

Richard A. Courtney, CELA
Certified Elder Law Attorney
4400 Old Canton Road, Suite 220
Jackson, Mississippi 39211
601-987-3000 or 1-866-ELDERLAW
For more Articles, go to:
www.elderlawms.com

Mid-Month
Musings

“Musing” (noun) – a calm, lengthy, intent consideration

Unlike our first-Tuesday e-newsletter, this monthly essay will not focus on practical legal cases and planning issues. The “Mid-Month Musings” will hopefully inform, inspire and provoke thought about many topics. We hope you enjoy it – and **let us know what you think!**

A Different Destination, a Different Life

My wife and I had a wonderful honeymoon in the Bahamas 34 years ago. A week of sun, fun and no responsibilities except to do what made us happy. When we returned, we began our jobs and activities with friends as we had planned. Then . . . almost 4 years later, we took a trip to a different place – Holland. Well, not really. But according to Emily Kingsley’s wonderful insight (below), that is apparently where we landed. The event could be more accurately characterized as a crash-landing in Holland, since our beautiful, identical, very different twin daughters were born eight weeks early – suddenly – in the middle of the night.

We, as all other parents of children with special needs, have many times asked “Why us?” and “Why don’t they understand?” “They” are the people who have not been to Holland for an extended stay. We understand that if someone has not been in our place, they cannot understand our life. We wish they could. We have endured to find that, while it may not be *the* good life we had planned, it is a good life.

In my practice as a special needs planning attorney, I have marveled at the strength, depth, creativity and goodness of those folk who are the parents, siblings, grandparents, aunts and uncles of persons with disabilities. The two pieces attached below may give you other folk some insight into what it’s like to live in Holland and let you know what the job description includes.

Welcome to Holland

© 1987 Emily Perl Kingsley

<http://www.ndscenter.org/resources/package1.php>

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The coliseum. The Michelangelo David.

The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome To Holland".

"Holland?!?" you say, "What do you mean "Holland"??? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy"

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around...and you begin to notice that Holland has windmills... Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy...and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes that's where I was supposed to go. That's what I had planned".

And the pain of that will never, ever, ever, ever go away...because the loss of that dream is a very significant loss.

But...if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland.

Wanted: Parents For Special Children

(Rewritten by Linda Reid)

JOB DESCRIPTION:

Long term (and occasionally lifetime) team players needed for extremely challenging permanent work in a guaranteed chaotic and often crisis environment. Candidates must possess excellent communication skills in sign language, signing boards and mental telepathy. Must have super-human organizational skills to communicate with various physicians, special teachers, therapists, medical insurance personnel, the federal government, the State Mental Health Authority, and the local school system. Must be willing to work long hours including evenings and weekends and be on call 24 hours a day, seven days a week with cell phone and pager for emergencies.

Travel required to hospitals, clinics, therapy (physical, speech and/or occupational), doctors' offices and school meetings, including occasional (or frequent as the case may be) trips to emergency rooms. Travel expenses not reimbursed. Extensive courier duties also required. Must be hard skinned enough to withstand IEP meetings, and soft hearted enough to help with

the Special Olympics.

RESPONSIBILITIES:

For the rest of your life: Must be willing to be known as the meanest Mom in the special ed school system until IEP's are signed. Must be able to give medications day and night with the expertise of a Registered Nurse. Must be able to operate a feeding tube, suction machine and/or ventilator. Also, must possess the physical stamina of a pack mule and be able to push a wheelchair while opening a door and carrying your purse and a backpack. Must be able to go from zero to 60 mph in 3 seconds flat to turn on suction machine in emergency. Must be willing to face stimulating technical challenges, such as dismantling a specially adapted wheelchair (including seat, back, neck and foot supports and tray) to fit in the back seat of your car if the trunk is too small, changing out a feeding tube, adjusting the lateral supports on the standing table (you will need an Allen wrench), special toy repair, and buttoning and zipping clothing around braces, supports, etc. Must be reached at all times day and night, maintain comprehensive calendaring system for numerous appointments, and coordinate production of special adaptive equipment that has never been invented or used before. Must have ability to organize unlimited stacks of insurance claim forms. Must be assertive, confident, determined and just plain tough one minute, and able to laugh at yourself and your situation the next. Must be persistent always. Must handle assembly and product safety testing of hundreds of expensive special needs toys and battery operated devices. Must always hope for the best but be prepared for the worst. Must assume final, complete accountability for the quality of the end product. Responsibilities also include floor maintenance and janitorial work throughout the facility.

POSSIBILITY FOR ADVANCEMENT AND PROMOTION:

Virtually none. Your job is to remain in the same position for years, without complaining, constantly retraining and updating your skills, so that those in your charge can learn as much as possible, and be as independent as possible, although progress is often slow and tedious.

PREVIOUS EXPERIENCE:

None required, unfortunately. On-the-job training offered on a continually exhausting basis.

WAGES AND COMPENSATION:

You pay the insurance companies, the doctors, the hospitals, the therapists, the school systems, the federal, state and local special agencies whenever required, various attorneys, and the regular and respite caregivers. Payments never stop even after age 18. When you die, you give them whatever is left via a special needs trust. The oddest thing about this reverse-salary scheme is that you would never trade your client for another one, and wish you had the energy and funds to do more.

BENEFITS:

While no health or dental insurance, no pension, no tuition reimbursement, no paid holidays and no stock options are offered, job supplies limitless opportunities for personal growth and free smiles for life.