Together

A tribute to our
experts by experience

By Hannelies Hokke

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Colophon

Bartiméus

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Dedicated to all our
experts by experience

Preface

It has been a great joy and an honour to record the stories told by our experts by experience. And I see this publication as a means to pay homage to all hands-on experts. They enrich the work we do at the Collaborative Centre Affect-us, with their lucid and down to earth points of view. They know what it is to grow up with a disability and how challenging it can be to find one's place in the world. They travel a path that demands great resilience; that has been made clear in the stories they have shared with me.

Almost all experts by experience point out that they appreciate being able to contribute to the work done by Affect-us, to our various projects and to the lives of other people with disabilities.

A few random quotes from the moving and hopeful stories in this book:

"I feel I am really a member of the Affect-us team. My opinions count".

"It matters when I can make a difference".

"I can explain what it is like, to have a visual impairment and a learning disability. And so I may be able to help other clients who cannot make their voice be heard".

"It makes me happy to know that I am helping others".

"Most importantly: Affect-us gives me a sense of belonging!"

A heartfelt Thank You to all experience experts (including the ones whose stories were not shared in this book), for their contribution to Affect-us, which helps improve the overall care for people with a visual impairment and/or learning disability.

With the final quote in mind, may I add:

Most importantly: we belong together!

Hannelies

Prologue

Our wish is to help improve the care for persons with disabilities! At the Collaborative Centre Affect-us we collaborate to develop products (including interventions, questionnaires, apps and games) and to test and implement them. These products aim to improve social interaction and attachment.
We partly do this together with experts by experience. This book contains a collection of stories that several experts by experience have shared. Each story is unique. What they all demonstrate is an ability to rise above, and overcome adversity, to live passionately and to joyfully employ talents to help others.

All interviewees are experts by experience working with Affect-us. They are part of three separate co-researchers groups. Ten experts by experience convene every fortnight as part of the "Bartiméus researches..." a client forum. Another group of experts by experience meet monthly at Ons Tweede Thuis (Our Second Home) and Odion. Here Mark, who has been actively involved as an expert by experience for almost 10 years, has recently handed over the gavel to newcomer David.
A third group is active at De Twentse Zorgcentra (Care Centres Twente). Here, the experts by experience are part of the E-team, responsible for interviewing other users of the care system as part of ongoing research and assessment.

The stories reveal how people started out as experts by experience at Affect-us. And what the work as an expert by experience entails. The guiding principle is: everyone is unique and every one matters.
Every individual contributes in his/her own way and we value and cherish that.

In every group there are people who assist in building bridges between the research team and the experts by experience. They offer the professional support needed to ensure that everyone can effectively use their talents. It is important not to demand or to expect too much, while still inviting people to push their boundaries.

Key words are: take your time, be supportive, show respect, be committed, see the person!
All the experts by experience try to empathise with other people with disabilities, so that they may actively think along about what might be agreeable and feasible for these persons. And so, they effectively become “the other person’s voice”.

I am immensely proud of our experts by experience and of the people who offer them support and guidance. TOGETHER we are committed to improve the quality of care.

Paula Sterkenburg, endowed professor and coordinator at Affect-us

Doorn
2025

Contents

His place in the world

“Because of my kidney disorder I have always been a special case. I was used to not being ordinary. And frankly, I am not sure if I should like to be ordinary. Ordinary is a bit dull, really”.

The door swings open and I am welcomed by Mark and “the hairy managing director”: a cat who chose to stay with Mark when his previous owner moved out. He is a loyal and convivial housemate who makes Mark feel very much at home. They get on well together in Amstelveen.

Mark has been involved as a co-researcher with Affect-us, from the very beginning. It is his job and it is pretty demanding. Workshops, presentations, helping prepare for new research projects, simplifying questionnaires, you name it.

He is very eloquent, telling me about his life and how he first got involved with Affect-us. Born in 1976 in a village in the province of North-Holland, he did most of his growing up in hospital. According to his mother, he cried a lot as an infant and when he was admitted to hospital, aged 2 months, he was diagnosed with a rare kidney disease. Medical treatment started there and then and he is still on the same medication now. “A life sentence”, is his comment.

It was hard for him to keep up at nursery school. So at age 6 he was referred to a special needs school in the Western part of Amsterdam. Special needs transport by taxi was provided. The bullying that went on during these daily trips, still preys on his mind. At first, he tried to resolve matters but as the bullying continued, he tried to avoid attending school by calling in sick. His parents discovered what had been going on and they decided to cancel the transport arrangements.

At age 11 his mother took him on trial runs, using public transport to get to the school. And after a few weeks he was able to travel alone. He may have seemed like a vulnerable child, but in fact he was very proud of his achievement, taking the bus to travel to school.
Looking back, he says that being bullied had been awful, but that it caused no lasting trauma. “I have closed that chapter”, is his firm conclusion.

At secondary school he was placed in a special class for pupils selected for referral to a mainstream school. “But I always finished any given task last; I could not keep up with the other pupils in special class”. He was aware of it at the time, but it did not bother him very much. The school was a safe and positive environment: what worked was more important than what did not work. His parents also supported him, saying that nobody is perfect: everyone has his or her own issues and many roads lead to Rome.

His big dream was to become a master gardener. His father was a carpenter and during school holidays, Mark was sometimes allowed to go with him to the building site. On one such occasion, he was asked to help restore a neglected garden. That is how he discovered the joys of gardening. The plan was to finish secondary school and then to train to become a gardener. Everything was in position to fulfil his dream. But then during an internship it was found that the physical work would be too taxing for him, due to his kidney complaints. The doctors strongly advised against it. Everything fell to pieces. And he struggled for years on end to find his bearings again.

He found an internship with a chain of supermarkets and ended up working there for a period of 10 years. On hindsight, these were not happy years. The workload gradually increased and became quite a burden. It was a dark period, he suffered from stress and exhaustion and his kidney problems also got worse, badly affecting his ability to do the job.

After rapidly completing the training programme at Ons Tweede Thuis (OTT, Our Second Home), he exchanged his rooms for a flat in an assisted living facility. He enjoyed living at both places and gradually he got back on his feet. He joined the participation council at OTT and it turned out he had talent for the work. Mark loved to contribute ideas and, in his own words: “has the gift of the gab” - so he was well able to put into words his views and opinions.

Somehow, he got wind of this training course for experts by experience. And he immediately knew it was what he wanted. The course was quite demanding. It addressed many issues and held up the proverbial mirror for him, so he had a good look at himself. One of the questions raised during the course, was what he was looking for in work. “A challenge”, was his answer. “I’m done with having everything ready and waiting for me”. So, he was given a proper challenge. He was asked for his first assignment at Affect-us before completing his training. As a member of the selection committee, he helped interview potential researchers and he was involved in the product development of the serious game “You & I”.
The pioneering role suits him well. Sharing of thoughts on new research projects and letting ideas come bubbling to the surface - it fits him like a glove. Mark is very pleased to be able to represent a group of people. And he is very conscientious about it. Playing an active part in the process makes him feel good. Sometimes an article will have his name included in the list of authors. “Naturally that makes me feel proud”.

Perhaps what matters most: “I am a full member of the Affect-us team. My opinions count”.

It’s hard to pinpoint a highlight in his work as co-researcher but if called to do so, he would say it was his presentation at a congress in Glasgow. He had attended an international conference before, but had not dared speak much in English at the time. In Glasgow he changed track and gave a presentation in English. “That was a day of great personal growth. A bit like that research project about ‘trusting others’. In Glasgow I was joined by a great team. I knew I could afford to trip and fall, and trusted that they would have my back”.

Qualifying as a gardener did not work out. But Mark has found his place at Affect-us. And if you were to see the work at Affect-us as a form of gardening, then this collaborative centre has obtained a master gardener. Mark offers ideas for the design, takes care of the hoeing and weeding and adds a bit of aroma and colour.

Amstelveen
2023

Researcher

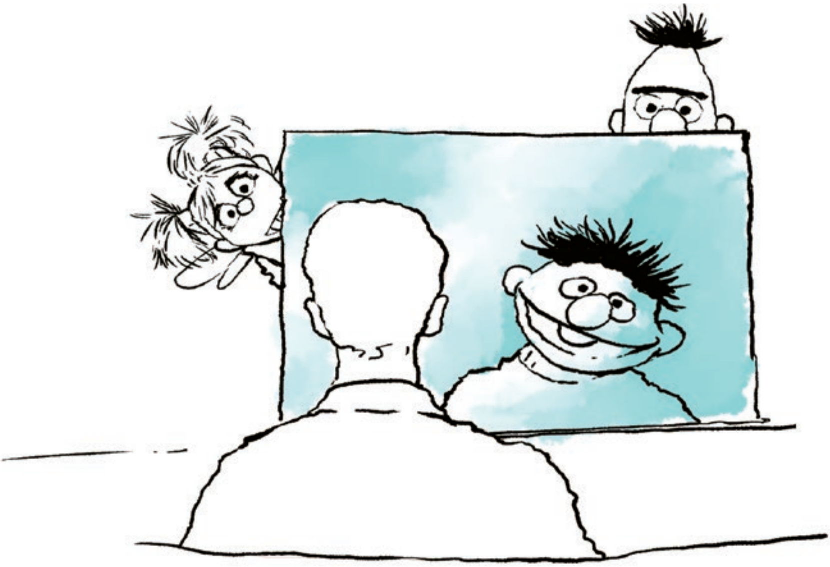
We are happy to introduce to you our specialist in aids and devices for people with a visual impairment: Mitchell, aged 31, lives at Bartiméus in Doorn and is as an expert by experience member of the "Bartiméus researches…" group. He is not a very chatty person, but research skills are in his blood. And even if his impaired vision only allows him to distinguish light from dark, he is a champ at navigating the internet. A webbox provides easy access to the internet and he uses it to search for the latest news and trends in visual aids. Mitchell loves to keep everyone informed about the latest developments in that area and that is when he demonstrates his skills as a storyteller. With his knowledge on the subject, he is a great asset at the Fablab monthly open door days! All residents who have a visual impairment and/or a learning ability are welcome at Fablab, where they can find technological assistance to solve any queries or problems they may have.

Geeke has joined Mitchell to help him tell the story about his life. She is his trusted supervisor and has assisted him for over half his life. She helps him clarify questions, checks whether he has understood and asks if she may add to his story. It makes him feel safe to have her there with him.

He was born 31 years ago in the Bijlmer area of Amsterdam. Mulling over his childhood, he is at once reminded of the plane crash near his parental home. He was only a few weeks old when the plane crashed into high-rise apartment blocks and totally destroyed them. The impact it had on his parents and family has left a lasting impression on him.

When he was 5 years old, he was taken for observation to a centre for learning disabilities. There were some doubts about his personal development. He never went back home again. It was found that he had vision loss and a learning disability, caused by the Bardet-Biedl syndrome.

He has been living in a Bartiméus residence since he was 15 years old. Together with Geeke, he explored his visual impairment, his learning disability and the syndrome itself. Whenever Mitchell mentions Bardet-Biedl, Geeke knows that she must give him her full attention and spend time going over the subject with him. He is not at ease being disabled, having this



syndrome. And his way of overcoming his difficulties is by learning as much as he can about his condition. He can list the various symptoms without faltering. “Features of Bardet-Biedl are: a visual impairment, obesity, learning difficulties, having extra toes, loss of the sense of smell, kidney disease, getting upset more easily”.

His research skills and his memory are clearly not affected.

A stable factor in his life is the Sesame Street character Ernie. Ernie’s playful and joyous disposition makes Mitchell feel happy. For years, his room has been modelled on Sesame Street, featuring Bert and Ernie in sunny shades of yellow and orange. And quite a few other favourite characters too. Whenever Abby is mentioned, Mitchell instantly turns from a shy and introverted man into a lively storyteller.

Abby Cadabby is a fairylike Sesame Street character who dabbles in magic and has stolen Mitchell’s heart. Her name is inspired by “abracadabra” and her skills and qualities mean a lot to Mitchell. Whenever he is feeling a bit down or upset, he will go to his room to find comfort with Abby. Geeke and other supervisors will give the puppets a voice to engage with him. It's a game they play to reach out to Mitchell.

During the Covid pandemic, Mitchell found an appeal on “I am online” (Bartiméus' own intranet) to join a research panel. That is how he got involved in research about Time and in a project called “Robot Bart stops stress”. Mitchell explains that he is able to give the researchers useful tips as to what they should adapt, so that questionnaires are made easier to understand for people with learning disabilities.

He enjoys collaborating in the research projects and he is always learning something new. During the interview for this publication, he gradually opens up. ‘I've met some really nice people at “Bartiméus researches…” and there is never a dull moment. People listen to what I have to say and I can really be of help. By helping others, I know I am doing something of importance!”

Doorn
2024

Simply

Sure, he is willing to give an interview - but it has to be brief. There is work to do. And Leroy loves to get the work done. The people at Spoorzicht, the work experience and training center at Ons Tweede Thuis (OTT) must love him, because he is Action personified. He works in catering in the kitchen and he also often helps in the workshop, packing orders. No matter the job, he enjoys doing it.

He does not remember much about his childhood, but he does remember coming to live at OTT because of a learning disability. “I am very open about the disability, I don't mind. But I'd rather talk about other things”. About simply being fond of his work, about simply being really happy with the apartment where he has been living these past five years. And about simply having learned to stand on his own two feet. Moving from a group-unit into an apartment where he is almost fully self-reliant. His supervisors help Leroy with some of the chores and he has his meals in the restaurant. That is great, as he has a full-time job and it is good to be able to sit at the communal table for dinner.

After dinner he will do a few domestic chores, before settling down on the couch to chill out: watch a film or play a game. Gaming has helped him master the English language. “It’s best to be chill in life - not to fuss and worry”.

It is with this chill attitude that he joined the team at Affect-us. He helped develop the serious game “You & I”. And Leroy is often seen and heard at presentations where he explains about the contributions that he and the other experts by experience, make to research. He is now looking forward to help host a presentation for Summerschool students. He will address a large audience of international students who have come to Amsterdam from all over the world, in order to learn more about attachment. And he will be quite relaxed about it. It’s times like these that his command of the English language really is an asset! He helps to translate and also shares stories about his active involvement with Affect-us…in English! It’s another job he loves doing for Affect-us. “There is so much you can learn and it’s great meeting so many people. And yes….I am pretty proud that I can do all this”.

“If you don’t mind, I’d like to get to work now. Just write that I am truly and simply a very happy person”.

Well…”.simply” hardly covers it!

Nieuw-Vennep
2024

Happiness all the way

Ever heard of Yakety Sax? It's a complicated instrumental for the saxophone. If you're lucky, you'll get to hear it in Volendam. When Gudy is in a good mood, she opts for this piece and her fingers hit the saxophone keys like lightning. Her parents died, one after the other, a few years ago. When she is overwhelmed by the sense of missing, she prefers to play a Bruce Springsteen solo. "That's when I really break loose. And I tend to hit repeat and play the Bruce number several times in a row".

Volendam is known as the village in the Netherlands of music and fish and of singer-entertainer Jan Smit. It's also Gudy's native village. She has lived here for 36 years, all her life. "I'd do murder for an eel sandwich", she jokes. "I used to live in the same street as Jan Smit. He was practically my neighbour". Jan's dad and her own used to be fishermen and worked the same trawler. Hard work, long hours away from home. When Gudy was born, her father opted for an onshore job.

Beaming with pride she shows us her flat in an assisted living facility run by care organisation Odion. And she points out her two shiny saxophones. Reaching out to one of the instruments, she declares that it is 'happiness all the way' when she plays. Making music is her passion and her life. The walls in her room are hung with her own artwork. A painting inspired by CoBrA. Pieces of ceramic art sit on the windowsills. She has a day job at Fred's giftshop, a centre for people with disabilities. It's where she can maximise her personal competence. She was deprived of oxygen during birth, which led to a mild learning disability.

It was never a problem at home, as she recalls. "That's simply how it was. And I don't try to hide it. But I'll only open up to someone about my learning disability when I get to know them a bit better".

Her parents included her in everything and taught her a lot. Managing her finances is the only real challenge; a cousin helps her with that. If something urgent comes up, she can get help from one of the supervisors of Odion, who are there on a day-to-day basis. And she can also turn to her family for support.

A while ago, a neighbour asked if she would be interested in becoming an expert by experience. As Gudy loves a chance to broaden her horizon, she jumped at the offer. She became an expert by experience and was soon involved with Affect-us. She has already played a major part in helping shape projects like Mentalisation and Epistemic Trust. Her creative input is also appreciated. The Affect-logo is based on one of her sketched ideas. Her own personal experiences feed a keen ambition to set up a research project on mourning strategies.

Naturally, she is at her best whenever creative input is required. She has previously entertained guests with her saxophone, playing at an Affect-us network meeting. And this year's Christmas card featured one of her drawings: Summer Santa, Father Christmas in a bathing suit. Apart from her work in the giftshop, she loves to participate in research projects as an expert by experience.

“I am always chatting away and that suits the job. I get to share my story, my feelings and my experiences. That's a great feeling”.

She ends by playing a tune on her saxophone. Her father always used to say: “You can have a good conversation with a saxophone”. Same goes for Gudy, actually. As she proves when we say goodbye:

“This is my life. It's who I am, it's what I can do and this is what I do”.

Volendam
2024

Wings

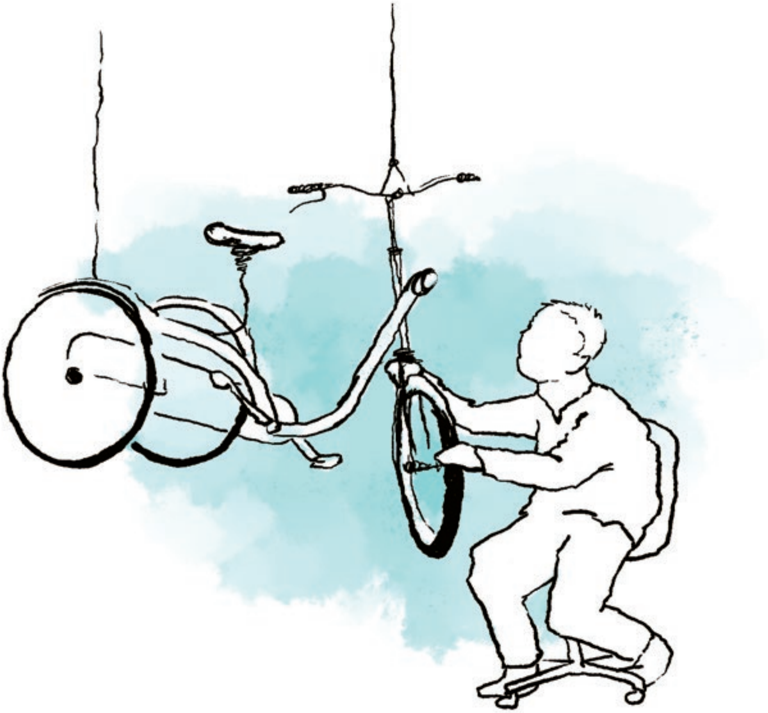
Ducks are unique creatures. They feel at home on land, but also in the water. In many cultures they are seen as symbols of resilience and balance. As you enter Johan's place, you'll immediately see a display cabinet with a collection of ducks in all sorts of shapes and sizes. He has been collecting them for ages. Johan says that he loves the way they sound: cheerful and content. "You should listen to them with your eyes closed", he suggests.

He was born in The Hague in 1977, near the Westland area. Born into a warm nest with two older brothers who were ten and twelve years old when Johan arrived. To them, he will always remain their little brother. And Johan does not mind; they are very fond of each other.

He started visiting the rehabilitation centre when he was a small boy, as he needed extra help learning to speak and walk. When he was five, he had surgery on his hand and his foot. A sixth finger and a toe were removed. That is when Johan's parents were told that he had Bardet-Biedl syndrome, a genetic disorder. The syndrome often affects vision. Johan does not remember much about it, but he did have some vision as a child. His vision gradually deteriorated until he was functionally blind at age 15. How that affected him? "Oh well, that's just how it is. No use getting upset about it". He knows quite a few people who have suffered vision loss. "Most of them are not as accepting as I was at the time", says Johan. "They'll either get angry or feel sad and uneasy. Of course, I quite understand, but it's really not helpful".

At age 18, he started going to an activity centre. Whole days filled with nothing. An activity centre with no activities for him. They did not know what to do with a person who is blind. "That was not a success. Fortunately, I now live at Bartiméus. Lots on offer for me here", he beams.

In 2002, rooms in one of the Driebergen residential facilities became available. It appealed to him.



“At age 24, I wanted to live by myself. OK yes, with a little help”. He describes his parents as caring people. His mother used to do everything for him: fix his sandwiches, dish out his food, clean up after him. “When I came to live in Driebergen, I was completely useless. The supervisors had to do everything for me”. But step by step, he achieved greater self-sufficiency. A mobility coach helped him find his way to the shops. And now he is able to prepare his own meals and he has mastered the skills of independent living. He can even take the train to visit his family in The Hague, thanks to the National Rail passenger assistance service. He has grown from a person who was fully looked after to a person who can stand on his own two feet and can take part in society.

Johan lives in an apartment building for people with visual-and-learning disabilities in the country’s central region. He has a job at the Bartiméus bicycle repair shop, but he is also active at the creative studio. He makes ceramics and his pottery bowls are sold at the giftshop and find their way into many local homes. He also likes to keep fit and exercises twice a week with fellow Bardet-Biedle patients.

And of course there is always a lot to get on with at home. The laundry, cleaning and preparing food. He does not mind. It's all part of the routine. Evenings are for relaxation. Enough is enough. Although he is always up for an evening at the theatre or dinner in a restaurant. He and his sister-in-law recently attended Aïda, the musical at the Circus Theatre. A fantastic experience: for the first time the audiodescription app enabled him to follow what was happening on stage. He had already used to app with his favourite TV programme. In the theatre, it really made a huge difference.

An important theme is 'religion'. Every Sunday, a volunteer picks him up and they go to church together. God is a source of comfort to Johan. His faith shields him from loneliness. Even during the Covid pandemic, when he had to self-isolate 7 times over. Each time, he had been in contact with a colleague or a supervisor who tested positive. "And there I was again, all alone behind lock and key". A bleak period that he does not like to dwell on. "It's not right for someone to have to feel so lonely". But there were also moments during that period when he keenly felt the presence of God, and knew that he was not alone.

Apart from working at the studio and the bicycle repair shop, he is also actively involved with the client council and he contributes to the forum called 'Bartiméus researches...', currently helping shape a new Affect-us research project. His task is to assess voice computers, rating the quality and clarity of the voice. During the research into the "Smart Sock" he tested whether this sock was comfortable enough for people with severe learning disabilities. "It is good to be able to help. I can explain what it is like to have a visual-and-learning disability. I can be of great help to other clients who may not be able to express themselves. I can act as their voice".

This man, who calls himself a relaxed and contented person, is no longer tucked under a mother duck's wings. He has grown his own wings. He has spread them and he flies.

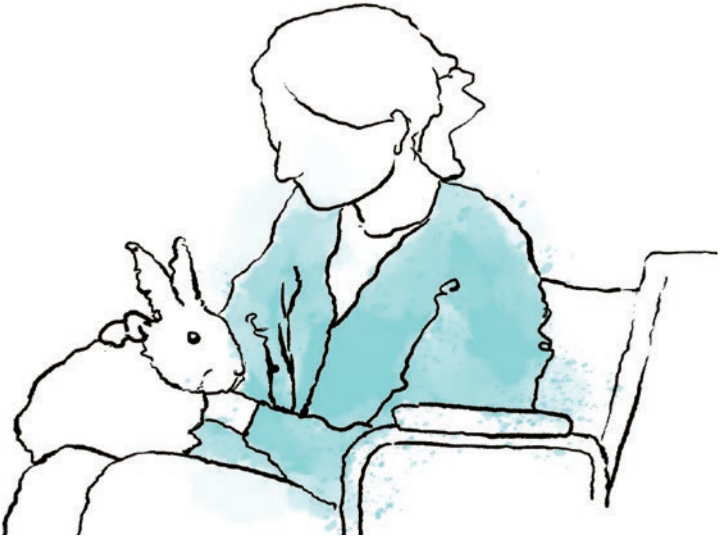
Driebergen
2023

Compassion

“Come in, so you can see who I am”, she says. As you enter the room, you have the impression of landing in a huge soft fuzzy pluche nest. Cuddly toys in all shapes and sizes, everywhere. Even a few interactive plush toys – purring cats and fluffy dogs with wagging tails – live in Melanie’s velvet room.

“Would you like to sit on the sofa? I shall ask Luna and Spooky to join me on the bed”. With a contagious laugh she explains that there is always room for more toys, even if it means she won’t have any space left to sit down herself. She is a proper animal lover. “I quite like people too”, she adds jokingly. “I love getting together and I make friends wherever I go”.

The feline robot toy helps her to settle down and relax, through its purring and the softness of its fur. “I hold him in my arms, day and night”. Even her doorbell reflects her need for softness: it chimes a smooth romantic guitar tune.



Her school days were not the easiest because, as she puts it, she could not get her head around things. She swotted away, but she simply could not keep up. She attended a great many different schools. The special needs school for children with a visual disability was great. But it was a long way from home so she had to board and she felt very homesick. She and her parents spent a long time searching for a suitable school. Some schools nearer to her home simply did not cater to the needs of visually impaired children, so Melanie was kept on her toes again. She finally found the right place at a school for vocational secondary training.

She was a weekly boarder at a group residence and went home on weekends. One of the other boarders had serious behavioural problems. Chairs and crockery would sometimes hit the walls. It frightened Melanie and so she had to look for yet another school and new accommodation. Eventually she enrolled at Bartiméus and found a place to live at the Tweesprong; a pleasant and convivial residential facility for young adults. From there she could venture out to more independent living arrangements. Melanie now has a self-contained flat and can ask for extra support when needed.

She has had a visual-and-learning disability from birth. For Melanie it is just part of life. She does find it hard to accept the fact that the physical symptoms are getting worse. “Walking is difficult and the muscle spasms are never welcome. My muscles are shortened and my leg muscle is hard as a stone. It’s very painful”. A wheelchair offers relief when the spasms come and the pain is bad. And she always needs to respect her boundaries. If she doesn’t, she will invariably regret it the following day.
She will always take her wheelchair on Special Social Club outings - the organisation that takes away obstacles for disabled people, both literary and figuratively speaking. “Wheelchair dancing is fun, you know. And a party can be held on the ground floor”, she says.

Melanie works at the Bartiméus farm where she looks after the rabbits. She feeds them, cleans out their hutches and gives them lots of cuddles. She also works at Affect-us. It’s a job she enjoys very much. “The research topics are very interesting. I see it as my other part-time job”. Sometimes she needs to pick and choose, so she can manage the workload. She is not going

to be kept on her toes again. Fortunately, that is well understood at Affect-us. She gets to help filling in the questionnaires for various research projects and is asked to share her views in the forum ‘Bartiméus researches…’
“The research is mega interesting. It makes me so happy, to be able to help other people. And who knows, I may get to benefit from the results, myself”. The project she appreciates most is concerned with compassion. It’s about looking after yourself, allowing yourself a little extra time when you need it, not setting the bar too high. She knows all about it. “Not an easy thing, but I always tell myself: tomorrow is another bright day. The project is called Compass, isn’t it? Well….set your compass so it points to Compassion!”

It is how Melanie steers herself, and many others, towards a brighter tomorrow.

Driebergen
2024

Getting everything out of life

“We’ve come from far and we have come very far”. Mark spreads his arms, sticks out his chest and smiles broadly. He is referring to the client forum ‘Bartiméus researches…’, where he helps with research initiated by Affect-us. A couple of years ago he was asked to join the forum. And of course, he said yes, “…because helping other people is one of my favourite things in life”. So far, he has contributed to several projects, like the ones about compassion and mentalisation. And he enjoys attending network meetings and seminars. There is usually enough room left in the taxibus for his large wheelchair. He revels in those days. Even if he does not understand all that is said in the presentations, he loves the buzz and he is pleased to say that so much is being done for people with a disability. The best thing yet was having been asked to act in a film aimed at canvassing customers for a project called Growing old. “That was great fun and I happened to be quite good at acting. Everybody who was there during the shoot said so”.

It’s not just the forum (where a large group of clients now actively participate) that has come a long way; Mark himself has also made good progress. He was born 40 years ago as a twin. He comments: “According to the doctor, I would never be able to speak and I would hardly be able to do more than just vegetate”. Fortunately, Mark did not become this “vegetable”. He is proud of everything he has achieved, but it has never been easy. His twin brother was a quick learner, he could go and do as he pleased. In Mark’s view, he was the stronger one. Mark had to make more of an effort to get by. His father used cassette tapes to help him to learn to speak and it took a lot of practice, but he managed it in the end. “I can get by now, but I still need lots of help. People who can use their legs live like royalty. They don’t realise how hard it is to be confined to a wheelchair”.

Mark loves to learn new skills. Like learning to read, as he did at the Bos School. What he enjoys most, is showing off his skills. And where better to do so than at the forum, or else at his job?
He faithfully delivers the post on the Bartiméus premises, come rain or shine. Despite his visual impairment, he navigates the narrow corridors and passageways in his large electric wheelchair. Attached to his wheelchair is a large tablet that he uses for mobile calls or messaging. It took them a while,

but he and his supervisor eventually found a model that is shockproof and waterproof. Just what a postman needs. And like his hero Max Verstappen, Mark likes to get things moving. Watching Formula 1 Racing is a hobby that he shares with his parents. They will often watch it together. He also plays racing games on his computer. “And I’m pretty good at it, if I say so myself”, he adds with a grin. He customized his own wheelchair and it has become a proper piece of art, in Red Bull colours and logos. He appreciates the finer things in life. “And driving my electric wheelchair means that I, too, can now go and do as I please”.

He used to be a bit shy and did not dare say much in public, but he feels that joining the forum has helped him grow. “I get everything out of life and I’m never too old to learn something new”, says Mark.

He repeats what the doctor said about him when he was born. “A good thing the doctor’s prediction did not come true. Could a vegetable participate in a client forum?”

“I rest my case!”

Doorn
2023

“I matter”

In beautiful, lush Uithoorn Yvonne pours coffee for her fellow residents who are seated at the coffee table. Her mobility is badly affected by a herniated disc. She’s due for more tests in hospital in a few weeks’ time and it’s all she can think about. But she is determined to keep a positive frame of mind and regularly gives herself a little pep-talk: “Come on, Von, it will be alright”. She has also swallowed her pride and now uses a rollator, that she has named “Harry”. “Not the best deal, being stuck with a rollator at the tender age of 49. But seeing that it’s Harry, I suppose I mustn’t grumble”, she giggles.

Yvonne was born in 1974 in Amstelveen. Her mother says she must have wished to be born in the summer and not the autumn, as she arrived at seven months. She spent two months in an incubator in hospital. In nursery school, her older sister said that Yvonne lay in a glass box and the teacher was shocked. She thought that the baby had died, like Snow White. ‘Not at all”, said her father to the teacher. “Yvonne is alive and kicking. She is a strong little lass and she will be just fine”. And a strong little lass she turned out to be. From an early age she helped with the chores at home. Her mother, her brother and her sister also had a learning disability and so an extra pair of hands were much appreciated. As little as she was, Yvonne went out to get the groceries and helped with the vacuum cleaning. And when her mother was diagnosed with a severe kidney disorder, Yvonne accompanied her to the hospital and offered her support. She had to work hard and she carried quite heavy responsibilities. But she now feels very proud of that. It makes her happy to know that she was able to look after her parents. “It has helped shape the person I am now”.
Caring for others is part of her DNA. The supervisors at the residential facility where she lives often jokingly remind her that “We are the carers here and we get paid to do the job. You don’t have to look after the other residents”. Yvonne appreciates being reminded of that, as she tends to go far beyond her own limits.

Yvonne attended special needs schools, where she had a good time. After keeping everything at home running and on track for many years, she got a phone call saying she would be taken into care with immediate

effect. She was 17 at the time. The authorities stated that her mother could no longer look after her. She was placed in a residential facility and she felt bewildered and terribly upset. It was aiming too high and she was moved around into different homes several times. It's not until she came to Westwijk, an Ons Tweede Thuis (Our Second Home) residence, that she started to feel at home. She felt safe there; she stayed for 22 years. It is where she met Mabel, the supervisor who became her rock and her salvation. Mabel stood by Yvonne and helped her face the good and the bad. She was there when Yvonne had to press charges against a colleague, when her father died and also when she brought home a kitten. This cat called Mabe, who is her passion and her life, was named after Mabel. Yvonne often visits Mabel and her family at home and joins them on family holidays. And then one day Mabel asked Yvonne how she would feel if she were to be adopted by her. Yvonne's first reaction was raucous laughter: she thought it had been said in fun. "After all, who gets adopted in their late forties?" But when she realised that it was all in earnest, she immediately said a great "yes". She had already been a part of this warm family for quite a while. But through the adoption, she would officially belong to Mabel's family.
After training as an expert by experience, Yvonne came to us at Affect-us. And soon after, she got deeply involved in the preparations for the serious game 'You & I' that was to be developed. She helped to make a questionnaire more comprehensible for people with a learning disability. Yvonne remembers how she made a very useful contribution by suggesting that the words like "must" and "should" be omitted in the questionnaire. "People with a learning disability tend to be allergic to the word "must". It's because they live a life dominated by that very word".

Yvonne has been working for Affect-us for about five years and she also has a job at a community centre. It has brought her a lot. She is now better able to set boundaries; she has learned a lot about subjects like autism and she is no longer inclined to take a backseat. She used to stay in the background, but now she actively participates in presentations and workshops.

The strength that was evident just after she was born, is still with her. And this strength increasingly helps her to show her talents. People have noticed this.

A good friend recently told her that she had grown in a very positive way. Yvonne thinks this is due to her move to a new accommodation in Uithoorn, but also to her work at Affect-us. She is happy to work alongside her colleagues and other co-researchers there, and to have their support. People place their trust in her and they take her seriously. That is an enormous boost.

She ends by saying: “The most important thing about Affect-us is that I belong and that I matter!”

Uithoorn
2023

Clear language

“Wonderful that you are writing a story about me. Then more people will get to know me”.
He is a man of few words but when he speaks, it is usually spot-on. He has been working with ‘Bartiméus researches...’ and loves the job. “I have participated in a research project about time and about that other difficult word....something menty...yes, mentalisation. People should come up with a different word for that. How am I supposed to remember it?”

Clear language, that is what he likes. No endless banter, please. He was born on a farm in the rural Eastern parts of The Netherlands and as the eldest of three children, he knew how to juggle a busy family life. He would help look after the livestock: the cows, the chickens and the goats.

He lived with his mother until he was forty years old. He became visually impaired at a later age. And gradually, it became harder for his mother to look after him, as she herself had progressive dementia. It is recorded in Jan’s memory as a Black Day: the day both of them had to move into sheltered accommodation. All of a sudden Jan found himself living amongst strangers at a Bartiméus residential facility, with just a tiny room to call his own.

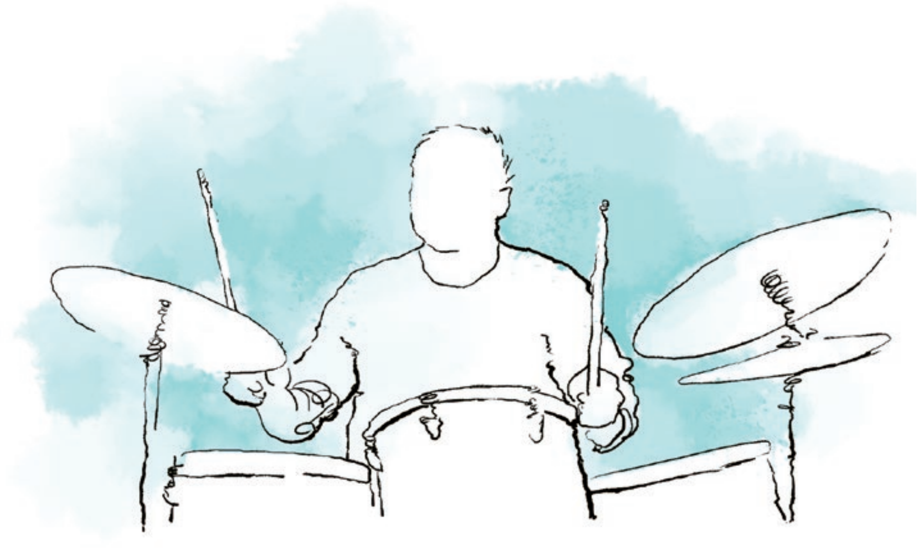
“Yes, that was quite hard”. He falls silent.

“I was homesick”.

“And I held back and kept it all inside”.

“But then I had psychotherapy. And now I no longer hold back”.

“What also helped me a lot is when I played music”. Soon after he came to live at Bartiméus, he joined Smash. Smash is the Bartiméus house band and Jan got started as their drummer.
It’s the rhythm section and he provides the beats. They play all sorts: the Beatles, the Stones and classic Dutch hits like Brandend Zand. He taps out the beat on his knees, so we can hear how groovy it sounds.



He brings clear language to the band. It is his clear and direct drumming that gives the others a footing. He loves that: “Clarity makes me know exactly where I stand”.

The work at Affect-us puts him into contact with others, so he gets to learn about new research and hears stories that would otherwise not reach him. He currently assists in research about aging. He is almost 62, but he still feels young. “You are as young as you feel. I can still do quite a bit: walk a trail, empty the dishwasher, play the drums. It works best if you simply accept that there are things that you can’t manage”.

A certain bear is to be found in his room. Different editions of Winnie The Pooh cast a sunny yellow hue. Winnie too, is a person of few words. But when the bear speaks, he utters gems of wisdom, like: *You are braver than you believe, stronger than you seem, and smarter than you think*.
They are quite similar, our Winnie and our Jan. Clear language!

Doorn
2024

Proud

“It pleases me no end, to be of use to other people. When I see my fellow residents smile, when they feel good, it makes me so happy. It makes me want to do even more for them”. Rika is a proper little busy bee. Always on the go to help others. It’s in her nature; she cannot remember it any other way.

Take her contribution to the Summer Tour – or rather: Rika’s Summer Tour. As Rika is the central axis of the Tour, the event has been named after her. During the summer months, when many of the staff take their holidays, Rika provides extra sunshine by organising all sorts of activities. Residents can join in flower arranging sessions, there are smoothie making workshops and frequently held Barbecues. “You name it and we’ll fix it”. It makes her a welcome and familiar sight at the Losserhof residential facility.

Bold and enterprising Rika, who gives the impression that she can handle it all, has quite a story to tell. She was doing so well, she had the world at her feet. A sound education in the hospitality industry and a fine career working for canal cruises. But then 20 years ago a serious road accident messed up everything. After the accident she spent three months in hospital, followed by a prolonged period of rehabilitation. She ended up in an electric wheelchair, her memory has been affected and she has to make sure she does not take on more than she can chew. Now there’s a challenge for this woman of action. “When I’ve done a bit too much, my head goes in overdrive and I can’t fall asleep”. Her supervisors have been helping her achieve a better balance.

Self-sufficient living was no longer an option and she moved into temporary accommodation at a residential care centre. She liked it there and fortunately she was offered a permanent place. She now has her own apartment, on the premises of a residential facility for people requiring a great deal of care. Persons with dementia, or people receiving palliative care. And Rika wouldn’t be Rika if she did not join the auxiliary troops. Handing out comfort and sympathy, when someone is feeling homesick. Lending a hand in the kitchen, to fix sandwiches for the residents. Loads of other little chores. And she puts her heart and soul into all she does.

When she came to live here, it soon became clear that she possessed skills that would come in handy in the client council and also at Bureau4impact. This agency is the place where Rika can channel her talents. She is part of the E-team, the group of experts by experience. Previously, she collaborated on research about mentalisation and she is currently involved in a research project on epistemic trust. It is a novel approach, as normally the researchers would handle the interviews themselves. But Rika is quite adept at it. "This is such interesting work, too". Wherever she can make a difference, she will.

At home, working with building kits to make intricate models helps her relax. Knitting and crocheting also bring her peace of mind. She is currently making fortune dolls. Soon, it will be Doors Open Day at Bureau4impact. Not a problem: Rika will have crocheted 200 fortune dolls to hand out to all the visitors.

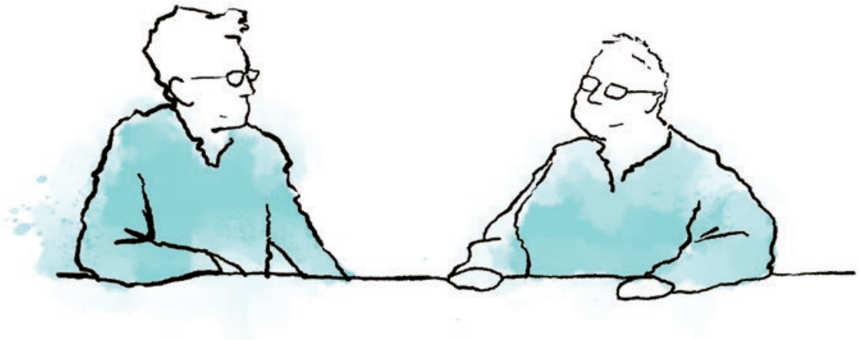
She also writes poetry. She thinks the following poem best reflects her personality.

I am different.
Yes I am.
Different than the others.
Or so the outside world has decided.
But I am **proud** of myself.
People look at me and do not speak.
In muted silence they say nothing.
They fit me in a frame instead.
It makes me angry, not **proud**,
because I am different.
Different than most grown up people.
Who possess their heart's content.
I am who I am.
I am **proud** of myself.
Proud of whom I can and may be.
Proud of my supervisors, standing by me.
Proud of where I live.
Proud of all who help me.

Proud of those who understand my difference.
So I need not feel ashamed.
Because I am different than others.
No matter who or what I am....
I am **proud** of myself.

It is good that she is proud of herself. This woman who puts her heart and soul, and a few fortune puppets, into spreading joy.

Losser
2024



Thank you!

It is really special that these stories will find their way into the world. They deserve to be shared.

A big thank you to all the experts by experience who contributed to this publication: Gudy, Jan, Johan, Leroy, Mark, Mark, Melanie, Mitchell, Rika and Yvonne!

As I mentioned before, we are immensely grateful to all our experts by experience, for everything they do at Affect-us. Together we do a lot of important work.

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Thanks to Joyce, who always checks the spelling for us. We can always count on you, thanks so much.

And of course, none of this would have been possible without Paula. Our endowed professor who is the living example of “Together and with each other”. Thank you, Paula!

Together

This book contains the life stories of experts by experience who are involved with Affect-us. From the start of each research project, they contribute ideas and share their views, bringing to the project a wealth of experiential knowledge. These stories speak of the difficult road that they have often had to travel. Through their own resilience and the support of key people in their lives, they have come a long way. We are grateful that we can do this work TOGETHER!

"This book offers a wonderful insight into the lives of some of the most important people at Affect-us: the experts by experience. The stories radiate immense strength. After reading this book, I feel even more connected as a member of Affect-us."

Aline Honingh, Researcher at Affect-us

"A booklet that everyone should read! What a beautiful glimpse it offers into the emotional and experiential world of these individuals. After reading the stories, no one can deny it: experts by experience are proper participants and members of the team!"

Coby Wouda-Speelman, Sibling and Advisor in Religious Education

"What if you have a visual impairment and a learning disability? What does your life look like, what do you have to say and to offer, despite the fact that you're 'different'? This little book shows how they give voice to this, in a language all their own. Colourful stories, spoken straight from the heart – honest and delightful!"

Gina Peeters, coordinating counselor

"Such beautiful stories, and people have been through so much! Curious for more..."

Leo Koopman, Expert by Experience at Affect-us

"How wonderful and valuable it is to be able to read more about the lives of the experts by experience at Affect-us. What they share is a passion for experiential expertise. They feel seen and heard! This collaboration enriches the work of Affect-us."

Marise van Montfoort, Manager at Bartiméus

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