History and Purpose of Assessment and Diagnosis of Autism

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Introduction to History and Purpose of Assessment and Diagnosis

Assessment is a broad term that encompasses evaluation of a variety of types. When considering assessment of autism, diagnostic assessment is typically the first to come to mind. However, assessment of individuals with autism frequently extends beyond diagnosis; professionals may assess challenging behavior (e.g., self-injurious behavior, aggression), intellectual functioning, adaptive skills, etc. among this population. Nonetheless, the current chapter covers the history of the assessment and diagnosis of autism in particular. In later chapters, authors discuss the other aforementioned types of assessment, as well as current diagnostic criteria and assessment practices.

The diagnosis of autism spectrum disorders (ASD) has changed substantially since its inception, with screening, assessment, and monitoring techniques continuing to evolve. In the recent past, children with autism were frequently identified and diagnosed when they entered school. This practice is changing rapidly for a variety of reasons: increased autism awareness, widespread screening requirements, recognition of the importance of early intervention, etc. (Fountain, King, & Bearman, 2011). At present, reliable identification is possible as early as infancy (Dover & Le Couteur, 2007; Klaiman, Fernandez-Carriba, Hall, & Saulnier, 2015; Zwaigenbaum, Bryson, & Garon, 2013). Reliable diagnosis at this age is crucial for access to early intervention, which leads to greatest developmental gains and best prognosis for most individuals (Bryson, Rogers, & Fombonne, 2003). Early diagnosis is also reportedly responsible for a variety of other positive results, including lessening family stress, decreasing societal costs, and earlier recognition of medical, developmental, and psychiatric conditions that may co-occur with core symptoms of autism (Dover & Le Couteur, 2007; Klaiman et al., 2015).

Despite the ability to diagnose reliably in infants, the average age of diagnosis in the United States remains later (e.g., average of 38 months in a study sampled by Valicenti-McDermott, Hottinger, Seijo, & Shulman, 2012). This trend may be due to the finding that early diagnosis is not uniform across groups. That is, variables such as race, access to relevant healthcare, and severity of symptoms influence the age of the individual when he or she is diagnosed (Wiggins, Baio, & Rice, 2006). Further, being male, having an IQ below 70, and experiencing developmental regression have all been associated with earlier

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diagnosis (Shattuck et al., 2009). With increased focus on screening, which allows for the determination of need for further, comprehensive assessment, diagnosis is likely to continue to occur earlier in development. Further, recent efforts have included the goal of determining "at-risk" symptomatology (i.e., signs even earlier in life that autism may develop later) (Klaiman et al., 2015), which has the potential to allow intervention to start before further symptoms develop.

Kanner's Autism

Although Leo Kanner, an American child psychiatrist, is commonly credited with "discovering" autism in the 1940s, individuals who exhibited symptoms of ASD had long been recognized as evincing atypical development. Before Kanner's *Autistic Disturbances of Affective Contact* in 1943, such persons were frequently considered to have an emotional disturbance or intellectual disability (Wing, 1997). The symptoms he identified among his patients represented the core domains we recognize today as characteristic of autism: communication deficits, difficulty with social interaction and forming relationships, and the presence of restricted and repetitive behavior and interests. He used observations of behavioral symptoms as well as parent-reported family, medical, and developmental history to make his classifications. His method was based on clinical presentation and predominantly atheoretical, a departure from the popular psychoanalytic thinking of his era (Blacher & Christensen, 2011).

Kanner coined the term "early infantile autism" to describe the constellation of symptoms exhibited by the children he studied (Kanner, 1951). With his publication of detailed case studies (Kanner, 1943), he was considered the first to recognize the denoted behavioral phenotype as disparate from childhood psychosis (Blacher & Christensen, 2011). Nevertheless, his first work on the subject did not specify diagnostic criteria in 1956, Kanner and Leon Eisenberger delineated specific symptoms required for classification (Eisenberger & Kanner, 1956). This development of diagnostic criteria based on observations of child clients was unusual for the time period, when criteria for disorders among children were simply modifications of criteria for syndromes seen in adults (Rutter & Schopler, 1988).

Deviations in Conceptualizations and Criteria

In the late 1950s and early 1960s, diagnostic criteria and terminology for autism remained controversial. From Kanner's original observations, other diagnostic criteria were created but with notable changes. For instance, Polan and Spencer (1959) published the 30-item *Checklist of Symptoms of Early Infantile Autism*, which included language distortion, social withdrawal, lack of integration in activities, obsessiveness and nervousness, and family characteristics. These criteria aimed to evaluate the "perceptual apparatus" and "psychogenic factors related to deviant styles of interpersonal relatedness" (Ward, 1970).

In 1958, a "Social Psychiatry Research Unit" was opened due to the British Government's impending enactment of the Mental Health Act. There, Hans Eysenck and other influential scientists led the charge for experimental psychology, including the use of statistical analyses and behavioral measures. Eysenck was a strong proponent of direct observation rather than psychoanalytic theory, arguing against Freudian speculative impressions (Evans, 2013). In particular, the psychoanalytic theory of the time suggested that autism was a "reaction to an overwhelming inner or outer assault at a vulnerable developmental stage" (Garcia & Sarvis, 1964, p. 530).

This shift in thinking toward an empirical-based study of psychology helped influence Mildred Creak, a British child psychological professional who studied psychopathology in infancy, to unite prominent members of the field to identify specific features of childhood schizophrenia. Her purpose in forming the work group was to help establish quantitative, reliable research of childhood psychopathology, which included creating criteria that all psychiatrists could agree on in order to enable population-based studies (Evans, 2013). The work group's efforts resulted in a set of nine key features: impairment of emotional relationships with people; unawareness of personal identity; preoccupation with particular objects; resistance to environmental change; abnormal perceptual experience; acute, excessive, illogical anxiety; a lack of or delay in language ability; distortion in motility patterns; and impaired cognitive function that sometimes occurs with savant skills (Creak, 1961).

Another example of criteria appearing in that era was that by Schain and Yannet (1960). Their criteria for autism included children who displayed "an extreme preoccupation with self and unrelatedness to people" and who thus failed to develop relationships with caregivers as expected by age 2 years (p. 561). These authors noted that they might have included cases that other professionals would not consider to have infantile autism but that they had required Kanner's "common denominator" of difficulty with social relationships. Their criteria, therefore, did not include display of insistence on sameness or similar symptomatology included in Kanner's original description.

Unlike the others originating at the time, the criteria authored by Ornitz and Ritvo (1968) emphasized perception issues, considering them fundamental to the other problems in autism. Their criteria encompassed symptoms in the areas of perceptual integration, motility patterns, capacity to relate, language, and developmental rate. That same year, an additional conceptualization was published by Rendle-Short and Clancy. Their "screening test" included 14 symptoms, of which a child needed to exhibit half or more per caregiver report, that the authors considered most representative of the essential characteristics of autism (Rendle-Short & Clancy, 1968). These symptoms were: difficulty engaging with other children, acts as though deaf, resists learning, no fear of real dangers, resists routine change, indicates needs by gestures, inappropriate laughing, not cuddly, marked physical overactivity, no eye contact, inappropriate attachment to objects, spins objects, sustained odd play, and standoffish manner. With the continual development of varying definitions, the boundaries of the disorder remained unclear.

Despite a lack of agreement in the field as to what exactly constituted autism, Dr. Victor Lotter published the first paper to give the results of an epidemiological study of autism among a population of children of varying intellectual function in 1966. To meet his criteria and be considered to have autism, a participant had to have a profound lack of affective contact and elaborate repetitive, ritualistic behavior, whereas early age of onset was not included (Feinstein, 2010). Results suggested a prevalence rate of 4.5 per 10,000 (Lotter, 1966).

Beginnings of Diagnostic Assessment of Autism

In the 1960s, the practice of the family physician completing screening for developmental issues including autism was already in place in a less formal variation than today (Fotheringham, 1969). At that time, the physician might compare the child's development to established milestones (e.g., motor, communication) and gather more in-depth developmental history from caregivers (e.g., age at first concern, significant biological or social events that affected functioning). If the child was school-aged, a sampling of schoolwork or a brief achievement test may be administered. Nonetheless, in Wing and Wing's "Early Childhood Autism" (1976), contributor Dr. P. H. Connell noted the deficiency of adequate comprehensive assessment measures for diagnosis, not just screening, of autism.

The aforementioned *Checklist of Symptoms of Early Infantile Autism* by Polan and Spencer (1959) was considered one of the pioneers of standardized autism assessment. This measure required that each respondent endorses or denies the presence of a specific list of symptoms for the child being evaluated (Rotatori, Obiakor, & Bakken, 2011). In 1964, Rimland, inspired by the aforementioned checklist, attempted to translate Kanner's definition into an empirical rating scale to identify early infantile autism in children up to age 7 years. The *Diagnostic Form E-1* (Rimland, 1964b) was a parent-report measure that included 76 questions inquiring about birth history and onset and characteristics of symptoms. The form was subsequently revised to reflect the need for information about children before age 5 years. Thus, the *Diagnostic Checklist for Behavior-Disturbed Children*, *Form E-2* (Rimland, 1964a) included questions about early development (i.e., from birth through age 5 years). The form included characteristics of autism described by Kanner and symptoms of childhood schizophrenia described by experts in that field. According to Rimland, 31 children had been diagnosed by Kanner prior to their completion of Form E-2, and the E-2 scores correlated strongly with these diagnoses (Rimland, 1971). In addition, he found that the parent-reported presence of "autistic speech symptoms" among children with and without classification of early infantile autism, indicating language issues alone, was insufficient for an autism diagnosis (Rimland, 1971). Although reliability of parent-report measures had been questioned in terms of reliability and accuracy, Rimland argued that diagnosis should require retrospective information, making caregiver report a necessity (1971). To further justify his use of parent report rather than direct observation, he also suggested that behaviors may differ within and outside of the diagnostic session (Rimland, 1971).

Soon after the publication of Rimland's checklist, Ruttenberg and colleagues published the *Behavior Rating Instrument for Autistic and Atypical Children* (Ruttenberg, Dratman, Fraknoi, & Wenar, 1966). Reportedly this measure was unable to accurately differentiate between autism and intellectual disability (Parks, 1983). Despite this, teachers and therapists found the measure useful for goal formulation and in predicting future development among children exhibiting atypical development (Feinstein, 2010).

Both Creak's (1961) criteria and Rimland's (1964b) original checklist lacked consideration of symptoms among very young children. To correct for this exclusion, Reichler and Schopler developed a 15-scale rating system, initially named the *Childhood Psychosis Rating Scale* (CPRS), in 1971. Their aim was to incorporate Kanner's original description, less common characteristics of autism noted by Creak, and symptoms of autism common in younger children. The observational scale required each of the 15 included domains to be considered in terms of atypicality, frequency, and duration and given a corresponding rating from 1, which represented behavior within normal limits, to 4, which represented severely abnormal behavior (Schopler, Reichler, DeVellis, & Daly, 1980). This measure was later renamed the *Childhood Autism Rating Scale* (CARS). An updated version of the CARS is commonly used for assessment at present.

Clarifying Distinct Definitions

Kanner's purpose for his descriptions of autism as a syndrome was to recognize a constellation of certain behaviors that differed from symptoms of other mental health issues (Rutter & Schopler, 2012). To clarify the definition, work was needed to establish which symptoms could potentially occur in autism and which were characteristic of autism and therefore requisite behaviors for such a classification. Renowned psychiatrist Sir Michael Rutter was extremely influential in this endeavor. He found three primary types of symptoms evinced by almost all children with autism and that occurred much less frequently among children with other disorders. These symptoms confirmed Kanner's work and are the same as those core domains we recognize in the field today: difficulty developing and maintaining social relationships, problems with language development and use, and ritualistic or compulsive behavior (Rutter, 1970, 1971). Additional symptoms that occurred frequently among children identified as having autism included stereotypy (e.g., repetitive motor movements), self-injury, poor attention span, and delayed bowel control (Rutter, 1970, 1971).

Most researchers in Britain, Australia, Canada, and the United States supported autism and childhood schizophrenia as discrete syndromes by the 1970s (Green et al., 1984). In 1971, DeMyer and colleagues made an empirical comparison of five diagnostic systems for differential diagnosis between the disorders. The diagnostic systems they used included Polan and Spencer (1959), Rimland (1964b), Lotter (1966), Rendle-Short and Clancy (1968), and Creak/British Working Party (1964). The authors administered all of the checklists to each of the 44 participants. Results indicated overlap of only 35 % across all five systems, reflecting the great disparity in definitions of schizophrenia and autism that existed in that era despite the recognition that the disorders were distinct. Furthermore, the authors noted that all of the checklists lacked rigorous validity studies at the time the study was conducted and, as such, could only serve as screening instruments of relatively equal value (DeMyer, Churchill, Pontius, & Gilkey, 1971). That is, any one of the checklists studied could differentiate early schizophrenic and autistic children from nonpsychotic children, but not necessarily to differentiate within the "psychotic" group. To excuse the low amount of overlap, DeMyer and colleagues pointed out that professionals in close collaboration (e.g., working at the same facility) are much more likely to experience agreement on diagnosis than those experts who do not engage in constant feedback and comparison of diagnoses, despite the use of standardized or structured assessment instruments.

In the late 1970s, two definitions of autism that were evidence based rather than strictly theoretical were most prominent (i.e., those by Rutter (1978) and Ritvo and Freeman (1978)). The definitions were similar in that they both included impairments in social development, problems with language and cognitive function, and early onset of symptoms. Additionally, both recognized that although these core symptoms were required, variation among individuals was extensive (Schopler et al., 1980). However, whereas Rutter (1978) included behavioral rigidity (e.g., insistence on sameness) and stereotyped behavior (e.g., play), Ritvo and Freeman (1978) highlighted sensory issues and added disturbances in developmental rates or sequences. Rutter recognized and noted several flaws in his 1987 formulation; his four diagnostic criteria did not include consideration of distinct subtypes of autism, nor how to classify individuals who exhibited only some of the features he delineated (Feinstein, 2010).

Further Progress for Assessment and Toward Consensus on Definition

Recognizing the need for objective diagnostic criteria and normative behavioral data that would allow for accurate comparisons across individuals, Freeman, Ritvo, Guthrie, Schroth, and Ball (1978) developed a systematic way to code behaviors among children with developmental disabilities as well as their typically developing peers. Their measure was named the *Behavior Observation Scale*. In their factor analysis of the measure, the authors found that the group with autism was best characterized by symptoms of inappropriate interaction with people and objects. This was in contrast to their group of individuals with intellectual disability, who exhibited solitary behaviors (Freeman, Schroth, Ritvo, Guthrie, & Wake, 1980). Later, they further differentiated between high- and low-functioning autism; "relation to examiner" best differentiated the children with low-functioning autism, whereas "solitary stereotypic" and language behavior best differentiated the children with high-functioning autism (Freeman, Ritvo, & Schroth, 1984).

In 1980, the authors of the CARS compared their measure to the aforementioned Rimland checklist and the existing definitions to evaluate correspondence among these options (Schopler et al., 1980). They found that their classifications, based on behavioral observations, differed substantially from those that used the Rimland checklist, which were based on parent report. Their study also indicated significant overlap in the Rutter and Rivto and Freeman criteria, with those individuals meeting both criteria evincing higher scores on the CARS (i.e., more likely to be in the severely autistic range according to the measure). Schopler and colleagues (1980) emphasized that although the CARS was helpful for classification purposes and to provide a “descriptive summary of a child’s pathological behavior” (p. 102), the measure was not intended to replace the gathering of information from multiple sources (e.g., developmental history, behavior across settings).

The same year, the third edition of the DSM was released (1980, American Psychiatric Association). In DSM-III, childhood schizophrenia was excluded, and “infantile autism” was included for the first time (DSM-III, American Psychiatric Association). Infantile autism was included in the pervasive developmental disorder category and was clearly distinguished from childhood-onset schizophrenia. These criteria were based on Kanner’s original descriptions (Kanner, 1943), his more specific delineation with Eisenberger (Eisenberger & Kanner, 1956), and Rutter’s later description of behavioral manifestations of Kanner’s proposed core symptoms (Rutter, 1978).

Empirical comparisons supported the differentiation between autism and schizophrenia. For instance, in their comparison of DSM-III-diagnosed children with schizophrenic disorder versus DSM-III-diagnosed children with infantile autism, Green and colleagues (1984) found that the disorders differed in terms of age of onset, behavioral symptom profile, intellectual functioning, pregnancy and delivery complications, and socioeconomic status (Green et al., 1984). Further, the groups remained distinguishable as the children developed, despite some overlap in behavioral profiles (Green et al., 1984).

In the late 1980s, Rutter’s (1978) four criteria and Ritvo and Freeman’s (1978) criteria were most commonly used, but there was still difficulty formulating criteria that would delineate a clinically homogeneous group (Fein, Pennington, Markowitz, Braverman, & Waterhouse, 1986). As the field worked on a neurophysiological model of the disorder, some researchers suggested autism was a neurological disorder that primarily affected social and emotional development (Fein et al., 1986). Nevertheless, focus remained on behavioral observations and caregiver-reported developmental history, with standardized ways of measuring both emerging out of necessity to compare across populations. Behavior checklists were fairly common (e.g., Behavior Rating Instrument for Autistic and Atypical Children by Ruttenberg, Kalish, Wenar, & Wolf (1974); Autistic Behavior Checklist by Krug, Arick, & Almond (1980)), but more comprehensive standardized assessment measures were just being formulated.

For instance, the *Autism Diagnostic Observation Schedule* (ADOS) and the *Autism Diagnostic Interview* (ADI) were both published in 1989 (Le Couteur et al., 1989; Lord et al., 1989). The ADOS was described as a standardized protocol to observe and code social and communicative behaviors by way of structured and semi-structured cues for interaction (Lord et al., 1989). The purpose of this observational measure was to acquire a quantifiable sampling of a client’s behavior in the clinic, to which other information (e.g., observations in familiar settings, caregiver interviews) about the child’s behavior are incorporated in the clinical synthesis of the case. The) ADI was described as a standardized investigator-based interview of the primary caregiver (Le Couteur et al., 1989). The authors aimed to create a measure that captured a lifetime range of behaviors in order to differentially diagnose pervasive developmental disorders in individuals beginning at 2 years of age. Questions cover reciprocal social interaction, communication and language, and repetitive, restricted, and stereotyped behavior, as well as symptoms not required for diagnosis but that frequently occur among individuals with autism and related disorders. These included self-injury, pica, aggression, and overactivity. The authors created the measure to fill the need for a standardized interview that covered the symptoms of autism across levels of cognitive functioning. As with the CARS, more recent versions of both measures are still being used today; updates and clinical uses are discussed in depth in later chapters.

In the later revision of the DSM-III, DSM-III-R, the criteria for autistic disorder were expanded in an attempt to include a broader range of ages and developmental levels (Volkmar, Cicchetti, Bregman, & Cohen, 1992). In their study, Volkmar et al. (1992) found that the ICD-10 was the closest official diagnostic system to clinical diagnosis. Additionally, there was evidence that DSM-III-R overdiagnosed autism when compared to DSM-III or clinical diagnosis; DSM-III-R diagnosis was found to be highly sensitive but less specific than clinical diagnosis (Volkmar et al., 1992). Indeed, the DSM-III-R criteria identified clinically diagnosed atypical pervasive developmental disorder as autism (Volkmar et al., 1992). Nevertheless, Volkmar and colleagues noted that since there was no "gold standard" for diagnosis, there was no reliable way to tell whether over- or underdiagnosis was "correct," only that it was problematic for research efforts that official diagnostic systems of that time differed so widely in their criteria.

The Last Decade

In both ICD-10 and DSM-IV-TR (APA, 2004), the diagnosis of autism required evaluation of current behaviors and cognitive and language abilities, as well as consideration of developmental history. Evaluation was advised to take place across multiple settings and could involve standardized measures. Clinical judgment of several experienced professionals was recommended.

Publication of the DSM-V in 2014 enacted substantial changes for the criteria of autism with significant results (APA, 2014). The new autism spectrum disorder (ASD) would drop its previous subcategories and become a one-dimensional category. Additionally, the triad of symptom categories was reduced to just two: social communication/interaction and restricted and repetitive interests. Prior to the publication of the new criteria, the work group responsible for its development claimed the result would be increased specificity while maintaining sensitivity. Nevertheless, there was a concern that individuals with less severe symptoms of autism would no longer meet criteria and subsequently lose access to valuable services (Matson, Kozlowski, Hattier, Horovitz, & Sipes, 2012; McPartland, Reichow, & Volkmar, 2012; Worley & Matson, 2012). Indeed, several research groups suggested relaxed diagnostic algorithms following research studies that found many individuals with severe, interfering symptoms would be missed (Frazier et al., 2012; Matson et al., 2012; McPartland et al., 2012). Nevertheless, the DSM-V criteria for ASD were published as originally conceptualized. As such, controversy continues about the most accurate definition of autism; it is yet unclear which diagnostic system will be most widely used in the future (Volkmar & McPartland, 2014). Additional information about these most recent changes and their implications is provided later in this book.

At present, practice parameters indicate the necessity of screening for core symptoms of ASD, particularly issues with social relatedness and display of repetitive or unusual behaviors (Volkmar et al., 2014). A follow-up comprehensive diagnostic assessment is recommended if the screening indicates the presence of significant symptomatology. Information should be gathered from the child, the child's caregivers (e.g., parents, legal guardians), and the child's service providers (e.g., classroom teachers, therapists). Because genetic factors and biological markers have not yet been established for the diagnosis of ASD, assessment primarily consists of behavioral observation of the client (McCray, Trevvett, & Frost, 2014; Volkmar et al., 2014). The use of standardized measures is helpful in information collecting for both clinical observation and caregiver report, as data can be compared across children, allowing for more accurate assessment of development and functioning. After diagnosis of autism by a qualified professional, a multidisciplinary evaluation is suggested, which may include a medical examination, genetic testing, and/or neurological assessment (Volkmar et al., 2014). Further assessment of psychological components (e.g., cognitive abilities, adaptive behavior) and communication, occupational, and physical evaluations provide valuable information for treatment planning individualized to the client (Volkmar et al., 2014).

Although autism has a long, oftentimes controversial history in terms of diagnosis and evaluation, the above history provides a glimpse into what was the foundation for our current practice. The early criteria and assessment measures provided a basis for our current diagnostic process, although most components have been refined, empirically tested, and standardized. As briefly discussed, current goals of assessment include quantifying symptoms as much as possible through both live observation and caregiver report. More in-depth information regarding current assessment practices and commonly used, psychometrically sound measures is provided in the following chapters.

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