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Losing

Mel Baggs

June 30, 1995.

Alone. In a bare room. For new people. They've left me here while they do my paperwork. First time in a mental institution.

For hours, I explore every inch. The unbreakable window looks out on an overgrown courtyard full of windows. There's a small circular hole with an oval impact crater. I wonder what happened. I find some graffiti on the bed, where nobody could see it without lying on the floor. It reads, "FOR THE ONES WHO DIDN'T MAKE IT."

Throughout the wait, I become aware I still exist. I haven't disappeared. I agreed to admission because I thought disappearing might be easier than suicide. It didn't work. I'm still here.

Crazy people are supposed to disappear. People disappear when they go in the front door of an institution. But I'm still here. I don't understand. I'm afraid. I often get things wrong. I know in my bones I'll never be

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normal. I must be crazy. But crazy people in institutions vanish off the face of the earth. Everything in my whole life has told me this.

The whole world can't be wrong. Institutionalized crazy people disappear. I'm crazy, I'm in an institution, yet I still exist. Something has gone wrong. I must've screwed up if I'm still here. My innards twist with a mixture of worry, guilt, and frustration. Underneath, a bottomless, nameless dread. I'm still here, can think and feel, am alive, am whole, am suffering, am aware. Something somewhere has gone terribly wrong. I don't know what to do.

The most disturbing thing I've found in this room isn't the starkness, the unbreakable glass, the hole, the graffiti, the weight of untold stories, or the location. It's myself. I'm still here.

June 30, 1995.
Saint John's Autism Listserv. Known in the autistic community as ADH-L—Academic Dick Heads List. People debate whether some people with developmental disabilities belong in institutions. Cal Montgomery writes an email about why institutions are bad and nobody belongs there. Things move on. Cal believes he's lost the argument.

Fast forward to my early twenties. I debate people who think some of us belong in institutions. I'm different, they say. I'm a different kind of person from those people who slam their heads against walls.

I remember that first time in a mental institution. I discovered that slamming my head against a wall led to being tied to a table until my arms and legs went numb, then injected with a drug that immobilized me so much I couldn't open my mouth. They have no idea.

I read archives of the Saint John's autism list. I do that: I try to find the roots of things, things that happened before I was around. I find Cal's 1995 message:

> <redacted> wrote: (original message by <redacted> in italics, Cal's comments in normal font)
>
> *I worked for over 5 years at the Eunice Kennedy Shriver Center for Mental Retardation which is located at the Fernald State School just outside of Boston, Ma. (this is where Christmas in Purgatory was filmed). I worked…*

I have worked for nearly 5 years in various staffed apartments in the community, some of whose residents used to live at Fernald, Wrentham, or other state schools. I have been on the Fernald campus only once.

…under a contract to provide the medical care for all the residents at all the state schools in Mass. I became very familiar with all of the facilities, most of the residents, and married one of the staff. Like any…

I am intensely familiar with the people who live in the staffed apartments where I have or do work, especially since I generally work with people with several disabilities, or with severe or profound MR [mental retardation], or both. I know fewer people than you do, but probably far more intimately. I am not familiar with any of the large institutions, but I do know a wide variety of current and former staff both in the state institutions and in the community residences.

…large facility, it was not what it could have or should have been, but it had improved quantum leaps from when it was filmed. And no one has been admitted to them since the mid 70's. Most of the staff are kind, and…

That is true.

…caring individuals who really grew to love the people they cared for and treated each of them as individuals. Many of the residents had been placed…

I cannot say anything about "most" since I don't know enough people. But while some of the staff at institutions are kind, some are truly cruel. I know this from observing former State School staff who have obtained jobs in community-based programs, from hearing stories from former State School staff who were horrified at what they saw, and from hearing stories from former State School staff who fondly reminisced about beating up residents of the Schools, or dropping water balloons on people trying to navigate icy paths, or … Some of the things that people have told me about almost proudly would make you sick.

This is not to say that you don't get some of these people in the community-based programs, as well. But I have worked for a number of the agencies around here and have done relief shifts in others, and I have yet to see the acceptance and approval of this sort of behavior that I hear existed in some sections of each of the Schools. In the staffed apartments, there is more monitoring—from families, housemates' families, and neighbors, if from no-one else—available.

I have worked with clients who had nightmares about the School they grew up in, who refused to visit with friends who still live in cottages on campus, because they will not go to the campus, and who will not even stay in the room with you if the word "Fernald" or "Wrentham" comes up. (This is clearly the more verbal end of my caseload.)

…there as children by families who had been told to forget that they had ever

been born. This was the prevailing advice from the professionals in the

40's and 50's. They may not now have families who want to or who are able…

That is true.

…to care for them. The functional level of some of those individuals is…

That is true. But there are (or should be) other options. Other options can be found, if we make finding them a priority.

…breathing. The staff work very hard with them and rejoice when a resident…

I have never ever met a person with MR whose functional level was breathing. And, as I say, I have been working with people with severe or profound MR full time (sometimes two jobs simultaneously) for 5 years and I have worked with others dating back to when I was 12. I *have* met many people whose abuse or mistreatment or neglect was rationalized because "he's retarded and doesn't understand" or "his level of functioning is so poor that there's nothing we can do for him." I have worked with people who, according to charts, don't communicate, but who in fact get a great deal across, consistently (same methods, same message received), to people who know them. I have *not* met anyone who is able to provide medical care for as many people as you say you have who has had the time to get to know those people well enough to accurately assess their functional level, so I'm assuming you are relying on other people. Given the facts that I've seen a lot of data fabrication from staff who used to work at State Schools, that I've seen wildly inaccurate assessments in charts of people who have come out of State Schools, and that the staff at State Schools may have been working in a 2:20 or lower staff:resident ratio in any case, I tend to doubt *any* assessment of functionality that comes out of those places. They are often simply wrong.

…they have cared for and worked with learns to sip from a cup or smiles. The staff do their best to make it as good a place as they can.

I am certain that many, and possibly most, of the staff, do. That does not mean that they are capable of making it a good place. Most people do not want to go live in a nursing home, no matter how hard the staff try to make it a good place to be.

Remember 15 years ago when the state psychiatric hospitals were closed in many states. The persons responsible for the closings did it with the best of intentions but the closings resulted in problems and mistreatment of the former residents that were much worse than any treatment they could have ever received in the facility.

For some of the former patients of State Hospitals, this is true. For others, freedom from the Hospitals freed them to get their lives together (yes, I do know such people). In any case, it was very very poorly planned and executed. There is no denying that. But that does not mean that such a move has to be poorly planned and executed.

This is my fear of what may result from the closing of these other facilities. Will proper care be taken to insure that the tragedies will not happen again? Before closing the facilities are appropriate…

Well, that is the responsibility of those of us in the community, isn't it? That is the responsibility of you, and me, and my neighbors (who are clearly not going to take on that responsibility—there is a great deal of hatred for people with disabilities around here).

…residences and treatment in place for all of who are those being uprooted?

> It isn't enough to just keep saying, we can't close the Schools because we don't have appropriate places to put people. We need to look at the fact that direct care staff in Massachusetts have not received Cost of Living pay adjustments in about seven years, and that some could make more money on Welfare [sic] than they can at their jobs. So capable, competent, or even trainable people are not being attracted to these jobs. We need to look at the fact that Massachusetts does not mandate adequate human rights trainings so that these staff don't even know what they are supposed not to do. We need to make licensing a process that reflects more than how well the paperwork is kept. QUEST [Quality Enhancement Licensure and Certification Survey Process and Tool, a survey and certification process for providers of services for people with developmental disabilities] is a start. Recent changes in the rules for medication administration are a start. We need to make appropriate residences a priority instead of an excuse.
>
> *Remember, for most of these individuals this is the only home they have ever known. And while being a resident in a state facility may not be the best life, it is better than the streets.*
>
> Just because they've never known a better home, or a home with more actual choices, does not mean they don't deserve to know one. And just because there are things that we (as a society) could do that are worse, does not mean that we do not have an obligation to do better.
>
> *Just my opinion, but an opinion based upon an intimate knowledge of the state facilities in Massachusetts.*
>
> As mine is based on knowledge of group homes.
>
> Cal

I'm floored. The same day I entered that place, Cal said people like me don't belong there. Everything connected. Someone was on my side, even though I didn't know. The arguments I'm having now were going on before I knew the community existed. I was exactly the person being discussed:

an autistic person in an institution while people were arguing whether we belonged in institutions.

I order my records. They come in a giant box. I'm shocked. I'm not always aware how people see me. The papers have words I never knew people said about me: Low functioning. Severe and complex developmental disability. Unsalvageable. Violence. Headbanging. No future.

A group of autism parents attack an autistic woman named Michelle Dawson. They say she's not autistic. They target her viciously. I'm part of the response.

I describe myself in third person, using the most pessimistic terms professionals used on me. I reveal I'm that person, that I'd far rather have Michelle Dawson, Cal Montgomery, Laura Tisoncik, Joelle Smith, or Larry Arnold, speaking on my behalf than these parents. I call it "Past, Present, and Future."

The Autism Society of America puts out a website called "Getting the Word Out." It uses black-and-white stock photos and tragic language to describe us. They say our existence destroys our families. They're "spreading awareness."

I write a parody based on "Past, Present, and Future" called "Getting the Truth Out." I take black-and-white selfies, mash together every negative description professionals have used on me, then reveal who I am, what I think, what issues we face, and why "Getting the Word Out" harms us. I emphasize how you can make anyone look terrible if you describe them selectively.

I ask others to contribute their photos, selectively negative descriptions, and actual opinions [1]. But I'm the only one. Instead of a website starting with multiple pictures you can click, it ends up just me.

"Getting the Truth Out" becomes better-known than I expect. I remain unaware of the overall effect this website has had.

What I remember is people:

- Not grasping it was a parody, especially after the ASA took "Getting the Word Out" down.
- Thinking I meant it as straight autobiography.
- Not noticing I was highlighting the dangers of using a selective pathological description of anyone.

- Thinking the selective descriptions and stereotypes must be true, or I'm claiming they're true.

But the message was what I got from Cal: Those of us making the online arguments, and those of us described pathologically, can be the same people.

I'm not a different person than the scared child who found she still existed despite being in an institution. Who slammed her head against the wall of that room until brutally restrained. Who attracted pathological descriptions that stripped her of her humanity and future. I didn't become a different person once I started saying, "Institutions are bad."

Every person who could be described as an autistic child banging their head on the wall of an institution, is a hell of a lot more than that. It conjures a stereotype, a story. But it's not a type of person. It's more how others see us than who we are.

I'm not good at knowing the impact of my writing and videos. Just as Cal thought he lost the argument in 1995, that's how I assumed things went with "Getting the Truth Out." I thought people hadn't understood what I was trying to say, that I'd failed to convey my message.

From what people tell me that's not true. Yeah, lots of people misunderstood. But lots of people got the message. They affected others, who affected others. Everything we do has ripple effects we may never know. Maybe the day I put up that website, some child described in similar words was in an institution. That child may discover my writing and make the same connections I made when I found Cal's writing. You never fully know the impact of your own actions. Some of it may stretch beyond your death.

In writing this, I've done my usual: Described specific situations, in detail. But I didn't write this to tell my story. Each thing I mention can apply to many people and situations that aren't identical to the one I describe. That's how all my writing works: I write the specific but aim for broad applicability.

Our actions matter. We may never recognize the full impact we have. Everything we do can have a profound effect on others. Remember that when you think you've lost the argument, that you've failed, that nobody understood. Most of the effects of our actions are unseen but important. Without Cal's single email, there'd have been no "Past, Present, and Future," "Getting the Truth Out," or "In My Language" [2].

I owe debts to different disability movements: Developmental disability (DD) self-advocacy, Deaf culture, psych survivors, the independent living movement, others. They have shaped everything I've ever done in the autistic community, far more than the autistic community itself has.

Like everyone I know who's been called a leader within the autistic community, I took in many perspectives from outside the community, and functioned within a broader sphere than one community. We're part of the disability rights movement. Other disability communities influenced everything I'm known for within the autistic community. Some things people say as "about autism," were not only never "about autism," but came out of things like the DD self-advocacy movement. "In My Language" was an act of DD solidarity with a girl with cerebral palsy whose parents mutilated her, not a statement about autism. I told CNN this. They edited it out, replaced with something I never said [3].

Whatever perspective we come from, we need to be prepared to think we've failed, to never know our full impact. Cal may've lost an argument in 1995, but he showed me a way of seeing myself and other disabled people that proved central in nearly everything I ever did that had an impact. I'm sure even my least pleasant contributions have had important effects I'll never know about.

Sometimes we think we've lost, but it's only the beginning of things we can't imagine. We have to do the right thing even when it looks like we're failing. One email can spark important things we'll never see from people we've never met.

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