Intellectual and Developmental Disabilities

The IDD Paradigm of Shared Citizenship: Its Operationalization, Application, Evaluation, and Shaping for the Future --Manuscript Draft--

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Abstract:	Changes in the field of IDD over the last five decades has resulted in the emergence of the shared citizenship paradigm, which envisions, supports, and requires the engagement and full participation of people with IDD as equal, respected, valued, participatory, and contributing members of every aspect of society. The IDD paradigm, whose goals are to further advance and focus on people with IDD as active agents in the change process and improve valued, person-referenced outcomes, is currently guiding the development of IDD-related policies and practices, and providing a framework for application, research-based inquiry, and evaluation. This article describes and discusses the paradigm's operationalization, application, evaluation, and shaping for the future.

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The IDD Paradigm of Shared Citizenship: Its Operationalization, **Application, Evaluation and Shaping for the Future**

Running Head: IDD Paradigm

Key Words: Intellectual and Developmental Disabilities; Shared Citizenship Paradigm;

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The IDD Paradigm of Shared Citizenship: Its Operationalization, Application, Evaluation, and Shaping for the Future

Introduction

A paradigm is (a) a model or framework derived from a world view or belief system about the nature of knowledge or a phenomenon, and (b) the collective and unifying set of values, assumptions, perceptions, and concepts that guide inquiry and application. Within a field, such as intellectual and developmental disabilities (IDD), a paradigm guides the development of policies and practices and provides a framework for application, research-based inquiry, and evaluation (Gomez et al., 2021 a; Kuhn, 1974; Guba & Lincoln, 1994; Lincoln & Guba, 1985; Mittner, 2015; Thompson et al., 2014).

Historically, the field of IDD has been impacted by different belief systems, values, assumptions, perceptions, and concepts (i.e., paradigms) regarding people with IDD. For example, Trent (2021) used the concept of "historical foundation eras" to trace seven historical paradigms related to IDD. Briefly, these eras involved associating people with IDD with immorality, peculiarity, or crime (e.g. the "idiot fool"); relegating IDD to the sole purview of medicine and regarding people with IDD as pitiful or godlike; establishing institutions initially to educate but later to provide custodial care; classifying people on the basis of IQ test scores, which led to the creation of the concept of "idiot/imbecile/moron", total institutionalization, and involuntary sterilization; establishing large institutions during the 1945-1970 era, closing institutions and integrating people with IDD into the community from the 1970s to today; and more recently, incorporating the construct of IDD into the social construction model of disability. Similarly, Wolfensberger et al. (1972) used the concept of "socio-historical role expectations" to summarize historical expectations regarding the roles played by people with

IDD. These historical role expectations involved viewing people with disability as a subhuman organism, a menace, the object of dread or pity, holy innocent, diseased organism, object of ridicule, or an eternal child. Today, the field has rejected these historical roles, and instead recognizes the humanity of people with IDD and the right to equitable participation in all aspects of society.

One can conclude from these historical eras and role expectations regarding people with IDD that paradigm shifts occur (McDonald & Raymaker, 2013; Newman & Brannon, 2003; Schalock, 2004; Thompson et al., 2014; Verdugo et al., 2021; World Health Organization, 2001). A *paradigm shift* occurs when there is a changed perception and actions regarding how things should be thought about, done, or made. Over the last 50+ years, a number of international social-political movements, legislative accomplishments, legal actions, advocacy movements, and professional activities have changed society's approach to people with IDD. These changed perceptions and actions, which became the catalysts for the emergence of a new IDD paradigm, are described in the following section that provides an overview of this new paradigm. We name the new paradigm the *shared citizenship paradigm*.

Overview of the IDD Shared Citizenship Paradigm

Paradigm Shift Catalysts

The international social-political movements, legislative accomplishments, legal actions, advocacy movements, and professional activities that have occurred over the last 50+ years have not only been catalysts for the new paradigm, but have also contributed to its universality and applicability. These 'paradigm shift catalysts' have included: (a) the ICF model of disability that represented a major shift in the conceptual model of disability, emphasizing functioning and participation (World Health Organization, 2001); (b) international civil and human rights

covenants such as the United Nations Convention on the Rights of Persons with Disability (United Nations, 2006); (c) the strong and effective advocacy by family, self-advocate, and disability rights groups for policies and practices that insure inclusion, empowerment, and human and civil rights of people with IDD (Fleischer & Zamas, 2011; SABE, 2020); (d) adoption of changes in public laws and system practices that focus on equity, inclusion, empowerment, community participation, and self-determination (Wehmeyer, 2014); (e) the universal incorporation of the concept of individualized supports and systems of supports into organization and systems-level policies and practices (Luckasson et al., 1992; Thompson et al., 2014; Wehmeyer et al., 2017); and (f) activities by professional organizations such as AAIDD and The Arc (Luckasson et al., 2017), the [Canadian] National Institute on Mental Retardation (Wolfensberger et al., 1972), and The International Association for the Scientific Study of Intellectual Disability. These catalysts underscore three important characteristics of the new paradigm. First, its formulation and expression have evolved over time, and incorporates evolutionary changes in the field. Second, it derives from international changes in policies and practices, and thus has widespread and universal applicability. Third, it integrates the current collective and unifying set of values, assumptions, perceptions, and concepts that provide the rationale and best practices framework to guide both the development of IDD-related policies and practices and the paradigm's application and evaluation.

Name

We name this new paradigm the *shared citizenship paradigm*. Naming is a powerful process that carries many messages about perceived value and human relations. In reference to the paradigm's name, *citizenship* refers to a state of belonging; it is a recognized inclusive relationship between a person and a whole group such as one's community, country, or society.

Citizenship includes an acknowledgement that each person is not only included in the group, but has the privileges, rights, and obligations that such belonging entails. *Shared* refers to the experience of each person who belongs to the group having a common stake in the past, present, and future of the group and its resources. *Shared citizenship* is the state of belonging and experiencing the common stake by every person in the group.

Definition

Defining explains a term precisely, and establishes the meaning and boundaries of the term. We define the new paradigm as follows:

The shared citizenship paradigm is one that envisions, supports, and requires the engagement and full participation of people with IDD as equal, respected, valued, participating, and contributing members of every aspect of society.

Attractiveness and Impact

As discussed in this article, the *shared citizenship paradigm* incorporates the characteristics of the current transformation in the field of IDD, is guiding the development of IDD-related policies and practices, and is providing a framework for application of the paradigm and conducting related research. Its attractiveness and impact are due to the fact that it:

- Incorporates an updated and contemporary set of values and beliefs about people with IDD and their right to participate fully in all aspects of life and society (Keith & Keith, 2020; McIntyre, 2008; Nussbaum, 2011; SABE, 2020; Wehmeyer, 2014; Wehmeyer et al., 2017).
- Moves the field from a general reference regarding environmental factors to specific
 multidimensional analyses of contextual factors that influence the manifestation of IDD,
 ameliorate the barriers to the shared citizenship of people with IDD, meet the needs of

- people with IDD, and support their optimal health and functioning prior to birth and throughout the life course (Schalock et al., 2020; Shogren et al., 2021).
- Is characterized by a holistic approach to IDD, a contextual model of human functioning,
 disability rights principles, and person-centered implementation strategies (see Table 1).
- Incorporates the exponential growth in knowledge about the causes and characteristics of IDD and factors influencing its amelioration (see, for example, Brown et al., 2017;
 Glidden et al., 2021a, b; Schalock et al., 2021a).
- Is reflected in international covenants such as the *United Nations Convention on the Rights of Persons with Disabilities* (United Nations, 2006), and international policy goals and associated personal outcome domains (Claes et al., 2016; Gomez et al., 2020; Lombardi et al, 2019; Shogren et al., 2015).

Although the *shared citizenship paradigm* is guiding IDD-related policies and practices and providing a framework for application of the paradigm and conducting related research, its specific components are not yet well delineated, nor has there been a systematic approach to its operationalization and a detailed description regarding its application, evaluation, and shaping for the future. Such are described in subsequent sections of the article.

Operationalizing the Shared Citizenship Paradigm

Operationalizing the shared citizenship paradigm involved three sequential steps. The first was to identify the current characteristics of the field of IDD; the second was to identify the core components of the paradigm; and the third was to align the core paradigm components with current IDD-related policies and practices.

Step # 1: Identifying the Current Characteristics of the Field

The IDD field is currently characterized by using precise terminology, incorporating a functional and holistic approach to IDD, embracing the supports model and evidence-based practices, implementing outcome evaluation, empowering individuals and families, understanding better the multidimensional properties of context, and incorporating an explicit notion of professional responsibility (Schalock et al., 2021 b). These characteristics were used in Step # 2 as a basis for determining which characteristics are the primary drivers of the paradigm—which in turn identified the core paradigm components.

Step # 2: Identifying Core Paradigm Components

The identification of the core paradigm components was made by a group of international colleagues working actively in the field of IDD. Respondents, who were provided with a list of the current characteristics of the field of IDD, the definition of a paradigm, and the draft definition of the shared citizenship paradigm, were asked, based on their experience, to identify the primary drivers of the new paradigm. The consensus among respondents was that the paradigm was driven by four factors: a holistic approach to IDD, a contextual model of human functioning, disability rights principles, and person-centered implementation strategies. The authors refer to these four factors as *core paradigm components*.

A holistic approach to IDD. The holistic approach incorporates four current perspectives on IDD: biomedical, psychoeducational, sociocultural, and justice (Schalock et al., 2018, 2021a). Each perspective includes a presumed locus of disability, identified risk factors, and perspective-related interventions and supports. This core component is a driver of the shared citizenship paradigm because it (a) emphasizes an integration of the multiple causes of IDD and

its amelioration (i.e., biomedical, psychoeducational, sociocultural, and justice), and (b) reinforces a whole person approach to services and supports.

A contextual model of human functioning. This core component of the shared citizenship paradigm integrates the multifactorial, multilevel, and interactive (i.e., multidimensional) properties of context (Shogren et al., 2021; Vanderdruik & McPherson, 2017); the social-ecological model of disability that explains disability as resulting from the interaction between the person and their natural, built, cultural, and social environments/contexts (NIDILRR, 2021; Thompson et al., 2014, 2017); and a functional approach to IDD that incorporates a systematic and multidimensional understanding of human functioning, including human functioning dimensions, interactive systems of supports, and human functioning outcomes (Luckasson & Schalock, 2013; Schalock et al., 2021a). This core component is a driver of the paradigm because it (a) emphasizes the key role that personal and contextual factors play in the manifestation and amelioration of IDD, (b) focuses on reducing the discrepancy between personal competency and contextual demands through systems of supports, and (c) provides a framework for a supports-based service delivery and evaluation system.

Disability rights principles. The international disability rights movement emerged from the civil rights movement of the 1960s and focuses broadly on freedom from neglect and abuse, equal rights, equal opportunities, and reducing discrimination based on factors such as ability, race/ethnicity, gender, and age (Bogart & Dunn, 2019; Fleischer & Zames, 2011; SABE, 2020). Underlying the disability rights movement has been a number of core principles that have been incorporated into international covenants, public policies, organization and systems-level practices, and theories of quality of life and subjective well-being. These underlying principles involve belonging, equity, inclusion, empowerment, participation, and self-determination.

Disability rights principles are a driver of the shared citizenship paradigm because of their: (a) consciousness-raising, sensitizing, and universal nature; (b) impact on policy development and organization and systems-level practices across ecological (i.e., micro, meso, and macro) systems; and (c) essential role in encouraging personal goal setting, self-advocacy, self-determination, and consumer empowerment and participation.

Person-centered implementation strategies. Since people with a disability are the fulcrum of the shared citizenship paradigm and its application and evaluation, the fourth core component of the paradigm is the use of person-centered implementation strategies that involve person-centered planning and person-centered evaluation. Person-centered planning: (a) incorporates the disability rights principles discussed above; (b) builds on individual interests and goals, human capacities, and the potential for change; (c) supports the person to self-direct and self-determine their lives; and (d) focuses on systems of supports that are an interconnected network of resources and strategies that are person-centered, comprehensive (i.e., choice and personal autonomy, inclusive environments, generic supports, and specialized supports), coordinated, and outcome focused (Schalock et al., 2021a). Person-centered evaluation: (a) focuses on the assessment of the pattern and intensity of support needs (Thompson et al., 2015, 2016); (b) involves broad-based assessments that incorporate the four perspectives on IDD (Schalock et al., 2018); and (c) encompasses person-centered outcome evaluation strategies that align the current understanding of IDD with individualized systems of supports and valued outcomes (Schalock & Luckasson, 2021). These person-centered planning and evaluation strategies represent best practices and drive evidence-based practices that are based on current best evidence that is obtained from credible sources that use reliable and valid methods derived

from a clearly articulated and empirically validated theory, model, or rationale (Schalock et al., 2017).

Step # 3. Aligning Core Paradigm Components with Current IDD Policies and Practices

The third step in operationalizing the shared citizenship paradigm involved aligning the four core paradigm components with exemplary (but not exhaustive) current policies and practices in the IDD field. The alignment was done by the authors based on their experience and the results of an extensive literature review. The alignment, which is shown in Table 1, allows for the paradigm's formulation, application, evaluation, and shaping for the future. These processes are described in the following sections of the article.

<Table 1>

Applying the Shared Citizenship Paradigm

A multidimensional framework can be used to apply the shared citizenship paradigm.

This framework: (a) involves the four core components of the paradigm (i.e., a holistic approach to IDD, a contextual model of human functioning, disability rights principles, and personcentered implementation strategies); and (b) relates these four components to contextual factors associated with the microsystem (i.e., individual, family, and circle of friends), mesosystem (i.e., the organization and local community), and macrosystem (i.e., larger service delivery system and wider society).

As an example of this multidimensional framework, a holistic approach to applying the paradigm addresses biomedical, psychoeducational, sociocultural, and justice risk factors that impact the individual, the family, the organization and community, the service delivery system, and the larger society/culture. A contextual model of human functioning emphasizes the integration of the totality of circumstances that comprise the milieu of human life and human

functioning and the critical role micro, meso, and macrosystem-level contextual factors play in the manifestation and amelioration of IDD. While disability rights principles focus on individual outcomes, these outcomes are impacted by organizations, systems, communities, and society. Similarly, while implementation strategies focus on person-level supports, their acceptance and implementation depend on an organization or systems' culture and its capacity to leverage the understanding and power of multilevel contextual factors to change the status quo and produce change.

As summarized in Table 2, the multidimensional framework can be used to apply the shared citizenship paradigm in reference to facilitating the provision of individualized services and supports; guiding organization transformation and/or systems change; and framing evidence-based inquiry. As shown in column 2, each of the three application areas involves one or more of the paradigm's core components and multilevel (i.e., micro, meso, and macrosystem) context-based application strategies. The exemplary strategies listed in column 2 are similar to or the same as the exemplary current policies and practices listed in Table 1 (column 3). This alignment of core paradigm components, IDD-related policies and practices, and potential application areas shows the potential of the paradigm to guide additional application areas to those listed in Table 2.

<Table 2>

Evaluating the Shared Citizenship Paradigm

The shared citizenship paradigm can be evaluated based on the (a) incorporation of underlying principles in its application, (b) the degree of its utilization, and (c) its effects on valued outcomes (Gomez et al. 2021; Gullickson, 2020; Ozeki et al., 2019; Patton, 2008, 2018). As summarized below, this evaluation involves principle-focused evaluation, utilization-focused

evaluation, and/or outcome-focused evaluation respectively. The form of evaluation used depends on its stated purpose and intended use. As an overview of these three forms of evaluation:

- Principle-focused evaluation assesses whether paradigm-related principles and values are clearly stated and implemented (Patton, 2018). In reference to the shared citizenship paradigm, principle-focused evaluation determines whether the human rights principles and person-centered implementation strategies core components of the paradigm are evident in policies, practices, and research activities.
- Utilization-focused evaluation assesses whether one or more core paradigm components (i.e., a holistic approach to IDD, a contextual model of human functioning, human rights principles, and person-centered implementation strategies) are reflected in current policies, practices, mission statements, research endeavors, and communicative information (Patton, 2008).
- Outcome-focused evaluation assesses the changes and benefits to individuals and families, organizations, systems, and society accruing from the paradigm's application (Gomez et al., 2021b; Gomez & Verdugo, 2016).

Table 3 describes each of these three forms of evaluation in more detail. In reference to each type, the reader will find a listing of the most relevant core paradigm components, an overview of the evaluation focus, examples of possible research designs, and respective evaluation standards.

<Table 3>

The use of information obtained from the evaluation of the paradigm using principle, utilization, and/or outcome-focused evaluation strategies extends beyond determining the

paradigm's effectiveness and the extent of its application and utilization. Evaluation information is also used to shape the paradigm for the future, and to facilitate and enhance its ongoing effectiveness and acceptance. The following section discusses a number of strategies that build on the many aspects of the paradigm that are currently impacting the IDD field. One or more of these strategies can be used to further shape the paradigm and increase its acceptance, utilization, and effectiveness.

Shaping the Shared Citizenship Paradigm for the Future

One benefit of operationalizing, applying, and evaluating the shared citizenship paradigm is the opportunity to use information obtained from the paradigm's evaluation to shape its future application. Shaping involves aligning current perceptions and actions with the paradigm's core components, and is based on contextual analysis and the use of a context-based change model. The shaping process employs strategies that when implemented will enhance the further application of the paradigm and its use to guide the development of policies, practices, theories or models; align policies and practices across the micro, meso, and macrosystem; and futher the understanding of IDD. Table 4 lists a number of strategies related to each of these three uses. Although literature-based, the exemplary strategies presented in Table 4 should not be considered as exhaustive or all-encompassing; they are examples only, and based largely on the published work of the authors and close colleagues who are also working on implementing, evaluating, and shaping the paradigm.

<Table 4>

Shaping strategies involve conducting specific activities to produce change at the micro, meso, and/or macrosystem levels. These activities, which frequently involve unfreezing the status quo and leveraging the power of context to produce the desired change, are facilitated and

enhanced through employing *a context-based change model* (Shogren et al., 2018, 2021). Although it is beyond the scope of this article to describe the model in detail, four model-based activities are most germane to shaping the shared citizenship paradigm for the future.

- 1. Conduct a contextual analysis that identifies the inhibitors and facilitators of change. Examples of inhibitors include having an inflexible mindset, ascribing limitations to the deficit model of disability, focusing exclusively on processes and not outcomes, and emphasizing facility-based services rather than individualized and community-based supports. Facilitators include believing in the potential of people to change, beginning with the end in mind and asking "what needs to be in place for the desired change to occur?", employing positive systems of supports, and using strategic execution that involves team development and implementing Individualized Support Plans (Shogren et al., 2018).
- 2. Engage in context-based planning based on the results of the contextual analysis. This planning involves: (a) focusing on supports provision, organization transformation and/or systems change, and evidence-based inquiry; and (b) developing specific context-based strategies that incorporate the facilitators of change (Shogren et al., 2021).
- Implement the specific context-based shaping strategies. Examples are provided in Tables 2 and 4.
- 4. Evaluate the effects of steps # 1-3 on the quality and quantity of individualized supports provided, the impact of any planning, supports provision, or policy changes on outcomes, the degree of organization or systems change, the amount of paradigm-related research, and/or the results of principle, utilization, and outcome-focused evaluation.

The IDD Shared Citizenship Paradigm:

Strengths and Implementation Challenges

The transformation that has occurred in the field of IDD over the last five decades has been significantly shaped by core components of the shared citizenship paradigm. Regarding the paradigm's future acceptance and full implementation, one needs to understand its strengths and address a number of significant implementation challenges.

Strengths

As discussed by Kuhn (1974) in his seminal text *The Structure of Scientific Revolutions* characteristics of a new paradigm include attracting converts, being testable, and being attractive and optimistic. According to Kuhn, if a new paradigm is accepted, it is because of factors that include resolving issues that previous paradigms have not; promising to preserve concrete problem-solving ability; being sufficiently open-ended to provide reinforcement to researchers, advocates, policy makers, and practitioners; and being marketed by multiple stakeholders using various channels and platforms. These factors indicate clearly that a new paradigm needs to be relevant to the field and actionable by multiple constituents.

The shared citizenship paradigm is *relevant to the field* because it: (a) represents an updated set of values and beliefs about people with IDD and their rightful place in the world; (b) envisions the full participation of people with disability in society; (c) incorporates the current understanding of IDD and its amelioration; and (d) encompasses the essential properties of a paradigm that involve ontology (i.e., a holistic approach to IDD), epistemology (i.e., a contextual model of human functioning), values (i.e., disability rights principles), and methodology (i.e., person-centered implementation strategies).

The shared citizenship paradigm is *actionable by multiple constituents* because of its: (a) preciseness in terms of definition, operationalization, application, and evaluation; (b) potential for multiple uses including policy development, individualized services and supports provision, organization transformation and systems change, and evidence-based inquiry; (c) comprehensiveness, including specific aspects of its implementation, evaluation, and shaping; and (d) integration of the characteristics of the current transformation in the field of IDD.

Implementation Challenges

Despite the shared citizenship paradigm's strengths (i.e., relevance and actionability), there are a number of significant challenges to its acceptance and full implementation. We have combined these challenges into three broad categories: lack of knowledge, systemic marginalization, and lack of resources.

Lack of knowledge. Transferring information regarding the relevance, utility, and components of the shared citizenship paradigm into the hands of policy makers, service/support providers, consumers, and researchers is a significant implementation challenge, and applies to both those persons who are receiving formal services and supports and to those people with IDD who are not using formal disability services. Understanding and using knowledge management and knowledge transfer facilitate both acceptance and wide-spread implementation.

Knowledge management thinking has evolved from simply making knowledge available, to active dissemination to known audiences, including those who may not yet know of the existence and utility of the knowledge available (Wingate et al., 2018). Given this evolution, effective knowledge transfer involves three activities. As discussed by Hasford et al. (2019) and

Wandersman et al. (2008), these activities involve synthesis and translation, support, and implementation.

- Synthesis and translation involves clearly describing the phenomenon and sharing that information through accessible and relevant multiple platforms such as publications, information briefs, white papers, press releases, web pages, texts, and presentations. In reference to the shared citizenship paradigm, synthesis and translation involves defining the paradigm operationally, with a clear description of how it can be implemented, evaluated, and shaped for the future (see Tables 1-4).
- Support focuses on productive encounters that incorporate contextual factors, interactions among key stakeholders, technology, and the demonstrated alignment of paradigm core components with potential or current policies and practices (see Table 1 for examples of this alignment). In reference to the shared citizenship paradigm, the goal of support is to build the capacity of individuals, families, informal support providers, organizations, and systems to effectively implement the new paradigm.
- Implementation involves applying the skills, knowledge, attitudes, infrastructure changes, and motivation acquired from the above-referenced synthesis and translation and support activities. To be most effective, implementation strategies should be clearly understood and focused, relevant to heterogeneous constituents, and outcome oriented. In regard to the shared citizenship paradigm, implementation involves using the paradigm's core components in the provision of individualized supports, organization transformation and systems change, and evidence-based inquiry (see Table 2 for examples of specific multisystem context-based application strategies).

The goal of knowledge transfer is to enhance the acceptance and implementation of a new idea, such as the new IDD shared citizenship paradigm. Achieving this goal involves the three knowledge transfer activities just discussed (i.e., synthesis and translation, support, and implementation), plus an awareness of the *innovation-decision process*. As discussed by Rogers (1995), the innovation decision-making process is the process through which an individual (or other decision-making unit) passes from first knowledge of an innovation to forming an attitude toward the innovation, to a decision to accept, reject, or implement the new idea, and finally to confirmation of the decision. This decision-making process is more effective when the innovation has these characteristics: relative advantage, compatibility, complexity, trialability, and observability (Rogers, 1995). These characteristics are consistent with—and complementary to—the strengths of the shared citizenship paradigm discussed above (i.e., relevance and actionability).

Systemic marginalization. Historically, people with IDD have encountered structures in society and stereotypes and biases that have excluded them from the mainstream of life. They are not alone, since other groups have experienced similar systemic marginalization (Bogart et al., 2019) and many people with IDD experience multiple forms of marginalization, or intersectionality. Such marginalization can have a number of negative consequences, including restricting one's shared citizenship. In addition to guaranteeing one's human and civil rights, mitigating systemic marginalization can be achieved through changes in systems and structures to ensure they are designed based on the shared citizenship paradigm. This can be achieved by integrating the paradigm's core components into the provision of individualized supports, organization transformation and system's change activities, evidence-based inquiry, and outcomes evaluation (see Table 3). Within systems that are designed with the shared citizenship

paradigm, there is also a need to focus on asset-based approaches and ensuring a commitment to the development of generosity, independence, mastery, and belonging that embeds the person within society, with opportunities to share and participate in systemic change (Brendtro et al., 2002).

Lack of resources. Resources can be defined broadly as involving time, money, and expertise. In reference to the current IDD field, there is concern regarding the lack of resources as reflected in social-political factors, person power shortages, and budget short falls. The authors recognize the significance of these concerns, and acknowledge the considerable literature devoted to potential solutions to these factors and issues. We believe, however, that overcoming this implementation challenge can best be achieved by drawing on the expertise that is available in the field and focus on collective efforts to increase effective knowledge transfer, reduce systemic marginalization, and equitably allocate resources.

Conclusion

In conclusion, as we consider the future of the IDD shared citizenship paradigm, it is important to emphasize that the overall goal of the paradigm is to further advance and focus on people with IDD as active agents in the mainstream of life and improve their person-referenced and valued outcomes, including their access to and opportunity for shared citizenship. As discussed in this article, the shared citizenship paradigm is guiding the development of policies and practices that help achieve this goal. Although the paradigm provides a new way of thinking, a clear vision of what is possible, and what needs to be in place for the goal to be achieved, the paradigm's acceptance and full implementation will require both a concerted effort and coordinated actions by a partnership of multiple constituents. These efforts and actions should be guided by the universal nature of the paradigm that includes engagement and full participation,

respect and being valued, equal rights, contribution to society, and full membership in all aspects of society.

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Table 1The Alignment of Core Paradigm Components with Current IDD-Related Policies and Practices

Core Paradigm Component	Description/Explanation	Exemplary Current Policies and Practices
Holistic approach to IDD	Incorporation of the four current perspectives on IDD into an integrative approach to IDD: biomedical, psychoeducational, sociocultural, and justice. Each perspective includes major concepts used, presumed locus of disability, identified risk factors, and related services and supports.	Risk factors and support strategies associated with each perspective on IDD Multidisciplinary planning/ treatment/support teams Multiple perspective model of etiology Integrative approach to IDD and its amelioration Multidimensional classification system Broad-based assessments
Contextual model of human functioning	A focus on human functioning and human functioning outcomes. The proposition that human functioning is the product of the interaction between the person and their natural, built, cultural, and social environments/contexts. The model leads to a context-based supports delivery system, and the use of context-based models of change.	Assessment of support needs Provision of personalized supports Interactive systems of supports model Individual Support/Program Plans that involve the individual in their development, implementation, monitoring, and evaluation Person-centered support teams Community-based and inclusive environments Family supports Multidimensional model of
Disability rights principles	Principles that involve equity, belonging, inclusion, empowerment, self-determination, and participation. Efforts to enhance the civil, human, and legal rights of persons with disability.	A policy framework that incorporates equity, belonging, inclusion, empowerment, self-determination, and participation. Examples include ADA, DD Act, IDEA, Rehabilitation Act, Rosa's Law, and international covenants such as the UNCRPD Advocacy models and activities

	Policies and practices that focus on self-direction and self-determination.	Legal protections and statutory entitlements Quality assurance standards and mechanisms An emphasis on personal outcomes Self-directed services and supports
Person-centered implementation strategies	Person-centered planning activities that incorporate disability rights principles, build on human capacities, and focus on the provision of systems of supports. Person-centered evaluation practices that focus on the assessment of support needs, employ broadbased assessment strategies, and use evaluation models that align the current understanding of IDD with individualized support strategies, and valued outcomes.	Person-centered planning that incorporates personal goals, support needs, and valued outcomes Positive support strategies that promote the development, interests, and self-determination of the person Evidence-based practices Person-centered outcome evaluation Human capacity and enhancement models Focus on human functioning Consumer involvement in ISP development, implementation, and evaluation, and in participatory research and evaluation approaches

Table 2Parameters of a Multidimensional Application Framework

Application	Multilevel Context-Based Application Strategies
Area	
Provision of	Microsystem:
Individualized	Tailor individualized support strategies to cultural identities
Services and	Employ systems of supports elements (i.e., choice and personal autonomy,
Supports	inclusive environments, generic supports, and specialized supports) that
	accommodate the person's adaptive behavior and intellectual function Base support planning on the individual's personal goals and the pattern and intensity of the person's support needs
	Emphasize self-direction and self-determination in the provision of
	individualized services and supports
	Mesosystem:
	Develop and implement Individual Support Plans that are based on the
	individual's goals and support needs, and aligned with specific support strategies and valued outcomes
	Ensure that the person is at the center of the development, implementation,
	monitoring, and evaluation of the individual's support plan
	Macrosystem:
	Increase awareness of the civil, human, and legal rights of people with IDD, and counter ableism and systems bias
	Develop policies, rules, regulations, and funding that are aligned with the above-referenced micro and mesosystem context-based application strategies
Organization	Microsystem:
Transformation and/or Systems	Base individualized supports planning on the assessment of the pattern and intensity of the individual's support needs
Change	Involve people with IDD through participatory research approaches
	Mesosystem:
	Foster an organization culture that incorporates the four components of the shared citizenship paradigm
	Develop policies and practices that empower and engage people with IDD in the transformation and change process
	Implement quality assurance metrics that include monitoring and evaluation practices
	Employ strategic execution/management strategies that include support teams, a commitment to outcome evaluation, and the use of person-referenced outcome information for quality improvement
	Macrosystem:
	Develop systems-level policies, rules, and regulations that are aligned with the above-referenced micro and meso-level context-based application strategies

Implement funding mechanisms that are aligned with the above-referenced micro and meso-level context-based application strategies

Evidence-Based Inquiry

Microsystem:

Assess personal outcomes along with personal characteristics

Operationally define and objectively assess specific support strategies Determine the relation among assessed personal characteristics, person-

referenced outcomes, and individualized support strategies

Use multimethod data collection and evaluation strategies and analyses to determine predictors of enhanced human functioning and personal well-being

Mesosystem:

Analyze Individual Support/Program Plans to determine: (a) the perspectives on IDD incorporated into the plan; (b) the type, frequency, intensity, duration, and effects of the individualized supports provided; (c) evidence of the incorporation of disability rights principles; and (d) the extent of person-centered implementation strategies

Evaluate the relation among quality assurance metrics, costs, and benefits Develop organization profiles that aggregate and summarize longitudinal changes in assessed personal outcomes, and use this information for quality improvement across contexts

Macrosystem:

Analyze organization and systems-level policies to determine discrepancies between the shared citizenship paradigm core components and current policies and practices

Engage people with IDD in setting the research and evaluation agenda and communicating impacts

Use aggregated individual and organization data to develop systems-wide profiles for reporting, monitoring, quality improvement, and policy development

Table 3Forms of Evaluation for Assessing the Impact of the Shared Citizenship Paradigm

Type of Evaluation	Most Relevant Core Paradigm Components	Evaluation Focus	Possible Research Design	Evaluation Standard
Principle-focused (Patton, 2018)	Implementation strategies Disability rights principles	Evidence of value-based implementation principles in current policies, practices, and	Participatory research designs (qualitative and quantitative)	Credibility (i.e., confidence in the truth of the evidence)
		models (Table 1-row 4). Evidence of civil, human, and legal rights in current policies, practices, and models (Table 1-row 2).	Qualitative designs (e.g., grounded theory, ethnography, case studies, emancipatory research)	Confirmability (i.e., extent to which the findings are shaped by the participants and not research perspectives and interests)
			Quantitative designs (e.g., document analysis, policy analysis, descriptive, correlational)	
			Mixed methods, including qualitative and quantitative	
Utilization-focused (Patton, 2008)	, Holistic approach to IDD	Individual level: Evidence of personal involvement in the development, implementation, and evaluation of Individual Support/Program plans	Participatory research that engages all members of the IDD community, including those from	Flexibility of paradigm- based/core components implementation
			marginalized groups	Transferability (i.e., demonstrating or
	Context model of human functioning	Organization level; Evidence that the paradigm's four core components are used in	Qualitative, quantitative, and mixed methods – see above	confirming that the paradigm and its core components can be utilized/implemented in

	Disability rights principles Person-centered implementation strategies	organization policies and practices related to assessment, diagnosis, classification, and planning supports Systems level: Evidence that public laws and statutes reflect and incorporate the four perspectives of IDD		multiple contexts/environments) Dependability (i.e., showing that the above-referenced flexibility and transferability are sustainable)
Outcome-focused (Gomez et al., 2021a; Gomez & Verdugo, 2016)	Context model of human functioning Disability rights principles	Individual level: Changes in valued personal outcomes resulting from the provision of personalized services and supports Organization level: The use of person-centered outcome data for multiple purposes including supports provision, reporting, monitoring, and quality improvement/ organization transformation across contexts Systems level: The use of aggregated personcentered evaluation data for multiple purposes including policy development, monitoring, quality	Descriptive information obtained from between group or within group designs and using bivariate statistics Comparative designs that test and evaluate the changes in outcomes Multivariate research designs such as multiple discriminant analysis, multiple/hierarchical regression analysis, economic analyses Multi-level analysis that analyze changes at the individual, organization, and systems level	Quality of the evidence (i.e., reliability and validity) Robustness of the evidence (i.e., statistical significance, effect size, percent of variance explained, predictive accuracy, explanatory power) Relevance and utility of the evidence

improvement, and system change

 Table 4

 Exemplary Strategies to Shape the Shared Citizenship Paradigm for the Future

Paradigm's Use	Exemplary Refinement Strategies
Develop policies, practices,	Involve people with IDD in all development activities to align with values of the shared citizenship paradigm
theories, and/or models	Critique and update Public Laws and organization and system-level policies and practices to ensure alignment
	with a contextual model of human functioning, and disability rights principles
	Implement Individual Support/Program Plan models that align personal goals and support needs with specific support strategies, and value-based personal outcomes
	Formulate IDD-related theories that are based on validated conceptual models that explain the impacts of various factors influencing IDD
	Design training and continuing education of staff and professionals on the core components of the paradigm
Align policies and practices across the micro, meso, and macro-system levels	Systematically align the service/supports delivery system both horizontally and vertically. <i>Horizontal alignment</i> positions the service/support delivery system components into a logical sequence for planning, implementing, monitoring, and evaluating. <i>Vertical alignment</i> ensures that at the "input" level, macro-system value-based policies are aligned with organization (i.e., meso system) resources, the service delivery framework, and administrative principles. At the "throughput" level, vertical alignment ensures that the service/support delivery framework and administrative principles are aligned with organization-level services, supports, and managerial strategies, and that individualized supports are provided. At the "outcome" level, vertical alignment ensures that outcomes associated with support provision, organization transformation, and systems change are conceptually and operationally consistent with core components of the IDD paradigm Align covenant and policy goals such as those proposed in the UNCRPD Articles with specific organization and systems-level support strategies and valued personal outcome indicators
Further the understanding of	Use the four perspectives on IDD to guide research studies that investigate the multidimensional and context-
IDD	based nature of IDD
	Conduct person-centered outcome research that uses a logic model that integrates and aligns a conceptual framework based on the core components of the IDD paradigm with individual services and supports and valued personal outcomes
	Use a multidimensional model of context to study and understand the dynamic nature of context, the impact of built environments (e.g., universal designs and assistive technology), and the public policy contexts in which IDD is addressed
	Use a context-based change model to guide research and evaluation studies that determine how best to unfreeze the status quo and drive organization transformation and systems change

Supplemental Material

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