

The Autonomic Storm:

Donna Williams ('Nobody Nowhere')

'A feeling kept washing over me. It was like a tingling in the back of the neck. It began with the feeling one gets from eating lemons. It spread to every fibre of my body like cracks in an earthquake. I knew this monster. It was the Big Black nothingness and it felt like death coming to get me. The walls went up and my ears hurt. I had to get out, out of the room, out of this thing stuck on me, suffocating me in my shell of flesh. A scream rose in my throat. My four year old legs ran from one side of the room, moving ever faster and faster, my body hitting the wall like a sparrow flying at the window. My body was shaking. Here it was. Death was here. Don't want to die, don't want to die, don't want to die.... the repetition of the words blended into a pattern with only one word standing out, the word die. My knees went to the floor. My hands ran down the mirror. My eyes frantically searched the eyes looking back, looking for meaning, looking for something to connect. No-one, nothing, nowhere. Silent screaming rose in my throat. My head seemed to explode. My chest heaved at each final breath at the gates of death. Dizziness and exhaustion began to overtake the terror. It was amazing how many times a day I could be dying and still be alive.'

Gunilla Gerland ('A Real Person')

'All the time I was growing up I experienced a constant shudder down my spine. Periodically the shuddering grew worse, while at other times it kept relatively quiet so I could live with it. It was like that feeling you get before you sneeze, only as if it had got stuck and was suspended in my spine in order to turn into something permanent...I became slightly used to it but it was a constant torture, most noticeably when it changed in intensity. It was like cold steel down my spine. It was hard and fluid at the same time, with metallic fingers drumming and tickling the outside. Like sharp clips digging in to my spine and lemonade inside. Icy heat and digging fiery cold. It was like the sound of screeching chalk on a blackboard turned into a silent concentration of feeling, then placed in the back of my neck. From there, so metallic, the feeling radiated out into my arms, clipped itself into my elbows but never came to an end, never ever came to an end.'

Gunilla Gerland ('A Real Person')

'When they saw the sound of a moped made me act strangely they started scaring me. They would wait for me to pass them and then suddenly rev up. The din made the ground under my feet disappear and I could neither see nor feel the world round me. Up and down were suddenly in the same place and I had no idea where my feet were. So as not to fall over or explode from inside, I had to grab the fence where I was standing, pressing myself against it and holding on hard. I had to feel something that stood still, something anchored in a world that had become totally unpredictable.'

Lindsey Weekes

'I would do anything to stop it, bang my head against a wall, run in front of a car.'

Self Injury

Donna Williams ('Somebody Somewhere')

'There was a rip through the centre of my soul. Self-abuse was the outward sign of an earthquake nobody saw. I was like an appliance during a power surge. As I blew fuses my hands pulled out my hair and slapped my face. My teeth bit my flesh like an animal bites the bars of its cage, not realising the cage was my own body. My legs ran round in manic circles, as though they could outrun the body they were attached to. My head hit whatever was next to it, like someone trying to crack open a nut that had grown too large for its shell. There was an overwhelming feeling of inner deafness – deafness to self that would consume all that was left in a fever pitch of silent screaming.'

Sensory overload: youtube link

www.youtube.com/watch?v=BPDTEuotHe0 (zero)

BOSE 'Quiet Comfort 15' Acoustic Noise cancelling Headphones

REFERENCES

www.phoebecaldwell.com

Papers

1. How Rapidly does Intensive Interaction promote social engagement for adults with profound learning disabilities?

Zeedyk, S, Caldwell, P. and Davies, C

European Journal of Special Needs Education, Vol 24. 2009, p.119-137

2. Fostering Social Engagement with Romanian Children with Communicative Impairments.

Zeedyk, S, Davies, C and Caldwell, P.

British Journal of Learning Disabilities 2009, 37 (3) p 186-196

3. 'Intensive Interaction: Using body language to Communicate'

2012 www.intellectualdisability.info

4. 'Intensive Interaction: Using Body Language to Communicate'

Journal of Developmental Studies

Caldwell, P. JoDD Vol 19 No 1. 2013 (in press)

Training Films

1. **'Learning the Language'**

Follows a three day intervention using Intensive Interaction to get in touch with a young man with very severe autism, using his body language. Pavilion Publishing

2. **'Creative Conversations'**

Demonstrates Intensive Interaction being used with people with multiple disabilities, mainly Cerebral Palsy. Pavilion Publishing.

3. **'Reaching Ricky'**

Working with a child with autism in school. 'Available Light'.

See Website. Google Phoebe Caldwell

4. **'Autism and Intensive Interaction: using body language to get in touch with children on the autistic spectrum'**.

A three part training film to be published in April by Jessica Kingsley Publishers.

Includes a twenty minute intervention with an eight year old child, whom staff cannot make contact with and whom Phoebe has never met before. The film moves from initial rejection to total attention. Other interventions with children aged 3-18.

Books

1. **'Finding You Finding Me'** Caldwell, P (2006)
ASD and Severe Learning disabilities Jessica Kingsley Publishers
2. **'From Isolation to Intimacy'** Caldwell P (2007)
ASD and Severe Learning Disabilities Jessica Kingsley Publishers.
3. **'Using Intensive Interaction and Sensory Integration with people with severe autism'** Caldwell P (2008) Handbook for working with intensive interaction. Jessica Kingsley Publishers
- 4 **'Listening with all our senses'** Caldwell, P. (2012) (Re-launch of three earlier books as one book, 'Person to Person', 'You Don't Know What It's Like' and 'Crossing the Minefield') Pavilion Publishers
5. **'Delicious Conversations'** Caldwell, P. (2012) Pavilion Publishers Using Body Language to Communicate.

Chapters in Books

1. **'Speaking the other's language: Imitation as the gateway to relationship',** in 'Infant and Child Development',
Special Issue: 'Imitation'.
2. **'Intensive Interaction: Getting in Touch with a child with severe autism',** in 'Promoting Social Interaction for Individuals with Communicative Impairments. Making Contact.' ed Suzanne Zeedyk
3. **'Self-injury and loss of sense of self'** (2012) Chapter 11 in 'Understanding and working with people with learning disabilities who self-injure'. ed. Heslop, P . Jessica Kingsley Publishers.
4. **'Autism Spectrum Disorders'**(2013) Bradley, E., Caldwell, P. and Underwood, L. Chap 11 in Handbook of Psychopathology in Intellectual Disability, ed Tsakanikos, E. and McCarthy, J. Pub. Springer

Simple Handouts.

- 'Can We Talk' and 'Speak to Me'**
(Free download from website)

Sensory Problems: Useful Equipment

Vision (Scotopic sensitivity or Irlen syndrome)

Irlen lenses

Coloured light bulbs

Dimmer switches

Peaked caps

Grey Sunglasses (where the problem is caused by intensity of light rather than colour or pattern.)

Contacts for Colorometric test

Irlen Lens Centre, 4.Park Farm Business Centre, Fornham St. Genevieve, Bury St. Edmunds, Suffolk, IP28 6TS 01284 724301

Contact local Dyslexia Society for information regarding local practitioners.

Sound

BOSE Quiet Comfort 15 Acoustic Noise Reduction Headphones (cuts down on distant sound while allowing close up conversation.)

or,

contact a good music technician, who should be able to measure the frequencies that are causing pain and using a specially designed acoustic material, build this into headphones that cut these out.

Proprioceptive/Vestibular/Boundary Problems (Inputs need to be frequent, topping up with short sessions several times a day to make a real difference.)

Trampoline

Pogo Stick

Swing

Space Hopper

Climbing frame, Wall or Bars

Exercise sandals with ridges inside

Astroturf to walk on

Weights

Weighted clothes

Weighted blankets

Compression vests/stockings

Sheet of Lycra (use under supervision)

Athletes Pressure Vest

Biohug Vest (Google)

Vibration

