

Everyone Has a Story

Although my participation at Respond has gradually diminished over the past 25 years, somehow the number of hours spent in our offices in Euston has never quite matched the intensity of involvement and the preoccupation I have felt with the organisation and the work it does. It's been in my life for 25 years and 75% of my working life. I'd like to share some thoughts about my experiences. I want to talk about Respond's origins, and how they're reflected in what happens there today and also how they might continue into the next stage of Respond's life. My focus will be on the psychotherapy that Respond does, but also I'll explore how that is in constant dialogue with the other services that are there

I am an integrative child psychotherapist and Respond's therapy model is an integrative one. This means that we don't stick rigidly to one therapeutic approach – for example, psychoanalytic, person-centred, or behavioural – but try and take the best bits of each and mould them together to find the best fit for each individual client that comes through the door.

Another key element of an integrative approach is that, ideally, the different approaches and ideas that inform one's work, fit together, or integrate: they can, in the best cases, work 'in conversation' with each other to the benefit of all. There are also some connecting, or unifying aspects which link the work that goes on, and these are consistent. I think of these as 'throughlines' which is a word I've borrowed from another aspect of my life: I like to write stories. I'm currently working on a collection of short stories many of which, while very firmly fiction, have been inspired by the work I've been doing with people over the years. In fiction we talk about throughlines as the things which join up a story – the beginning will always link to the end and as we read a story, we need to feel we are on a trip, which, while containing surprises and things of interest, is taking us in a recognisable direction. Then we can settle into it, with lively curiosity, but an underlying sense of confidence in the coherence of the whole.

So, in thinking about Respond's origins, I thought about what those throughlines might be. Our starting point was about providing support to people with learning disabilities who have experienced bad things, often sexual things. We also wanted to provide support to other people who are in that abused person's life, and who mind about what's happened. These two things are still there in everything Respond does. But how did that come about?

The seeds of Respond were sown in the 1980s, with the self advocacy movement of that time, along with the growing recognition, culminating in the Cleveland Enquiry of 1988, that child sexual abuse was widespread and poorly investigated. The long stay hospital closure programme begun in the late 1970's was also an important driver of the development of Respond.

When I talked with people who had come back in to their communities from long-stay hospitals, it turned out they wanted what I wanted - what most of us want: friendship, companionship – to love and be loved. Their sexuality had been largely denied and I was young and gung ho about trying to put this right. Of course, I thought, everyone has a right to have sex education, freedom of sexual expression and equal rights. However, it took me sitting down and listening to people's individual stories, to discover that, for a lot of people, sex equalled pain and horror, exploitation and injustice.

I'm going to share an extract from a story I wrote called '*What Goes Around*'. It was inspired by

what I heard from adults with learning disabilities early on in my career. The narrator of this story is Pauline, an elderly woman with learning disabilities. She used to live in hospital. Mr Wildacre was a member of staff there. She is standing at a window of her terraced house, looking down on the garden next door, where a small boy is playing while his baby sister sleeps in a pram. Pauline is preoccupied with the next door baby. Here, she is reminiscing,

This memory I've got now, this one's playing like a telly programme in my own stupid head. Wildacre and me are in the storeroom, at the back, where patients aren't allowed. He's got a system, chooses what girl he wants, gets Joyce Baxter to bring them in. Gives her four more biscuits and if any nurse asks he's told her say, 'Overtime Special Delivery'.

First time she came for me, she held her fist up, 'You tell anyone Pauline G. and you'll get this.'
Even if I could say I wouldn't. He chose me.

Joyce shoves me through the door and Wildacre's waiting. There's a mattress on the storeroom floor and a grey blanket with red sewing all the way round. Hospital Property it says. Laying on my back. Stiff twisted hurting. He'll be finished soon. I look at the shelves up to the flaky paint ceiling. Watch the pale brown boxes with black letters on and toys inside. Think of a roast dinner, like before with Ma, a little kid. I almost don't know it was me then. Wildacre presses hard on me, jabbing sharp, breath moaning loud. I take my mind away. Set the table with knives and forks, tiny circle plates with blue stripes round, gravy in a boat too small to fit a fly. Sit the family down. Ma and Dad, me sat between them, propped up safe on a cushion. Baby in his highchair, banging a spoon wants his grub. All laughing.

Wildacre's put tissues there for when it's over. Soft, not the rough stuff. Then its extra biscuits if I'm lucky. That's what he says, pushes one daft shaking leg, then the next one into my trousers. Helps me up.

'Fig Rolls for you, Pauline G. Must be your lucky day.'

'You're getting fat, Pauline G,' the nurse says, weeks months later, 'You want to eat less afters you do.'

No-one's thinking baby.

I feel my angel kicking but I can't say. First it's small birds swoop fluttering inside. Later she spins and dances. Nurse gives me the belly ache medicine and she dances wilder. Then my angel's almost here and it's a big panic and they've called the doctor for the ones on the ward who have fits. He's rushing angry, saying he's not brought a baby into the world since he don't know when and I'm hard screaming so they give me an injection. I only just see her, my angel my Alison, before they take her off and away for good. Her black hedgehog hair poking out of the grey blanket. I reach out but nurse's hand stops mine,

'Better not Pauline G, better not.'

Later she tells me, 'It won't happen again, Pauline G. No more babies, Doctor's seen to it.'

They think it's one of the patients did it to me and it's not like I can say different.

Then it's back to the ward and the workshop, and it's like my angel never was. Never was a life in me.

Next year and next after I don't know when but we're all getting old in there. Wildacre's long gone dead of a heart attack. Hospital closes down and it's back to the normal world. The High Functionings go first but now even the ones what lay in cots all day like babies is out. The hospital turns into posh flats and they put me here, in a house on a street. With a baby right next door.

The experiences that people have had, before we ever knew them are highly significant. This is something we hold on to very tightly at Respond. It informs a tremendous amount of what we do: that offence committed by that young person with learning disability? That came from somewhere. That behaviour? That distressed and angry parent? That traumatised victim of sexual abuse coming in to the ISVA service, that family struggling to reconcile their fears for the future

Inaugural Tamsin Cottis Annual Lecture 2016: Throughlines – Tamsin Cottis

of their learning disabled son or daughter with their rights to marry who they wish – they all bring a story to the table. And if we're going to help them, we need to understand that story. Having the time the skill and the inclination to discover that story, well that's what Respond staff specialise in.

Back in the 1980s, when I realised what people had been through, I was shocked. I didn't know where to turn. I wrote about it and the fact there didn't seem to be anywhere to go for help. And that brought me into contact with others who were concerned too – Respond co-founder Steve Morris and then very soon after that, Alan Corbett. This talk is a chance for me to pay a tribute to him and his part in Respond's story. Many of you here have, like me, benefitted hugely from his wisdom, humanity, vision and hard work over the years.

We made contact with others in the field and began to get organised. Valerie Sinason was an early and invaluable support to us, as was the late and still missed, Ann Craft. We made a lot of fuss and I remember being quite stroppy and unafraid when making the case for our work. Always, I had peoples' stories in my head – the realities of what they had experienced and were continuing to experience. We got our first small grant in 1993, 2 years after sketching out our ideas at the kitchen table. Anyone who has heard Noelle talking on various media platforms, or face to face about the scandal of ATU's, or Richard highlighting the injustices of offenders with complex histories and learning disabilities denied access to justice will recognise that a certain strong-voiced expression of what needs to be done, is another throughline of Respond. Not always angry, but the intention, and the strength of the wish for change is unarguable and deeply, sincerely felt. Though the focus of our wish for change may have altered in the specifics, the speaking out about the treating of people with learning disabilities as other, or less, or overlooked is, I hope, *never* going to change.

Two years after that, we got a more sizable grant and with that we came to Euston, to Stephenson Way. Then, there were homeless people sleeping in the doorway, then they went away and the area began to change. Sadly, the homeless people are back. And with the tenacity that I am now going to name as throughline, we are still here! However, in 1995 we faced an organisational crisis which we nearly did not survive. This was a short but difficult chapter in Respond's history but I think relevant to this account. The move to Euston, with extra funding, was a big leap for Respond and we did not have the necessary governance in place at that time to make a secure transition from being a small to a medium-sized organisation. The Director at that time, struggled to manage and turned to fraud in the face of those stresses. It was very nearly the end of Respond but a number of things kept us afloat:

Firstly, we had a strong wish to carry on doing the work we'd started and a determination to do so and a demand from service users that we did so. People kept on coming through the doors for their therapy. Also, we had good friends and supporters, such as Valerie, and Earl Hopper and Trustees who stood by us. Finally, we tried to be honest and authentic in facing what had happened. It was terrible to discover a close colleague was corrupt and also to think that speaking out about it could destroy the organisation. That was an insight into how destructive the dynamics of any abuse can be. Critically, we learned then that you can't cope with that kind of thing alone. Alan and I were in it together and, with staff and Trustees, worked hard to keep things going. Another throughline for Respond has been the recognition that what we do at Respond is difficult, fraught with management stresses and strain caused by the nature of the

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work itself. It is only possible to manage that if there is a genuine sharing of responsibility, and of a commitment to have honest dialogue about those stresses. It was a reminder, if we needed it that financial issues are always fraught: the aftermath also gave us a first flavour of what has become another throughline for Respond: financial insecurity. Then, we rallied, we worked together, we changed some of the ways we did what we did, we got through it. There's absolutely been no more fraud, but dealing with the financial challenges has become another familiar aspect of Respond's story. It's very encouraging that we now have more robust and strategic financial systems in place.

In the years that followed this episode, I think the purpose and intent of Respond got clearer and more bedded in. The forensic work expanded and our idea that 'we all have a story and it needs finding out' informed those services greatly. We didn't split between the bad and the good – this was even more clear to us as essential after our own internal brush with criminality.

New schemes started such as the Equal Access project, in response to our recognition that people of different heritages did not always get the same opportunities to use our service. You can see that commitment reflected in Luthfa's work on the Forced Marriage project today. The telephone helpline expanded: we've always answered the phone to people who need our advice support and expertise but finding that work has always been a challenge. But we've never given up and the demand has only got greater and more complex, as Liz Gow, our Family Support Worker, will attest. A new millennium arrived and soon afterwards Alan and I both stepped down as directors, though stayed involved in other ways. Richard Curen and then Noelle Blackman arrived at Respond to take on the challenge taking the work forwards. I started writing more and I also trained as a child psychotherapist. For me, developing as a therapist has been critical. I am proud of the therapy Respond offers. We are leaders in the field and our reputation is hard-earned. We have some truly excellent therapists and case managers working here, and I feel privileged to have worked alongside them as colleague and supervisor, developing and disseminating our Clinical Model to make it the best it can be. Maintaining and strengthening the therapy services can be very hard work, especially in these cash strapped times. We need to be flexible, of course, in how and where it is offered in our contemporary climate, but are always striving to operate in ways which ensure that we are truly reflecting the user's voice. In this, as in all our work we are greatly assisted by the Respond Action Group whose expertise by experience is so helpful to us and whose commitment to Respond over many years has been invaluable.

The relationship between therapy and the projects is a constant dialogue – take the CoSA project for example, led by Julia Dick and, like the Helpline, made possible by the hard work of a fantastic group of volunteers. In Circles of Support and Accountability, young people with learning disabilities with potential or actual dangerous sexual behaviour have a circle of support to enable them to make good choices and fulfil their potential without risk to themselves or others. We can also see the benefits of circles for vulnerable people with learning disabilities who are currently too easily sent away from home to inappropriate services. The family work is essential here, and reflective of our original response to systemic injustices. We work extensively with children and young people now –we didn't do that at the beginning. – I'm so pleased about it and the fact we are out in schools working with some of the most severely disabled children in

our society and I honour Jason Upton and James Hawkins and Rosie Creer in establishing and developing that work.

I hope that therapy will continue to be central to Responds' work – it is where the stories get told and made sense of, and where individual lives change. It is the engine of Respond's work. And while the therapy will continue to adapt and develop, I think and hope it will continue to be informed by our understanding of the following things:

1. Trauma: Respond service users have had awful things happen to them.
2. Psychodynamic approaches – the best support is given and received in the context of relationships in which all players are affected by each other. We resist the notion of a 'lofty expert' or set-in-advance, formulaic treatment programmes.
3. Attachment Theory: services are informed by the understanding that our early relationships have an impact all our lives and that the development of long-term secure relationships can have widespread positive impact on human potential.
4. Systems and networks of care: we work alongside others who are concerned - at home, in schools, colleges and the care and safeguarding system etc, and we see our work always in the wider context of our society and culture.
5. Creativity: words are not always the most effective means of communication and the arts have a crucial role to play in facilitating the expression of feelings and providing opportunities for the shared making of meaning. We also have to be creative and adaptable as workers and as an organisation.
6. Forensic Psychotherapy: – many of our clients' experiences have a connection with crime and the law – as victims or as perpetrators and sometimes both.

Psychotherapy can feel like existentialist philosophy at times. It offers a space for the cultivation and fostering of hope. It's a place to be seen and heard in a very particular way and to be enjoyed and treasured. This is especially precious if you haven't had enough of being enjoyed and treasured in your life so far, as is too often the case for our clients. And for us to be developing and providing therapy services of the highest quality is an equality issue: it's what we'd want for ourselves and those closest to us. It should be no different because our clients have learning disabilities, may struggle to articulate what they want for themselves and may never be able to measure their worth in terms of the economic productivity.

So – 25 years on, why do we still need Respond as much as ever? Surely, with so many changes in terms of the legal protections afforded to adults with LDs, the embedding of safeguarding systems in adult as well as learning disability child services a lot of the work that needed to be done in those early days is complete? It's true there has been progress but sadly it is also the case that people with learning disabilities are still currently vulnerable to abuse, trauma and sexual violence. There have been changes in the landscape, some of them for the better, but many of them, especially in these times of austerity or – as film director Ken Loach put it recently - a time of 'conscious cruelty' towards those who need most protection and whose needs are the most enduring and complex. The criminal justice system still does not do enough to rehabilitate, which is why the CoSa scheme is so important as a pioneering model for restorative justice and for preventing sexual crime against others. We know and understand more about the mental health of young people now, but at the same time as our knowledge is growing, we find ourselves living in a society which has chronic and systemic under provision of the services that

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could and would help. These things are infuriating and enraging and just two some of the reasons why Respond still has work to do and a voice that should be heard.

And perhaps Pauline's hospital may have closed but we now see the ongoing scandal of young people with learning disabilities and behaviour that challenges us, being sent away from home, often hundreds of miles away from to live in Assessment and Treatment Units. Here they are vulnerable to abuse, as the scandal of abuse at Winterbourne View, in Southern Health and Atlas Homes has shown. Government pledges to end this institutional provision are no nearer to being fulfilled and abuse and neglect continues.

Here's an extract from another story, *I Hear What You Say*, which has its roots in this terrible situation. Jude is living away from home against his will. He's waiting for his sister and in the night was very keyed up about her planned visit the next day. He's very into cars and car names. He's been listening to a conversation between staff :

Leon my keyworker comes out surprised, sees me voice sharp says, 'I'm disappointed, Jude. Your behaviour is not acceptable. You're an adult now. It's not fair on Eva. Today is your six month review. What's your social worker going to say? Your sister Martha too? You said to her no more tempers, remember?'

'Sorry Leon don't tell Martha she be here soon. Leon, you must say, Jude's been good sensible.'

Martha my sister you are the reason I am in trouble. You are the reason for my bad night. Stamp feet walk bedroom floor, back and forward bang fist on my head chuck that chair. Night staff Eva came in don't like her. Light on shock my eyes. Don't understand what she says all foreign. Doesn't know what I need my photo of you, my book Top Gear.' Eva won't read won't look at the cars says, 'It's night time Jude and time for sleep.'

Swear at Eva say fuck off loud. My bad temper. Want Leon. Want you. Want to leave this place say goodbye Beech Lodge. Live with you home Martha. Find the right car words. Not Live Here. Nissan Lexus Honda.

In morning get ready for you. Brush my hair tidy say, 'Is it time yet for Martha to come?'

Leon busy resident medication not look up phone ringing in the office says, 'Don't ask the question lots of times, Jude. Once is enough, remember.'

Tells me calm but the words won't fit. My head is very full of worry full of you. Can't think forwards stuck in now. Last time I was waiting for you bad traffic. My head full of bursting red hot exploding. Leon held me carefully Positive Behaviour Response Plan. PBRP till every spark burn gone the dark came swallowed me angry.

Sometimes I'm upset we do a jigsaw Leon and me, The Joy of Motoring old fashioned cars Leon helps find the edges. Sometimes it's a good day calm I promise behave. Martha my sister I know you do your best for me your big brother. You've got your husband Pete, your baby Ella. Our mum getting old now needs your help. But Got a map on my wall show the road from your house to here. Its far. Twisting Sick Road I call it: the road to Beech Lodge where I got put.

Respond is working hard with others, joining campaigns and offering support to those affected by ongoing institutionalisation, including people with learning disabilities whose very challenging behaviour may be the only way they have to communicate the distress they feel at being separated from their families and their communities.

To conclude, I want to list those Respond throughlines: I think they are

Tenacity

Commitment

To be a place of stories – many of them hard to hear

Fighting for justice

Inaugural Tamsin Cottis Annual Lecture 2016: Throughlines – Tamsin Cottis

Financial pressures

A need for shared responsibility and good governance

Honesty and authenticity

And even though I will not be around so much, I'm still going to mind, and be interested in what's happening and be willing you on. I reluctantly accept that you may not share my view that Bruce Springsteen is of central importance to everything we do, but I shall pop in every now and then to remind you and in the meantime share a thought of his.

In one song he asks, 'What are we without hope in our hearts?' And perhaps even more helpfully, given how very tiring it can all be sometimes, he said very recently, 'A worthwhile dream isn't an illusion, it's a form of work.' The idea that life could be better, fairer, safer and kinder for people with learning disabilities, as well as the rest of us, well sometimes – maybe never more so than now, when ideas of equality seem to be under attack as never before - that dream does feel like an illusion, but I think, and at Respond we've shown, that it's not just an abstract thing : the dream is work we can do and do together.

So - here's to the next 25 years of hearing and making stories together, and weaving the threads that have been consistent in our life so far with hope, creativity and flexibility, team work and bloody minded determination .

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