

Looking at autism now

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Abstract: Science and community are changing their ways of looking at autism and at how persons with autism and their families may be best integrated into society today. This paper discusses ongoing changes from the viewpoint of a Gestalt therapist who has occasionally worked with adults on the autism spectrum.

Keywords: autism, autism spectrum, neural sensitivities, neurotypical, neurodiverse.

Introduction

In my thirty years of practising Gestalt therapy, I have had a handful of clients whom I understood to be persons with autism. Only two came to me with explicit diagnoses, the others I presumed to be autistic based upon their style of interacting with me and by the way they expressed their needs in our work.

Rather than working with them through improvisatory explorations of the emergent self, as I do with most of my clients, I found it helpful to use my training as a Gestalt life coach, as a psychoeducator and, at times, as a singer to help them develop using clear and describable day-to-day procedures for living in relation with others.

This paper is based on that work with my autistic clients and on my review of the literature on autism which I undertook after having been invited to present at an international conference on autism organised by the archdiocese of Palermo, Italy in 2018.

Working with Marsha

There was a quiet knock at my studio door. I had been expecting a new singing student, a sixteen-year-old whose mother had confided to me that her daughter was diagnosed with Asperger's syndrome. She wondered whether I would be willing to teach her daughter; she asked this as though expecting to be rejected.

I opened the studio door and there was Marsha¹ who stood stock still, staring over my head and past me. Her stillness surprised me, and for a moment I too hesitated, holding the door open, assuming she would enter.

Our standing in silence, each waiting for the other's cues, was the beginning of a year in which we learned

together to understand social regulation in a world most of whose inhabitants functioned more fluidly than did Marsha.

Realising that Marsha had not learned how to arrive somewhere new, I smiled, gestured for her to enter, and introduced myself. We began our year-long experiment which included singing lessons on a ground of Gestalt life coaching. I had completed my life coaching training at the Gestalt International Study Center, and used those new learnings to initiate an experiment in helping my client fulfil her practical needs.

As a Gestalt therapist since 1991, I had learned to meet the client where he or she was and to listen carefully to what they were asking for from therapy. As a Gestalt life coach, I had been trained to do the same, working more actively, though, as figures emerged from our experiments together.

Marsha explained to me how much she wanted a leading role in the school musical. She was a graduating senior and up to now had been cast only in the chorus. She believed that this year was her last chance. She made it clear to me how much she wanted to sing solos in the spotlight. I did not judge this goal, rather I set out to help her try to achieve it organically.

By that I mean helping her heighten awareness of her feelings, thoughts and body sensations, with respect for herself, as she strove to improve her skills and become more integrated into her social field.

Taking her request seriously, we started upon an intensive program of voice development (she had a beautiful natural voice), repertoire mastery, body awareness, social engagement, practice in casual conversation, learning self-introductions, risking confiding to teachers what she was working toward, organising and keeping schoolwork and musical work schedules, entering rooms and developing perception

of surroundings, pausing and trying to think about here-and-now situations, and in general learning through rules creation and checklists to do those everyday things which most people take for granted.

At the end of the school year, Marsha performed a leading role in the school musical and was accepted as a musical theatre major in an arts college. She had come to me for singing lessons, yet what she got was considerable help in growing as a human being. Her sense of self expanded so that, at the end, she felt accepted into her peer group of musical theatre aficionados. We had spent the year working with emergent figures, taking her requests for next steps seriously, developing a professional relationship in which she could share her vulnerabilities and disappointments with me along with her developing pride and triumphs.

Describing autism

This brief description of working with Marsha illustrates how I work with persons on the higher end of the autism spectrum – actively, following emergent figures and choosing activities based on them, as well as through psychoeducation, and role playing in a ground of appreciation for their unique strengths.

What is important for me as a Gestalt therapist is to be alert to moment-to-moment details of each human being I am working with, some of whom come to me with an official diagnosis and some of whom arrive without one. Our here-and-now interrelations inform us both as to how to choose experiments which will help a client encounter what is novel for her or him and learn what to do to try to integrate that into their set of understandings about satisfying living.

What is autism? I searched the literature and found many siloed definitions of the complex condition, whose emphasis depended upon the scientific speciality of the person writing. These definitions fell into categories which may be described as behavioural, neurologic, biologic, genetic. However, I did not find a definition which seemed clear enough and appropriate for use by helping professionals, by parents and teachers, and by high-functioning autistic people themselves. So I created a definition to help those groups have a starting point with which to discuss the condition with others:

Autism is a neurodevelopmental condition, beginning *in utero*, based upon brain alterations thought to be caused by genetic inheritance in conjunction with environmental toxins taken in during pregnancy or infancy. Epigenetics plays a part in triggering brain changes which cause atypical behaviours in infants or youngsters who have been diagnosed with autism.

Historical overview

In the early years of the twentieth century, autism was called childhood schizophrenia; and children displaying its symptoms – including jumping, screaming, twirling – were most commonly committed to asylums. There was little study of the condition.

In the 1940s, doctors in two different locations, Leo Kanner in Baltimore and Hans Asperger in Vienna, began, almost simultaneously, to study small cohorts of boys brought to them by parents looking for help for their sons. Because WWII was under way, the two doctors did not learn of each other's work until some years later. In their reports, based upon observations and what we today call qualitative analysis, both doctors arrived at the word 'autism' to describe their patients' diagnostic categories. Dr Asperger emphasised the existence of impressive special abilities among his patients, including prodigious memories and passion for details which existed alongside 'clumsiness and lack of [social] instincts'. By contrast, Dr Kanner pointed to two qualities which his patients had in common, a 'will to self-isolation' and 'a fear of change and surprise'.

From the 1950s to the 1980s, parents in the United States, Great Britain and Australia formed local and national organisations which lobbied for scientific research to find cures for their autistic children. Autism was regarded as a lifelong condition and parent-members of these organisations shared information about interventions which might help them and their households cope.

In the 1960s, one of the most long-lived approaches, Applied Behavior Analysis (ABA), was introduced by psychologist Ivar Lovaas, whose aim was to help autistic children become 'indistinguishable from their peers'. He wanted to help develop a 'highly normative ideal child', based on the work of behavioural psychologist B.F. Skinner. Because Lovaas's treatment protocol included aversive stimuli (punishment), it has become a highly controversial, though much used, approach.

ABA has yielded many praised results, when positive reinforcement is emphasised, as it is in its use for special needs students within the London school system. A contrasting way the approach is used, including both positive reinforcement and punitive measures, is particularly found in residential treatment centres in the United States, where it has been the subject of several lawsuits asserting child abuse, especially among families whose members are incapable of speech.

This ABA approach – from the outside in – still persists, with millions of dollars spent yearly in behavioural and pharmaceutical research despite the fact that we now understand that autism is a neurodevelopmental condition which develops *in*

utero and for which there is no actual cure, only an achievement of appearance of being neurotypical. Part of the approach includes attempts at the use of pharmaceuticals, vitamin therapy, chelation therapy, dietary adjustments, and several training programs for attempting to help autistic people seem to integrate into the wider population.

All of this seems similar to the ways I taught Marsha singing. The important difference is that she was in charge of naming next steps, pausing at any time along the way, controlling the pace of development, while I was charged with creating graded experiments which helped her take next steps and process them, within a therapeutic field of caring and positive regard.

In the early 1990s, there began to be a change in the efforts made to meet the needs of autistic people. This is because the internet allowed teenage and young adult autistic persons to find each other in chat rooms and websites, as well as at self-organised conferences and vacation retreats. Vacations from what? From the strain, as these young people express it, of having to appear socially 'normal' at all times. These young adults began to advocate for their own needs as they perceived them, radically changing the conversation.

This rising of self-advocacy included demands for practical training and research around such everyday needs as conversation skills, toileting skills, independent living skills, jobs training, and other practical activities. Also advocated for was insistence that autistic persons have a say in each project undertaken on their behalf. The expression 'Nothing About Us Without Us' was adapted from South African political advocacy movements. Additionally important was learning to apply for government resources, as for example under the Americans with Disabilities Act which was established by the US Congress in 1990, and under similar programs developed in Britain and throughout the Commonwealth and in Scandinavia. In societies without these programs, finding help for autistic persons remains much more difficult.

In 1993, Jim Sinclair, an autistic writer and organiser, gave a speech entitled 'Don't Mourn for Us' in which he criticised the earlier approaches which looked upon autistic people as essentially incapable and needing to be rescued by so-called normal people. He advocated for acceptance and appreciation of the special abilities of autistic people and asked that they, including himself, be understood as important human beings on the spectrum of human diversity.

Since the 1990s, many essays and books written by autistic people have been published. For example, *The Reason I Jump* was written in Japan in 2007 by a thirteen-year-old boy who, unable to speak, composed the text using an alphabet board (Higashida, 2007/2013). It became a worldwide bestseller, revealing to readers the

deep and touching sets of experiences autistic people were heretofore unable to convey to others.

In attending to the voices of the many self-reflective autistic authors, found for example in the book *Loud Hands* (ASAN, 2012), in which Jim Sinclair's 'Don't Mourn for Us' was republished (Sinclair, 2012a), I do not mean that we should take our attention away from autistic people whose methods of communicating may be through other means – movements or non-linguaged sound-making, for example – and who may be more limited in attending to their own basic needs of living than are some others on the autism spectrum. Now it is understood that descriptions of the wide variety of human qualities to be considered along the spectrum are essential where research, training and advocacy for everyone is to be included.

Pause

Can you recognise an autistic child or adult living in your neighbourhood, or perhaps sharing your dinner table? What are you experiencing when in relation with them? What are you sensing, feeling or thinking? Or, if you are working with an autistic individual in your practice, what are you observing or experiencing? Please notice that these are the same Gestalt therapy questions regarding the relational field that we ask in our work about all people, not just those who are autistic.

Gestalt therapy viewpoint

As a Gestalt therapist, I was trained to heighten my curiosity about the behaviour, thoughts and feelings of each client, from the most subtle to the most overt, and to sense the field between and around us which is thereby created. From these sensed, felt and understood experiences, I take as my job to make contact with whomever I am working by feeling what I am experiencing when we are working, and by being aware of the field we create together.

We Gestalt therapists believe that there is not a correct or an incorrect way for us to sense the other and ourselves in the field. As just one example, it is neither better nor worse to look directly or indirectly at one's interlocutor, as I experienced on the very first day Marsha stood in my doorway, and as Judith Bluestone talks about in her book *The Fabric of Autism* (2005).

Judith Bluestone is an autistic therapist. She explains that for some of her clients who suffer with various sorts of sensory overloads, speaking quietly or very loudly has to do with sound sensitivity. Preferring particular foods may have less to do with flavour and more to do with pain in the temporomandibular joint or with the noisiness of chewing as heard through the Eustachian tubes. Sensitivity to touch may play a part in a person's refraining from shaking hands. She reminds us that it is important not to quickly judge

these examples as unfriendly, antisocial or unable, but rather to understand them as results of extreme physical discomforts with which, we are now aware, autistic people suffer. As a Gestalt therapist, I strive to bring empathy and curiosity rather than judgement to interactions with autistic people, and to all people, who come to me for help. The two 'Pauses' which I have inserted into this paper are classical Gestalt therapy experiments inviting you, the reader, to bring experiential involvement to the text.

Pause: a sensory experiment

Many autistic people exhibit a set of typical behaviours – spinning, hand flapping, turning to the wall, echoing what the other is saying – during moments of sensory overload. How do you yourself respond during a sensory overload, such as when a person is screaming or a siren is blasting? How do you respond to blinding light, or to acrid odours, the scrape of a torn fingernail on your skin, or someone's demand that you continually change seats? What movements do you make to counter these sensorial interruptions? What happens to your heartbeat, your breathing? What is the emotional tone of such a moment for you? Let's imagine that our own everyday sense range is an overload for an autistic person, especially one who hasn't the language to explain what she or he is reacting to. In such a situation, how might a neurotypical person inadvertently misjudge an autistic person's reactive behaviours?

Working with Teresa

Teresa has been my client for four years. She is a project manager at a health research corporation in the US. Throughout our time together we have worked on developing her theory of mind; she has needed to learn that not all her colleagues think the same way she does, nor do they all approach their work with her exacting attention to detail. To work productively with them, she has needed to become accepting of them as they, slowly, have of her.

She has expanded her communication skills, replacing long, rambling emails with brief, targeted suggestions and requests. Through the reciprocity of our professional relationship as well as through psychoeducation, she has learned to appreciate who she is. She has learned how her attention to detail has made her work successful, while sometimes also being shaming for others.

She undertook training for effective public speaking, and by practising at club meetings and following their set of guidelines, she learned to make highly effective presentations to large groups of people at work. She became more able to hear her own voice, to modulate its prosody so that others could take in her training presentations with a sense of safety, as Steven Porges's research points out (Geller and Porges, 2014).

Through role play, Teresa has learned skills for socialising at company events. Practising these skills is not easy for her, although she has experienced that they help prevent her from feeling lonely at work. She has learned to understand and appreciate her unique style instead of being filled with shame about her personal way of being in the world. She is learning to reflect upon what she is experiencing, moving past fear to a fuller self-management in which she can more often think before speaking or acting.

In these four years, Teresa has won awards at work, been promoted twice, received a salary increase, and been lauded in public for her work by the president of her company. Through graded Gestalt experiments, gentle exploration of her earlier life and its relation to her life now, along with my modelling by sharing carefully selected experiences from my own life, she now has an enlarged sense of self which supports her as she looks toward the future. All of this occurred through our following the figures of interest which arose in our sessions.

Teresa had been referred to me by another Gestalt therapist who saw that their foundational work together did not ameliorate Teresa's anxieties or self-effacing thoughts, and that she continued to suffer with acute frustration at work. At the time she came to me, she was over-occupied with perceived maltreatment both in her job and by members of her family of origin. My colleague suggested she take 'coaching' with me, a way of putting it which allowed her to accept the change without believing herself to be abandoned by her first therapist. The active, practical way that we worked allowed her to blossom. And although she had never received an official diagnosis, it was clear to me that our working together as if she were officially diagnosed autistic, without naming it, could prove productive without being shaming. *Shadow Syndromes*, by Ratey and Johnson (1997), emphasises that point.

Approaching diagnosis

Until a few years ago, high functioning autistic people were called persons with Asperger's syndrome. Now they are included on the spectrum as persons with ASD, Autism Spectrum Disorder. As laid out in Fletcher-Watson and Happé's brilliant book *Autism*, revised in 2019, we may diagnose persons on the spectrum by looking at three domains:

1. Behavioural – Often referred to as stimming (soothing or calming self-stimulation) which may include hand flapping, moving in circles, rocking, lining up objects, repeating movements and phrases, jumping, hours-long engagement with fine motor activities, interest in timetables and lists, maintenance

of routines; or sensitive reactions to light, noise, tastes or textures, anxiety, sleep difficulty, digestive particularities, echoing words and phrases, lack of spoken language, or epilepsy.

2. Brain research – This includes many scans and tests which fascinate neuroscientists, but which are not presently useful in short-term therapy; whereas speech training, toileting, independent living skills, and special training to invite helpful and empathic caregiving are all understood by autistic self-advocates to be ongoingly useful.

3. Biologic – Exploring aspects of development which have been influenced by genetics and epigenetics as understood through brain research. This is laboratory science with lots of data collection and long-term possible predictive uses, though it is not immediately relevant for the needs of autistic people here and now.

In the 1980s, several autism associations reported that there was about one autistic person in every 1,000 population members. By 2004, one in every 166 persons was found to be on the autistic spectrum. That ratio is even smaller now. There are many reasons for this:

- Many fewer autistic people are hidden from view in institutions, in which they were previously diagnosed as either ‘retarded’ or ‘schizophrenic’, thus more autistic people are being counted.
- A much higher number of pollutants (including additives) are now found to be in the air, water, food, medicines. This greatly increases the numbers of toxins taken in by pregnant women and infants, thus causing more cases of autism.
- Large numbers of higher-functioning autistic persons are able to obtain jobs in technical fields, including IT, and can support themselves and live independently. In being able to support themselves, many can now marry and raise children, producing a larger next generation of inherited autistic traits.
- Since autism is presently understood to be a hereditary condition, a large number of autistic persons’ offspring now receive special support in school for their inherited difficulties in social and educational arenas. Thus a growing number of autistic children and adolescents are part of our population today.
- Many from this next generation benefit from special employment opportunities, such as those recently described in *Forbes* magazine’s ‘Where Is Autism Employment Heading In 2017?’ (Bernick, 2016). This article describes programs established by several large corporate entities, including Google, SAP, and Microsoft to specially train and integrate higher-functioning autistic persons into their workforces, making autistic persons more visible in society.

- There is a steady growth in the number of neurotypicals who work with, appreciate, and accept population members with ASD, making it possible for more autistic persons to stop feeling that they must try to hide in plain sight, and thus more are counted.

A communal approach

All of this points to a developing communal-helping approach for autistic persons, as articulated by several recent authors. Narzisi and Muccio (2015) point out that the inclusion of family in the treatment of autistic people is essential; while Jim Sinclair declares, ‘An autistic person’s personal satisfaction with their life depends ... on the capacity and willingness of those around them to understand, accept and support them’ (Sinclair, 2012b, p. 22). And in ‘Establishing Relationships with Children with Autism...’, Athanasiadou and Karkou write, ‘A person’s self-regulatory skills become integrated and developed within a relational context’ (2017, p. 272).

What provides that relational context? It is all of us together, the neighbours, schoolmates, family members of persons on the autistic spectrum – all of us who ride a bus with, work alongside, sit in the park near, take a meal with those whose ways of communicating and interacting may diverge from our own yet whose internal need for contact is very much like that of neurotypical people. We are all on a continuum of neural functioning, rather than being parcelled out into binary groups.

Conclusion

How can we Gestalt therapists best interact with and care for autistic people and their families within our practices and in the everyday life of our communities? In my view, it is by practising classical Gestalt therapy where we approach our client with open curiosity and care, and by using our training to suggest experiments which help our clients encounter and integrate the novel as is appropriate for each of them. We can help them heighten their awareness of their social and physical environments, provided such an undertaking does not become overwhelming. We can support their becoming enlivened to their five senses and their proprioceptive sense within boundaries tolerable for them. We can teach them to name feelings and experiences which are important to them and others in their circle. And we must foster caring professional relationships which, by example, teach them to care about themselves.

In other words, we need to go on doing what we do with each of our clients, autistic or not, with special considerations as to pace and sensorial sensitivities of

people on the spectrum. Most importantly, we need to respectfully appreciate this growing segment of our society, and embrace rather than try to eliminate it. That would be the next enriching undertaking for all of us in acknowledging that we live in a contemporary, neurodiverse world.

Notes

1. Clients' names have been changed.

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