

How personalisation disrupted my professional practice (And I know I'm not the only one!)

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(And I know I'm not the only one!)

I've been an OT for 30 years – Wow!! – I don't even feel that old and would rarely admit it – frequently letting people know that “I'm only 27!!! Thing is - I can't seem to help being an O.T. even in my everyday life – I'm forever facilitating and enabling. My family know exactly what to expect if they ever say they don't know how to do something.....before we both even realise it we'll have worked together to find out where the gaps are and they're off doing whatever it is for themselves!! Of course, tailoring support around what an individual needs always creates the best results.

So, when Personalisation came along, of course it all made sense to me. In fact, as caring professionals, we as a group are all strong believers that our approach is person centred – it is only a natural course of events as we go about ensuring people are involved in the discussions about how we can help them. It's an integral thing to make sure people are part of their assessment and planning process – so of course Personalisation wouldn't really be a challenge.

For many the landscape of Personalisation brought about changes such as Care Act eligibility criteria, personal budgets, decision support tools and personal health budgets but for me as an accredited Independent Support Broker it reached well beyond these and disrupted my professional world to its core. The principles of Personalisation have transformed the way I think, believe and work. I've found that the way I need to work with individuals and families is no longer about my OT assessment, my professional plan and my professional recommendations.

Why? I found that when people themselves were enabled to be in control and plan and manage their own lives and solutions amazing things can happen – and I mean instantly to the person from the moment of taking their place in their own driving seat, and long term - in relation to what happens to their lives and their well-being.

Not only have I seen this in my professional work but on a very personal level with my best friend and her son too. After many discussions together

trying to appreciate the difference it might make to their lives, my friend agreed to try something they'd not experienced before. We tried a very person-centred approach - one not initiated by any services, any assessment or any review process.

We sat around the kitchen table - this young man, his mum and dad, brothers & PA's; flip charts on the walls, post-it notes for all to write thoughts and ideas on, bacon butties and "Aunty Ange" (pronounced "Anty" Ange) supporting them all to take to reflect, write and listen. They each took time to think about this young man as an individual and the things that make him tick; to consider what works well and what doesn't in his life; what's important to and for him and how he wanted his life to be. My friend's son totally enjoyed the opportunity to be listened to and participated fully, even taking each of the flip charts from the wall and reading everything - warts and all, with and to his circle, ensuring everything from everyone's perspective was very much appreciated, challenged and understood. This process and that of creating a life plan from it, transformed the conversations about him and with him, and placed him in control. The young man has diagnoses of autism and learning difficulties and at the time, there were numerous fluctuating decisions about his future placement after his education ended. These support decisions he and his family had no particular say or control over, and the distress this all caused resulted in his care needs escalating in front of their eyes to 2:1 support; and increasingly resulting in no one knowing what to do to help. The continuously shrinking options consisted only of care services and only ones that were somewhere available and able to offer 2:1 support.

He had to be referred to a psychiatrist as his anxiety heightened, as the situation progressed. He had less and less understanding of what was happening and what his routine would be and his supporters were unable to say or reassure him as they saw things spiralling out of control too. It was not surprising his support needs were escalating - a situation most of us would find difficult to cope with but especially here, where clear routine and what to expect underpin this young man's well-being and autism.

Agreeing to try something different in their conservatory that day, came really from desperation and the fact that my friend truly trusted in me - I've been with her along the way. However, only now with hindsight does she and her family really know what I tried for so long to encourage them to try and what I found so difficult to explain. It took me almost a year to convince

her – it was desperate to watch the situation unfold and to know that what they needed was to be able to be listened to and to be able to have at least some control.

Now a few years on from that life-changing day, he has his own supported living flat with support part of the time, he has been discharged from his psychiatrist, has had 2 different jobs of his choice and takes on opportunities to attend conferences and stand up and train others – with support of 1 as required.

His mum has always been proactive and supportive in helping her son have a life, and has faced all the numerous challenges with him but the focused conversations that happened that day were an important turning point and led to the creation of personalised life plan.

Having a life plan that was now owned by this young man, placed the fact that every professional and service provider had plans in his name, under the microscope. It became obvious that these plans were led by the conversations of what these services could offer and what they knew of what was available. The life plan instead, provided everyone involved including social workers, health professionals and all his Provider services with one single focus - how he wanted his life to be, the challenges that needed to be overcome and knowledge about what worked well

Once this new journey started my best friend reflected on that they had travelled before. She saw there were more “plans” for her son than she had ever realised, and yet this was just accepted by everyone as the norm. Often these plans were written in isolation of one another and when put together as recommendations – they could end up counterintuitive and counterproductive. For them as family supporters they had learnt to negotiate life with and around these plans but as her son became a young man, they didn’t really make sense to him and how he wanted his life to be, and this left him feeling frustrated and unfulfilled. What became apparent after working with him and his family, using the “In Control” approach, was that he needed just one plan – his own plan and for those services and professionals to work with him, to make his life plan a reality.

So now as I say, I have a different perception and a different approach, a new language and redefined way to make use of my OT skills. I definitely don’t use my OT process –it is not my role to assess and give what I think the person needs - I am not in control. It is not my role to plan and prescribe, intervene, review, treat etc. I am a resource and the use of my skills and

expertise is there to be explored, and together - negotiated to fit what the person needs of me.

I have found a new way to work – not in a traditional ‘professional gift model’ way but one that fits instead within the ‘Citizenship model’. (The two models are explained [here](#)).

Individuals who have a disability have the right to live a life that is meaningful to them. For this to be achieved, theirs has to be a journey where this is truly listened to, so that it becomes the basis of planning and living **their** life rather than receiving a service and receiving various care and support plans.

It can still be inordinately important to have “How to support me” resources, if people are not to spend their lives repeating themselves but these need to be within the persons domain and control - “about me and led by me (or my key supporters as I feel most comfortable about)”. This is something we all need to STOP and consider fully. Why? Because one day it will be us or our most loved ones that are in this position. WE will still desperately want to carry on leading the lives that matter to us. WE will be desperate to be listened to and to be enabled to continue to be part of our family, our community, our lives!! We won’t be desperate about living a life prescribed by someone else or receive a team of people who are passing through who are doing the best job they think that they can offer. It is a waste of public money to repeatedly offer expertise and services if so often the outcomes don’t deal with how things need to be or consider the whole variety of community resources that are available – chargeable or non-chargeable. Many solutions don’t necessarily have to cost, many that enable us to be valuable citizens rather than recipients mean that everyone can give something of themselves and gain wellbeing. We all want to belong, contribute and be valued – no matter our age, ability or challenges.

So HOW is my role so different?

- I listen and listen and oh, I listen some more. I reflect and travel a journey with the person in the driving seat of their own life. Sometimes it is individuals and sometimes it is with family or other important

supporters of that person – some are also travelling the journey with them – some are also needing to consider a time, when they will no longer be able to be there.

- I am not in the driving seat leading via my professional process – in fact, I’m not even back seat driving with my professional process in my mind and hand. Process is not important - not unless it is created with and belongs to the person. Instead, we work to their priorities and what needs to happen for them. We create communication that clearly advocates what is happening and how they would like their life to be so that exploration can take place communicating with those around them as they choose and as makes sense to them, finding solutions that are meaningful.
- I do not need my OT process. I just have to be honest from the beginning – I don’t and won’t have the answers that people need. How can I? People’s lives, challenges and resources are all unique and personal to them and I can’t possibly have dealt with every challenge and every eventuality. But what we do have between us and around us, is a set of insights, knowledge, skills and experiences (in them, in myself, in their support circle and in their communities).
- Working together often reveals deeper insights for the individual and the supporters that the individual chooses to share the journey with. Understanding where the person wants to get to in their life and unravelling the parts of what can sometimes feel like a puzzle, can initiate and nurture thoughts and conversations. New ideas can often start to develop around new and different possible solutions - something that can be particularly important when what is being made available is just not the answer. Sometimes it’s not even about trying to achieve something new but instead is about keeping the life they already love to lead but it is in some way being challenged. Whichever, this same process can be used and lead to some innovative thinking.

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- The conversations include supporting the person to explore the risks that they wish to take and how they want to be able to manage them. An approach which inherently follows the principles of the Mental Capacity Act.
 - What I bring are my professional skills and approach – particularly the Occupational Therapy PEO (Person Environment Occupation) approach but the power base between us has shifted. This PEO approach is combined with a Person Centred Planning approach – continually exploring and returning to the questions that people with disabilities identified as being important to them – “What’s working well? What isn’t? What’s important to and for you? And how would you like your life to be?” Exploring these and how the environment impacts on these things and on the activities they want to pursue. Bringing these two approaches together creates insights and conversations in a very revealing and empowering way.
 - Together we travel a journey of discovery using analytical questions – “What, where, when, why, who and how” and when you sit back and look at where we have been, we find that we have explored challenges, strengths, passions and potential solutions (and learned about ourselves along the way). Meandering our way through a PEO approach creates self-insight, creative communicative mind maps and a confidence to use problem solving skills along with an ability to advocate more confidently around what an individual and their supporters need. This journey can support individuals and supporters alike. It is beautiful to watch people grow, creating self-efficacy, self-acceptance and their own insight and opportunities. All of this gives people the chance to remain in or learn how to be in control - be in their own driving seat and enjoy thriving as a result. It also equips them with a language and evidence of what doesn’t work well which helps to justify doing things in the way that they need and fulfils their needs – including their assessed needs. It demonstrates the existence of well managed needs and enables others including the MDT to understand the detail of how things need to be and why and enables discussion,

negotiation, creative approaches to solution finding and risk management, the finding of least restrictive solutions and the inclusion of long-term planning – after all life is a journey – not just the here and now of “how many hours of support do you need?”

So how did I get here?

I have always felt it my role to help people live a meaningful life - I've not met many OT's that don't – it's fundamentally the way we're trained. However, we do get sucked into roles where process is king and often it is as much more about meeting the needs and the pockets of the organisation we are employed by. In this position, we are often left trying to “kindly” shoe-horn people's needs into what our organisation also needs of us, usually time limits and financial constraints and neither we nor the person we want to help, have much control over that. We know what our role is expected to achieve, the time and resources we have to do our “allotted bit” and where to refer on to next. We are often left hoping what we have done is enough and has been done, has been in a sensitive way but the long term or overall picture is not ours to help. I've done and given what I can and as such, my OT process comfortably fits this and is exactly what I now understand as - the 'Professional Gift Model'.

I have always tried to counteract some of the process wherever possible – listening to what mattered to people and trying to advocate where I could to try to provide their care and support somewhat closer to how they seemed to need and want it to be. Working in the community in a care coordinating role helped to a degree with achieving some of that but still that was only within the boundaries of what the organisation could and would allow. I had in my early days as an OT worked with a colleague who tried to make things possible via creative thinking and collaborative working within the confines of her OT role and I have as a result, also tried to do the same. Case conferences, in my care coordination work for people with complex dementia, were a speciality of mine - bringing families and Providers together to find creative, tailored personal solutions to help people retain their independence, but it was all still based on my OT process – assess, plan, implement, review.

I then became involved in innovation, setting up an assistive technology service and later on I coordinated a case where some unusual technology was being requested. In fact, for 3 years the individual had been batted between health and social care as these two organisations argued over who was going to fund the equipment - equipment that had been professionally recommended by a regional health team. I became involved through my technology role and the case was offered a lifeline through the advent of personal budgets. By the time I became involved, the technology had become obsolete but the experience of the training I received and the provision of a personal budget was life transforming for us all - for me, for the individual concerned and as a result, for her family too.

My work initially involved needing to get to know the person through an OT assessment to identify her skills, abilities, cognitive difficulties and goals and identify how these would be helped by the technology concerned. I did my usual OT process.

For the purposes of the personal budget pilot, I then sat down with the lady and used a different set of questions the ones I went on to use with my friend's son. For the first time in her 30+ years of life she was asked about how she would like her life to be. She was asked about what worked well, what didn't and what was important to and for her. She created a beautiful photo album showcasing her incredible talents with craft and it was and still is a dramatic and empowering backdrop, to present the plan she has for her life. She blossomed as a result of the process and gathered in confidence and ability. Her health challenges remained the same, but she had changed - she had been listened to.

When I facilitated the same process with my best friend's son and supporters he too changed - he became happier, his confidence and sense of self grew from that very moment on. He asked to present his life plan to the MDT professionals at his own Social Services panel meeting and managed this with notes he and his psychologist prepared, that were meaningful to him. No-one had been to their own panel meeting before, and he astonished everyone when at the end of the meeting he spontaneously apologised to everyone for the recent difficulties they had all been experiencing in trying to support him - stating candidly:
"No one was listening to me".

Even my friend's jaw hit the floor – apparently along with everyone else's in the room.

We cannot underestimate what that phrase meant.

Is it all about asking a different set of questions?

I knew that I had not been functioning as a traditional OT for some time and had consciously been stepping away from the professional-led approach since being introduced to the Person Centred Planning philosophy. I knew I was doing something different, more than just asking a different set of questions but I could not articulate what the difference was.

In one of my many forays around LinkedIn, I came across the concept of Independent Support Brokerage where the focus is on the person being enabled to be in the driving seat of the decisions that are being made about their life and how they can be enabled through creativity and the use of a variety of resources including their own strengths, their own community and different sources of income, including personal budgets.

At the time there was a huge emphasis on Peer Support Brokerage. An approach that recognises that people with lived experience can be the best placed to offer the functions of a support broker. I can't say I have a personal lived experience and as such I could not see where I, as an OT could fit. An individual's experience and expectation would be of me working within the 'Professional Gift Model' and at the time I certainly couldn't articulate what made me different. Am I an OT or not? Am I assessing or not? I couldn't make sense of what I was supposed to be - I had seen all these amazing changes in people using the Person Centred Planning approach and I knew I had lots of knowledge and experience to share.

It was when a family approached me for help (they already knew of my skills) that I decided I needed to articulate my identity-crisis. I completed the accredited Support Brokerage course with Imagineer (Imagineer Development UK CIC, n.d.), and found myself amongst a group of people with a variety of backgrounds. Together it was clear that we can all enable people to advocate for themselves, find meaningful solutions and make best use of resources available to them, financial or otherwise. Whatever our skill background it didn't matter – here were people doing things that my OT profession has also been trying to do for years. But these people weren't OT's

they were just listening and putting people at the centre of their own lives. Here I learned not to be precious about my profession. I was humbled by the skills of those around me and inspired by the passion of everyone present.

The reason we could all make a difference was our approach – the approach of embracing personalised support, the values of inclusion, of asset based community development and the Citizenship Model. My OT skills and PEO approach just add a different dimension.

Through understanding the two different models – (Professional Gift model and Citizenship model), I began to understand why I have struggled in my work for the majority of my career - continually experiencing the tensions of trying to make a real difference to the person whilst also meeting organisational needs and imposing my OT process on them. I had always been so proud of my OT process!! I can still remember how proud I was at college when the penny had at last dropped enabling me to answer my final exam questions that were all based around the OT process!!

But now, with my new insight, I can see that my OT process can be an unnecessary challenge to those I am trying to help. It's a professional process – it's not a natural part of living a life. We get so much further when we deal with life challenges from the person's experience and how and when they want to deal with them. I've also learnt the true meaning of choice and control and to be comfortable in ensuring it sits with the person. I have the right to say what I cannot assist or be a party to, and the person has the right to have these discussions and responses of mine explored, justified and for them to be transparent. It is no longer the case of "I'll tell you what I can do as a professional and you be in control of choosing from what I know and can offer".

By exploring what I cannot help with is as enabling as any other conversation – the person has the knowledge and insight they need to be able to take that conversation where they then need it to be and with whom.

I am a resource. Within the image that accompanies the 'Citizenship Model', I sit alongside the individual, as and when they want me to be, supporting them to find and negotiate solutions including how they want to use my knowledge. I share my skills of how to analyse what is happening and what the options and next steps could be. This can often include understanding the processes, policies and key agendas that affect how the health and social

care systems work, so that an individual can more knowledgeably advocate for themselves. Sometimes the challenge faced is that of communicating and translating the persons experiences into the language understood by service professionals – the language that fits these policies and agendas. This skill comes from years of experience of being within the MDT, and when this situation arises, we may agree that I will professionally advocate and become an intermediary between the ‘Professional Gift’ and ‘Citizenship’ Models. Sometimes I will act as translator and mediator, always ensuring the professional knows I’m not in the driving seat and no decisions are mine to make. Possible scenarios are always explored before any professional conversations take place, the majority of conversations involve the person unless they choose not to and what the person does and doesn’t want and why, are always understood. Any emails that someone wants to come from me are written together and agreed before sending.

It isn’t easy fighting the challenges that people face when accessing the funding and solutions they need to lead a life that makes sense to them. This includes the insight and understanding they need professionals to have, to underpin the decisions they require, including risk management strategies, but this has to meaningfully happen if *people* are to be set free *from the constraints and restrictions placed on them*, particularly from the constraints brought about by process and the bureaucracy that often comes their way.

It’s been an interesting journey and one I know I don’t regret. Seeing the impact of how things can be when they are done differently is heart-warming. Seeing older parent carers gain some peace of mind for the future is priceless. If and whenever it’s my turn to be the person with life changing needs, I hope there are many professionals around me who are willing to work in the same way.

If reading this has resonated in some way with you – I can only say that’s wonderful.

You are very welcome to come and share further in my shoes and where you can take time to reflect on some the similar challenges I’ve sat with and tried to understand

- Where do I truly sit, when offering choice and control?
- How do people truly gain from the skills that I can offer?

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- And I suppose most importantly - how do people really manage to live the lives they truly want to lead, after I've left their door?

With many thanks to those who have inspired me along the way - friends and colleagues, and especially those who have welcomed me as a guest into their lives with the privilege of working with them.

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