

A black and white close-up portrait of a middle-aged man with Down syndrome. He has a serious expression and is looking directly at the camera. The lighting is dramatic, with strong shadows on his face. He is wearing a light-colored, possibly white, t-shirt.

KAREL DE CORTE

DON'T
LET ME
DOWN

DOWN
SYNDROME
THROUGH
A DIFFERENT
LENS

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“My parents are okay with it”

That’s what Danny always says whenever another mysterious disappearance happens in the community.

His obvious sense of guilt is both charming and disarming, and it always throws me off course. There’s just no way to go up against it.

And yet...

One way or another, you have to get the missing item back. But beyond that, you wish you could make Danny understand you’re not always in the mood for his jokes.

Parents, sibling and caretakers of people with Down Syndrome will know exactly what I’m talking about. You feel powerless, because you don’t know how to deal with that much charm. Should I be strict? Get angry? Wait patiently? Perhaps I should read a book...

Karel De Corte’s book deals with situations exactly like these. It’s not a boring work of strict rules to be followed, but a collection of thoughts, tools, tips and inspiring examples.

A remedial educationalist who has been working at Den Dries vzw [a multi-level facility aimed at adults with intellectual disabilities] for more than 30 years, Karel was struck by the outlook people with Down syndrome have on life and developed a passion for finding a way to integrate their view in how we interact with them.

The book deals with key concepts like the need for structure, building a relationship, developing psychological scripts and how people with Down Syndrome experience struggles.

But how do you handle that need for structure--also known as stubbornness? How do you build a relationship with someone who has very peculiar notions of what a relationship entails?

How can you attempt to rewrite the psychological script without making it a struggle?

This book doesn’t provide all the answers. Rather, it was written from a position of concern for people with Down syndrome, in the hope readers will develop a new perspective on their somewhat different world.

Parts of the book are funny while others force you to face reality, but throughout it, the author shows a deep sense of respect for those people who have been a part of both of our lives for many years.

I have had the pleasure of reading it before you, and it has provided me with new insights as well as entertainment. I wish you the same.

Luc Verbeke

preview

PREFACE

This work is the result of several hundreds of consultations with people with Down syndrome, over the course of the last twenty years. These experiences were anonymized and bundled into the book you're holding now. The only two exceptions to this rule are Chris, the man whose last words were included in the book, and the story of Arthur's mother. The book also includes some longer case studies that combine different elements from different cases into one fictional character.

I have tried to appeal to a broad audience: those who live with and work near children or adults with Down syndrome. That target audience includes both new parents of preschoolers with down, teachers working in special education, group home staff and psychiatrists.

I have done my best to describe ideas as thoroughly as possible, and have used over a hundred professional and personal anecdotes. If a particular case study seems tedious, you can simply skip ahead. Hopefully, you'll find the next one more appealing.

The first part of the book discusses psychological and social functioning, vulnerabilities and risks. This is where I try to paint an elaborate picture of what makes people with Down syndrome so unique and vulnerable. I can imagine this part will leave you somewhat confused. You might even be thinking, "now what?". Still, I chose to first provide you with a thorough insight into what makes people with Down syndrome tick. The elaborate description leaves many questions unanswered, which will hopefully motivate you to keep on reading.

It's my hope that the second part, "How do we make life easier for them?" will provide the answers and tools you're looking for. Of course, we are aware of how this setup tests your patience. However, I believe that the descriptive first part acts as a crucial framework for the tools offered in the second part, regarding the interaction with people with Down syndrome. Understanding the strengths and vulnerabilities of people with Down syndrome will help us provide them with proper support in times of need.

At the end I want to add that some stories and ideas are spiced up with some maybe typical Belgian humor. I have done this as a reminder of the importance of humor, both while reading and in the interaction with other people—Down syndrome or not. It is said that life is a mixture of joy and sadness. Well, sometimes we cry from laughing so much. People with Down syndrome love to laugh, so why shouldn't we?

Psychological need for structure → Psychological script

As I have mentioned before, it's in their nature for people with Down syndrome to process reality through recognizable patterns. Any experience deemed important is saved and formatted into a manageable format, then added to what you might call a mental **database**. See for example Floris and his "I don't do stairs" database.

Floris...

Floris, a thirty-something with Down syndrome, has been looking forward for several months to moving in with his four future housemates. Soon, the five of them will leave behind the group home they shared with seven others to move into a respectable semi-detached home in the center of town. Their new home will have one bedroom on the first floor and four on the second. One of the housemates, Joe, is in his sixties and has been partially paralyzed since birth, to the point where he can barely use his right arm and leg. Although he can walk, it's slow going, and he does virtually everything with his left hand.

When they signed the rental agreement, the caseworkers assumed that Joe would be moving in on the first floor because of his physical disability. However, Floris didn't agree... Several weeks before the move, they all went to see their new home for the first time. As soon as they arrived, Floris made his way to the downstairs bedroom: "This is my room!" Joe's personal caretaker Eva was nearby when it happened, and briskly told him: "We'll deal with the details later, Floris! Right now, we're just looking around."

At the following staff meeting, they decided to each broach the subject with Floris individually. "Surely Floris will understand that it will be impossible for Joe to navigate those stairs multiple times a day. They get along well, and he's always willing to lend a hand," Floris's caseworker Bart had said.

In the next few days, several of his coworkers told him that their conversations with Floris hadn't gone that well. Eva felt compelled to protect Joe's interests, and wasn't pleased with what she called "Floris's egocentric attitude." Bart knew it was a challenge to get Floris to change his mind, but he was convinced he'd be able to do so anyway. Confident in his own abilities, Bart told his coworkers he'd take care of things.

Floris had told Bart countless times that he didn't "do stairs." His older sister had confirmed that he once missed a step when he was younger and ended up twisting his ankle slightly. From then on, he was scared of stairs, seeing himself as "incapable of navigating stairs". Bart had been through many taxing staircase incidents with Floris whenever they visited malls or train stations. After lots of coaxing to get him near the staircase, Floris would always shut down once he was halfway, unable to go up or down any further. These episodes always ended in an argument, including lots of screaming and crying.

One day soon after, Bart started the conversation from an empathic angle. "Floris, I know you don't like navigating stairs, but have you noticed how difficult it is for Joe to get around?" he asked. Floris, every inch his engaging self, took the opportunity to wax poetic about Joe's skills. "Did you know Joe can trim the hedges one handedly?" Floris asked, rhetorical as ever. Before Bart could say anything, he continued: "I feel really bad for Joe. It was so hot last week, and he was sweating like a pig as he walked home after working on the farm. He has so much trouble walking..." Bart seized the

opportunity to breach the bedroom issue. “That’s very perceptive of you, Floris. Have you considered that navigating the stairs in your new home will be too difficult for Joe also as well?” he asked hopefully. Once again, Floris stated Joe had trouble walking. Bart figured this was the opening he needed, and asked him outright: “Floris, do you think you could try taking the stairs in your new home? We feel that Joe should have the bedroom on the first floor.”

Floris looked at him, offended: “But Bart, you know I don’t do stairs. I picked the downstairs bedroom. By the way, I’m thinking of putting my wardrobe next to the window and my bed by the long wall. What do you think?” Bart made one last attempt to convince him. Floris answered lightheartedly: “I don’t do stairs, Bart.”

The week after, Floris, Joe, Eva and Bart went back to the new house to discuss who’d get which bedroom. History repeated itself. Floris immediately set up for the downstairs bedroom, and he was totally preoccupied by his well-thought-out furnishing plans. Joe calmly observed it all. While Floris went over where to put his wardrobe, desk and bed one more time, Bart and Eva went to see if Joe managed to navigate the stairs. This wasn’t Joe’s first rodeo, and he tugged on the handrail with his left hand to make sure it was sound. Gripping it carefully, he dragged himself upstairs one step at a time, then gave them the thumbs up once he got to the top. He’d be all right. Relieved, Bart and Ivar went downstairs to tell Floris the good news. “Floris, Joe just tried to walk up the stairs. It won’t be easy, but he’s prepared to try. Isn’t that wonderful? Now you can have the downstairs bedroom!” Lost in thought, Floris replied: “Okay... What do you think, Bart? Should I ask my sister to hang the yellow curtains from my old room here?”

Granted, spraining your ankle is painful, but most people will consider it to be a relatively mundane occurrence—certainly not something worth remembering for years after the incident. Floris isn’t like most people, though. That pain and fear were a traumatic experience to him. Due to his intellectual disability and the inexplicable sense of pain—and despite his parents and doctors repeatedly trying to soothe him—he doesn’t understand how minor the injury is, nor that it will heal completely. In his mind, the doctor’s well-meant remark to be more careful when navigating stairs quickly became a major warning, even a prohibition to take the stairs. Once that’s been added to his database, no attempts to dissuade him—however gently or sensibly—will work. Quite the opposite, in fact. Almost imperceptibly, Floris’ reality changes into one which has no room for stairs. Every situation or incident involving him having to go up or down a flight of stairs only serves to reinforce the pattern. The more people fuss over his behavior throughout the years, the stronger the “I can’t do stairs” database is imprinted, until it becomes an essential part of his reality.



The psychological script: requiring focus, concentration, energy

Ticking off everything in that psychological script every day is anything but relaxing. We may find that difficult to understand, because to people with Down syndrome, activities that come easily to us actually require a lot of energy on their part. For example, getting ready in the morning will hardly feel like a lot of work to us. People who love watching a certain show will do so to unwind. We often get more energy from leisure activities than we put into them.

This is not necessarily true for people with Down syndrome. Sometimes, activities that start out as interests— and that their inner circle may even encourage them to pursue—can evolve into time-consuming obsessions. Over time the person with Down syndrome seems to lose himself entirely, while those around him can only anxiously watch from the sidelines.

Andrew...

30-Year-old Andrew has Down syndrome and is a man of the world. He has strong communication skills and is very self-sufficient. However, his brother feels he's overdoing it and worries about how much he shuts out the rest of the world. Sometimes, Andrew won't answer the phone for days on end. His brother has tried to visit on several occasions within the past few months and while Andrew was home each time, he didn't answer the door. When his brother questioned him about it later, Andrew always explains he didn't hear the doorbell because he was "busy on his computer". Andrew has been living in a spacious studio apartment near the center of town for several years now. Although he lives independently, a caseworker comes by to check on him every day. The caseworkers have their own key, something Andrew often complains about. However, both his parents and his caseworkers have conveyed to Andrew that this arrangement isn't likely to change.

Andrew grew up in a cultured family and has a broad range of interests. His parents confirm that Andrew has loved watching television from a young age. Video tapes of his favorite children's series fill almost an entire room, and the family loves taking a trip down memory lane. It's not all sunshine and rainbows, though. "One day, we found Andrew on the roof of the addition. He was wearing a cape and thought he could jump from one roof to the next, just like Superman.

Lately, the people in his inner circle feel Andrew has been withdrawing from the outside world too much. He feels fine, and he doesn't understand why everybody is concerned. Andrew feels they are overreacting. In the past few years, Andrew has developed a liking for a popular police series that has been running for several seasons. It goes without saying that he's watched every episode multiple times. He started with DVDs but has since learned to navigate YouTube and now watches episodes on his laptop.

His caseworkers and family feel he's been spending too much time watching the series lately. Andrew is honest itself, and always tells his social worker when he's been up watching the show until the early morning. He enjoys binge-watching entire seasons, and it doesn't take a genius to figure out that means over eight hours of screen time. His mom has been worried for some time that he is very tired, and his caseworkers confirm he doesn't get as much done during the day as he used to. Every other day, they would by stop mid-morning to find him still in bed.

Project coordinator Cal only stops by sporadically but has been filled in on everyone's concerns. He usually runs into Andrew in the street every now and then, and he hasn't seen him in a very long time. Cal decides to visit Andrew but he doesn't have a key. He rings the doorbell three times to no

avail. Cal is about to give up when a coworker with a key happens to pass by and he offers to let Cal in. Cal hesitates, but strongly feels the need to check up on Andrew.

He makes his way into the living room, calling out "Andrew! Visitors!" several times. The door to the bedroom is closed, but he can hear Andrew talking to himself. Andrew doesn't acknowledge Cal or his knocks, so Cal decides to go into the bedroom. Andrew is sitting at the computer with his headphones on, focused on the screen. He pauses the episode, takes his camera and photographs the still image, then presses 'play' again, repeating the ritual when the scene changes. Cal taps him on the shoulder, and Andrew jumps. His expression changes from tired to upset. Cal apologizes profusely: "Sorry to drop in like this, Andrew. It's just been so long. I'm a little worried because we don't get to see much of you these days. How have you been?" Andrew recovers quicker than expected, and excitedly starts telling Cal all about the photos he has taken. "Here, you see this building? Dad looked it up and promised to drive me there this weekend, so I can take a proper photo of it to put in my binder." Cal, who feels he still has some making up to do for the way he barged in unannounced, looks at it with interest. Before he can respond, Andrew jumps up and takes one of his many photo albums from the cabinet, and he goes on to talk about the location for the third episode of season five in great detail. Cal realizes Andrew is unable to stop talking, even if he wanted to.

Now in full swing, Andrew starts quizzing Cal with trivia questions about the series. "Do you know this actor from season one?" Cal isn't a fan of the genre, but he does happen to know the name of the lead actor. "What about this one?" Andrew continues. This actor is as famous as the last one and again, Cal provides the correct answer. Andrew suddenly scowls, seemingly angry. He appears upset someone else might know as much about the series as he does. Cal gets the next question wrong on purpose, and Andrew repeats the correct answer no less than three times. Although Andrew seems proud, Cal notices he is still upset. Time flies, and Cal has other places to be. As soon as Andrew notices Cal leaving, he turns around and gets back to work.

As he leaves the apartment, Cal can't help but feel troubled. "It's almost like Andrew doesn't enjoy his hobby any longer.", he thinks to himself. He had noticed the tired look on Andrew's face, and the way his obsession turned to anger within seconds. In fact, now that he has seen Andrew, Cal is even more concerned than before...

Ticking off every box in that psychological script costs people with Down syndrome lots of time and energy. Their inner circle may not be aware of that, since many of the interests in that script are technically leisure activities. To the fourteen-year-old with Down syndrome, spending hours in her room lip-syncing into a toy microphone is nothing more than a hobby. And while she enjoys doing it, it could eventually grow into a time-consuming, draining activity that *has* to be done. It's only logical that those around her try to prevent her interests or hobbies from evolving into compulsions. In my opinion, it's important not to make this a point of contention but to maintain a dialog, and to utilize your shared bond to influence them.

SORE SPOTS

“Dan, the sensitive class clown”

Dan is in his early forties and was born in a rural area, the beloved son of the village pub owners. Shortly after he was born, his parents learned their son had a disability. They weren't very familiar with Down syndrome yet. The news was a bitter surprise, but they thought little Dan was very cute. While they felt some uncertainty and shame at first, the love for their little rascal soon blossomed. Dan would toddle around the pub, looking cute and causing mischief. The regulars quickly embraced him as one of their own. In fact, Dan was both the pub mascot and its main attraction during village festivities. Some customers would joke around after having one too many drinks, especially if Dan had been up to something. Dan's brother was quick to come to his defense if they took it too far—even physically, if need be. No matter how drunk, they'd think twice about trying that again. Over the years, Dan could be seen all around town, usually running errands for someone. Everyone liked him, but they also knew there was a certain risk in asking Dan to help out. After all, he could be forgetful. Other times, things would simply disappear. The farmer down the street figured there was no harm in slapping Dan to make him own up to what he had done. The next day, he would always come down to the pub to make it up, armed with Dan's favorite kind of dessert: chocolate with banana cream filling.

Dan's body matured over the years, but his mental capacity never progressed past early childhood. He could not read or write but was very socially adept. Whenever he had trouble verbalizing what he wanted to communicate, he would pull a funny face to get the message across. Time went by, and Dan got increasingly bored. His ageing parents eventually made the difficult decision to have him transferred to a care facility nearby. It took him a long time to settle in, and he loved being back home on weekends. Occasionally, he would get upset when they arrived to pick him up on Friday afternoons, stating that he wouldn't be coming with them. And some Monday mornings, he'd hide under a table at the pub when it was time to go back. All in all, though, he adapted to his new surroundings relatively quickly, and the other residents liked him a lot.

Dan has been at that facility for twenty years now, living in the same group home all that time. Well, he still lives in the same building, but pretty much everything else has changed since he first arrived. Only two of his original fellow residents still live there, and he is currently on his 54th social worker. Both the staff and his family were adamant Dan should not be moved during his time at the facility, stating it “wouldn't be good for him.”

One gloomy fall morning, social worker Kate breaks the silence with a modest knock. She wishes Dan good morning as she enters the room, carrying a stack of clothes.

His eyes look a bit tired—it took quite a long time for everyone to settle down last night. And since Dan habitually waits until everyone else is asleep before heading to bed... Every night, he makes a few rounds to see who is still awake, checking for light spilling through the minuscule crack under their bedroom door. He then opens the door without bothering to knock and urges the occupant to go to sleep. His caseworkers have told him numerous times that he is not supposed to do that, to which he always mumbles a disgruntled reply: “what if someone forgets to turn the lights off?”

Kate resolutely tugs the curtains aside. Still only half awake, Dan notices the heavy sweater Kate is holding. Confused, he thinks to himself: "isn't that the sweater I hid in the back of my closet last night?" Kate has moved on to talking about the weather, mentioning how it will be cold and rainy that day—hence the need to bundle up. Dan is only half listening, still confused about how Kate managed to get her hands on his sweater. She puts the clothes down on the foot of the bed, her smile friendly but firm. After all, she knows her coworker had a lot of trouble getting Dan to wear his sweater yesterday. Dan has refused to wear a sweater for several weeks now. Of course, his concerned mother will then complain to the staff about not dressing him warmly enough. Kate leaves the room, then turns back to say: "Dan, you know Mom wants you to wear your sweater, right? We don't want you to catch a cold! Okay?" Annoyed and somewhat bewildered, Dan agrees. "Yeah, yeah..."

To say Dan takes his time to get dressed would be an understatement. He keeps staring at the foot of his bed, and at long last decides to put the sweater on after all. He is cheerful by the time he comes down for breakfast. As usual, he sits down next to Rita, who is wheelchair-bound because of her spasms. Knowing she has very little use of her hands, Dan teases her by taking away her coffee cup. And as usual, Rita responds with an angry yell, prompting Kate to tell him to return her cup. Despite the weather, everyone at the breakfast table is in high spirits. Kate and her coworker, Tom, are running back and forth to get everybody ready to leave. Dan spots the keys to the van next to the phone and he decides to pull a prank. He secretly grabs the keys and hides them in the kitchen drawer. Then he enjoys a hearty breakfast, feeling very pleased with himself.

It is close to 9:30 AM, and Dan is getting ready to go to work at a workshop several miles away that is owned by the care facility. Everybody always meets in the parking lot, so the van can leave on the dot at 9:30. Dan makes his way over to the van. He's already spotted Paul sitting next to the driver's seat, so he yanks open the passenger door and stares at him. He doesn't have to say anything— Paul cuts his losses and moves to his customary seat in the back.

Everyone has since found their way to the van. Tom will be driving today—at least, that's what Dan heard while on his rounds. By now, 9:30 has come and gone. Tom comes running, out of breath. The workshop staff doesn't like it when they are late, because the days are short enough already. Tom gets settled behind the wheel, then realizes he doesn't have the keys. Luckily, he's in good shape from all the football he plays, so he sprints back to the group home. The keys are usually on the hook by the telephone, but not today. He takes a quick look at the desk but can't find them there either. Tom dreads having to ask the janitor for the spare set—he already has a reputation for being disorganized. Fortunately, Rita comes to his rescue by simply pointing at the kitchen drawer. All Tom can utter is, "Oh, for crying out loud... not Dan again!" After grabbing the keys, Tom storms over to the van and its impatient occupants. He barely manages to hold back his anger when asking Dan if he hid the keys. Like every time he's being questioned, Dan hangs his head and remains silent. Tom starts the van, and continues admonishing Dan, ranting about how "this isn't funny at all." Dan doesn't understand much of it, nor does he understand why Tom seems so upset when he usually doesn't mind him joking around. He just stares at the floor and doesn't say a word the entire trip. Fortunately, they don't have very far to go. He hopes the staff members at the shop are in a better mood...

On his way from the van to the workshop, Dan realizes he still has to get rid of that annoying sweater in some way because it doesn't fit his outfit script. He slips into the cafeteria where they usually have their coffee break and he throws the sweater onto his chair. Ben once dared to sit in it during the

break, but all that was sorted out a while ago. Dan sets out for the workshop as his favorite activity supervisor, Patricia, returns from a bathroom break. She tells him it's much too cold to only be wearing a T-shirt, and recalls his caseworker telling her about Dan's issues with getting dressed. Fuming, she says: "How on earth did they let you leave the house this morning dressed like this? Didn't you bring a sweater?" Dan tries his best to look convincing as he tells her no, because he knows from experience most people—and especially his father—aren't easily fooled. It seems to have worked this time, though. Patricia drops the matter and just tells him to go inside. Fred, the workshop's new intern, is quick to welcome Dan. "Good morning! Wow, you're not exactly dressed for this kind of weather. Aren't you cold? Maybe you should ask your caseworkers to lay out your clothes in the morning, so you won't forget to dress warm on a day like today." Dan doesn't offer much of a response, but just starts working.

An hour later, it is coffee break time. Nancy, one of the other caseworkers, is tasked with making coffee just before the break. As everybody shuffles into the cafeteria, Nancy asked Dan if that's his sweater on the seat. Before he can say anything, Patricia makes a beeline for them. "So, Dan... you managed to get rid of your sweater, huh? Why do you always lie to me? Did I ask you whether you brought a sweater today?" Dan studies Patricia's expression, jumbled thoughts running through his head. "She looks like she'll tell the caseworkers back home what happened, and then they might discuss it during a staff meeting, and then they might put a lock on my wardrobe, and..." He feels ill at ease as he finishes his coffee, then goes back to work.

Thankfully, something else catches his attention and by noon, the feeling has passed. The vans have arrived and everyone is getting ready to leave. As usual, Dan lets everybody else go ahead of him. He can't resist the temptation of secretly turning off the heating before he leaves—all in good fun, of course...

After lunch, it's time for Dan's daily rounds. He knows everyone in the building by name. Catching up with the social worker, joking around with the managing director, asking the educator what he had for dinner last night, etc. The last one to leave for the night is supposed to keep unwanted visitors from going upstairs by locking a chain across the bottom of the stairs. Whenever Dan goes down those stairs, he can't resist locking that chain. He thinks back to a few days ago, when the managing director had come down those stairs with his hands full. After loudly exclaiming "Oh. For crying out loud, DAN!" he had to go back upstairs to put everything down so he could unlock it. Dan had quickly disappeared around the corner...

It is Tuesday, almost time to start work on the farm just down the road. The sun has broken through the clouds by now, and it's a beautiful day. Like a fox leaving a trail, Dan aims to leave a trail of pranks wherever he goes. Nearly everyone has left the house, and the temptation is getting too much for him. Dan quickly turns on the lights and TVs in each room as he does every week, then sneaks out the back door and heads for the farm. Eva is a new staff member on the late shift. On her way back from the parking lot, she bumps into the managing director who is heading towards Dan's house. He looks worried: there is an issue with the heating, and he wants to get an idea of how expensive the repairs will be. We really can't afford any additional expenses that were not budgeted for right now, he thinks to himself. Although he is preoccupied, he takes the time to ask whether Eva feels like she's settling in among the staff. Eva gives him a shy nod.

They enter the house together and encounter a wall of sound and blazing lights. The managing director's mood sours instantly. He asks Eva if she normally leaves the lights on at home before going

to work as well, and whether she has a habit of turning on the TV if nobody is watching. Eva desperately tries to explain how Dan is responsible for all this, to no avail. Angrily, he counters: "Dan lives here, but you work here! It's your job to make sure this doesn't happen. It's not like we have any money to spare, you know!" The managing director marches out before Eva works up the courage to respond. Still shaking, Eva is barely able to think straight and she panics at the thought of getting her pink slip in the mail tomorrow.

Nevertheless, she's sure about one thing: Dan will be seriously reprimanded when he gets back from the farm, and she'll be adding "Dan's problematic behavior" to the next staff meeting agenda. Her coworker Tom arrives soon after, and he immediately notices Eva is upset. He shows compassion when she tells him what happened: "Don't take it personally, Eva. You can't help it—you were simply in the wrong place at the wrong time. Our managing director just wants us to be more careful about our energy use. And as for Dan, I agree we should discuss that subject at the next meeting."

Dan returns home, tired from his day at the farm. He doesn't do a lot of actual farm work, but running errands, making conversation, and pulling pranks keeps him busy all the same. Eva is still upset about her encounter with the managing director, and she doesn't quite know how to handle Dan. Even though she already knows the answer, she hesitantly asks him whether he had turned on all the lights and televisions. Dan picks up on her insecurity and gets angry, calling her names and pushing over a chair. Then he slams the door and retreats to his room. Eva's not okay with that and decides to take action. With a firm knock on the door, she enters his room. Dan feels cornered and upset, so he snaps at her. He grabs a glass from the sink and smashes it on the floor in front of him. Eva's assertiveness melts away. She leaves the room to ask for Tom's help, quickly explaining the situation. Tom remains calm, telling her this isn't unusual for Dan. "It's better to just leave him be at times like this," he comforts her. "Leave it to me—I'll go check on him in ten minutes or so." Although she is relieved, Eva can't help but be disappointed in herself as she starts to prepare dinner instead.

Dan's hiding under his blanket, rubbing his forehead with the palm of his hand. He stops fidgeting when he hears someone tapping on the door. Tom gently asks if he can come in. No immediate response. "I guess that's a yes," Tom figures as he enters the room. He quickly spots the bulging blankets, and he has heard that rubbing sound before. He also knows that when stressed, Dan will rub his forehead hard enough to injure himself. Tom sits down on the bed and gently turns the blankets down, then strokes the back of Dan's neck and asks him if he's okay. Dan stops rubbing his forehead and says: "Tell the new one to leave me alone! I never want to see her again!" Tom puts an arm around Dan's shoulder, who leans in for a hug.

After a while, Tom tries to convince Dan to come down for dinner but he is rebuffed—as expected. Dan digs his heels in again, stating he doesn't want to eat. Tom knows a lost cause when he sees one, and he decides not to press the matter any further. Instead, he leaves the room after promising he'll be back a little later.

Tom and Eva discuss Dan's behavior over dinner. Tom thinks back to the missing car keys and the sweater incident the workshop staff had told him about. Eva is still upset about her earlier encounter with the managing director. They agree that it might not be a bad thing for Dan to stay in his room for a while. "Maybe he will realize he's crossed the line," Eva adds. In the meantime, Dan is still in bed rubbing his forehead, but not as vigorously as before. He hears people start clearing the table and he decides to stay in hiding. He will spend the evening rubbing, rocking back and forth, and vocalizing.

Tom has gone home for the evening and Eva is finishing up, writing up an account of Dan's behavior the previous day in the staff handover book. She tells her coworker coming in for the night shift that Dan's already asleep, and she refers her to the handover book to read for herself "what he was like today." Dan is still wide awake, taking in the nighttime silence settling over the house. His stomach rumbles, begging to be filled—loud enough to drown out the sound of rubbing. He doesn't hear anything, which means the night shift is checking on the house next door and he decides to check out the pantry for some cookies. It's pitch black in there, but he can tell from the size of the packaging that he has found his favorite: sugar waffles. He is about to sneak back to his room when he bumps into Ann, who's on night shift. Dan drops the cookies, and she snatches them up before he can pick them up. Dan is scared to look her in the eye, knowing she will stare at him. He opts to head for his room instead. As he walks away, Ann yells at him for sneaking into the pantry like a thief in the night.

Now starving and desperate, Dan resumes his earlier compulsion. He can feel his forehead starting to hurt, but he doesn't care. Eventually, he falls asleep still rubbing and rocking. Not for long, though. He hasn't done his rounds yet, and he can't help but wonder: "Are everyone's lights off?" Like every night, he just has to go see for himself. Dan stumbles down the hallway in a daze, randomly opening doors for good measure before returning to his room. He doesn't even take off his clothes before getting back into bed. Then it's back to rubbing and rocking, falling asleep, waking up in pain with blood trickling down his forehead, falling asleep again...

The next morning, Kate reports for her shift. She goes to wake Dan, just as cordially as the day before, but hasn't brought his sweater this time. "Good morning, Dan! Do you know where your sweater is? I can't find it anywhere, and you know Mom wants..."

Fixation with people

The majority of stereotypical behavioral patterns focused outward have to do with other **people**: celebrities, regular people, or fictional characters. At the heart is a certain interest in a real or imaginary person, which can develop in any number of ways. A positive fixation will mean fondness, appreciation, friendship, admiration, love, adoration, etc. A negative fixation will elicit jealousy, irritation, teasing, bullying or aggressive behavior toward a specific person or group of people.

I want to stress that these emotions and behaviors are a part of human behavior in general and that they are not limited to people with Down syndrome. Nevertheless, it is clear that many people with Down syndrome develop a strikingly similar and highly structured way of dealing with these emotions and behaviors. These positive and negative emotions and their corresponding behaviors may occur in rapid succession, depending on how their environment responds to them.

Isaac...

Isaac, a 30-year-old man with Down syndrome, has had a crush on Carmen, the adult care center's pedagogue, for several years. Actually, it's more than just a crush. Even though everyone tells him that is "not allowed", Isaac is secretly in love with Carmen. She supervises the center, which makes her the boss, and Isaac thinks she is very good-looking. Beauty and authority, an irresistible combination for Isaac. All has been in good fun so far; Isaac tries to charm her even if it is inappropriate, but Carmen believes he is harmless and she enjoys their interactions nonetheless.

Isaac is the care center's entertainer and he is usually in a good mood. He's always up for a joke, even if they are not always appreciated. Whenever something goes missing, all eyes are immediately on him. Despite his indignation, those who suspect he had something to do with it are usually right.

Six months ago, his fellow resident Alyssa's bag had suddenly disappeared. Alyssa is very meticulous about her things, so she was understandably upset. After three days of stress and uncertainty, the bag suddenly resurfaced. The staff didn't get Isaac to confess to stealing it until much later. Last month, the exact same thing happened again. It took several days of questioning by Carmen before Isaac confessed to the prank. To put it in legal terms, Carmen—as a representative of authority at the care center—personally oversaw the investigation of both incidents.

Isaac was left feeling conflicted about both incidents. On the one hand, he did enjoy Carmen's presence and exclusive attention during all their conversations. He liked being close to her. On the other hand, he remembered how strict she was with him and how she informed Alyssa's parents in writing both times. Ever since, Isaac has repeatedly offered stereotypical excuses to all his caseworkers, who feel he was being insincere.

Isaac hasn't gone to the adult care center much in recent weeks, his parents calling in sick on his behalf. Carmen decides to pay them a visit. She is very disturbed by what they tell her. "When Isaac came home last week, he looked at us straight-faced and told us you were dead. We were shocked but soon realized it was an inappropriate joke." His mom still seems distraught. "He also keeps referring to two so-called incidents he blames you for. He says once you forgot to engage the emergency brake when parking a van, so it kept rolling for another few yards, and that you got upset with another resident over a cookie on another occasion," she says doubtfully. Although she feels it's too mundane for words, Isaac's mom wants to hold nothing back in her discussion with Carmen. With effort, Carmen is able to recall the emergency brake incident that happened a very long time ago. She doesn't remember anything at all about a cookie. Since none of her coworkers do either, they suspect Isaac

made it up. Near the end of her visit, Carmen asks a visibly upset Isaac to join them for a while. He's been told everything that has been talked about, that nobody is angry with him, and that they can start over with a clean slate. Isaac doesn't say a word.

Ever since, Isaac behaves very differently when he comes to the care center. Carmen describes it as follows: "He comes up to me to apologize all the time, constantly asks for confirmation and is generally very quiet. His spontaneity and sincerity are gone, and Isaac doesn't interact much anymore with the other residents." His attitude towards her is conflicted, she says. "He still seems upset with me, but he also feels attracted to me. I receive countless apologies, kisses, and hugs."

However, Carmen says things really got out of hand last week. "He just came up to me in the hallway, trying to kiss me and fondling my breasts," she relates, still dumbfounded by the experience. "During our end-of-day session a few hours later, I said goodbye to everyone. Isaac didn't respond, so I asked him, "See you tomorrow, Isaac?" He apparently felt admonished and just started hitting me." She is obviously upset as she concludes her story.

Isaac's response to Carmen is a good example of how a fixation on a particular person can have its pluses and minuses. While the starting point was positive, even affectionate, Isaac's behavior quickly turns negative and destructive. Over time, Isaac's behavior is a chaotic rollercoaster as he experiences opposite feelings like harmony and conflict or love and hate.

Welcoming and easy to approach

Fiona...

Fiona is the youngest of three girls born into a loving family. Her being diagnosed with Down syndrome came as an incredible shock to the family. Neither the doctors nor her parents noticed it at the time of birth, but several days and consultations later, Fiona's trisomy 21 diagnosis became quite obvious.

Fiona's medical issues made for a difficult start in life, but she has since grown into a happy, cuddly preschooler. Her mom and dad love to reminisce about the countless hours they spent snuggling with their youngest daughter: in bed, during bath time, and on the couch. Fiona's parents feel it's important for their daughter to have a 'regular' childhood alongside 'normal' children. They were adamant about sending their daughter to a regular school for as long as possible. She goes to the same school as her two older sisters and is loved by many. However, her mother knows Fiona has always been distant, even dismissive, towards other children. The relationship with her sisters has occasionally been troublesome as well, especially when they were toddlers.

Fiona has been drawn towards grown-ups all her life, and we mean that literally. She will literally hang on to teachers, aunts and uncles looking for another kiss or hug. Throughout the course of her childhood, Fiona's parents have developed a keen sense for this kind of thing. When Fiona greets the new cashier at the local grocery store with a bear hug, her mother pays close attention to how the cashier responds. At even the slightest sign of unease or irritation, she immediately saves the 'prey' from her daughter's clutches. Of course, that doesn't always go smoothly. More than anyone else, Fiona's mom knows what it's like to have to wrap things up quickly in the store because her daughter is causing a scene and is rolling around on the floor screaming. However, if the new cashier's response is spontaneous and friendly, Fiona's mother has learned to let her do her thing. Letting go may take some time because Fiona can't get enough, but it generally ends with both people feeling like they've made a friend.

Fiona has grown into a young adult, and her mother fondly remembers the time when she was smaller and easier to handle—physically speaking. Now that she is in her teens, her carefree and decidedly physical approach to strangers has become a bit more complicated. She still approaches people the same way as she did when she was a young child. Fiona doesn't see the difference, but the other person definitely does. Although she might still act like a preschooler in situations like these, Fiona's body has the physique of a young woman. In other words, the behavior people thought was cute or slightly quirky when she was young is now considered off-putting and wildly inappropriate. Fiona has recently returned from a group vacation to Italy. On day two, the group took a field trip to the local Cathedral. Out of nowhere, Fiona fell into the arms of a handsome young Italian. The situation was apparently so hilarious that the supervisors—who weren't that familiar with Fiona—got quite physical in their attempt to break them up. The rest of the trip was apparently quite hard on Fiona. "We've been told by the travel agency's management that it may be better to find something else for Fiona next year," her mother states.

There are many more stories like Fiona's. When they are in a good place emotionally, people with Down syndrome are generally very sociable. Those in their inner circle may worry about how easily they approach strangers. Nevertheless, it's important to remember that the way they welcome the world with open arms is what makes them such interesting people in the first place. In that sense, we shouldn't regard their typically carefree nature as an issue. While it may be a stretch to call it 'our

problem', it is essentially up to us to embrace them—carefree spontaneity and all. For caseworkers and other healthcare professionals, the 21st century buzzword is **inclusion**. Inclusion means society adapting so people with Down syndrome can be fully themselves and get a proper seat at the table. In other words, it is up to us to drive that change and manage our expectations.

Of course, that doesn't mean that we as parents, teachers, and other involved adults shouldn't teach a child the limits of what is acceptable—that is at the core of our role as educators. When a parent thinks their son is being too pushy, it's their job to correct him in such a way that he will know better next time. Whether or not the son has Down syndrome shouldn't matter. However, when the child does have Down syndrome, it is important that we manage our own expectations around their carefree nature.

preview



Many contextual changes (in adolescence and young adulthood)

Besides the physical changes and often tumultuous development of our identity, we also experience other changes between the ages of 15 and 30, both in ourselves and in our environment. For many of us, this is a crucial stage during which we make a number of decisions that will shape much of our future. Growing up, we usually share our lives with parents and siblings. Once we reach adolescence, some of us will enter into a romantic relationship with someone who we want to spend the rest of our lives with. As young adults, many of us graduate from school and our social circle changes from fellow students to coworkers. We move out and find a home of our own. Some of them will have a child by the age of 25. In other words, our lives change more between the ages of 15 and 30 than they do in all the years before and afterward.

Cooper...

Cooper is twenty three and he has a close relationship with his family, especially with his only sibling, Emma. Both of his parents have always held demanding jobs, and it was Emma's job to watch her baby brother during countless school holidays and summer breaks.

They shared the same room—even the same bed—for a long time. Mom always knew this would become an issue sooner or later, and regularly brought up the subject with her daughter. Like any teenage girl, Emma really wanted a room of her own. She has struggled with her desire for privacy since she was fourteen, but compassion and concern for her brother won out every time. Her parent's friends have warned them countless times that Emma would be moving out one day, but they never found a way to factor that into their planning.

Two years ago, Cooper transitioned from a special needs school to adult care. Every weekday, he is working at the adult care center down the road. The van picks him up at home every morning and he is dropped off in the early evening. Cooper isn't very verbal and he mostly keeps to himself. His final school days were relatively uneventful, but he did have a really hard time saying goodbye to his teacher, Josh. For over ten years, Josh had been Cooper's guardian angel. Every time he had issues at school, Josh was there to give him a pep talk or to calm him down. "Cooper always thought very highly of Josh," his mother says.

There are no issues whatsoever at the adult care center, their psychologist assures us, but his behavior at home is a different matter. There, he exhibits "difficult and aggressive behavior." When we meet at the adult care center, his mother sums it up as follows: "Cooper will only wear certain sweaters. It doesn't matter if they are weather-appropriate or worn to rags. He also insists on turning off the heat, even in winter. It is not easy to trick him, and he gets very upset when he notices." His mother continues: "He's always been good about shower hygiene, but it's really getting out of control. If it were up to him, he would use a whole bottle of shower gel every time. He's always looking for our shampoo stash, too. The other day, he was walking around the house, all wet and soaped up, looking for more shower gel." The following week, his psychologist tells me Cooper has also developed bedtime routine issues ever since Emma moved out. He keeps wanting to turn off all the lights, so his parents will go upstairs early to make sure Cooper does the same. Then they wait until he's finished his 45-minute bedtime routine, and they sneak back downstairs after he has fallen asleep. If Cooper happens to notice, he gets out of bed and the whole saga starts all over again.

Emma moved in with her boyfriend three years ago. At the time, Cooper spent school nights at his boarding school on weekdays. She initially returned home every weekend so Cooper wouldn't notice

she had moved out. Of course, now that he spends every night at home, the cat is out of the bag and he realizes that Emma has moved out for good. These days, when Emma and her boyfriend come to visit, Cooper sits down in between them.

In the previous chapter on psychological functioning, I have discussed in some detail that dealing with change isn't exactly a core competency of people with Down syndrome. Much like Cooper, many young people with Down syndrome have to learn to cope with a great deal of drastic change. Leaving school to start life among adults, siblings moving out, the first grandchildren being born, perhaps the death of a grandparent... We recognize that this is part of life, but for people with Down syndrome, these events put incredible pressure on their psychological script. To Cooper, graduating from school and starting at the adult care center doesn't merely constitute a change in his existing psychological script, it rather requires an entirely new one.

It is understandable that people with Down syndrome struggle with the many changes that typify adolescence and young adulthood. The context of their everyday life is undergoing so many changes that they have trouble structuring and processing their ever-shifting reality. And because these events are a part of life, there is very little we can do to protect them from that reality. Adults can't stay in school indefinitely, and sisters don't usually spend the rest of their lives living with their younger brother. Later on, I will make some suggestions on how we can deal with these vulnerabilities. As a preview, below I share some excerpts from my report for Cooper's parents and caseworkers.

"...Like many people with intellectual disabilities, Cooper is experiencing delayed cognitive puberty. Despite the fact that he's physically mature, he is only now experiencing the cognitive difficulties connected to his identity and personality development. This explains in part why many of the issues he struggles with take place in the home and target his parents specifically. While knowing that Cooper is experiencing the same emotional turbulence any other teen faces doesn't offer a solution to his behavioral issues, it does make it easier to understand..."

"...We have to realize that Cooper's life has been turned upside down over the past three years. We know his need for structure is a major vulnerability of his and we are expecting a lot from him. His psychological script has basically been thrown out the window. One way to understand this is by seeing all these desired and unwanted changes as a multitude of losses. Let's list the most important ones: The relationship with his sister Emma has undergone major changes. Emma has moved out, Cooper now sleeps alone, and his sister's boyfriend represents serious competition for her affection. I suspect this is linked to his bedtime routine issues. In addition, Cooper has suddenly had to leave his familiar life at school, and all the relationships he had built. His mother describes the ending of his close relationship with Josh as especially upsetting. Then there's his moving back home to live there full-time, after all those years..."

About getting older and confused

Ethan...

Getting dressed no longer means struggling to put on his jeans. His weight is no longer an issue, Ethan has shed many pounds. People who haven't seen him for a while feel like Ethan has aged more than ten years in the past two. In the old days, everyone used to worry about him being overweight—his sister more so than anyone. Nowadays, it is the opposite. His caseworkers keep a close eye on the weight, because they don't want him to get any skinnier. By now, Ethan receives more medical screenings than any of his fellow group home residents, because the staff wants to exclude any medical reasons for his weight loss. Fortunately, every doctor he has seen has given him a clean bill of health. His caseworkers have come to the conclusion that Ethan simply ages quickly and early in life, as is the case for many people with Down syndrome.

Although his passions have not changed— he still loves Michael Jackson and worries about the environment—they are nowhere near as all-encompassing as they were five years ago. There are occasional flashbacks, but Ethan now rarely spends days or even weeks preoccupied with big plans and major projects. Ethan used to spend almost every waking hour dreaming up all kinds of ideas. Now, he increasingly withdraws to his room, sits in his chair and stares into space. He doesn't bother anyone anymore. Many of his caseworkers experience a sense of nostalgia when they recall the endless discussions they used to have. But they don't miss the countless hours they spent explaining how his ideas were "once again unattainable and unrealistic".

His current behavior is best described as 'blunted.' Everything seems more subdued. What used to make him laugh out loud now barely draws a smile. The mischievous fire in his eyes has disappeared, and all that's left is a blank stare. Enthusiasm has made way for apathy. His once rich imagination has deteriorated to stereotypical habits and rituals. His self-confidence and poise are all but gone, replaced by confusion and insecurity.

The latter is especially worrying. His helpless wandering around the parking lot during his birthday party is the latest in a number of similarly confused episodes that made his last few months at the group home quite problematic.

This particular January is definitely earning its reputation as the darkest month of the year. The days are short to begin with, but dark clouds obscuring the limited sunlight make the days even more dreary. Ethan soldiers on through the long winter, generally going to bed extremely early. When caseworker Jay stops by at six thirty one night, Ethan is already in bed. Several of Jay's coworkers have mentioned Ethan's increasingly earlier bedtime at the latest staff meeting. And even though he knows his own sleep cycle is not a valid frame of reference, Jay still feels six thirty is much too early. He immediately notices Ethan is merely staring at the ceiling, and he tries to get through to him. "Come on, Ethan. You've got your wires crossed!" Ethan jerks up, as if waking from a nightmare. All he can say is, "Huh?" He obediently removes the comforter and struggles to sit upright. "Did you think it was time for bed already?" Jay continues. "Nah, man. Not yet. Your show hasn't even started," Jay says, trying to cheer him up. Ethan silently shuffles towards the couch to watch TV 'as requested,' but his blank stare betrays that he doesn't even register what is happening on screen. Jay leaves after an hour. He hasn't even gotten into his car yet when Ethan quietly drags himself back to his bedroom.

Ethan has trouble sleeping. He dozes off eventually, but not for long. Nobody knows Ethan hasn't slept well in ages, and tonight is no exception. All of a sudden, he wakes up wondering if his mother is there. She passed away more than twenty years ago, but Ethan has been losing track of time lately. He gets up to use the bathroom, feeling quite drowsy. Then he makes his way to the kitchen and sits down at the breakfast table. As usual, Lisa already set it last night. "It's still dark out... But that's normal in winter," Ethan figures. He is always the first one down for breakfast, but today he fails to realize how quiet the house still is. The next step in Ethan's morning routine is to deliver the grocery cart to the facility's central kitchen, a few hundred yards down the road. He doesn't think to change out of his pyjamas or to grab the key. He downs the last of his milk, closes the front door behind him and hurriedly sets off for the facility, dressed only in pajamas and house slippers. He's not exactly dressed for the weather but doesn't notice the bitter cold. However, he does think it is strange that the light is not on in the facility's central kitchen. Ethan presses his face up against the window, but it is pitch black inside. Even now, he hasn't noticed he forgot to bring the cart—the whole reason for his trip. Another thing that strikes him as odd is how there's no cat stalking around the facility courtyard.

Ethan doesn't move for a few minutes... He knows something is off, but he isn't clearheaded enough to realize what's going on. It's like he's trapped inside his own head, unable to think beyond, "There's something strange going on around here!" He starts moving his body without him consciously deciding to do so. He just keeps on walking, heading down the facility grounds and back towards the road. It feels like his body is in full control while his mind is just along for the ride, unable to question or influence what's going on. Ethan just keeps on walking... After quite a while, something clicks and he suddenly realizes he is cold. "I want to go home," he thinks. He looks around, but he doesn't recognize the street he is on or any of the houses. For a fleeting moment, his mind clears enough for him to worry. He turns around and picks up the pace, not knowing at all if he is going in the right direction.

By now, Lisa is awake. The eldest resident, she is in charge of Ethan's group home. Lisa's disabilities are very minor and she is a reliable help to the staff members when it comes to running the household and informing them when issues come up. She immediately notices someone already has had breakfast: the bread bag is left open, the table is covered in crumbs, and there is a trail of milk leading to Ethan's cup. Lisa quickly checks his room. When she notices Ethan is not in bed, she immediately realizes there is a serious problem. She hurries to the phone to call the staff member on duty, something she does almost every day. The staff has mixed feelings about that. On the one hand, they're counting on Lisa to quickly sound the alarm in case of trouble. On the other hand, this routine also serves to reinforce her dominant position in the household and her reputation as a bossy tattletale.

"Ethan's not in his room! He's missing!" Lisa yells into the phone. Jay—still in bed, after all, it is six thirty in the morning—immediately realizes Lisa wouldn't lie about this. He gets dressed while they talk, assuring her he'll be there in fifteen minutes. Once in the car, Jay goes through his mental to-do list and considers who to inform. Lisa and the other residents, who have been woken up by all the commotion, are waiting for him by the front door. After a quick check of the house and garden, Jay comes to the same conclusion as Lisa: "Ethan is missing!" Jay tries to reach as many of his coworkers as possible and then informs the managing director, who immediately calls the police. The search starts about thirty minutes later.

By now, Ethan is really cold. He's walking down a country road, and the only houses in sight are all far away. He no longer realizes those houses represent an opportunity to ask for help. Quite the opposite—Ethan's afraid their residents might be angry with him. Down the road, a farmer crossing to feed his animals notices Ethan, whose bright yellow pyjamas stand out in the twilight of early dawn. He tentatively makes his way over, then realizes he's looking at a person with disabilities. Even though the farmer is friendly, Ethan shies away when he notices him. Fortunately, the farmer has his cell phone on him and he immediately calls 911. He tries to get close, but Ethan just keeps running, faster and faster. The farmer struggles to keep Ethan in his sights.

While worriedly searching the block, the managing director gets a phone call from the police. "We've found your resident, sir!" the dispatcher says cheerfully. "You can come pick him up at the station. He's recovering from the cold, but he seems fine. A little confused, though..."

These past few months, Ethan's lucid times have been interspersed with episodes of confusion and disorientation. The abovementioned incident was the final straw. Interrupted sleep cycles, angry outbursts seemingly out of nowhere, crossing the road without looking, getting lost in familiar places... All of these were signs Ethan needed permanent supervision.

Real-time shutdowns

Professional experience has taught me that people with Down syndrome sometimes have difficulties dealing with transitions *in real-time*, which leads to a mental or physical shutdown. Transitions are unexpected disturbances of the psychological script; moments marking the shift to a new paragraph.

When people with Down syndrome are caught up in their own world, a simple question, comment, or expectation is actually a difficult changeover for them: instead of the paragraph they were expecting, they now have to deal with an unexpected, unknown addition to the psychological script. This real-time changeover from the familiar to the unknown may lead to a shutdown involving problematic behavior.

Fatima...

Fatima is 3.5 years old and is about to join a preschool playgroup. Her parents describe her as a happy toddler, generally outgoing and very talkative—even though she can be hard to understand at times. She gets along quite well with her older brother, although he tends to give in to her more often in times of stress—and gets extensively complimented for it by their parents. The whole family is anxious about Fatima's first day meeting the other kids. Nevertheless, her parents feel like all will turn out right in the end.

The first few months go by quietly. Literally, that is. Fatima seems generally uninterested and doesn't say a word. Every morning, her exasperated teachers see her undergo a total transformation after she has said goodbye to her parents: in mere seconds, she'll go from a happily smiling chatterbox to being silent and withdrawn. When one of her parents comes to pick her up after school, the process repeats itself in reverse. There are a few moments throughout the day when Fatima does break that silence, though.

The transition from recess back into the classroom is especially difficult. Miss Tina explains: "Fatima usually spends recess by herself, sitting on a bench in the far corner. When the bell rings at the end of recess, she won't move a muscle. The recess aid's patience and gentle approach are of no help: time and time again, we have to physically escort Fatima back to the classroom, and she yells and cries all the way. After recess, she spends the first 30 minutes hiding in the play corner, and we can't do anything about it. No matter what class activity we start, she refuses to take part," Miss Tina grumbles.

Multi-stage communication can be helpful

True, multi-stage communication does require a mindset that is not always well aligned with our hectic lifestyle. It can be difficult to take some time when your child shuts down just as you're heading out the door to a party, or when a caseworker feels she needs to be in three places at once. Time pressure, frustration, and impatience are the biggest threats to successful multi-stage communication. In some sense, this is a bigger challenge for able-minded people than it is for people with Down syndrome.

Fatima...

Fatima has difficulties dealing with the transition from recess to class. In a school staff meeting after the team consulted with me, we agree on the following approach:

Recess supervisors on shift will take turns seeking out Fatima five minutes before recess ends, and they will gently point out to her where they will be standing when the bell rings. The message is practically the same every time: "I'll wave at you when the bell rings, so you can come up to me. We'll return inside holding hands on our way to the play corner, okay?"

Fatima's teachers have successfully implemented the three elements of multi-stage communication in their new approach. Five minutes before the end of recess, Fatima's teacher tells her the bell is about to ring, giving her **time** to get used to the idea of going back to class. She **prepares** Fatima by communicating on her level. The teachers make sure to always stand in the same place, and to clearly indicate that. Waving at Fatima also helps her understand and recognize what's going on. Finally, the new approach involves teachers showing **compassion** for young Fatima. Their interaction with her is gentle and takes place at her safe space in the corner of the schoolyard, and they have put in place a waving ritual specifically for her.

After several months, we meet again to evaluate the new approach. Once we get to discussing the transition from recess to class, the teachers all pitch in. In short, everyone likes the new approach but doesn't feel it's entirely doable all of the time. Miss Malia explains: "We rarely manage to talk to Fatima before recess is over. There's always something that needs our attention: someone really has to go to the bathroom, someone got hurt, or we need to break up a fight..." One of her coworkers nods, then freely admits she doesn't always remember the agreement.

However, everyone agrees that when they do manage to approach her in several steps, Fatima manages the transition much better. Miss Rita is last to add her two cents, and she neatly sums up the added value of the new approach. "I don't always manage it either, and when I don't, at least I know why she's struggling in class. Knowing that Fatima can't help it and that I'm at fault makes it easier for me to accept her withdrawing in the play corner. Last week, I let her put a frowny face sticker on my sweater because I "hadn't been a big girl". She seemed to enjoy admonishing the teacher that way."

Miss Rita's words are key here. Multi-stage communication doesn't always work. Sometimes, we just don't have the time, the energy, or the patience. However, the value of multi-stage communication is not measured in the number of times we manage to use it successfully. It is sufficient to try a multi-stage approach with people with Down syndrome whenever we *do* have the time, the energy, and the patience. Let us not use those impossible moments or situations as a reason not to use it at times that do allow for it.

Steak and fries, or spaghetti?

Everett, the forty-something with Down syndrome we talked about earlier, moved to an assisted living facility four years ago. He lives in a group home with four other people, all of whom have intellectual disabilities. Everett's living situation is called semi-independent, which means the home only receives a few hours of supervision daily. Everett's disability is very mild: he can read and understand simple texts, but has struggles with writing. He is outgoing and spontaneous, has lots of hobbies, and is normally the life of the party—especially when there is food and drink involved. In short, Everett enjoys life to the fullest.

One gloomy fall morning, Everett sits down for breakfast when caseworker Ivy enters, noticeably early. As usual, he walks up to her and gives her one of his signature bear hugs. Ivy usually takes the initiative to pull away, since Everett would be more than happy to spend the entire morning hugging her. Not today, though. Today, she just holds still and hugs Everett tightly. Confused, Everett pulls away himself this time, then looks at her in apprehension.

"Everett, I have good news and bad news," Ivy says gently. "The bad news is that today will be my last day..." Everett knows Maria will soon return to work as she returns from maternity leave. While he looks forward to Maria's return, he is sad that Ivy is leaving. He can be very picky, but Ivy has been Everett's favorite since her first day there. Although, to be honest, Everett tends to favor young blondes over middle-aged men...

Everett knows the days of the week, but it is very difficult for him to keep track of things over a period of several weeks or months. He sits back down at the breakfast table and stares out of the window into the misty garden. In an attempt to cheer Everett up, Ivy exclaims: "The good news is that we'll be having a goodbye party next Friday at your favorite place in town!" Everett's inner bon vivant is stronger than his misery, and he jumps up for another hug. In between the kisses and exclamations, he whispers that he's already looking forward to his steak and fries. Ivy doesn't even hear...

The next few days, Everett can't stop talking about his favorite caseworker's party. He and his fellow residents passionately debate important matters such as what to wear, what would be a suitable gift, and who gets to give it to her. Other conversations—led by Everett—focus on what everyone will have to eat.

The days fly by, and as his alarm goes off, Everett realizes it's Friday. His morning ritual is the same as it is every day: He sits up excruciatingly slowly—when he was in his early teens, the family doctor once told him he shouldn't get up too quickly to avoid fainting—and first stretches his arms, then his legs. He turns up the heat full blast, regardless of the time of year, and opens the window as far as it will go. The fact that Everett's caseworkers are perpetually upset with him wasting energy doesn't enter his mind. He spends 20 minutes thoroughly washing himself, using hot water all the time—another thing Ivy and the others have repeatedly admonished him about. Next, he carefully considers his different outfits for the day: one to go work on the farm, another to do the ironing this afternoon, and a party outfit for tonight's going away dinner. All three stacks are neatly arranged on his freshly made bed. Today, Everett doesn't remember to turn off the heating, and it takes him over 90 minutes to get ready for breakfast...

As the evening approaches, the dinner party guests gather at Everett's house. Eventually, 15 excited partygoers set out for the restaurant—Everett and Ivy walking arm in arm. Joe and Frank shoot the duo a jealous glance and try to conquer a place at her side as well, but Everett just glares at them.

As they come in, Everett takes a while saying hello to the entire restaurant staff, clearly differentiating between familiar faces and people he has never seen before. The former are on the receiving end of his signature bear hug, while the others have to do with a handshake. Once the formalities are concluded, Everett promptly sits down next to Ivy. Frank wants to sit on the other side of the guest of honor, but he quickly reconsiders after Everett glares at him again. Everett is obviously enjoying being around so much great food and beautiful women. The moment of truth has arrived: what to eat? Everett doesn't need a menu, though. He just whispers to Ivy that he will have the steak and fries. Ivy still doesn't realize he had already told her last week. While browsing the menu, she sees the restaurant offers fries, but no steak. She double-checks more carefully, to no avail. As she passes the menu to the next person, she says nonchalantly: "Would you like to pick something else, Everett? They don't serve steak here." He frowns as she hands him the menu, and he leaves the menu untouched.

After all, he's very busy with the important and serious job of waving at other patrons—mainly the female ones. Once Ivy is done helping Mary pick out her appetizer, she turns to Everett and asks him if he had a look at the menu. Surprised, Everett responds: "Sure, Ivy. I'll have the steak and fries." Thinking he may not have heard her over all the noise, Ivy gently repeats they don't serve steak here. She doesn't worry about it, since Everett is something of an omnivore.

By now, Ivy has turned to the other side to help Lily pick out her food and she doesn't notice Everett's bright smile fading into a suspicious scowl. Still, it doesn't take long for him to get back into the party mood, trading mischievous glances with the female clientele. After a few minutes, Ivy asks him if he's already had a look at the menu to pick something else. Everett doesn't say a word, so Ivy turns it up a notch and urges him to look at the menu. He knows she means business, and obediently lowers his head to stare at the menu in front of him. She decides to leave it for now...

Ivy turns back to the party, and doesn't notice Everett still staring into space, now growing pale. After a while, Ivy once again asks Everett if he's made his choice. That's when Maria joins the discussion, unaware of what came before. Even though she had felt bad about leaving her baby at daycare on her first day back at work, she soon felt at ease. "Everett, Mr. Very Hungry Caterpillar! What will you have?" He replies straight-faced, if somewhat baffled: "Steak and fries!" Ivy is obviously annoyed by now. "Everett, you know you can't have steak. You've seen for yourself that it's not on the menu. Come on, let's have a look for something else you like." Everett can't even look at the menu, still stubbornly staring into the distance. Ivy doesn't understand—she knows that despite his intellectual disabilities, Everett is smart enough to understand his request is impossible—but she still tries to help him pick something else. Everett just keeps staring straight ahead.

The others have all decided some time ago, and the waiter is ready to take everyone's orders. The others start to figure out about what's going on with Everett and Ivy, who is now desperately trying to get him to pick one of three options, including spaghetti with meat sauce. Everett just scowls: "Steak and fries!" From across the table, Finn shouts that he's tired of waiting for Everett to decide. The other caseworkers also voice their displeasure, telling Everett it had gone on long enough. In one final attempt, Ivy tries to convince Everett to have the spaghetti. Everett doesn't reply one way or another, so the others signal for the waiter.

As he makes his way down the long table, the other party guests excitedly tell him their choice of meal. Then he comes to Everett, who is a regular at the restaurant. The waiter smiles at him: "Everett, buddy, what will you have?" Everett looks up, his voice nearly a desperate whisper. "Steak and fries, please." The waiter's smile falters. "Everett, I'm so sorry. I don't have any steak, not even in the fridge.

If you'd asked me yesterday to prepare a steak for you tonight, I would have done so gladly." Ivy comes to his aid: *"It's no big deal, though. Everett also likes spaghetti, so he'll have that tonight."* The waiter moves on to take the next order, and Everett still doesn't say a word. The others simply don't understand why he's acting this way...

Everett was all smiles at the start of the evening, but none of that remains. He just stares at his empty service plate, pale and mumbling: "Steak and fries... Spaghetti... Steak and fries... Spaghetti... Steak and fries... Spaghetti..." He keeps mumbling for a minute or two, as if he's recalibrating after this unexpected shift. He's been looking forward to having steak and fries for over a week, and they suddenly expect him to have spaghetti instead. He ponders the matter for another fifteen minutes, the fun passing him by entirely...

Twenty minutes later, as the appetizers are served, he shows a tentative smile. It doesn't take very long for Everett to get back to his usual party mood, enthusiastic and extraverted as ever. 'Steak gate' is long forgotten, and Ivy is having a great time.

Sometime later, the noise dies down as everyone focuses on their meal. One by one, the dishes are served. Then the kitchen door slams open and their waiter rushes in excitedly, holding a single plate. He beams as he holds the plate up high, making a bee line for Everett. "Hey Everett, I have a surprise for you! Guess what? That's right: steak and fries! I felt bad for you, so my sister-in-law made it work and managed to prepare your favorite dish." Everyone is loving this ending to the story, commenting how the waiter truly went above and beyond to get Everett his favorite after all.

However, their excitement quickly fades when they notice Everett staring at his plate in dismay. He looks up at the waiter: "But... I ordered spaghetti." The others can't believe their ears, and many get upset. *"Talk about being ungrateful! The nerve! What a spoiled brat! If my kids dared to pull anything like that..."* the caseworkers exclaim. Distressed, Ivy tries to salvage the situation: *"Thanks so much! Everett's just a little confused, but he's really happy about the steak..."* she calls after the waiter, who has turned away in disappointment.

As for Everett, he doesn't understand why everyone's so upset. He keeps looking back and forth between the astonished waiter and the steak in front of them. Now that the worst of the outrage has passed, none of them can resist the delicious food they were served. Everett stares at his plate for another few minutes, but the others are too engrossed in their dinner to notice.

After a while, Everett takes a tentative bite of his steak and soon overcomes his hesitation. He even finishes his food before everyone else, proceeding to lick the plate clean as usual. After all these years, the facility staff has given up on telling him that is inappropriate when eating out...

The rest of the party is uneventful, and Everett's disappointment is a thing of the past. He's almost back to his old self again. When they return to the group home, everyone has all but forgotten the whole episode, although Everett still doesn't understand why they were so angry with him... Still basking in the afterglow of the evening, Ivy whispers to Maria that it was fun. Maria nods in agreement, adding that Everett was a little more quiet than usual...

If you want to know more about how we can help Everett and other people with Down Syndrome in difficult situations..., you can find some answers in “Don’t let me Down. Down syndrome through a different lens.”.

Best regards!

Karel De Corte

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