FROM FRAGMENTATION TO COHERENCE

Explaining autism and derealization/depersonalization in the context of child development

Creating 'Reality'

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INTRODUCTION

A new human being has been born! From the darkness of the womb into the light, into the world ... naked, vulnerable and dependent.

Each human being may be regarded as a fragment of humanity. To develop and to survive, the newborn cannot remain an isolated fragment, but must instead become an interested, interacting member of society. The fragment must become connected to the others that make up the greater whole: the human community.

In the first place an infant must possess the intrinsic ability to interact and bond, but at the same time, others must create, to a sufficient degree, the conditions that make interaction and bonding possible. In the natural order of things, the infant's mother is the first partner in interaction, and she is also the first person with whom the infant bonds. If all goes well, children become securely attached to their mother/parents and develop into interested, interacting members of society. In some cases, however, too little engagement and bonding with others develops, or none at all: the child's development stagnates. Such a child may be diagnosed at some point as having "autism".

Autism is widely believed to be organically based. But as yet extensive research in this field has not been able to generate information that can explain autistic behaviour. Autism has never been diagnosed in a child immediately after birth. Autistic behaviour does not begin to manifest itself until some time has elapsed. We all know that interaction is not a solo activity. Newborn infants have had no experience of interaction. Parents have, and so it is they who must take the initiative to lead and guide interaction such as to secure its satisfying continuation. In spite of all this, whenever the process of interaction falters or stagnates, the cause of the child becoming autistic is sought in the child alone; the question of whether the child's partner in interaction may have fallen short in some way is evaded. Why? J. Richer, S. Coates (2001): *"The history of theorising about autism has had some unfortunate features. Most unfortunate was the early "blaming" of the "cold refrigerator" mothers for causing their child's autistic withdrawal. The main effect of this was* to cause huge distress to parents who had already lost the child they had been expecting. A subsidiary effect was to over- sensitise many to see any research on the children's social behaviour and relationships as ipso facto a return to the bad old days of parent blaming".

Meanwhile, research on child development continued. Thanks to the interest in it that was aroused by the superb work of John Bowlby and Mary Ainsworth, researchers started to focus on attachment, in the first place the infant's attachment to its mother. Mother-child interaction was subjected to close observation: given that many studies have demonstrated clearly that the mother's behaviour exerts a fundamental influence, whether positive or negative, on the process of interaction and bonding.

Am I pointing an accusing finger at the mother or father? No, parental behaviour is strongly influenced by a lifestyle that has been created collectively by our human community. This too needs to be examined. Does our modern society perhaps offer infants less favourable conditions for learning to interact and to become securely attached? I believe it does. All this can only be said when silence does more harm than speaking up, and when information becomes available that can help to enrich our insight. Not just parents but every one of us who contribute to the modern ways of life and others, who have done so over the past few decades, have together created modern society. And hence it is the responsibility of us all.

Research on attachment has generated findings that can help to explain autism. But something important needs to be added: an explanation for the phenomenon of derealization/depersonalization. Someone who experiences severe derealization/depersonalization no longer feels her or himself to be real. Overall reality has lost its significance and power to attract; interaction becomes impossible or can be achieved only with the greatest of difficulty. The 'fragment' has become detached from the larger whole. If there has already been sufficient development before this happens, the person may be able to explain what he or she went through before derealization/depersonalization and is able to describe the actual experience of 'detachment'. This information may help to identify factors that can cause autism and open the door to the closed world of the non-speaking person with autism. As far as I have been able to ascertain, autism and derealization/depersonalization have never before been linked under the heading of a single theory. That they are unconnected would appear to be an untenable proposition, when the observed behaviour of autistic children is compared to the subjective accounts of people experiencing derealization and depersonalization.

The fact that no link has previously been posited between the two phenomena is probably attributable to the difference in manifestation. An experience of derealization/depersonalization is scarcely visible, if at all. It is the personal account that makes it clear. Autistic behaviour, on the other hand, is in general quite conspicuous. Autism manifests itself in early childhood, while derealization/depersonalization does not become apparent until a later stage of development. Autism is seen as an independent disorder, while derealization/depersonalization may occur among individuals who are not suffering from a psychotic disorder; it may be triggered by a state of shock, for instance. Autism is generally attributed to a biological cause, while this is not the case with derealization/depersonalization: *"The disturbance is not due to the direct psychological effects of a substance or a general medical condition"* (DSM IV, 300.6).

In the course of the twentieth century, psychopathological behaviour was intensively analyzed, studied and 'charted' more clearly, and was gradually divided up into diverse disorders. The distinguishing and labelling processes were performed with great care, creating order, making psychopathology appear a more neatly-defined field, and enabling research to be given a more precise focus. Diagnostic guidelines were set down in the *Diagnostic and Statistical Manual of Mental Disorders*. This book is updated periodically on the basis of new research findings, re-evaluations and new approaches.

Some disorders have now been explained. Where others are concerned, targeted research has generated a wealth of findings and information, but without producing a sufficient explanation for the disorders concerned.

The classification agreed upon has acquired considerable authority. But while major disorders remain unexplained, we cannot be sure that the divisions inherent in this classification are correct. Differentiation and labelling have brought about a degree of fragmentation in psychopathology. Might this fragmentation not impede our view of certain meaningful connections?

You may well be familiar with the following image:



Fragmented, the image represents the profiles of two faces; unfragmented, it reveals a vase. Profiles and vase cannot be held in distinct focus simultaneously. A viewer wishing to see the image clearly as a vase must focus not on parts but on the unfragmented whole. The same applies to psychopathology. Anyone seeking to identify meaningful connections will have to adopt a different perspective, at least temporarily, abandoning fragmentation and seeking central coherence.

This book sets out to provide an explanation for autism. To this end, autism had to be placed in a wider context. In particular, the book describes and seeks to clarify the connection between autism and derealization/depersonalization. As long as important phenomena in the sphere of development and/or psychopathology are insufficiently explained, one's mind must remain open and receptive to new ideas and possibilities. The relevance and/or interpretation of earlier research data may change when they are placed in a wider framework and placed on a new or different theoretical basis.

Chapter 1

PUTTING THE INEFFABLE INTO WORDS

As far as I have been able to ascertain, at least where the Dutch and English literature are concerned, autism and derealization/depersonalization have never before been linked under the heading of a single theory. That they are unconnected would appear to be an untenable proposition, when the observed behavior of autistic children is compared to the subjective accounts of people experiencing derealization and depersonalization.

AUTISM

DEREALIZATION/ DEPERSONALIZATION

Affect

Kanner refers to the syndrome of autism as "autistic disturbances of affective contact". (1973)

Asperger: "In dealing with these children, one has the impression of a pronounced emotional defect, which appears to be the ultimate cause of their disturbed relationship with the world around them." (1944) Janet states: "Experiences of emptiness, as are seen in patients who take no pleasure or interest in anything, who are never distressed by anything, appeared to us to be characterized by a lack of emotion". (1928)

Janet's patients:

- "Every emotion that added charm to life has gone. It is sad to find all the feelings that one has had since childhood have gone forever."
- "I don't care about anything any more, I can't love any more."
- "It is awful not to be unhappy;
 I would be happy if I were able to be unhappy."
- "I am a living statue; whatever happened it would not affect me." (1928)

Patient of M. Revault d'Allonnes

complains that she can no longer live because she no longer feels any distress, sadness, anger, disgust or affection. (1928)

Mayer Gross: "Lack of feeling is found in all the cases of my series. In both depersonalization and derealization." (1935)

Cattell: "There is an attendant loss of affective response with complaints of no feeling for loved ones, no emotions and no pleasure." (1966) **Lower:** "In twenty of my patients who

have experienced episodes of depersonalization, some of them multiple, all have reported a degree of affect loss." (1972)

Experiencing the outside world

Kanner: "The common denominator ... is the children's inability to relate themselves in the ordinary way to people and situations from the beginning of life." (1973)

Janet's patients:

- "Nothing I see is real. You are just a phantom like so many others; how can you expect someone to be obedient and affectionate to someone who doesn't seem real?"
- "Oh, to hear his family members in the neighbourhood, playing and talking, and to feel no need whatsoever to become involved in their lives, to feel completely detached from what they are doing, not to join in their conversations, unable to empathize, not to share their sadness, only to hear, nothing else, unbelievably awful." (1928)

Renée: "People became void and lost their souls. Only their bodies were left to them, moving like automatons, and their movements were deprived of emotions and feelings – I was rejected by the world, on the outside of life, a spectator of a chaotic film unrolling ceaselessly before my eyes." (1994) Kanner: "Profound aloneness dominates all behavior." (1973)

Eveloff: "Their extreme isolation is perhaps the most obvious major symptom." (1960)

Eveloff: "Parents will frequently say of their child that they had an obedient, well-behaved baby who didn't cry or interfere much in their lives, but who in retrospect did not seem to recognize them." (1960)

Schopler: "Others refer to children who walk 'over' or 'through' other persons. This child did not go out of his way to walk over people but he made no effort not to do so. In a similar vein autistic children have been described as unable to discriminate between living and inanimate objects." (1965)

Snijders-Oomen: "They appear to look through and over people and things." (1975)

Renée: "In absolute solitude, I am terrifyingly alone." (1994)

Janet's patients:

- "I see people without seeing them, they have vanished into the distance, I've lost them and I feel alone in a vast emptiness."
- "I feel abandoned in terrible loneliness. God has withdrawn, [along with] heaven and earth."

Patient of Hartmann: "This morning, for instance, I had the feeling that I was seeing mother for the first time. She seemed so alien, so unfamiliar." (1922) Renée: "I recognise nothing, nobody." (1994)

Janet's patients express a similar inability to recognize close relatives, e.g.:

- "That's a good imitation of my sister, but it's not my sister."
- "It's not worth the trouble taking them with me, since they're not my children." (1928)

Shorvon: "The complaint is not infrequently heard that everything, although well perceived, is with difficulty recognized."(1946)

Janet: "When this disorder takes on a severe form, other people lose not only their affect and their kinship quality, they actually lose the qualities of a living being. They are not people but puppets, machines, wooden ducks." (1928)

Janet's patients:

 "I see people without seeing them, they've disappeared into the distance, I've lost them." Austen Des Lauriers: "Eyes and ears are normal and functioning at least at receptor level yet he does not seem to see and hear as a normal child does." (1969) O'Connor: "In clinical practice the similarities in the behavior of blind and autistic children have been frequently noted." (1971)

Snijders-Oomen: "No child who deviates from the norm is suspected of deafness as often as one who is autistic." (1975)

- "I've suddenly become stupid: people speak to me, people show me something and it enters my eyes and ears but not my brain."
- "It's as if there's a fog, a cloud in front of my eyes preventing me from really seeing anything."
- "I see without seeing, I'm a blind person seeing." (1928)

Janet: "Some patients go to a doctor and ask for better glasses. In this context I examined both so-called deaf and socalled blind patients. These were people who denied their auditory and visual perceptions, because they had the feeling that these had vanished." (1928)

Desire, interest, action

Autistic children display little or no general interest in the outside world. When they act, they often repeat their actions.

Clara Claiborne Park: "Elly seemed strong. But between her and any normal development lay this terrible weakness that was no less real because it seemed to lie not in the muscles but in the will. Impossible to separate this physical inertia from the mental and emotional inertia which accompany it.

 What seems impaired is not only the capacity for affect, but another capacity perhaps even more fundamental, the capacity for undertaking exploratory behaviour and sustaining it." (1968) Janet: "She is indifferent to everything she used to enjoy and be good at. Whatever anyone suggests, she responds, "It makes no difference to me, I can't do anything, I can't draw, I can't write, what would be the point? Everything I do is banal and meaningless." She makes no effort to do anything, and she has no desires." (1928)

Schilder: "All patients complain to a greater or lesser extent of a lack of desire." (1914)

Mayer Gross: "A considerable number of my patients did describe a loss of activity: "I lost every interest, I do not want to do anything, I am terribly aimless, without desires and ambitions." (1935)

Patient of Doornenbal: "Sensing no boundaries or anchor, I drift around soulless, aimlessly." (1978)

Remembering and imagining: the inner world

Hermelin: "I would like to suggest that autistic children lack 'inner pictures' or to put it more generally that there may be in their case an absence of internal representation of external events which normally serves as a code which is used to interpret the environment." (1978) **Rimland**: "The child with early infantile autism is poorly impaired in a function basic to all cognition: the ability to relate new stimuli to remembered experience." (1964)

Volkmar, Klin, Cohen: "Fantasy is impoverished if present at all." (1997) Austin Des Lauriers: "Hallucinations are absent." (1969)

Claiborne: "What she misses is having a sense of purpose. Purpose is inherent to another faculty, one that plays a big part in motivation, namely the power to imagine something, to conjure up an image of something, to take something seriously, without experiencing it, or not immediately in any case." (1968) Patients of Mayer Gross: "I cannot make any mental picture. If I shut my eyes, for instance, it is like a complete blackout, there are no thoughts coming through at all." (1935) Catell: "There is a loss of ability to evoke visual imagery." (1966) Hartmann: "W.S.'s main complaint is an inability to imagine anything, from people to places or things." (1922) Jacobsen: "Patients often complain of an inability to imagine people or things that are familiar to them." (1974)

Janet's patients:

- "I used to feel, to have mental images when I said something, now there is none of that, when I see things I feel nothing, no image is invoked, I have a permanent curtain in front of my mind's eye. I am in a void, I am a body without a soul. When I go somewhere it's as if I have never been there before."
- "I don't have the strength to imagine people or to preserve a little feeling for them. I forget them as soon as they are out of my sight." (1928)

Patient of Janet: "I'm like a dog that doesn't know where it has come from or where it's going." (1928) Patient of Doornenbal: "I drift aimlessly". (1978) **Rutter**: "The autistic child is particularly poor in the understanding of the meaning of spoken words. The verbal recall of autistic children was found to be relatively independent of the meaning of what they had heard. They lack the ability to associate words semantically." (1971)

Hart: "If you couldn't understand words that others use, like 'then', 'sometime', 'did' or 'will', would you become confused when others used them? Would it make you angry if you thought other people used those words at their whim, or that they didn't keep their promises? Would it make you angry like Ted?" (1989) Patient of Hartmann: "Experiencing words is so strange that I can't describe it. Words don't mean anything to me any more. They're like skeletons. Words like possibly, probably, faithfulness, love, sense, meanings, will, must, are unintelligible to me. I can spend hours thinking about what a word like that might mean." (1922)

The self: sense of identity

When autistic children speak, they generally don't use the word 'I' to refer to themselves. Or if they do, they do so only at a later stage in their development.

Bosch: "Duché writes that the disturbances in view of the body and consciousness of self are constant in autistic psychoses and are at the centre of the clinical picture." (1970)

Bettelheim: "In a strange way they are just as alienated from the body and its normal signals as they are from the external world; witness the fact that their muscle coordination is poor, that they walk in strange ways and move so differently from normal children." (1967) Patient of Janet: "What is missing is myself, it's dreadful to lose yourself, to live and not to be." (1928)

Patients of Mayer Gross:

- "I can't seem to find my actual self.
 When walking it is as though there is nothing there."
- "I feel funny, I feel I have no body, I am only a head. If I hold up my hand and look at it, it does not seem to be my arm. If I try knitting I cannot go on, it does not seem to be my hands." (1935)

Pietö: "He felt surrounded by a mist and could scarcely distinguish his own body from the rest of the world. He felt his own personality to be something strange, his various limbs behaved like independent bodies." (1955) Austin Des Lauriers: "He can walk and run, though somewhat later than normal and, initially at least with a strange stiff, clumsy gait as though he was not aware of walking or running." (1969)

Bettelheim: "Like others who have worked with autistic children, we were again and again confronted with a parallel blotting out of all pain." (1967)

Mahler: "Most autistic children have a relatively low cathexis of their body surface which accounts for their grossly deficient pain sensitivity. These children show such aggressive habits as head knocking, self biting or other self hurting mutilating activities, along with a mixing up of oral, anal and phallic contents. Auto-aggressive manipulations seem to help these children to feel their bodies; some of these activities definitely serve the purpose of sharpening the awareness of the body-self boundaries and the feeling of entity if not identity." (1969) **Patient of Hartmann**: "I feel like a wreck wandering aimlessly about. When I walk around town it seems as though it were someone else's movements. It is as if these legs were not mine at all." (1922)

Patient of Mayer Gross: "If I could only feel some pain!" (1935) Patient of Janet: "My hand was pinched but I expected to feel that it was me that was being pinched and feeling pain... I do feel the pain but I don't feel the reality of the objects that hurt me... You might say that it is pain, but that the surface of my skin is three kilometres away from my brain, and I don't know if I am feeling the pain." (1928)

Patient of Stein: "I felt numb. I pinched myself to hold on to my feelings. When I got home I was black and blue from the pinching." (1964) Lower: "Sicker patients may injure [part of] themselves in order to feel it again." (1972)

Speech: the voice

Bettelheim quotes Despert: "Speech presents peculiarities which, however varied, have one common characteristic, the voice lacks the emotional tone which stamps the individual as himself and unlike others; it is often described as unnatural, peculiar; it lacks expressiveness and often does not seem to belong to the personality." (1967) **Doornenbal**: "His voice struck him as strange when he spoke." (1978) **Patient of Mayer Gross**: "My speech went, has lost its sound, my laughter sounds not natural as it should." (1935) **Patient of Doornenbal**: "I speak words from another mouth." (1978) **Eveloff:** "When they do say something one is immediately struck by the peculiar words and mechanical sound quality of the voice which makes it sound like that of a ventriloquist." (1960)

Sigman, Capps: "Studies carried out in the United States, England, Germany and Czechoslovakia have found that autistic individuals' speech is characterized by improperly modulated intonation, loudness, pitch, stress, and rhythm. Autistic persons' speech is commonly described as "arrhythmic," "hollow," "dull," and "wooden," as well as "excessively sing-song," and "over-precise in articulation." (1997)

Time: continuity

Mesibov: (quoted by C. Hart): "These people have a poor concept of time." (1989)

Hart: "Sumner: he had a problem typical of autistic people, an inability to gauge how long an activity should last or how long it is appropriate to anticipate an event." (1989)

Kaufman: [of his son Raun]: "he was cemented to each experience with no capacity to draw upon a previous situation or understanding." (1976) Janet: "Experiencing emptiness, where memories are concerned, primarily changes estimates of time. This young girl who experienced such severe depersonalization complained of losing her sense of time; she did not understand the meaning of the words yesterday, today, or tomorrow. Many patients report something similar." (1928)

Lewis: "The inability to evoke the past readily or clearly, to distinguish the present from the past and the future, to seize the present, to look into the future or to anticipate a future for oneself; there is paradoxically the increased quickness with which time passes, though it seems also to drag along; the seeming remoteness of the recent past; the confirmed feeling of inability to judge length of time." (1931)

Patient of Janet: "It is indisputable, time exists only as an illusion. Spiritual (mental) time is really highly irregular, one can live for years and years without it seeming in one's mind to have lasted even a minute, and a minute of this earthly life can appear in one's mind as a countless number of years." (1928)

Chapter 2

PERSONAL EXPERIENCE

My initial forays into this subject area were prompted by my own personal experience. Several decades ago I myself experienced derealization and depersonalization, in varying degrees. The first, severe, episode was in May 1961, eighteen months after the birth of my first child. A little earlier I had run into a psychological impasse so grave that it became imperative for me to work out how this serious crisis had arisen. Suddenly I realized how tenuously connected I actually was to the outside world, that I took no interest in it, that I had no real contact with others, spoke little, seldom exerted myself to achieve anything, and was frequently tired. Lacking purpose and application, I had rather allowed myself to be carried along by the current of life.

Up until that moment, I had seen a mother's value and function for her child only in terms of loving and caring, but suddenly I understood that she also had to connect her child to the outside world, and that to do so, she had to be connected to this world herself. How could I connect my child to a world with which I felt so little connection and knew so little about?

From my position of responsibility, I realized that I would have to completely change my attitude to life. I would have to give my life substance and direction. I knew virtually nothing about what was going on in the world around me; I would have to look and listen, gather information. I would have to make contact with others and start communicating. It is possible, in response to a growth of understanding, to change one's attitude and intentions from one moment to the next. But the habits of years cannot readily be abandoned or transformed.

Directing my attention to the outside world and endeavouring to take part in it, I found myself unable to do so. It is scarcely possible to describe what I experienced; there are basically no words for it. That world, with which I had set myself the task of establishing contact, had now lost all meaning. It was as if all colour had been washed away: not physically, but in terms of emotional connotations. The world outside appeared insubstantial,