Where Autism Professionals Connect

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Spoons and other metaphors: how I use my social care budget.

I'm going to bit a bit blunt. If you are reading this and you're an autism professional then I probably won't like you.

It's not personal. It's just that if we met in real life we probably wouldn't agree on many autism things. Especially if you started talking about people "with autism" or using phrases like 'high functioning'.

You see, well-meaning autism professionals, possibly people like you, almost killed me. I trusted you a lot and you let me down. You taught me that if I really tried, if I committed, if I put in the effort, I can and should overcome my deficits. I could be more normal. Oh wow. Maybe one day I would be acceptable.

My value to some of you was in how well I hid myself. How well I conformed. How far I collapsed who I was for who you wanted me to be. This ended in disaster. I tried so hard I destroyed my body. The mask didn't work. I lost my home - I almost lost my life, sanity and liberty.

It's taken me months to write this article. I couldn't find a nice way to start it. I'm afraid this was the nicest I could come up with.

This article is about where I am now. How I approach my life and the lenses I use to understand myself and my world. But before we get to that, we need to be clear about a few things.

Ahem, here's my disclaimer!

1. I am one autistic person and I am telling you anecdotes. This isn't science. I only speak for myself. I am sharing something so personal in the hope that it is helpful; but this is offered just as one account.
2. From here till the end all the terms will be identity first. If you don't like it then tough. If that offends you then stop reading now, this article isn't for you.

3. Finally, the tone will stay assertive. Autism professionals serve autistic people. For the few that I work with, I am not their client, I am their boss.

Let's move on to the good stuff - I have a couple of concepts I'd like to explain to you.

Disability & autism in context

How I use my social care budget won't make much sense unless we cover a bit of theory. There are two concepts that provide the lens through which I view the world and shape my life. The first is the wider context in which I view disability and autism.

The dominant model for disability is medical. Science, research, psychology etc. On the whole, behaviours are labelled and then attempts are made to change them. It's often phrased as "recovery", "progress" or "treatment".

This model works well for things like broken legs and cancer. But the medical model doesn't work very well for diversity aspects. For example in the 1950s being gay was considered an illness. People were tortured by medicine. Eventually gay people got a voice and rejected the pathologising. They pushed back and sexual diversity become a civil rights movement …. a model for us all perhaps?

For me, the medical model is misapplied when it's applied to autism. It was extremely dangerous in my life. So these days I choose to use a different lens.

The lens I prefer is known as the social model. To me, disability is what happens when my needs are not met by an environment. Or to put it another way, I experience plenty of impairments (speech, planning, road crossing, sensory etc) but I'm not disabled by them. I am disabled by badly designed environments.

Hopefully this isn't new to you but if it is please take a moment to think about this concept. Try applying it in your own life. For example, what would happen if everything in your kitchen was moved so it was beyond your easy reach? You wouldn't gain a 'height disorder', but you would become disabled. How long before your behaviour became challenging?

Adopting the social model has been fundamental to improving my life. I don't pathologise my life. I avoid medical terms and try to use more descriptive terms instead. I am not mentally ill, I am not disordered. I just experience lots of badly designed environments which place barriers in my way.

Spoons

So, we have the first concept down. Change environments not people. The second key concept is the idea that personal energy is a resource which needs to budgeted and used efficiently. Not squandered. The unit of energy I use is the "spoon".

If I sleep well then I will have about 10 spoons a day. Everything I do takes spoons, and resting returns spoons. I don't have many spoons and my challenge each day is to make the most of the spoons I have. Wasting spoons on barriers in my environment doesn't make sense. I need to get the most out of my spoons. I need to spend them wisely. To give a concrete example, if I didn't have support to make the pasta meal I eat every-night, I wouldn't have the spoons to hold down my job.

These two concepts are the foundation of how I approach social care. They guide how I use the support I get, and shape many of the decisions I have made about my life.

In a nutshell

In a nutshell, I use my social care budget to:
- provide structure and routine into my day to day life, so I can better budget spoons.
- remove barriers from my environment.
- take over a few key tasks for me. Accept help so I don't struggle wastefully.

Along the way I achieve various goals like autonomy, accessing the community and employment. But the social care part is mostly focused on environments and spoons. By looking after those, the rest sort of looks after itself.

My life is structured around my support, which in turn, is built around my routine. The routine is also where most of my personal budget is spent.

Meet my routine

Starting from the top, my routine runs from 7:00pm to 10:00pm, 10 days in 14. For the other nights friends visit me, or I visit friends.

The carers (mostly Family Mosaic) come to my flat at 7pm. When they arrive they go into the lounge and I hide in my bedroom. My speech is very unreliable, so generally I communicate via text messages or augmentative communication apps. We then follow my routine together. I eat a meal, have a bath, sort out my laundry and do the weekly shop etc. This is also where we discuss any barriers that day (for example getting stuck paying bills), and work out how to resolve the barriers.

At 10pm, I then head to bed. I have an overnight routine based on a colour changing clock. Blue is sleeping time, yellow is waking time. It counts down the hours till morning with little star icons. This helps provide structure while I sleep.

The routine lasts till 7am when the carer leaves, and if all has gone well then I'm ready to get on with a productive day of work. I mostly work from home but I also take lots of work related adventures with support via Access to Work. In the last year I've been to the USA, Sweden, Norway and even Bristol. But I digress.

The routine replaces complex negotiation with predictable demands and expectations. This allows me to budget my energy (aka spoons) more effectively. We also tie other demands (like medication when I am ill) into my routine.

The routine is simple but powerful. The power is a bit subtle. But the effectiveness is not.

Autonomy and control

I mentioned before that one thing my routine helps me to achieve is autonomy. I'm not achieving independence and that's okay. Independence isn't my goal. I find autonomy more important.

I define effective autonomy as being able to make decisions as, and for myself. It's not autonomy if the options all require masking who I am, or worse, permission from others. However, autonomy does not mean that I always need to be in control. If I was in complete control all the time, I'd quickly get overwhelmed and run out of spoons.

I cede control of my evening to the carers via the routine. They get me through the routine. They don't ask me to do things, they tell me to do things. The goals they guide me to achieve are my own, so by giving up a little control I gain more autonomy.

I don't treat carers as interchangeable units. I make an effort to establish relationships and trust. If I am not comfortable with the carers then nothing else will work out very well.

Going outside

In total I receive around 15 hours of waking support per week. However, because I use the support to change environments and make good use of spoons, the support (and care budget) stretches much further than 15 hours.

My routine is strong and predictable, so I know how much energy I need each evening. I know exactly when the demanding part of my day will end. This allows me to budget my spoons effectively and in turn pace my day. I don't use support hours to visit the local cafe. Instead, the support hours give me a foundation which I can use to do other things. I have built a cafe routine around the spoons I have, and I do it myself.

If a cafe visit goes wrong, then "oh well". I found a limit. When stuff goes wrong I can contact my support team for a rescue. If it is going wrong often, we look at how we can better optimise the routine or the environment to release more spoons. This can be as simple as changing brand of bedsheet or using a different type of cup. As the routine is repeated often, small optimisations quickly accrue into big changes. If I have 10 spoons and a small change saves me half a spoon per day, then every 20 days I get an entire extra day of usable energy!

We optimise the evening to use as few spoons as possible, and optimise the overnight to generate as many spoons as possible. I am supported for 12.5% of my waking hours, but the support provides the foundation for everything else.

The stability of this foundation has enabled me to slowly expand the areas that I access in a sustainable way. I can visit the local cafe, sometimes travel into town (by bus!) and occasionally visit the local autism hub. All of this is remarkable considering I don't have any usable speech when out alone and have a lemming-like sense of danger. The world is a scary space without communication. I'm not blind to my vulnerability, but I can have adventures because I know I have a safety net.

Adventures come in many forms. For example employment.

My work

I mentioned before that I mostly work from home. This is possible because I have a home office, a flexible employer and a system to keep me safe.

Open plans offices rob me of spoons. If I had to go to the office every day I probably wouldn't be able to hold down a job. I work from home because it gives me a stable, controllable environment. The carers also support me to keep it that way. We keep my home office clear, clean and simple.

I work for the BBC. My job at the BBC is within the Design and Engineering team. If you have used the BBC website or apps you have touched something I was involved with. If you use the website then you are directly running code I wrote. You're in good company, some of my code is used by astronauts in space.

My team work to remove barriers from the digital environments we create (such as websites and apps etc), so no one is disabled by them. We support hundreds of other teams to be inclusive. We develop guidelines, inform standard work and build tools which affect the lives of millions. I develop tools, teach people and explore future technologies through the social model lens. The same lens which informs my use of social care.

At the weekends, I collaborate with friends to build financial crime fighting tools. I also build kit cars, fly planes and record podcasts.

My work is important to me and it is made possible due to my social care. However, my work is not the most important thing that my social care supports. The most important thing my social care supports are my friendships.

Friends

I have friends. They are an amazing bunch. When 'professionals' let me down, they stepped into the gap. I moved to live close to them, found the support I needed which helped me to develop the tools I have today. They are all peers from the web and tech industry. None of them are near my age but they all come together to provide a second layer of support.

The most important use for my social care is that it safeguards key relationships. I am protected from them, and our friendship is protected from my support needs. My friends do lots of support things with me, but I am not dependent on them. They are friends, not carers.

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Some closing thoughts

I said right at the start we probably wouldn't agree if we met in real life. I feel as though I have done what I have **despite** professional input, not due to it. I had to work out my own path and for the most part, I did this by trial and error. Adopting the social model and viewing the world through the lens of "spoon" usage completely changed my life.

If you take anything from this article please let it be this.

My autonomy, my employment and my friendships are not based on a mask. I don't try to fit in and be normal. I focus instead on:

- working out what I need from environments
- how to deploy the limited energy I have in the best possible way.

I would ask you to focus on driving change for the autistic people you serve, not attempting to drive change in them.