

A French Fable and the Dignity of Risk

Jennifer Harrison

“Overprotection may appear on the surface to be kind, but it can be really evil. An oversupply can smother people emotionally, squeeze the life out of their hopes and expectations, and strip them of their dignity. Overprotection can keep people from becoming all they could become. Many of our best achievements came the hard way: We took risks, fell flat, suffered, picked ourselves up, and tried again”

-Author of Dignity of Risk, Robert Perske, 1972

The Little Prince, French author Antoine de Saint-Exupéry’s traveling lad from a galaxy far from ours, fell in love with a rose. He adored that rose with everything within him. He spoiled her with water, barricaded her space (lest caterpillars trample her with their six loathsome legs), and – most important – placed her under a glass globe to keep her safe and warm. It appears to be the epitome of care, this affectionate fortification. But perhaps our petite princeling was a little overzealous (he does later admit, “I was too young to know how to love her...”) or wasn’t properly primed for the task, as the rose eventually expires in the soil. Could he have saved her? Was it simply beyond his sway? We cannot know. What we do know, however (as our planet promotes evidence-based practices), is that LP’s approach to protection is not appropriate for us. For we are not flowers, and our dreams reach much further than can petals.

That probably sounds better in French.

But, still...

People with intellectual and developmental disabilities have goals and passions, just like their neurotypical counterparts. They want to achieve things that may be difficult, that people may say are over-ambitious. These dreams range from Mundane to Beyonce, but the conundrum remains the same: how do we allow those we love or care for to take the potentially treacherous steps toward achievement while at the same time preserving their security? The answer is called The Dignity of Risk.

The Partnership for People with Disabilities (PPD) at Virginia Commonwealth University defines this concept as “the right of a person to make an informed choice to engage in experiences meaningful to [them] and which are necessary to personal growth and development.” And although there is no direct mention of it, the risk is baked right in. Because, as we know, few pursuits are executed without at least a little gamble. Stakes are high when

we care about outcomes: hearts can be broken, as can glasses, teeth, and bones. On the flip side, records can be broken, as can patterns, barriers, and The Proverbial Mold. So, how are we to know when the uncertainty is worth it? Because it always is. If it's done safely. According to North Dakota Health and Human Services, the guiding principles of the Dignity of Risk include:

1. Treating people fairly
2. Being an advocate for exercising their rights to the fullest extent possible
3. Supporting the person's preferences and values, rather than one's own
4. Providing supports for health and safety by using least restrictive methods
5. Being realistic with expectations

And why should we employ this approach? Simply put, because it is their right. Like all humans, people with IDD have the right to self-determination, and require it for building self-esteem, confidence, and empowerment. Does that mean if Cousin Leo develops a yen for skydiving we should pile on the parachute packs and get ready to defenestrate? Not quite.

PPD explains that "rather than protecting people with disabilities from disappointments and sorrows, which are natural parts of life, support them to make informed decisions," emphasis on "informed." In short, feed the dream, but first arm the dreamer with education. This is what keeps D of R from coming into conflict with, well, care. We have to take into account the wants, needs, strengths, and capacities of our loved ones with IDD, as well as their family, friends, and lifestyle, then help them achieve their goals in a safe and thoughtful way. Working with this in mind is known as "person-centered planning," which entails including people with IDD in all decisions concerning them - a swanky way of saying, "Nothing about us, without us."

To be sure, it is a delicate balance. A person's autonomy and a caregiver's

intervention can be at odds, and a tip too far to either end can easily jeopardize both success and safety. Australia's LifePlan.org of Perth recommends, "providing [people with IDD] with the tools and information they need to make decisions effectively" as well as "knowledge and support about their rights, abilities, and opportunities." It is about truly working together, in which ambition is tempered with caution, aspiration with prudence, and impulse with a healthy dose of education. In short, making yourselves a Dream Team. LifePlan goes on to advise:

- Taking a holistic approach to assessing a loved one's needs and providing

care

- Including families and friends in the decision-making process
- Focusing on strengths and goals, and working within a positive framework
- Supporting values, rights, beliefs, and positive relationships
- Encouraging choice wherever relevant and within an environment of

respect

And Virginia Commonwealth adds:

- Openly discuss options a person may have when they are faced with making a decision
- Take time to engage in multiple conversations to understand the level of risk involved
- Be clear about your role: What is your core responsibility? How will you use creativity and judgment? What is not your responsibility?
- Remove your own personal values and beliefs about the person's situations and choices

It seems so easy, paring back the transparent barrier, exposing our rose to the cold and the vermin and the wonderful unpredictability of wide-openness. After all, it just takes the strength of a few fingers to remove the cloche. But we know how difficult it can be to refrain from fending off peril when it comes to ones we love and after a lifetime of doing so. So, it comes down to finding that balance - a comfortable space to settle into where each side gives a little and each side gets some, in turn - and forging that accord. Knowing they are strapped tightly into their driver's seat, airbags activated and all systems go, we can sleep much better at night... and our loved ones can dream much bigger.