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Review article

The making of a field: The development of comorbid psychopathology research for persons with intellectual disabilities and autism

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ABSTRACT

Knowledge in the area of developmental disabilities has been expanding rapidly. One area that has received particular attention is the topic of related comorbid conditions. This phenomenon is not exclusive to the field of developmental disabilities. However, research with this population is of recent origin. The purpose of this paper is to review the origins of this field including some of the notable developments and potential future trends.

Contents

Developmental disabilities consist of a range of conditions including intellectual disabilities (ID), autism spectrum disorder (ASD), cerebral palsy (CP), sensory impairments, and developmental coordination disorders among others (Boot, Pel, Evenhuis, & van der Steen, 2012; Chen, Wilson, & Wu, 2012; Meyns et al., 2012; Szumski & Karwowski, 2012; van Gent, Goedhart, & Treffers, 2012). These disorders are well defined and have been the subject of assessment and treatment research for decades. This state of affairs is largely due to the severity and chronic nature of these conditions. However, these developmental disabilities may be moderated over time, and various physical and psychological supports can be put into place to assist in establishing more typical functioning.

Early on the development of the psychological and educational treatments was very limited as were assessment methods. Similarly, the understanding of etiology and symptom expression was in its infancy. Persons with ASD were characterized as

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young children (Kanner, 1943). In addition, it was believed that the condition was caused by poor parenting and occurred primarily among well-educated families (Kanner, 1943). An impediment to the comorbid psychopathology field in developmental disabilities was a protracted debate over whether children could experience depression (Costello, 1980; Lefkowitz & Burton, 1978; Timimi, 2004). Many professionals suggested that childhood depression did not exist. Since that time a cultural revolution has occurred with respect to these attitudes. Massive amounts of data are accumulating which contradicts this position. Similarly, ADHD and ASD are now recognized as disorders which co-occur at high rates (Mayes, Calhoun, Mayes, & Molitoris, 2012; Montes & Halterman, 2007). This research has been advanced very recently since the DSM-IV did not allow for a comorbid diagnosis of ADHD with ASD.

The field is maturing at an exponential rate. The basic theoretical foundation of these changes is the recognition of the complexity of human behavior. Developmental disorders overlap with a variety of conditions (Amr et al., 2012; Kishore, Nizamie, Nizamie, & Jahan, 2004; Matson & LoVullo, 2008; Matson, Smiroldo, Hamilton, & Baglio, 1997; Matson et al., 1999). Additionally, researchers are becoming aware not only that co-occurring disorders exist within the context of ID and ASD, but also that these developmental conditions put individuals at an increased risk of comorbid psychopathology (Smith & Matson, 2010a, 2010b, 2010c). It is critical to be able to accurately diagnoses these comorbidities in order to plan and implement comprehensive intervention packages (e.g. Matson et al., 2005; Rojahn, Aman, Matson, & Mayville, 2003).

Becoming increasingly pertinent is the concern of what specific symptoms exemplify overlapping disorders, where the cutoff points occur in differential diagnosis, and how to most accurately measure symptoms and diagnose comorbid conditions. As a result, a good method of tracking the field's development is to analyze the number, type, and complexity of assessment methods that have been developed on this topic. For the current review, the focus will be restricted to ID and ASD.

1. Early developments

ID has a longer history of research on comorbid psychopathology compared to ASD. This observation is understandable as ID has a much longer history as a field of study in the disciplines of education, health, and mental health. Binet famously developed the Binet–Simon intelligence test as a method of identifying and separating children with ID into classrooms separate from typically developing children. These developments occurred in Paris and culminated in the first version of the Binet–Simon test in 1905. Later, Terman translated and modified the test for use in the U.S. The first edition of the Stanford–Binet appeared in 1916 with revisions following in 1937 and 1960 (Sears, 1957).

Formative efforts in defining ASD came much later. Almost 40 years had passed since the development of the Binet–Simon before Kanner (1943) first described autism in a professional journal. Even at that point, major modifications and changes to the diagnosis of ASD continued, with scale development following even later. This preoccupation with defining core symptoms in our view was an impediment to the development of the field of comorbid conditions.

For some time after the development of modern definitions of ID and ASD, and accompanying tests to help identify these conditions, comorbid conditions had not been addressed. Additionally, various rationales for why these disorders could not overlap with mental health conditions, in particular, were common. Insufficient ego strength or poor insight into their own problems were reasons cited for these beliefs. It was not until the 1960s that researchers began to acknowledge the presence of co-occurring psychopathology among persons with ID (Gardner, 1967).

Despite these developments, there was considerable resistance to change in the field. One of the primary difficulties was the general separation of services into two tracks: ID and mental health. Thus, persons with ID and mental health concerns often found themselves in a proverbial health services no-man's-land. This service model also shaped how services were provided and how patients were viewed. The ID centers and outpatient programs tended to focus on psychological and educational services. Over time these services became more and more focused on methods and procedures adhering to an operant conditioning paradigm. These methods as a group are often referred to as applied behavior analysis. The mental health side, conversely, adopted a medical/biological model. The focus has been on differential diagnosis and psychotropic medication. Supportive psychological therapies were also employed in some instances. Thus, the types of services received were greatly affected depending on to which of the two types of agencies the individual was assigned. In truth, another problem with this approach was that both treatment models have merit. However, while these methods certainly could complement one another, that approach was seldom followed. Rather, many professionals tended to gravitate to one model or the other. The opposing camp was viewed as a rival treatment model rather than a potential asset to a particular program. The notion was more about sorting out if the person fell into an ID or a mental health box, with no consideration for overlap. This drastically limited the focus on comorbid mental health conditions in persons with ID.

ASD also developed as a singular disorder with respect to the delivery of services. Once the condition had been defined, early researchers were of the opinion that the disorder was rare and occurred among children with above average intelligence. As a result, most programs tended to be housed in medical schools or were administered by private providers. It was not until the 1960s and 1970s that the disorder was reframed. At this point, ASD made the move from being defined as a mental health disorder to a developmental disorder. Later, it became evident that a high overlap occurred between ASD and ID (Hill & Furniss, 2006; Matson & Shoemaker, 2009). In essence, this became the first major advance into the field of ASD and comorbidity. One could also argue that research showing as many as 70% of individuals with ASD also evince ID hastened and solidified the establishment of ASD as a form of developmental disability.

2. Scaling methods

The development of scaling methods was a major step in the codifying and popularizing of comorbidity as a discipline within the ID and ASD fields. The first scale for comorbid psychopathology among persons with ID was the Psychopathology Instrument for Mentally Retarded Adults (PIMRA; Kazdin, Matson, & Senatore, 1983; Matson, Belva, Hattier, & Matson, 2012; Matson, 1988). At this point, many professionals still denied that comorbid psychopathology could occur in persons with ID. However, this situation would soon change. This new approach was typified by the development of a variety of comorbid psychopathology measures specific to ID. The change was rapid and worldwide. Thus, a "new guard" of professionals rapidly transformed how ID was viewed with respect to assessment and treatment. Moss et al. (1993) reported on a British measure for adults with ID called the Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD). Additional studies have been published reporting on the psychometrics of this measure (e.g. Hatton & Taylor, 2008; Moss et al., 1998). Reiss and Valenti-Hein (1994) also developed a measure of psychopathology for children with ID: the Reiss Screen. This measure is also still in widespread use. The PIMRA, PAS-ADD, and Reiss Screen all have been used within a wide age range.

In addition to these general measures, other methods were designed for more specialized populations. For example, the Diagnostic Assessment for the Severely Handicapped (DASH) was designed specifically to measure psychopathology and challenging behaviors in persons with severe and profound ID (Matson, Kiely, & Bamburg, 1997). Additionally, the Assessment for Dual Diagnosis (ADD; Matson & Bamburg, 1998) was designed for persons with mild and moderate ID.

A host of researchers worldwide also became very active. Koskentausta and Almqvist (2004), for example, used the Developmental Behavior Checklist to assess psychopathology in a Finnish sample. The PIMRA has been used in Norwegian (Linaker & Helle, 1994), Dutch (van Minnen, Savelsberg, & Hoogduin, 1994), and Italian samples (La Malfa, Notarelli, Hardoy, Bertelli, & Cabras, 1997). Zeilinger, Weber, and Haveman (2011) used the PAS-ADD with a German sample, and Kishore, Nizamie, and Nizamie (2010) employed the Reiss Screen on an Indian population. These studies provide a few examples. Nonetheless, the scope of this research is broad, and the acceptance of comorbid psychopathology in the study of ID worldwide is asserted.

The late 1990s saw the first spate of papers on various forms of psychopathology among persons with ASD. Wozniak et al. (1997) used the Child Behavior Checklist to report on the occurrence of mania in children with Pervasive Developmental Disorder (PDD, a category of ASD in the DSM-IV-TR). They studied 727 children, 52 of whom met criteria for PDD. These authors reported that among the 52 children, 14 presented with mania. Similarly, Tonge, Brereton, Gray, and Einfeld (1999) assessed psychopathology in 52 children with Asperger's Syndrome and 75 children with high functioning ASD. They used the Developmental Behavior Checklist and found that children with Asperger's Syndrome had higher levels of psychopathology than persons with high functioning ASD. The Asperger's group was more likely to evince disruptive, antisocial, and anxious behaviors. Kobayashi and Murata (1998) describe psychopathology in 187 young adults with ASD. They employed the Achenbach Child Behavior Checklist. These authors noted high levels of obsessive and compulsive behaviors and the presence of psychotic symptoms in a few cases. Tsakanikos, Underwood, Kravariti, Bouras, and McCarthy (2011) used the PAS-ADD to assess 150 adults, 60 of whom had an autism diagnosis and 90 who did not. They noted that males with autism were more likely to evince personality disorders and schizophrenia while dementia was more evident in females. The reader will note that all of these studies used scales which were designed for a general population rather than measures designed specifically for persons with an ASD. However, as with the trend in comorbidity measures with ID, measures specific to comorbid conditions in ASD quickly appeared.

The Diagnostic Assessment for the Severely Handicapped (DASH-II) was probably the first scale that would qualify as such a measure, although only for a subset of the population which included persons with severe and profound ID (Matson, Coe, Gardner, & Sovner, 1991). The scale has been studied extensively and measures symptoms of autism as well as a broad range of psychological disorders. Psychological disorders assessed by the DASH-II include depression, anxiety, mania, and schizophrenia. Behavior disorders such as self-injurious behaviors, eating, sleep, and elimination problems are also addressed. The autism subscale has been validated against other autism scales (Belva, Matson, Hattier, Kozlowski, & Bamburg, 2012). Given the high overlap between autism and ID, this measure captures a good number of cases (La Malfa et al., 2007; Matson & Shoemaker, 2009).

More recently, a number of comorbidity scales have been developed specifically for the ASD population. Helverschou, Bakken, and Martinsen (2009) developed the Psychopathology in Autism Checklist (PAC). Their 30 item scale has been studied with adults. These individuals with autism were assessed for psychosis, depression, and anxiety, and obsessive compulsive disorders. Matson and Boisjoli (2008) reported on the development of a scale called the Autism Spectrum Disorder – Comorbid for Adults. This measure was normed on persons with ID, and with or without autism. A second scale for infants, the Baby and Infant Screen for Children with aUtIsm Traits (BISCUIT) was developed for 17–36 month old children (Matson, Boisjoli, & Wilkins, 2007). The comorbidity scale measures tantrum/conduct behavior, inattention/impulsivity, avoidance behavior, anxiety/repetitive response, eating problems, sleep problems, and total comorbidity. This scale has been extensively researched with thousands of children (e.g. Matson, Hess, & Boisjoli, 2010). Stratis and Lecavalier (2013) used the Repetitive Behavior Scale-Revised to assess 72 children with ASD aged 5–17 years and found scores on the ritualistic and sameness scales of the measure predictive of anxiety, depression and ODD, and stereotypy scores predictive of ADHD. Worley and Matson (2011) reported on the Autism Spectrum Disorders – Comorbid for Children. This measure is based on assessments done throughout the United States from children aged 3–17 years. Areas assessed are repetitive behavior,

worry/depression, avoidant behavior, under-eating, conduct problems, and over eating. Other problems included ADHD, conduct disorders, obsessive–compulsive disorder, phobias, and tics.

Specialized scales for specific disorders have also begun to appear. Groden et al. (2001) developed the Stress Schedule for Persons with Autism and Developmental Disabilities. The purpose of this measure was to assess potential stress triggers. A second measure of this type is the Autism Co-morbidity Interview – Present and Lifetime Version (ACI – PL; Leyfer et al., 2006). The measure is based on the well-known structured interview, the Kiddie Schedule for Affective Disorders and Schizophrenia (KSADS; Chambers et al., 1985). Topics covered by the ACI – PL include panic disorder, social anxiety, social phobia, specific phobia, obsessive compulsive disorder, and generalized anxiety disorder.

3. Conclusions

The fields of ID and ASD have seen rapid developments in how they are viewed conceptually. Initially both disorders were seen as unitary constructs. Given this theoretical model, the notion of comorbid psychopathology fell outside the scope of clinical thinking and practice. As the field evolved, research began to appear suggesting not only that a range of comorbid psychopathology existed, but that a wide range of emotional problems were evident in this group of individuals. The amount and breadth of research in this growing area is expanding very rapidly.

Researchers now have a consensus that comorbid psychopathology is a frequent phenomenon among individuals with autism. No one knows with certainty what are likely to be the major trends in the future. Nonetheless, past trends of ten point to potential future behavioral trajectories. The most likely scenario is that the amount of research will increase in this field. The marked increase in publications thus far, for example, has led to a huge increase in the number of journals devoted to developmental disabilities during the last two decades. Also, the comorbid psychopathology field will continue to develop subspecialty areas. At this point, anxiety disorders and ADHD among persons with autism have developed to a point where each has become a subspecialty area.

The study of ASD in particular has seen a breathtaking increase in interest, particularly in the last decade. This interest is likely to continue for some time, and is further bolstered by various new public and private funding sources. The funding supports the development of research for both research and clinical services.

On the other hand, ID as a whole occupies a much smaller piece of the research pie compared to decades past. ASD in particular but also Developmental Coordination Disorder, Cerebral Palsy, and other developmental conditions have become more prominent in the research. As research has led to better assessment and diagnostic practices, persons previously diagnosed as ID now often fall under the category of ASD. This phenomenon is referred to as diagnostic substitution. This phenomenon is likely to continue as the adjustment of boundaries between various developmental disabilities evolves. These modifications are a characteristic of the field which will be with us for some time to come as trends in diagnosis and the development of additional knowledge about these various disorders continue to emerge. The field of ID has been a leader in the development of understanding comorbid psychopathology among persons with developmental disabilities. Similarly, the study of many specific developmental disabilities has mirrored the advances in the ID field, with research into comorbidities rapidly advancing. This trend is likely to continue. The future of research in this area is as a result both interesting and promising.

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