

You listen up here's the story about a little guy who lived in a blue world...ⁱ

Prologue

This article has been written in the style of a narrative story or a play. It charts my experience working with 'Jake' as a dramatherapist on a one- to-one basis. The story unfolds in the same way that I experienced it as a therapist and I hope you feel part of the audience, as a reader, or as if watching a play. It is a play of comedy and drama, which is tinged by extraordinary external events, which lead to a dramatic and tragic end.

I have worked as a dramatherapist for the last two years at a specialist unit for people with severe learning disabilities, and challenging behaviour, in the midlands. The centre has twelve clients, a care team, with a music, art and dramatherapist working on site. The centre has always had a sense of 'chaos' about it and for those unfamiliar in working with such a client group it can be both disturbing and difficult; as it is for those who have worked there for some time. The unit constantly stretches my notion of whom I am and what I do as a therapist, how I do it and where my boundaries as a therapist lie. At a psycho-dynamic level the pain, suffering and chaos presented by the clients become a mixed bag of transference's and counter transference's between the care team, therapy team and management, – staff sickness is always high in what is a highly stressful and difficult environment.

Act One – Setting The Scene

'Jake' was a small slight man, who had Down's Syndrome. He had no spoken language but a wonderful sense of humour and a loud smile with accompanying voice. Jake had been given up for adoption at birth and had spent his childhood in institutional care. He moved to an adoptive home of older foster parents in his late teens and had remained there until just before I began to work with him two years ago at the age of 30.

There had been considerable concerns over the appropriateness of Jake's foster care in recent years. His carers were now in their late sixties early seventies and had been 'uncooperative' with local services. Jake's behaviour in day care had become steadily worse, there was concern that he was profoundly unhappy with his present living accommodation. This was coupled with concern over the restrictions and over management placed upon him by his foster carer's and that his needs were no longer the central concern.

Jake's behaviour had become *extreme*. In day care on a typical day he may, pull people's hair, bang his head on the wall and floor, remove his clothes, attempt to masturbate publicly; urinate and faeces on the floor of the corridor, cover his body with his own faeces and often eat them. Also he may hit out and grab at staff and other clients. He would have to be showered and encouraged to re-dress. On the worst days this process may happen several times. Despite this extreme and seemingly bizarre behaviour Jake *was* well loved by staff, he had a cheeky smile and somehow reminded me of a circus clown, especially in his gait and walk.

Act Two – The Chaos and Beginning of The Process.

At the time I began to work with Jake he was just being moved from his foster home of some ten or more years into respite care with the hope of finding him a home of his own. His extreme behaviour began to reduce almost immediately, however it carried on spasmodically for some time.

Jake had a great love of three things, tea, biscuits and loud pop and rock music, with a good beat. I began to work with Jake in October of 1998. My biggest challenge at first was not how we might work together or even what we might do, but, could Jake bare to stay in the same room as me for two minutes. For the first month or so the answer was, no, he could not. I had tried to use relaxing slow music, staff advised me the key might be to play loud fast music with a good beat. Early in January we had a break-through, Jake

remained in the room for fifteen minutes. I had a room full of materials, a brightly coloured parachute to depict the playing area, a box of materials and balls, and a rock anthem album playing loudly beneath the glitter ball and glowing coloured lights of the sensory room; which, we worked in. Jake briefly passed a ball back and forth before asking for the inevitable biscuit, with his limited sign language.

The following week Jake unprompted by me draped himself in a variety of colourful pieces of material and sitting on the floor bounced forward and backward to the beat of the rock anthem album.

The problem with many of our clients was their complete lack of boundaries. When did the session begin? When did it end? Work often spread out of the therapy space we were using, into corridors and nooks and crannies of the building. As a therapist I tried my hardest to have a designated beginning and acknowledged end. The following week we had bounced and danced to music and made our goodbyes, five minutes later I discovered Jake alone in the music therapy room banging loudly and furiously on a drum. Had the session finished or had Jake continued without me? Up to this moment I had used little speech, as my work with Jake was physical in context using movement, dance, objects, and a rock anthem album. Speech had seemed almost unnecessary, the boundaries of our work were strained, my training appeared to have gone out of the window; and I had a deep unease that I had no idea what I was doing. In reflection once I had begun to put things into perspective through supervision, I knew exactly what I had been doing, and realised it was right.

Clients in Jake's position have a powerful effect on the environment and those around them. They externalise very well the inner feelings of chaos, rage and lack of a 'normal' structure to their lives, which, are often not only their personal inner feelings and early life experience, but transversely exist in the chaotic world of the care they receive. Endlessly key workers, social and care workers come and go. The clients within the centre do this on mass very effectively. Why should I have expected anything less in our sessions together? In effect I should have expected more 'chaos', and more strongly focussed in my direction, especially when 'I' as yet another 'carer' actually began to allow Jake to examine and acknowledge with me his feelings about his life experience.

Act Three – The Sense in stupidity and the handicapped Smileⁱⁱ

'People who are close to great grief and cannot bear it encourage 'happiness.'ⁱⁱⁱ That's not to say that Jake had moments when he wasn't genuinely happy and smiled gleefully. Especially in the more macabre moments, when he happened to be pulling large clumps of hair out of an unsuspecting member of staff's head. There is a well-known dramatherapy saying, at least on the side of my Badth cup, 'stay with the chaos and the meaning will emerge'. The chaos for me was spending several months in which Jake and I rocked 'happily' to the rock anthem album. We said little. There seemed no point. I was becoming concerned we were going nowhere, however I felt that there was a side of Jake that had been completely ignored throughout his life. Underneath that sense of stupidity and the 'handicapped smile' there lay a Jake who was in desperate need of coming to terms with and making sense of his life, there was a sense in his 'stupidity' that asked for people to go further and deeper. I hoped I could find a dramatic metaphor through which I could attempt to do this.

On one occasion during this period of apparent bareness in our work Jake took the fluffy colourful rope out of the box and wrapped it around his wrists like handcuffs. I copied this; Jake then pulled the material off and gently patted it. I saw for the first time someone who may be showing me he felt trapped and imprisoned confused or stuck^{iv}. This was the beginning of the central core of our work.

In retrospect of course it is apparent that our work should have a barren, stuck or confused quality about it, and that there was an element of me 'not knowing' what was happening. As I said earlier the clients within the centre often show elements of their outer existence as well as their inner experience in very strong tangible ways. This was paralleled at this time in Jake's life, being in respite care, between his former foster parents, and something yet to come.

Act Four Transitional Objects, Symbolism, The Mother and The Child.

It was in June of 1999 that I finally began to come to grips with some of the issues Jake was trying to describe to me. Winnitcott suggests that:

‘When symbolism is employed the infant is already clearly distinguishing between fantasy and fact, between inner objects and external objects, between primary creativity and perception.’^v

Jake and I had in almost every session played a simple copying game, which involved me copying him rub in a round movement the hair on the crown of the top of his head. He would take pleasure in watching me copy this simple act, which I felt was for him a comforting act, his ‘piece of blanket’, which was safe and felt good. One day he reached across and simply kissed me on the crown of my head three times. A moving moment.

I introduced, probably from an unconscious urge, a basket full of fluffy toys, which had one human like shape, a character I came to fondly call Rag-Dolly-Anna. She wore a blue dress, long brown hair, rosy red lips and cheeks and a wicker basket in her hand. She was the quintessential natural, though stereotypical wholesome woman. A milkmaid from a Thomas Hardy novel. It was Rag-Dolly-Anna who became the centre of our work for some time.

I suspect, but don’t know, that Jake’s early life in institutional care thirty years ago left him with little chance to have a nurtured up-bringing. Attachment theories suggest^{vi} that Jake probably had no significant other to attach himself to in the first two or three years of his life, especially a mother. Jake picked up Anna and to my surprise began at first to rub the crown of her head. In the third week of working with Anna Jake played with her hair, kissed her, and dribbled over her. He also began a curious ritual which I don’t fully understand, he would remove his socks and bang her head against the sole of his foot, and at the end of the session he threw the rest of the contents of the toys from the basket across the room. Later on he would gently rub her head against the sole of his foot. Over a period of weeks Jake became exclusively obsessed with Anna.

Three months into this phase of our work Jake picked up Anna and held her, I began to verbalise what I felt was going on. I said, I understood that what he was doing was important, we all needed friends with whom we could share. Jake leant over and hugged me twice. I said that I understood what he was trying to say to me. Later in the kitchen after our session Jake came over to me sat on my knee and again hugged me as if to say, “thank-you for understanding.”

I shall never know for sure exactly what Jake was saying, although there is a high probability it may have had something to do with the need for mother, for being nurtured, and most definitely had something to do with the need for relationships of the most intimate kind. Pertinently after that admission of acknowledgement by me and the hug in the kitchen, his relationship with Anna began to change. He seldom gave her the attention, or obsession that he once had. I only realise that now as I read through my notes. A transitional moment had arrived and passed partly because of our understanding and acknowledgement of it together. I was surprised at the depth of feeling that had arisen at that time between us, a bond, an understanding. It came at an interesting time that paralleled issues within my own personal therapy.

Act Five – The Room in Focus – Transitional Phenomena – Embodiment, Projection, and Role.

‘The transitional object and the transitional phenomena start each human being off with what will always be important for them, i.e. a neutral area of experience which will not be challenged.’^{vii}

Suddenly and dramatically Jake’s work began to shift. Towards the end of our work with Anna, Jake would hand her to me after kissing and cuddling her and I would copy his actions. It was almost as if he was ready to move on from this infantile state into the next phase of growth and development. He had in essence maybe experienced that intimate, childhood, relationship through play in dramatherapy, and more

importantly, had the need for them acknowledged. Although I continued to bring Anna into the room the focus began to move away from her.

I realise now that Jake was using a classical paradigm at this stage in our work, that of embodiment, projection and role.

'It is the dramatic action which is created from the imagination, the action that is embodied and vocalised, projected into images and dramatised.'^{viii}

Jake was able to use Anna as way of connecting inner emotional feeling, and embody it, take ownership of it, and dramatised it through the doll. Through a series of very simple developmental stages Jake was able to express something very complex into a dramatic form that allowed him to share, and possibly understand the experience with someone else. The power of dramatherapy!

At this time Jake and I had moved our regular sessions from the sensory room into a more neutral room which was small, which had none of the paraphernalia associated with a sensory room. It had windows plain walls and ceiling. Jake was now becoming more interested in me changing the music, no longer was it just the rock anthem album, but other fast, loud, chart music with a beat, which he would sit and rock to. Regularly he would ask me to change the music, and he would flick the light switch of and on. His focus was moving away from the rag doll, although occasionally he would pick her up, and on one occasion he threw her on the floor twice.

Jake was experimenting with the wider environment. One pop song had the words rocking and wailing in its lyrics, and Jake began to rock and let out a wail like cry followed by laughter. The song talked about someone being left without anyone and I feel Jake understood the words and identified with them. I expressed this to him verbally saying I felt I understood how he was feeling about being left alone, but now there were people around him. Jake hugged me several times.

You listen up here's the story about a little guy who lived in a blue world. And All day and all night everything he sees is just blue like him inside and outside blue his house with a blue little window....^{ix}

By now some massive changes had occurred in Jake's life. A few weeks prior to this Jake had moved to *his own* flat. Another transitional phase, and rite of passage. He had moved on from respite into a small, two bedroom flat, that was staffed 24 hours a day. But it was *his* flat; he lived there with a member of staff. He helped to choose the furniture, the wallpaper and the colour of the paint. Jake had at long last arrived in circumstances that most of us take for granted. Hence his interest in the space around him which, before he never had any power over, but now he could make it his own. He was exploring this new found freedom of being able to exert influence over the space around him through his new flat, through his work with me, by turning the light switch off and on, and by asking me to change the music. As opposed to influencing the space around him by pulling someone's hair or defecating on the floor.

Act Six – Final Act

Our last few weeks exploring the environment through movement, music and the light switch was suggesting that Jake was approaching a new transitional phase. Circumstances never allowed us to discover what that might be.

I had been away on holiday for two weeks in early January 2000, the height of the flu outbreak. On returning, the manager promptly took me to one side as soon as I arrived. She said that Jake had suffered from a bout of flu whilst I was away, he had not recovered. Jake had died the previous week.

At that time I had no feelings, just numbness. Jake was my second client that day. I had been expecting to work with him in an hour, I would no longer work with, or see him again. Several colleagues had tried to contact me whilst I was away so that I wouldn't, 'have to find out like this'. Their messages had not reached me. Jake was dead our work didn't finish, it stopped.

‘Within the internal world of the therapist is the wish to stay alive and work. We cannot make this assumption on behalf of the patient...’^x

In her article on thoughts on illness and death Jennifer Silverstone talks about the death of a therapist colleague. However in a sense the therapist and therapy, or an aspect of them, does die with the sudden and unexpected death of their client. Silverstone goes on to say:

‘We often see and experience the resistance within the medical profession to let a patient die, to ‘give up’ and let the psyche live and the heart/body ultimately stop.’

To work with a patient who was so profoundly disabled in life, allowed me to face up to the concept of the ‘sick therapist’. Silverstone talks about a therapist colleague who through their physical sickness was able to find a deeper connection with that of their client’s illness. In life Jake’s disability allowed me to come to terms with aspects of the vulnerable within me personally and professionally.

Within my work as a therapist at the unit, I often struggled with a lack of being able to be really creative in the work I did. Often I was only able to use the smallest amount of my skills, I was limited from being more creative by people who themselves were also limited. The ‘sickness’ and ultimate death of Jake allowed me to reflect on the nature of my role as a therapist working with disabled clients with whom I could not be as creative as I wished.

Because of the closeness of our relationship, Jake’s death opened up for me at a personal level a whole new resource, allowing me to have a clearer understanding of the importance of the relationship we had had. The work we had done together in those last few months before he died. And at a professional level the ‘sickness’ transferred to me as a creative arts therapist who found it difficult to be creative with these clients and in this environment.

Jake’s death affected everyone, at the day unit, he had always been the loveable rogue, Pepe the clown, the little man with the big smile who liked tea and biscuits, and, when you weren’t looking, would pull your hair and shriek with pleasure. And for me at a personal level as a therapist it allowed me to explore and understand more fully my role.

I had occasionally known clients with whom I had contact die, but never with one whom I had worked at such a deep level. In the intervening time between hearing about his death and the funeral I reasoned about why his death had happened. For the first time in his life some two or three months or so previously he had moved into his own house. Many people who cared for him in a range of different ways surrounded him. He was being able to make decisions, affect his environment and circumstances. He had been able to explore with me his feelings, aspects of his childhood, and allowed me to acknowledge these feelings and in his death allow me to more fully understand my role as a therapist. But why at this most perfect time in his life should he choose to die?

The pragmatist in me would say, ‘it was the flu he couldn’t fight it’. One of my arts therapy colleagues suggested, and a psychotherapist, that maybe it was the most perfect time to die and the most ultimate statement he could make. He strived his entire life to find what he needed, and when he found it, he could rest.

Epilogue – The Last Goodbye

There was however one final complement we could all pay and that was to attend his funeral the following week.

The funeral also fulfilled another need for all those from the unit who were involved in his life it gave us the chance to say goodbye. His death had been so sudden, none of us were given a chance to say goodbye whilst Jake was still alive. In one way he had lead a life that had been isolated from much of society and his death had been isolated by circumstance from the staff and clients at the unit. The funeral was the final way in which we could say goodbye, and was a poignant reminder that separation is something that many

people with learning disabilities have to deal with all their life. He had struggled all his life to get what we all deserve, now he had just about achieved it, maybe there was no need to struggle anymore. Maybe he was presenting in his death the ultimate transitional phase of our work together.

Anna Chesner suggests that:

‘Loss and bereavement often emerge at the heart of the therapeutic process when working with this client group. The loss of the chance to lead a ‘normal life’, the loss of freedom to fulfil dreams...’^{xi}

Jake’s death was not only the ultimate transitional phase, in some strange way, maybe it could be seen as the ultimate expression of the work we had done together.

The funeral was a beautiful service, marred only by the absence of his ex-foster carers who had in no uncertain words placed the blame for Jake’s death at our feet. One of his carers sang a song. And as the coffin came into the church, whose numbers had been swelled to over 30, there rang out the tune to a very popular hit record which I found out later was apparently Jake’s favourite record...

Do da ba di da ba do

You listen up here’s the story about a little guy who lived in a blue world

And All day and all night everything he sees is just blue like him inside and outside blue his house with a blue little window and a blue corvette and everything is blue for him and himself and everybody around, cause he ain’t got nobody to listen and blue da ba dee daba di da ba dee da ba di daba a de da ba di. I’m blue daba di daba di daba de daba di^{xii}

For me this had summed up Jake’s life, he had led a very blue life. The quality of the colour suggested to me, starkness, and a coldness he had probably always felt. And that blue life despite allowing Jake eventually his own door and window - his own little house; left me with the feeling that he had had very few people to listen to him. I hope in a one way I was able to listen a little. As Valarie Sinason painfully admits

‘Devalued children and adults have, with a few shining historical exceptions, received the worst services, the worst schools, the worst teachers, the worst medicine, the worst hospitals and homes and little pioneering treatment...’^{xiii}

To me the blue colour of the song represents a coldness that people in Jake’s situation have always felt. We had begun to ease Jake away from this, but he had, in the last few months of his life, achieved his own house, with his own window and his own door and maybe the colour for Jake wasn’t as blue as it had been in his past.

Sleep well.

This article is dedicated to the memory of ‘Jake’. I hope it is a fitting epitaph.

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MUSIC

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Word Count 4291

ⁱ Eiffel 65 – Blue (Da Ba Dee) 1999 Warner Music Uk Ltd

ⁱⁱ Sinason Valerie Mental Handicap & The Human Condition Chapters 1 and 6

ⁱⁱⁱ dito pg 141

^{iv} I have only recently found out from one of the staff who worked with Jake, (after writing the main article), that one of the bizarre and probably illegal things Jake's foster parents did, was to wrap colourful, fluffy handcuffs around his wrists when he was being difficult as a way of restraining him. I had no knowledge of this while we were working together. I can only assume that Jake wished to share with me this intimate secret of what was going on in his life. By copying him I was inadvertently showing him I shared his feelings of pain and suffering. He felt our relationship strong enough to show me this abuse. I was oblivious to the real reason as to why Jake did this at this time in our work, and so will not refer to it directly in the article. Ironically it fits in perfectly with the deeper development of our work, which was to follow, and in many ways it may unwittingly have been the turning point in our work together.

^v Winnacott DW Playing and Reality pg 6.

^{vi} See Bowlby J ' The nature of the child's tie to his mother J of Psycho Anal 39 350-73

^{vii} Winnacott DW Playing & Reality pg 14

^{viii} Jennings S in The Handbook of Dramatherapy pg. 96-97.

^{ix ix} Eiffel 65 – Blue (Da Ba Dee) 1999 Warner Music Uk Ltd

^x Silverstone Jennifer LCP Journal Reflections 1993

^{xi} Chesner A. Dramatherapy for People with Learning Disabilities. Pg 76

^{xii} Eiffel 65 – Blue (Da Ba Dee) 1999 Warner Music Uk Ltd

^{xiii} Sinason Valerie Mental Handicap & The Human Condition pg 12