

Benjamin's Hope: Dignity in Action

by Krista Mason, Executive Director of Benjamin's Hope and Mom of Ben



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Dignity in Action

When Ben was a child, the high point of summer was a week at Springhill Camp. Early in May, he would start saying, “go camp go camp go camp.” At last, the joyous day would arrive, and we would pile in the car to make the two-hour drive to Springhill. Arriving at camp was, for Ben, akin to reaching the promised land.

For me, it was a mixed bag. I knew Ben LOVED camp. Yet, as a parent, leaving my non-verbal autistic child with a bunch of young camp counselors required a herculean act of blind trust. Will they understand him? If he gets angry, will they know how to help him be calm? What if he gets hurt? What if, what if

Each day, I eagerly checked the photos posted to the parent portal. I would see Ben swimming. Ben riding a horse. All the usual camp stuff.

Then, one day I opened the portal and saw Ben strapped into high-ropes gear, sailing down a zip line high above the ground. I was thrilled, exhilarated, relieved (because it was clearly over), and shocked.

This is my point. I was shocked. A picture of my older son (who is neurotypical) on a zipline would not have shocked me. Why did this picture of Ben shock me?

Duty of Care vs. Dignity of Risk

Wikipedia defines [Dignity of Risk](#) in this way:

Dignity of risk is the right to take reasonable risks that are essential for dignity and self-esteem and so should not be impeded by excessively cautious caregivers, concerned about their duty of care.

When we find ourselves in a position of providing care, or seeking care, for a loved one affected by disability or mental health issues, or an aging parent, what is our highest value?

Independence, safety, autonomy, and the skill of care all matter. How do we make the best decisions when there are so many considerations?

Sometimes we can offer a cure, sometimes only a salve, sometimes not even that. But whatever we can offer, our interventions, and the risks and sacrifices they entail, are justified only if they serve the larger aims of a person's life. When we forget that, the suffering we inflict can be barbaric. When we remember it, the good we do can be breathtaking. (Gawande, 2017).

Breathtaking is beautifully illustrated in the movie Peanut Butter Falcon. The main character is a young man named Zak who has Down syndrome. Zak has run away from his care home to pursue his dream of becoming a big-time wrestler. Elanor, a social worker from the home, has spent days in search of Zak. She finds him on a beach with a dubious tattooed new friend named Tyler.

Elanor rushes to Zak, laying bare chested on the sand. “Are you OK? Oh my God, are you OK?” While Elanor frantically checks Zak from head to toe, Tyler casually tosses Zak a shirt, saying, “Here, put this on.” Elanor grabs the shirt, pulling it over Zak’s head.

“He can do it.”

“No. Here you go buddy. Let me help.”

“He can do it. He’s a 22-year-old guy. Let him do it.”

Over Zak’s head, Elanor shouts, “He needs help and appropriate care. There are rules. There are regulations. There’s medication. There’s paperwork.” With a mischievous grin, Tyler looks Zak in the eyes and says, “OK. Well, while you’ve been doing paperwork, we’ve been living life. Right, brother?”

We think our job is to ensure health and survival. But really, it is larger than that. It is to enable well-being. And well-being is about the reasons one wishes to be alive. (Gawande, 2017).

How do we get this right? Ben’s Hope is an adult foster care community required to provide care. We’re paid to do this and we’re highly regulated. So, how do we hit the right balance between duty of care and dignity of risk? How do we ensure that we hold the dignity of people who live at Ben’s Hope as our highest value?

We begin by seeking true understanding of what makes life worth living for each person. Then, we apply ourselves to helping life reflect the ideals and values of the people we support. We seek to serve the larger aims of people, in the big things and the small things.

Here’s one example of what this looks like. Joe lives here at Ben’s Hope. A couple of years ago, Joe’s dad died. Joe and his dad were incredibly close, and Joe deeply grieves the loss of his dad and best friend. A SideKick (this is what we call our Direct Care workforce at Ben's Hope) learned from Joe that he and his dad had loved riding on a Harley motorcycle together. You know what that SideKick did? He borrowed a Harley from a friend and showed up with that big,

beautiful bike. Joe jumped on the back, grinning ear to ear, wrapped his arms around his buddy, and off they went.

Yes, the risks are justified when they serve the larger aim of a person's life. And the good we can do is breathtaking!

Thoughts Thus Far

It was 2006 and we were just a few visionaries sitting around my kitchen table dreaming of a farmstead community where people with autism would “live, learn, play, and worship.”

One day, we found ourselves trying to think of a name for this embracing community where people with autism would thrive. I commented that for my son Ben, having such a place would bring almost unimaginable hope for his future. It was a light bulb moment for Dr. Dave Laman. He said, “That it. Benjamin's Hope. That's the name.”

And it stuck.

Now, 15 years later, our 40-acre campus is a buzz of activity, life, and joy! Ben's Hope is a destination for community families, schools, youth, and volunteer groups. And now that spring is here, neighbors are out walking the trails with their dogs, children are playing on the playground, men and women who live in the Ben's Hope neighborhood are riding bikes and leading alpacas and goats around on a leash. The Church of Benjamin's Hope is vibrant and growing as people travel from all over western Michigan to worship at this exuberant and wildly inclusive all-abilities church. And for 32 people, this is home.

Life at Ben's Hope is an everyday wonder! And for me, this is the answer to the deepest prayer of my heart.

Ben's Hope is receiving national attention as communities across the country seek creative and sustainable ways to ensure people with autism enjoy lives of purpose, safety, joy, and friendship.

Benjamin's Hope Today

As we live into the fulness of our “live, work, play, worship” mission, we celebrate abundant life happening in our residential homes, at the Life Enrichment Day Program, and through the Church of Ben's Hope. Hundreds of people are directly touched by Ben's Hope each week.

Ben's Hope is now debt-free and blessed by an engaged community that shares time, treasure, and talent.

Live: 32 men and women live at Ben's Hope in 6 beautiful, farm-style homes

Work: Over 100 people work at Ben's Hope as SideKicks. A SideKick provides care and support and is, by definition, "a friend and a companion in adventure." 25 men and women participate in our weekday Life Enrichment program where they learn skills in gardening and animal care. Participants also volunteer all over the community at places such as Kid's Food Basket, The Holland Museum, Resthaven Assisted Living Center, and Renew Therapeutic Riding, to name just a few.

Play: There is no shortage of play at Benjamin's Hope! In September, we typically have around 2,000 people join us for the Harvest Festival, complete with hayrides, antique cars and trucks, and even a helicopter! Ben's Hope men and women are regularly out and about town at sporting events, concerts, and the library. On Thursday nights, we offer Club Connect, a super cool club for people of all abilities run by local college students.

Worship: The Church of Ben's Hope meets every Sunday night at 6 pm. This refreshing and wildly inclusive all-abilities worship is a great place to connect with the Ben's Hope community. We invite you to join us!

Sources: Benjamin's Hope

Benjamin's Hope. (2024). <https://www.benjaminshope.net/>

Gawande, A. (2017). *Being mortal: Medicine and what matters in the end*. Metropolitan Books.

Nilson, T. (2019). *Peanut butter falcon* [Film]. Lionsgate.

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