How to hear voices that are seldom heard

Dr Sara Ryan
People's experiences

A problem shared...reliable health information from patients, for patients.

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"Support, encouragement, empathy is best when it comes from someone in the same situation as you."
Some women described self harming and “wandering in and out of bulimia and anorexia” and several people described being bullied either at school or at work. One man said “I was very good at hiding depression from my mum and dad. When I was bullied at school I used to always come home happy or that’s what they thought”.

Harriet talks about taking an overdose and self harming during her adolescence.

Catherine wrote a letter to her mum saying she wanted to kill herself and had years of therapy before Asperger syndrome was diagnosed.
Why are some voices ‘seldom heard’?

- because some people are invisible
- and some people aren’t listened to

- ‘diagnostic overshadowing’
- lack of thought
- lack of interest
- fear
- it’s too hard
- too time consuming
- not conceived of as valid participants

Not understanding the importance of listening to marginalised groups
The oppressed are better practical sociologists and, possibly the only ones truly awake to the social world. (Lemert 2005, p164)
Riding the bus with my sister
(Rachel Simons, 2003)
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It takes a year of period immersion in her sister’s life to realise that their reaching out is reciprocal and that she, Rachel, may have as much to gain from it as Beth does. (Couser, 2005)
LB and the failed kebab

“Hey LB! How did meal prep go today?”
“Not good Mum.”
“Oh. Why not?”
“I failed Mum.”
“Whaddayamean, you failed?”
“I failed Mum.”
“Why? What did you cook?”
“Kebabs Mum.”
“Oh, I don’t get it. What went wrong?”
“I didn’t have a skewer Mum.”
“Oh. Why not?”
“Dunno Mum.”
“So what did you eat for lunch?”
“Bits Mum.”
LB, the unlikely ethnographer

I’ve mentioned Garfinkel before on this blog, in relation to old Chicken Bone Man and the extreme porn. (And for the geeky among you, here is a lovely conference paper about Garfinkel, space and the achievement of the ordinary.) I used to think having a dude like LB was like having a permanent little rule breacher. Now I’m beginning to think a bit differently.
“I’m starting to think of learning disabled/autistic people more as unlikely ethnographers than rule breakers. Unlikely ethnographers of normality.”
The Unit: Day 107

LB died this morning. In the bath. In the unit. He would be pleased the CID are involved.
Thinking about listening

• Asking the right questions (even of the seemingly bleedingly obvious…)

Example 1
Thinking about listening

I am an adult with aspergers syndrome and would like to know more please. I cannot find a way for health people to listen to what I say as communication is not good.....I get confused and people do not wait long enough for me to get what I want to say in order so they fill in the rest of the sentence and I get scared.

Thank you

Hi, I don't know if you have thought any more about taking part in the research project but I am planning to come to your part of the country in the next couple of weeks. Would you like me to come and interview you?

i have thought about it but i am not wanting to be identified and am a bit scared because i am not clever and don't really know what is wanted and so i think i have nothing to say. Thank you
I am doing an OU degree at the moment - science - and it is amazing and is keeping me safe at the moment - a constant that keeps me grounded when everything else is changing and frightening.

My allotment is good - peaceful and beautiful with frogs, toads, fox, - I have a grassy area which I mow and beds of veg that I share with the wildlife (only as much as I say - I plant more than I need so we can share but if they get greedy then I cover the food!) as it is there home I am cultivating for me.

The children from school come and visit in the summer to see the pond and guess the veg and even the most disruptive child is calm and understands that they are a guest of the wildlife and so am I.
Concluding thoughts...

- The importance of a) wanting to hear and b) listening carefully
- We have to rethink the ‘rules’
- Not hearing these voices leaves understandings of health/social care experiences impoverished
- *Who* is seldom heard can vary depending on what is being said and in what context
Imagination alone enables us to see things in their proper perspective, to be strong enough to put that which is too close at a certain distance so that we can see and understand it without prejudice, to be generous enough to bridge abyss of remoteness until we can see and understand everything that is too far away from us as though it were our own affair. (Arendt, 1994, p323)