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A balanced approach to decision-making in supporting people with IDD in extraordinarily challenging times

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ABSTRACT

A balanced approach to decision-making during challenging times is necessary in order to avoid risks that jeopardize the lives and wellbeing of people with intellectual and developmental disabilities (IDD). The COVID-19 pandemic is the recent example of a crisis that places people with IDD at risk for lopsided societal reactions and threats to them or their wellbeing. Attention to decision-making is required to safeguard hard-earned achievements, including public policies and organization practices that emphasize human and legal rights, self-advocacy, individualized supports, inclusive environments, choices, and community inclusion. We suggest maintaining a holistic approach to understanding the lives and human functioning of people with IDD, a balanced approach to accountability and performance management, an understanding of the multidimensional properties of context, and a heightened vigilance in professional responsibility. A balanced approach will strengthen the likelihood of a return to high quality services and supports to people after the crisis, reduce loss of critical progress, and enhance stability across future social, political, and financial changes and challenges.

"When catastrophic events occur, we naturally become frightened and look for immediate solutions. After 9/11, for example, our government began the fight against domestic terrorism through the Homeland Security Act of 2002. As Americans, we cooperated and changed how we lived our lives. However, we never surrendered our constitutional rights. None of us gave the government carte blanche to whittle away our freedoms" (p. A-11, Ramczyk, 2020).

What this paper adds?

This paper provides an overall strategy for decision-making during what is a very difficult time for people with IDD. Much recent discussion has focused on safeguarding health, but almost no discussion on the real and potentially long-lasting threats to decades of progress in assuring the rights and community integration of individuals with IDD, or the aftermath of the crisis.

1. Introduction and overview

Extraordinarily challenging times increase the risks that unbalanced decision-making will jeopardize the lives and wellbeing of people with intellectual and developmental disabilities (IDD). The COVID-19 pandemic is not the first time that people with IDD have...
faced a crisis or situation that places them at risk for lopsided, albeit well-meaning, societal reactions and even threatens them or their wellbeing. History shows repeated examples where the value and the lives of people with IDD have been put in jeopardy. As described so vividly in the book entitled, *Lives and Legacies of People with Intellectual Disability* (Keith & Keith, 2020), people with IDD have historically been stigmatized, dehumanized, abused, and neglected. Over recent years, however, the lives and circumstances of those individuals have improved through changes in public policies and organization practices emphasizing human and legal rights, self-advocacy, individualized supports, inclusive environments, choices, and community inclusion.

These considerable improvements are fragile, however, and the COVID-19 pandemic has challenged people, organizations, systems, and societies to protect the health of individuals with IDD and maintain the progress they have achieved, while trying to balance critical life-enhancing achievements with immediate public health dangers. In this article we suggest a way to avoid a dangerous “triage mentality” in which people with IDD are vulnerable to the loss of their hard-earned life enhancing achievements.

The current crisis provides the impetus to consider the role that people and organizations play during times of crisis, to not only protect the health and safety of people with IDD, but also to continue to support their personal development, social inclusion, interpersonal relations, rights, and emotional well-being. In the material that follows, we suggest that maintaining a balanced approach to decision-making in supporting people with IDD in challenging times is critical. This approach includes maintaining a holistic approach to understanding the lives and human functioning of people with IDD, a balanced approach to accountability and performance management, an understanding of the multidimensional properties of context, and a heightened vigilance in professional responsibility. In the article, we also stress that the suggested balanced approach strengthens the likelihood of a return to high quality services and supports to people after the crisis, reduces loss of critical progress, and enhances stability across future social, political, and financial changes and challenges.

2. Holistic approach to IDD

A holistic approach to IDD 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 of increased understanding and more valid decisions and recommendations. As described in existing literature and synthesized by Schalock, Luckasson, Tasse, and Verdugo (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 personal growth and development, and trauma associated with an unstable childhood. 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 influencing statutes, regulations, and judicial decisions.

A holistic approach that integrates these four theoretical perspectives on IDD has implications for both the current crisis and future challenges. Chief among these are: (a) a clear focus on human functioning and the multiple factors that influence its expression; (b) an increased understanding that the locus of IDD is not just in the person but also within the interaction between the person and multiple risk factors; (c) a framework 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 individual functioning; and (d) the incorporation of the justice perspective into the field of IDD, with its emphasis on human and legal rights.

Taking a balanced approach during decision-making helps assure that the consideration of potential solutions doesn’t overemphasize one perspective to the detriment of another perspective. For example, concerns for health and safety, viewed from the biomedical perspective, should not preclude the provision of special education and ongoing supports as viewed from the psychoeducational perspective. Concerns for prioritizing resources should not overwhelm an individual’s legal and human rights. It is important that past achievements and ongoing needs for supports from any of the four perspectives not be indiscriminately swallowed up in unbalanced crisis decisions. Such an imbalance may inadvertently cause significant losses of rights or generate new inequalities which erode important achievements that may hurt the lives of people with IDD or create unnecessarily high hurdles after the crisis passes.

3. Balanced approach to accountability and performance management

As with multiple perspectives on IDD, there are also multiple perspectives on accountability, which is commonly referred to as performance management. As described by the International Research Consortium on Evidence-Based Practices (2013) and discussed by Schalock and Verdugo (2012) and Schalock, Verdugo, and Lee (2016) these four perspectives involve the customer, and the organization’s growth, financial analyses, and internal processes. The customer perspective focuses on personal goals, assessed support needs, systems of supports, and personal, valued outcomes. The growth perspective focuses on program options and partnerships. The financial analysis perspective uses an empirical, multi-data approach to resource allocation. The internal processes perspective focuses on the alignment of supports and capacity building.
During times of crisis such as with the current COVID-19 pandemic, it may be tempting for organizations to completely shift their emphasis to safety, security, and financial sustainability. Although this is understandable and may be necessary in the immediate term, maintaining a balanced approach to accountability and performance management that includes the perspective of the person with IDD (i.e., the customer) ensures a holistic approach to the services and supports provided during the current crisis while at the same time facilitating a balanced approach across future social, political, and financial changes and challenges.

4. Understanding the multidimensional properties of context

The lives of people with IDD must be understood in context. The COVID 19 pandemic is an important part of the current context. Recent work by Schalock, Luckasson, and Shogren (2020), Shogren, Luckasson, and Schalock (2020a and 2020b) describes how a multidimensional model of context can be used to identify, understand, and apply the multilevel, multifactorial, and interactive properties of context. The multilevel property of context includes the ecological systems (i.e., micro, meso, and macro) within which people live, learn, work, and recreate. The individual and these environments 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. The interactive property of context includes the variety of ways in which levels and factors interact to influence human functioning and personal outcomes. An interaction is a reciprocal action or influence that occurs between multilevel/multifactor contextual variables. 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. An understanding of the interactive property of context allows policy makers, support providers, and researchers to identify the multilevel/multifactorial interactions that have the highest potential to influence human functioning and personal outcomes. This identification facilitates the prioritization of support strategies during a time of crisis.

The importance of approaching context from a multidimensional perspective is that one's thinking goes beyond focusing only on the impact of the current crisis to focusing on how context-based factors and interactions can still be used to maximize supports provision. At the level of individual, for example, supports that enhance social networks, family involvement, choices and decision making, self-advocacy, and the use of information and assistive technology devices can still be provided by the individual, peers, support staff, advocates, and family members. Analogously, organizations can still align services and supports to assessed support needs and personal goals while continuing their use of person-centered planning. And at the macro-system level, multiple entities can continue to advocate for justice and fairness in the legal system and the protection of human and legal rights.

5. Vigilance in professional responsibility

Although there are many players involved in how people, organizations, systems, and society respond to a crisis such as the current COVID-19 pandemic, the current crisis also reinforces the need for a heightened demonstration of professional responsibility. As discussed by Luckasson and Schalock (2015) and Schalock and Luckasson (2014), professional responsibility is the driver of professional competency and earned respect. Professional responsibility incorporates evidence-based practices, professional ethics, professional standards, and clinical judgment. Evidence-based practices are based 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 mandate a system of moral behavior and 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., a focus on inner (guiding values), other (sensitivity to others), and outer (environmental/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.

Professionals need to be intricately involved in both the management of organizations and the support of individuals with IDD during this crisis and during other challenging times. Professionals can be key catalysts in ensuring that organizations and systems maintain a balanced approach to supporting people with IDD through their professional ethics, professional standards, and clinical judgment. Additionally, professionals have the responsibility to do all they can to promote and facilitate best practices. This would involve ensuring that: (a) service/supports recipients understand and are supported to implement ways to protect themselves from pathogens (e.g., washing hands, face masks, social distancing); (b) residential and support providers are trained in and supervised for disease prevention strategies; (c) residential staff and supports providers are provided with and use personal protective equipment; (d) people with IDD are not disadvantaged in hospital/department of health care policies regarding prioritization and rationing of life-saving measures (e.g., ICU beds and ventilators); and (e) the individual's human and legal rights are respected, guaranteed, and safeguarded. Professionals are also in a key position to explain to others the importance of maintaining a balanced approach by taking a holistic approach to both IDD and accountability, and understanding the multidimensional properties of context.

In summary, the challenges faced by people with IDD and the organizations and systems that support them will not end with the demise of the COVID-19 pandemic. The road back may be slow, challenges will remain, and people with IDD will still be vulnerable to the cracks that the current crisis has uncovered or creates in societies throughout the world. In this time of COVID-19, we must remain committed to those concepts, principles, and values that guided the field of IDD on December 30, 2019, and reaffirm that they will be the concepts, principles, and values that continue to guide the field post COVID-19. In the authors' opinion, that commitment encompasses the belief that the support needs of people with IDD can continue to be met in times of crisis through maintaining a
holistic view of IDD, balance among the multiple perspectives regarding how disability is understood, implementing multiple perspectives on accountability and performance management, acting on the multidimensional properties of context, and assuming a vigilant commitment to professional responsibility.

CRediT authorship contribution statement

Ruth Luckasson: Conceptualization, Writing - original draft, Writing - review & editing. Robert L. Schalock: Conceptualization, Writing - original draft, Writing - review & editing.

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