



An article about services for people with learning disabilities and/or autism

Over the years I've spent a bit of time working with adults with learning disabilities and autism in what are best called restrictive environments.

Who Do You Want To Be?

By this I mean homes and hospitals where people with autism find themselves when our community feels it has run out of support options for an individual. More lately in my current guise as itinerant trainer I get to speak to a lot of staff who support people with autism in these settings. Over and over again staff tell me about the same phenomenon - individuals who want Coke, cigarettes and McDonalds etc way too much. And that wanting too much leads to difficult situations and challenging behaviour. It's not exclusively those things and it's not true

of everyone who finds themselves in a restrictive setting but there is a pattern. Recently I have spent quite a lot of time wondering why. This is where my musings have got me to date:

1. People with autism were not born fixated on these things (though being autistic does mean that your brain can REALLY focus on things). Burgers and sugary drinks when used as rewards or bribes take on an iconic status for a person in childhood which later becomes a burden for them (and us) as adults.
2. It doesn't end there. Because people with autism have shown us they like these things they end up being used as a way of ensuring compliance. So, because you were a naughty boy/ girl that trip to Ronald's place is definitely off! And don't even think about asking for cola.

This has the effect of reinforcing their status and making the person want them more. Smokers know only too well the fear of the long haul flight. "I wasn't even thinking of cigarettes until you told me I can't have one!"

"If the behavior guy says I have to earn soda rather than just having it in the fridge, that is what happens. If the legalised drug dealer says that I should take this pill then that is what will happen, and if I spit it out it will be buried in my ice cream (that is if I am allowed ice cream and have not been put on a calorie controlled diet by a bunch of overweight suits calling themselves 'the team')." John Clements & Neil Martin 2002

3. When options for truly meaningful experiences that have a 'deep joy' factor are absent, some 'second-bests' get elevated to a position of supreme importance. For some reason I keep hearing in my head that Galagher fellow singing;

“Is it my imagination / Or have I finally found something worth living for? / I was looking for some action / But all I found was cigarettes and alcohol”

4. It would be silly to overlook the obvious - they each in their own way satisfy the brains chemical needs and are the things turned to when we need a fix for stress, anxiety, a broken heart etc. Nobody ever nibbled on a carrot in a crisis!

5. All of the above, in various combinations, create a gradient that heavily biases the person toward the pattern of needs and behaviour under discussion. However, I think there's something at work that may be bigger than all four put together.

There's nothing more culturally normative than Coke, Maccy D's and twenty Marlboro!

I got to thinking about the days when we were busy dismantling the old asylums and long-stay hospitals and reconnecting 'patients' to The Community. A chap called Wolf Peregrin Joachim Wolfensberger had fired us up with a concept called SRV. It is a concept for addressing the plight of societally devalued people.

The building blocks of SRV were 'culturally normative' experiences, activities, settings and support. This was a new naturalistic stage on which people with autism and LD would stand a better chance of being seen as, well, 'ordinary'. I for one welcomed it because life in the old institutions like Ely Hospital felt like a mix of the Theatre of the Absurd and the Theatre of Cruelty.

So as I was thinking about those times - the pennies dropped. There's nothing more culturally normative than Coke, Maccy D's and twenty Marlboro!

Coke adds life! The adverts had it right. I'd like to buy the World a coke. Oh, they already have one! Look. The Cola Community. We can all have one.

MacDonalds? I'm loving it. A shiny temple of choice and satiation. And the 'restaurants' are everywhere. In towns, on TV, on the back of my bus ticket... what am I saying, bus ticket? you can drive there. Drive thru there. And of course everyone drives a car don't they?

Who can forget the promise of the Marlboro man astride his powerful horse, nose pointed in the direction of freedom? Now that's who I want to be!

All three are badges of freedom, fun, status, self-determination and adulthood.

No wonder then that people with autism in restrictive environments want them so badly. They are symbols of the life they want.

Ours.

Chris Barson, Director, Positive About Autism™

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