

Alone and Unchanging: Kanner's Enduring Legacy of Social Isolation

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Introduction

In 1943, an Austrian-born doctor from the Johns Hopkins Psychiatric Clinic in Baltimore published a preliminary report lucidly describing 11 children with a unique and seemingly rare disorder. He constructed his ideas based on five years of clinical observations and detailed parent reports. *Autistic Disturbances of Affective Contact* was Leo Kanner's seminal article outlining the distinct characteristics of a condition which is now classified in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) as *autism spectrum disorder* (APA, 2013).

Close to 80 years later, Kanner's influence is still felt. Although he recognized "individual differences in the degree of their disturbance" (Kanner, 1943, p. 242), he strongly felt that there were essential, primary, and common characteristics that could be applied to all of his cases: *extreme autistic aloneness* and an *anxiously obsessive desire for the maintenance of sameness*.

To this day research is still largely guided by the notion that autism spectrum disorder (ASD) is a "distinct nosological entity" (Verhoeff, 2012, p. 410), contained within the individual to be observed and categorized. The bulk of extant and continuing research focuses on discovering the etiology of ASD and its neurological basis. This may be, in part an attempt to capture and classify what is now recognized as "ubiquitous heterogeneity" (p. 428). Yet situated in the midst of these research efforts is the person with autism, isolated from society by both the diagnosis itself and his lived experience of it.

The purpose of this paper is twofold: to outline the historical and research implications of Kanner's initial report, and to explain how ASD's evolution has occurred, less because of

revelations or discoveries based on scientific truths but more as a result of historical, cultural, and social influences which have altered the way we view and think about the disorder.

A moving target

Researchers have been tenaciously trying to capture the essence of autism since Kanner first described it in 1943. Indeed, even Kanner himself was unclear about the origins of ASD and over the course of his career indicated some ambivalence about whether autism was biologically or psychologically caused (Kanner, 1949; Kanner & Eisenberg, 1956). His acute observations and detailed descriptions, including information about medical, developmental, and family history were remarkable for the day but this was merely an exploratory report, intent on painting a vivid portrait of a unique syndrome that deserved further research. Kanner's concluding sentence in his 1943 publication foreshadowed not only the name he would give the disorder one year later, *early infantile autism*, but also the direction of the research that would follow:

We must then, assume that these children have come into the world with innate inability to form the usual, biologically provided affective contact with people, just as other children come into the world with innate physical or intellectual handicaps [sic]. If this assumption is correct, a further study of our children may help to furnish concrete criteria regarding the still diffuse notions about the constitutional components of emotional reactivity. For here we seem to have pure-culture examples of *inborn autistic disturbances of affective contact* (p. 250).

How is a child born incapable of establishing affective or emotional contact with other people? The medical profession was tasked with finding answers to another nature versus nurture debate, this time in regards to a "unique 'syndrome', not heretofore reported" (p. 242).

The only vague inference Kanner made about etiology pointed to the obsessive, highly intelligent, and not terribly “warm-hearted” (p.250), nature of his subjects’ parents. It was precisely this inference that spurred the now discredited “Refrigerator Mother” theory (Bettelheim, 1967), and has led to the fluctuating discourse and intense research efforts attempting to pinpoint the etiology and boundaries of ASD.

Borrowed terms

The term *autism* was not invented by Kanner. A Swiss psychiatrist, Eugen Bleuler who was already well-known for his research on schizophrenia used the word to describe his patients’ actively withdrawn behaviour. It was one of the core symptoms of schizophrenia but Bleuler’s term intended to describe a detachment from reality and logic to a withdrawn world of fantasy (1911/1950). In the case of the person diagnosed with schizophrenia, there was an obvious break from reality, “a departure from an initially present relationship” (Kanner, 1943, p. 242), rather than an inborn inability to relate to others.

Kanner admitted that the children he observed from 1938 to 1943 were probably initially diagnosed as either *feeble-minded* or schizophrenic but maintained that their behaviour differed markedly because unlike schizophrenic patients who withdraw from formerly accepted relationships, his children did not show obvious signs of connection to their parents from birth which was “...most characteristically expressed in the recurrent report of failure of the child to assume an anticipatory posture upon being picked up” (p. 248). He also felt that his children were intelligent and showed great potential for learning despite their language difficulties, preference for relating to objects rather than people, and insistence on sameness. Even two of the three mute children in his study were observed at some point by caregivers to speak clear

utterances although this action was rarely if ever repeated. Kanner felt that this implied a reservoir of intelligence that could be accessed if needed. He also noted the “strikingly intelligent physiognomies” (p. 247), which gave each child the impression of being serious-minded. Additionally, they all demonstrated excellent rote memory, and came from highly intelligent families. These observations seemed to clearly rule out feeble-mindedness but a possible connection to schizophrenia was still contentiously debated.

Modern controversy has been raised over how Kanner could not have known about or even referred to the work of his contemporaries. In a recent article, Fellowes (2015) asserts that Kanner built on ideas previously outlined by Louise Despert, a child psychiatrist living in New York. Despert had already published a 1938 clinical account classifying 23 children as childhood schizophrenic.

In a letter written by Despert in 1943, just after Kanner’s publication, she praised Kanner’s paper but objected to his claim to have discovered something new since she had already described something like autism. Kanner’s response, in turn praised Despert’s work but argued that the children in his report showed the symptoms from birth, whereas Despert’s children only showed some symptoms from birth. (Silberman, 2015). Interestingly, in Kanner’s later publications, he is sure to clearly reference Despert’s work and vacillates over whether early infantile autism and childhood schizophrenia could be the same disorder (Fellowes, 2015). Indeed, Kanner acquiesced three years after his initial 1943 report to the possibility that early infantile autism may actually be the earliest manifestation of schizophrenia (Chambers, 1969). His rationale was likely multifactorial. The combination of Despert’s criticism, fashionable interests in psychoanalysis at the time, and his still vague understanding of the etiology of early infantile autism confounded any attempt at clarity.

Another notable historical figure in the classification and understanding of ASD was an Austrian pediatrician, Hans Asperger. Asperger published a thesis in 1944 about a group of children so similar to Kanner's that the resemblance was uncanny. Despite the geographical distance between Kanner and Asperger at the time of publication, historians argue that once again, Kanner must have been aware of his contemporary's work since Asperger had delivered a lecture in 1938 using Bleuler's same terminology, *autism*. Kanner and Asperger were both of Austrian descent, and Kanner spoke German and was well-acquainted with European research (Lyons & Fitzgerald, 2007).

The coincidence is remarkable but this paper is not concerned with accusations of plagiarism. Rather, these historical irregularities speak to the way in which the understanding and advancement of ASD has always been mutable and based on existing socio-historical, and cultural ideas and values.

True advancements in autism research didn't start in earnest until almost 25 years after Kanner's initial report. An obvious shift from symptom-listing to a more coherent, theory-based criteria that defines autism in functional terms began with epidemiological and experimental studies throughout the 1960s and 1970s, but the desire to demarcate the specific criteria by which ASD is defined continues to this day. The rejection of theories that blamed parents for causing autism, de-institutionalization of "mental defectives", and the subsequent repair and reconciliation process in the form of parent advocacy efforts, especially by parent-researchers like Bernard Rimland and Lorna Wing also deserve recognition for helping to progress our current understanding of ASD (Evans, 2013).

The dark era of conceptualizing autism in terms of psychological disturbance was finally over and although Kanner was largely responsible for perpetuating the myth of *refrigerator parents* especially in his in his later writings (Kanner, 1949; 1951; 1956) he did try to clear himself of any responsibility for implicating parents in a speech he gave at the National Society for Autistic Children in 1969 where he exonerated parents of any blame for disorder (Eyal., 2015). Nonetheless, damaging stereotypes about parents being the cause of their children's misery were pervasive as was the belief that autism was a mental disorder. Ironically, Kanner's inadvertent and Bettelheim's overt historical diversion of parental blame and the subsequent attempts to reverse these detrimental effects gave rise to an active parents' movement. The process of trying to heal was just beginning and autism history was re-writing itself even as it was still being written.

Words without meaning

While autism advocacy efforts were gaining momentum, autism science was ready to wipe the slate clean and start at the very beginning. Once again, they looked to Kanner's detailed account and decided to tackle the problem of language which, following *aloneness* and *failure to assume an anticipatory posture to being picked up* were the next manifestations of the disorder chronicled in the discussion section of his report.

Kanner's vivid narratives of his subjects' unique uses of language are perhaps the most fascinating portions of the case studies partly because of their contradictory and uneven profiling but also because the cluster of unusual language characteristics that he outlined is still so recognizable in current diagnostic criteria (APA, 2013). True to his nature, Kanner clearly identified and catalogued characteristics such as immediate and delayed echolalia, pronoun

reversal, idiosyncratic words and phrases, and literal interpretation of speech. It stands to reason why language use would become the next significant area of study since language peculiarities were so prevalent and easily identifiable in children with autism.

Interestingly, Kanner did not feel that language problems were in and of themselves diagnostic criteria for early infantile autism. Rather, communication difficulties were a “derivative of the basic disturbance of human relatedness” and resulted from the powerful need to be left undisturbed (Kanner & Eisenberg, 1956, p. 557). Any language the children learned Kanner attributed to excellent rote memory and parents “stuffing” them with useless information in order to reflect their own intelligence. (Kanner, 1943, p. 243). The possibility that his subjects might actually be independently fascinated by words, music, and the rhyming verse of poetry was not considered. In fact, introducing and encouraging development and expansion of these interests might have provided parents with a means of connection where other attempts had failed.

Regarding communicative function he even went so far as to say that “...there is no fundamental difference between the eight speaking and the three mute children” (p. 243). This bold and unsubstantiated statement prompted researchers to initiate thorough investigations into the mechanism by which language and communication impairments arose. The emphasis on Kanner’s core deficits of *aloneness* and *sameness* shifted to include language and other cognitive impairments as part of the primary diagnostic criteria (Verhoeff, 2013).

In but not of the world

Cognition became a major field of study invested in areas of research surrounding information processing, and receptive and expressive language use. Theories about *social*

cognition also began to emerge in the 1980s and 1990s when psychiatrist and parent of a child with autism, Lorna Wing first popularized Asperger's work (1981). However, it was Uta Frith's 1991 translation into English of Asperger's 1944 paper, "*Autistic Psychopathology*" in *childhood* that is credited with igniting an explosion of research regarding the specific neurological processes that would refine and legitimize these cognitive theories that endeavoured to explain social and language deficits.

Asperger described four children who did not suffer so much from language impairment as they did from social challenges, restricted interests, and stereotyped behaviours. In contrast to Kanner's children who displayed recognizable characteristics of autism before age two, Asperger's subjects did not necessarily display unusual behaviours until well after age three. Asperger's emphasis on autism as a *social disorder* was widely embraced and soon became an integral part of the diagnostic criteria (APA, 1994).

This expanded view was sufficient to warrant the consideration that the symptoms of autism may reside along a continuum rather than being identifiable by narrow behavioural criteria. In light of this broader nosology, Kanner's initial attempts to define autism as a distinct, singular entity now seemed to stand in contrast to the more current ideas of autism as a spectrum disorder. But Kanner's circumscribed observations can still be traced back from his initial publication to specialized topics of research in joint attention, neurological deficits, and the broader autism phenotype. Further investigations regarding biological significance of brain size, head circumference, x-ray and EEG have also been linked to Kanner's original observations (Blacher & Christensen, 2011).

Autism inside out

In a compelling 2012 article, psychiatrist and philosopher, Berend Verhoeff states “Autism is imagined to exist as an objective entity independent of its embodiment in particular individuals” (p. 411). This raises questions about why we continue to view ASD as a distinct and singular phenomenon in light of empirical evidence that highlights the heterogeneity of its symptoms.

In recent years, much of our understanding of the core features of ASD have arisen from autobiographical accounts, many of which come from those identified as being the most severely disabled on the autism spectrum. According to philosopher Victoria McGreer (2004), there are two main reasons that these autistic authors have tried to convey the nature of the disorder. One is to hopefully improve the quality of interactions between those with ASD and those without, especially in cases of persons with non-verbal ASD. The second is to express a “basic human desire to be known and accepted by others” (p. 240). Paradoxically, this would seem incongruent with the Kannerian belief that individuals with ASD display “extreme autistic aloneness” and that any outside influences are regarded as a “dreaded intrusion” (Kanner, 1943, p. 242).

Temple Grandin is generally regarded as the most famous person living with ASD as well as one of the most influential people in the world (Time Magazine, 2010). Her writings and advocacy work have helped to reconceive notions of autism ever since the publication of her ground-breaking book, *Emergence: Labeled Autistic* (1986). She was instrumental in bridging the gap between science and practice and for bringing understanding of autism out of the clinical setting and into the real world.

Other prominent figures have also emerged from the shadowy margins of society, reconceptualising the idea that *aloneness* is a central feature of ASD. The vivid accounts of their personal lives and relationships to objects, people, and the environment continue to challenge our

understanding and practices surrounding the disorder. Examples of individuals whose writing has shaken our pervasive assumptions and cultural expectations about competency are: Tito Rajarshi Mukhopadhyay, Donna Williams, Lucy Blackman, Carly Feishmann, Naoki Higashida, and Stephen Shore. Their self-advocacy work in community with other critical disability theorists and activists should inspire and inform future research concerned with the lived experience of ASD.

Toeing the line

While science continues to pursue the underlying neurobiological mechanism of ASD with the aim of once and for all creating a valid disease category that clusters behaviours into a statistically coherent whole, those affected by autism continue to embody the disorder and face constant challenges with regard to securing appropriate and quality education, employment, and health care. The idea that autism has an essential core waiting to be identified is misguided and obscures the important social, cultural, and psychological issues that impact quality of life for those with ASD. We must recognize that all knowledge about abilities is contextually situated and socially constructed. Privileging certain forms of research as being more valid or uncontested should be avoided (Biklen, 2005). Incorporating participatory and interdisciplinary approaches to mainstream research which reflect the complexity of this disorder in terms of lived experience as well as being in society is the next crucial step in our evolutionary understanding of autism. True achievement in any field of research needs to acknowledge multiple perspectives and can only be successful when social, economic, cultural, and real-world debates are seriously, collaboratively and empirically considered (Singh & Elsabbagh, 2015).

Our current knowledge of ASD is thought to be progressive, cumulative, and linear. It “acts as an endpoint and norm to judge history” (Verhoeff, 2013, p. 444). Kanner’s initial observations in 1943 are inextricably woven throughout autism history and have been confidently connected to recent autism criteria, with a suggestion of continuity and refinement. However, the inconsistencies, deviations, and revisions in autism’s history have always been related to cultural norms and have reflected certain standards about an individual’s connection to the world. Kanner’s observations were constructed through a lens produced in his time. But even at that point in history, Kanner saw potential in his subjects and observed that although unconventional in their approach, they could, at times show a keen awareness of others and were able to establish connections and relationships (Kanner, 1943). Context mattered just as much as biology.

Autism steps out

Setting priorities in autism research will invariably bump up against contentious debates about how to socialize or even “normalize” the disorder. Society dictates what kinds of behaviour are appropriate or in need of correction or support based on both historical and current social, economic, political, and cultural constructions. Notions of how diversity is interpreted in society are fluid and influenced by these same factors. The decision to fully include a group of people (such as those with an ASD) into a previously constructed context may require not only a shift in our research priorities to ensure that scientific interpretations of ASD translate into real-world practice but also may require changes to the environment itself. Creating home, work, and public spaces that honour neurodiversity based on first-hand accounts and self-advocacy efforts of those affected by ASD will be paramount. Scientific progress should continuously be assessed

and evaluated by utilizing clinically valuable translations of neuroscience and genetics research into real-world applications (Verhoeff, 2015).

Conclusion

The notion of the autistic person's extreme aloneness has endured since Kanner's initial ascription of the term. Although our understandings of autism have changed significantly over the years they have been largely based on externally imposed interpretations that were influenced by socio-historical and cultural values of the time. Naming, categorizing, and diagnosing a lived experience is a thorny business. Describing a group of subjects on the one hand, makes them visible and distinct. But every group is comprised of heterogeneous individuals. Consequently they are also free to resist, reshape, and reform any diagnosis through their own actions and interpretations of being in the world. Inviting individuals with ASD to participate in decisions about their treatment and care, creating spaces of inclusion, and challenging our own notions about ability and diversity are hopeful future directions for research and practice that may finally bring the isolated autistic subject of historical study and debate into his or her rightful place in society to be valued, to be heard, and to belong.

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