

hen my husband and I decided to adopt a child with special needs - in adoption lingo, a "hard to place" child - we already had two children, and were young enough to feel confident that we were up to meeting whatever parenting challenges might lay ahead. The fact is, though, we knew almost nothing about developmental disabilities and, 21 years later, it's a bit startling to look back and see just how naïve we were. Now a young adult, our daughter's disabilities are such that she still needs 24/7 care and supervision for everything, from showering and dressing, to crossing the street, to anything that involves reading even a single word. And yet, if we underestimated the extent of the challenges we would face, we also underestimated what a gift her presence in our lives would become. She is an extraordinary individual who again and again connects to the essence of people she meets, drawing them to her, bringing out the best in them, and leaving a lasting impression of what matters most in this world. Ultimately, parenting Katie has revealed to us, like nothing else could, our strengths and our flaws, the love we are capable of giving, and the humbling recognition of our own limitations.

Several years ago, I started writing down some of my thoughts and feelings about parenting Katie. I'd written poetry for a long

time, and the urge to try and capture these experiences in poems became more and more persistent. The following are a sampling of poems from that collection, starting from the day we first brought her home at a year old, to trying to understand, without words to guide me, what she might yearn for in her adult life. What draws me to poetry is how it helps us to see the fundamental truths that are often hidden in the details of our day-to-day existence, and my hope is that these poems have done that in a way that resonates for other parents, regardless of the nature of their child's needs.•

Poetry Copyright © by Kathy Roberson

ABOUT THE AUTHOR:

For the last five years Kathy Roberson has facilitated a writers' group for family caregivers. Hearing the group members read at The Elizabeth Boggs Center on Developmental Disabilities' 30th anniversary celebration a couple of weeks ago – and seeing and hearing the audience's response – was, for her, an extraordinary testament to how people can respond to poetry. This past summer 10 of Kathy Roberson's poems won second place in the Judson Jerome Poetry Scholarship for the Antioch Writers' Workshop. The feedback she heard from a variety of people with whom she shared her work is that the poems speak to issues beyond just "disability" or "parenting;" they speak to some of the struggles and joys inherent in caregiving of all kinds.

MOMENT OF DEPARTURE

Does not knowing better count as courage? Or knowing but not caring? Or caring enough to act despite a gnawing dread? Was it all of this that day we came to bring her home? The third family with her few clothes packed, ready, holding her tight, wishing her a happy life, and us, the fourth and final ones, on whom it all depended, securing her in our old car seat like we knew what we were doing, and she, still a stranger at a year old with such mysterious labels: cerebral palsy, general developmental delays. For a moment I couldn't breathe, almost shouted aloud, Stop! What are we doing? We could lose everything we love! but didn't. We pulled away, doubt devouring whatever daring I'd imagined, until our son, barely six, kissed her cheek, whispered softly, Welcome home, Katie, and in that one small breath made all things seem possible once again.

IN HINDSIGHT

At birth, handed to one, then two, three, four by the end

of her first year, a thousand small upheavals unnoticed

by anyone but herself, each mother with a certain style

of cradling an infant in arms more or less fleshy, touching

skin with fingertips roughened or smoothed, bathing with a brisk,

efficient or gentle, pensive stroke, telling her you are

with someone else, forget all you know. What uncertainty

about the world must have been conveyed each time she was lifted

from her crib in the morning, dark eyes wide open, alert, ready

to be held.

AWAKENING

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.

GLANCING UP

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, beggedfor-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!

NAVY CONVERSE

Even quite young she'd spot them a mile away, along long aisles of shoes of all sizes and styles, men's, women's, teen's, children's, formal, casual, blue canvass that were not the same. She could tell at a glance as she sped by, crying out "NO!" when I tried to suggest they'd do just fine. Somehow, in a world overwhelming in its chaotic unpredictability, struggling to anticipate the hidden, unseen, mysterious piecing together of one moment into the next, she still finds them with unerring accuracy, tossed in bins, buried under piles of miscellaneous discounted footwear. Whatever else might be

beyond comprehension, of these she's certain, clutching them close, begrudgingly donning other shoes only when required for social events, like weddings – and then once back home again she comes shuffling from her room, laces untied, right on left, left on right, secure in her own firm conviction of what is necessary to take the next step.

ANOTHER WORLD

Arriving at a dusty courtyard in the midst of Malawi, unfathomable distances from my home, I am surrounded by singing, soft harmonies tightly woven, bright patterns of cloth wrapped close, babies cradled against backs, women dancing, clasping my hand, nodding their heads in greeting,

smiling a generous welcome to this world. I do not know their words, nor they mine. Zikomo, is all I can say, thank you, thank you, over and over, Zikomo, they reply. Our eyes meet, we parents of children who are different, dismissed, sometimes feared or reviled, whose futures depend upon whatever resolve we can

muster each day, who do not fit in, not on their continent, nor mine, whose vulnerabilities call forth heartbreak, the constant yearning for acceptance and communities that will make room at last for those we love; this is a language we recognize as ours.

THE POINT

Radiant, her smile beckons, across sharp reefs and shoals, we make our way to her.

She stands straight, waiting always for others to clean, polish, make her presentable. Left alone, she would keep standing, waiting, dimming, disappearing.

Dependent on us she lives at risk,

of our busy lives, our carelessness, forgetfulness, or worse, our aging weariness, our insistent need for ease.

She beams
with delight
when we arrive,
and for a moment
it is terrifyingly
clear how if ever
we lose sight of her
we will crash,
our hearts splintering
and breaking apart
against those
darkened shores.

GUESSWORK

Lying next to her, stroking her back, attempting to comfort with no idea why, what was dreamt, what vivid picture, what memory this disturbing.

She sits cross legged on the floor, listening to childish songs, talking alone. What fantasy makes her giggle so coyly? Or call out when touching herself on a bed littered with the toys of a toddler?

On the cusp of adulthood, what does she yearn for? What future feared? Or life coveted? Is there a restlessness stirred that she can't name? And if I could, would it matter?

It's a mystery that persists, along with this insistent question: If granted one wish for anything, anything at all, what should I choose? What would she?