

We Are NOT Helicopter Parents ...by choice

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hel-i-cop-ter par-ent
noun informal

a parent who takes an overprotective or excessive interest in the life of their child or children.

To the outside, uninformed world, parents of persons who have Prader-Willi syndrome look like Helicopter Parents. This column is *not* for parents. This column is for everyone else.

Dear Outside Not-Yet-Informed-Enough World:

Please believe us when we tell you we are **not** Helicopter Parents by choice but by sheer necessity.

In our world, if we are not managing and supervising and directing and educating and organizing our child or adult child's life, he no longer has one – or any quality of one.

Please believe us when we tell you that we don't *want* our child to become "dependent" upon his class aide or his house staff or his work coach. *Even more than you*, we *want* our child to be independent, self-regulating, self-sufficient, self-reliant, flexible, productive citizens. Our reality – at least for now – is that supervision or shadowing or aide support or *whatever* you call it is *necessary for our child's survival*.

Please believe us when we tell you we don't *want* to direct who our child plays with, what activities they play, and how they play. We don't *want* to scrutinize our adult child's computer and phone and Facebook account and every nook and cranny of their bedroom. We don't *want* to have to have one ear at the door listening to every interaction, on the ready to intervene or intercede or re-direct. We *want* our child or adult child to have his alone time, his solitude, his privacy.

Please believe us when we tell you we don't *want* to supervise or coordinate or oversee or do for him our adult child's activities of daily life. We *want* him to be able to wipe his bottom sufficiently, shower, bathe and groom himself satisfactorily without prompts or reminders or arguments. We *want* him to be able to select the proper attire according to the weather or the event he plans to attend. We *want* our adult child to manage his own finances, to shop for and prepare his own meals. Shoot, we'd *love* for him to prepare a meal for us! Please believe us when we tell you our adult child needs 24/7 *awake* residential staff supervision and that securely locking access to food reduces anxiety. We *want* him to be independent, ride his bike or drive his own car or take public transportation or even walk to where he needs or wants to go all by himself.

Please believe us when we tell you we don't want to volunteer in our child's classroom *so* often and attend *every* class event, and we don't *want* to be the only adult who stays at the only-kids/adult-kids party. We don't *want* to chaperone every work party or school dance (especially the ones with painfully, deafeningly loud music) and station ourselves near the food

tables until our bums become as flat and cold as the folding metal chair we're sitting on. Please believe us when we tell you that the behavior plan you developed may be perfect for someone else but is *not* appropriate for our child, or that our child still needs help wiping his bottom *not* because we haven't been teaching him but because his motor planning skills aren't proficient enough yet or his back brace interferes with his reach.

Please believe us when we tell you that arriving late to pick up our child will *not* teach him to be more flexible and that we are *not* coddling our child when we do not react to his temper tantrum. We don't *want* to have eyeballs on our child at all times and scrutinize and override and argue about our child's food consumption at family parties and reunions and celebrations and holiday gatherings and barbeques. We'd *like* to enjoy *ourselves* at parties and gatherings and barbeques, but if we take our eyes off our child for even a few minutes, that could mean his death.

Please believe that we *want* our child to make friends on his own, watch and learn from his contemporaries, work out disagreements on his own. We *want* our child to have a girlfriend or a boyfriend, to one day walk elegantly down the aisle under a beautiful wedding veil, or stand secure and confident as the love of his life walks down the aisle toward him.

Please believe us when we tell you we don't *want* to be overly protective or excessively involved in our child's life. *Even more than you* we want our child to be an independent, self-sufficient, mature adult. Until we are absolutely confident that the individuals in our child or adult child's life understand how Prader-Willi syndrome impacts him, we will have to continue to educate and advocate and supervise and scrutinize and yes, sometimes even "helicopter" because this is what is *necessary* to keep our child secure and happy and safe. This is our job and, like any pilot who is entrusted with the comfort and safety of his passengers, we take our job very, *very* seriously.

For more information about Prader-Willi syndrome contact
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