

The following is an excerpt from the book Nobody, Nowhere by Donna Williams.

I found it so amazing to have a person with autism explain the meaning behind certain actions... since Luke cannot yet tell us himself. Not all of these apply to Luke, so I have added my thoughts in green to the end of the ones that resonated with our situation.

### **1. The matching or pairing of objects.**

Making connections between things.

Showing that relationships between two or more things can exist. Seeing this objectified, through objects, in the most concrete and undeniable way. Seeing this and doing this again and again gave her hope that if the concept was possible, then it would one day be possible to feel and accept these relationships in "the world."

She was always within this world of objects.

[Luke does this a lot. Every day he usually has one object in each hand, and they must "match"... ie two blocks (same size, usually the same colour, but not always). The other day he had two Tim Hortons lids in each hand (Luke LOVES lids). We call him "Luke LidHands" or "Luke BlockHands" as opposed to Edward Scissorhands :). He gets very upset when we try to take these away, but will put them aside when he chooses to, and will put both down to fold his hands to pray or to try to sign with his hands.]

### **2. The ordering of objects and symbols.**

Proving that belonging exists and giving myself hope that she,, too, could one day feel this same special and undeniable place where she fit in and belonged in "the world". Also, creating order and thereby making this symbolic representation of "the world" more comprehensible.

[Luke used to line up teatowels (draped between the railing, or line up lids on the baseboard)... he no longer seems to need to line anything up.]

### **3. Patterns**

Continuity. The reassurance that things will stay the same long enough to grasp an undeniable guaranteed place within the complex situation around me. As surrounding circles or borderlines, these are set up as a means of protection from invasion by that which exists outside, in "the world".

[Luke does seem to like structure and routine, however I don't feel this is any different from most homes. Luke is not rigid... he does not care if you change up the schedule.]

### **4. Blinking compulsively**

To slow things down and make them seem more detached, and therefore less frightening, frame-by-frame film. Switching lights on and off very fast had an element of this, too.

[Luke never did this, however we had to contend with his absence seizures... which is retrospect must have slowed his world down.]

### **5. Switching lights on and off**

Similar to above, but the clicking sound is an impersonal and graspable connection with things outside oneself, like bells and musics. It gives the pleasure of sensation denied by almost all touch, and provides security. The more patterned and predictable, the more reassuring.

[Luke enjoyed doing this for awhile, especially at dinnertime (lightswitch was above/behind him on the wall), however now he will only turn the lights on and off (once) when asked.]

## 6. Dropping things repetitively

Freedom. Proving that escape to freedom is possible. Symbolically this is the freedom to allow good emotions to touch you without pain, and the freedom to allow them out and not be so afraid of them within.

[Luke did this all the time! We thought it was typical behaviour at first, but he continued to do it for a very, very long time. He still does once in a while, but has learned that "throwing" is not acceptable. Luke would also throw things out of the crib when he was ready to "come out" and today still throws things "over the gate" to say he wants over (we have baby-gates by the stairs to keep Joel safe.)]

## 7. Jumping

Jumping from heights means the same as the dropping of objects, though it is less secretive. This action also gave hope, confirming that the concept of hope exists so that the feeling of it, which is missing, is, in theory, possible. It is also a way of getting one's whole body into a rhythm, as with rocking.

[Luke has never jumped as he is very cautious and unsure of his body... we're working on it.]

## 8. Rocking from one foot to another

She always saw a foreboding darkness between herself and "the world". The fact that getting through this imaginary darkness to the other side would take quite a leap is possibly captured by the preparatory rocking from front to back foot so indicative of someone about to take a running leap: "Ready, on your mark, get set, jump through the darkness to the other side," probably describes it well. Strangely, she was always too afraid to jump when other people tried to get me to. She once ran straight through a series of hurdles, letting her legs crash against them, as she was too afraid to jump them at the last minute.

[Luke was never a "rocker".]

## 9. Rocking, hand-shaking, flicking objects, chin-tapping

Provide security and release, and thereby decrease built-up inner anxiety and tension, thereby decreasing fear. The more extreme the movement, the greater the feeling she was trying to combat.

[Luke's "stim" (self-stimulation) as these are referred to, was a little hand-flapping when he was really upset; and he still rubs his cheek to calm/soothe himself. His stims were never extreme. Interestingly enough, a few months ago Luke was agitated and his hand was flapping a little and I noticed he was looking at it in a funny way, like it was an involuntary movement and he did not want to do it... he seemed perplexed at why his hand was doing this? He hasn't done it since.]

## 10. Head-banging

To fight tension and to provide a thudding rhythm in her head when her mind was screaming too loud for her to be able to hum or to repeat a hypnotic tune in order to calm down.

[This one freaked us out. Whenever he was upset... especially when he tripped or lost his balance, he would lie down and bang his head on the floor. We thought this was typical 2-year-old tantrum-type behaviour, and I read you can a) choose to ignore it or b) choose to hold him. I tried ignoring it a few times, but ended up holding him while he took his time to calm down. He has not done this for at least 6 months. When he's upset now, though, he will sit on his butt (kind of seat-drop gently once or twice) and he gets over things MUCH quicker.]

## 11. Staring past things, seemingly at something else

An attempt to take in what was happening around her while escaping her fear by experiencing a visual image indirectly. Looking at things directly often robbed them of all their impact and meaning. She managed to learn so much in her final year of primary school this way, although the teacher had no idea that this was her only way of taking things in in any depth. Similarly, she would lose the ability to play music by looking at her fingers and thinking about what they were

doing. If she looked away and switched to “automatic pilot”, the music flowed and she could create. All things must be indirect. She constantly had to trick her mind so it would relax enough to take things in.

[For a while when Luke was much younger he would not look at people or us. Especially when he was about 1–1.5 years old. Fortunately, we had infant development support that helped us train Luke to look at us if he wanted anything. His eye contact today is phenomenal for a child with autism. We can be very direct with Luke now, however I do find that I can ask him to do something without looking at him and he’ll do it, so I’m not sure if he feels safer with indirect requests than with direct requests.]

## **12. Laughing**

Often a release of fear, tension, and anxiety. Her true feelings were too well protected to really show any experience of pleasure in anything so direct and able to be experienced and understood by others.

[This one really upsets me. Often, in the middle of the night, we would hear Luke laughing and “playing” by himself... it breaks my heart now to know that he was afraid. I had always thought 2-year-olds at some point begin to feel “afraid of the dark” and was waiting for Luke to call for me... and it upsets me to know he was, but I didn’t understand his “language”.]

## **13. Clapping**

Clapping has always been a better indication of pleasure with her than laughter. However, clapping also indicated finality—the signaling of the end of one event or activity and the beginning of another. It could also be an attempt to try to snap herself out of an inescapable dreamlike state.

[Luke used to clap to “If you’re happy and you know it, Clap your hands”... so I’d like to think he was displaying pleasure. We have a “sign” for “Finished” which Luke obeys quite seriously with rarely any objection.]

## **14. Staring into space or through things, also the spinning of things or oneself and running in circles**

A means of losing awareness of self in order to relax or cope with boredom caused by an inability to express one’s self or feel for the things one did.

[When Luke was still in the highchair nothing would entertain him more than a spinning lid! He still likes to see a lid spin when it does (when he drops a lid by accident), but does not initiate this action. For awhile (around 3 years old) Luke would want us to “chase” him around the kitchen, around and around and around again. Luke LOVED this game; especially when we “scared” him. He did not at any point spin himself in circles as child with autism often do.]

## **15. Tearing paper**

Symbolically disintegrating the threat of closeness. A symbolic act of separation from others in order to reduce fear. She often did this when she had to say goodbye to anyone, as though she had first symbolically to destroy the closeness in order not to feel any sense of desertion or loss.

[Have not seen this.]

## **16. Breaking glass**

Symbolically shattering the invisible wall between self and others. Is this the wall between conscious and sub-conscious?

[Luke is not destructive or harmful in any way.]

## **17. Fascination for coloured and shiny objects**

Grasping the concept of beauty in simplicity. Also a tool for self-hypnosis, needed to help calm down and relax. Often closeness to particular people lives within these objects whether or not they were actually given by the other person. A particular colour of blue always stood for her Aunty Linda, a bright golden yellow button stood for another friend, a piece of cut glass stood for Carol she met in the park, tartan stood for her

grandmother, and so on. She had merely assigned them these connections because they captured “the feel” of these people.

[For about 6 months, whenever we would go to Grandma B's... Luke would play in her button drawer... and often found a very specific one that he liked best. He enjoyed all the shiny, colourful buttons and would play with them for hours. Perhaps they are a reminder of Grandma? He has also liked the tabs from pop/beer cans – nice and shiny?]

### **18. Hurting oneself and also knowingly doing embarrassing things to cause a shock reaction in others**

Testing as to whether one is actually real. As no one person is experienced directly, because all feeling gets held at some sort of mental checkpoint before being given to self by self, it is easy to wonder whether one in fact exists.

[Luke has not done anything self-injurious.]

### **19. Deliberate soiling**

For her, this began in a semiconscious state. It was, she believes, a subconscious drive towards conscious self-awareness and “freedom to be”. It was an act of self-assuredly breaking free of excessive self-control through defying that behaviour regarding which conformity and self-control are so demanded and disgust from others is so easily inspired. It was, at the same time, an expression of frustration at having to conform without actually getting any emotional reward from this conformity. It is an act of self-determination, proving that one can let go of self-control in exchange for control over external expectation. This self-assurance of “freedom to be” that one gets from this act gives one the courage to keep trying to reach out. She went through this once, when she again found the courage to try to come out of her withdrawal, and as annoying as it must

be to parents, she must say that it was an important phase she had to get through in order to progress. It is also a way of making one’s surroundings symbolically part of “one’s world,” which is the beginning of accepting a world outside the confines of one’s own body. From a body to a room. From a room to a house. From a house to a street. From a street to “the world”.

[This one rings a little bell only in the phrase... “having to conform without actually getting any emotional reward from this conformity”... perhaps in Luke’s world there seems to be no real reward (even if we gave him a candy or other reward) for peeing in the toilet, so he’s not real motivated to “conform” in this way. Luke has never “intentionally” soiled himself for shock value... he usually waits to pee or poo until he’s in his bed.]

### **20. Safe physical contact**

That which does not threaten to hold or consume. Hair brushing and tickling are examples of this. In particular, tickling forearms is unthreatening, as this is a less personal and more detached part of oneself. It is also less socially valued than, for example, touching one’s face. For this reason, it carries less social significance for the person doing the touching. Hair, in this sense, also seems detached from one’s body. Again, this is as close as one can come to the fine line between direct and indirect touching without robbing the recipient of all physical sensation from touch. Otherwise, all touch is either experienced as pain or tolerated as though one is made of wood. Quite simply, it is as though the spirit leaves the body there to be tormented by what others may think is a kind act of touching.

[Luke LOVES to be tickled, and also enjoys having his hair brushed or “massaged” (he becomes quiet and relaxed.) Fortunately, Luke loves to sit on my or daddy’s lap and does not mind when others touch him. He does not seem to detach from the touch, as far as we can tell.]