

# WE ALL FOLLOW BIANCA

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Bianca is a sweet young woman who looks much younger than her years. She needs the constant attention of her carers to get through the day. She enjoys listening to music and she loves being softly tickled on her back. Bianca is given one-on-one-care in her own individual apartment by her own group of personal carers, Team Bianca. Every now and then, she joins the rest of the residents, but she spends most of her time in her apartment.

Bianca began displaying self-injurious behaviour when she was nine years old. It is likely the result of a sinus infection, possibly in combination with the constipation and acid reflux issues which arose at the same time. Since then, self-injurious behaviour has had a huge and lasting impact on her life. Her most common behaviour is rubbing and pressing her right ear on her shoulder. This caused a large wound on her outer ear, which ultimately needed to be amputated. She also pokes her fingers into her cheeks, bites her wrists and her upper arms, bangs her head against objects, pokes her legs, and throws herself against walls or onto the floor. This self-injurious behaviour has resulted in serious bodily harm and could even be life-threatening for Bianca. She is also violently aggressive with her carers, biting and hitting and kicking them. And she is also violent with the things around her: she throws objects, pulls the doors off of cupboards, and kicks doors. Over the past few years, multiple CCE consultations were conducted to attempt to reduce this behaviour. With some measure of success: the use of nightly restraints is no longer necessary, and a number of wonderful activities were started involving music, for example, which Bianca really enjoys. But the frequency and severity of her self-injurious behaviour and her aggression remained unchanged. It was decided that joining the CCE Project “Self-Injurious Behaviour Restrained” might afford relief. The project is based on an interdisciplinary approach, and assembles a team that includes a psychiatrist, a medical doctor specialised in treating patients

with intellectual disabilities, a psychologist, a behavioural specialist, and the facility's own medical doctor. The team uses fresh eyes to review all possible causes of Bianca's self-injurious behaviour. This led to a huge change in Bianca's care.

## IDIOPHIC THEORY

Bianca has Cornelia de Lange Syndrome, also known as CdLS. Importantly, thanks to the examinations performed during the "Self-Injurious Behaviour Contained" project, she was also diagnosed with Autism Spectrum Disorder. It was quite the journey arriving at this diagnosis, because people with CdLS tend to have different ASD symptoms, particularly with respect to social interaction. For Bianca, this diagnosis reflects the fact that she is not really able to see connections or relations, to interpret social meaning, to take part in social interactions, to plan or organise, or to put herself in others' shoes. She loves to have social contact and interaction, but she has trouble initiating or maintaining that contact. Bianca has a severe intellectual disability, and, in line with ASD, a disharmonic development profile. Further examination revealed that Bianca is at the developmental level of a 17 to 19 month old, and that socio-emotionally and communicatively, she functions at a much lower level than had always been supposed. Her socio-emotional developmental level could be compared to that of a five to seven month old. Communicatively, she is at the level of a nine to 11 month old. In addition, as a result of ASD, her sensory processing of auditory, visual, and tactile stimulation is disrupted. Bianca needs a lot of time to process information and can only deal with a single sensory stimulus at a time. When she wants to pick something up, for example, she glances at the object, but then turns her head away and reaches for it without looking. All of this means that Bianca has great difficulty following and understanding any information in her environment. Moreover, she also has very few ways to express herself or respond adequately. Bianca's communicative skills are quite limited, and her care has not been

sufficiently adjusted to meet her needs. For a very long time, she was being addressed at a higher level than she is capable of understanding. The result is that she is easily stressed, which leads to anxiety, frustration, confusion, and fear. She expresses these emotions with self-injurious behaviour and aggression.

In addition, Bianca has physical complaints which are commonly associated with Cornelia de Lange Syndrome such as problems with vision, constipation, acid reflux, disrupted sleeping patterns, menstrual issues, urinary tract issues, and side-effects from medication. These complaints contribute to her stress. She also has wounds due to of her self-injurious behaviour. They are painful and itchy and again, contribute to her stress.

Because of all of these issues, Bianca has been stressed for a long period of time. In order to protect her and prevent serious situations in the future, her carers and the other professionals have been searching high and low to find treatments and measures that might help her. However, every time a form of physical restraint such as arm casts or binding up her ear is used, it results in Bianca exhibiting new kinds of self-injurious behaviour such as biting her lips or throwing herself on the ground. To address the issues of Bianca's aggression towards her carers and surroundings, she is taken to her bedroom and the door is closed, but this only amplifies the risk of increased self-injurious behaviour. There don't seem to be any measures that could ameliorate the consequences of her behaviour.

There are many people involved with Bianca: her parents, her carers, the care manager, the behavioural specialist, the medical doctor, and professionals from other disciplines. Despite all their efforts and their dedication, there has been no improvement and the situation is worsening. Everybody seems hesitant to take any action, and this is causing a huge turnover rate in Team Bianca. It is getting more and more difficult to find carers who are willing and able to work with Bianca. The situation is also leading to ad hoc actions. This makes it difficult to evaluate what is and is

not working and a methodical approach is impossible. Everyone around Bianca feels great concern but feels isolated and alone in their concerns. In the hectic reality of the facility's daily routine, it has not been possible to remain in touch with one another and review any possible future action together. Everyone is feeling more and more powerless, and suiting Bianca's care to her needs is growing more and more difficult.

## INTERVENTIONS

### **INTERVENTION 1: ADJUSTING TO HER DEVELOPMENTAL LEVEL**

The first intervention is based on the determination that Bianca has Autism Spectrum Disorder and the discovery that she functions on a much lower emotional and communicative level than had been supposed. The intervention aims at doing things together. A carer will take Bianca's hand during transitions and will accompany her from the completed activity to the next one.

We also ensure that Bianca can always follow what is happening visually. The carers reduce the number of indicators in the communication system to those addressing only the here and now.

### **INTERVENTION 2: REST AND RECOVERY**

The second intervention aims at providing sufficient periods of time for rest and recovery in the presence of a carer. Bianca's daily care routine is adjusted to suit what she is capable of and can deal with at any given moment. What Bianca indicates and what she is capable of is the main focus, and not what has been written down in the daily programme. This means that carers can slow down the pace of everything if necessary and can introduce moments of "doing nothing". During these times, nothing is required of Bianca, but she is able to observe what is going on around her. The carer will then sit down and relax or do something without involving Bianca such as tidying the apartment. This gives Bianca her space to

process all earlier stimuli, to recover, and when she's ready, to direct her attention back to her surroundings.

### **INTERVENTION 3: INTERDISCIPLINARY COOPERATION**

The third intervention is aimed at addressing the inability to take a methodical approach, and the lack of connection between all of the people involved in her care. During the “Self-Injurious Behaviour Restrained Project”, it became clear that interdisciplinary cooperation has a great value-added. For Bianca, an interdisciplinary team was formed comprising her parents, her personal carers, the behavioural specialist, the doctor, the manager, and the night-shift carer. There are fixed times following a fixed schedule during which members will meet and confer with one another. During these meetings, information about how Bianca is doing will be exchanged, as will the signals she is currently using, what her present circumstances are, and what is now necessary. Bianca is regarded as a whole human being, with all of her different facets. This means that everyone consistently takes a broad view when looking at optimising Bianca's quality of life. The subject might be improving her physical wellbeing, or disability modifications in her environment, or the introduction of new activities, or fine-tuning communication support. Everyone's input is equally important, as everyone is equal, and the foundation is mutual trust and respect. There is a shared sense of responsibility for the entirety of Bianca's care and support.

### **INTERVENTION 4 SUPPORTING THE TEAM AND TEAM MEMBERS**

The fourth intervention aims at supporting the team and the team members. Working alone with Bianca, often in difficult circumstances, requires a lot from carers. Bianca's team is integrated into the team attached to her residence. This gives carers the opportunity to rely on others for support and feedback. A further advantage is that this way of working gives Bianca a chance to interact with the other residents. In

addition to her own regular carer, an additional trusted carer is also usually present.

## RESULTS FOR BIANCA

Bianca feels safer and more secure during the times when she is struggling. Her self-injurious behaviour and aggression have diminished. It is no longer a life-threatening situation.

Bianca is relaxed, follows her carers' lead, and seems to enjoy her life more. She smiles a lot more often. The doing things together approach and the rest and recovery periods are working for her.

She initiates more. She now occasionally visits her parents and goes on little excursions away from the residential facility.

Her physical complaints have lessened.

## LESSONS LEARNED

We learned that taking an interdisciplinary approach when looking at Bianca's situation and finding a shared vision have been deciding factors. The cooperation during the Self-Injurious Behaviour Restrained Project between the psychiatrist, the doctor, and the behavioural specialist has led to new insights. Based on these insights, Bianca's daily care and support could be tailored to better suit her needs.

But this has to be done very carefully and it takes time. To actually take that time during a situation which calls for an immediate response requires patience and determination from all of those involved.

There is no guarantee that things will always go well for Bianca. But we learned that things can be improved once again after they go wrong, as long as her team keeps their focus on her, they continue with interdisciplinary cooperation, and the organisational requirements are met.

Once, after a period when things had been going very well for Bianca, her self-injurious behaviour began to escalate again. She was far less relaxed, and she began to create wounds: poking in her cheeks, biting her wrist, throwing herself on the ground. We decided to go back to the drawing board and reassess her situation to find other possible causes of her self-injurious behaviour.

The first cause we found, was that we - yet again - had been overburdening Bianca. Because she was doing so well, we expanded her world by adding multiple excursions off the premises as well as new activities. We think we did this far too quickly. We narrowed Bianca's world again, we reduced the number of large activities and this calmed things down.

Another important cause of Bianca's relapse was that it had not been possible to fully anchor the organisational requirements. Team Bianca was chronically understaffed, there were problems finding and hiring suitable carers, and changes made to the interdisciplinary team all had a direct impact on Bianca. Measures were taken to find reinforcements for the care staff as well as the interdisciplinary team. It also became evident that the organisation needed to be far more committed to anchoring the organisational prerequisites for this new approach. A proposal is now being drawn up which will be discussed with upper management so that the care and the support that Bianca, her carers, and the interdisciplinary team need can be guaranteed.

## CONCLUSION

This was the case We All Follow Bianca.

We did in fact manage to influence Bianca's self-injurious behaviour. We were able to do this by not focussing on her alone, but by inspiring everyone involved to assume a shared sense of responsibility for her care,



and by anchoring this approach in both the interdisciplinary team and the organisational support for her carers. We of course are not labouring under any illusion that we have solved the complex problems that Bianca faces. But we do have faith that that together, we can ensure her quality of life is as high as possible. Thank you for listening.

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