

EVERYONE IS DIFFERENT

MOVING FROM REALIZATION TO PRACTICE

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This is a personal reflection on a workshop and a panel discussion organized by VUB Crosstalks in the series *Shake the Disease*.

The workshop took place at the Guislain Museum in Ghent on 19 April 2023 under the title *Neurodiversity as a norm, not a label*. **Kirsten Catthoor** (psychiatrist at Stuivenberg Psychiatric Hospital and chairman of the Flemish Psychiatry Association) led the workshop with an impassioned plea against stigma. She was the prelude to the keynote by **Rachel Elliott**, professor of health economics at the University of Manchester, with a fresh look at therapeutic interventions and their effects on mental health. Her story was expanded upon in five testimonials from 'experts by experience': **Leonie Delay** on dyslexia, **Evangeline Agape** on art and her own mental struggles, **Ann Ceurvels** and **Tania Poppe** with a summary of their theatre performance BEN, **Els Van Beneden** on her autism and professional career and **Inke Gieghase** on language, poetry and being queer.

The panel discussion 'Minority stress. Discrimination makes sick' was just one session in a well-filled day programme at the symposium Medische Wereld [Medical World], held on 22 April 2023 at the VUB Faculty of Medicine and Pharmacy in Jette. Lawyer, artist, writer and activist **Olave Nduwanje Basabose** steered the session in the right directions. The panel included **Ama Kissi** (clinical psychologist and researcher, UGent), **Veerle Soyez** (psychologist, therapist and researcher associated with BRussels University Consultation Centre) and **Kimberly van Megen** and **Marion Melissen** (fat activists of Stichting Dikke Vinger [the Fat Finger Foundation]). They discussed with each other and the audience after a short video message from **Steven Laureys** (neurologist, Laval University Canada).

Normal?

What is 'normal'? Everyone has an idea about what is normal or not normal, but if we try to define it precisely, it quickly becomes apparent that the concept is not so obvious. Worse than that, it's a problematic concept that does more harm than good. This is evident from the recent book *Am I normal?* by historian Sarah Chaney, researcher at London's Centre for the History of Emotions.

Medicine is permeated with the idea of 'normal', and that

what deviates from the norm needs to be treated. In case of manifest damage such as a broken bone, a torn tendon or a cerebral haemorrhage, medical intervention is a therapeutic action to restore functioning. With blood pressure or body weight, it is much less clear what the normal state is that should be restored. Although blood pressure or BMI can be measured objectively, they are only values in a broad spectrum on which a cut-off point is marked quite arbitrarily. That point lies in a grey zone in which people are no sicker or

healthier than people who register just a little more or less mmHG or grams. Standards in medicine have proven their worth, but they also cause unnecessary suffering (due to the fear and uncertainty and the side effects of the treatments). It only becomes really tricky and unpleasant when we seek to distinguish normal from abnormal behaviour, such as in mental health or sexual experience. There are no objective biomarkers for psychosis, addiction, body image disorder, depression, or bipolar disorder. For this reason homosexuality was branded as a psychiatric disorder not so long ago. Many psychiatric symptoms occur to a greater or lesser extent in everyone. Only when they take on extreme forms and disturb the quality of life and interaction with others and the world do we talk about a disorder and look for a diagnosis. It usually comes with an accompanying label. The labels themselves can also have side effects.

Being or having to be

The concept of 'normal' started its life in the nineteenth century (courtesy of the Belgian Adolphe Quetelet) as a statistical concept, a mathematical approach to the variation in reality, and used initially only in the natural sciences. The 'norm' was the result of a mathematical method to approach the real value as closely as possible in a multitude of slightly deviating measurement results. However, that mathematical standard was gradually extended to become a social or ethical standard, a misleading step from 'that's how it is' to 'that's how it should be'. This normative understanding of what is normal has great potential to alienate people and to exclude and stigmatize those who deviate. Sarah Chaney explores in her research the many aspects of this problematic concept at the crossroads of medicine, biology, sociology and philosophy and concludes: 'normal people' do not exist, variety is more normal than the average. When normal is elevated to standard, everything that deviates from it is stigmatized as abnormal.

Stigmatized

For Kirsten Catthoor, stigma, the branding of the deviant, is a recurring theme in her work as a psychiatrist and her passionate ambassadorship for the psychologically vulnerable in our society. Stigmatization is a destructive phenomenon that causes much damage. It causes sadness, guilt and shame, it is the reason that people withdraw and become lonely. Stigma is not limited to psychiatry. People with psoriasis or other (physical, visible) abnormalities, obesity, AIDS

or (formerly) leprosy are labelled unclean, contagious or dangerous. People who survived cancer are no longer regarded as fully human, wheelchair-bound persons are subjects of conversation, as are the aged, even without dementia or Parkinson's. People living in poverty get fewer opportunities, and it is supposedly their own fault.

Stigma festers on four levels. Partly under the influence of the media, the general public is permeated with negative stereotypes. Individuals internalize the stigma: self-stigma with the thought of being unwanted or inferior. Stigma creates social alienation: people who have relationships with stigmatized individuals share in the prejudices. Stigma is also becoming structural: inequality is anchored in laws and regulations, research into brandmarked areas (such as mental health care) is less funded, people who work in mental health care receive less pay and appreciation.

Stigmatizing labels affect people of all ages and on all planes of life, with negative effects on education, work, housing and care. Stigmatized people are treated negatively from a legal and insurance point of view. They also receive less care ('first lose weight or kick the habit before we do something about that knee') and less good care. They are less well examined and receive fewer and worse treatments. Their life expectancy is therefore less high. Men with integrated care needs (formerly SMI, Serious Mental Illness) live on average of 20 years less, women 15 years. Mental illness is even more deadly than poverty. (The latter takes an average ten years off a person's life expectancy.) Migrants have it even worse, combining psychopathogenic living environments with discrimination as outsiders in a culture that is not their own, with a language they often do not speak, with low incomes.

Mental problems and poverty go hand in hand. Three-quarters of those living in poverty have psychological problems. The one also encourages the other, the two reinforce each other. However, there is a glimmer of hope: this problem, which has been raised for years by the UN and WHO, is receiving increasing attention, both in professional aid and at policy level and in the media. But of course attention alone is not enough.

The stress of exclusion

Steven Laureys did not mention the chronic and therefore toxic stress of people living in poverty in his video message. He did show how meditation helps athletes, entrepreneurs and professional Buddhists to relax their worrying network and to concentrate better. It is bittersweet to realize that such 'luxury meditation' meanwhile has not been reserved for the

so many who suffer from the disastrous effects of never-ending stress – such as those who are excluded or stigmatized. It is true that stress response is an ancient and vital biological system that allows living organisms to evade or survive moments of threat. But it becomes a physically and mentally undermining factor when the stress alarm is on constantly.

That's what happens when people live in permanent uncertainty, threatened or excluded, viewed askance or condemned. They feel targeted because of their supposed 'differentness'. They get fewer opportunities, worse care and are treated denigratingly. They are branded as inferior, forcing them into a state of perpetual alert, permeated with guilt and low self-esteem, which narrows mental bandwidth and diminishes cognitive, emotional, and executive abilities.

This way stress makes you sick. This stress takes many forms, one of which is 'minority stress', the specific chronic stress experienced by individuals in marginalised, stigmatized and discriminated groups. Think of sex workers, people of colour or with 'strange' names, people living in poverty, people with disabilities, refugees, lgbtqia+ people, women, the elderly, the overweight, etc. It is no coincidence that such people also suffer disproportionately from mental disorders and chronic illnesses. They are also the groups most likely to report discrimination and poor communication in the treatment room.

Voices from the stigma

The various 'experts from experience' testified to what it feels like to be on the other, inferior side. They hit up against a systemic failure of the medical profession. Fat people are constantly being told that they must first lose weight, medicine wants to make them thin first. People with disturbed eating behaviour must first eat 'normally' before their psychological problems will be looked at. A mother of colour admits that she is glad that her son (with a white father) is light-skinned, knowing the obstacles she herself has encountered due to her skin colour. The long-term sick, people with migration backgrounds, young people from youth care, people with disabilities, ... are constantly encountering (invisible and unspoken) thresholds. In youth care, young people (and their families) often look for a diagnosis in order to gain recognition (because with recognition comes care). Tragically, they sometimes search until they find recognition somewhere, even if the diagnosis and associated label are not necessarily the right ones.

Despair sounds time and time again from all the stories. Three-quarters of fat people (as they unabashedly call them-

selves at Fat Finger) have had bad experiences with care, eighty percent avoid care – they now know that they will be sent away to lose weight first. Their body weight is also blamed on them, as if it were their own fault. If only they had have snacked a little less. How culturally determined all this is is shown by the testimony of an African woman who, back on a visit to family in her home country, is greeted with compliments because she has 'put on weight'. Even in Rubens' time, a voluptuous body was the norm for beauty.

At school, fat children receive lower marks, and this downward appreciation is later reflected in education and work. They get lower salaries. Fat women also receive a lower salaries than fat men.

A similar scenario plays out with children of lower socio-economic status (SES) and of colour. They get fewer opportunities and fall down the social ladder. They have to prove themselves more than their peers with high SES or white skin. Just like people in poverty, they are told to pull themselves together, take better care of their budgets and look for work.

The stigmatizing prejudices and misconceptions about pain are also very much alive. However, pain is a leader in chronic complaints. It is also an emotion, the colouring and significance of which is strongly culturally and contextually determined. Different people experience and express their pain differently. One of the misunderstandings is that children and young people feel less pain (not so long ago it was even thought that babies do not feel pain and therefore do not need pain relief) so that their pain complaints are not taken seriously. The pain of black people is systematically rated as less than that of white people. (Their skin, the prejudice goes, is supposedly thicker than that of white people.) Half of doctors and medical students believe there are biological differences between black and white.

Similarly, women are taken less seriously than men. The poignant lack of medical interest in menopause, menstrual pain or endometriosis, and the unfamiliarity with typical female heart attack symptoms speak volumes.

Not one size

Moreover, due to historical-economic confluence of circumstances, studies of medical normality have been carried out on a small minority. That subgroup of the human population is the weird-population, a term made up of the first letters of the words western, educated, industrialized, rich and democratic. Less than 12 percent of the world's population falls into this weird group, but they predominate in psychological and medical studies with 96 percent of all participants. In ad-

dition, clinical drug research is almost exclusively conducted on healthy young men. And about all those other people, we don't really know much.

In that way it is not surprising that not everyone is included and that so many people fall outside the 'norm'. Because we don't all fit the same size. Unfortunately, this implies that fat people often do not fit in chairs made with the average hip width as a starting point, that no blood pressure monitor fits around their upper arms, ditto for MRI scanners. It's a recurring story: people in wheelchairs have been complaining for years about the poor accessibility of a world that does not take differently-mobile people into account.

Meanwhile, mainly white, highly educated men with correspondingly high incomes are turning the policy knobs. They are far removed from the real world in which so many people live. Certainly also from people who do not feel safe and who dream of a world that is safe for everyone, without the micro-aggressions that fall upon them as 'others' and that cause a constant 'on guard' feeling, with all the stress and health problems that entails.

Diversity-sensitive thinking ought to be able to become common-day. For this, education and awareness-raising will prove essential. That takes practice and that can start with people being curious, asking open questions about what people want and how they want to be treated, addressed or handled. There is no one rule that determines the best way. Everyone is too different for that.

Living with and thanks to

Living with being different would be easier if variation were normal and every person could go through life without labels. For the time being, that remains a dream and we have to make do with the role models of countless individuals who find strength or inspiration in their individuality.

Evangeline Agape was depressed as a teenager, but deprived of the right word, concept, or label, so she didn't know what was wrong with her, which only fuelled her anxiety. Collages and other creative work allowed her to shape it and share it with others. She now writes poems and accompanies creativity sessions with children. She shares her insecurities on Instagram and receives responses from which she learns that she is not alone. Her art earned her recognition and connection. However, she also warns against a romantic prejudice that a troubled mind leads to better art. Her open question: would I still be a (good) artist without my fears? They are just one facet of her life. She is convinced that the grief or loss we acknowledge in each other can bring people closer together.

Leonie Delay has a reading disability and has a hard time reading what it says on the page or screen. She needs minutes to decode texts. That has advantages and disadvantages. She is orally proficient in different languages, but reading and writing are a challenge. At school she was considered 'not intelligent enough', which led to her being placed in special education. In practice, she was articulate and strong and so eventually made it to college, even though she had to work twice as hard as the rest and it took her a few years longer to complete her studies. Her diagnosis often got in her way by always emphasizing what she couldn't do. She would rather have talked about where her strengths lay and how she could let them flourish.

Els 'out of office' Van Beneden has lived with autism all her life, but not all of it with the label. She only received that label eight years ago, after a long career in government administration. After twenty years there, she got stuck in a burnout, as a result of the clash between her atypical neuro-constellation and a new manager. It brought her to a psychologist and psychiatrist for whom the diagnosis was quickly clear. Her life changed for the better. She now knew why she was different in the world. With her ultra-precise mind, she had her own way of dealing with an uncertain world. Understanding how the brain works, like a prediction machine, helped improve her quality of life. Or as she puts it herself: "...I'm missing one corner, but that gives me two (soft) corners where others only have one. I do have less surface area, which makes me tired or overstimulated faster." As a result, she was constantly exhausted outside of work. She argues for a 'neuro-harmonic' world in which different neurotypes each live together in their own way. That is the *raison d'être* of LAVA!, a reading and advice group on autism in which she is active. It is part of Leuven Autism Research, where 'experts by experience' participate in research. In this way the research is inspired by the real experience and needs of autistic people without loss of scientific quality.

With their 'therapeutic' theatre intervention, Ann Ceurvels (neuro-diverse son and partner) and Tania Poppe (super busy family and man with a burnout) argue for more attention to developmental problems and survival patterns. What is behind the behaviour of their fictional protagonist Ben, of whom people say 'that's not normal, is it?'. BEN is an acronym for **B**rain (knowledge of how the brain works can remove a lot of stigma, because an understanding of this brings human understanding), **O**wn (**E**igen in Dutch) story (the narrative of how someone stands in the world and society may times creates lots of tension) and **N**orm (is someone normal by ex-

hibiting socially acceptable behaviour? or who is perfect?). What doesn't fit or rubs is quickly experienced as threatening or unsafe, even if this usually only concerns the outside. If we were less quick to judge, listening to the stories might become healing.

As a non-binary activist, Inke Gieghase wants to show that the world is not as black and white as we sometimes think. More and correct reporting on the LGBT and transgender community is desperately needed, which is why Gieghase participates in training and consultancy on gender and orientation, on inclusive writing for journalists and making work or school environments more rainbow-friendly. In spoken word performances, their art can break taboos and make the unspoken expressible: "poetry is not a luxury ... it's a way of giving names so things can be thought."

Does it help? And how much will it cost?

The mental and physical consequences of exclusion are great. Given that they are the result of contextual factors, therapy focusing solely on individual symptoms will never be an adequate solution. (A sleeping pill won't give someone a better night's sleep if they're kept awake by noise in a dangerous neighbourhood or worrying about debt.) But what does work? And which recovery-promoting approaches are effective?

Rachel Elliott trained as a pharmacist and worked in intensive care for a long time until she became a health economist, with the aim of gaining more insight into the effects of specific interventions or measures in healthcare: what is the return on the investments made in healthcare? What benefit (in health terms) do all those many and expensive efforts in healthcare yield? She presented two research projects that illustrate this. (And which are not yet fully completed and therefore no final results are available yet.)

NEON (Narrative Experiences Online) is an online, non-clinical intervention for people who identify themselves with mental health problems. RECOLLECT stands for Recovery COLLEge Characterization and Testing, a programme that focuses on psycho-education in healthcare, community or forensic settings.

NEON wants to find out how effective narrative approaches are in the recovery processes of people with mental health problems. These narratives can take many forms. In words and images, people tell their (sometimes raw, but also hope-

ful) recovery stories, as in *Beyond the storms* at recoverydevon.ac.uk. For people with psychosis or other non-psychotic symptoms, these stories appear to have both positive and negative effects. What is supportive and restorative for one person - by not feeling alone, which reduces self-stigma - can for another confront them with feelings of powerlessness or worthlessness. This method does appear to reach people with psychosis who are difficult to reach in other ways. Again with this form of help, further research is needed to find out what works for whom, and which form works best. In addition to looking for answers to questions such as: how do we measure its effects (there are no biomarkers for recovery) and who should set up and finance these forms of aid or care?

RECOLLECT is a form of recovery academy in which 'experts by experience' and professionals work together as co-students in psycho-education. There are no patients in this academy, everyone is a student. (In the UK there are already 88 recovery academies, in Belgium 14.) The RECOLLECT research attempts to measure the effects and cost-effectiveness of recovery academies. But how do you measure the effect of people regaining their self-worth and strength so that they can resume their lives? How can you capture and measure the potential benefit (for individual or community) in economic terms? How does this fit into other healthcare budgets? And to whom should you allocate the necessary funds? Meanwhile, these narratives are gaining a place for themselves. And what is told can be heard.

Everyone themselves, together

The many and varied stories elicited the comment from those present that 'thirty years ago we could not have met like this'. Much more can now be discussed, vulnerability in its many forms is now being named and acknowledged.

However, society has not yet become inclusive. But while intolerance seems to be hardening here and there, diversity and the space being given to it have increased even more.

Neuro-diversity is a concept that affects everyone, and involves more than just people with autism spectrum or attention disorder. It covers equally psychosis susceptibility, gender, depression or bipolar traits, in an astonishing multi-coloured spectrum. We are all still learning every day how to better deal with that multiplicity. We are all 'different' in our own ways and that takes some getting used to.