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How Conceptualizations of Intellectual Disability Drive Assessment Practices, and Vice Versa

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Abstract

Changing conceptualizations of intellectual disability (ID) influence changes in the assessment practices used by professionals who work in the field of ID. The opposite is also true; new approaches to assessment can modify conceptualizations of ID. The purpose of this article is to summarize historical and current trends in regard to conceptualizing ID and the assessment practices used with people with ID. Recommendations for future directions for conceptualization and assessment are provided. These recommendations focus on understanding people by their needs for support to participate in culturally valued settings and activities of daily life and adopting assessment practices that inform the identification and arrangement of personalized supports.

Keywords: Conceptualizations. Intellectual Disability. Practices.

INTRODUCTION

In this article, I summarize different conceptualizations of intellectual disability (ID) over time and describe the assessment practices that both grew out of different conceptualizations as well as shaped conceptual changes. I conclude that a social-ecological conceptualization of ID offers the most useful perspective for people with ID and their families, as well as the professionals who support them in their daily lives. The social-ecological conceptualization calls for assessment practices to shift from identifying deficits to identifying support needs. Progress in developing ways to meaningfully assess and measure people's support needs will lead to a better understanding of how individuals interact with their environments and inform the most effective ways to support them to experience a positive quality of life.

HISTORICAL ASSESSMENT OF INTELLECTUAL DISABILITY

People with ID are a naturally occurring part of human diversity, so they have always been a subgroup of the human population (CRAIG, 2013). The earliest written references to people with ID were found in the documents from the Imperial Roman Empire (BERKSON, 2004). Although there

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were several early publications on disabilities produced during the Middle Ages that included a mixture of reasoned knowledge claims based on observations (e.g., trauma to the mother during pregnancy was correctly identified as a potential cause of disability) and irrational knowledge claims based on superstition (e.g., demon possession was also identified as a potential cause), the first scholarship of true significance about ID emerged during the Renaissance. Understandably, it coincided with the first substantive writing about the construct of human intelligence (SCHEERENBERGER, 1983).

Considered by many to be the first seminal work in the field of ID (e.g., see Scheerenberger, 1983), the English philosopher John Locke (1690/1959) distinguished ID from mental illness by surmising that “madmen put the wrong ideas together, and so make wrong propositions, but argue and reason right from them; but idiots make very few or no propositions, and reason scarce at all” (para 13). In Locke’s view, deficits in cognition (e.g., difficulties acquiring knowledge and possessing limited knowledge) and reasoning (e.g., difficulties using logic to make sense of the knowledge that one possesses) were the essential features differentiating people with ID from the general population.

The central proposition underlying Locke’s (1690/1959) understanding of ID was that ID was a *deficit trait* residing within a person. Thus, Locke’s conceptualization was consistent with what has come to be referred to as the medical model of disability. This paradigm holds that disability is an internal pathology which is evidenced by deficits (PLEDGER, 2003). As mentioned at the onset of this article, conceptualizations of ID influence assessment practices and vice versa. Adopting the medical model of ID prompted the development of assessment processes that were focused on identifying and documenting the presence mental deficits.

Assessment results and disability determinations became of practical significance (not just philosophical significance) as training schools and residential institutions were established in different parts of the world throughout the 1800s. In the earliest days, there were no assessment protocols. Several activities were carried out for the purpose of identifying who would be appropriate candidates to receive access to the limited specialized human services that were available. The need for valid assessment practices to inform gatekeeping decisions intensified over time, especially as the first public funded special education programs were established (SCHEERENBERGER, 1983).

Early assessment era. The first structured assessment approaches diagnose ID were developed for physicians’ use. The assessment protocols required doctors to conduct clinical interviews with people suspected of having ID as well as those who knew the person well, and to conduct superficial physical examinations of the individual who was being assessed. The interview guidelines were flexible, but included questions related to how a person was functioning in daily life (e.g., Could an adult hold a job? Was a child failing in school?) and whether the person had experienced developmental delays growing up (e.g., Was a child's speech at a level consistent with what was expected for a child of the same age? Did an adult experience delays during childhood, such as learning to walk or learning self-care skills?). The physical examination portion of the physician's assessment required the evaluation of indefinite biological markers. Although some physical markers have stood the test of time as reasonable indicators of conditions related to ID (e.g., physical features associated with Down syndrome), most of the information provided by the physical examination used in the early days of ID assessment was completely spurious (e.g., phrenology evaluations focusing on measuring bumps on the skull; BRUININKS; THURLOW; GILMAN, 1987; SCHEERENBERGER, 1983; SMITH; WEHMEYER, 2012).

Although the loosely structured assessment interviews were much like other processes that physicians used to assess and diagnose health conditions in the absence of biological evidence, these early assessment interviews had many shortcomings in terms of diagnosing ID. For instance, protocols were not uniform, and consistency across interviewers was never established. Two physicians could ask similar questions, receive similar answers, and come to different conclusions regarding a diagnosis; and neither one would necessarily be wrong (SCHEERENBERGER, 1983; SMITH; WEHMEYER, 2012).

It is also noteworthy that not all assessment practices prior to 1900 were concerned with diagnosis. In the mid-1800s, Edouard Seguin (1866/1907) began measuring and documenting the progress his students were making as a result of receiving a treatment method he had developed known as *The Physiological Method*. His method was based on the premise that people with ID had arrested mental development that could be successfully addressed through motor and sensory training (some of Seguin's techniques are similar to practices used by occupational and physical therapists to the current day). Although Seguin did not develop sophisticated assessments that allowed a clear connection to be established between aspects of his teaching methods and his students' outcomes, he regularly evaluated the progress of his students in relation to *The Physiological Method* and he showed that his students had become more competent in the exercises they were being taught. Thus, Seguin's efforts can be considered a forerunner to the collection of progress monitoring data associated with formative assessment. He concluded that "most idiots, and children proximate to them, may be relieved in a more or less complete measure of their disabilities by the physiological method of education" (p. 50).

Returning to the major thesis of this paper, the events in the field of ID prior to the 1900s revealed ways in which conceptualizations of ID and assessment practices influenced one another and changed over time. Locke's (1690/1959) conceptualization of ID as the presence of mental deficits stemming from a neurological basis (medical model) remained, but Seguin's assessment data provided optimism that mental deficits were not intractable. Also, prior to the 1900s, mental deficits were thought to be evidenced by difficulty functioning in daily life. Therefore, evaluating overall competency in daily routines and independent functioning was the focus of the physician's diagnostic interviews. There was no pretense of measuring natural brainpower or predicting ceilings on intellectual aptitude.

Despite the modest progress made prior to the 1900s, by the end of the century there was a desire for a more objective approach to assessment for the purposes of diagnosis. Specifically, there was a need for assessment protocols that would assure that a diagnosis of ID would consistently be made across multiple examiners of the same individual (SCHEERENBERGER, 1983; SMITH; WEHMEYER, 2012). The introduction of the IQ test in the early 1900s ushered in a new era for assessing of people with ID, and with it came important changes in how ID was conceptualized as well as how people with ID were understood.

IQ test era. IQ tests were first introduced in the early 1900s and by the 1920s had replaced the physician's interview and physical examination as the gold standard for assessing and diagnosing ID. IQ tests quickly gained traction because they offered an efficient and seemingly objective approach to diagnosing ID. The psychologist replaced the physician as the assessor and diagnostician, and a uniform testing procedure for collecting information replaced the semi-structured interview and physical examination. IQ assessments generated norm-reference scores (based on the number of right and wrong responses) which were less open to interpretation than the information that was garnered from physician interviews and physical examinations. IQ scores precisely indicated the extent to which a person's intellect deviated from the average person's intellect, and, therefore, the results offered the opportunity to establish specific cut off scores that would determine whether someone was in or out of the ID subgroup (SCHEERENBERGER, 1983; SMITH; WEHMEYER, 2012). For instance, Terman (1916) categorized people in the lower ranges of the IQ distribution in the following way: Dullness (80-89); Borderline retardation (70-79); Moron (50-69); Imbecile (25-49); and Idiot (below 25).

IQ-driven assessment did not only change assessment practices, but also changed how ID was conceptualized. The conceptualization of ID shifted from a condition characterized by difficulty functioning in the activities of everyday life to a condition characterized by a lack of natural intellect (SMITH; WEHMEYER, 2012). IQ test purported to measure the construct of human intelligence, and mental deficits were evidenced by low scores (i.e., poor performance) on the test. IQ testing was not concerned with *typical performance* in daily life; rather, the validity the IQ test relied on evaluating a person who was doing the best they could (*maximal performance*) while the test was being administered (GOULD, 1996; THOMPSON; MCGREW; BRUININKS, 1999; SALVIA; YSSELDYKE; BOLT, 2017).

Additionally, with much of the population either illiterate or with only rudimentary literacy skills throughout the 1800s, there was not a heavy emphasis on measuring academic proficiency as part of the physician's diagnostic evaluation of how a person was functioning in their daily life. But, since IQ tests were initially developed as a screening tool to identify children who might be at risk of school failure in the future, IQ test items were closely aligned with academic achievement. Thus, "intelligence" became more narrowly defined with the introduction of IQ tests (Gould, 1996). Basing diagnosis of ID on only the IQ score meant that little to no attention was paid to evaluating abilities connected to personal independence and social vulnerability. However, a considerable emphasis was placed on abilities associated with school success such as verbal and logical-mathematical skills and abstract reasoning (THOMPSON; MCGREW; BRUININKS, 1999, 2002).

As conceptualizations of ID changed, so did the way in which people with ID were understood. By the 1920s, when the IQ test had become the sole type of assessment used to diagnose ID, people with ID were understood less by their difficulties in regard to independence/adaptation to society and more as an inferior subgroup of the population that had chronic deficits in mental prowess and aptitude. There were obviously broader cultural factors at play, most notably the Eugenics movement which gained special prominence in Europe and North America. However, IQ testing was a factor in defusing the optimism of the early pioneers of the field because intelligence was perceived to be a fixed trait. Seguin and others had come to conceptualize ID as a condition that could be eradicated (or at least diminished) with education. IQ testing reinforced the more pessimistic perspective that ID was an immutable condition. Like other human traits (e.g., eye color, height), intelligence was considered to be something that was not changeable. The fact that IQ scores were stable over time was viewed as evidence that people's level of intellect was generally fixed from birth, and therefore interventions for people with ID were unlikely to make much difference (GOULD, 1996; SMITH; WEHMEYER, 2012; TRENT, 2017).

But, from outset not everyone was convinced that IQ tests were useful to society (e.g., LIPPMAN, 1922) or to the assessment of ID (e.g., BERRY; GORDON, 1931; DOLL, 1936b; TREDGOLD, 1922). The American journalist, Walter Lippman (1922), wrote six articles for *The New Republic* in which he vehemently criticized the Eugenics movement, and in the process offered this assessment of IQ testing:

> It is not possible, I think, to imagine a more contemptible proceeding than to confront a child with a set of puzzles, and after an hour's monkeying with them, proclaim to the child, or to his parents, that here is a C- individual. It would not only be a contemptible thing to do, it would be a crazy thing to do, because there is nothing in these tests to warrant a judgment of this kind. (p. 297)

A review of the historical debate regarding IQ tests is well beyond the scope of this paper, but it is worth noting that a myriad of controversies surrounding IQ testing remain to this day (e.g., see SAINI, 2019; FLYNN, 2007). In terms of the field of ID, the most prominent concerns about IQ tests are that they are biased against specific types of people (e.g., people from different races, socioeconomic classes; Saini, 2019), the information collected during IQ testing represents a narrow range of mental processes which do not capture most of what is considered to be evidence of human intelligence (THOMPSON; SHOGREN; WEHMEYER, 2017), and the results from IQ tests provide no value in planning supports, instruction, or any other aspect of human services (YSSELDYKE; ALGOZZINE; THURLOW, 2000).

By the 1930s there was growing recognition that a singular focus on conceptualizing ID and assessing ID in relation to the construct of human intelligence was not defensible. An overreliance on IQ, as well as misconceptions about IQ, reinforced the notion of incurability and provided justification for dehumanizing practices ranging from forced sterilization, confinement in large institutions that offered few opportunities for education or treatment, and exclusion from publicly funded education that was available to the rest of society (SMITH; WEHMEYER, 2012). Berry and Gordon (1931) argued that deficits in social competence was the defining feature of ID, not human intelligence (especially as it was measured by IQ tests). They wrote, "the acid test of mental deficiency is not, and should not be, scholastic educability, but this power of fending for one's self in life, or an adaptability to the environment" (p. 5). Edgar Doll (1936a) created the *Vineland Social*

Maturity Scale in response to what he perceived as a need to shift the focus of field of ID back to understanding people with ID by the way they interacted (i.e., functioned) with the world in their daily lives. Doll’s scale became the forerunner for all future adaptive behavior scales (AB SCALES; SCHEERENBERGER, 1983).

The advent of adaptive behavior assessment showed how, once again, advances in assessment practices can influence a change in how ID is conceptualized and people with ID are understood. By the 1950s the conceptualization of ID had shifted away from a singular focus on deficits in intelligence as measured by IQ tests to a focus on *current functioning* as measured by both intelligence tests and AB scales. The American Association on Intellectual Disability (AAIDD) specified in its terminology, definition, and classification manual that nobody should be diagnosed with ID solely on the basis of IQ testing (Heber, 1959). The dual criterion era had begun.

Dual criterion era. Every definition and classification manual on ID published during the past 60 years has included diagnostic criteria stipulating evidence for concurrent limitations in intelligence and adaptive behavior (e.g., see GROSSMAN, 1983; JACOBSON & MULICK, 1996; SCHALOCK et al., 2010). Whereas intelligence has always been conceptualized as an innate mental capability that was largely fixed, adaptive behavior has always been conceptualized as a measure of achievement (i.e., what someone can do) that is alterable through teaching and learning. Seguin’s optimism of the “pre-IQ era” returned with the introduction of AB scales and curricula to teach adaptive skills. Importantly, ID was once again conceptualized as a condition that could be eradicated (or at least diminished) with education.

Of course, the optimism of the field of ID that began after World War II and continues to the current day was not simply due to new conceptualizations of ID and new assessment practices. Rather, the optimism, conceptualizations, and assessment practices of the postwar era were consistent with a larger societal consensus that marginalized populations should be offered better opportunities than they had in past years. In the field of ID, the societal zeitgeist was apparent in the spread of the normalization philosophy (i.e., society should provide people with ID “normal” life patterns and conditions; Nirje, 1969) and deinstitutionalization policies (i.e., moving people out of institutions and preventing new admissions; KUGEL; WOLFENSBERGER, 1969).

The dual criterion standard for diagnosis paired with the increasing numbers of citizens with ID living in the same communities populated by the general population created a market for the publication of large numbers of AB scales throughout the 1960s, 1970s, and 1980s. Some scales were intended for diagnostic purposes. For example, Doll's (1936a) original scale was modified several times and it is now known as the *Vineland-3* (SPARROW; CICCHETTI; SAULNIER, 2017), and to the current day it is used mainly as a diagnostic tool. Other AB scales were intended to provide a baseline for teaching skills. For example, *The Checklist of Adaptive Living Skill*s (CALS; MORREAU; BRUININKS, 1991) included approximately 800 specific adaptive behaviors, and each could be linked to precise learning objectives, teaching strategies, and instructional activities.

However, the heavy push for people with ID to acquire enhanced adaptive skills began to face a backlash of its own beginning in the 1980s. Although nobody was opposed to people learning skills, the idea that acquiring skills should be a prerequisite to accessing culturally valued settings and activities was challenged. Group homes were conceived as training grounds for independent living skills that would prepare someone to move to their own residence (some day). Sheltered workshops were constructed as training grounds to learn work skills that would prepare people to get a job in the community at a competitive wage (some day). Special education classrooms were the place students went to get ready to attend general education classrooms alongside their same age peers (some day). Despite the best of intentions, for many people with ID, "someday" never came. According to Taylor (1998), people with ID were *caught in the continuum*; they remained in segregated settings and activities and did not have access to cultural valued settings activities because they supposedly had not yet sufficiently mastered the skills they needed to participate.

Although detailed instructional procedures grounded in principles of applied behavior analysis were effective in teaching people with ID functional skills that were useful in their daily lives (DAVIS; REHFELDT, 2007), the idea that people should spend their entire lives trying to become sufficiently qualified to experience the life conditions and activities that were freely accessible to the rest of society was questioned based on civil rights arguments (FERGUSSON; HIBBARD; LEINEN; SCHAFF, 1990; MEYER; PECK; BROWN, 1991; TAYLOR, 2001). Critics pointed out that expecting people with ID to make progress and learn skills was not equivalent to expect them to become competent at navigating all the demands of community life (TAYLOR, 1998, 2001). There was a need to place less emphasis on skill acquisition and more emphasis on assuring access to culturally valued settings and activities of a person's choice. The proposition that, instead of more skills, people with ID needed better supports called for the conceptualization of ID to change again. No longer should ID be conceptualized as a *deficit trait* characterized by a lack of adaptive skills that most others in society had mastered, but rather as a *state of functioning* characterized by a need for supports that most others in society did not require (LUCKASSON *et al*., 1992). As in the past, a changing conceptualization of ID called for the development of new assessment tools and practices.

CONTEMPORARY ASSESSMENT OF INTELLECTUAL DISABILITY

Social-ecological era. Understanding ID as a *state of functioning* instead of an *internal trait/pathology* represented a seismic shift in the way in which ID has traditionally been conceptualized. As discussed at the beginning of this article, ever since John Locke's (1690/1969) seminal essay, ID has been understood as a pathology (a defect of the mind). Jane Mercer (1973a; 1973b) was one of the earliest and the most prominent critics of the assumptions underlying the medical model of and the dual criterion approach to diagnosis. She pointed out that in the absence of a biological verifiable medical condition, the diagnosis of ID amounted to creating a pathology based on a statistical distribution. That is, when "Normal" is defined by a statistical range and is equated with the absence of a pathology, then anything outside of the statistical range and is equated with the presence of a pathology. Mercer argued for focusing on the disparity between (a) expectations that the larger culture held for people to function in society and (b) what people were able to do. According to Mercer, the locus of the problem to be solved was in the disparity, not inside the person. Her ideas were expanded by other scholars over the years (e.g., SWITZKY; GREENSPAN, 2006) and provided the basis for what has become known as a social-ecological conceptualization of ID.

In the social-ecological approach, disability is understood to be a "state of functioning characterized by a significant and chronic mismatch between a person's competencies and the demands of settings and activities associated with participating in an inclusive society" (Thompson et al., 2017, p. 31). Both the AAIDD (SCHALOCK *et al.*, 2010) and World Health Organization (WHO; 2001) have proposed models of human functioning that are consistent with a social-ecological understanding of disability due to their focus on the interaction between people and environments. Understanding people with ID through a social-ecological lens provides a contextual basis for conceptualizing ID that is quite different than the traditional medical orientation.

It is important to acknowledge that the social-ecological approach does not call for ignoring personal limitations and avoiding the reality of skill deficits or social vulnerabilities. Rather, the limitations people with ID experience in personal competency are acknowledged. As Thompson et al. (2009) pointed out, “there is a reciprocal relationship between impairments and support needs in that greater personal limitations will almost always be associated with more intense support needs” (p. 138). There is no doubt that deficits in intelligence, adaptive behavior, physical and mental health, and social skills are going to critically influence the types and intensity of support that a person needs. In both the social-ecological approach and the traditional medical approach, it is acknowledged that skill deficits exist. The critical difference is that in the social-ecological approach relative deficits are always considered alongside relative strengths. A person’s competencies are recognized holistically and in relation to environmental demands. Moreover, the focus of professional interventions is never on fixing deficits. Rather, the focus is on fixing the mismatch between personal competencies and what is needed to successfully participate in culturally valued settings and activities (SCHALOCK e*t al*., 2010).

The social-ecological approach was presented by AAIDD in early 1990s (LUCKASSON *et al*., 1992) and by the WHO in the early 2000s (WHO, 2001) as a new way of conceptualizing ID. Despite being widely applauded as a more useful orientation for organizing human services at the macro, meso, and micro levels (THOMPSON; SCHALOCK; AGOSTA; TENINTY; FORTUNE, 2014), the operational definitions of ID have not reflected a move away from the medical to a social-ecological conceptualization of ID. A review of the most recent definitions published by the AAIDD (SCHALOCK *et al*., 2010), the American Psychiatric Association (APA; 2013), and the WHO (WHO, 2019) reveal that all of these organizations have retained the dual criterion (i.e., evidence of concurrent deficits in intellectual functioning and adaptive behavior) as the standard for diagnosis. The most plausible reason why current diagnostic guidelines default to the deficit-based criteria is the absence of valid measures which aligns with the social-ecological approach.

Wehmeyer et al. (2008) pointed out that the AAIDD’s 1992 manual and subsequent editions (i.e., LUCKASSON *et al*., 2002; SCHALOCK *et al*., 2010) provided two definitions of intellectual disability: an operational definition which “operationalizes the intellectual disability construct and provides the basis for diagnosis and classification” (p. 311) and a constitutive definition which “explains the underlying construct and provides the basis for theory-model development and planning individualized supports” (p. 311). The operational definition provides guidelines that are workable for psychologists who are responsible for documenting the rationale for making a diagnosis. The constitutive definition, in contrast, is centered on promoting a contextual understanding of people and the environments in which they live and interact. The underlying assumption of the constitutive definition is that “the most salient difference between people with intellectual disability and the general population is that people with disabilities need different types and intensities of support in order to fully participate in and contribute to the settings and activities of daily life” (Thompson et al., 2018, p. 3). However, at the current time, there is not a scientifically defensible way to compare the relative intensity of supports needed by the general population with that of people with ID. As has been the case previously in the history of the ID field, it is time for assessment practices to change and catch up with the new conceptualization.

ASSESSMENTS NEEDED FOR THE SOCIAL-ECOLOGICAL APPROACH

The premise of the social-ecological approach is that ID is manifested when personal competencies are poorly aligned with the demands of culturally valued environments, so there is a need for assessments that will indicate what supports people need to minimize the person-environment mismatch and empower them to successfully participate in the settings and activities that they choose. Valid measures of support needs are essential to incorporate the social-ecological approach into assessment practices. Promisingly, a number of support needs assessments have been published during the past 15 years.

The first attempt to provide the field of ID with a support needs assessment process was initiated in the early 1990s by the authors of the 9th Edition of AAIDD’s manual of ID terminology, definition, and classification. Luckasson et al. (1992) proposed evaluating support needs against 10 adaptive skill areas using a 4-point metric, with each point corresponding to a different level of support intensity. The four intensity descriptors used in the metric were Intermittent, Limited, Extensive, and Pervasive (ILEP), and instructions required a rating for each adaptive skill area (suggestions for specific types of support were also recorded).

Although this approach offered a starting point for support needs assessment, it was criticized because the 4-points on the ILEP scale were not operationally defined, and the distinctions between the 10 adaptive skill areas were unclear. Also, there were no data to indicate that the assessment process was defensible from a psychometric perspective, which was particularly problematic because Luckasson et al. (1992) were suggesting that it be used for purposes of classification (JACOBSON; MULLICK, 1992; MACMILLAN; GRESHAM; SIPERSTEIN, 1993; 1995). Despite generating considerable discussion in the field of ID about how to measure support needs, the ILEP process was never widely adopted in practice and no professional literature was published regarding its implementation.

Partially in response to the ID field's rejection of the ILEP approach as a mean to assess people's support needs, the AAIDD convened a *Support Needs Assessment Task Force* and charged them with developing a uniform procedure to assess the pattern and the intensity of needed supports of people with ID (WEHMEYER *et al*., 2009). The work of this task force resulted in the publication of the *Supports Intensity Scale* (SIS; Thompson et al., 2004). The original SIS was revised in 2015 and is now known as the Supports Intensity Scale – Adult Version (SIS-A; THOMPSON et al., 2015). Additionally, the Supports Intensity Scale – Children's Version (SIS-C) was published a year later (THOMPSON *et al.*, 2016). AAIDD (2019a) reported that 27 jurisdictions in North America are using the SIS-A or the SIS-C to inform planning and/or resource allocation for individual support budgets. Moreover, the SIS scales have been used in some capacity in 17 countries outside of North America and have been translated into 13 languages (AAIDD, 2019b).

In their review of the professional literature on the two SIS scales, Thompson et al. (2018) synthesized the findings of 44 peer-reviewed studies (18 in the original English version and 26 in 9 different translated versions) in regard to 10 psychometric indices of reliability, content validity, criterion validity, and construct validity. The collective findings revealed that both SIS scales demonstrated excellent psychometric properties.

In regard to support needs assessment instruments other than the SIS scales, Thompson and DeSpain (2016) found that psychometric properties had been reported for six additional scales in nine peer-reviewed articles. There was, however, great variability in the sophistication of the research designs and knowledge claims made among the studies. The six other support needs scales were the Care and Needs Scale (CANS; Tate, 2004), Checklist of Child Characteristics (CCC; TADEMA; VLASKAMP; RUIJSSENAARS, 2007), I-CAN (Llewellyn, Parmenter, Chan, Riches, & Hindmarsh, 2005), Need of Support and Service Questionnaire (NSSQ; JANSSON; WENNSTROM; WIESEL, 2005), North Carolina – Support Needs Assessment Profile (NC-SNAP; HENNUJEM; NYERS; REALON; THOMPSON, 2006), and the Service Need Assessment Profile (SNAP; GUSCIA; HARRIS; KIRBY; NETTELBECK; TAPLIN, 2005). In terms of the number of peer-reviewed articles reporting psychometric properties, the CANS, CCC, NSSQ, and NC-SNAP each had one article where findings were reported. Two and three articles reported psychometric findings for the

SNAP, and I-CAN respectively. Thompson and DeSpain (2016) concluded that although other scales that imply to measure support needs have not been investigated to the extent of the SIS scales, their technical adequacy is general equivalent to what has been reported for AB scales.

All the scales mentioned above, including the two SIS scales, focus on assessing people's intensity of support needs. The SIS scales are unique regarding to provide standard scores, but the norms on the SIS scales only apply to a standardization sample comprised of people with developmental disabilities. This limitation is glaring in terms of the potential for using current support needs assessment scales for purposes of diagnosis. The lack of norm-referenced data on the general population prohibits meaningful comparisons between people with ID and the general population, and the diagnosis of ID is primarily concerned with distinguishing people with ID from the general population as well as other disability groups.

The modern world is characterized by interdependency. Everybody need and use supports (from others, from technologies, etc.) throughout their daily lives, and for the majority of the population having access to supports is necessary for survival. The next generation of support needs assessment instruments should be developed with the capacity to distinguish the types and the intensities of supports that people with ID require that are different than those used by the general population. If it is true that people with ID have extraordinary support needs, it is essential that future support needs assessment scales identify and quantify these extraordinary needs.

Another conspicuous gap in the development of support needs assessment scales is the lack of research on how information from the assessment process can be used by planning teams to develop support plans and improve outcomes. The logic of how support needs assessment information should relate to planning and outcomes is not difficult to grasp: (1) gather information about what the person wants to do in their daily life (where they want to be, who they want to be with, what activities they want to do); (2) complete a support needs assessment to determine the types and the intensities of supports they need to do what was identified in #1; (3) identify and arrange the supports identified in #2; and (4) monitor the quality of support provision and evaluate outcomes in terms of quality of life. Although the process described may be easy to grasp, there is a dearth of research regarding the effectiveness of systematic support needs assessment and planning processes.

Publications by Thompson et al. (2017) and Schalock, Thompson, and Tassé (2018) provide guidance on how to proceed with a support needs assessment, planning, and outcome evaluation process. However, the only two studies published thus far on implementing a structured process from start to finish are a case study by van Loon, Claes, Vandevelde, Van Hove, and Schalock (2010) and a single subject study by Walker, DeSpain, Thompson e Hughes (2014). In the absence of findings that demonstrate a functional relationship between support needs assessment, supports planning, and outcomes it is likely that arguments for adopting a social-ecological orientation in the field of ID will continue to be more philosophical than actionable.

A final concern with current support needs assessment approaches involves the lack of attention on evaluating the demands of different environments. Environments can be adapted to make them more accessible, and principles of universal design can be incorporated when creating settings so that adaptations are not as necessary (PREISER; SMITH, 2001). Furthermore, environments that are more accessible and welcoming will allow for the provision of less intrusive personal supports (THOMPSON *et al.*, 2009). Current support needs assessment scales need to allow for a more sophisticated evaluation of the demands of settings and activities in which a person will be engaged.

FINAL CONSIDERATIONS

The most important assumption underlying the social-ecological approach to conceptualizing ID is that providing supports that are aligned with a person's support needs will lead to improved personal functioning, positive personal outcomes, and an enhanced quality of life. In order to provide people with the right types and the right intensities of supports, one must first obtain an accurate understanding of their support needs. Thompson et al. (2009) defined support needs as "a psychological construct referring to the pattern and intensity of supports necessary for a person to participate in activities linked with normative human functioning" (p. 135). Because progress in any field is dependent on being able to accurately measure critical constructs of interest (Sydenham, 2013), it is essential that more progress be made in measuring the support needs of people with ID.

Support needs assessment is still in its infancy, and the scales that have been developed to date are hopefully akin to the Model Ts that appeared when the automobile industry began. The next generation of support needs assessment scales need to allow the types and intensities of supports that people with ID need to be compared with those of the general population. Also, information gleaned from support needs assessments must provide a clear direction for supports planning that leads to desirable outcomes. Finally, support needs assessment scales must incorporate processes that that encourage a careful examination of the demands of environments. Should support needs assessments reach this level of quality, it is likely that assessment practices will be in the position to once again push the conceptualization of ID to new and exciting frontiers.

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