

My son Steve is 45 - I am 71. In addition to having an IDD, he has multiple physical disabilities, the most recognizable of these being Cerebral Palsy. His overall diagnosis is Trisomy 8 Mosaic, a quite rare condition. Despite years and years of caring for this young man, I still quite often find myself learning something new about his limitations. And as we grow old together, I am also recognizing that we are both growing considerably weaker together as well.

It is this last point, that we are both growing weaker, that concerns me the most about the prospects for his future care. I contribute a lot of time and effort to keeping him healthy, clean and presentable to the community to preserve his dignity and provide him the best opportunity I can so he can enjoy his life without stress or worry.

Steve is a wonderful person. He never has an unkind word to say about anyone or anything. He's quite outgoing once he gets to know you and very personable. He rarely lets his multiple physical disabilities get him down. His personality is such that people tend to think that he is more capable than he truly is. But intellectually he is a babe in the woods. He's not capable of simple math, or handling money, and doesn't seem to have much of a concept of time. He is extremely dependent on the guidance of others for nearly anything that requires decision making, including much of daily living. There are things he's learned to do by rote – simple repetition. And yet there are other things that he just does not seem to be capable of utilizing a thought process to accomplish. An example is washing his hands. Left to his own he will obsessively wash only the back of his left hand. The CP that dominates his left side is a partial explanation for this, but he does have the capability of washing both hands when guided through it – it just doesn't seem to occur to him. He knows there are things he must do at certain times, such as taking his medications for example, but he can't be trusted to retrieve the proper medications at the proper times.

Some might say that we've been over protective of Steve, that he could do more for himself if it was demanded of him, and I'm sure there's at least some truth to that. He does have an annoying habit of waiting for others to do things for him that he could do himself. I'm sure any outsider would say we've developed extremely co-dependent relationships, but I guess that would be true of nearly any caretaker relationship. That co-dependence has developed as a result of years of love and caring. And as a result, Steve may be a bit spoiled.

I think what will be hardest for Steve when we pass on is that his caretaker(s) are likely to expect him to do things for himself that they "think" he is or should be capable of doing himself. I opened this essay by stating that I am still learning after all these years that my expectations of his abilities are sometimes over-demanding. How will he react when his caretakers are expecting him to do something he either can't do physically, or doesn't have the thought processes to guide him through it? How will the caretaker react when Steve tries her/his patience because the caretaker doesn't fully understand his mental limitations?

I also worry about the physical capabilities of future caretakers. Steve falls fairly frequently. The frequency he is able to get up by himself seems to be decreasing. My ability to lift him also seems to be decreasing.

I would love to have the opportunity to work with his eventual caretaker over a period of time to provide coaching – time for discussion and feedback during a transition period. I think this would be the most humane way to set his future without his parents.

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