Intellectual and Developmental Disabilities

Ongoing Transformation in the Field of IDD: Taking Action for Future Progress

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Ongoing Transformation in the Field of IDD:

Taking Action for Future Progress

Introduction and Overview

There has been a significant transformation in the field of intellectual and developmental disabilities (IDD) over the last five decades. This transformation is characterized by using more precise terminology, incorporating a functional and holistic approach to IDD, embracing the supports model and evidence-based practices, implementing rigorous evaluation methods, empowering individuals and their families, understanding better the multidimensional properties of context, and incorporating an explicit notion of professional responsibility. These transformational changes have been incorporated into IDD-related policies and suggested practices, including, for example, those promulgated by AAIDD and the Arc (see, e.g., AAIDD/The Arc, 2017; Luckasson et al., 2017).

Although the changes associated with this transformation have profoundly influenced people with IDD and their families, service delivery organizations and systems, clinicians, educators, and researchers, the transformation is currently at a critical juncture due to social, political, and financial challenges that will require future policy, practice, and research collaborative actions to ensure that the progress achieved to date is maintained and that there is further progress (see Luckasson & Schalock, 2020; The Arc, 2020; Thompson & Nygren, 2020).

Given the current and future significant challenges faced by the field of IDD, the purpose of this article is to describe nine characteristics of the transformation to date and suggest, based on the authors' experience and a synthesis of IDD-related literature, future actions that policy makers, service/support delivery organizations and systems, consumers, clinicians, educators, and researchers can take to enhance the on-going positive transformation in the field of IDD.

Precise Terminology

Terminology regarding intellectual disability (ID) and developmental disability (DD) has become more precise due to the close alignment of the definition of ID among AAIDD, DSM-5, and ICD-11 and the common use of the definition of DD promulgated through the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 2000 (Schalock & Luckasson, 2021). Specifically:

- **Intellectual disability** is defined, with slight variation among the above three organizations, as significant limitations both in intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates during the developmental period (Schalock et al., 2021).
- **Developmental disability** is defined as a severe, chronic disability that is attributable to a mental or physical impairment or a combination of mental or physical impairment; is manifest before the individual attains age 22; is likely to continue indefinitely; results in functional limitations in three or more major life activity areas; and reflects the individual's long-term need for a combination and sequence of special, interdisciplinary, or generic services and individualized supports (Developmental Disabilities Assistance and Bill of Rights Act Amendments of 2000). Some but not all people who meet the criteria for DD as set out in the DD Act of 2000 are considered to have ID (Havercamp et al., 2019). DD also includes people with physical disorders (such as cerebral palsy or spina bifida) and other disorders that emerge during the developmental period, such as Fetal Alcohol Spectrum Disorder and Autism Spectrum Disorder (AAIDD, 2017; Brown et al., 2017).

The **term IDD** is used as a broader, combined field of ID and DD (Schalock & Luckasson, 2021). Examples of the term's use include "persons with IDD"; "a bounded field of study, policy development, service/supports provision, and research" (e.g. "the field of IDD"); and organization names and journal titles where the focus is on both ID and DD (e.g., AAIDD, IASSIDD, AJIDD, IDD).

Action Steps:

- Assure continued alignment of definitions of ID and DD across diagnostic systems.
- Use precise terminology associated with ID, DD, and IDD.
- Use precise terminology and definitions in current and future documents, policies, and statutes related to ID, DD, and IDD.
- Continue to understand and clarify the similarities and differences between ID and DD.

Holistic Approach to IDD

A holistic approach to IDD is a way of thinking that establishes a clear foundation for multiple perspectives about human functioning rather than emphasizing professional disciplines. The holistic approach to IDD described below integrates the biomedical, psychoeducational, sociocultural, and justice perspectives on IDD. Each perspective has a philosophical foundation, represents a particular world view, explores the impacts of various risk factors, provides a theoretical basis for interventions and supports, and organizes relevant information into a usable form for increased understanding and more valid decisions and recommendations. As described in existing literature and synthesized by Schalock, Luckasson et al. (2018), the *biomedical perspective* emphasizes risk factors associated with genetic, chromosomal, biologic, or metabolic abnormalities, brain injury, or teratogens. Biomedical interventions and supports focus on specialized diets, genetic modifications, surgical procedures, pharmacology, and medical or mental health interventions. The *psychoeducational perspective* emphasizes risk factors associated with parenting; lack of early intervention; lack of opportunities for appropriate education, personal growth and development; and trauma. Interventions and supports focus on parenting skills, personal development strategies, counseling, special education, decision making supports, and information and assistive technology. The *sociocultural perspective* emphasizes risk factors related to societal attitudes, and impoverished or segregated environments. Interventions and supports focus on natural supports, changing public attitudes/perceptions, environmental enrichment, and environmental accommodations. The *justice perspective* emphasizes risk factors associated with social inequality, injustice, discrimination, and the denial of rights. Interventions and supports focus on rights affirmation (e.g., the UNCRPD; United Nations, 2006), person-centered planning, and advocating for just statutes, regulations, and judicial decisions.

There has been progress in integrating these four theoretical perspectives into IDD-related policies and practices. Specifically, we have seen:

- A clear focus on human functioning and the multiple factors that influence its expression, and an increased understanding that the locus of IDD is not just the person but the interaction between the person and multiple risk factors.
- A multiple perspectives approach to risk factors that incorporates risk factors associated with each perspective of IDD.
- A framework developed for directing specific support strategies towards identified risk factors and implementing systems of supports to prevent, mitigate, or ameliorate the risk factor and thereby enhance the individual’s functioning and well-being.
- The incorporation of the justice perspective into the field of IDD that has influenced the development of policies and practices to enhance human and legal rights.

Action Steps:

- Assure diversity within support teams so that multiple perspectives on IDD are included.
- Implement Personal Support Plans that incorporate, as relevant, interventions and supports that address the biomedical, psychoeducational, sociocultural, and justice aspects of disability.
- Develop a societal shared vision of valued, personal outcomes based on the multiple perspectives on IDD.
- Operationalize a multiple perspectives approach to etiology that incorporates biomedical, psychoeducational, sociocultural, and justice risk factors.

Functional Approach to IDD

A functional approach to disability has its origin in the *International Classification of Functioning, Disability, and Health* (ICF; WHO, 2001) and has been incorporated into the 10th, 11th, and 12th Editions of the AAIDD Manuals (Luckasson et al., 2002; Schalock et al., 2010; Schalock et al., 2021). As currently conceptualized, a functional approach to IDD encompasses a systems perspective towards understanding human functioning dimensions, interconnected systems of supports, and human functioning outcomes.

A functional approach to IDD has impacted the field in numerous ways. Chief among these are to: (a) better understand the constructs of adaptive behavior and intellectual functioning; (b) emphasize the interactive nature of human functioning dimensions, systems of supports, and human functioning outcomes; (c) provide a unified language that can be used across disciplines, organizations, and systems to promote public policies, professional standards, and organization practices; (d) facilitate the understanding of the social-ecological model of disability and the multilevel, multifactor, and interactive properties of context; (e) provide an operationalization framework to describe and analyze the impact of personal and contextual factors on human functioning outcomes; and (f) use the concept of human functioning as a measurable indicator of health.

Action Steps:

- Operationalize the role that human functioning (e.g., intellectual functioning and adaptive behavior) plays in defining and diagnosing a condition.
- Integrate a model of human functioning into clinical and professional practices and outcomes evaluation.
- Develop Personal Support Plans based on maximizing human functioning dimensions.
- Expand the current work on developing and evaluating indicators of each human functioning dimension.

The Supports Model

The supports model focuses on “the fit” between people and their environments, and conceptualizes disability as the expression of limitations in individual functioning within a social context. The model posits that: (a) disability is neither fixed nor dichotomized but rather can be fluid, continuous, and changing, depending on the person’s functional limitations and the supports available within the person’s environment; and (b) one can mitigate a person’s disability by designing interventions, services, and supports based on consumer participation and an understanding of disability that comes from lived experience and knowledge (Luckasson et al., 2002; Thompson et al., 2014).

The supports model has impacted the field of IDD in numerous ways. Chief among these has been to:

- Use standardized supports assessment scales to provide objective information about the pattern and intensity of support needs of children and adults across major life activity areas and exceptional medical and behavior support need categories (Stancliffe et al., 2016; Thompson et al., 2015, 2016).
- Expand our understanding that systems of supports are interconnected networks of resources and strategies that promote the development and interests of a person and enhance an individual’s functioning and personal well-being; are characterized as being

person-centered, comprehensive, coordinated, and outcome oriented; and encompass choice and personal autonomy, inclusive environments, generic supports, and specialized supports (Coulter, 2005; Schalock et al., 2019; Shogren et al., 2018; Stancliffe et al., 2016; Thompson et al, 2014).

- Develop supports standards based on values, facilitating conditions, and relationships (Buntinx et al., 2018; Onken, 2018; Qian et al., 2019).
- Implement Personal Support Plans that align an individual's support needs, personal goals, support strategies, and valued outcomes (Schalock, Thompson et al., 2018).
- Provide personalized service options such as self-directed supports enabled through 1115 or 1915 Medicaid Waivers (Bogenschutz et al., 2019; DeCarlo et al., 2019), and use empirically-based resource allocation methods (Agosta et al., 2016; Thompson et al., 2014, 2018).
- Implement horizontally structured support teams that assist support recipients in bridging to the community (Reinders & Schalock, 2014).

Action Steps:

- Use a supports-based assessment and classification system.
- Expand emphasis and techniques involved in environmental accommodation.
- Increase use of technology to reduce the discrepancy between the level of personal competency and environmental demands.
- Implement Personal Support Plans that are developed jointly with the person and their family and that align personal goals, assessed support needs and specific support strategies.

Evidence-Based Practices

Evidence-based practices (EBPs) in the field of IDD are interventions and supports that are based on current best evidence that is obtained from credible sources that used reliable and valid methods derived from a clearly articulated conceptual model, theory, or rationale (Drake, 2014; Satterfield et al., 2009; Schalock et al., 2017). The increased use of EBPs is reflected in clinical and professional practices related to diagnosis, classification, planning supports, and clinical judgment.

Diagnosis

The diagnosis of individuals with IDD is increasingly being based on the use of evidence obtained from standardized assessment instruments. For example, in the field of ID, two of the three criteria for a diagnosis of ID require demonstrating, based on a standardized assessment instrument, significant limitations in both intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical skills. The increased precision and validity of a diagnosis of ID has been significantly improved with the increased use of standardized instruments assessing adaptive behavior (Tassé et al., 2012, 2016, 2017; Tomaszewski et al., 2020).

Subgroup Classification

EBPs are used to establish subgroup classification bands and categories based on the standardized assessment of the intensity of support needs, the extent of adaptive behavior limitations in conceptual, social, and practical skills, or the extent of limitations in intellectual functioning. For specific examples see Arnold et al. (2014), Painter et al. (2018), Schalock & Luckasson (2015), Schalock et al. (2021), and Shogren, Shaw et al. (2017).

Planning Supports

The use of EBPs in the planning of supports incorporates support need assessment information, systems of supports, support standards, and Personal Support Plans that align assessed support needs, personal goals, specific support strategies, and valued outcomes. EBPs are also evident in the development and application of strengths-based supports (Thompson et al., 2017), and positive behavior supports (Carr & Horner, 2009; Dunlap et al., 2017).

Clinical Judgment

A clinical judgment framework is increasingly being used in the field of IDD to enhance the quality, precision, and validity of the clinician's decisions and recommendations in a particular case. Clinical judgment is operationalized through clinical judgment standards that are based on both explicit and implicit respect for the individual and specific and extensive knowledge of the person and his/her context. Clinical judgment standards require that the clinician use EBP in diagnosis, classification, and planning supports, and systematically collected and extensive data as the basis for making decisions and formulating recommendation (Luckasson & Schalock, 2015).

Action Steps:

- Implement clinical judgment standards in all clinical activities.
- Select and implement validated evidence-based interventions and support strategies, recognizing the different levels of evidence that include causal, indicative, descriptive, and theoretical.
- Implement measurement standards regarding the quality, robustness, and precision of the evidence.
- Operationalize current perspectives on evidence that include the empirical-analytical, phenomenological-existential, and post-structural.

Outcome Evaluation

Over the last five decades, the field of IDD has seen the increased expectation that the outcomes of policies and practices be measured and evaluated. Outcome evaluation has emerged as a systematic endeavor to accomplish this objective. As an evolving area in the field of IDD, there is an emerging consensus that outcome evaluation: (a) involves a collaborative partnership among an individual and an IDD service/support organization or system that is committed to the measurement and use of outcome information, and a team that has the knowledge, skills, and resources to contribute to the evaluation; and (b) requires a conceptual model and measurement framework, and a clear understanding of the impacts of the evaluation.

Conceptual Model and Measurement Framework

There are a number of conceptual models and measurement frameworks that have emerged to guide and drive outcome evaluation. Two commonly used *conceptual models* are those related to human functioning (e.g., Dinora et al., 2020; Esbensen et al., 2017; Luckasson & Schalock, 2013; Schalock et al., 2021; Stucki & Bichenbach, 2019), and quality of life/ personal well-being (e.g., Bradley & Moseley, 2007; Claes et al., 2012 ; The Council on Quality and Leadership, 2017; Gomez & Verdugo, 2016; Lombardi et al., 2019). These two conceptual models are associated closely with a functional and holistic approach to IDD, the supports paradigm, and EBP. Measurement frameworks that are aligned with these two conceptual models involve, respectively, human functioning dimensions and quality of life domains and personal well-being indicators.

Impacts

The impacts of outcome evaluation are embedded in the intended use of outcome information. Specifically, outcome information can be used to: (a) be more transparent through collaborative planning, assessment, and decision making (Horner, 2020); (b) be more accountable through reporting outcome information to individuals, families, organization personnel, and systems-level funders and regulators (Azzam & Levine, 2015); (c) expand our understanding of the factors that influence person-referenced outcomes through inferential and contextual analysis (Schalock & Luckasson, 2020; Shogren et al., 2020); and (d) enhance personal well-being (Shogren et al., in press).

Action Steps:

- Develop a shared vision of desired outcomes for people with IDD in the society.
- Incorporate into public and organization/system policies best practices related to the alignment of personal goals and support needs, individualized systems of supports, and conceptual model-based valued outcomes.
- Use outcome information to increase transparency and accountability.
- Incorporate an understanding of the factors that affect person-referenced outcomes into interventions and supports that enhance human functioning and personal well-being.

Understanding Context

The importance of context and its role in human functioning has been referenced in the AAIDD's *Terminology and Classification Manuals* since 2002 (Luckasson et al., 2002; Schalock et al., 2010; Schalock et al., 2021), and in the *International Classification of Functioning, Disability, and Health* (ICF, World Health Organization, 2001). The role that context plays in disability policy development, implementation, and evaluation has also been discussed by Buntinx (2006), Turnbull and Stowe (2017), and Verdugo et al. (2017). Despite the widespread use of the term "context" in the disability field, until recently there has been a limited understanding of—and specificity regarding—the term. As described next, recent work has increased our understanding of its operational uses and its multidimensional properties.

Operational Uses

Based on an extensive synthesis of current IDD-related literature (Shogren et al., 2017) context can act an independent variable, an intervening variable, or an integrative framework. As an *independent variable*, context includes personal factors that are not usually manipulated such as age, language, culture and ethnicity, and family. As an *intervening variable*, context includes organizations, systems, and societal policies and practices that can be manipulated to enhance human functioning. As an *integrative concept*, context can be used to describe and analyze context-based phenomena that affect human functioning; for supports planning and policy development; to delineate the context-based phenomena that effect, both positively and negatively, human functioning; and to unfreeze the status quo and produce change (Shogren et al., 2018, 2020).

Multidimensional Properties

The complexity of context is captured through a multidimensional model of context that explains the multilevel, multifactorial, and interactive properties of context (Schalock et al., 2020; Shogren et al., in press).

- The *multilevel property of context* includes the ecological systems (i.e., micro, meso, and macro) within which people live, learn, work, and enjoy life. The individual and these systems interact over time and thereby influence human functioning and personal outcomes differentially over time.
- The *multifactorial property of context* includes the potentially influential factors within the ecological systems. Some of these factors (e.g., age, language, culture and ethnicity, and family structure) are not typically manipulated or changed to enhance outcomes but need to be understood in order to design and deliver effective services and supports. Other influencing factors (e.g., policies and practices) can be changed to achieve disability policy goals and enhanced functioning and personal outcomes.
- The *interactive property of context* includes the variety of ways in which levels and factors interact to influence human functioning and personal outcomes. Examples include the reciprocal influence of the person on the micro, meso, and macro level factors reflected in supported employment, supported living, inclusive education, and aging in place.

Understanding the operational uses and multidimensional properties of context has impacted the field of IDD in numerous and significant ways. Although the impacts of this understanding are just emerging in the field, there is evidence of its application in the areas of human functioning and health (e.g., Stucki & Bickenbach, 2019), disability policy development and implementation from a cross-cultural perspective (e.g., Verdugo et al., 2017), outcome evaluation (e.g., Gomez et al., 2020), contextual analysis (e.g., Shogren et al., 2020; Verdugo et al., 2017), and context-based change models (e.g., Shogren et al., 2018).

Action Steps:

- Apply the multilevel, multifactorial, and interactive properties of context in policy development and outcome evaluation.
- Use context-based influencing factors as independent or intervening variables in multivariate research designs and outcome evaluation studies.
- Apply an understanding of context to unfreeze the status quo and drive change in organization and systems-level policies and practices.
- Use the construct of context to integrate micro, meso, and macro level factors that affect human functioning and personal well-being.

Empowering Individuals and Their Families

The origin of this transformation characteristic can be traced back to a number of significant events that occurred during the 1970s and 1980s. In the 1970s, the Pilot Parents Program, the Consortium for Citizens with Disabilities, the Coalition of Citizens with Disabilities, and the Centers for Independent Living were founded; the Social Security Amendments of 1972, the DD Act of 1970, the Education of All Handicapped Children Act of 1975, and the Rehabilitation Act Amendments of 1973 were passed by Congress; and the first convention of People First was held. In the 1980s, funding of family supports was authorized, which was augmented later through self-directed service options such as self-directed supports that were enabled through 1115 or 1915 Medicaid Waivers (Bogenschutz et al., 2019; Friedman, 2018). Throughout this formative period, advocacy groups and organizations such as People First, Inclusion International, The Arc, and AAIDD advocated for legislation and supported litigation as “Friends of the Court” in major deinstitutionalization and right to treatment cases brought by the Civil Rights Division of the US Department of Justice.

Although it is beyond the scope of this article to discuss all of the significant impacts of empowering individuals and their families, most readers will be familiar with the following impacts. These include the increased participation of students and adults with IDD and their families in Person-Centered Planning and developing education programs and support plans; the active involvement and influence of self-advocates in policy formation and service provision; the increased use of self-directed funding and individual budgets; the active participation of people with IDD in Participatory Action Research models; and the key role that self-advocates and families have played in formulating the IDD-related policies.

Action Steps:

- Ensure that individuals and their families are involved in the development, implementation, and evaluation of Personal Support Plans.
- Assure legal and ethical structures that support the empowerment, dignity, value, and personal autonomy of people with IDD and avoid unnecessary guardianships.
- Help families advocate for and support a family member with a disability to achieve community membership.
- Collaboratively develop measurable support strategies that align UNCRPD articles to support provision and outcome evaluation.

Explicit Notion of Professional Responsibility

Professional responsibility incorporates EBPs, professional ethics, professional standards, and clinical judgment (Luckasson & Schalock, 2015). *Evidence-based practices* are predicated on current best evidence that is obtained from credible sources that used reliable and valid methods derived from a clearly articulated and empirically validated theory or rationale.

Professional ethics, which mandate a system of moral conduct are reflected in the principles of justice, beneficence, and autonomy. *Professional standards* are characterized by competence (i.e., using best and up-to-date practices), respect (i.e., giving focused attention to the person, showing concern for the individual, respecting the person's human and legal rights, and engaging in person-centered practices that facilitate the individual's health and well-being), and balance (i.e., guiding values, sensitivity to others, and understanding contextual factors that affect human functioning and personal outcomes). *Clinical judgment* is a special type of judgment that is built on respect for the person, and emerges from the clinician's training and experience, specific knowledge of the person and their context, analysis of extensive data, and the use of critical thinking skills.

Professional responsibility encompasses many aspects of the ongoing transformation in the field of IDD. Specifically, professional responsibility involves: (a) employing a holistic framework that incorporates the multiple perspectives on IDD and the multidimensionality of human functioning that leads to a better understanding of IDD; (b) providing or procuring needed and relevant systems of supports; (c) employing evidence-based practices to increase the effectiveness of interventions and to enhance personal outcomes; (d) using clinical judgment to enhance the quality, validity, and relevance of decisions and recommendations; (e) envisioning valued outcomes for people with IDD so as to place the person with IDD at the center of the support delivery system; and (f) using precise terminology that increases clarity of thinking and communication (Schalock et al., 2021).

Action Steps:

- Develop a Code of Professional Responsibility for the field of IDD based on EBPs, professional ethics, professional standards, and clinical judgment.
- Expand technology-based knowledge transfer, platforms, and EBPs registries..
- Integrate professional responsibility into training programs and on-site technical assistance.
- Incorporate the biomedical, psychoeducational, sociocultural, and justice perspective of IDD into professional training programs.

Conclusion

Successfully implementing the suggested next steps associated with each transformation characteristic will involve a collaborative effort among individuals with lived experience, advocates, policy makers, funding and regulatory bodies, service/support providers, and researchers. Many of the suggested steps/actions, such as incorporating theoretical perspectives on IDD, a functional approach to IDD, and specific desired valued outcomes, will require *policy initiatives*. Other suggested actions, such as incorporating a better understanding of the multidimensional properties of context, using technology for knowledge transfer, developing Personal Support Plans that align assessed support needs, specific support strategies, and personal outcome domains, and systematically assessing valued outcomes will require *practice innovations*. Other steps/actions, such as conducting cross-cultural Delphi studies to produce a consensus model and framework for aligning UNCRPD Articles to specific support strategies and valued personal outcome categories, identifying specific evidence-based support strategies that facilitate human functioning dimensions, expanding our understanding of the properties of context, and developing practice guidelines to evaluate evidence will involve *research endeavors*. Still other, such as developing an interdisciplinary code of professional responsibility will require collaborative efforts by professional organizations.

As described in this article, significant progress has occurred over the last five decades in the field of IDD. Changes associated with this transformation have profoundly influenced people with IDD and their families, organizations, service/support delivery systems, and IDD-related policies and practices. Despite these positive changes, further policy, practice, and research actions will be required, however, to facilitate and sustain the field’s transformation.

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