

Good morning everyone, first of all I would like to apologise in advance for my English and hope to be understandable.

My name is Claudio Diaz, I am 43 years old, I am from Italy and I have FASD... among other things.

I am also the founder and president of the Italian Association of Foetal Alcohol and/or Drug Exposure Disorders (AIDEFAD), the first and only association in Italy to deal specifically with this spectrum of neurodevelopmental disorders.

The Association was born on 9 September 2018 on the occasion of the International FASD Awareness Day, so a few days ago was also its 4th birthday!

Since its inception, our association has truly accomplished an enormous amount of work for which I am deeply proud and grateful. We have carried out many activities to support families and people with FASD, collaborating with professionals, organisations, associations, health facilities and institutions, achieving truly historic goals in Italy considering that before us, I can say without fear of contradiction, there was nothing concrete for those affected by FASD, or using an acronym we coined, FADED (DEFAD) (Foetal Alcohol and Drug Exposure Disorders).

There was also very little information and awareness-raising; not to mention networking with other organisations dealing with pathologies or adoption, since we know well how sensitive the pairing of adoption and FASD is, and with health facilities in order to make the possibility of obtaining correct diagnoses more widespread.

The title I have given to my talk is 'FASD: from the "psychiatrisation" of complexity to "Patient-centred care" (better still, Person-centred care)' and I go even further by calling FASD 'an exceptional opportunity' to change the current paradigm of care.

I chose this title because I felt that this change is not just a concept, but a concrete, tangible, achievable reality, and in part, perhaps not in a structured way, already realised in some individual cases, and that it is the right path to follow if one really wants to allow people with FASD to define their correct identity and allow them to mature, to grow in an environment that can concretely see them and accompany them in the enhancement of their strengths, recognising their frailties, but not focusing on them in the construction of the care pathway.

And to develop this argument I will only tell you my story, which is the story of my families (natural and adoptive), but which is also the possible story of many other boys who will become men

and women. And I will tell it to you with my heart in my hand in the hope that my enormous pain and the dramatic feeling of being alone against the world will resonate and connect with you and that this will enable you to understand the devastating intrusiveness of the suffering that FASD, or rather the non-recognition of FASD, brings.

Next, I will try to tell you what in my personal experience and in drawing on the hundreds of stories I know personally, I have noticed to be the things that professionals and society could do to make our lives better and optimise the economic resources that are instead being profusely wasted with the current paradigm of care.

At the end of the day, it is a matter of intervening in the trajectories of neurodevelopment at various stages of life, knowing that the goal is the best developmental trajectory with the least number of subsequent adjustments, but that no matter how far a trajectory has tended towards the abyss, the possibility of changing its direction is a possible reality.

To conclude, what are the things that work and what don't in our lives with FASD, but I would say in the case of all lives of people with certain types of disorders, particularly cerebral/psychiatric, therefore less visible, if not invisible.

Then let us begin. Know that I am trusting you!

I was born on 22 June 1979, so 43 years ago.

At that time there was little, if any, knowledge of FASD, and at the same time there was a boom in drugs, particularly heroin, hallucinogens and cannabis. Moreover, culturally, our country has always been dramatically steeped in the alcoholic culture, for which wine is a ubiquitous food on family tables. I think, making a small parenthesis, I can safely say that in every Italian household there is a person with an alcohol-related problem.

In those years, there was also the HIV boom.

I was born into a family that lived in a very poor country area of Italy, where the malaise and conditions just described found the ideal climate to take root and metastasise.

My birth mother, Monica, had me at the age of 20, but before me she had another child, my brother. I was luckier than him because in the sixth month of pregnancy there was an intervention by the police and social services, under pressure from my grandmother, and my mother was taken to a religious home for single mothers. In this way, unlike my brother, the last three months of my pregnancy were definitely more serene and peaceful for me and I was also spared the neglect and violence that my brother suffered for about the first two years of his life and which went on to imprint a certain direction on his developmental trajectory.

The first six months of my pregnancy I was heavily exposed to alcohol, tobacco, heroin, LSD, cannabis, and who knows what else, as well as to the HIV virus, which fortunately I did not contract. At birth, my mother did not recognise me, did not even want to hold me or breastfeed me. She simply refused me, and this we now know more and more how much influence the imprinting of that child's neurodevelopmental direction has on the development of gastro-intestinal problems. In fact, in neurodevelopmental disorders, all of them, especially in autism, this is being investigated and highlighted, but we also see it in our children with FASD in whom there is a large presence of gastro-intestinal disorders.

As soon as I saw this world, I was immediately moved to a room in the nursery and there, not much weight was given to the signs, symptoms and clinical findings I was showing from the very beginning.

In those years the view was: he is born, he is alive, now we give him the best care, then he will go to a loving family, with economic possibilities, who will give him opportunities and the child will recover. This, unfortunately, accompanied those years and did so much damage.

Unfortunately, it became apparent early on that something was wrong with me, although consistent with the beliefs of the time no one gave it any weight; it was not until more than 30 years

later that these findings gained significance. I showed a neonatal abstinence syndrome, which is now unequivocal, low weight, the initial APGAR was 7, the amniotic fluid was heavily stained, the placenta was poor, the length was not optimal, the head circumference was at the lower limits and my electrolytes were all out of whack. In addition, even this 40 years later, some facial dysmorphisms were detectable.

Ten days later I was taken home to what had become my parents. Here the clonias, sleep problems and other NAS-related symptoms persisted for a long time, which the paediatrician explained at the time as the trauma of abandonment...

As time passed, as the complexity of the world and the demands of the world increased, so did my difficulty in coping with it. The more basic the world became, the more I was able to fit in, albeit with obvious but socially acceptable quirks. The more complex the world became, the more my brain began to have difficulty understanding it.

The most deficient area was that of impulse supervision. So I was increasingly unable to handle the anger resulting from rejections, confusion, meltdowns.

It showed very early on, a difficulty in the management of the sexual impulse, I experienced a hyper-activity in this sense that pushed me to seek this pleasure. Probably, it was an instrument of self-care because the gratification of sexual pleasure extinguished, momentarily, the hyperactivity, the anxiety, it

helped me to fall asleep, in short, like alcohol years later, the gratification of sexual pleasure had a therapeutic function for me.

But the pursuit of the fulfilment of this pleasure being the result of impulsiveness and my failure to understand the consequences of certain actions was repeatedly the cause of great embarrassment for my family and inevitably for me as well, though perhaps more due to the perception of their embarrassment than to any real understanding of the inappropriateness of that particular behaviour.

All of this, if one does not know why it happens, if one does not know what the mechanism is that causes that problem, makes one an unwitting victim and increases one's sense of shame, confusion, embarrassment, 'dirtiness' by starting to nurture the belief that one is wrong. And this is a heavy blow to the evolutionary trajectory, this is the beginning of the self-fulfilling prophecy.

Here then is the genesis of the psychiatric disorder, of the secondary disability, which is more related to these aspects of misunderstanding and self-understanding, rather than purely to aspects of altered brain function. It is clear that they are two sides of the same coin, that one favours the other, but much is caused by lack of understanding.

Thus came the time for school. Ever since primary school, if not kindergarten, hyperactivity, difficulty in concentrating, oppositionality, disturbances in sensory integration were immediately evident: the overload often resulted in meltdowns, explosions of anger due to too much information, too much noise, too many lights, too many stimuli that were all going into my head without my brain having the tools to process and integrate them. For many years I could not tolerate T-shirt labels or certain fabrics like jeans, having to wear unfashionable velvet trousers. Sudden changes in mood: one day I was the teacher's pet, the next day I was very nervous, I responded badly, I insulted and then I was punished because, clearly, that behaviour was not understood as a neurological problem, but was interpreted as the behaviour of a spoilt or rude child who should be punished. On the other hand, my great imagination, creativity, the ease with which I spoke to the class was immediately evident.

And so, day after day, misunderstanding after misunderstanding, punishment after punishment, humiliation after humiliation, my evolutionary trajectory was heading more and more towards disaster, far from the work of co-construction of a life, of an identity in which we are aware of what is happening to us and can strive for the greatest possible autonomy and the sincere reinforcement of our strengths. In defining this trajectory, the redefinition of parents' expectations also plays a vital role, and this is not an easy and obvious step, because it requires

acceptance of one's child's disability. This is never easy, but in the case of adoptive parents, who are often betrayed by those involved in adoption because information is omitted and issues are downplayed that then explode in the family unit causing irreparable damage, this can be even more difficult.

And so the second secondary disability materialised: school failure; the first was inappropriate sexual behaviour.

At a certain point I realised that I just could not follow and understand some subjects in particular and this failure of mine turned into a great fear. I began to do everything I could to get my parents to exempt me from going to certain classes, the mathematical-scientific ones. The mere thought of having to enter that class made me very anxious, not because there was a problem with the teacher, on the contrary, I have very good memories of that teacher, but precisely because there was a block on my part that stemmed from the perception of not being able to understand what the rest of the class understood.

Time solved nothing, indeed time added to the problems and so I saw my family's frustration increase, I saw my mother go crying from teacher to teacher, from professor to professor, praying that they would help me, that they would promote me. I saw my family hide everything I did inadequately at school, with friends, and the older I got, the more this inadequacy increased.

I can actually say that I saw them hiding me, and this, which I only realise today as I write, is very sad and falls under the

secondary disabilities of FASD in my opinion. Unfortunately, in those years there was a complete lack of opportunity, or perhaps they did not want to do it because the culture of the time suggested it, an assessment of my cognitive, intellectual and psychic abilities, but they just swept it under the carpet, put a patch on it as a problem came up.

I lived in a very bourgeois small town of a few thousand inhabitants, which contributed to an 'omertous' attitude that made possible all these actions of containment, concealment, mystification acted by my family, also strong from the power their name had in that place. Thus, either because of the knowledge of the time, or because of the family's attitude, the psychiatric vision, the psychoanalytical vision, prevailed over the organic explanation of my behaviour, the vision 'it is the consequence of abandonment, it is what happens to adopted children' prevailed, which certainly has a part of truth, but only a part.

When I imagine myself today in my mother's belly drinking the beer or wine she is drinking, smoking the hashish she is smoking, or absorbing the heroin she is injecting, it seems so obvious, so clear, so simple to understand how my behaviour, my comprehension skills, my senses were so deficient. But at that time we were light years away from being able to think about these things and instead we were in that period of history when,

unfortunately, psychoanalysis brainwashed everyone a bit and therefore everything was observed according to this key. And that, unfortunately, did a lot of damage, just look at the history of autism: the refrigerator mum etc. I suggest watching 'Le Mur', a French documentary that tears the veil off this subject.

At the age of 12, the use of alcohol began (the third secondary disability) and before that I had already started smoking tobacco; from 16/17, I then gradually tried all the drugs of the time. So did my natural mother, so did her siblings, so did my brother, so did my father. The goal was altered state of consciousness. The goal was not to suffer. The goal was to be accepted by the group, not being able to form fruitful relationships. The goal was not to be inside my own head, but, through the use of these substances, to seek the cure that I, on the other hand, had always sought because my discomfort, my suffering, I never hid them, but always shouted them out. Unfortunately, in the course of my journey, I never found professionals who were able to understand, in reality, what was happening to me. Basically trivially because they did not know FASD and we know that we recognise what we know. So no one ever thought I had a neurodevelopmental disorder and so everyone focused exclusively on the psychiatric aspects. When I was 22 years old, within five minutes a famous psychiatrist diagnosed me with bipolar disorder (fourth secondary disability), which was basically just to be able to give me medication. From

that moment on, I was prescribed every possible and imaginable active ingredient that the market offered and then arrived at ad vitam therapy with Lithium, Depakin, Rivotril and Methadone. Fortunately, I never stopped believing that there could be a better future, that I could know serenity, and I never stopped doubting, questioning and trusting that I would meet serious, honest professionals who would ethically choose to help me.

But many years passed in the dark: therapeutic community, endless admissions to psychiatric wards, life on the streets, justice (fifth and sixth secondary disabilities), inability to hold a job (seventh), but finally that trijectory that seemed immutable turned: I managed to stop drinking, using drugs, taking psychotropic drugs, and for a little over a month even smoking. The development of other health conditions, which psychiatry and family unfortunately denied for a long time, attributing them to hypochondria or conversion, contributed greatly to these results. This caused a deep desire for redemption, for justice, to arise within me. I began to tell myself: 'yes, all right, I have done wrong; all right, I have made you suffer, but I have suffered too, and now, as much as it is my right to have proper care, so much is your duty to help me'. Unfortunately, however, it was not that simple and I was forced to start a battle to survive with my family and with the doctors who pretended not to see what were the real health problems that were now undeniably becoming evident and in the end I was unfortunately right: ignorance, arrogance,

shame, stigma were going to kill me and certainly stole almost 20 years of my life!

At this point, the hypothesis that there was a genetic alteration at the root of the neuromuscular disease, which was partly confirmed, prompted me to tackle the search for information on my biological origins. I then went through the whole Italian legal process and thus obtained the name of my mother who had unfortunately died of AIDS. Thanks to the court decree that allowed me to know my mother's name, I was able, on the one hand, to reconstruct relations with that part of the family that is still alive, a small part, because unfortunately they have all suffered in some way from the consequences of exposure to alcohol: a veritable epidemic, a true multi-generational chain; on the other hand, to reconstruct what had been my mother's life that I have told you about. I therefore had confirmation that during her pregnancy and, unfortunately, also afterwards, she had been a slave to addiction to alcohol, substances, tobacco, psychotropic drugs, and that she had had a life of great suffering. This made it possible, at the age of 40, together with cognitive and compartmental assessments and the re-reading of my neonatal and childhood history, to arrive at a diagnosis of ARND and at the same time I discovered that she, in all likelihood, had FASD. My grandfather's chronic alcoholism seems to have left unmistakable marks on his offspring...: my mother was born with a slight intellectual retardation and with a series of neurobehavioural

disorders that were evident even as a child and which then resulted in what we now know as secondary disabilities.

When I finally got the diagnosis at the age of 40 it was a liberation for me, it was something that I can somehow call 'magical' because all of a sudden I could answer the endless series of questions that I had been carrying around inside of me for as long as I can remember. Questions that were related to my behaviour, my difficulties, they were related to those situations that I was living in a certain way and I couldn't understand why I was living that way. And since the diagnosis came, I started to read, to learn more about what this diagnosis meant, what FASD was, what it consisted of, what symptoms it had. And the more I read, the more I studied, the more I looked into it, the more I saw myself in everything and thought: 'That's why this happened to me when I was in noisy environments! That's why I had those violent, explosive reactions that I couldn't control! That's why I had that sexual hyperactivity already at such a young age! But then I am not crazy! Then I am not wrong! Then I don't have to be ashamed of myself, I don't have to feel guilty! Then I can finally know myself, understand myself, forgive myself and live!" This discovery allowed me to stop taking psychotropic drugs. Today it is more than 10 years since I stopped taking psychotropic drugs for Bipolar Disorder, which clearly turned out to be a misdiagnosis of convenience, not alcohol, not drugs. The

diagnosis was a rebirth, awareness, it allowed the creation of the association.

And from the diagnosis, which is only the starting point, I began the weaving of a huge network of friendships, of collaboration, I began to esteem myself and to feel that I was esteemed.

I remember very well how that psychiatric diagnosis was never explained to me, never anyone telling me what it meant, what it did not mean. It was given to me, I was told that all my life I would have this problem, all my life I would have to take psychotropic drugs. I, however, while submitting to family and medical wishes, crushed by a deep sense of guilt, never stopped feeling inside that I did not actually have bipolar disorder, that what I felt was different, was different, but, unfortunately, the stigma that accompanies the person with a psychiatric diagnosis, the weight of the actions related to the use of substances and alcohol makes the world around you, even the health world, no longer sees you as an individual with his own identity, his own personality, his own questions that deserve answers, but sees you, fundamentally, only as a culprit and a nuisance and therefore an unreliable person who must listen, keep quiet and stay where he is put without giving too much trouble.

What I realised from observing my developmental trajectory, which, as you can see, had started badly and developed even worse, going more and more towards destruction and self-destruction, towards the development of secondary disabilities, lack of

autonomy, critical capacity, institutionalisation, subjection, manipulation, is that at a certain point it found a first shore: the diagnosis, and then others: people and professionals who accepted this diagnosis and changed their point of view on me, bringing me back to the centre. I was again a person living with a series of complex problems. I was a human being who needed help and answers. And so, what seemed to be a condemnation, a story already written, changed direction.

All of this is to tell you how important this paradigm shift is, to emphasise that the person is more than a series of symptoms to be compartmentalised so that you have a stomach ache you go to the gastroenterologist, you walk badly you go to the neurologist, you are depressed you go to the psychiatrist, having to twist, twist, twist and desperately trying to pull the strings of what is and is not happening to you.

I am not just my gut or my brain or my lungs, I am a person composed of many interconnected systems. I am body, mind and spirit and one does not exist without the other. It is not me that has to turn around, it is medicine, it is society that has to put me at the centre, as much as any system today allows it, but that must be the direction.

I have the right to be able to trust and entrust to a Centre, to a professional, to a team that coordinates to start as soon as

possible this path of Care, which is much more than the prescription of a drug from time to time, but is the planning, construction, readjustment of our neurodevelopmental trajectories in constant dialogue with the family, the school, society, Justice and, first of all, with me, with us!

And if the wish is for continuous dialogue, one can only start with the ability to communicate. In FASD, language is often impaired, particularly receptive language, but so too can be the organic ability to articulate it, due to the damage that prenatal exposure to alcohol may have caused to the mouth, palate, throat...

One of the things that has weighed most heavily on me along this path, apart from not being believed and being psychiatristised, has been the absence of communication that was familiar with the characteristics of FASD. And this absence has had a dramatic impact on my mental health and on my always perceiving myself as inadequate. The fact that I have always had a very good expressive capacity has instead hidden what was my great receptive difficulty. Today I am reading because I do not know English so well, but I am a person who has a very good expressive language, I read a lot during the period when the attentional focus was higher, I like to talk, write and I believe I have a good vocabulary, but I have a very deficient receptive language. Certainly less today than yesterday. I find it very difficult to follow long sentences because I start to get lost, to listen to

someone if there is noise or if others nearby are talking, I get lost both in sentences and, while a person is talking, in their non-verbal language and so if I concentrate on the non-verbal language I lose the verbal one and vice versa. All these mechanisms are triggered, so that changing, for example, every time a doctor speaks is deadly because, very often, during that first visit one cannot get the general picture that instead is outlined hours or days later when the brain slowly begins to put the pieces together and the next time there is no longer the possibility of asking for clarification because one no longer has in front of one's face the person who said those words. Thus further doubts, confusion, contradictions begin to be generated in me, all of which weigh on both mental health and adherence to treatment (compliance).

To close: what is helpful and what is not?

I believe that it helps, first of all, to simplify the diagnosis process.

Our point of view as an association, which is also shared by professionals and other associations, is that a serious reflection should be opened up in this sense, turning a spotlight on the possibility of using the diagnostic criteria proposed by DSM 5 for Neurobehavioral disorder associated with prenatal alcohol exposure (ND-PAE).

The ease of understanding a diagnosis is crucial for the patient and the family, who must easily understand what the problem is and what it entails.

It would be of great help to compile a birth record in which the maternal and paternal use of toxic substances would always be clearly reported and which would allow the paediatrician at the first manifestations of atypical developmental trajectories to have clear elements on which to begin clinical reasoning.

It would be a great help if clear and complete clinical reports of adopted children and the social and medical files of the birth parents were provided, and if adopted children had the legal right to access this documentation at any time if they did not have it at the time of adoption. It is devastating for a person not to be able to obtain the diagnosis because the information of alcohol or drug exposure is not written down or has been reported by a source that is no longer traceable or unavailable to confirm it.

What is not helpful?

It is not helpful to continue to believe that the brain is not plastic, to continue to believe that the findings of neuropsychological assessments are immutable. To continue to

believe that psychiatric symptoms always correspond to psychiatric pathology and that it has no possibility of cure.

It is not useful and it is harmful to continue judging and interpreting the behaviour of those with FASD according to clichés and continuing to be betrayed by the invisibility of brain damage.

I believe that we can really all take a big step forward together, always guided by science, and realise that neurodevelopmental trajectories can vary, can vary all the time, can vary so much.

Cognitive and behavioural capacities are affected by many factors together, they are affected by age, they are affected by the environment in which the person lives, they are affected by the drugs he or she takes, they are affected by how the brain functions, but that brain will continue to develop and if the environment around the person with FASD changes the way he or she behaves, the brain of the person with FASD changes the way he or she reacts. In this way, strategies are created to which deep awareness of the disorder one has also contributes, not just 'I have FASD because they told me so', but 'I know what I have'.

Let me give you an example: a neuropsychological assessment of mine in 2010 found 'global cognitive impoverishment'. Years later, several aspects of this first assessment had been profoundly downgraded. This does not mean that either assessment was false, wrong, but simply that they were a snapshot of two profoundly different moments, in the first my trajectory plummeted, in the second it rose again...

Another aspect that does not help is judging a person's difficulties on the basis of what one sees fleetingly from the outside. This is a cause of great suffering. It is not because you see me here today, like this, that you can think you have sufficient elements to make an assessment of my capabilities and difficulties, it is in my everyday life, in my privacy, in my comfort zone that they become more evident. Therefore, to give in to this trivialisation, simplification, is to be ourselves victims of preconception and stigma.

It doesn't help to receive a series of diagnoses that add up: Asperger's Syndrome, Antisocial Disorder, Borderline Personality Disorder, Bipolar Disorder, ADHD... No, it doesn't help, it harms. To provocatively paraphrase Ginsberg: "I have seen the best minds of my generation destroyed by the *psychiatry of complexity...*"

What helps?

It helps to make the person aware of what their disorder is: what it means, where it comes from, how to intervene and this needs to be done as soon as possible and as much as possible because it is the only way we have to drastically reduce mental health disorders, drug or alcohol addiction disorders, school problems, dropping out of work, disesteem...

It helps the confrontation, support, resonance between peers and would greatly help the institutionalised introduction of the *Peer Specialist* figure in Health and Mental Health pathways.

So - and with this I end - I hope I have contributed with my 'from within' vision to stimulate the desire to dialogue, to listen, to build **together with us** and **not in our place**, this new paradigm of Care in which, at last, our deep sorrow is welcomed and our needs listened to!

Thank you again very much for your attention!

Let me give special thanks to Dr **Diane Black for** inviting me and for considering my participation useful; to Dr **Stefania Bazzo**, who is here with me, for her patience, for being always precise, helpful, competent. Stefania really is the only person I know who really knows how to translate her deep theoretical knowledge of FASD into practice.

I still want to thank with all my heart a true and great Friend: Dr **Giuseppe Battistella**. He is the person who allowed me to arrive at the diagnosis and therefore the person who allowed me to be reborn! Without him, our AIDEFAD association would not exist!

And again a personal thank you and on behalf of the entire Association to dr.ssa **Simona Pichini** for her friendship and support

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And last but certainly not least, the biggest THANK YOU goes to **Sharon**, my partner, who I am glad could be here today! Thank you for being able to be by my side for more than 7 years now because I know it is not easy, despite the hard battle life has forced you to face. From the outside it's easy to talk, but from the inside it's hard, I know, it's not easy to be close to someone who has FASD for so many reasons. I thank you for your being able to put up with my stringent need for routine, for my mood swings, for having to repeat the same things over and over again because I forget them, for my not understanding your joking, for my continual need to understand everything in detail, for my often deficient ability to put myself in your shoes and in those of others, for the rigidity of my thinking, for my being lonely and argumentative, for the weight of the traumas that are unfortunately always with me...

So, my invitation to all those who, professionals or not, are always ready to judge, are always ready to believe that they know everything, that they know **THE** truth, is to stop and think about how deep the pain of people who are living with this disability can be, about the pain of natural mothers who have been drinking, about the drama of families who do not know how to help their children, and on what the priorities are, and the priority is to help these people, these families, by stopping judging, interpreting, and allowing them to be able to understand their own suffering.

"Because if medicine really wants to fulfil its great task, it must intervene in political and social life. It must point out the obstacles that prevent the normal social functioning of life processes, and remove them. "

Rudolf Virchow.

Thank you very much and a big hug to everyone.