

BALANCING SELF- DETERMINATION AND BOUNDARIES

The importance of multidisciplinary cooperation

LEONIE STOKKENTRE, BEHAVIOURAL SPECIALIST-GENERALIST

DE TWENTSE ZORGCENTRA



leren van
casussen

beschrijf je eigen casus



Maarten was a healthy baby with normal intellectual abilities. He grew and developed very well into a happy toddler who liked to do things and to decide things for himself, and he was immensely proud of the little projects he made at school. When Maarten is five years old, he is struck by an automobile and falls into a coma. Maarten tells this story himself.

[Interview with Maarten]

THE PROBLEM

When Maarten awakes from his two-month coma, he is spastic and has lost muscle strength in both his arms and his legs. He also has problems with his vision and his speech. And he has cognitive issues. He is now slower in processing information, has trouble concentrating, his memory is poor, and he is very impulsive with a short temper.

Maarten is transferred to a rehabilitation facility; he needs to relearn all of his skills. And he has changed dramatically. He is now a loner, takes much less initiative and has difficulty expressing himself. After two years of rehabilitation, Maarten is back at home and receiving daily outpatient treatment. He has problems dealing with the changes which are just business as usual in a family with four children. Caring for Maarten requires a great deal of his parents' time and attention, and the other children are now underserved. When Maarten is eleven years old, he goes to live in a home for children with intellectual disabilities.

The home considers Maarten to be a calm, usually good-tempered boy who likes doing things alone, but it is clear that he is a bit out of his league.

During group activities, such as playing board games, he needs a carer to be right next to him so that he can participate. Maarten has difficulty conversing about things that have only just happened. He is at times destructive, and carers have the impression that this could be a signal related to unfinished emotional business. Maarten doesn't talk much about



himself or about what might be troubling him. Carers must pick up on his non-verbal signals in order to speak with him at all.

Maarten is moved to a place that is more suited to his abilities. He seems to adjust smoothly but doesn't quite know what to do with himself at times, and thus appears insecure. He blossoms when carers pay attention to him and is visibly proud when he completes an important task successfully. He doesn't accept new carers easily; they are first thoroughly vetted on their knowledge of "the rules".

Over the course of several years, Maarten's challenging behaviour increases. He has become more and more destructive; he smashes things, he rips things apart, he scratches himself, curses, screams, and is physically very restless. Maarten withdraws a lot more, becomes apathetic, and defies his carers. He is often tense and restless. The professionals involved analyse the situation and devise a treatment plan. The plan, however, results in a debate about Maarten's quality of life. In the idiographic theory section I will elaborate on how that debate began.

IDIOGRAPHIC THEORY

Maarten has acquired brain injury (ABI). This has several consequences for him. First, his information processing is terribly slow. It takes him more than a minute to begin responding to a question. When he isn't given the time he needs, Maarten becomes stressed. He then expresses his stress by smashing things or screaming and cursing.

Due to ABI, he has trouble processing stimuli. His slow information processing exacerbates this. Maarten must expend a lot of energy to process and learn new things. Because of his ABI, it is difficult for Maarten to regulate his emotions and control his impulses. Sometimes, it seems to those around him that he loses his temper for no reason at all, and he starts kicking and hitting others, smashing things, and scratching himself.



It's extremely hard for Maarten to accept that because of that childhood accident, he is now different than other people. He says, for example, 'I'm a baby, so I should just act like one'. And after one incident, when asked why he decided to spit at people, his answer is: 'because at least I'm still able to do that!'

The daily activities that Maarten is still able to do give him great satisfaction. He is especially proud of delivering the facility's mail.

A few interventions were devised to address Maarten's challenging behaviour. One was to put him on medication. After trying a few different medications, Nozinan is prescribed. This antipsychotic pain reliever with tranquillising effects seems to be gradually achieving the desired result. In addition, a day programme is worked out to provide structure, and predictability for Maarten. The use of pictograms is introduced to facilitate communication. And Maarten is also given 24-hour care: day or night, a carer is always nearby to help ameliorate overstimulation. All of these interventions result in Maarten feeling more secure; there are fewer escalations, and things are becoming relatively peaceful. And so, the night shift is slowly phased out.

However, this treatment, combined with Maarten's ABI ultimately result in negative effects which slowly increase. Nozinan has side effects such as an inability to maintain balance, so it is decided to wean Maarten off it. His balance quickly improves, but the escalations resume, so he is put back on a full dose. They continue to try and lower the dose because Maarten has more and more trouble walking, easily loses his balance and is at risk of falling and injuring himself. But the results are not good. During the latest attempt at lowering his dose, Maarten became very confused and could cope even less well with stimuli than usual. He just isn't himself. And that is hard on the people around him. But of course, the Nozinan side-effect of Maarten losing his balance and falling, is also very difficult for staff. Maarten has a few falls that are so severe that he has to receive medical attention.



This has an impact on his carers. They are afraid that Maarten might be seriously injured and don't want to leave him by himself.

Because on the ongoing intensive support, Maarten's autonomy is under pressure. His carer is always in his space, and always determines how his day will unfold.

This intensive level of care is also a burden for the carers, who must be on constant alert for stimuli and anticipate how these will affect Maarten: whether his stress level is increasing and whether a threatening situation is developing. The difficulty Maarten has accepting being 'different' is also an emotional burden on the carers. They are all becoming overextended.

Because Maarten is having more and more trouble walking and bicycling, his work as a mail delivery person at the facility is becoming increasingly difficult. And that means his self-esteem and self-sufficiency are impacted.

This leads to complicated trade-offs. The risk of Maarten having serious falls is hard to accept for his carers. They feel responsible for him and want to prevent him getting injured. But Maarten feels that his decline is horrific; he experiences his body not being able to do what he tells it to. Once again, another loss for him.

One side's preference is difficult for the other to accept. Self-determination is extremely important to Maarten, while those around him see that he also needs boundaries. Striking a balance between the two is quite a challenge.

In this illustration, we can see the consequences of self-determination for Maarten on the left. For him, his sense of self-esteem and autonomy; and for the facility, risk, and lack of control. On the right are the consequences of boundaries. For Maarten, this means patronisation and dependence, and for the facility, safety, and control.

A perfect intervention would be one in which Maarten's self-esteem and autonomy were at the forefront while safety and control remain



uncompromised. But in practice, these goals are hard to reconcile. An intervention targeting the greatest possible amount of self-esteem for Maarten in which autonomy is key means too great a risk for carers and too little control, which makes that intervention unacceptable for the facility. An intervention targeting Maarten's safety and controlling the situation results in Maarten feeling patronised and dependent. People who know him well, his parents and his main carers, know that this is unacceptable for Maarten, and they have serious concerns about the effects on his quality of life.

As an example, there is his ability to urinate while standing. In terms of Maarten's self-esteem and autonomy, this is an especially important activity that he be able to perform, 'because men can pee standing up'. But, at night time, when not fully awake, Maarten has on occasion lost his balance and had a nasty fall. Carers began to worry. With at-distance care, Maarten could have a fall and wind up spending a long time on the floor with a serious injury. They could not guarantee his safety and did not have enough control over the situation. The question arose whether Maarten could be allowed to continue to urinate on his own. Perhaps it would be best if he were to be diapered at night, which would reduce the risk of falls. Then Maarten developed pneumonia and he had to be confined to bed. He was too weak to urinate without help. The idea of diapers was put into practice and Maarten was taught to urinate in the diapers. This situation resulted in lower risks and more control for the carers. But Maarten objected. He felt patronised, as dependent as a baby, and he became sombre and angry.

The problem in this case isn't so much Maarten's behaviour as it is the dilemmas everyone involved faces, and the impacts on them. The interventions are targeted at doing justice to all parties. How can care be provided that is acceptable for all those involved?

INTERVENTION 1: BALANCING SELF-DETERMINATION AND BOUNDARIES



Perfect interventions don't exist. The challenge is to strike a balance between self-determination and boundaries and while doing so, realising that this isn't just about Maarten, it's also about the facility.

When weighing the trade-offs, input from all the people involved is important.

In the first place, his parents, who know Maarten through and through, both as an adult as well as when he was a child, before the accident.

In addition, all the carers involved, each of whom contributes input based on expertise.

In search of that balance, regular team meetings with all the people involved were crucial. These multidisciplinary team meetings were held every six weeks. The tone during these meetings was open and honest. Maarten's autonomy was discussed, as were uncertainties on the part of carers, and vulnerabilities of care in the facility. Via his parents and carers, Maarten was able to communicate his own concerns and wishes. They would always ask him about his worries and were familiar with his signals. In this way, Maarten was able to participate in, and provide input for the multidisciplinary team meetings, and was assured his issues would be addressed.

The issue of Maarten being allowed to urinate while standing mentioned earlier is an example of a topic which was discussed during the multidisciplinary team meetings. A consensus was reached that it was just too dangerous to allow Maarten to stand by himself. Both the physical therapist and the ergonomic specialist looked for physical solutions and potential adaptations that could decrease the risk factor. His parents indicated that Maarten held freedom of movement higher than anything else in his life. They understood the concerns about physical risk but could also eloquently explain why Maarten would be subject to an even greater mental risk if he were not allowed to urinate on his own. They said they



would not be angry if Maarten were to fall. This gave the carers a different perspective, so that they were better able to accept the risk of falls.

INTERVENTION 2: HOME AUTOMATION

Interventions making use of home automation are also applied in search of a balance between self-determination and boundaries. A bell is installed in Maarten's room he can use to summon a carer. He is able to use this bell during the night, after receiving training during the day. He is also given a disability chair which will allow him to move about independently in his apartment without having to walk. The facility experimented with several devices to be used during the night, such as an infrared system and a mattress alarm that would go off after a certain amount of time had passed. Maarten could then get out of bed, but his carers would be alerted if too much time passed before he returned.

INTERVENTION 3: FOCUS ON THE RELATIONSHIP

When Maarten doesn't feel a connection with someone, it's then awfully hard for them to provide him any care at all. People have realised how crucial the bond Maarten has with others really is. To nurture that bond, it is key that one takes Maarten seriously. This means no babytalk, and no talking down to him. He must be recognised and reassured that he's fine as he is. This can be done by validating him and complimenting him for what he is able to do and accomplish. It's important to be actively involved with Maarten. Explain things to him, know what he is dealing with, and be able to read between the lines.

It is agreed that Maarten will only be given care by a substitute or a new carer a maximum of two times in one month.

RESULTS



Maarten has been given more control, although this control is restricted to the limits set by carers. Those limits have become more flexible thanks to the discussions taking place during the multidisciplinary team meetings.

Maarten has more influence on the proximity of his carers. His autonomy and self-esteem have increased.

The carers feel less uncertainty about his care and are less anxious because responsibility is being shared. This allows them to be more confident, which has a positive effect on Maarten. He feels secure.

Maarten is **happy**. Despite his issues with regulating emotion and impulse control, he is becoming increasingly more adept at expressing himself and he knows that he is being listened to and taken seriously. And that the carers, even when it is a bit frightening to do so, will do everything in their power to keep him as independent as possible for as long as possible. Here is a video of Maarten telling us he is happy at 't Bouwhuis.

[Interview with Maarten]

LESSONS LEARNED

It has become clear that regular contact with all the people involved in caring for Maarten, even when there is no specific topic to be discussed, is especially important. This contact means that signals are recognised early and there is a low threshold for discussing them. Potential problems are nipped in the bud. Regular contact also ensures that there is mutual trust so that difficult topics can be discussed more readily. The team meetings cannot be cancelled, even when they seem unnecessary. We found this out when we reduced the frequency of the meetings and we were then chasing our tails. Personnel changes in particular are a risk factor when the time periods between team meetings are long.



The parents' role is an important one. They are the true constant in Maarten's life, in the realities of the care sector with its high attrition. The parents know Maarten better than anyone else and can make carers understand what is important to him.

As a carer, you must have a certain skillset to work with Maarten. A lot can be learned, but having a connection with him, and the ability to read between the lines seems difficult to transfer to others. Good instincts are key. Maarten lets you know that in a heartbeat.

CONCLUSION

This was the case study Balancing Self-Determination and Boundaries which focussed on the importance of multidisciplinary cooperation when facing complicated trade-offs.

Visit the Case-Based Learning website: <https://cce.nl/leren-van-casussen> (in Dutch) or <https://cce.nl/expertise> (in English)

Visit the CCE website: <http://www.cce.nl>