

# Intellectual and Developmental Disabilities

## Professional Responsibility in the Field of Intellectual and Developmental Disabilities: Its Definition, Application, and Impacts --Manuscript Draft--

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<b>Abstract:</b>	<p>This article addresses the need to clearly understand professional responsibility and the critical role it plays in the lives of individuals with intellectual and developmental disabilities (IDD), in shaping professions for the better, and in enhancing the functioning of society for the benefit of all. This is especially timely during the current transformation in the field of IDD. We discuss what is a profession, who is a professional, and what is professional responsibility. Using a logic model framework, the article describes the components of professional responsibility; its use of nine professional practices; its outcomes in terms of mutual trust, the improved effectiveness of clinical functions, and professional accountability; and its impacts regarding individual benefit, professional integrity, and societal enhancement.</p>

## TITLE PAGE

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## **Professional Responsibility in the Field of Intellectual and Developmental Disabilities: Its Definition, Application, and Impacts**

Professionals are involved in a number of significant roles in the lives of people with intellectual and developmental disabilities (IDD) and their families. Chief among these roles, which have evolved over time, are those related to defining, diagnosing, classifying, and planning and implementing personalized supports and services. As these roles continue to evolve and become even more important in peoples' lives during the current transformation in the field of IDD (Schalock et al., in press; Thompson & Nygren, 2020), there is an increasing need to understand clearly what is a profession; who is a professional; what is professional responsibility; what are the building blocks of professional responsibility; how is professional responsibility applied through professional practices; what are the outcomes of professional responsibility; and what are the impacts of professional responsibility? Answering these seven questions is the purpose of this article.

The approach we use to define and apply professional responsibility is based on the *Professional Responsibility Logic Model* presented in Figure 1. Logic models, with their input, throughput, outcome, and output/impact components are commonly used as an organizing framework to articulate the relationship among a phenomenon's components and provide the basis for understanding their application. In reference to the latter two components (outcome and output/impact), outcome is defined operationally as changes that result from the input and throughput components of the professional responsibility model, whereas output is defined

operationally as long-term impacts of the input, throughput, and outcome components (Gomez, Schalock, & Verdugo, 2020).

<Figure 1>

### **Definitions of Profession, Professional, and Professional Responsibility**

A *profession* is an occupation that is the result of structured, specialized preparation; is based on skills and knowledge; is guided by professional standards; and focuses on obligations to others, one's profession, and one's society. A *professional* is one who engages in a learned profession and who: (a) successfully completes a structured sequence of education or specialized training; (b) meets high and exacting standards of knowledge, performance, and conduct; (c) passes the internal monitoring by the profession itself; (d) fulfills one's obligations to clients and other professionals; and (e) earns the trust of society for members of their respective profession. *Professional responsibility* is the obligation to use and be accountable for professional practices, client goals, and professional duties. In the field of IDD, professional responsibility: (a) is built on respect for the individual, professional ethics, professional standards, critical thinking skills, and clinical judgment (Schalock & Luckasson, 2014); (b) involves using professional practices; and (c) focuses on enhancing the individual's valued outcomes, facilitating a profession's socially responsible development and integrity, and contributing to a stronger society.

### **What are the Building Blocks of Professional Responsibility?**

Professional responsibility is built on respect for the person, professional ethics, professional standards, critical thinking skills, and clinical judgment. We are precise about what professional responsibility is; it is not about creating a common set of specific standards and ethics that every discipline must abide by. We regard professional responsibility as the overarching idea, no matter the discipline, containing the building blocks of respect, ethics,

standards, critical thinking skills, and clinical judgment. Although different disciplines relevant to the field of IDD often have slightly different codes of ethics and practice standards, members of each are accountable for professional responsibility and its five building blocks. Each of these building blocks is described in this section of the article, along with a listing of the professional responsibility and obligations associated with the respective building block.

### **Respect for the Person**

Professional responsibility starts with a posture of deep respect for the person. Respect is characterized by 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 that person's human functioning and valued outcomes.

When professional practices are built on respect for the individual, then the diagnosis one makes is more likely to be based on best practices in the assessment of intellectual functioning and adaptive behavior. Similarly, respect for the individual promotes selection of an optional subgroup classification process that has a clearly defined and relevant purpose, is based on valid information, and is used to understand better the function of the specified purpose of the subgroup classification. Analogously, when one bases their professional practices on respect for the individual, planning, implementing, and evaluating systems of supports is based on the individual's assessed support needs, personal goals and interests, and support strategies that are individually referenced and outcome focused.

As a building block of professional responsibility, respect for the individual obligates the professional to:

- Ensure respect for personal autonomy.

- Inform the individual about important matters in their lives and the relevance of the information being obtained.
- Involve the person in the development and implementation of services and supports.
- Provide or procure opportunities for increased personal development, interpersonal relations, social inclusion, and community inclusion.
- Attend to the individual's needs to feel safe and secure, to have positive experiences, to be free of excessive stress.
- Attend to the person's well-being, including their health, safety, and bodily integrity such as obtaining valid consent prior to intervening with an individual.
- Provide or facilitate opportunities for the person to enhance their material well-being, including financial status, employment status, living arrangements, and personal possessions.

### **Professional Ethics**

Professional ethics are a system of moral behavior and rules of conduct recognized in respect to a particular class of human actions or a particular group. As a building block of professional responsibility, ethics obligates the professional to:

- Treat all people equitably (i.e., justice)
- Do good (i.e., beneficence)
- Respect the authority of every person to control their actions (i.e., autonomy)

Examples of these professional ethics are included in the codes of ethics published by The National Alliance of Direct Support Professionals (NADSP) and The American Psychological Association (APA). In reference to NADSP, their Code of Ethics (NADSP, 2016) defined the principle of "justice" as follows: "*As a DSP, I will affirm the human rights as well as*

*the civil rights and responsibilities of the people I support. I will promote and practice justice, fairness, and equity for the people I support and the community as a whole”* (p. 5). In reference to the Ethical Principles for Psychologists and Code of Conduct [Code of Conduct; APA, 2017], justice is defined in Principle “D” and stipulates the obligation of all psychologists to recognize that fairness and justice entitle all persons to equal quality in the processes, procedures, and services conducted by psychologists.

The APA defined “beneficence” as striving to do no harm and endeavoring to deliver services that benefit those with whom they work. Similarly, the NADSP Code of Ethics stipulated the obligation of DSPs to promoting the emotional, physical, and personal well-being of the people they support.

The “autonomy” principle is defined in the APA Code of Conduct as ensuring the respect for people’s rights and dignity and guides psychologists to respect the dignity and worth of all people, and the rights of individuals to privacy, confidentiality, and self-determination. The NADSP Code of Ethics stipulated that the mission and vitality of their profession is to assist people in leading self-directed lives.

### **Professional Standards**

Professional standards provide the basis for developing professional training curricula, evaluating the everyday practices of members of a profession, preparing personnel, enforcing rules of conduct, and accreditation. As a building block of professional responsibility, professional standards obligate the professional to:

- Use current information and valid information-gathering strategies.
- Demonstrate profession-related skills, knowledge, and competencies.
- Respect client and professional relationships.

- Assure consent and assent (including the elements of capacity, information, and voluntariness).
- Use personal information properly.
- Avoid any conflict of interests.
- Recognize one's level of competence in specific areas and act only in areas of expertise.

### **Critical Thinking Skills**

Critical thinking skills are an essential building block for both professional responsibility and professional practices. Although definitions vary widely, over the years we have identified five critical thinking skills that incorporate the critical thinking activities that enhance the professional's effectiveness and efficiency (e.g. Schalock & Luckasson, 2014). These five skills involve analysis, alignment, synthesis, systems thinking, and transformational thinking. Their definitions and exemplary uses are summarized below.

- *Analysis involves examining and evaluating component parts of a phenomenon.*  
Examples of using analysis include evaluating the extent and relevance of historical information, the quality of the assessment information, and the consistency of information; weighing any contradictory explanation for findings; and understanding the limits of anecdotal evidence.
- *Alignment involves placing or bringing clinical functions into a logical sequence.* In classification, for example, alignment allows professionals to logically sequence relevant data sets to the subgrouping's purpose, the data-driven procedures used to establish the subgroup classification categories employed, and the empirically based subgroup classification bands used to establish the subgroup classification categories. In supports

planning and provision, alignment allows professionals to logically sequence assessed support needs and personal goals with specific support strategies and desired outcomes.

- *Synthesis involves integrating information from multiple sources.* In diagnosis of either intellectual disability (ID) or developmental disabilities (DD), for example, synthesis involves integrating current assessment information with historical data, and includes addressing possible reasons for the inconsistency in the obtained information and recognizing the factors that affect assessment results. In planning supports, synthesis involves integrating information from multiple sources in light of the individual's values, beliefs, judgment, strengths, personal goals, contextual factors, and current circumstances.
- *Systems thinking involves focusing on the multiple systems that affect human functioning and personal well-being.* At the microsystem level, human functioning and personal well-being are influenced by factors related to the person and the individual's family, close friends, and colleagues; at the mesosystem level, by community and organizational factors; and at the macrosystem level, by the larger society, including societal attitudes and cultural mores and folkways.
- *Transformational thinking involves expanding one's thinking and practices to accommodate transformational changes.* These changes require expanding one's thinking and practices especially at the individual and organizational levels. For example, at the individual level, people with IDD and their families are increasingly involved in policy formulation and decision making, shared responsibilities in outcome evaluation, and team membership in supports planning and monitoring. At the organization level, service support organizations are becoming more laterally structured, team focused, outcome

oriented, and committed to providing individualized supports within community-based environments.

### **Clinical Judgment**

Clinical judgment is defined as a special type of judgment built upon respect for the person. Clinical judgment emerges from the professional's specialized training and experience, specific knowledge of the person and their context, extensive data, and the use of critical thinking skills (Luckasson & Schalock, 2015; Schalock & Luckasson, 2014). Clinical judgment underscores the importance of using thinking strategies that are: systematic (i.e., organized, sequential, and logical); formal (explicit and reasoned); and transparent (i.e., apparent and openly communicated).

As a building block of professional responsibility, the use of clinical judgment obligates the professional to:

- Clarify and state precisely the question before the professional and determine if the question relates to diagnosis, classification, or planning supports. This practice allows the professional to identify needed activities and align data collection efforts to the critical question(s) at hand.
- Conduct or access a thorough history of the individual, including a thorough social history, medical history, and educational history. This practice provides an understanding of the personal and contextual factors that affect disability
- Conduct or access broad-based assessments. Effective clinical judgment requires incorporating data from a variety of relevant assessments that are valid and reliable for the questions asked. Sometimes, however, in rare cases when information obtained from standardized assessment instruments does not validly answer the question(s) asked

because of lack of opportunity, lack of appropriately normed tests, significant functional limitations of the person, contradictory information, and/or linguistic factors, additional assessments (e.g. a functional analysis of behavior) may be required along with a heightened reliance on clinical judgment.

- Synthesize the obtained information. This procedure results in information that is used to:
  - (a) generate and test hypotheses; (b) consider the relative weight and possible combination of information as a basis for decisions and recommendations; and (c) improve the quality, validity, and precisions of decisions, recommendations, and actions.

### **What are Professional Practices in the Field of IDD and How are They Applied?**

Professional responsibility in IDD is applied through professional practices that incorporate the above building blocks (respect for the individual, professional ethics, professional standards, critical thinking skills, and clinical judgment) and the transformational changes that are occurring in the field of IDD. As described by Schalock et al. (in press), these changes involve using more precise terminology, incorporating a functional and holistic approach to IDD, embracing the supports model and evidence-based practices, implementing outcome evaluation, empowering individuals and their families, and understanding better the multidimensional properties of context.

The changes associated with this transformation are profoundly influencing people with IDD and their families, organizations and systems, educators, and researchers. As discussed by Luckasson and Schalock (2020), The Arc (2020), and Thompson and Nygren (2020), the transformation is currently at a critical juncture due to social, political, and financial challenges, and will require professional practices to ensure that the progress achieved to date relative to individuals and the field of IDD is maintained and enhanced. The nine professional practices

described in this section of the article describe how professionals can contribute to this goal by incorporating into their professional practices the building blocks of professional responsibility and the transformational changes described above.

### **Empowerment**

Increased recognition of the empowerment of people with IDD and their families has affected each of the professional practices discussed in this section of the article. Because of the changes in public and organization policies, one sees 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; and the active participation of people with IDD in Participatory Action Research (PAR). This increased empowerment of people with IDD and their families requires that professional practices:

- Ensure that individuals and their families are involved in the development, implementation, and evaluation of Individualized Education Programs and Personal Support Plans.
- Assure legal 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 personalized support strategies that align the United Nations Convention on the Rights of People with Disabilities (UNCRPD; United Nations, 2006) Articles to supports provision and personal outcome measures.

## Precise Terminology

Professional practices incorporate precise terminology to establish and communicate the parameters of a condition, and operationalize the criteria used to validly determine its presence. Within the field of IDD, terminology has become more precise regarding the terms intellectual disability, developmental disabilities, and intellectual and developmental disabilities.

Specifically:

- **Intellectual disability** is defined 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, which is defined operationally as before the individual attains age 22 (Schalock et al., 2021).
- **A 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, 2000). Some but not all people who meet the criteria for a diagnosis of developmental disability as set out in the DD Act of 2000 are considered to have intellectual disability (ID). As discussed by Havercamp et al. (2019) and Larson et al. (2001), persons with developmental disabilities (DD) also include 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/The Arc, 2017; Brown et al., 2017).

- **Intellectual and Developmental Disabilities (IDD)** is used as a broader, combined field of ID and DD (Schalock & Luckasson, 2021). Examples of the term's use include "people 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, AJIDD, IDD).

The use of precise terminology results in professional practices that:

- Align definitions of ID, DD, and IDD across diagnostic systems and professions.
- Express clearly the meaning of ID, DD, and IDD.
- Incorporate precise terminology and definitions in current and future documents, policies, and statutes.
- Recognize similarities and differences between ID and DD.

### **Broad-Based Assessments**

The transformational changes occurring in the field of IDD have resulted in an expanded notion of what constitutes relevant assessment and evaluation of people with IDD. A "broad-based assessment" encompasses (a) assessing intellectual functioning, adaptive behavior, and origination during the developmental period, (b) establishing the pattern and intensity of support needs across major life activity and exceptional medical and behavioral areas, (c) analyzing and synthesizing information from social, medical, and educational histories, (d) evaluating the risk factors associated with the multiple perspectives on IDD, (e) analyzing the contextual factors that influence human functioning and personal well-being, and (f) assessing changes in human functioning and indicators of personal well-being that follow the receipt of personalized services and supports. Conducting broad-based assessments will not only result in information that increases the precision, validity, and scope of the professional's clinical judgment, decisions and

recommendations, but will also provide information that can be used to develop effective personalized services and supports and target service/support areas for continuous quality improvement.

Specific details regarding these broad-based assessments are discussed in those professional practices discussed on subsequent pages related to a holistic approach to IDD, contextual analysis, evidence-based practices, individualized supports, and person-centered evaluation (see also “clinical judgment” in the preceding section). The importance of identifying broad-based assessments as a separate professional practice is that it encourages professionals to employ an integrative approach to their understanding of IDD and perform relevant assessment/evaluation activities.

### **Functional Approach to IDD**

A functional approach to IDD involves a systems perspective towards understanding human functioning, which includes human functioning dimensions, interactive systems of supports, and human functioning outcomes (Luckasson & Schalock, 2013; Schalock et al. 2021). Incorporating a functional approach into professional practices results in those practices: (a) reflecting a better understanding of the constructs of adaptive behavior and intellectual functioning; (b) emphasizing the interactive nature of human functioning dimensions, systems of supports, and human functioning outcomes; (c) providing a unified language that can be used across disciplines, organizations, and systems to promote public policies, professional standards, and organization practices; (d) facilitating the application of the social-ecological model of disability and the multilevel, multifactor, and interactive properties of context; and (e) providing a framework to describe and analyze the impact of personal and contextual factors on human functioning outcomes.

The use of a functional approach to IDD results in professional practices that:

- Focus on the five dimensions of human functioning that include intellectual functioning, adaptive behavior, health, participation, and context.
- Implement systems of supports that are an interconnected network of resources and strategies that promote the development and interests of a person and enhance the individual's functioning and personal well-being.
- Use a comprehensive framework to evaluate human functioning outcomes related to intellectual functioning/executive functions, adaptive behavior skills, physical and emotional status, involvement and engagement, and context-based opportunities.

### **Holistic Approach to IDD**

A holistic approach to IDD provides a framework for approaching human functioning and personal well-being from biomedical, psychoeducational, sociocultural, and justice perspectives. 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.

Integrating these four perspectives into one's professional practices results in those practices:

- Providing a clear focus on the multiple factors that influence human behavior, and an increased understanding that the locus of IDD is not just the person but the interaction between the person and multiple risk factors.
- Incorporating a multiple perspectives approach to identifying risk factors associated with each perspective on IDD (see above).
- Implementing specific support strategies that prevent, mitigate, or ameliorate the identified risk factor(s) associated with each perspective (see above).
- Emphasizing the justice perspective to influence the development of policies and practices to enhance human and legal rights.
- Assuring diversity within support teams so that multiple perspectives on IDD are included in the development and implement of education and support plans.
- Operationalizing a shared and holistic vision of valued, personal outcomes that incorporate the multiple perspectives on IDD.

## Contextual Analysis

Professional practices need to go beyond the historical concept of person-environmental fit or interaction to the *transformative concept of the individual in a context*, and how an understanding of context and contextual factors can be leveraged to enhance human functioning and personal well-being. As described and discussed by Shogren et al. (2018, 2021), context can act as 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 and personal well-being. As an *integrative concept*, context can be used to: (a) describe and analyze context-based phenomena that affect human functioning and personal well-being; (b) develop policies and practices; (c) delineate the context-based phenomena that effect, both positively and negatively, human functioning and personal well-being; and (d) unfreeze the status quo and produce change.

The complexity of context is captured through a multidimensional model of context that explains the multilevel, multifactorial, and interactive properties of context (Shogren et al., 2021). 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 factors within 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 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 and addressing the multidimensional properties of context and applying that understanding to people with IDD and the organizations and systems with whom they interact is facilitated through the use of *contextual analysis*. Contextual analysis is an analytic and measurement method that allows professionals and support teams to implement context-based professional practices. These practices involve identifying contextual factors that influence human functioning and personal outcomes, targeting contextual factors that bring about change, and building contexts that leverage the power of context to produce change.

- *Identifying contextual factors.* Contextual factors that influence human functioning and personal outcomes can operate at the micro, meso, and/or macrosystem levels. For example, at the microsystem level, some of these factors, such as age, language, culture and ethnicity are relatively unchangeable, whereas personal strengths/assets, level of function within human functioning dimensions, availability of individualized supports, and self-advocacy are. At the mesosystem level, contextual factors such as social networks, environmental accommodation, systems of supports, person-centered organization policies and practices, and transportation availability strongly influence human functioning and personal outcomes. At the macrosystem level, influencing contextual factors include opportunities for increased independence, productivity, and community integration; community access and participation; living and employment

supports; justice and fairness in the legal system; and societal attitudes and public policies.

- *Targeting contextual factors.* This practice requires an understanding of the interactive component of the multidimensional model of context described above. An interaction is a reciprocal action or influence that occurs between multilevel and multifactor contextual variables. Because some of these interactions may be more preferable than others, and some easier to address or change than others, there needs to be a partnership among the individual, the professional, and the person's support team in selecting which contextual factors to target. For example, the team may target the availability of supports (micro-system) to facilitate communication to facilitate inclusive education or self-advocacy (meso), or they may target opportunities in inclusive environments to increase productivity and community integration (macro) by providing augmentative communication systems or decision-making skills (micro).
- *Building contexts.* Once the contextual factors are identified and targeted, then interventions and supports focus on unfreezing the status quo and actually bringing about the desired change. This is done through implementing a *context-based change model* that begins with contextual analysis and proceeds to planning, doing, and evaluating. A description of this model with specific process actions steps is presented in Shogren et al. (2018).

### **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). EBPs are incorporated into professional practices related to diagnosis, subgroup classification, planning supports, and evaluating personal outcomes.

- The diagnosis of individuals with IDD is based on the use of evidence (i.e., objective scores) obtained from the reliable and valid standardized assessment of intellectual functioning and adaptive behavior.
- Subgroup classification is based on the use of EBPs 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.
- Planning supports is based on scores from standardized support needs assessment instruments, strength-based and positive supports (Carr & Horner, 2009; Dunlap et al., 2017; Thompson et al., 2017), and support standards (Buntinx et al., 2018).
- Outcome evaluation, which is based on a conceptual model of human functioning and/or personal well-being, employs reliable and valid evaluation strategies that are objectified through a partnership among the individual, human service organization or system, and a team of which the individual with IDD is a member.

### **Individualized Supports**

Individualized supports are operationalized within a supports model that focuses on the fit between people and their contexts, 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 is fluid, continuous, and changing, depending on the person's functional limitations and the supports available within the person's context; and (b)

one can mitigate a person's disability by designing interventions, services, and supports based on client 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 professional practices in numerous ways. When one incorporates the supports model into professional practices in IDD, these practices:

- Incorporate scores from standardized supports assessment scales to provide objective information about the pattern and intensity of support needs of the individual across major life activity areas and exceptional medical and behavioral support need categories (Stancliffe et al., 2016; Thompson et al., 2015, 2016).
- Use systems of supports that 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 (Schalock et al., 2021; Stancliffe et al., 2016; Thompson et al., 2014).
- Reflect support standards that are based on values, facilitating conditions, and support relationships (Buntinx et al., 2018).
- Facilitate the development of Individualized Program and Personal Support Plans that are developed by person-centered support teams and align an individual's support needs, personal goals, support strategies, and valued outcomes (Schalock, Thompson et al., 2018).

### **Person-Centered Outcome Evaluation**

IDD-related policies and practices incorporate the expectation that the outcomes of policies and practices should be evaluated. Person-centered outcome evaluation has emerged as a systematic endeavor to accomplish this objective. There is an emerging consensus that person-centered 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; (b) requires a conceptual model and measurement framework; and (c) results in outcome information that is used for multiple purposes (Schalock & Luckasson, in press).

The focus on person-centered outcome evaluation has impacted professional practices in a number of ways. Chief among these are to:

- Incorporate a conceptual model that operationalizes a shared vision of desired outcomes for people with IDD.
- Implement a measurement framework to assess human functioning and personal outcomes. There are a number of conceptual models and measurement frameworks that can be used to guide and drive this professional practice. 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 provision of individualized supports, and evidence-based practices.
- Use outcome information for multiple purposes. Chief among these are to: (a) be more transparent through collaborative planning, assessment, and decision making (Schalock

& Luckasson, in press); (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 contextual factors that influence human functioning and personal outcomes (Schalock, Luckasson et al., 2020; Shogren et al., 2020); (d) enhance human functioning and personal well-being through continuous quality improvement (Reinders & Schalock, 2014; Shogren et al., 2021; and (e) use the established relation between interventions and outcomes as a basis for evidence-based practices (Schalock et al., 2017).

### **What Are the Changes and Results of Professional Responsibility?**

#### **Mutual Trust**

A major outcome of professional responsibility is the establishment and maintenance of mutual trust. An often-unspoken *quid pro quo* relationship between the individual and the professional characterizes professional responsibility. Individuals, families, community members, and society grant to members of a profession respect, the opportunity to practice their valued career, and rewards such as employment, high status, and fees. In return, they expect that: (a) professional responsibility includes respect for the individuals, professional ethics, professional standards, critical thinking skills, and effective clinical judgment; and (b) that members of the profession successfully complete a structured sequence of professional education; meet high and exacting standards of knowledge, performance and conduct; pass the internal monitoring by the profession itself; and fulfill their obligation to clients and other professionals. Meeting the mutual expectations of these relationships leads to the outcome of mutual trust that is experienced by the individual, family, community, and society.

#### **Improved Effectiveness of Clinical Functions**

Professionals in IDD are involved either directly or indirectly in clinical functions related to diagnosis, classification, and/or planning and implementing personalized services and supports. The effectiveness of these clinical functions is determined by the degree to which they are accurate, valid, and reliable. In that regard, the desired result of the diagnostic process is to produce an accurate, reliable, and valid diagnosis that enhances the precision and relevance of the clinician's decisions and recommendations. In classification, the desired result is a better understanding of the person and their needs. In supports planning and implementation, the desired result is to enhance human functioning and personal well-being through providing resources and strategies that promote the person's development and interests.

The effectiveness of these clinical functions is improved through incorporating the building blocks of professional responsibility and implementing professional practices that are evidence-based and responsive to the current transformation in the field of IDD. Specifically, the accuracy, validity, and reliability of the clinician's diagnosis is improved when (a) the diagnosis is based on scores from appropriate standardized assessment instruments and review of social, medical, and educational histories, (b) the 95% confidence interval is used (in reference to intellectual functioning and adaptive behavior) to establish the score interval within which the individual's true score falls, (c) the age of onset of the disability is verified to have occurred during the developmental period, and (d) equal weight is given to intellectual functioning and adaptive behavior in the diagnosis of ID. The effectiveness of the subgroup classification system used is improved when the clinician: (a) establishes the primary purpose for classification, which is to better understand the individual and that person's needs, (b) uses an explicit framework and a systematic process to subdivide the group with the disability into smaller groups, (c) aligns relevant data sets to the subgrouping's purpose, and (d) classifies or groups on the basis of the

standardized assessment of the intensity of support needs, the extent of limitations in conceptual, social, and practical adaptive skills, and/or the extent of limitations in intellectual functioning. The effectiveness of supports planning and implementation is improved when the personalized services and/or supports: (a) are based on a standardized assessment of the pattern and intensity of support needs, (b) are built on values, facilitating conditions, and support relationships, (c) incorporate choice and personal autonomy, inclusive environments, generic supports, and specialized supports, (d) integrate and align personal goals, support needs, and valued outcomes, (e) are person-centered, comprehensive, coordinated, and outcome oriented, and (f) are coordinated through a personalized supports plan that focuses on human functioning dimensions and/or quality of life domains.

### **Professional Accountability**

States, regulatory boards, and professional societies regulate a designated professional group and have established ethical guidelines and standards that their members must comply with in order to remain in good standing and maintain their license to practice their profession. Most of the codes of ethical practices and standards of professional practice promulgated by these states, regulatory boards, and professional groups (e.g., psychologists, social workers, lawyers, physicians, etc.) share many commonalities including practicing beneficence, putting the client's interest at the center of one's actions, maintaining one's knowledge and skills, and practicing within one's area of competence.

A number of other professional groups that offer credentialing or certification to their members, typically identify the essential competencies that their members must demonstrate and maintain in order to establish their status as a profession. A good example of this is the pioneering work done by Hewitt, Larson, and their colleagues (see Hewitt, 1998; Hewitt et al., 1998; Larson et al., 2007; Test et al., 2004). Their work on identifying essential competencies

for direct support professionals in the field of IDD encompasses 14 distinct competencies including crisis intervention, assessment, health and wellness, consumer empowerment, and advocacy. In parallel to these efforts, the NADSP focuses on competencies that ensure that the direct support workforce meets competencies reflecting minimal training requirements, standards of practice, a code of ethics, and sets a standard for quality care and services among their members. These groups provide important professional oversight, including professional guidelines, training resources, monitoring, and corrective mechanisms that ensure professional accountability and on-going quality-assurance.

### **What are the Impacts of Professional Responsibility**

#### **On the Individual, Profession, and Society?**

The impacts resulting from fulfilling one's professional responsibility extend beyond the individual. Indeed, the cumulative effects and benefits associated with the input, throughput, and outcome components of the *Professional Responsibility Model* depicted in Figure 1 extend beyond the individual to the respective profession and society at large. To show clearly these cumulative impacts, we have developed Table 1 which summarizes the relationship between core aspects of each component of professional responsibility (i.e., building blocks, professional practices, and changes/results) to exemplary benefits to the individual, profession, and society. As noted in Table 1, many of the benefits relate to the input component of professional responsibility that includes respect for the person, professional ethics and standards, critical thinking skills, and the use of data-driven clinical judgment. Many of benefits also relate to the effectiveness of the professional practices used (i.e., the throughput component of professional responsibility), including precise terminology, empowerment, a functional and holistic approach to IDD, contextual analysis, evidence-based practices, and individualized supports). The

outcomes that result from professional activities associated with these input and throughput components impact not only the individual, but also one's profession and society at large.

<Table 1>

The relationships summarized in Table 1 also indicate why the authors advanced the definition of professional responsibility and its building blocks described at the beginning of the article; discussed how one's professional responsibility is applied through professional practices; and identified the multiple outcomes associated with fulfilling one's professional responsibility. These relationships also illustrate what a profession is, who a professional is, and the parameters for professional training.

In conclusion, a profession's credibility rests largely on its ability to establish, monitor, and regulate the professional conduct of its members. A clear understanding of professional responsibility provides a unifying vision and moral purpose to the profession and a guiding framework to use when circumstances challenge tenets of the profession. Professional responsibility is often dictated by the ethical principles and code of conduct set forth by one's profession that start with one's professional obligation to exercise professional responsibility. A code of conduct of a profession is also directly linked to the professional responsibility, actions, and effective contributions of its members and the enhancement of individuals and society.

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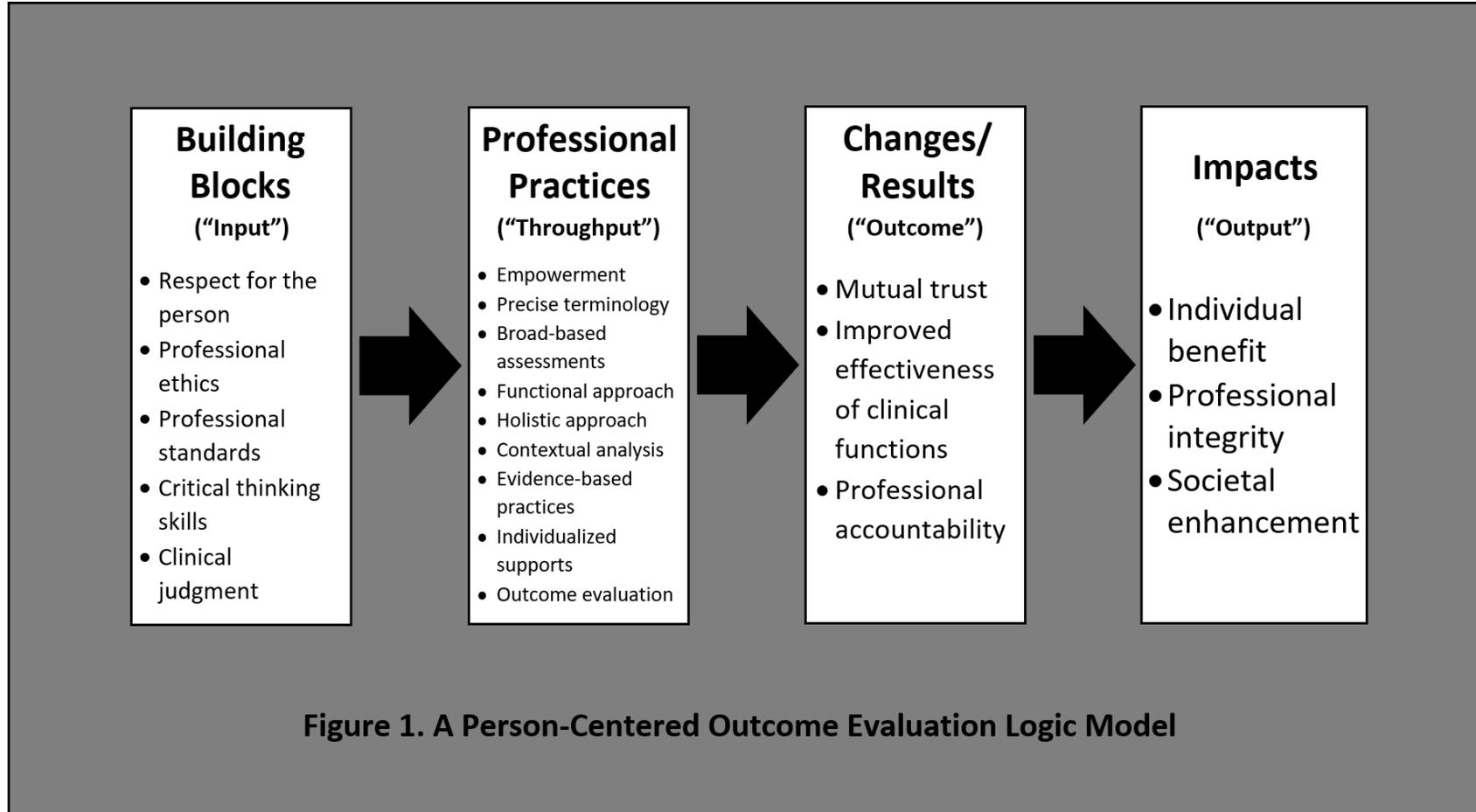
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**Table 1***Impacts of Professional Responsibility at the Level of the Individual, Profession, and Society*

<b>Professional Responsibility Components</b>	<b>Impacts on the Individual</b>	<b>Impacts on the Profession</b>	<b>Impacts on Society</b>
Building Blocks	Respect from professionals Ethical interactions Standards-based interventions and supports Use of data-driven critical thinking skills and clinical judgment	Increased credibility Unifying vision Moral purpose	Confidence and predictability that professional practices are built on professional ethics and standards Equity, diversity, and inclusion
Professional Practices	Evidence-based clinical functions related to their diagnosis, classification, planning and implementing supports Individualized supports Transparency in practices and their outcomes Opportunity to make decisions and evaluate the professional's work	Focus on continually improving professional development and skills that are meeting the requirements of professional standards and best practices Ability to establish, monitor, and regulate professional conduct and actions A unifying vision and code of conduct for the profession	Increased understanding of professional responsibilities Safety, efficiency, and transparency Effectiveness
Results of Building Blocks and Professional Practices	Mutual trust Improved effectiveness of clinical functions Improved functioning, and quality of life Structure to hold professionals accountable	Mutual trust Improved effectiveness of clinical functions Ability to hold the profession accountable	Stronger, more resilient, stable, and sustainable society



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