

Reprinted from the December 2016 Autism Society of San Francisco newsletter:

Defusing Some Autism Vocabulary Stinkbombs



Now we'll do an exercise, a game I'll call "Fun with Words."

This is a planning conference. And good planning requires a foundation of good concepts. But autism seems to be in such a persistent state of conceptual muddiness, made all the more complicated by competing dogmas, mushy and inadequate terminology, sanctimonious judgmentalism, and various on-trend then off-trend euphemisms and doublespeak that can divert our attention from important issues and dilute the seriousness and severity of the situations we are facing.

I find this rather unfortunate because a lot of people in this room and in our community are facing some overwhelmingly difficult problems. We bear tremendous responsibility for some of the most deeply disabled and dependent people in our society, and yet the roadblocks are huge for families as they search for solutions and understanding.

This exercise is intended to open our brains and our discourse to make way for more clarifying concepts. I'll discuss just six terms (though I could probably think of 20 more...).

A small version of the "FUN with WORDS" graphic, with "FUN" in blue, "with" in dark, and "WORDS" in red.

"Autism"



AUTISM

Let's be clear, "autism" is not one thing, it's a hodgepodge term and there really is no such thing as autism. For example, Temple Grandin has nothing in common with my daughter, who is nonverbal and severely impaired, functioning at closer to a toddler level than at the level of the 10 year-old beauty that she is. But both Temple and Sophie are labeled as having "autism." This problem is absurd and sadly pervasive.

When we talk about "autism" we are talking about differing causes, genomics, neurobiology, cognition, functional abilities, and behavior. What is true for one person is probably not true for another. So let's just recognize and accept the great diversity of experience represented by this overbroad term "autism" and not get stuck in any single dogmatic rut.

FUN
with
WORDS

"Institution"



INSTITUTION

This is a word with a deservedly bad reputation, but one I believe should come back into style and in a big way. Let me explain.

Look in any dictionary and you'll see there are two completely separate definitions for the word "institution." There are what I call the "capital I" Institutions, which are coercive and restrictive massscale housing for people deemed undesirable by society, and then there are the "small i" institutions, which refer to stable, community-based, mission-driven organizations, usually nonprofit, that serve a fundamental public purpose — in our case of providing essential supports and services to those who cannot care for themselves, and who are served a voluntary basis.

Big I and small i institutions are very different things. We are actually sitting here in a small-i institution — Stanford is one of the great educational institutions in the country (I can say that as an alum). There is no shame and much pride in being a valuable institution serving an important public purpose.

Make no mistake about it — if we are to avoid the Big I institutions, our future depends on the cultivation and support for the small-i institutions that serve people with autism/DD. We have many outstanding live-saving absolutely vital basic human services institutions here today, I can name a

few: Morgan Center, Friends of Children with Special Needs, Gatepath, Harambee, Good Shepherd Fund, and a number of supported living agencies, and the list goes on.

In my view, institution is not only a GOOD WORD, our grown children's futures depend on the flourishing and nurturing of small-i institutions. Deinstitutionalization without recognition of this fact is nothing more than abandonment of our most severely disabled. Let us not be ashamed or fearful of this word.

Autism-Pennsylvania Note: Even large institutions can be superbly appropriate like Western Center, the one deliberately destroyed – feature by feature—by the ideologues and social engineers of the Pennsylvania Department of Public Welfare (1990-2000). Results: 38 deaths and skyrocketing wait lists for out-of-home-placements, and human suffering.



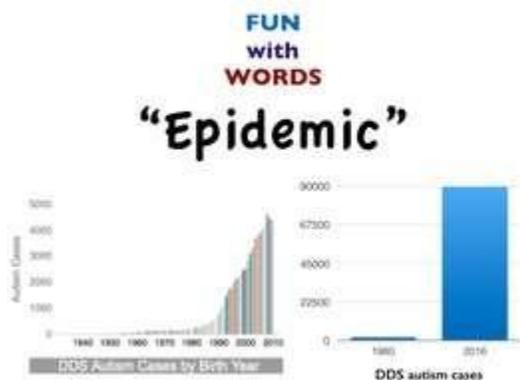
INTENTIONAL

Here's another word that deserves to be back into fashion. The idea of creating "Intentional" housing or programs has come under fire in recent years. This is absurd and an outrage.

I'm in the special needs landlord business and let me assure you that when you are dealing with longterm housing and care for an adult with significant intellectual and behavioral challenges everything, every facet, must be absolutely intentional. The decision to rent. The terms of the lease. The protections from eviction. The safety measures. Sometimes the amenities and materials. The source of the monthly rent (which in our area by the way is never enough to actually hit market rate). And various accommodations, which often go far far far beyond what ADA requires.

Intentional is a GOOD and indispensable word, it protects and helps and caters to our people. For autistic adults housing is not a room. It's much more, and it all requires INTENTION.

The opposite of intentional, which is casual, haphazard, or off the shelf is a recipe for disaster for many adults with autism or DD.



EPIDEMIC

Here’s another hot potato word—Epidemic. Let’s be clear about what we are facing (and sadly it would take me an hour to do this topic justice, but I only have a minute today—hopefully we’ll have a webinar on this subject soon), over the past three decades California’s autism population has exploded.

By birth year, you can see we have about 200 DDS cases per year before the early 1980s, but now it’s about 5,000 per year. From a caseload perspective, we’ve skyrocketed from a few thousand cases in the early 1980s to nearly 100,000 today, and only a fraction can possibly be attributed to diagnostic shifts.

So no matter what you call it—staggering surge, dramatic increase, whatever—we are facing evergrowing numbers of Californians with very significant and often incapacitating mental disabilities. And it’s not just the raw numbers that are alarming. DDS data also show: —Adult autism cases more expensive to serve than other DD categories.

—They are also more complicated to serve bc of often severe functional limitations and behavioral challenges.

—They live longer than the once-dominant developmental disabilities that used to dominate the regional center rolls.

This all adds up to an unprecedented social services challenge that we are not even coming close to addressing. In fact in some areas we seem to be going backwards.

Epidemic is not a bad word. It is just reality. No, vaccines have nothing to do it. We cannot solve a problem —here the massive crush of adult autism — unless we first acknowledge the problem.

FUN
with
WORDS

“Self Advocate”



SELF ADVOCATE

I have nothing against this term, it's a great term to describe some people. But it's just insanity to think it applies to all or even most people with autism. Here's a video of my son being interviewed by the conservatorship court investigator the other week. (20-second video clip of nonverbal young man not responding to simple questions posed by the investigator).

My son has many excellent qualities, but as you can see, he is just about the farthest thing from a selfadvocate I can think of, he could not self-advocate himself out of a box, and neither could my autistic daughter, and it's preposterous and insulting to call them self-advocates, which many people have done. It denigrates the reality of their stupendously incapacitating mental disabilities and also denigrates those who actually bear the physical, intellectual, financial and legal responsibility of caring for them.

Self-advocate is a fine term, but a limited one, not to be used injudiciously.

FUN
with
WORDS

“Person-Centered”



PERSON-CENTERED

I have nothing against this term. I love love love person-centered planning. But speaking for myself and my two autistic children, it's actually not my first priority when it comes to long-term planning. My priority is to find people who love my children and love their work, and are rewarded psychically and financially for that work. In other words, while your reality may be different, I think if I have caring and happy caregivers, I am more likely to have happy adult children.

Jim Ball, the former board chair of ASA, says something important: He calls autism a “whole family condition.” I think that view applies not just to blood relatives but to all their caretakers. So when we talk about person-centered planning, let’s not forget those who are also part of this whole-family condition. Caregivers are too often invisible or absent from the dialogue about autism. Sometimes they are actually treated like dirt.

What’s the point of this exercise? Words are like our filters on reality. They are abstractions with real-life consequences. Words should empower us and reflect our reality. I hope we can use our words to free up our thinking, to reflect the urgency we feel, and ultimately help us take action to do what’s best for our children and ourselves.
