

The Story of Joey

Post 1 - Session 1-6

Introduction

Joey is a pseudonym for a youngster suffering from cerebral palsy who I trained some years ago. There are a couple of caveats to keep in mind as you read this account. I made a number of protocol changes, perhaps too many, following the curve of his symptom presentation. Our filters at that time were only fine enough for 1/4 Hertz changes and as I read back over this, I think he could have profited from shifts of even 1/8 Hertz. He was also only able to come once a week and often even less than that. It's a far from optimal regime for him but it was what was possible. Whatever the drawbacks to the training this is a fascinating study of a fascinating and lovely boy. It's a study of affect, its regulation and sense of self. I'm going to provide it in sessions, one posting every week on the social media platform of your choice. Enjoy! All feedback is welcomed.

Joey is a slender 13 year-old boy, who could be mistaken for ten or eleven, with dark brown hair and large, soft brown eyes. He comes to me diagnosed with PDD NOS, hypotonia of unknown etiology (a "low tone baby") dyslexia, expressive language disorder, Non Verbal LD, short term memory impairment, fine and gross motor difficulties and possible incipient schizophrenia. He had a normal gestation and delivery but did have jaundice after birth. Apgar scores were normal. He did not walk independently until he was 18 months, did not speak single words until the age of 3 and 1/2 and not in sentences until age 6. In neurofeedback terms, this boy could be described as suffering a "timing disorder NOS". He attends a special school for learning disabled boys. Everyone likes him. He is cooperative and easy to get along with. He perseveres with the very difficult tasks of math, reading and trying to articulate. He can, for good reason, feel frustrated and is often impulsive. As soon as an idea occurs to him, he has to act on it. There is no malice in him. He is on 300 mg of Wellbutrin.

Joey has a very compelling internal reality. People come from around the world and enter his body. They are there to be trained as trainers and to go out to help others by, in turn, entering their bodies and doing for them what they learned to do in him. This corps of trainers is responsible for the well being of 5 billion people, soon to be 9 billion. He described how they all drink coffee all night (amazingly, this boy sleeps well, although he has had three episodes of sleep walking). They have to be on the phones all night because of the difference in time zones (sic) and the level of their responsibility. He reported all of this to me without hesitation, genuinely and earnestly. As you will see, he is able to provide me with excellent feedback on the way he is affected by neurofeedback through reporting from and on this interior system.

Joey also believes that he is from a different planet and that there are others here with him that none of us can see. They speak their own language. In our time together he will make reference to these origins but unlike the international training company and the high school that he runs, he doesn't tell me much about this.

Beginning TOVA scores:
Inattention- 0
Impulsivity- 73
Response Time- 96
Variability- 81

Joey begins neurofeedback.

Session 1 & 2

With some gentle prompting from his mother, Joey looks at me and shakes my hand, limply. Handshakes are one of the first skills I teach troubled children. This boy is more jumbled than troubled but he still does not know how to shake hands. Next time I will teach him and then shaking hands will feel good to him-it will give him proprioceptive feedback and a felt connection between us. Because of his apparent need for training of both hemispheres, the global nature of his difficulties, his good attachment to his mother and his history of sleep walking, I decide to begin training at T3-T4, expecting to bring the frequency reward lower during the course of the session. If he were autistic or attachment disordered, or there was less evidence of left hemisphere difficulty, I would have begun at T4 or C4. Throughout the session, he talked about the people in his body and the coffee they were drinking so that they could answer all the phones to make plans for the upcoming meeting of five billion people. He enjoys their presence, says they never rest, that they (and he) feel constantly busy in this important work. You can hear the pressure he is under in his speech. It's not clear but it is urgent.

Protocol: I began at 10-13 Hz, 2-7 inhibit and went down to 5-8 Hz, by the end of the session.

The next day, Joey reports that after the training the people inside his head were "so quiet it felt as if they'd left". "They are working again today". He did not like their absence last night. But he also said that "they liked the training (NF), a little bit". There is, of course, a possible problem here. This child has lived in this system all of his life. Rapid changes in it could be hard for him. Helping him to adjust to these changes may well become the central therapeutic challenge. At the end of session two we were down to 4-7 Hz and he says, "I feel good"! And calm. His speech is slower paced. He gives me a firm handshake and smiles at me.

This child has been assessed multiple times and he comes to me with many descriptors but essentially with no real diagnosis. Since we don't yet have 'diffuse bi-hemispheric dysrhythmia' as a DSM category, I can only attempt to describe the "feel" of him and "the look" in the best terms (and those least frightening to his parents) that I have available. Schizophrenia has been suggested and ruled out on several occasions, perhaps, again, because he doesn't have that 'feel'. His internal system is facilitating his relatedness, not replacing it. He is with me and describing this elaborate internal world as opposed to being in the internal world and barely related to me. For the same reasons, he does not feel autistic. This "world" may represent many things but I think it is primarily an elaborate and concrete narrative of the effort it takes for him to organize himself, to get his legs to walk and his voice to speak and the good he wishes to do with this great expenditure of resources. It is a description of circuits being overwhelmed by demand; a description of not only his mental processes but of his brain. We all spin our narrative selves from the firings of the brain. Due to his disability, Joey's narrative may be closer to the source than most of ours.

We trained for 30 minutes each session. I am doing nothing more than neurofeedback and listening, as he generously introduces me to his interior world. We are new to each other. Joey is engaged in neurofeedback training daily when he is home from his special school.

Session 3:

Joey is back after a one day break. His response to my inquiry is enthusiastic. "Good!" We talked about the internal system's reliance on

coffee which he defended because they had to stay awake, "there is too much to do". I asked him if he knew that caffeine was a drug. He didn't know this. I said that in all of my work with peak performers, it was the goal to reduce reliance on drugs; that I was for a drug free environment, was he? Perhaps neurofeedback could make it possible to do all this work efficiently without drugs. Joey hedges his bets. He can't quite imagine this system functioning around the clock on multiple time zones without using caffeine but he also does not at all like the idea of drugs. We will see how this plays out for him over time but with the discussion of coffee, I have tried to provide a context, acceptable to him, for the changes he has already begun to feel.

His mother reports that he seemed to stand straighter than usual when he was on the treadmill. On the drive to the session, he was talking with her about planning a Lego city instead of the people in his body. In general, however, Joey is good on making plans, but poor on executing them. He read a book with his mother with less frustration than expected even though he is making the typical number of mistakes. His sleep and appetite are good, as usual.

Joey seems to be tolerating T3-T4 well. This session is 12 minutes at 4-7 and 9 minutes at 3-6. Mother is most concerned about his articulation, and since I want to understand, from him, the nuances of his experience, so am I. I introduced F7-F8. (In a little boy suffering anoxic brain damage at birth this protocol had a dramatic impact. It not only enhanced his ability to articulate but his comprehension of what was being read to him.) I trained Joey here at 2-5 Hz. He reported being a little tired after F7-F8, but good.

Session 4:

After the last session his mother called to report that Joey is "peaceful". There is some increased hesitation in his speech that wasn't there before the last training but that has happened in the past. Otherwise, there is no change. I had asked her to be aware of any change in speech fluency because of the introduction of F7-F8. He is reading without protesting and without any evident frustration. The increased hesitation makes me suspect that the frontal reward frequency may be too low.

Joey, of course, has his own feedback. He pointed at F7-F8 and said, "These guys used to drink only coffee, now they are drinking ginger ale". (!) He feels too that it is important that these guys get off drugs, (i.e. caffeine). He reports that he feels good and that "most people have a day off today". There is only the "repair crew". There are nine of them and only three are drinking coffee. They are reporting to him that "things look good, that they will be finished soon and that they won't have to return in quite awhile."

I don't see any evidence of fear or loss about the changes he seems to be experiencing. A week later, the young woman who came in before him shared this observation: "I wanted to tell you about something. I was waiting for my ride and I saw a little boy arrive here with his father. He really wanted to see you. He ran up the stairs ahead of his dad. You could tell he really wanted to be here."

During the training the day before I went at low as 3-6 Hz at T3-T4. While training, he reports no difference from his state at the beginning at 3-6 and there is no evidence that I have gone too low. At 2-5 Hz, after only a few minutes, he tells me that his hands feel heavy and demonstrates this by lifting his arms with elbows still on the chair in a pantomime of weight. This is not the kind of response during training that worries me, generally speaking. It is usually transient. But Joey is a precise reporter and I want to respond to his reports immediately, both because I think they are likely to be very accurate-he is oddly quite "tuned in to" his body - and because I want to enhance his sense of agency. I went up to 2.5-5.5 and the heavy feeling went away. It may be important to note

that he reported this body sensation directly as a body sensation. There were no middle men. He wanted me to train again at F7-F8 and so did I, so we trained a half a Hertz higher at 2.5-5.5 for three minutes.

Session 5-6

This is Joey's fifth session. He is clearly enjoying being at the office. He is at ease and begins his report. "Five of the repair crew are off caffeine. Four still want to drink it." He fell asleep easily and awoke early to use the bathroom. When he saw the snow, he was excited but was able to go back to sleep. His father, who is with him today and who is not entirely unlike his son, reports that this is unusual. Joey would not have been able to return to bed, much less to sleep. There is, it seems, increased flexibility of state.

We continue training pretty much as before - T3-T4 at 2.5-5.5, 2-7 inhibit for twenty-one minutes, the frequency at which he had been comfortable last session, and 2.5-5.5 at F7-F8 for nine. Joey's father had reported not much change in speech and mother who had called before they arrived still heard some hesitation in the gait of his speech. I don't want to go much lower because of his learning disabilities and my prior experience in other situations, in which training too low frontally had increased dyslexic confusions. I don't know quite where to 'place' this symptom in the frequency domain, although it is clear to me that it relates directly to the training.

During the session, Joey comments. At four minutes he says: "The company called up and said no more coffee, putting bad things in coffee." At 7 minutes he says that "the repair people are finding other bodies to work in". Joey reports that he himself is feeling good. "It is a little busy [in his body], due to the holiday season." Again he asked for F7-F8, saying that it felt good to him. Before switching placements, the people asked him to set his watch (!!). I wonder if he is telling me about a timing change. Could it be that all of his metaphor about timing zones and the amount of resources required to keep them all communicating is real information to me about timing faults (Llinás)?

At the end of the T3-T4 epoch, he reports that the crew "training for the job do not want to get off caffeine." This could mean that we are training too high, that his brain still feels like it is on caffeine or that we trained too low and that he feels the need for more stimulation. To date, I have taken the caffeine to signify overarousal. I will stick to that hypothesis even with the rather sudden turn of events later that day.

Joey's mother called to report that he was very 'hyper'. He could not sit through dinner without jumping up to attend to whatever had just occurred to him to do. As we talked about it, his mother agreed that his behavior seemed more impulsive than hyper. He had to act, it was purposeful, it just could not be postponed. The family had never seen this behavior before. After dinner, he went to his room and initiated a project, also something they had never seen him do. He recorded the 'sounds of his planet', the strange noises of the place he comes from. He wrote about himself and smiled and laughed, appropriately, at himself and at what he was writing. I wonder if he is constructing an archive.

Both mother and Joey report that he has been happy. He slept well and he is still craving and 'sneaking' chocolate. Mother, who is an OT, felt that it was harder for him to articulate, that he wasn't placing his tongue in the right place to make the 'th' sound. This was not new; it was an old pattern, but one he'd learned to correct. As has been true since the beginning of the training, he is reading without frustration even though he makes a lot of mistakes. He still has no bilateral movement but mother reports that he stands more upright.

I think it's time to try a new protocol. I decided to keep nine minutes of T3-T4 (2-5) in the picture, mostly in an attempt to keep the hemispheres talking to each other and to address, however minimally, the profound left hemisphere deficits. My objective at the beginning of this boy's training is to help him quiet himself. I began at T4-P4 at 6-9 reward, 2-7 inhibit. At 6 minutes, he reports not feeling the training so I dropped it to 5-8 then to 4-7 Hz. Altogether, at T4-P4, he trained for 15 minutes. He liked the right side training at 4-7 Hz and told me that "the files are being cleaned out. It smells bad in there, like someone forgot a sandwich." A little later, "All the old files are getting a good cleaning." He told me this with a lot of delight.

He was feeling this mostly in the back of his head. This is where his "files" were - right where he makes alpha, in "the back of his mind". (quotation marks mine, just where I think we may all find some old memories. He did not want to train at F7-F8. We didn't. On reflection now, I think I was training him too low, or that he might have trained better at F7 alone. It is of note that at the same frequency today that several days ago led to heavy hands (T3-T4, 2-5 Hz), he felt fine. He shook my hand with a firm handshake, one that was close to being his own.

I asked his mom about whether it was unusual for Joey to talk about his body sensations directly, as he had about his hands when he was training earlier in the week. She said that typically he would only be able to say that his hands felt "funny". "Funny" is his ubiquitous descriptor for strange body sensations. It was unusual, she said, that he used the word 'heavy' to describe his hands. Of course, I am now not sure whether I gave this word to him. I am sure that he showed me that they were heavy and used the word readily. I wish I knew, just because you like to recognize openings in another's mind and not create them in your own.