

Transcript of “Learning the Language” DVD by Phoebe Caldwell.

Building relationships with people with severe learning disabilities, autistic spectrum disorder and other challenging behaviours

This video looks at a method of communicating with people with profound learning disability or who are separated from us because their behaviour is very challenging. This method is known as Intensive interaction.

The video focuses on the work of Phoebe Caldwell, who has used intensive interaction techniques successfully for many years. It shows her working over 3 days with Gabriel, whose learning disabilities are linked to severe autistic spectrum disorder.

GABRIEL

Day 1

Phoebe Caldwell: I knew nothing about Gabriel until I met him during the first session, I hadn't even seen him before.

Support Worker: He is one of our longer-term students: he's been here 7 or 8 years. He's one of the students who we find the hardest to communicate with. That's one of the reasons we've asked Phoebe in.

PC: Our senses may work perfectly well but on the way to the brain the message gets scrambled and this is very often the case with people who have autism. It's not the brain itself so much as what happens on the way to the brain. The messages and information that come in are interpreted wrongly so their perception of reality is different to our perception of reality. This is really important because one of the problems that we have is that we tend to assume that others people's perception of reality is the same as **ours**.

Gabriel was very locked into his own world, completely ignoring people, locked into his repetitive behaviours in a way that didn't offer much access.

SW: He is diagnosed as having severe autism with severe learning disability and severe epilepsy.

PC: He spends a lot of time walking around doing his own thing.

SW: He's on his own agenda. If his pattern is disrupted he may show some behaviours. He is unable to join the modular programmes that we have here so we have designed an individual programme for him.

PC: I thought “This is going to be very hard,” but then that happens quite often! I feel my way into it and I try different things. I look for the feedback that the person is giving themselves. In this case he was fixated on various objects and I had to look at exactly what stimulus he was giving himself. In fact when I looked carefully, it turned out that an awful lot of his flicking was not *just* flicking but was tapping on to his left hand with a fairly specific

rhythm. So I started tapping him with **his** rhythm so that he got a related feedback, which his brain recognised and he started to be interested in what **I** was doing as well as what **he** was doing. “The fascination is here actually, that’s where he’s stimulating himself, whether it’s a string or whatever, it’s always rubbing there”.

If our points of view are limited or distorted the world around us becomes very confusing and scary. A lot of the people that we work with are in this situation - the ones that we can’t communicate with. They tend to focus on their inner world rather than the world outside, because that’s too confusing or scary. That very often ends up in repetitive behaviours where people are listening to themselves; they are self-stimulating. What happens when people are in a repetitive mood is that they tend to focus on the inner world. What we’re going to try to do is to shift their attention from the inner world, to an exchange with the world outside. And shift their attention from solitary self- stimulation to shared activity.

“He wants a break now doesn’t he?”

SW: “That’s a plus really, because him letting you have that..... He normally wouldn’t let anything go. He will try and self-abuse.”

PC: What we need to ask ourselves is “What does a person with autism experience? What is their reality? Can we actually modify the difficulties they are experiencing? How can we actually help them?” We have to look at what is meaningful for that particular person and work from that. You are looking for the thing that has meaning for them and you are using that to get access to their inner world, draw their attention to interaction rather than solitary self-stimulation. I started to work with his string flicking. What I’m looking for is things that actually have **meaning** for him, so that I am responding to the things that he does, so that he knows that when he does something he will get a response that is meaningful to him and which is in **his** language and on **his** terms.

SW: Phoebe sat down next to him for a full 20 mins. And echoed back to him what he was doing and eventually he showed some sort of interest.

PC: The interesting thing that I noticed when I was working with him was that a lot of his flicking is actually aimed at his hand and that he’s actually getting some physical stimulation. In fact where he’s giving himself that meaningful feedback it is very often through touching his hand. You look at what they’re doing and you do it with them and that says “I value what you’re doing”. We can join these activities and they are surprised to see their activities happening somewhere else. This gradually leads their attention from their inner world to the world outside.

As soon as you start to use the language with the person that they are using themselves, they will start to respond. I worked with an electric massager and he liked that very much indeed. He was very interested in it in fact a bit too interested! Only having one it was a problem to use it for interaction with him. He was very interested in trying to get it to stand it up. Balancing is one of the things that you can tap into, but it was quite difficult here, because as you can see, as soon as I intervened with it to balance it, it became an issue

about controlling what was going on. What he didn't do was give us a feeling that he had completely finished with it.... he got it standing up in the end. So we got some blu-tac and stood it up for him - and he walked out on us!

Day 2

PC: "It's going to be a question of a certain amount of luck. At least I know now I can do it with him. It's a question of getting it *right* and also of course his epileptic status. What we've got is him being interested in something but what I want is for him to be interested in the person he's working with."

We had about half an hour of him running around the room, flicking, and I was beginning to wonder whether we were going to be able to get through to him. We need know what people are getting out of these repetitive behaviours. Suppose you live in a world which is totally unpredictable. Let's take this room, you are the bits in a kaleidoscope and this is the kaleidoscope which is going round and round and you are the bits swirling around.... their reality is *different* from our reality; their sensory experience of the world is different from the world that we experience. They live in a chaotic sensory environment. When they do their particular thing they are fixated on, turning the light switch on and off, ripping up paper, or whatever, they actually know what they are doing because it's as if their own language is hard wired in, it doesn't break up and cause them difficulties and sensory chaos. Therefore it's not threatening. If I'm stroking my arm I'm giving myself a sensation and I'm wallowing in that sensation; it excludes the world outside. When I'm doing that, I know what I'm doing, because the world is *so* confusing and *so* disturbing and in some cases painful. There's a guy called Sean Barron, who wrote a book called "There's a boy in here". He said "When I switched the light switches on and off it gave me a wonderful sense of security because I knew what was going to happen - it was exactly the same each time".

You begin to notice that their attention *intensifies*. They'll begin to do something and wait for your response. That's the point at which you know that *they* know that if they do something, they will get a response which is meaningful for them. What happens when I echo back someone's breathing rhythm, what the brain says is "Yes, I recognise that! That is a stimulus that I actually recognise but I didn't do it!" No matter how profoundly a person is disabled, they always recognise their own signals, the ones that are familiar to them and they can distinguish between that sign made by *me* and that sign made by somebody else out there. They can always make that distinction. It's like a secret doorway or to put it in more contemporary language, it's like a personal code which you have to get hold of and then you have to key it in to get access to that person.

It's extremely rare indeed that there's no way of getting through to a person. I've worked with over 1000 people in the last 6 years and I would say about 12 of those we didn't see any effective change.

When I feel self-conscious, it's because I'm focussing on myself and not the person I'm working with. It's actually an extremely good reminder to forget yourself and all the other people. I made a deliberate shift when I feel that self-consciousness, which I do sometimes, but I know that it's a sign of actually not focussing in the way that I should be on the other

person. I do recommend that when you first try it's probably better to try on your own with the person, so that you're not surrounded by sceptical people. Once you start to get a response from them, you'll lose that self-consciousness.

When we are doing this with a person we are emptying ourselves. We are giving our absolute total attention. When I say 'emptying' myself, I still have to be there for them. I have to respond to them. It's not a question of me being a mirror exactly. It's a case of me being a living, responding person whose attention is totally focussed in that person when I'm working with them.

There were times when Gabriel turned his back and he was quite happy for me to join him. He got tired at times and wanted a bit of respite.

Other people will say what about mimicking, isn't it disrespectful? There is a very, very long distance between mimicking a person, which is unpleasant, to valuing a person *so* much that you take the trouble to learn their language, so you can talk to them. If they seem to get upset or overexcited, then you have got to go back to copying them exactly. Some people who have profound multiple learning disabilities actually will interact very well for a little while and then you see a glazed look coming over their face - and you think, "Oh goodness I've lost it, what did I do wrong?" And, in fact, all they need is to rest because actually it is a way of working that their brain is not used to and they need time to take it on board; time to think about it, time to assimilate what they've actually done. And so if you wait, they'll almost certainly come back. Sometimes they'll give a deep sigh as if to say "I've got that! Lets go on". You do need to wait. They actually get tired, so don't expect people to go on too long. One of the problems is we tend to think of doing things in sessions, so we may actually try to do things for much too long with people, when in fact their capacity is to take quite a small and short intervention.

What's going on in the brain is a sort of heroic struggle to try and make sense of the environment. Gabriel was mostly focussing on a bead so I put a bead on my string. Immediately I did, that he really started to focus in on it, and he didn't try and grab it for quite a long time and I just flicked *my* bead and we did this together.

An interaction is more than just the way you talk to each other; it's a flow which is almost a sort of bonding. People will say, "I've know this person for years but I've never really known them and now I've suddenly become a friend and we are on terms of complete equality" We talk an awful lot about equality and valuing people, but real equality is when you're using the same language with each other, the same *emotional* language and you value each other.

Eventually, he really started looking extremely closely at my face, in an interactive way and smiling. I blew into one of his ears, as it was close to me and he turned around for me to do the other one. What I get from them is total attention and we begin to attend to each other with this extraordinary bonding feeling. You never feel quite the same about the person again once you've actually got this response.