

## SIX IDEAS THAT ARE CHANGING THE IDD FIELD INTERNATIONALLY

### *Seis ideas que están cambiando el campo de las discapacidades intelectuales y del desarrollo en todo el mundo*

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Recepción: 6 de noviembre de 2017  
Aceptación definitiva: 7 de noviembre de 2017

**ABSTRACT:** The purpose of this article is to discuss six ideas that are currently impacting policy makers and service/support providers in the field of intellectual and closely related developmental disabilities. These six ideas are that people are influenced by multiple systems, disability should be approached holistically, disability policy needs to be approached systematically, supports should encompass elements of a system of supports, evaluation is multifaceted, and organizations need to transform to be sustainable.

**KEY WORDS:** intellectual disability; developmental disability; supports; organizational transformation; systems; disability policy.

**RESUMEN:** El propósito del presente artículo es presentar seis ideas que en estos momentos están teniendo influencia en los legisladores y en los proveedores de servicios y apoyos en el ámbito de las discapacidades intelectuales y del desarrollo (que están íntimamente relacionadas). Estas seis ideas son las siguientes: las personas se ven influidas por varios sistemas, debemos enfocar la discapacidad desde un punto de vista holístico, las políticas sobre discapacidad deben tener un enfoque sistemático, los apoyos deben abarcar los elementos de un sistema de apoyos, la evaluación tiene diversos factores y las organizaciones se deben transformar para poder ser sostenibles.

**PALABRAS CLAVE:** discapacidad intelectual; discapacidad del desarrollo; apoyos; transformación organizacional; sistemas; política social.

## 1. Introduction and Overview

**I**DEAS ARE THE BASIS OF THOUGHT AND ACTION. Over the last three decades a number of ideas and concepts have changed how societies view people with intellectual and closely related developmental disabilities (IDD) and how service delivery systems have responded to these ideas and concepts by changing the services and supports they provide to persons with IDD. Chief among these ideas were the quality of life concept, the definition of intellectual disability, the factor structure of adaptive behavior, and the supports paradigm. Details about these ideas, concepts, and changes can be found in Schalock (2017), Schalock and Verdugo (2013), Turnbull and Stowe (2017), and Verdugo, Navas, Gomez and Schalock (2012).

Today, policy makers and practitioners are challenged by additional ideas that are changing the IDD field internationally. The purpose of this article is to describe six of those ideas, and to discuss how each is impacting IDD-related policies and practices. These six ideas are that: (a) people are influenced by multiple systems, (b) disability should be approached holistically, (c) disability policy needs to be approached systematically, (d) supports should encompass elements of a system of supports, (e) evaluation is multifaceted, and (f) organizations need to transform to be sustainable.

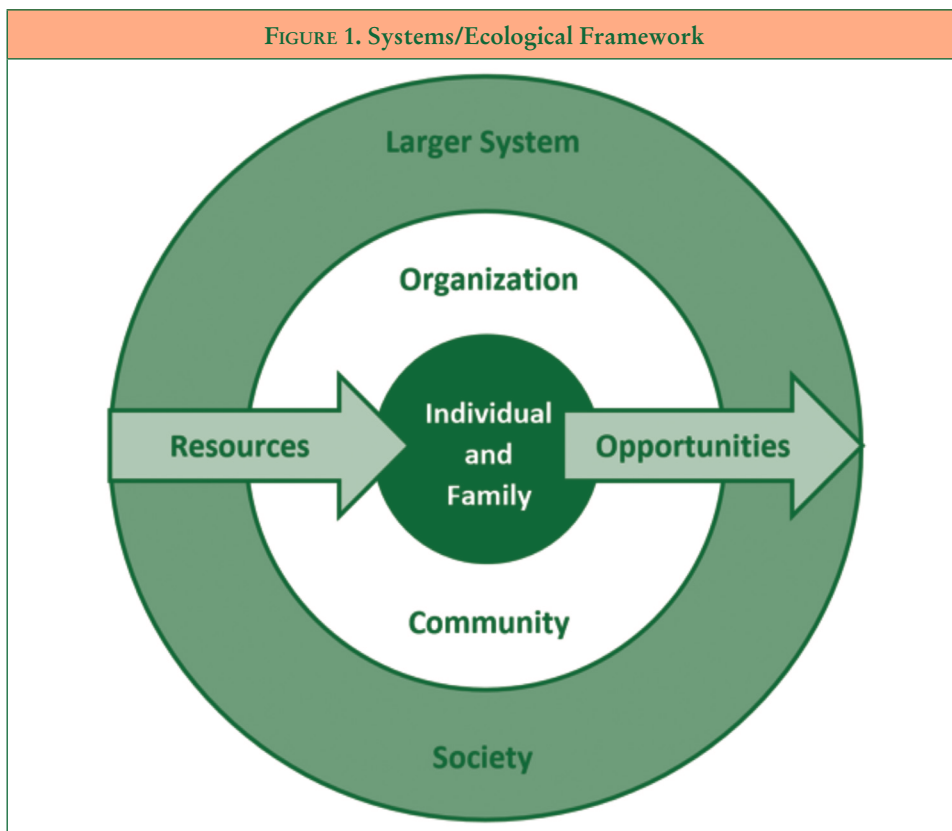
## 2. People Are Influenced by Multiple Systems

All of us live in societies that encompass the individual and family (i. e., the micro-system), organizations and one's community (i. e., the mesosystem), and the larger system, including one's culture (i. e., the macrosystem). These three systems define the context within which people live, interact, are schooled, work, and recreate. Understanding these systems and using systems thinking provides a framework for envisioning the role of resource allocation and opportunity development to enhance personal outcomes, and identify factors that influence personal outcomes.

### 2.1. *Resource Allocation and Opportunity Development*

Resources are more than financial capital. Resources also include time, expertise, experience, technology social capital, and partnerships. Analogously, opportunity development involves creating environments that encourage growth and development, support people, and accommodate psychological needs related to autonomy, competence, and relatedness.

As depicted in Figure 1, resource allocation and opportunity development can be viewed from a systems perspective. Note that opportunity development flows from the microsystem to the macrosystem, whereas resources flow from the macrosystem to the microsystem.



## 2.2. Factors Influencing Personal Outcomes

A multiple system framework can be used to identify systems-level factors that influence personal outcomes. Table 1 summarizes those factors based on the work of Claes *et al.* (2012), Schalock and Verdugo (2012), and Shogren, Luckasson and Schalock (2015).

<b>TABLE 1. Factors Influencing Personal Outcomes</b>	
<b>Systems Level</b>	<b>Exemplary Influencing Factors</b>
Microsystem	<ul style="list-style-type: none"> <li>- Personal goals and assessed support needs</li> <li>- Strengths/assets</li> <li>- Functional limitations (e. g., intellectual functioning, adaptive behavior, health)</li> <li>- Family involvement</li> </ul>

TABLE 1. Factors Influencing Personal Outcomes (cont.)	
Systems Level	Exemplary Influencing Factors
Mesosystem	<ul style="list-style-type: none"> <li>– Services/supports delivery practices</li> <li>– Support strategies employed (i. e. a system of supports)</li> <li>– Stable, predictable environments</li> </ul>
Macrosystem	<ul style="list-style-type: none"> <li>– Public attitudes</li> <li>– Policy initiatives (e. g., supported employment, supported living, inclusive education)</li> <li>– On-going supports provision</li> </ul>

### 3. Disability Should Be Approached Holistically

There are currently four perspectives that help explain intellectual disability (ID). Each perspective represents a particular worldview, explores the impacts of various factors influencing ID, provides the basis for interventions and supports related to that worldview, and organizes relevant information into a usable form for increased understanding and as a basis for better recommendations and decisions. These four perspectives approach ID from a biological, psychoeducational, sociocultural, or justice perspective. Although each of these four perspectives currently serves and will continue to serve important purposes, individually they do not explain the complexity of ID, nor do they individually provide a holistic theoretical framework to understand ID and guide efforts to mitigate its impact. The *biomedical perspective* emphasizes genetic and physiological factors that result in ID. The *psychoeducational perspective* emphasizes intellectual, psychological/behavioral, and learning limitations associated with ID. The *sociocultural perspective* emphasizes the interaction between people and their environments through which social meaning of ID develops from society’s common beliefs, behaviors, language, and events around people with ID and the responses of individuals to the interaction. The *justice perspective* emphasizes that all individuals, including those with a diagnosis of ID, have the same human and legal rights.

Recently these four perspectives have been integrated into a *holistic theoretical framework* that can be used to explain intellectual disability (ID) and organize relevant information into a usable roadmap to guide understanding and application. The five components of this holistic framework are listed in Table 2 and discussed more fully in Schalock Luckasson, Tasse, and Verdugo (in press).

TABLE 2. Components of an Integrated Approach to Intellectual Disability	
Component	Description
Explanation of Intellectual Disability	Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. ID originates during the developmental period.

TABLE 2. Components of an Integrated Approach to Intellectual Disability (cont.)	
Component	Description
Explanation of Intellectual Disability	Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social and practical adaptive skills. ID originates during the developmental period
Locus of Intellectual Disability	Genetic/neurological/physiological impairment; significant limitations in intellectual functioning, and conceptual, social, and/or practical skills; environmental conditions and situations.
Interventions and Supports for Prevention or Mitigation of Intellectual Disability	<ul style="list-style-type: none"> <li>– Professional interventions</li> <li>– Inclusive environments</li> <li>– Individualized support strategies</li> </ul>
Subgroup Classification of Individuals with Intellectual Disability	Etiology; levels of development, intellectual functioning, adaptive behavior, intensity of support needs; legal/statutory designations (e. g., competence/incompetence; eligible/not eligible)

#### 4. Disability Policy Needs to Be Approached Systematically

Disability policy needs to reflect three recent trends and developments in the field (Schalock, 2017). First, we are experiencing change and transformation not only in the field of IDD but also in the social-political environments within which people with IDD and their families live and service delivery systems operate. Second, there is an increasing need to evaluate how disability policy influences the lives and valued outcomes of persons with IDD. Third, we have come to realize that disability policy is not just high-level actions of federal, state, or regional governments, but also involves multiple and varied approaches by organizations and systems that affect social circumstances, access, educational opportunities, employment, housing, financial necessities, and the delivery of services and supports.

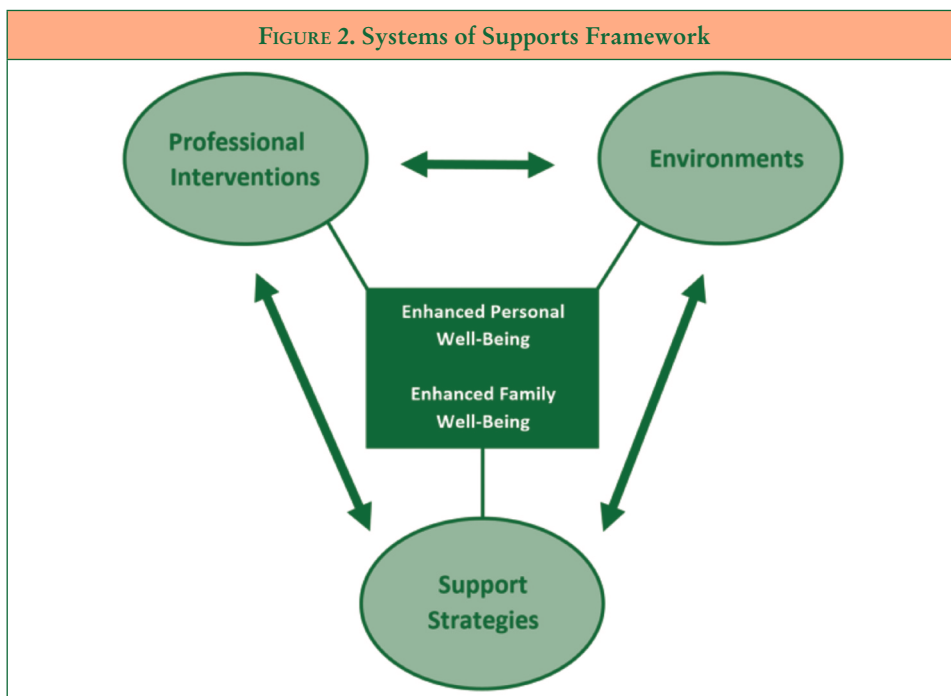
Successfully addressing these trends and developments requires that we realize that disability policy development, implementation, and evaluation are dynamic processes, and that these processes are best understood and operationalized by using a systematic approach. An overview of such an approach is summarized in Table 3 and described in more detail in Claes *et al.* (2017), Schalock (2017), Turnbull and Stowe (2017) and Verdugo *et al.* (2017).

TABLE 3. Components of a Systematic Approach to Disability Policy	
Policy Phase	Key Factors
Development	– Base policy on core concepts and principles such as the UN Convention on the Rights of Persons with Disabilities and the quality of life concept

TABLE 3. Components of a Systematic Approach to Disability Policy (cont.)	
Policy Phase	Key Factors
Development	<ul style="list-style-type: none"> <li>- Include desired policy outcomes in policy development to guide policy implementation and evaluation</li> <li>- Incorporate current knowledge about IDD</li> </ul>
Implementation	<ul style="list-style-type: none"> <li>- Conduct a contextual analysis to identify factors that hinder and facilitate change</li> <li>- Align policy goals with specific interventions, services, and supports</li> <li>- Form partnerships</li> </ul>
Evaluation	<ul style="list-style-type: none"> <li>- Focus the assessment on personal, family, or societal changes</li> <li>- Incorporate an evaluation model</li> <li>- Identify and assess evidence-based indicators</li> <li>- Use best practice evidence-gathering strategies and evaluation standards</li> </ul>

### 5. Supports Should Encompass Elements of a System of Supports

The supports paradigm and the provision of individualized supports have become the primary service delivery mechanism throughout much of the world. The supports paradigm brings together the resulting practices of person-centered planning,



personal development and growth opportunities, community inclusion, self-determination, empowerment, and outcomes evaluation. It does so by: (a) stressing that any person-environment mismatch that results in needed supports can be addressed through the judicious use of individualized support strategies rather than focusing on “fixing the person”; (b) shifting the focus of services and supports to bridging the gap between “what is” and “what can be”; and (c) approaching persons with IDD on the basis of the type and intensity of needed supports rather than on the basis of the person’s limitations or diagnosis.

The concept of supports and support provision has evolved over the last two decades based on our better understanding of *the concept of systems of supports*. This expanded concept is shown graphically in Figure 2. As depicted in Figure 2, a system of supports involves providing professional interventions, creating environments, and delivering individualized support strategies. Elements of each component are summarized in Table 4. The components and elements presented in Table 4 are based on the synthesis of current literature presented in Lombardi Chiu, Schalock and Claes (2017) and Schalock *et al.* (in press).

TABLE 4. Components and Elements of a System of Supports

Component	Elements
Professional Interventions	<ul style="list-style-type: none"> <li>- Dietary/nutritional</li> <li>- Medical/surgical</li> <li>- Prosthetics</li> <li>- Parenting/staff/teacher training and development</li> <li>- Educational support strategies</li> <li>- Environmental accommodation</li> <li>- Employment</li> <li>- Community engagement</li> <li>- Policy reform</li> <li>- Rights affirmation</li> </ul>
Inclusive Environments	<ul style="list-style-type: none"> <li>- Environments that: (a) encourage growth and development and support people, and (b) accommodate psychological needs related to autonomy, competence, and relatedness.</li> <li>- Examples include supported employment, supported living, inclusive education, and aging in place</li> </ul>
Individualized Support strategies	<ul style="list-style-type: none"> <li>- Natural supports</li> <li>- Technology</li> <li>- Prosthetics</li> <li>- Education across the lifespan</li> <li>- Reasonable accommodation</li> <li>- Dignity and respect</li> <li>- Personal strengths/assets</li> </ul>

## 6. Evaluation Is Multifaceted

Evaluation involves an explicit, planned activity whose purpose is to determine the effect of IDD-related policies and practices. As depicted in Table 5, IDD-related evaluation can focus on personal outcomes, organization outputs, public policy outcomes, or social value. Each of these foci has primary stakeholders, a perspective on evidence, and consensual evidence indicators.

Table 5. Evidence-Informed Evaluation Matrix			
Evaluation Focus	Primary Stakeholders	Perspective on Evidence	Evidence Indicators*
Personal Outcomes	Individuals Families	Phenomenological-existential	<ul style="list-style-type: none"> <li>– Individual: Individual QOL domain scores; human functioning measures</li> <li>– Family: Family QOL domain scores; measures of family integration and unity</li> <li>– Measures of socio-economic position (education, health, occupation)</li> </ul>
Organization Outputs	Program managers Board of Directors Funding/regulatory bodies	Performance management	<ul style="list-style-type: none"> <li>– Effectiveness indicators (personal outcomes; program options)</li> <li>– Efficiency indicators (unit costs, overhead rates, percent of budget allocated to direct supports, vertical and horizontal alignment)</li> </ul>
Public Policy Outcomes	Policy makers Program recipients Society	Post-structural	<ul style="list-style-type: none"> <li>– Education status</li> <li>– Living status</li> <li>– Occupational status</li> <li>– Health Status</li> </ul>
Social Value**	Social policy analysts Policy makers Funders/OMB	Empirical-analytic	<ul style="list-style-type: none"> <li>– Cost estimates</li> <li>– Benefit indices</li> <li>– Benefit/cost ratios</li> <li>– Social Return on Investment (SROI) indices</li> </ul>

\* Evidence-gathering strategies and evaluation standards are discussed in SCHALOCK *et al.* (2017) and SCHALOCK *et al.* (2011).

\*\* Social value, benefit-cost analysis, and social return on investment are discussed in NICHOLLS (2017) and YATES and MARRA (2017)

Although it is beyond the purview of this article to discuss Table 5 in detail, two aspects summarized in the table are most germane to this fifth idea that is not only changing the IDD field internationally, but also directly impacting policy makers



and service providers alike: the different perspectives on evidence and the evidence indicators used to evaluate personal outcomes.

### 6.1. *Perspectives on Evidence*

Evaluation requires evidence. Evidence is defined as the available body of facts or information indicating whether a belief or proposition is true or valid, and is used to make informed decisions, and can be viewed from different perspectives. As described more fully in Schalock *et al.* (2017) and Schalock, Verdugo and Lee (2016), there are currently four perspectives on evidence:

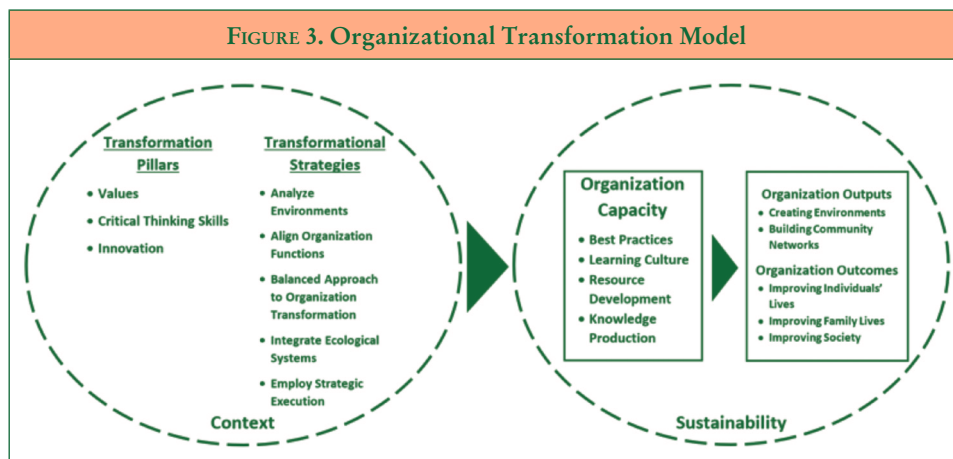
- *Empirical-analytical* that focuses on experimental or scientific results obtained from data gathering strategies including random trials, experimental/control designs, quasi-experimental designs, multiple baseline designs, and/or multivariate designs.
- *Phenomenological-existential* that focuses on reported experiences and enhanced human functioning, social participation, and/or personal well-being, with associated data gathering strategies including self-reports, case studies, ethnographies, participation action research, multivariate designs, and/or grounded theory.
- *Post-structural* that focuses on desired public policy outcomes assessed via mixed methods designs, multivariate designs, population surveys, meta-analyses, and/or data registers.
- *Performance management* that focuses on empirically-determined facts or information that be used by organizations for reporting, monitoring, evaluation, research, and/or continuous quality improvement. Data gathering strategies include outcomes evaluation, auditing results, self-surveys, program logic model analysis, and external reviews.

### 6.2. *Evidence Indicators*

In reference to evaluating personal outcomes, the most common IDD-related evidence indicators are individual quality of life (QOL) domain scores; human functioning indices related to adaptive behavior, intellectual functioning, participation, and health; family QOL domain scores; and measures of family integration and unity (Claes *et al.*, 2017). Regardless of the indicators selected, meeting the following criteria will insure the quality, robustness, and relevance of the obtained evidence: (a) the assessment is based on a well-formulated and validated conceptual model, (b) culturally sensitive indicators are used, (c) indicators are defined operationally and measured reliably and validly, and (d) standardized administration and scoring procedures are used (Gomez and Verdugo, 2016; Schalock and Keith, 2016).

## 7. Organizations Need to Transform to Be Sustainable

IDD-related organizations are transforming to adapt to current challenges and become more effective, efficient, and sustainable (Reinders, 2008; Schalock and Verdugo, 2013; Schalock *et al.*, 2016). A literature-based and experiential model to guide future organization and systems transformation has recently been developed by Schalock, Verdugo, and van Loon (submitted for publication). This model is presented in Figure 3.



Three aspects of the model are most germane to this article. First, two of the model's components are context-based (transformation pillars and transformation strategies) and two are sustainability-related (organization capacity and organization outputs and outcomes). Second, an organization's sustainability is related directly to its capacity and its ability to evaluate personal outcomes and organization outputs (see Table 5 for specifics regarding the two evaluation levels). Third, which represents a unique characteristic of the model, is that transformation strategies can be aligned to the critical thinking skills required for organization transformation. This alignment is summarized in Table 6 and described more fully in Schalock *et al.* (submitted for publication).

<b>TABLE 6. Alignment of Critical Thinking Skills and Transformation Strategies</b>	
<b>Critical Thinking Skill/ Associated Action</b>	<b>Associated Transformation Strategy</b>
Analysis: To Analyze Environments	<ul style="list-style-type: none"> <li>– Conduct a contextual analysis</li> <li>– Use results of the analysis for planning, doing, and evaluation</li> </ul>

TABLE 6. Alignment of Critical Thinking Skills and Transformation Strategies (cont.)	
Critical Thinking Skill/ Associated Action	Associated Transformation Strategy
Alignment: To Align Organization Functions	<ul style="list-style-type: none"> <li>- Arrange services/supports into a logical sequence of inputs, throughputs, outputs, and outcomes</li> <li>- Inputs are person-centered policies and practices and resources</li> <li>- Throughputs are personal goals and support needs aligned to elements of a system of supports</li> <li>- Outputs are environments and community building indicators</li> <li>- Outcomes are personal or family measures of well-being</li> </ul>
Holism: To Use a Balanced Approach to Organization Transformation	<ul style="list-style-type: none"> <li>- Customer perspective</li> <li>- Growth perspective</li> <li>- Financial analysis perspective</li> <li>- Internal processes perspective</li> </ul>
Systems: To Integrate Ecological Systems	<ul style="list-style-type: none"> <li>- Microsystem</li> <li>- Mesosystem</li> <li>- Macrosystem</li> </ul>
Synthesis: To Employ Strategic Execution	<ul style="list-style-type: none"> <li>- Communication</li> <li>- Shared or multilevel leadership</li> <li>- Engaged data</li> <li>- Networked partnerships</li> </ul>

## 8. Conclusion

In conclusion, we are living in a time of change. The change is driven in part by diminishing resources, the increasing need for services and supports, and shifting social-political factors. The good news is that the IDD field is adapting to these changes, challenges, and ideas discussed in this article. Increasingly, policy makers and service/supports providers are recognizing that people are influenced by multiple systems, disability is being approached holistically, disability policy is being approach systematically, supports are encompassing elements of a system of supports, the foci of evaluation are better understood and the importance of evidence-informed decision making is emerging, and organization transformation is occurring. The greatest challenge for policy makers and practitioners alike is to continue to evolve and make those changes in both policies and practices that enhance peoples' lives by creating environments that facilitate growth and development, support people, and accommodate the psychological needs of individuals and families for autonomy, competence, and relatedness.

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