A lot has happened over the years because of writing about my mother. Some of those stories and lessons serve as resources as I revision (Ellis, 2009) and remix (Navas, 2012) the original. Ellis’s (2009) volume, Revision: Autoethnographic Reflections on Life and Work, is a collection of previously published life stories about loss and other emotionally charged life situations. Layered between these stories, Ellis adds what she terms meta-autoethnography—situated vignettes of new interpretations and reflections on her prior work. The book she produces speaks reflectively back to her printed past; it is regenerative in quality and creates a reboot or remix. The final product is a genuinely fresh, rereading, revising, and revisioning of what went before. I embark on a smaller scale project in this chapter, remixing published vignettes about my mother and revisioning them (Ellis, 2009) to regenerate new meanings regarding the consequences of writing about my particular mother.

Although there was a journal in 1996 called Mental Retardation (now renamed Intellectual and Developmental Disabilities), referring to my mother as mentally retarded was already considered insensitive and certainly politically incorrect at this time. People challenged me, but I used the term because family and social services workers used it—it was common parlance. If this was to be an autoethnography about having Suzanne as my mother, then this was the most “authentic” approach, the unvarnished ethnographic reality. Meanwhile, this was not my best “self” showing up, anger simmered beneath the surface of that decision.

In that article and others (Ronai, 1995, 1996, 1999), I describe sexual abuse (involving my father, a child sex offender), physical abuse, and a deep sense of embarrassment and revulsion that she was my mother. I also describe someone who was a best buddy and an ally who fought to keep me alive at times. All these years later I wish I could regale the reader with tales
of growth, healing, and closure together, but that is not something we could accomplish.

I will revise one item at the outset—my mother had intellectual disabilities. She was never a "thing," or a "mental retard." The rest of the world saddled us with that. She was a person who had it rough and could not "catch a break," certainly not with my grandmother (her mother) or my father. I failed her, too. According to the American Association on Intellectual and Developmental Disabilities (2019) there are three factors to consider when evaluating intellectual disability: limited intellectual functioning, limited ability to adapt, and the condition must be present before age 18. Intellectual functioning is determined by an I.Q. test which falls below 70–75. Adaptive behavior takes into account conceptual skills (e.g., literacy, math skills, sense of time, and self-direction), social skills, and practical skills (e.g., personal care, occupational skills, adhering to schedules, handling money, and proficiency with a phone).

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In her 20s, my mother, Suzanne, was a full-figured, green-eyed blonde who tanned easily as she strolled the streets on her daily walks. Frequently, she evoked cat-calls from the men who drove by. Now she is 60 years old, stands 5 feet 4 inches, weighs 200 hundred pounds, and has the emotional maturity of a 7-year-old.

With a few exceptions, Suzanne is generally harmless. When I was a child, she was the one who yelled and stamped her feet in the store if she did not get her way. I was the one who gave in, hoping to calm her and avoid further embarrassment. One Thanksgiving she locked the entire family out of the house because, as she put it, “Everyone is ignoring me.” On other occasions, she ruined holiday meals by pouting, yelling, or otherwise making a scene at the dinner table. Once she rolled up a newspaper and beat my grandmother so hard that she ripped the skin off the surface of my grandmother’s forearm.

My mother’s intelligence quotient score has been estimated by several psychologists in social service capacities to range from 65 to 80. Reading at a second- or third-grade level, she stumbles over the text and makes up phrases when she cannot identify words. Although she has no math ability, she possesses a wide repertoire of television and movie trivia.

When people first meet Suzanne, they don’t know anything is “off” until they have spoken to her for a while. She monopolizes the conversation with talk of television and her life. Those who are patient find a way to leave politely after a few minutes; others bolt immediately. She is the butt of many jokes which, mercifully, are told behind her back or go over her head.

Suzanne enjoys hanging around malls and talking to sales people, store managers, or anyone who shows an interest in her. On occasion she has been asked by nervous clerks to leave their store because they were concerned that she was shoplifting or driving away customers. She also watches a great deal of television, avidly reads children’s books, colors in coloring books, paints by numbers, assembles simple crafts, and sings in the church choir. Giving the appearance of living a full life, she stays alone in an apartment paid for by a trust fund set up by my grandmother (Ronai, 1996, pp. 109–110).

***

I spent a great deal of time trying to fix her. As late as my early twenties I was still trying to teach her math. I also bought her outfits that I thought were more “hip,” here and there, when my budget would allow it, but these efforts often ended awkwardly, with me upset and her frustrated.

***

In my mind, (or is this my heart?) a reggae beat plays in the background. Paul Simon strums his guitar and sings to me that he would not give me any false hopes; that it is a strange and rather mournful day; that somehow a mother and child reunion would only be a motion away (Paul Simon, 1972, track 1). Maybe. But not on this side of heaven and earth.

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In 2015, Suzanne passed away at the age of 78. My best self, the one who should have had more compassion for her, did not show up, not even at her funeral where I was dumbstruck with silence. I will never know if she was capable of more, in which case my anger with her could be forgiven, or if it was not a choice on her part because the biology to evolve was not there. Said differently, I wonder if she could have tried harder. If so, then she was being lazy letting everyone take care of her. If not, I have been unjust, wanting more from her when it was not possible. In my ideal story, all of this would have been worked out before her death.

Having this experience with this mother is one thing; writing about it has added multiple dimensions of complexity to my life, much of it positive, some of it negative. Publicly putting myself out there as someone with this identity set me up for responsibilities and learning experiences which I would never have
thought possible. Perhaps there is still a chance for me to evolve? I cannot do it in tandem with her now. There will be no mother and child reunion.

***

I get calls occasionally from lawyers who want me to testify in court as an “expert witness” in child custody cases involving intellectually disabled parents. I know this is not my work. I turn them down.

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Over the next few years, I am cited by The New York Times, Sunday Magazine and interviewed for The Village Voice, Texas Monthly, and other publications. I am also featured on the cover of Folha De Sao Paulo, Revista, a Brazilian Sunday News Magazine. There are calls from folks about movies and television shows which do not pan out. Most of this attention is due to writing about my mother.

***

In 1998, I am speaking at a conference in New York on parents with disabilities. I have presented passages from the paper this story is about. I am warmly received; the presentation goes well. During the question-and-answer session I feel “in-the-zone” and “on.” Everything is working. The individual who invited me gives me a backhanded compliment afterwards, “No one has a right to be that poised.” The sponsors of the conference are happy with me (my existence, a PhD with a mother with intellectual disability, plays beautifully into their agenda) and offer to rearrange my travel plans to keep me in New York for a few days longer, which I decline. I say I have work obligations to get back to, which I do, but the truth is I do not like being away from my three-year-old son for long.

Later, I sit in the audience toward the back of the room. A long table and chairs are unfolded and set up toward the front of the room and a panel is seated. Before me are intellectually disabled parents, three individuals and a couple. They are billed in the program as “Intellectually disabled parents advocating for themselves and their children.” I am drawn in by their various presentations of self. [Who am I kidding here, I am riveted.] One can pass as standard, until she speaks. She is attractive and dressed in youthful, on-trend clothing; she will have troubles avoiding victimization. Some have something a little “off,” clothing, facial expression, but it is not necessarily attributable to intellectual disability, until it is. The dark-haired couple sharing the end of the table both have distorted appearance and speech—they will never pass, anywhere. I wonder if this is simply who volunteered to do this or if the conference organizers deliberately selected a “spectrum” of individuals to invite to the panel.

As I watch, I am gradually flooded with emotion. Things stir, pushing and pulling against my chest, crowding up into my throat and face; I do not know what is wrong with me. I am claustrophobic as tears threaten to spill, swept up in a shock-horror-disgust-fear-grief avalanche. I need to escape, I cannot hold it together any longer. I try to be discreet as I am forced to leave the venue; emotion is threatening to overwhelm me. I hope no one notices, I cannot explain myself if they do. Once in the hall, I run into the restroom, close the door, see I am alone, and finally let it go some; just a little, quietly weeping, doing the best I can to muffle the sounds yet let off some of the pent-up confusion roiling through me. I can’t function like this, I must get it under control. What the hell is wrong with me?

***

The parents are on display, a carnival freak show, for everyone to point and marvel at. I can almost hear a demented calliope in the background. This is a conference for social workers in general, advocating a specific program designed to provide resources for people with intellectual disability who parent their children. They should know better. Everyone stares at these folks, daily. Why set them up for this kind of attention?

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“Why exploit them like this?” may be a better question. Donors were also in attendance at this conference. It was for the donors that I was asked to stay longer in New York . . .

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I was marveling too, for a minute. And imagining each one as my parent, instead of my mother. Each looked like a different set of problems.

***

I am uncomfortable with intellectually disabled people. Of all the people on earth, I would think I would have this one under control. Funny, sad, it does not matter—it is true. I never know what to say or do with
them. I am afraid of setting them off. Don’t argue with me. They go off.

***

You mean you can tell them they are retarded, and they won’t break? The openness with which this is being done takes my breath away. Advocating for themselves?

***

I resent the imperative to pretend that all is normal with my family, an imperative that is enforced by silence, secrecy, and “you don’t talk about this to anyone” rhetoric. Our pretense is designed to make events flow smoothly, but it doesn’t work. Everyone is plastic and fake around my mother, including me. Why? Because no one has told her to her face that she is retarded. We say we don’t want to upset her. I don’t think we are ready to deal with her reaction to the truth. Something inside me longs to tell her so that she will finally be able to explain to herself the events in her life, yet I don’t know if she would be able to understand this information.

Because of Suzanne, and because of how the family as a unit has chosen to deal with the problem, I have compartmentalized a whole segment of my life into a lie. It is not fair to blame my mother, but part of me cries out to her, “How dare you passively sit back while everyone takes care of you?” and “Why don’t you demand to know what is going on around you?” and “Why does there always seem to be something everyone else knows that you don’t, as if there is an inside joke circulating that no one will tell you because no one thinks you will get it?”

The government has contributed to the pretense that everything is normal. They won’t certify her as too retarded to hold a job, but they will provide her job training. I worked many hours, on three separate occasions, over an eight-year period of time to get her vocational rehabilitation. Each time she stopped the counseling and vocational training the moment my back was turned. Since social service workers cannot force services on anyone, and since Suzanne has to want the help, no one can do anything about it. And so we go on protecting her from the truth, lying, keeping silent, and pretending everything is perfectly normal. In a sense we are complicit agents in her failure. If she did not have us, if she did not have the trust fund, if she could not go on living this fiction, she would be forced to go out and get job training. When I was 5 years old, my father went to prison for a year and a half for sexually assaulting someone. During that time my mother

obtained federal housing, food stamps, and other Aid to Families with Dependent Children by following the social workers’ instructions to the letter. When survival was problematic, Suzanne came through for us. So where is her fighting spirit now? Somewhere in my gut, I just know she is being lazy (Ronai, 1996, pp. 115–116).

***

I imagine my own mother up there, advocating on behalf of intellectually disabled parents and her child. Not. Going. To. Happen. Too lazy. Parallel to the meta-shame Carolyn Ellis (1998) describes in her article “I hate my voice” where she is ashamed, to be ashamed, of her pronunciation of the letter “s”; I am ashamed, of my shame, for my mother. It shouldn’t be this way. I should be ashamed of her and be done with it. Or know that I am wrong to be ashamed of her and stop. It is not a big deal. But it is or I would be over this.

***

Someone in the audience had asked, “Can’t you understand that she couldn’t help it? And the horrible man she was with? Can’t you forgive her?”

I answered, “You would think I could, wouldn’t you? In a cognitive way I know you are correct. The reality is I feel what I feel, and sometimes, I can’t stand her. I am sorry to say it.”

***

I pull myself together, adjust my eye makeup, and hope for the best. I exit the bathroom to find (almost “run into”) one of the conference organizers waiting outside the door. He asks me, “Is everything all right?” I really, really, do not want to talk to him, I have no idea what to say. I reassure him I am going to be fine. “May I ask what the problem is?” he says. The poor man feels obligated to do emotion work with a stranger, one of his speakers—this particular speaker—who he must have seen leave the room suddenly. His concern feels genuine and at the same time he is distant and obviously at a loss. He may feel pressure to get back to the conference but cannot put together a story for what is happening. I am barely able to put together a story for what is happening. He wants an explanation, so I let loose with my first knee-jerk response (not my best self, my defensive self). I fill in his blank space with the worst possible answer.

“I was taken by surprise with my reaction to this panel. It’s kind of a spectacle. Do you realize they are all on display, to be gawked at? You have made
a ‘show’ out of them. Do you know that, right?’ I ask. I am unaware of how I am deflecting, though it is obvious to me later.

He is clearly injured; he turns and falls forward against the wall as his forearms catch his weight. Slowly, with his right elbow braced, his right hand rises to support his head. Talking at the wall, holding his head, his voice goes up an octave or so and quivers almost imperceptibly, his professional demeanor is gone. ‘But, but, we talked about this and decided that wouldn’t be the case since everyone here works with intellectually disabled clients. Plus, if we don’t do this, we disempower the parents. Who best to speak for the parents, when the parents can speak for themselves?’

Wow, I read that horribly wrong. Or not exactly wrong, this is just difficult, as are many issues connected with intellectual disability. The organizers thought about it, he is clearly floored by my reaction. He does not understand I have experience only with my mother, and what that might mean. I quickly jump in, recognizing my response struck an unfair blow, our roles are now reversing, ‘It was me, it was all me. I was shocked. I’m not around this like you are. I’m just not used to it, that’s all. Of course, if they can advocate for themselves, they should. But I gotta’ tell you, I could never conceive of my mother up there. Trying to imagine her doing it, what you would be asking of her, it would not be possible. Seeing all of them, I was overwhelmed. It was just shocking.’

He turns to look at me, his arms still braced on the wall, his voice lowers, ‘We really did talk a long time about this, considering the ethics. We try to protect them, not exploit. We’re here to help and constantly discussing these issues.’ Then he adds, straightening up, most of his composure back, ‘People need to see this. Why don’t you come back with me and watch? See what you think afterwards. Besides, they want to meet you. I don’t want to disappoint them.’

We talk more as I walk with him. ‘Meet them?’ I think to myself, ‘Oh God.’ Another voice within me is curious.

We enter the room and I sit down where I was before, the session is already underway. I am stunned and in awe of their openness. It is refreshing, healing, showing me a new way to engage with this topic. They are teaching me. No one is protecting their feelings, they all self-identify as people with intellectual disability. All of them speak of how much they love and want their children. Each speaks of the circumstances of having their children taken from them, pointing out various injustices, judgments, misinterpretations, and their resulting powerlessness in their situations because of their status as intellectually disabled. They are a class in themselves, for themselves, they know ‘what is what.’ When you cannot read and keep track of paperwork, all kinds of things can go wrong that have little to do with your ability to be a good parent. I am convinced by some of them and question others. There are vibes I do not like and holes in stories. The attractive young woman seems flighty, capricious, I want her and her kid to know each other, but she is too much of a child herself. I am not too sure about independent living for them. A young man claims he did not beat his child, but I am not so sure, my radar registers violence in him. The thought he could be sexually abusive crosses my mind, though I do not know why. I am also aware of my mild phobia and personal biases and realize that I do not know them. Maybe with these services, they can handle parenting.

The couple is particularly compelling. They are clearly a “mess” in my shallow judgment, yet I am bowled over to realize that, through all the slurred speech, strange lip formations as they speak, awkward head and hand gestures, and misshaped bodies, they both have sharp emotional intelligence. He comforts her as she cries while telling the story of losing their three-year-old son, his arm around her, his hand brushing away her hair from her tears. For a moment the weeping is all there is, the room is quiet, otherwise. Then he turns to the audience, mildly angry, and emphatically states, “I know what you think you see when you look at us.” The words come out twisted, yet firm. This is a man standing up for his family. She sits up straighter, still crying, and pets the back of his head and says “shhhh” to calm him. She softly tells him, “It’s going to be all right.” He lowers his volume and head, and continues, ”Just because we aren’t good at math and have a hard time talking and filling out forms, just because we are different, does not mean we should have our child taken from us. Kids need their parents. We are his parents. He has disabilities. Who better to understand his disabilities than us?” He points to himself with a gnarled hand, as he looks at all of us.

This realization regarding their rich emotional lives, and their efforts to take care of each other, pierces my heart; it is powerful, epiphanic. I see them as heroic, fighting for custody of their child in the face of incredible odds. They are bonded and every bit as much in pain when they are away from their child as I am when away from mine, particularly at this young age. Taking their son from them is cruel. And God help me, their story is an epic love story, pure, straight, and true. This has been a live demonstration of how emotions are a separate dimension from intellect; a person can be smart there and cognitively impaired otherwise. That counts for a lot. I am convinced that, with help, this couple could live with and care for their child. The
services being offered with this organization include a center where parents can bring their kids in to play together and get help with their school work. As they get older, some of the kids go to the center on their own. They also offer parenting classes and pragmatic advice on scheduling, budgeting, and organizing their homes for children, as well as home visits from social workers, when needed. This couple would never hurt their kid on purpose, it would be an accident, and services like these would go a long way toward preventing such accidents.

My tears spill openly now, but I am at peace with it. No confusion, no twisted emotions. I had no idea you could be intellectually disabled and emotionally mature at the same time. We did not expect enough from my mother, or demand enough. Either that, or there was no one around my mother to role model it for her.

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Am I out of my mind? I just might take this couple as parents over the pair fate handed me. That realization too, makes me cry.

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My mother stood nearby as he grabbed my small arm, practically pulling it out of the socket. “No,” I said, planting my feet and pulling away, “I don’t want to.” “You know you like it,” he said, pulling me toward the bed. “I don’t like it today,” I said, flinging all my weight in the opposite direction in an effort to counterbalance his pulling on me. If I put up enough resistance, sometimes he would give up, regarding the whole matter as not worth the effort. This time the strategy wasn’t working. My feet were dragging across the multicolored shag rug of the efficiency apartment, burning from the friction. “No,” I screamed, flinging my bottom to the floor as he continued to drag me. When I kicked at him and missed, he laughed affectionately, as if reacting to something “cute” I might have done.

Upon seeing the violence I was willing to employ, my mother intervened and pulled on my other arm. “It’s her bed time, Frank, let her be,” my mother stated. “Since when?” he asked, dubious of my mother’s motives, forgetting to pull me for a second. “It has always been 8:00, ‘cause she has to get up to go to school in the morning,” my mother replied, yanking my right arm, pulling me away from him. He thought about this for a moment, then pulled my left arm and stated, “That can’t be right, it’s too long to sleep.” My mother and father pulled on me back and forth like this for several rounds.

Each time my mother pulled I leaned into her direction, hoping to break his grasp and run. Ultimately “logic” won out. “I’m her father and I’m setting a new bed time, 8:30.” I flashed a desperate look to my mother as she let go. “There’s nothing I can do,” she said, as she turned her back and left for the bathroom. “NO!” I screamed, vibrating from the effort to keep the word airborne. “No, no, no,” I whimpered as he dragged me to the bed, raking my panties down my legs, scratching long red welts with his nails. “No,” escaped from my lips, now barely a whispered sigh as he parted my legs and descended, face first between them. “You always like this once we get started,” he said. “Not today,” I replied, watching my mother watch from the bathroom doorway (Ronai, 1996, pp. 113–114).

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I used to fantasize about having different parents as a child. I would read stories about orphans and foster children with envy. One story was about the daughter of migrant farmers who was temporarily cared for by a young wealthy woman who could not have children. While the family recuperated from their disaster, the woman came to love the little girl and offered to educate, support, and raise her. The family gave the girl the choice (they loved her too). While she adored the woman, and was sad to leave, she went with her family, and the woman understood.

“What was wrong with the writer?” I thought to myself as a kid. It was such a great story until the ending. Why wouldn’t you go with the woman? I did not understand how loved and connected the girl in the story felt with her family, even if they were poor and had a hard life. Just because they were poor did not mean they were abusing her. I assumed abuse went with poverty.

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What if there had been services around like this for my mother? How different would our lives have been?

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I stay afterwards and meet everyone, we are a milling crowd. I tell the parents how much I admire them and wish them the best. I take a moment to privately tell the couple how lucky I think their child is, and that they are going to do great. The three of us self-consciously but sweetly touch hands for a moment. I do not cry, but I want to.

A young man who was not on the panel awkwardly asks the organizer if he can take me “out.” I snap my
head toward the organizer who was not about to rescue me. He said, “Well buddy, I think that is up to her, don’t you?” There are sly smiles and some shocked expressions in the group. All eyes are on me.

As he gears up to ask, I quickly say, “I doubt I have the time. I am not in town very long and there is a lot the conference organizers want me to do still.”

He asks the conference organizer, “Maybe later?”

He responds, “Maybe later.”

A woman wants my attention and I excuse myself from the group. We go off to the side and sit in the sea of empty chairs. She is a social worker, perhaps in her mid-twenties, pretty in a wholesome, pragmatic way (shoulder length hair, not a lot of adornment), and very energetic. I like her immediately, and how could I not? She tears up and thanks me for coming to the conference. She says, “You are the reason that I do what I do.” I am puzzled but stay quiet. Some time passes, she gathers herself and then continues, “I am working with a little girl now just like you. She is so incredibly smart, but because of her mother, she has some challenges. You,” she gestures at me with her finger, “are her, in the future. Just meeting you helps me know what I have to do. It is not impossible.”

Damn, I have been the biggest crybaby at this conference. [Hell, in this paper, I hate it.] I listen to her tell me the details about the girl’s situation. Her father is not quite as awful as mine, she says, but he is abusive to her and her intellectually disabled mother, the situation is not easy. Like mine, he comes and goes, and he is in and out of prison. “Sometimes an absent father is a blessing,” I say. A good social worker is a blessing too . . .

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Without discussing it, we all knew that social workers were bad news. I secretly liked them because they always brought groceries, but I’d never say that to my father because he took it as an insult to his ability to provide for us. Besides, he hated the social workers because they might take me away from the family. I had the strictest orders not to talk to any strangers. Almost everyone was a stranger (Ronai, 1995, p. 401).

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When I was 10, Grandmother said she was sick of supporting us and we had to find a way to contribute or she was going to kick us out. My mother and I applied for welfare, which included Aid to Families with Dependent Children (AFDC) and food stamps. When my mother and I met with the social worker, my mother threw a temper tantrum, refused to answer the social worker’s questions or fill out any forms, and stormed out of the AFDC office. I panicked, begged the social worker to wait, ran after my mother and begged her to come back. When she returned, I filled out the forms and answered the social worker’s questions. Later, when my mother went to the bathroom, the social worker came to me with tears in her eyes, hugged me, and said, “God, this must be awful for you.”

I saw myself through her eyes and realized what a spectacle my mother and I must have made, and yet it was okay. I was the kid here; it was not my fault. Someone finally understood how hard this was for me. Self-consciousness and relief swept over me, simultaneously flushing my face and filling my eyes with tears that I fought to control. “Poor baby,” she said maternally, motioning to two of the other workers. The concern and sympathy on all of their faces were too much. My body went limp in her arms as the dam burst and tears flowed. I wasn’t allowed to do this, I shouldn’t have been doing this, but it felt so good. Crying was simply not allowed at home. When it occurred, it was handled much like masturbation—you do it in private and hope you don’t get caught.

My mother came out of the bathroom, saw me crying, screwed her face up and said, “What’s she acting like that for?” The other two workers led her away from me, telling her that everything was going to be all right. Our caseworker took me aside and showed me how to answer the questions differently so that she could approve us for aid. It was important that these questions get answered the same way every year. I understood that I was going to be responsible for this process from now on (Ronai, 1996, pp. 116–117).

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I share with her, “One thing that helped me is that my family, my aunt and uncle, had high expectations of me. They let me know, just because my mother and father were the way they were, did not mean I could not go to college and accomplish things. They expected it. I took it simply as ‘the way things were.’ I was going to college. It also helped me when social workers and teachers let me know I was okay. I needed that too.”

In for a penny, in for a pound, I decide to dive in deeper, “When I was a little girl, I would have loved having someone like you around.” I tell her about being 12 when I was arrested for shoplifting. I had never told anyone, but I was getting prepared to runaway from home. I had it planned with a girlfriend who also had a sex offender father. It was in the nick of time when they put me into a diversion program called Circle of Concern and paired me up with an 18-year-old counselor named Robin who would
meet with me once every two weeks, for six months. I adored Robin and mourned her loss when I was discharged from the program.

She shares with me that her girl, too, has been arrested recently. And she has already run away more than once.

After a bit, the conference organizer comes to get me. The child that I was, earnestly speaks through me, to the social worker. “If I am your girl’s future, you are my past. Thanks for doing what you do. It matters. I promise.” We are both in tears as we hug and part ways.

As I walk toward the exit with the conference organizer, I notice the young man from earlier, tracking us, waiting. I should have said I did not want to go “out” with him. We are being insensitive; he is waiting to “take me out.” I say something to the organizer, and he brushes off my concern. “Do you really want to go out with him?” he asks, stridently. “I don’t. This just sucks, is all,” I reply. I was trying to spare his feelings when “later” was never going to happen. Things do not always turn out okay, not everyone’s feelings can be accommodated.

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Be careful of what you ask for when you write something like “My Mother is Mentally Retarded.” Oh, the places you’ll go, and the things you will see (Dr. Seuss, 1960). You could be taken as an “expert” on the topic, when you are not, or maybe something else . . .

***

I have written about this event elsewhere (Ronai, 1999). For this remix, I summarize and reword. I am in New York again, filming an interview for CBS’s Public Eye on America, with Bryant Gumbel. I am being interviewed by Bernard Goldberg, an Emmy award winning correspondent. I was warned that I could be ambushed in this situation, but I did not give proper weight to those warnings. We negotiated not using my mother’s name or my maiden name in anything. We negotiated not discussing sexual abuse. I thought I had all the bases covered for what could go wrong. Then Bernard read the following, out loud, on camera: “I am disgusted that this creature, Suzanne, is my mother. She is horrifying, vile, potentially defective genetic material, someone I or my child might take after” (Ronai, 1996, p. 117).

I don’t know what to say. I imagine my mother hearing this, flip channeling through her television stations, and I am crushed. This guy is thoughtless and sick, can’t he imagine my mother hearing that? Do ya’ really want to pick on a retarded lady? Can’t he take on her role, or hell, at least my role, and know that I would not want that to represent the entire sum of our relationship? In a layered account, that sentence is a moment in the flow of experience, one of many “takes” or “samples” of experience between my mother and me. There were happy times too, and a great deal of ambiguity. “I don’t understand what you are looking for,’ I respond. ‘You wrote it, you tell me,’ he states” (Ronai, 1999, p. 150).

Heatedly he and I go back and forth. He accuses me of regretting writing the article. I accuse him of ambushing me. He accuses me of being paranoid. I accuse him of getting his producers to lie to me to get me in there for the interview by telling me that this was going to be an “uplifting piece.” The cameras are still rolling. He tells me that he has been professional and all the questions he has asked are reasonable. He suggests I ask anyone in the room, producers, camera people, anyone. He insults my institution. “It’s not like we ask people from where? University of Memphis? To come on and speak” (1999, p. 150).

And then finally we get to it, he asks, “But really, should mentally retarded parents be allowed to parent?” (1999, p. 151).

This question, I am ready for. This is THE QUESTION, the weight, the onus, the responsibility, the one I did not know I was taking on when I wrote the original article, the one everyone wants an answer for, the one I had to read up on and decide for myself. I inform him that while this is a common question, indeed, an understandable question, it is not a good question. It implies that there is a choice. The intellectually disabled are going to have sex, they will have children. The real question is what will we do about that? I advocate for services to support them having access to birth control, education about what raising a baby is really like, and services for when they become parents.

He pushes a series of “yeah buts.” “In an ideal world, wouldn’t it be better if they didn’t have children?” (1999, p. 151). I keep answering his questions and he keeps pushing aside everything I refer to in the real world, with his ideal world. I am frustrated, again. I ask him if he thinks I should say that I should not exist. He gets why I would not say that, but what about the ideal world? He rephrases, and asks if alcoholics should have kids, in an ideal world. I respond that they will, and they need help, too. For the life of me, I cannot figure what it is he wants to get me to say.

Eventually, they wrap up this hellish taping session. They need some B-roll of Bernie talking to me, and me listening, so my job is to be quiet. With a sense of indignation, Bernie comes at me:
The uplift of this story is that you exist at all. Do you understand that? That you are a professor. Let’s face it, your father was a pervert, you mother was retarded, and your grandmother was an abominable character. That you made it at all is the uplift of this story. … You wrote this article and to tell you the truth it depressed me. You wanted to reach someone and you did. You reached me. I was very moved.

(Ronai, 1999, p. 153)

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If I am honest, I was flattered that a journalist told me my story moved him. But his words also infuriated me. There is a saying that goes something like this, “It’s not how well the horse talks, it’s that the horse can talk at all.” That I exist at all …

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I spent the next several months in terror that our fight on camera would air. Some cameramen came to Memphis, TN, to film me on campus, walking outside, walking to my office, in my office; more B-roll. They assured me that if Bernie looked bad it would never air. They were right. The piece was considered “fluff” by the intellectual disability community, and my role in it was vanilla. Not one controversial thing aired. I was grateful not to shame my department and university and disappointed that little of the complexity of being raised by a mother with intellectual disability came across in their story. With all those cameras filming us, I mistakenly thought they had room for multiple “takes” on our situation.

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In Sydney, Australia, the story is different. There is a conference being held in the Olympic Park for those who work with parents with intellectual disability. I am flown in to speak and become aware that there is a small group looking at me warily. Some talk about boycotting my presentation. I am not angry, barely hurt, mostly perplexed. I do not know these people. A conference organizer takes me aside and says, “They are worried you are going to come out in favor of removing children from their parents. They have read your work.” I smile, tell her “I’ve got this, no worries” (this is what you say in Australia, everywhere, “No worries”), go to my room, and revise my talk.

The next day, my presentation on social workers and their role in my survival was a hit with a standing room only crowd. Afterwards, there is talk I should have had a longer visit. Some of the former provocateurs even float the idea of me moving there and perhaps working with one of several consortiums and teaching at the University. I do not know if they are serious; still, it is an exciting revisioning of my life and my purpose.

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This chapter incorporates “sample” passages from an original article (courtesy of Roman & Littlefield), “samples” from other articles, and new materials, in a remixed contemporary story about my article, “My Mother is Mentally Retarded.” The genre is decidedly blended. Aspects of this remix (Navas, 2012) are selective, where material has been added and subtracted from the original; reflexive, where this chapter depends on the original for its existence, yet few samples are used; and most notably regenerative, where meta-autoethnography and revisioning (Ellis, 2009) add a temporal dimension to writing, thus enabling other data streams to change and update the original. While the regenerative process is less kinetic here because standard publication practices move much more slowly than the collective, rapid fire, posting on the internet; the structure implied by regenerative remixing is parallel.

As other scholars have noted (Ellis, 2009), it is rare to have the opportunity to revisit our work; I am grateful to the editors of this book. Without the invitation to write about writing this story, I would have never consciously engaged in this process. Be clear, it is a process. I have unwittingly remixed my own materials many times over the years, layered accounts are highly amenable to this process. A story that serves one purpose in manuscript A, serves a different one in manuscript B. Here, I sample older work to shed light on meaning making in more contemporary events, even as I use contemporary writing to make sense of the past.

Meta-autoethnography (Ellis, 2009), autoethnography about autoethnography, and revisions, create a space where regeneration is the project, in every sense of the word. Reliving and remixing this autoethnography about my mother forced me to lay down a “beat” or story line which connected these events in a way I would not have, otherwise. As I look over my stories, many times I show up to perform an identity I am unprepared for, only to muddle through and learn something despite myself and my fears. Intellectually disabled people taught me about the regenerative qualities of openness and kindness. A journalist who meant well, and was “amazed I existed,” taught
me about the lack of regeneration, the retardation of openness and growth, that can occur in the high-pressure, insulated, environment of a major news network. Few data streams reach him. Or too many so that he is overloaded.

In the final analysis, I now know to be mindful regarding what I write. My words may come back to haunt me or be taken out of context in a sensational manner. And they may have larger implications for myself and others than I could initially foresee.

REFERENCES


