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The Clinical Gestalts of Autism: Over 40 years of

Clinical Experience with Autism

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Abstract

The clinical gestalts of autism are very broad and much more heterogeneous than people realise. DSM V [1] gives a more narrow and condensed description of what autism is in the twentieth century. DSM focuses on problems with socioemotional reciprocity, nonverbal communication and difficult interpersonal relationships, restricted, repetitive patterns of behaviour, early onset and functional impairment. First, I want to flesh out the autism spectrum disorder gestalts as it presents to experienced clinical practitioners. It is the opposite of the "tick box" approach to diagnosis so common today. It focuses on the phenomena as they would have been focused on in the late nineteenth and early twentieth century, an approach that has faded into the background in the late twentieth and early twenty-first century. It is critical at this point of the twenty-first century that we re-engage with phenomenology and with the clinical gestalt of psychiatric conditions which show a great deal of overlap with much mixed phenomenology. We will start by examining social relations in autism spectrum disorders. Clearly, this is central to autism.

Keywords: clinical gestalts of autism, evolving concepts of autism

1. Introduction

There has been a very considerable evolution of the concept of autism since the Kanner 1943 paper [2]. The move has been from a very narrow concept of autism with Kanner to a much broader concept of autism today, which was foreshadowed by Hans Asperger in 1938 [3] and 1944 [4]. I will describe the characteristics of the broader autism phenotype as I have observed them over the past 40 years.



2. Social deficits

When professionals meet families with autism, they often very quickly become aware of how very clingy to one parent the child with autism is, with a fear of groups but being less anxious in a one-to-one situation, particularly with adults or having one "friend". In groups only relating to one person is common, often to the point of fixation, making inappropriate comments is extremely common to peers and adults, for example, saying to a doctor, "you are very trendy". Hiding behind mother when they are in consultation with the doctor and the doctor asks them questions is extremely common. When they come in to a doctor or examiner's officer, they will often sit on the "parent's chair" or alternatively sit away at the furthest point from the examiner, in the room. Extreme positions are very common.

They often will hold mother's face roughly to get her to look straight at them. In communication, they will often look past people and have reduced eye contact in consultation and elsewhere.

One parent often describes themselves as loners and good mixers at the very same time. They mean that sometimes they are loners and sometimes they are good mixers, but do not and cannot come down on either side. Ambivalence and inability to make up their minds on emotional matters are extremely common. One parent often emphasises their private time, while saying they are sociable. Children with autism can engage in extreme interpersonal aggression, but less degrees of interpersonal aggression are very common. Children, when they engage in rough play, will cause considerable upset at school and home and can include attempts to choke other children. These children with autism experience a great deal of suspicion and paranoid thoughts of people and feel people are against them, talking about them, and not liking them. They are extremely sensitive to highly expressed emotion.

In the marital situation, you often find a change in roles where the wife will go out to work and the husband will become a house-husband. The house-husbands will very often have autistic traits, if not autism. Being unemployed will not be rare in persons with autism or Asperger's syndrome. This is the default position from the stress of work and interpersonal relationships at work.

Girls (and to a lesser extent boys) with autism may live their lives one second after others around them and will copy the behaviour of people around them one second later and then hide their autism. The paradox is that persons with autism can be profoundly observant. This can lead to "as if" or chameleon-like personalities "hide" and "hide" their autism in this way.

3. School and college years

For young children, biting and kicking is fairly common in preschool and at home. They often show disrespect to teachers and other pupils in the school. They will speak to a teacher as a "mini-adult" and as if they are on the "same level" as the teacher. They will terminate

friendships if the friend does not do exactly what they want them to do. They have huge difficulty allowing other peers to have autonomy and to take control of interactions. Pinching and biting is common in preschool. They may make up their own social rules in school. Going under the desk at school is very common as a sensory avoidance, as is putting their head on the school desk. Because of their lack of social skills, they commonly, as children or adolescents, show oppositional defiant behaviour, which at times can be the biggest challenge for parents and teachers with them often losing temper, often arguing with adults, often being defiant, often being angry with adults, often being touchy and easily annoyed and being spiteful and vindictive, with a comorbid diagnosis for oppositional defiant disorder. This is often because of their empathy deficits and theory of mind deficits. They are often very controlling and dominating, which causes major problems at home and school. They always have to win. They have great difficulty in understanding the rules of a social game and particularly difficulty in engaging in group sports, which they do very rarely anyhow. Sports have formal rules, but also unwritten rules, that is, what they can get away with. This is why referees are necessary. They may be over-rigid in following the rules, and this causes major difficulties in social behaviour.

They often have very little sense of danger about roads, or strangers, or in school and particularly dangerous social situations. As they get older, they will often engage in school refusal and isolate themselves in their room on their computers. While some may only want to play with the opposite sex, or get on better with the opposite sex, others have a hatred of the opposite sex. They can sometimes relate reasonably well to siblings or family members or survive in school when looked after by a sibling, but others can be vicious and dangerous to their siblings. When they describe someone that they would call their friend or a bully, they will often describe the same person. Excessive and inappropriate sharing of their thoughts about self and others is common and can cause them to be bullied. They are often the "class clown" as a way of getting attention, and this can be very disruptive in school. In the school class, they will often shout out answers and have difficulty with timing, because of their social communication difficulties. Sometimes they will want to answer every question in the classroom, which causes problems in the classroom and for teachers. Children with autism can control their abnormal social behaviour in school with massive and exhausting effort, but only to "explode" at home with temper tantrums and oppositional defiant behaviour later in the evening. Some with very high IQs may find some other cognitive strategies to help them survive at school.

4. Transitional object and autism

Comfort blankets, teddy bears, etc., are very commonly carried around by children with autism. Winnicott [5] mistakenly called these transitional objects. They have nothing to do with child development in the Winnicottian sense, but everything to do with comfort, anxiety reduction, preservation of sameness and sensory issues. This is an example of psychoanalysis over-complicating simple and obvious phenomena.

5. Emotional and cognitive problems

Problems understanding their own and others' emotions are very common and probably universal. They often do not understand depression and ask, "What is the depression?" When asked whether they are happy or sad, they will say, "both happy and sad" or "I don't know". They often have low capacity for emotional expression and great difficulty in expressing emotions, including feelings and thoughts. Sometimes they want to give the absolutely correct answer, and there is therefore a great delay in answering a question. In a public intervention situation, they can therefore give the impression of not cooperating. They are often either fearless, show evidence of serious risk taking, or the opposite, huge fear, anxiety and panic. Autistic novelty seeking can also be seen [6]. They often also showed generalised anxiety.

6. Language

They will commonly be delayed in language, but will begin to speak in full sentences when they do begin to speak. Imitating accents is very common, particularly accents the child with autism will hear on television. They will often imitate these extremely accurately, and this will be noted as being different from neuro-typical children. Irish children will often be described as having an American accent, or a posh English accent, or an unusual tone to their accent. Small children often have a soulful or plaintive cry, which can be a most disturbing cry to listen to and it can go on for many hours. They often use a "babyish" immature voice at any age. Older persons with autism can have marvellous sense of verbal humour [7], playing on words, etc. They will often change their accent to suit their situation or copy the accent of the person they are talking to. They engage in a great deal of talking to themselves—self-talk. This is an effort to sort out emotionally cognitive puzzles and experience. Some children will often speak like adults, another reversal. They may engage in repetitive questioning and always want the questions answered exactly the same way. Some of the children will have a very high-pitch tone of voice, others low-pitched, other a monotonous tone.

They will sometimes pronounce every word accurately. They mostly have difficulty doing personal, emotional writing in the social sense. The autistic narrative will not give people a sense of social context. This is being called autistic narrative [8], seen in autobiographies of persons with autism. They are often obsessed with words, language and numbers. They will express too much, which is inappropriate sharing of personal thoughts. There will often engage in sub-vocal talking and singing. They pick up accents very rapidly. They very commonly answer questions with "I don't know". They will be very hesitant in answering questions, and it will take a long time for them to answer the questions. Loss of language or babble and words in the first 2 years does occur, not uncommonly. Sometimes the loss can even occur into the third year.

While most are extremely truthful and indeed, inappropriately truthful in social areas, a number can make up stories have a fantastic imagination and can fabricate false stories about parents. This is due to the difficulty of separating fact from fiction in their minds. Often their

conversation is not very coherent, difficult to understand, which leads to misdiagnosis of thought disorder and schizophrenia. They often ask, "What's going to happen next?" They often make up words or their own language ... neologisms. If something is spoken about as going to happen, then it must happen at exactly the time it was spoken about.

Parents with autism and very high IQ can use language to camouflage their symptoms, which leads to later diagnosis.

7. Identity

Identity diffusion is central to autism, and this will include their sexual and other identities. This is probably due to the neural connectivity problems in the brain [9]. Contradictory identities can exist side by side in their mind. They can switch to another and opposite identity very rapidly. This can be confused with so-called multiple personalities. This identity diffusion can cause stress in making decisions and in employment, and despite intelligence and good education, they may withdraw and cease to seek employment. They can confuse people with these contradictory identities. They do not have a clear sense of themselves and people find it difficult to understand them. This makes it very difficult for them to have a clear sense of other people. This increases interpersonal stress. They are often mistaken for the opposite sex and come across as being androgynous. Males can appear to have a soft female facies and females with a somewhat harder male facies. They may dress more like the opposite sex, which always causes confusion and shows signs of gender dysphoria. A small number will have transgender problems. Sometimes they feel unreal and de-personalised as living in a film and having an "as if" personality. Older adolescents with autism or Asperger's syndrome often appear to be "asexual". This can be very deceptive as the very same people can get involved in perverse, dangerous sexual activities.

8. Sensory problems in autism are almost universal

The sounds that cause major difficulties include the sound of a hoover or babies crying. This can be extremely upsetting and on rare occasions, put the crying baby at risk of violence from the persons with ASD. There were always contradictory findings in the sense that I have seen a child with ASD who loved the sound of hoovers. They often smell everything, are extremely sensitive to the texture of food and do not want different foods touching on the plate. They often find haircuts extremely upsetting and will wear their clothes inside out, because of sensory issues, to avoid clothes tags on their skin. Others will put everything in their mouth for sensory reasons, including towels. They often chew their clothes. Often they are not bothered by their own noise but bothered by the same noise created by someone else, which is contradictory.

They can overeat because of difficulty knowing when they have eaten enough/satiety. This may be due to the sensory issues in the gut, which doesn't tell them that they have sufficient food eaten. This requires empirical research. They often find the visual very stimulating and

are fascinated by lights, by pictures and by spinning objects. Some are the opposite and are hyposensitive in relation to pain or hypersensitive, another contradiction.

9. Narrow interests

They are often very interested in nature, with gardens, with dogs, animals, sharks, horses, bugs, etc. Other and possibly the most common of all interests now are computers, iPhones, iPads, computer games and technology in general. They love to take things apart and work out how things work. No wonder so many are attracted to engineering work. Making lists is very common. This probably gives them some kind of control or order to their life. Some are massive collectors. The younger children love turning pages of books, per se. Older children love reading them, particularly novels on science fiction, history, encyclopaedias, books of facts, or Egyptology, palaeontology, physics, science, cosmology, etc. Being talented at music or being interested in music is quite common. Some are fascinated by younger children. They are often preoccupied with just one person. Others are obsessed with time, and of course Albert Einstein had autism [10] and was obsessed with time. At Christmas time, they can be fascinated with Christmas trees. Other fascinations include guns [11], ammunition, horror movies, violent movies and the topic of death. They are often preoccupied with their own and their parents' death. In rare cases, they can be very interested in serial killers [11] and a tiny number can engage in so-called mindless violence.

They are very easily led and can easily be led into criminal activities. They often love to push buttons, switch on and off lights, open and close doors.

Sometimes they will not change their clothes and wear the same clothes every day. They may fixate on a television character or a teacher. Girls will often have no interest in dolls. Boys and girls often will have no interest in toys and be more interested in everyday objects and can find small things missing, where others would miss them, with their massive attention to detail.

10. Physical issues

They often have low immune system and are highly prone to infections, particularly ear infections. Delayed toilet training is very common. Parents will often tell you the child had pyloric stenosis, hiatus hernia, difficulties feeding (poor eating, fussy eating), and swallowing, "was a colicky baby", or had eczema. Hypermobility of the joints and muscles is very common. They often somatise their problems and present with unexplained physical illness, or Alexithymia [12], which often occurs with Asperger's syndrome. Cerebral palsy and a vast number of chromosomal abnormalities occur. Many brain abnormalities can be presented, including agenesis of the corpus callosum or optic nerve hypoplasia. Clearly, these last two conditions would be extremely rare. A large head has been shown to be associated, but I have often seen a large head at birth. It would be interesting to measure the head circumference in utero. These children are often very tall for their age, and indeed, I have also noticed parents being equally tall. They can be confused with Marfan's syndrome.

11. Motor issues

It was an error in DSM V [1] to leave out motor issues from the main criteria and only mention them as associated features. The most common features that a parent of an autistic child will mention are motor issues including tippy-toe walking and "bum-shuffling". They often describe the "combat crawl". They will talk about the child having never rolled over. Other mothers describe a "crabby crawl" and "walking on their knees". Other features include the child having "one leg out and one leg under him". Sometimes you see a stiff gait with the hands rigidly by the side of the body and a rigid tense body. There is hugely reduced nonverbal expression. Moving sideways through a door has also been a feature. Other parents say the autistic child never crawled, but just stood up. Some mothers describe their child as walking very carefully, while more commonly they describe their children as walking awkwardly. Another feature can be "crawling on the abdomen", as described by parents. Other features can be unusual motor movements with legs crossed and jumping up and down. Sometimes severe clenching of teeth is noted. In lower functioning children with autism, head-banging is not uncommon. There are parents describing their children as having clumsy walk or walking like a "monkey". Another description by a mother was of "frog-like crawling" or crawling backwards. Asymmetric movements of the body, pulling of one leg after the other, can be seen. Clinicians need to be much more attentive to motor issues in the broader autism phenotype.

12. Non-verbal behaviour

Late smiling is noted or biting hands and rocking are common. The rocking can occur at any age. There is a huge amount of imitation and copying of others' non-verbal behaviour. Children and adults with autism can be brilliant at mimicking and very good at non-verbal humour, for example, slapstick humour [7]. Some will often stare inappropriately for a very long time or come excessively close and look at the other person in the face. They will often adopt the other person's attributes in an extreme way. Their dress can often lead to them being mistaken for a person of the opposite sex, which is probably due to their identity diffusion. Sleep problems are extremely common. They are often very tall, and this is one reason why a minority are therefore not bullied. They often wear, "rabbit type" uniforms, dress in a teddy bear outfit or of course nowadays, they will often have headphones to cut out noise. They can show a mixture of crying and laughing at the same time. Contradictory verbal and non-verbal behaviour is not uncommon. Clapping the hands when excited, flapping the hands and looking at things through the corner of their eyes are not uncommon.

13. Repetitive behaviour

They will often prefer to play with cups or other objects, rather than toys. They often particularly put things in and out of boxes repetitively. They love switching on and off lights. Indeed, Sigmund Freud's (who had Asperger's Syndrome) grandson, Ernest Freud played with a reel and this could be seen as a repetitive autistic play. He threw the reel out and pulled it back in,

in a repetitive way. Of course one feature does not give a diagnosis. They often love to calculate repetitively and can have massive memories.

14. Pregnancy and labour

Extremely, commonly here are some complications in pregnancy and delivery which are very difficult to interpret and whether this has some special meaning or is just coincidence has to be resolved. Long labour and assistance with delivery are common. Emergency caesarean section, because of foetal distress, is very common. Other reasons for caesarean section can be a failure to go into labour or labour stopping in mid-point. Other causes can be a failure to dilate. Prolonged labour, cessation of labour or extremely quick labour are not uncommon. There seems to be increased rates of autism, when there is assisted reproduction. Other factors which include reduced amniotic fluid, placenta previa, breech or face presentation, shoulder presentation or other abnormal presentations are not uncommon. Multiple pregnancies can be associated. Other issues can be very stressful pregnancy, various drugs in pregnancy, or hyperemesis and pre-eclamptic toxaemia in mother. Of course, many of these features could be just coincidental.

15. Parents

In terms of occupations, it's very common for one or both parents to be accountants, engineers, computer specialists, policemen, landscape gardeners, lorry drivers, mathematicians, scientists, engineers, butchers, soldiers, taxi drivers, stonemasons and painters. In more recent years, I've noticed fathers being unemployed as a more common feature. This may be due to them having autistic features and withdrawing from the work situation. "House-husbands" is becoming much more common as an occupation for fathers of children with autism.

16. Conclusion

The concept of the autism spectrum disorder is now almost universally accepted. This chapter outlines the broader autism phenotype. The National Institute of Clinical Excellence (NICE) guidelines [13] recommend no specific instrument in the diagnosis of autism. Unfortunately, it is widely believed that there is one gold standard instrument for the diagnosis of autism, and this leads to many children on the spectrum being excluded from autism and from the autistic diagnosis, with great distress to the children themselves, to their families and the schools that they attend. This then excludes them from the specific autism services, and unfortunately, this happens in many parts of the world. The great array of autism instruments can be useful for information gathering, for new mental health professionals in the field. They do not give you a DSM diagnosis as outlined by the National Institute of Clinical Excellence guidelines. One of the instruments which are widely used in clinical practice which is quite appropriate for use in research is the ADI-R [14]. This has been widely criticised, for example, by the

most experienced and distinguished professionals. An example is Professor Dorothy Bishop, Professor of Developmental Neuropsychology, University of Cambridge [15]. Professor Dorothy Bishop [15] states that, "the main problem with the ADI-R is not just the financial cost (although that is certainly prohibitive for many), but also the cost in time; time for training, time for administration and time for scoring and consensus coding", and "if it could be shown that there were real benefits in accuracy of diagnosis from adopting this lengthy procedure, then I'd be happy to say: "Ok, this is the best way forward and we just have to find a way to do it", but the originators of the instrument have never demonstrated that you actually need such a long process—it is really more an article of faith with them", and that, "part of the problem is that criteria for autism keep changing, and cut-offs are entirely arbitrary. I personally think we'd be better off with a dimensional, rather than categorical, conceptualisation of autism—that is, one with a measure that gave a quantitative index of level of autism symptoms on different dimensions" [15].

Professor Bishop points out that there are "plenty of children who come out as meeting criteria on one instrument only, and there seem no sensible guidelines as to how you then proceed, other than to seek expert clinical opinion". The bottom line, she told me [Adam Feinstein], was that those devising the diagnostic instruments for autism "should be doing studies to see what is the minimum set of items you can have to get reasonable diagnostic accuracy". I doubt that we really need a three-hour interview for each case.

The International Meeting for Autism Research (IMFAR) was held in London in May 2008 [16] "where many of the most experienced and distinguished Autism Researchers in the world lambasted the tool for missing many cases of Autism".

This creates a public health problem, the missing of these persons with autism. This is especially so in countries that put excessive emphasis on clinical use of the ADI-R [14] for the diagnosis and particularly where the prevalence of autism as we know now is much greater than in the past. The Centres for Disease Control, (USA) 2016, put the prevalence of autism at 1 in 68, that is, 1 in 42 for boys and 1 in 189 for girls.

From a clinical perspective, the most serious problem facing the autism field is missing the diagnosis of autism in many situations. Unfortunately, the NICE guidelines are so often ignored.

Dr. Lorna Wing [17] used the concept of the autism spectrum disorder or the broader autism phenotype which is accepted by clinicians in most parts of the world today and forms the basis of autism in the DSM V and also in the proposed criteria for ICD XI to be published in the next few years. Unfortunately, a few practitioners are still using very narrow criteria. This is a problem as I've shown myself that when you use criteria like Kanner and Eisenberg [18] for autism, one gets very low rates. Fitzgerald showed that using the same patients, the prevalence of autism varied in a total sample of possible autism patients of 309, with 85%, (256), meeting the DSM III/R criteria to 8% using Kanner and Eisenberg's criteria [18]. Professor G. Baird's study from the Lancet [19] gave a prevalence of 116.1 per 10,000 [20], and Professor Simon Baron-Cohen's study from Cambridge in the British Journal of Psychiatry (BJP) put the prevalence at 157 per 10,000.

I hope that this chapter will make the reader aware of the dangers of a narrow concept of autism and the severely negative consequences for children being excluded from a diagnosis of autism, which means they are excluded from services. Everyone in the field agrees the critical importance of early diagnosis and early treatment, and these children have a better outcome. Children deserve nothing less.

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