire in the fireplace, threw it on a stuffed chair, and had a blazing fire with high flames burning in the living room. He had no concept of danger and was jumping up and down waving his arms, very excited to see the flames flying in the air. I discovered it, called my parents, and they came running with water to put out the fire. We lost a rug, chair, and carpet, but we could have easily all lost our lives.

Another time he threw my mother's nightgown up on a ceiling light fixture where it smoldered and caught fire. That was discovered quickly and no harm was done. He liked to throw things. He hit our television and broke the glass. He threw things through many windows. My parents became experts at installing new glass in windows.

As John got older he liked to go for long walks by himself if anyone left a door open. One time he took off all his clothes and walked across several fields and down a road to a neighbors house. He scared the elderly woman that lived there when he opened her door and walked bare naked into her house. Thankfully her adult son was there, and he guessed who John was, got him in the car, and brought him home. If this happened where John was not known, he could have not answered any questions and it could end tragically. My frantic mother had no idea which direction he had gone as she tried to search for him.

I could tell many other stories of how four loving, caring family members that knew John well, could not keep him safe.

By the time John had reached age 17, our father had died, and my mother was age 60. She realized John was getting stronger and she could not provide the care he needed. She and my father knew this would happen someday, and they had previously put John on a waiting list to live at Polk Center. When John's turn came, she and my uncles made the very heartbreaking decision to take him to live at Polk. We could all visit him and he would be safe and well cared for. We thought for the rest of his life.

WE ARE NOT IN FAVOR OF TRANSFERRING JOHN OUT OF POLK!

John has been safe and well cared for at Polk. He has learned many things from the staff there about caring for himself, keeping himself clean and healthy, and even enjoyed being productive with simple employment to earn spending money. They have taken him outside the center to activities such as eating out and going to sporting and holiday events as money allowed. The staff know him and how to handle him. He knows them and trusts them.

One time, after he had passed out, he was taken to UPMC hospital for tests. I went to the hospital too, when Polk notified me. John allowed the nurses to insert an IV in his hand. When they had finished it, he ripped it out of his hand and threw it across the room at them. They all ran from the room into the hall. I could do nothing to calm him. I sat in his room and cried. The hospital contacted Polk and asked for help. When one of the men that regularly took care of John arrived, he calmed down immediately as the man entered the room. He still didn't cooperate with all the medical tests, but he obviously felt safe and content with that man. I am forever grateful to that man.

He still will wander off for a solitary walk if he can slip through an open door. But at Polk, the townspeople would know where he belonged if

they saw him. Someone would likely call Polk Center to have someone pick him up. In another location they might reach for a gun and shoot.

Our fears and concerns if John is moved are for his physical and emotional health and his safety.

He has so many medical issues that require constant monitoring and care. He cannot hear or communicate. He has no concept of danger. If he falls, his weak cervical spine could move and instantly kill him. His food must be specially prepared to prevent aspiration pneumonia. Anyone could take advantage of him. His dislike of change can cause him to be very stubborn and combative, possibly injuring himself or others. If he would wander into traffic, he is at great risk of being injured by a car or truck.

HE HAS NO CONCEPT OF DANGER OR THE CONSEQUENCES OF HIS ACTIONS.

He could put both himself and those he might live with at great risk.

To sum up, in the words of John's niece, Cathy McCoy, " Uncle Johnny didn't ask to be born with Downs Syndrome as well as deaf and mute. Please speak up to plead that he be allowed to stay at Polk Center where he's been as safe and happy as he has the capacity to be for most of his life."

Sincerely,

Jean McCoy Milliron, sister and guardian of John McCoy

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