centrum voor
consultatie en
expertise

GAINING DEBORAH'S TRUST

KYRA ALTHANNING,

BEHAVIOURAL SPECIALIST TWENTSE ZORGCENTRA

CENTRE FOR CONSULTATION AND EXPERTISE, 2020

GAINING DEBORAH'S TRUST

INTRODUCTION

This case was originally presented in Dutch by Kyra Althanning.

My name is Kyra Althanning, and I work as a behavioural specialist at De Twentse Zorgcentra. In this episode of *Cased-Based Learning* I will be telling you about Deborah, and how viewing her challenging behaviour in a different light brought a new perspective into her life.

THE PROBLEM

Deborah is a 22-year-old woman with a mild intellectual disability who lives in De Twentse Zorgcentra, a home for people with intellectual disabilities. Sexually abused and neglected as a child, she was removed from her home when she was six. Deborah can express herself very well verbally, and she seems very capable. She is a true girly-girl who likes make-up and playing board games. But Deborah also exhibits very challenging behaviour: hitting, kicking, pinching, and biting. She's very destructive, runs away, and threatens her carers. Because of her challenging behaviour, a lot of restrictive measures are used; she is often put in isolation and in restraints. She is unpredictable, and due to carers' inability to make any progress with her, she's been transferred from institution to institution 13 times.

Deborah was involuntarily committed to her current institution as an emergency measure when she was 18. While she was in transit, she had to be accompanied by six carers. Her residence in De Twentse Zorgcentra was supposed to be temporary, but the institution she came from is unable to provide the level of care Deborah needs. Therefore, her emergency admission to the facility has become a permanent one.

And here, again, she displays unpredictability with her aggression, running away and destructive behaviour. Deborah is regarded as dangerous and unmanageable. The inability to treat her in this facility has again resulted a lot of restrictive measures such as isolation and restraints. In addition, her apartment has been customised so that she cannot destroy anything or harm herself. The windows have been reinforced with plexiglass, for example, and items such as the television and the clock have been locked into unbreakable cabinets. Deborah also has plastic dishes and tableware. There seems to be no other way forward.

IDIOGRAPHIC THEORY

Deborah has a mild intellectual disability. She also has delayed socio-emotional development; she is estimated to be functioning at the level of an 18 to 36-month-old. This level is quite considerably lower than one would think of Deborah, due to her verbal and physical abilities. Because she can express herself well verbally, people often think she understands a great deal. However, this is not the case. The result is that her capabilities are overestimated by those around her.

Because of her intellectual disability, Deborah has limited skills. She is unable to adequately wash herself, for example. She also lacks coping strategies; she is unable to deal with difficult situations. People around her erroneously assume that Deborah understands many tasks and situations, with stress as the result.

In addition to her intellectual disability and her delayed socio-emotional development, Deborah also exhibits characteristics of Post-Traumatic Stress Disorder and attachment issues. These characteristics are a result of the sexual abuse, and of the neglect by her parents. At six years of age, both Deborah and her older sister were removed from their parents' care and placed in homes. These adverse life events mean that Deborah still experiences a great deal of stress in her daily life.

Deborah expresses stress in several different challenging behaviours. We see physical and verbal aggression such as cursing, threatening, hitting, kicking, and biting. We also see running away, resulting in dangerous situations. Once, Deborah lay down on a secondary highway – that has a posted speed limit of 80 kph. She also displays destructive behaviour such as breaking car windows, smashing cabinets, tearing sofas apart, wrenching toilets off walls, and pulling all the electrical wiring out of a ceiling. This is the kind of challenging behaviour that led to Deborah being transferred so many times, and thus having to say goodbye to so many people.

Deborah's history and her many transfers both contribute to her attachment issues. She feels rejected and is afraid of being abandoned. After an escalation, Deborah constantly asks herself 'am I actually an okay person?' (feelings of rejection) and 'do I have to go somewhere else again?' (fears of abandonment). Her feelings of being rejected lead to Deborah developing low self-esteem and needing a great deal of validation. It stresses her when she doesn't get the 'right' answer, which means she exhibits even more challenging behaviour. This creates a vicious cycle, because the result is that carers distance themselves from her, which only increases her feelings of being rejected.

She expresses her fear of abandonment by constantly testing the people around her: 'how reliable is the other person for me?'. These tests consist of challenging behaviour. The result is that carers become fearful. This ultimately leads to many team members refusing to work with Deborah, which only increases her fear of abandonment. And so, another vicious cycle which exacerbates challenging behaviour is created.

The carer's fears mean they do everything to forestall Deborah's challenging behaviour. Deborah is in isolation for most of the day, and she is put into restraints on a daily basis. The team's focus is on controlling her, which in the short term provides some measure of relief for both Deborah and the team. It is a familiar pattern for Deborah: 'when I feel stress, I start

hitting, kicking, biting, pinching, etc. and then carers solve this for me by restraining me or isolating me'. However, this solution is only a temporary one, because the next stress episode is immanent. Deborah and her carers are trapped in a third vicious cycle.

As more carers refuse to work with Deborah, this creates anxiety for the team's manager: shifts can no longer be covered. The manager's anxiety unwittingly affects the team and reinforces their controlling behaviour and use of restraints and isolation.

In this gridlocked situation, using restraints is a short-term solution but does not provide any perspectives for the future, neither for Deborah nor for those around her.

INTERVENTIONS

INTERVENTION 1: REDUCING STRESS AND DECREASING THE USE OF ISOLATION AND RESTRAINTS

A major cause of stress for Deborah are her attachment issues. To help reduce her stress, Deborah is told that she no longer has to face difficult situations on her own: we will be facing them **together**. The word 'together' refers to a select group of carers who will act as her attachment figures. The less able Deborah is to perform a task, the more a carer will assume of that task: but together, 100% of that task will be completed. Even when Deborah exhibits challenging behaviour, the carer will stay by her side, because by herself she is unable to find her way. The carer **stays close** and is receptive and responsive, so that Deborah's stress does not escalate. The carers recognise Deborah's emotional signals and verbalise what is happening ('I see that you are angry and sad that the MP3 player no longer works') and then they help Deborah find a solution ('come on, let's see if we can figure out how to fix the MP3 player together').

Because companionship is so important, especially when things are difficult, the separate isolation unit for Deborah is shut down. Due to safety concerns, the door to her apartment will sometimes be kept closed and locked, but only if a carer is present. This is the beginning of working towards an unconditional supportive relationship, saying to Deborah: 'no matter what you do, I'll always be there for you'.

When Deborah and her carer are not in her apartment, and her challenging behaviour leads to a situation which is unsafe for her or her carers, then she will be restrained by a maximum of three carers. Even then, the message is: **'you can stay here' and 'you're okay'**. Carers will also keep repeating this to her out loud.

INTERVENTION 2: SUITED TO HER CAPABILITIES

Carers will suggest activities and tasks which suit her cognitive ability and her socio-emotional development.

They will keep in mind all of her needs: physical, mental, emotional, and what is meaningful to her. To Deborah, it is for example particularly important that she feels useful and helpful to others. This is why she takes a fellow resident who is wheelchair-bound out for walks, for example.

A daily programme gives Deborah a clear overview of her daily routine. It is difficult for Deborah to process verbal information, so the daily programme is illustrated with pictograms.

Carers **refer her to the pictograms** when she is confused about her day.

Her activities and tasks are performed in tandem with her carer: again, to a combined 100%.

INTERVENTION 3: PEER-TO-PEER COACHING FOR THE TEAM

The team members' own fears and anxiety mean that they primarily respond to Deborah's challenging behaviour, and don't address its causes. To change this, the team is given peer-to-peer coaching. During coaching sessions, Deborah's carers and a multidisciplinary team try to get at the root causes of her challenging behaviour. This gives them insight into her needs. Participants learn to see that, socio-emotionally, Deborah is a little girl who needs our help.

One of the concepts used during the sessions is the image of an iceberg. The challenging behaviour is to be regarded as the visible top of the iceberg, while Deborah's true needs are underwater and thus invisible. The team watches footage of Deborah's behaviour to help them to analyse it. The question is: what is the behaviour we see, and what lies underneath? Deborah can act as if she were angry, which can be quite intimidating given her challenging behaviour, but she is actually frightened that, for example, some activity might be cancelled. In this way, Deborah's needs become clearer and clearer.

The footage is also used to reflect on the behaviour of the carers. The team looks for any of Deborah's needs that are not being met and together they think of other ways they can respond in order to better meet those needs. Coordination is essential here. It increases reliability and strengthens the bond between Deborah and her carers. Agreements have been reached on how to handle showering or how to react when Deborah strokes carers' legs. The message all of the carers give Deborah is identical, but carers are authentically individual in the ways in which they deliver the message. One will do it using humour, another will be stricter. It is important that the message remain unchanged: 'this is how we are going to do things, and everybody will be doing it this way'.

INTERVENTION 4: PSYCHOMOTOR THERAPY

Now that Deborah see her carers as more reliable, it is time to boost her self-esteem. Deborah will be attending Psychomotor Therapy (PMT) sessions with her carers.

According to Michel Probst and his colleagues, in Belgium and the Netherlands, psychomotor therapy as a kind of physical activity and body-oriented therapy has been well integrated into mental health care since 1965. In contrast to its acceptance in most European countries, the term "psychomotor therapy" has not found its way into the Anglo-Saxon literature. Psychomotor therapy is defined as a method of treatment that uses body awareness and physical activities as cornerstones of its approach.

Through physical activities and exercises, Deborah becomes more able to recognise her emotions. Then she learns how to manage them. For example, one focus is her intense bouts of anger. Together with her carer and the PMT therapist, she finds a way to describe her tension arc: it's a volcano. Deborah and her carer work together to figure out what she must do and what her carers must do whenever the volcano is about to erupt. They come up with alternatives for her aggression and destructive behaviour. Deborah learns to stamp her feet or jump up and down, and she's allowed to shout and to rip up hand towels.

RESULTS

The first vicious cycle Deborah and those around her were trapped in seems to have been broken. Deborah herself says: 'I'm doing very well; I'm even going on holiday! And I've never ever been away on holiday'. This says a lot about how Deborah views her own process.

Deborah experiences that she's allowed to exist, because the questions aimed at getting reassurance like 'am I allowed to stay?' and 'do you like

me?' are hardly ever asked any more. Moreover, she indicates that she's actually much less angry.

The number of times Deborah is put in isolation or restraints has been greatly reduced. Deborah was formerly put in her special isolation unit up to seven times on 'bad' days, but now weeks can go by without her needing to be isolated or restrained.

Deborah feels much less stress thanks to the method of performing tasks together with her carers, and by going through difficult times with her carers by her side.

She is learning to trust her carers more and more, and step by step she's learning to trust herself. The psychomotor therapy plays a huge part in the latter. She can now communicate when she is uneasy or feels anxious. Carers address this by having a short talk with her or making small adjustments to the task at hand, and in many cases further escalation is then prevented.

Deborah's life is becoming increasingly more 'normal'. Her apartment is now more decorated: she has pictures on the walls. And she can eat using normal dishes and normal tableware.

She enjoys tasks such as grocery shopping and preparing evening meals. It enriches Deborah's life when she can perform tasks with a fellow resident. This means she spends less time alone in her apartment. The companionship she feels and the caring role she has assumed for this resident make her visibly proud.

LESSONS LEARNED

This situation taught us how much influence the environment can have on a client's life. The reactions of the people around Deborah to her challenging behaviour were a cementing factor of that challenging behaviour.

The environment contained three vicious cycles: one reflecting rejection and low self-esteem, one reflecting fear of rejection and how carers responded to it, and one reflecting the team's fears and the effect they had. Ultimately, all three vicious cycles continually amplified Deborah's challenging behaviour.

We learned that changes in the environment – in the people around Deborah, so this means in us – were necessary to break these cycles. We boosted Deborah's self-esteem, passed Deborah's reliability tests, and had to learn to deal with our own fears. Then there was room for development and for growth; in us, and by extension, in Deborah.

Unconditional support for the team on the part of a multidisciplinary team including the manager is crucial and ensures that the team's trust grows and their fears diminish. In order to achieve this turnaround in how people view things and how they react, it is essential that the team is well looked after, that team members feel that there is a good collaboration in working towards creating new perspectives.

What happened with the team is comparable to what happened with Deborah: the fear was being enabled because the focus was on the problems and not on a wider perspective. There was a kind of parallel process in place.

The team showed great courage by being able to reflect on their actions. The team made the effort to see Deborah and themselves differently and had the courage to change their responses.

CONCLUSION

This was the case Gaining Deborah's Trust. A lot of wonderful developments are taking place, but we aren't there yet. Deborah and those around her are not yet through growing and learning. Our next goal is to decrease Deborah's attachment issues and PTSD characteristics through a

combination of Integrative Therapy for Attachment and Eye Movement Desensitization and Reprocessing (EMDR). It has been a substantive process and we have laid a good base for Deborah: having trust in herself and in those around her.

Comments are welcome. Thank you for listening.

Visit the Leren Van Cassussen website: http://lerenvancasussen.cce.nl (in Dutch)

Visit the CCE website: https://cce.nl/about-cce