Writing Our Journey:
Poems and Essays by Family Caregivers
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Dedicated to the memory of Elizabeth M. Boggs, PhD
April 5, 1913 - January 27, 1996
Foreword

Elizabeth Boggs would have been delighted by the Writers Group. She would have read this volume with the intense care of the scientist which was her original career. She would also bring to that reading the deep and shy heart of the parent she became, which shaped both her calling and what became the field of developmental disabilities.

Elizabeth Monroe Boggs was born in Cleveland, Ohio in 1913. She graduated from Bryn Mawr College, summa cum laude, with distinction in Mathematics. One of the first women to earn a doctorate from Cambridge University in England, her work in Theoretical Chemistry, a form of Mathematics, focused on the pre-cursor to the computer. In 1941, Elizabeth married Fitzhugh Willets Boggs, and during World War II they both worked on the Manhattan Project.

Jonathan David Boggs, their only child, was born in 1945 right after the end of the war; he survived an umbilical cord infection only because antibiotics had become available for civilian use. David, whose lifelong severe disabilities were a consequence of that infection, was the impetus for Elizabeth shifting her focus from the career in Mathematics for which she had prepared, to advocacy and the development of public policy for people with disabilities.

Services for children with intellectual disabilities were non-existent as David was growing up. Although Elizabeth joined other parents in starting programs, typically in church basements and staffed by volunteers, David’s disabilities were so severe he was never a candidate for these programs. His chronic sleep disturbances led to his being placed in a residential institution when he was seven.

As parents first began to join together in advocacy in the 1950s, Elizabeth, because of her scientific training and approach, began to serve as a link between families and governments, interpreting for each group their concerns and possibilities. She and Fitzhugh were involved with the creation of the Essex County Association for Retarded Children. A founder of the National Association for Retarded Children, Elizabeth served as the Association’s first woman President and long standing government affairs volunteer leader. Appointed by President John F. Kennedy to serve on the President’s Panel on Mental Retardation, she was also Vice-Chair of The Task Force on the Law, 1961–1963. Working with the International League of Societies
for the Mentally Handicapped, Elizabeth was a principal author of the United Nations Declaration of General and Special Rights of the Mentally Retarded. The promulgator of the concept of developmental disabilities as an overarching category defined by early onset disability and life-long functional limitations, Elizabeth was instrumental in the creation of the Children’s Supplemental Security program (SSI). With Justin Dart, Elizabeth co-chaired the congressionally appointed Task Force on Rights and Empowerment of People with Disabilities, an important impetus to the development of the Americans with Disabilities Act.

A towering intellectual leader and frequent testifier in Congress, Elizabeth was at heart a parent: the mother of David and deeply supportive of other parents. When she died at 82 years young in 1996, there was a huge outpouring from other families, not only for Elizabeth’s policy contributions but for the support and connection she provided to families. The recurring theme was how Elizabeth always had time to listen to other parents, would connect them with help, and would inquire after their family member by name for years to come.

Elizabeth’s dedication to families also extended to promoting the leadership of the next generation. She would be deeply pleased that the Writers Group has given families the opportunity to share their journey. There could be no better celebration of Elizabeth’s 100\textsuperscript{th} Birthday year than the voices in this volume.

Deborah M. Spitalnik, PhD
Professor of Pediatrics
Executive Director
The Boggs Center on Developmental Disabilities
Rutgers Robert Wood Johnson Medical School
Introduction

We were mothers whose children had labels like *Down Syndrome, Cerebral Palsy, Autism, Aspergers, Intellectual Disability, Muscular Dystrophy*. Our lives were complicated, and we tiptoed warily into the risky endeavor of finding the words to tell our complicated stories. We wondered if anyone would be interested in what we had to say, and insisted, “I'm not *really* a writer.” Eventually, to our surprise, we found we wrote prose and poetry that made others cry, and laugh, and nod their head in agreement, and rethink what they thought they knew.

We met once every other month for five years. Each meeting had a suggested prompt which people were free to respond to, or not. The prompts included such varied topics as the first three adjectives that came to mind when we thought of our child; a time when we really understood our child’s disability; a photograph; an item of clothing; a time when we were the recipient of care; a transition of our own; the word *shedding*; something we’d like the community to know about our lives.

We pushed ourselves to be open and honest, as writers and as caregivers. We discovered that telling our own stories, in our own words, and then daring to share those stories with others, helped us to feel stronger, more confident, and ultimately more connected, and cared for.

Our hope is that people who read this collection will feel inspired to share their own stories and, in turn, pass on the gift of inspiring others to do the same.

Kathy Roberson
Facilitator, Writers’ Group for Family Caregivers
Glancing Up

by Kathy Roberson

Sitting in the planetarium,
I try to decipher Polaris,
the Big Dipper, Orion’s
Belt, the stars everyone
else seems to find with
complacency. Is this
what it’s like when
she’s made to name
colors? How many
times has she been
told, look, this block
is red, this crayon,
this boot, this mitten,
leaf, berry, bicycle,
swing, shovel, begged-
for-balloon tied to her
wrist? It’s Valentine’s
Day, red hearts are
everywhere! So why
does she say, when asked,
blue? I am lucky to be
able to pare away
layers of observations,
know that eclipses
are not the same
as nightfall. My child
is too vulnerable, always
thinking in terms
of Happy, Sad,
Mad, unable
to see how smiles
can hide intent,
how frustration
can be masked
by exuberance.
Leaning my head
back, I see before me
a multitude of indecipherable points, luminous and stunning, I attempt to define.
I think of her, how she would fidget in her seat, suck her thumb, grind her teeth, rise with unchecked astonishment and shout to me – Look!
Notes To A Newlywed

by Gail Frizzell

Silly girl, afraid of heights! The mountain rising before you is small compared to the peaks and precipices that you will need to climb in the next thirty years. It is good, though, that you do not know what lies ahead. It would scare the pants off of you. You will need to be stronger and smarter than you could conceive of right now. Fortunately, time will allow you to learn all that you need to know. You think you have your future all planned out. Surprise! It’s not going to be anything like you think it will be. Don’t panic though; your life is going to be really interesting. At times you’re going to wish that everyone would just stop making your life so interesting.

Prepare yourself for worry, pain, and uncertainties that will be so overwhelming that it will be many years before you will gain perspective enough to realize that the years have also held riches and blessings. I wish I could tell you not to worry, “it will all work out”, but it is that very worry and fear that will motivate you to become the person, the mother, the wife that you will need to be. It will push you to find answers to unanswerable questions. It will motivate you to hang on longer than you think you can. It will make you tenacious, stalwart, and compassionate. Perfection only happens in fairy tales. Learn that early, because your life is not going to be a fairy tale. You could not understand yet that this is a good thing. You are going to make yourself crazy trying to pursue perfection. It’s hereditary. But really, try once in awhile to embrace the freedom, the wisdom, the mediocrity of the phrase “good enough”. Be careful of using the quest for flawlessness as a haven when you judge all around you to be so clearly deficient, so seriously wanting. Your most important lessons will be learned from that which will be most imperfect in your life. On the other hand, you’ll never simply settle. You’ll never just accept the status quo. That is going to be really important. You will amaze your shy, “scared of her own shadow” self. Where will you find your courage? In the soft, brown eyes of a very small child with very great needs.

You will spend so much time and effort in the care of that child that you will lose yourself. In order to find yourself again you will need to learn to recognize joy. That’s going to be really hard. You will fear letting your spirit soar lest the fall be too great. One of the hardest things you
will have to learn is that letting yourself be happy is not an indulgence, rather it should be your mission in life. Find what gives you joy. Figure out what is fun. Learn what really matters. Nepo said that, “…part of the blessing and challenge of being human is that we must discover our own true God-given nature.” One day you will realize that you’ve spent far too much time being who others wanted you to be, and who you thought you should be, rather than who you actually are.

I know that you think you’re a totally grounded, in control adult, but boy, are you clueless. The older you get the more you will realize how little control you actually have over your life. The struggle to gain control, to make sense of the insanity which will often surround you, will exhaust you. Though there will be brief respites, small victories, that struggle may never end, at least it hasn’t yet. I seriously doubt if it ever will. I hope to come to terms with that someday because time is passing, more quickly than seems possible. Yet, many days seem to pass too slowly to bear. Keep trying to find the balance in your life that will get you through the days and make the years memorable.

I can guarantee you just a few things. Opportunity will knock. Good people will teach, guide, and support you. And, you will be loved. It will be the love that will sustain you through it all. It’s going to be a bumpy ride. You don’t realize it now, but you’re up to it.
Apparition

by Brenda Considine

Invisible, yet apparent enough.
Aspergers.

Even without paying attention,
He knows you notice his
staccato gait, tilted, tumbling, falling forward;

his eyes, darting, or
fixed just above yours
   focused just beyond you.

He knows you notice the
practiced smile
pull across his face
a split second too late.

He knows you notice that this conversation,
Is floating,
   drifting,
   sinking,
   spinning,
   crashing.

He know that his supernatural wisdom
well beyond his years
will do him little good now.
Here Comes “Freakenstein”

by Dorothy Ryan

Shunned
in school

Abandoned
at recess

She stalks
the playground

Searching
four-leafed clover

As if
finding

One
shamrock

Compensates
losing

The game
of friends.

(This poem was originally published online in eparent.com, September 2009)
Awakening

by Kathy Roberson

In the dim shadows of the early hours I tiptoe to her crib where she lies, legs tucked under, rump in the air, thumb resting against slackened lips, breathing in the slow, peaceful rhythm of easy dreams, but there they are again, those tiny handfuls of soft, dark curls scattered like blossoms in the aftermath of a tearing storm across the carpeted floor below. Frantically, I gather close these last remnants of stubbornly sown hopefulness, the tangled roots of despair taking firm hold when she stirs, turns her face away to reveal patches of tender skin picked bare, the unmistakable evidence of self-inflicted harm in sharp relief as rays of light make their way, bit by bit, through each little crack in the blind.
Walking

by Lisa Nivison

When do babies start walking?
Normally by 18 months.
When will my baby start walking?
Perhaps in the next few years.

There’s plenty of time.
There’s plenty of hope.

When do we adjust the goals?
Not for many years.
One Two Three Four Five Six
Seven years crawl by.

There’s no more talk of walking.
We’ve moved on, without a single step.
A Stop At The Light

by Kathy Mullery

As I sat at the red light lost, I suppose, in the usual daydreaming, I could easily have missed it. The movement was subtle at first, almost imperceptible – the rocking in the minivan ahead. Was it someone adjusting himself to a more comfortable position… no, stronger now, steadier rhythm. And that’s when I realized, it’s a big strapping guy, with a disability, in the rear-most seat in an otherwise almost empty school vehicle, being taken to his summer school or program. He is – how old – hard to say. He is, I now see, fully engaged in his quirky rocking, the driver now turning to speak to him, trying to say something, to get through, to somehow interrupt this strange but stubborn behavior that puzzles her. How do you make it stop, she silently wonders.

And yet, watching this, it wasn’t the boy or maybe man that I thought of, or his driver, or their destination, or even the patterned rocking. It was his mom, the mom that he just left at the bus stop. The mom who is now, I imagine, back in the house, breathing that Monday morning first sigh of relief. She gave her whole weekend, after all, to her son and struggled, as she has for many years now, to care for him, understand him, engage him, pray for and plan for him. Dare she now reach for that second cup of coffee, head to the couch and put the feet up for just one quiet minute. Or does she hop in the shower and get lost in her own daydreams, half consciously wondering if the next day will ever be different from the one before it, if the rocking rhythm of her own life will ever feel like the gentle calm of a sailboat moored at sunset, instead of that mild but persistent queasiness or sleeplessness of a long overnight train heading to an unfamiliar town. Another sigh. A first moment to finally relax – or – no, what time is it? She is now late for work herself.

I think back to the bus stop I left this morning - was it only minutes ago? The son I waved to, the weekend we had, the quirky and strange stuff he does as his driver takes him away. The sigh of my own that I now breathe as I turn to the day now before me. The rocking in the car ahead. The rocking in my head, in my world, in my Monday morning. I reach now for the radio, for a distraction. Perhaps I will sing along, tap my hand on the steering wheel in a pattern that is my own, that helps me cope, that can been seen from the car behind me. Sigh. Time to go. The light is turning green.
Blisters

by Brenda Considine

At recess, first grade girls line up, waiting their turn at the monkey bars where they will hang. Rocking, arm over arm, they pull themselves forward across the cold metal rungs to the other side.

There are unwritten rules of play:
never cut in line;
if you fall midway off, you get to start again;
one way only;
and the blister rule.
If you get a blister, you stop. And rest. And heal.

When she began, my daughter’s hands were soft and fleshy. Still childlike.
But now, her palms have hardened.
Tough layers of skin built up in places of grip and wear, protecting her from repeated overuse.

The calluses look strong and hard but sometimes - for reasons unknown – the thick white rinds of skin peel open; and a fleshy flap lifts, exposing an oval of raw, pink tenderness underneath.

Now, life compels me to swing and grab that bar slightly out of my reach;
I am suspended, crawling through air – knees bent, twisting and swinging, hoping I can hold on, that I will not drop off.

Every day, day after day, I move in one direction.
I thicken in places of pressure and wear.

But sometimes - I cannot anticipate when - a bubble of pain swells up. I blister. I tear open.
Then, I must stop. And rest. And heal.
Sometimes Always

by Lisa Nivison

It’s so loud.
It’s so stressful.
It’s often unpredictable.

It’s so upsetting.
It’s so exhausting.
It’s been happening all the time.

First the anxiety or the anger,
Then the twisting of his body,
Then the grinding of his teeth,

Then the groaning and the tears,
Then the screaming and more twisting,
How long will it last this time?

Sometimes I clench my teeth
Sometimes I stomp my feet
Sometimes I yell back

Sometimes I am sympathetic
Sometimes I am comforting
Sometimes I am kind

Always I wish it were different.
Always I fight back the tears.
Always I feel sad.

Always I hope for harmony.
Always I hope for peace.
Always I hope for joy.
Fashion Statements

by Kathy Mullery

You are 13 and you are so cool. It’s that new bathing suit, the one you picked out. That must be it. The one with the loud and colorful, green and yellow pineapples and blue wavy – what are they – skulls? How in the world did anyone ever think to pair those two things on a bathing suit, the scary, aversive and mysterious with the sweet and succulent, most welcoming of fruits.

Who doesn’t love a pineapple? Whenever I see a lovely summer fruit platter, it’s the pineapples I reach for first. They both startle and soothe my senses and bring satisfaction like no other item on that tray. Skulls… I can barely move my mood away from that yellow and green to even glance at them or think much about them. I suppose they appeal to the cool kids looking for outrageous board shorts, like you. This is something only a cool kid would understand.

And there you have it. Every summer day I see you reaching for that suit when you have two others you could choose. You race to get changed on the hottest of days and say to me, “Wanna come?” and of course, I do. Only you can interrupt my busyness, my immersion in household tasks or on other less satisfying days, waken me from my malaise and invite me to the cool water. Who can resist? Who doesn’t love a pineapple? You have me jumping in and wondering if I can still dive, and then I do dive, forgetting to consider that I get water in my ears when I dive. We find the skipper, your name for that water frisbee and I am in the deep end laughing as you see how fast you can throw it, like me, better righty than lefty. You show me how you are now putting your head down when you dive and can hardly wait to show me that you can hold your legs straighter this time in the handstand. I watch you swim the length of the pool under water and you didn’t call my attention to it. “When did you learn that?” I ask you, and we laugh some more.

When we leave the pool (always my idea) you remember to bring that suit of yours to the deck railing to dry. I see it there often during the summer; glancing from the kitchen window, it seems to always catch my eye. It brings a smile because it gives you pleasure. It takes only water to please you. You wear it and you are showing off, telling me in the languages of fun and action that you are like any teenager, so cool.
Still, those scary, stubborn blue skulls won’t blur from my view. They use a different, more disturbing language that reminds me I had to tie that string for you because you can’t quite get it right; that you swim with your mom because there are no friends to invite over; that I still have to remind you about privacy when you take off that bathing suit; that you won’t get to be on a school swim team because your swimming techniques would be too slow and imperfect. You have no idea about skulls and skeletons, the mystery of them. At least I don’t think so. We haven’t discussed them. This is not something that cool kids, probably, discuss with their mom.
Hoodie

by Ann C. Martinelli

It’s a hoodie. Black. It’s a pullover, no zipper, size large. A white oval sits in the middle, across the chest area. “The” is neatly arranged in the area closest to his right arm. A large black “X” splays at an angle towards his left arm. 88.9 fm, written in smaller black lower case letters, can be seen near his left arm.

It lays neatly folded in the middle drawer of his dresser six days a week. On the day of the radio show, it emerges, ready to be worn. Six thirty a.m., time to get dressed. Carrie will be here at seven! He’s so ready for today; jumping in his chair…hurry, hurry, hurry. “Will Furg be there when I get there where’s my parking pass maybe Donna will be there first, you know Donna, she’s Furg’s helper maybe Donna will be in the parking lot when we get there sometimes we meet her in the parking lot did you know Donna sits outside the booth did you know we can see everybody walking past the booth while we’re on the air did you know that Furg makes faces at people from the booth are you going to listen to my show today where are you going to be when you listen to it in the kitchen are you going to listen to it on the radio are you going to stream it online did you know there’s a webcam and you can see me do you want me to wave to you can you call the request line Furg will answer if you call what do you want to hear you can ask for Bruce Furg can pull it up on his computer and play it for you Carrie’s mother watches it online from her desk at work she works in Pennsylvania and she can watch it online can you see my microphone don’t forget if you can’t see me call the request line and tell Furg and he will tell me to move closer to the camera so you can see me do you want me to wave to you do you think Furg will talk about the Yankees with me you know Furg is a Red Sox fan do you think he knows the Yankees are playing the Red Sox again this season do you think I should tell him we’re going to both Yankee/Red Sox games should I tell him Jenna is going, too he knows Jenna, remember she came with me last year when Carrie was in the Academy, she filled in for Carrie so I could still be on the show do you think Furg will be happy to see Carrie again?”

It’s a hoodie, but it shouts “I belong.”
Unmoored

by Gail Frizzell

Your leaving
has weighed the anchor
binding me
to the minutes and hours
to the need and the want
Directionless
I wander
heading unknown
Your life
has been
my compass
and now
unmoored
I drift
Shedding

by Susan Sklaroff-Van Hook

When I think of shedding, I always come back to Passover. It is here that we are asked to not only re-tell the story of our exodus from slavery in Egypt, but to re-live the journey. This slavery is also called mitzrayim, the place of tightness or restriction. And so, at Passover, we are asked to reflect on our own mitzrayim and our exodus from those tight places.

Questions arise. Where is the tightness? How do we rid ourselves or move away from restriction? By shedding ourselves of our enslavement, what will fill that space? Will we dance? Better yet, do we actually want to shed this tightness...do we want our freedom? Do we know what to do with freedom? What does that look like?

I am the mother of a 19-year old with congenital muscular dystrophy, and deafness. This child of mine is in his second year of college, a good five hour drive away. Certainly, the complexion of my life is different now. I turn around and see an older woman. There is some wisdom there. The hard work of living day by day has yielded a certain amount of insight, maybe even occasionally a little humor and perspective in the midst of challenge and pain.

I thought I had shed the confinement that accompanies all of the words that forced the construction of my life, long ago. That was much of my journey. I think in the 80’s we called it “living an authentic life”. I sought to rid myself of terms with their loaded and nauseating nuances. I turned my back on “developmental milestones”, “children like these” and “appropriate”. I thought somewhat naively and in volitional denial that my therapy and introspection, my spiritual direction and compassionate listening, had released me from these dictatorial road maps.

And yet, here I am, still new and rawly extricating myself from “transition”, finding myself slung head first into “empty nest”. Neither of these terms seem to really describe what it was like to watch my son develop into an adult, to help him move forward, along with his wheelchair, bipap, hearing aides, shower chair, medical records, and dreams. What I have now, at the end of the day, may be a nest, but it is far from empty.
Nineteen years seems like a long time to be absorbing, defining, and letting go of these words, in order to live my life. It seems as if the accumulating and shedding of these constructs, like the files and paperwork that fill-up my back room, threaten to suffocate me until I do some purging, re-shuffle piles, and make space.

There are some things that I would like to shed and be free from, but chances are slim that will happen. I am still held captive by a medical system that is no system at all. By the scrambling to react to withdrawal of support services, increasingly difficult to maintain against the backdrop of dwindling resources.

The piercing truth that individuals with disabilities must work harder for everything, as do their families, will likely never really change. On good days, I’ve learned to take that in stride, with a minimum of anger or resentment, a lot of deep breathing, and simple resoluteness. We won’t talk about the bad days that still, from time to time, occur.

The truth is that I am intrinsically bound to my son and his struggles. I’ve always been careful to understand that his experience is his to own. I don’t have muscular dystrophy and I am not deaf. The restrictions that he lives with are not mine. But I have had my own tightness, restriction, and sense of enslavement and everything he has lived has brought into question everything I am.

Our son’s Hebrew name is Moishe, Moses. We gave him that name with the hope that he would lead his own life. Not that he needed to be “independent” (whatever that is, as if any of us are independent) and not to fulfill some one else’s vision, but to have his life as he would and in someway to be free. I don’t know if he will make it to the literal “promised land”, as Moses famously did not. But, I know that his journey, including all of the restrictions and boundedness, is one of truth and substance.

I have gone along on this ride, incredulous at the intensity of it…wanting sometimes to only be numb to the experience, but finally realizing that by being constantly vigilant not to get tied up in words, notions, and expectations, I get to discover my own life on my own terms.

And so, as with all things, there is a duality of movement…the absorption and the letting go. As one thing falls away, another seems to enter. I want to try to be more honest, to leave behind assumptions about how I am or who I am or what I feel. I’d think I’d like to be free and see what comes next.
Emergence

by Cynthia Chiariello

On raising a daughter with autism:

Shedding assumptions,
casting off fear,
slipping off guilt,
losing old dreams.

Peeling away pride,
rejecting anger,
stripping away judgment.

Releasing perfectionism,
yielding expectations,
letting go of relationships.

Sweeping away sorrow,
relinquishing regret,
shedding the need to make it right.

Revealing strength,
unwrapping gratitude,
emerging by grace,
discovering purpose.
Afterword

We came together to share our innermost thoughts, our fears, our reflections, our dreams, through the written word. Often uncertain of our ability to give voice to the complicated, remarkable journey that parenting a child with developmental disabilities had taken us on, we found in our leader, Kathy Roberson, an insightful guide. She encouraged our faltering efforts, supported our need for self-expression, and unfailingly celebrated our work. It has been an honor, and a gift, to have Kathy lead us into places we thought we might not be able to go and help us share the insights that only we who have made that journey could share. We would like to thank Kathy for believing that powerful words were hidden within each of us. We have learned that ordinary voices can share extraordinary truths.

In sincere appreciation,
The Writer's Group for Family Caregivers
Writing Our Journey: Poems and Essays by Family Caregivers

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