Disorder 299.00
Aby Kaupang and Matthew Cooperman
DISORDER 299.00

ABY KAUPANG & MATTHEW COOPERMAN

#52
ESSAY PRESS STEREO SERIES

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Rage and catastrophe, diagnoses and advocacy, Disorder 299.00 specifies the uncertainties autism brings to parenting, and to language. What follows documents part of the journey of diagnosis, which precedes any action. But action is slow, and our child doesn’t sleep, doesn’t eat, doesn’t speak. This is felt as a strange intensity of Being, both an intricately connected rhizome of forms, agencies, doctors, codes, and an isolated island far out to sea with just enough room for four. Studies suggest parents of children like our daughter have cortisol levels akin to soldiers with PTSD. We are hyper vigilant. We are neither soldiers nor people with disabilities, but we are somehow a strange subcategory whose lives are entirely hijacked, consumed, coded. This is our attempt to code back.
GOOD DAY

And today was a good day, what with your rising to bathe and dress the daughter, put her on the bus and let me sleep. I sleep and sleep and cannot wash it out of me, tired fear that rests too much on now. The day goes on, backing up its horn of plenty to this house, that house, not this house. We think there is delivery, sometimes there is delivery. Then she sleeps, the wife, and I wake, and the daughter grinds her fists into her sockets. Nothing appears as it always does like nothing you’ve seen before, closer in the mirror, and more real, the collapse of time, dark bright hour, the house abed and blazing, a keening and a rocking and a whimper, make it stop. Present is this gift of the daughter’s enormous need, and absent is the dream of her own dream, a blue house and yellow car, two Chinese dogs and a child of her own. Baby body of brood, I cannot shake this futureless dream from sleep. It is not hopeless—she brings a joy as “swim” and “more” and “movie”—but it is wholly child, a simple life without her own earned heartbreak. I staunch the fear of my own death and her perpetual childhood. Today was a good day.
What is there to say of this child? She lived, lives through this. So did we. You want to know more about her. So did and do we.

The girl began, and then so did the book, a mirror for sorrow or anger or fear. The book is a messenger, out in front, it canvasses the halls of many hospitals. Again and again at the ER soothing her body. The daughter didn’t eat, didn’t sleep, didn’t laugh, didn’t shit, didn’t walk anymore. We went for a long visit. Doctors said *erythromycin*, they said tape a bag to her shoulder. We went again when they said she was crazy, a crazy summer when our little girl lived with other un-specifiable children. We met others there, and parents of others who cared for/were eaten by the unseen and unseemliness of it all. We were told it all in notes and looks and notations: “fear of a dog she doesn’t have” “a dog she needs for her night terrors” and “negligent mothers,” “attachment disorders,” we have heard it all. Clearly “the parents are rude.”

they that were in the hospital  they that on the pavilion parented  they that refined their faces in the sieve of seizure

in the daylight met the carded men  the parking arm  the vertical blades of the guillotine elevator

doctors rose as did their entourage
June  a morning
moving  a sun-glinted
box   of what   faces
people

disappearing

ey that were the cardiums wore it on their sleeves  their crimson gowns
their forehead temples and they wagoned   there were they that were in the wagons
and those that carted others in wagons  it was numerous   who or who all   were cardi-
ums

they passed through the foyer we drank coffee   averting our eyes from sadness to
sea tanks we admired the sea tanks we too being cardiums

cardiums: heart bouquets, whack jobs

staring
chairs were gliding smoothly  
door to door  
real wheel chairs  
into rooms where procedures occur  
it was icecapades  
linoleumcapades

balloons on wrists  
carnations on laps  
those that were more cardium stumbled in the parade

we feel lucky often during
the parade

our daughter not being in certain parts during of the spectacle  
she is in pageant
on an elevator  
20 –ISTS in entourage

and us—
a theory of causation

The epidemiology of autism is the study of factors arrayed as suns in the code of spectrum. Genetics, vaccines, parental error, environmental toxins, voodoo, refrigerator moms, sin. It is rising incidence, or global prevalence, it is one in a million, 62 cases per ten thousand, a lack of evidence from low- and middle-income countries. It is a vision of difference in the very First World. A 4:1 male-to-female ratio. The number of children known. Has the number of children known to have autism increased dramatically since the 1980s? It is an increasing strain and a prescriptive condition. Cumulative incidences, point prevalence, p-values, e-values, editorial error, hopeful outlook, juice boxes and the children are unknown.
They that were in the hospital one more time and one more time and—

I’d had an appointment with my midwife in June and I cancelled because I couldn’t slug off the grief or the cumulative exhaustion. It was her birthday and she had stopped walking. We had to give her enemas because her GI stopped functioning. There was an explosion of poop all over the carpet and hallway and it wasn’t the first time and Matthew cussed and cursed and scrubbed the birthday away and I walked the park loop with Maya Möbius-ly as she whimpered and screamed and whimpered and was four that day and there was no joy. No party.

There was so much shit in those days. Enemas and Calms™ and a diuretic hum. She couldn’t digest anything even with the g-tube. 2200 calories a day and she still was wasting away. The joints of my fingers ached from working the carpet. Weeping and gnashing and plotting the violent act. I was a violent act.

The next day my midwife came and straight-talked, “Aby, I helped bring her into this world; I can help you bring her out.”

And we talked about hospice. Talked about removing the feeding tube. Talked about what a future without Maya would be and I said I could never continue as an occupational therapist and I doubted I could continue at all and who knew if a marriage could survive it? We’d have to move away from this house. Far. We would have to go very far away.
it is our ethical duty to not escape
most children do not die in children’s hospitals
in the air *en route* they die in helicopters
on East Colfax in ambulances they die they do not die
with such a smashing view of the Rockies

the truth of the hospital system is
death prevention and sometimes
death theft and the truth of the
ER more so so acuity
decreases in proportion to the
degree of the field therapy in
the hospital then is polish is a
strategy of low tiers and sympathizers

... arise fluffing the nimbus
helicopter blades whir up and
up the light soulpuffs

dollars to distance
material affect
pages of reconnaissance
a theory of causation

Hospitals, contemporary and ancient, clear a time and smudge a space. They make a habitable house. Legal credentialing and financing frameworks are established to make structures stay. By individual governments, augmented on occasion by international organizations, churches and blood banks, these stay. The characteristics of any house determine the care of its visitors. Wide windows, colorful hallways, lines on the floor to soothe and direct...a peaceful architecture. Delivery may be by sunlight or angels. Sometimes the angel is mercy, sometimes death. We are waiting in the hall when we are not with the daughter we visit the offices of payment and records we walk walk again somehow we are walking we

stunned by the elevators the gift shop the loan library the Jelly Belly food truck the red wagon and wheelchair station the hand sanitizing station check in / check out

stare at photos of stars like John Elway and Kermit in fundraisers and patients in medieval sun chairs and hydro-therabaths and centered in puppies and flowers we

weaving among the the the cardiums and anti-guides

walk back

gain 12x

my forehead tent
I went to the pharmacy she was not there

I went to the surgeon she was not there

I went to the TV the nurses’ station the family respite station
she was not there I was not there

a we everywhere

MOCs and FOCs as assemblies
of pills
inoperative pillars

they that visited the Medicaid offices they who suspended themselves hung themselves on pleas for assistance they who hanging there found they needed additional help were Medicaided or not or knotselves knotted we fought a way to lower

our self

a challenge

with limbs in our various

stumbling mouths
they that suffered beyond the blinds the blind themselves the parents requested watched not so much the patient though they recorded her but the MOC and FOC the unusual parents of the child they were paid to survey

they surveying the parents found the surface a veritable landmine love and the dove not returning a gaze of horizon shifts the surveyors then sat awake turned inward they changed professional dreams like the diapers of a child they swore or prayed they never would birth they themselves afraid of being those parents

they themselves afraid of being the parents became increasingly exuberant showy

de-

- monstrous
- lighted
- stroying
- licious
- liqueesce

I went to the neuropsychiatric ward I found us there
The patient

_____ accomplishes some part of self care
_____ identifies a problem with materials
_____ indicates a choice by pointing
_____ sustains an emotion with an adult
   (two out of three consecutive trials)
_____ imitates the sound or action of an animal
   or person
_____ sings in the places of others
_____ is a wild
_____ engages in a steady thump
_____ imitates others as they move about the room
   to music
_____ runs, marches, gallops, screams at the music
_____ expresses suitable emotion
   (ex in conflict with another child, child
   responds by vocalizations or pugile action)
_____ makes something with materials

they that saw the ladies wondered what the ladies in the neuropsych ward did
   what
   they did
   they did their nails
   did them daily

they did up their bodies like porn stars like vampires

they are paraprofessionals taking our babies off drugs

vampish

staring
ADLs

tasks are defined as objective representations of all possible activities available in the universe of bodies and minds. The daughter will do $x$ tasks in $x$ minutes over a course of $x$ possible data trials with min assist. We will make the tasks meaningful. Tasks are activities in daily living.

documents and poems are like -ISTS. Wet herrings when misconstrued.

de-

-structive
-bilitating
-laminated

something in their mean. We call it faces. Faces from the outside poised against glass which is skin my dears. I am sorry. We are vampirish. I wrote this. An outside then. That's always masking. That's all I'm

Truly, I was angry, angry and baffled, at the feedback this manuscript received. It was like I was at the hospital again.

Do you mean how the readers said they “weren’t sure we loved our daughter”?

Yes, and that they “wanted to know more” about her. As if we didn’t. As if our attempts at bringing her to the hospital were not an enormous effort at knowing her. As if, if we knew the problems, we might provide the solutions. As if the repeated diagnosis “Not Otherwise Specified” wasn’t such a blow because no one could specify, could lead us to the her that was more than ill body, body ineffective. Damned up mind. No one could tell me why my baby daughter wouldn’t eat, wouldn’t sleep, why she screamed out and bruised herself, why she stopped walking, why her taut gut protruded and her legs and arms went to bone. No one could name a thing. We couldn’t treat a thing.

You are breaking my heart, our heart. Should we have known that Maya means “illusion”? We endlessly wander, looking for her.

We named her, we should have known. This is the deepest pit of hell, wondering if we did this to her. If your genes or my genes, or your drugs or my drugs did this. It’s not that the reader knows anything. We wander and wonder and blame ourselves all alone.
an outing, 5:17 p.m.
sunlight glint and Freon
off our skins breathing

an outing
we love drugs  we used to not love drugs  so it was me that didn't love drugs like other people in our line did now I love drugs more  I love pills principally for sleep  I love them like I live in a pilloried dichotomy

such complex child

a drug is not necessarily a child

somebody's fault
Were we going to fail? There were times I thought we were going to fail. I remember thinking if we can just move out of our old house, that dear little house that creaked and trembled with no shelter, if we could just move out of that house it would be all right. We moved out of that house, and it never got “simply all right.” NOS.

Not otherwise specified, the problem or the solution.

NOS. No one knew. Not if the daughter, the mother, the father, the brother, the marriage, could survive. Only that days keep coming. And some are unspecified.

on the way to the psych ward  there are elevators that are glass and elevators that are steel  this is clear  most designers and children who do not die in helicopters prefer glass elevators

to open

infinitive open

somebody's fault
then / now

Maya has a g-tube, and eats her entire world through something better described as a button on her belly. We feed her unrecyclable boxes of Peptamin Jr.™ or Neocate™, elemental formulas made by Nestlé and Monsanto. In the early days it was the feeding machine, two hours per cycle, five times per day. These days we bolus feed on the kitchen floor, try to wipe up the endless sugary white sticky residue. She is a paradox entire, our little messenger, for now she takes the world into her mouth, railings and door knobs and shirt collars and toys. And yet she does not swallow, obtains and does not obtain the world by mouth.

Maya always wears boots and prefers red ones. She has a few ideas and they always seem novel when they strike her: Horses?!? Horses!!! Swimming?!? Swimming!!! Drive?!? Drive!!! Ride bikes? We shall ride bikes!!! Helmet on, standing on the running board of the scooter, she is out front, our messenger. She has mastered the signs for all types of going and no types of staying. She signs, sloppily, quickly and is exasperated with our poor telekinetic capacities. We believe she is from Rigel 4, and her strange hoots and gestures are messages to the Mothership. These people...

She pushes and pulls and uses bodies as means to get her will done. We forget that she doesn’t speak because she is communicating so sincerely always and we can’t explain this to anyone anymore. She still doesn’t eat/sleep/talk and she is still in diapers. She is an environmental crisis. We imagine the mountain she’s made, she daily makes, of diapers and shit and wipes and shampoo bottles and soiled car seats and plastic toys. She doesn’t care. How can such a little pliant body make so much? She pushes and pulls and climbs her diaper mountain to the end.

The Patient

______ writes using pictures written on air
______ is in a letter-like form
______ says what a picture says
______ is a symbol that represents
______ sings simple songs as they please her
______ pushes buttons pleasing her
______ stacks blocks in sand in paper in water
______ identifies with the tag on her sleeve
______ identifies as a diagnoses
______ is a picture of a simple diagnoses in air in water in slipping
car jacking in the distance
   electrical fuzz
   oxide and injera
   _____ an outing

we are alternating preferred and non-preferred activities     being at the ward is called
   attending     MOC is mother of child like me     we here at the psych ward call the
   retarded     intellectually disabled     disabled too being less preferred than those living
   with disability

I wish the daughter proffered

pain being universal and being on the floor visits each child personally
a proffer:

blessed are the children
for they shall see god
blessed are the children who see god
for they shall be given drugs

father:

no one loves children
we all love children

packs of overweight parents in the Zebra lot
in the food court passels searching

somebody's fault

singular gaunt in the hospital staring

we need wife: I need an outing
they that are at the psych ward are mostly male if they are children mostly female if they brought someone here

one man guards the door 40 woman staff it

stimming and laughter and tantrum and laughter and hooting and grinding your head banging

MOCs/FOCs here your parents
I have multiple degrees and multiple sadnesses I have painted my nails multiple emotions
though now they are nude and ivory which is a way of telling though the message is mixed

incriminated by -ISTS I confess histories

more and more histories

I confess I am more

I is angering

our -ISTS have never begun to provide solutions

one ruling is a life well lived and a risk in the number of sons all nights are long nights though the drugs are not long the sadnesses isolatory we seize them repeatedly

we want drugs
working-class drugs
drugs that WORK

someone is absent
during | of
someone is always en route
she is out front our messenger

she proffers and proffers her glass guillotine

who are they that enjoy

the sun

everyone enjoys the sun

on an outing

through the glass

Maya doesn't enjoy the sun

they that were on the fence before began new names Jesus names and model names names like TeaKettleBlack one name was a name to be mouthed by a Down's boy the MOC and FOC thought out his mouth in advance
what does not speak
has a mouth
is instancy
through glass

everything we do is an intervention
disabilities lie in the environment
notherbodynothermind

our mouth is an elevator of crime

if poetry were a straight straightforward social action
if base not a part of lovely
if lovely on all sides of seizure
if memoir not memory but tongue of the mind
if development a linear delay
if retardation only late
if healing a normative sabbath
if I lovedog loved East Colfax

CODE

299.00 Disorder, autistic
315.90 Developmental Delay, NOS
783.41 Failure to thrive in childhood
788.39 Symptom, incontinence, urinary, NEC
318.20 Disorder, mental retardation, NOS
307.42 Psychophysiological Insomnia, NOS
296.90 Mood Disorder, NOS
782.00 Sensory Integration Disorder
784.30 Sensory Dysphasia
300.90 Self-injurious behavior, NOS
WORDS FOR THOSE WHO DON’T SPEAK THEM

when our daughter rises it is with and without her mouth
she sings in phones of plosive thirds that do not complete

	the scheme and yet they are awake they are very awake

third third third

she sings with her body and to her body a plateau of sinew
to hold a twitch of song

she moves the bed by pressing everywhere

 up  up  up

she levitates the bed by hanging hours on the bed

our messenger she is out front

Song--

she sings in hunger or wetness

and we rise
AUTHOR BIOS

Aby Kaupang is the author of *Little “g” God Grows Tired of Me*, *Absence is Such a Transparent House* and *Scenic Fences | Houses Innumerable*. She holds masters degrees in both creative writing and occupational therapy from Colorado State University, and lives in Fort Collins with the poet, Matthew Cooperman, and their two children.

Matthew Cooperman is the author of, most recently, *Spool*, winner of the New Measure Prize (Free Verse Editions/Parlor Press, 2016), as well as the text + image collaboration *Imago for the Fallen World*, w/ Marius Lehene (Jaded Ibis Press, 2013), *Still: of the Earth as the Ark which Does Not Move* (Counterpath Press, 2011), *DaZE* (Salt Publishing Ltd, 2006) and *A Sacrificial Zinc* (Pleiades/LSU, 2001), winner of the Lena-Miles Wever Todd Prize. Four chapbooks exist in addition, including *Little Spool*, winner of the 2014 Pavement Saw Chapbook Prize. A founding editor of Quarter After Eight, and co-poetry editor of Colorado Review, Cooperman teaches at Colorado State University. He lives in Fort Collins with his wife, the poet Aby Kaupang, and their two children.
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