Service Inclusion for the Wellbeing of People with Intellectual and Developmental Disabilities

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Abstract. People with disabilities still find it extremely difficult to fully participate in society despite the international community's strong commitment to inclusive and sustainable development. Through the lens of service science, we aim to frame the concept of service inclusion as a value-co-creation among the actors of the system supporting the well-being of people with intellectual and developmental disabilities (IDD). Based on a service-dominant logic, we establish linkages between service inclusion, the goals of sustainable development, and the socio-ecological context. We extract a conceptualization around the sustainability of inclusive services for the well-being of people with IDD, indicated by sustainable value co-creation and exchange through continued service availability across the spheres of interaction in the socio-ecological context. With this work, we extend the potential for a wider research agenda on service inclusion for the well-being of people with IDD, tied to service design practices that focus on the priorities of the people with IDD.

1 Introduction

“All of us do not have equal talent, but all of us should have an equal opportunity to develop our talent”; these words pronounced by John F. Kennedy relate to the issue of differences among people and highlight the importance of providing them with equal chances. An increasing body of evidence shows that inclusion for people with IDD, especially the youth, is an important development issue since persons with disabilities experience worse socioeconomic outcomes and poverty than persons without disabilities. Even with the international community's strong commitment to inclusive and sustainable development, it is still very difficult for people with disabilities to fully participate in society due to many challenges including unfavorable viewpoints, stigma, prejudice, and a lack of physical and virtual settings [1].

1.1 Motivation

Lack of opportunities is still a major concern among people with disabilities and most specifically among youth with intellectual and developmental disabilities (IDD). Many

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individuals with intellectual and developmental disabilities (IDD) live in isolation and lack substantial chances to engage in community life and from social networks. Even when people with IDD do have more autonomy and live in the community, their participation does not seem to be fully inclusive, rather often marginalized \[2; 3\]. The absence, lack or limited access to services seems to exacerbate the provision of inclusive services, especially in low- and middle-income countries leading to exclusion \[4\]. This affects all aspects of public life and their wellbeing.

Practical strategies are proposed to advance community inclusion for people with IDD. These strategies recommend a human rights approach to person centered planning, incorporating evidence based practices and participatory action research to increase community action advocacy \[5\]. Our work looks at the problem from a different perspective. Through the lens of service science we aim to frame the concept of service inclusion as a value-co-creation among the actors of the system \[6\] supporting the well-being of people with IDD. We therefore seek an answer to the question: “What are the foundations of service inclusion for the wellbeing of people with IDD?”

2 Methodology

This paper adopts a descriptive methodology which helps to provide an in-depth understanding of the main components and theories that affect the establishment of an inclusive service delivery system to improve the wellbeing of people with IDD, in particular the youth. It describes how the interconnectedness of these entities contribute to the sustainability and strengthening of inclusive systems by embracing the service imperative that leads to improving people’s quality of life \[7\]. We draw on service-dominant logic and socio-ecological theory as theoretical lenses to inform engagement research.

We hence establish a mapping and a linkage between the socio-ecological contexts of Bronfenbrenner's Ecological Model and the sustainable development goals in a way to align the inclusive services with socio ecological levels and major sustainability challenges as stated by the United Nations agenda 2030. Our objective is to provide a potential framework for value co-creation through the exchanges between the socio-ecological spheres. Furthermore, the interpretation and examples provided offer a broad perspective on how the interactions between service entities influence the well-being and the quality of life defined as value co-creation in the case of people with IDD.

The next section lays the foundation for the paper on the connectedness of the concepts of service science, inclusion and the socio-ecological context. Then we follow with a section that illustrates the framework of value co-creation among the socioecological spheres. That leads us to the concept that aligning sustainable healthcare and education that rely on resilient and intelligent infrastructure to promote wellbeing among people with IDD, through the enablement of meaningful and value creating interaction within the close society, community and the environment (economic and natural) to sustain the viability and wellbeing of people with IDD.

3 Background

IDDs are differences that are typically present at birth and that have a particular impact on how a person develops physically, intellectually, and/or emotionally. Any time before the age of 18, a kid can develop intellectual disability, which is characterized by difficulties in the ability to study, think and solve problems, and a challenging adaptive behavior including daily social and life skills. A broader range of frequently lifelong difficulties that can be intellectual, physical, or both is referred to “developmental disabilities.” Instances of
intellectual impairment and other disabilities are frequently referred to as "IDD" circumstances [8].

3.1 Service Science and Inclusion

Service science combines the knowledge within a system to define how service systems interact and evolve to co-create value with the goal is to improve our ability to design, improve, and scale service systems [6]. At the core of service science, a service dominant logic argues that in order to create value, actors engage in interdependent and reciprocally beneficial resource integration and service exchange [9]. Service science for people with IDD must focus on their needs. In other words, the service must include a person with disabilities and remove barriers to participation from all actors in the ecosystem, addressing vulnerabilities and enabling the way that provides actors with fair access, fair treatment during a service and fair opportunity to exit a service [10]. Enabling opportunity in various service contexts, offering choice, and relieving suffering and fostering happiness, is known as service inclusion [10].

The process of inclusion uses diversity as a resource to enhance the ability of a community to include all its members and avoid excluding any of them, leading to inclusiveness. Inclusive services need to be designed to facilitate transition points in the lives of disadvantaged people and address the challenges of accommodating increasingly diverse human needs (e.g. mobility issues, hearing difficulties, disabilities, etc.). This must occur within and across micro-meso-macro structural levels to enhance the resilience and sustainability of the contextual social-ecological spheres. Inclusive services are transformative services aiming to create uplifting experience towards the well-being of individuals, communities, and ecosystems [11]. Therefore, service inclusion reflects a paradigm shift toward greater levels of understanding of service systems and its core function in promoting human well-being [11].

3.2 Service Science and the Socio-Ecological Context

We start our reasoning with the acknowledgement that value, in our case, is the ability to maintain and increase wellbeing of people with IDD, where the actors live in the spheres of interaction in the socio-ecological context.

Bronfenbrenner [12] divided the person's environment into five different socio-ecological contexts: the intrapersonal and individual sense of wellbeing (microsystem), the Interaction within the close society, such as with friends and family (Mesosystem), the community, formal and informal social structures (exosystem), the socioeconomic status, wealth, poverty, and ethnicity (macrosystem), and the environmental changes that occur over the lifetime (chronosystem). In their close environment, parents of young people with IDD need the proper services and assistance to maintain the health, safety, and wellbeing of both themselves and their kids. When supporting services are tailored to their learning capabilities and capacities, living situations, and communities, people with IDD and their families can succeed. Appropriate resources for these families are still lacking [13]. Over the past two decades, knowledge, skills, and abilities of youth service practitioners are recognized as the centerpiece of a successful workforce development system [14]. We have witnessed the transformation of services to encourage community participation through activities that promote interaction between the youth with IDD, their parents, the community. Examples are found in healthcare [15]; recreation activities [16]; education [17]; and living spaces [18], with concerted efforts in including marginalized communities in urban development and smart cities [19]. Inclusive communities, having full and equitable access to activities, social roles, relationships, and community belonging and membership, recognize people with
intellectual and developmental disabilities (IDD) and their families, ensure equal opportunity for full participation in community life, and promote a sense of full belonging [20]. As a result, people with IDD, benefit from networks and connections, physical and mental wellness, as well as optimal quality of life [21].

The latter has been connected to fairness, inclusion, sustainability and resilience², as drivers of satisfaction experienced by an individual, in their “perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”³. Interpersonal relations, social inclusion, personal development, physical and material well-being, are cornerstones of quality of life of people living with IDD [22].

### 3.3 Discussion

The environment of a person with disability has a significant impact on the experience of disability and extent of inclusion. A sustainable service is essential for the wellbeing of people with IDD, especially the youth [23]. Once we establish a service in its context, we must assure the continuity of this service, especially for the underserved population that is completely dependent on the sustainable value offered by the service. The lack of sustainability in environmental factors, such as safe water and sanitation, nutrition, poverty, working conditions, climate, or access to health care, can adversely affect the wellbeing of people with IDD. Inaccessible environments create a form of disability by creating barriers to participation and promoting exclusion.

The convergence between service science and sustainability science helps integrate resources and value that align with the co-creation of sustainable services [24]. The intersection of the two thrives on the knowledge exchange between actors and systems to ensure that the service continues to provide value, even faced by disruptions related to changes in the resources available for the service, and the resilience of the social-ecological context. Therefore, in the context of people with IDD, sustainability science inspects global, societal, and human systems interactions, develop the intricate mechanisms that cause these degrading systems to become resilient, and continue to create value in the form of well-being, even under the associated hazards of disruption.

In practice, the 17 Sustainable Development Goals (SDGs), promoted by the UN, offer an opportunity to align the necessity of inclusion at local, national, and global scales while defining major challenges for sustainability [25]. We therefore suggest a mapping between the concept of socio ecological context and the SDGs (Table 1) to reveal how sustainability of the services that affect IDD wellbeing relies on inclusive services across the spheres of interaction in the socio-ecological context.

Evidently, the United Nations organization recognizes the importance of supporting sustainability for people with disabilities [26], especially in reduce inequalities (SDG 10), making cities inclusive (SDG 11), providing equitable quality education (SDG 4) and ensuring sustainable economic (SDG 8) through the strengthening of global Partnerships (SDG 17). Furthermore, sustainable wellbeing for people with IDD requires fair opportunities for flourishing through reducing poverty (SDG 1) and hunger (SDG 2) and ensuring healthy lives (SDG 3), with inclusive education (SDG 4). This includes promoting inclusive and sustainable economic growth (SDG 8), building sustainable communities (SDG 11), with resilient infrastructure to promote inclusive services (SDG 9).

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² [https://www160.statcan.gc.ca/infosheet-infofiche-eng.htm](https://www160.statcan.gc.ca/infosheet-infofiche-eng.htm)
³ "WHOQOL: Measuring Quality of Life". World Health Organization.
Table 1. The concept of socio ecological context and the SDGs.

<table>
<thead>
<tr>
<th>UN – Sustainable Development Goals</th>
<th>Suggested Socio Ecological Context</th>
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<tbody>
<tr>
<td>SDG 3 - Ensure access to health and promote wellbeing</td>
<td>Individual Sense of Wellbeing</td>
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<td>SDG 4 - Inclusive and equitable quality education</td>
<td>Interaction Within Close Society</td>
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<td>SDG 5 - Gender equality</td>
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<td>SDG 10 - Reduce inequalities</td>
<td>Community</td>
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<td>SDG 11 - Cities inclusive and safe</td>
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<td>SDG 16 - Peaceful and inclusive societies</td>
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<tr>
<td>SDG 1 - End poverty</td>
<td>Socioeconomic Status</td>
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<tr>
<td>SDG 2 - End hunger</td>
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<td>SDG 7 - Access to affordable energy</td>
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<td>SDG 12 - Sustainable consumption and production</td>
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<td>SDG 8 - Sustainable economic growth</td>
<td>Environment (Growth)</td>
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<td>SDG 17 - Strengthen global Partnerships</td>
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<tr>
<td>SDG 6 - Sustainable management of water and sanitation</td>
<td>Environment (Resilience)</td>
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<td>SDG 9 - Resilient infrastructures for inclusive and sustainable industrialization</td>
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<tr>
<td>SDG 13 - Climate change</td>
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<td>SDG 14 - Promote sustainable use of water ecosystems</td>
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<td>SDG 15 - Promote sustainable use of terrestrial ecosystems</td>
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Therefore, sustainability of inclusive services for the well-being of people with IDD is indicated by a sustainable value co-creation and exchange through a continued service availability across the spheres of interaction in the socio-ecological context (Fig. 1).

A complexity in the sustainability paradigm is that all SDG are connected. To illustrate concepts of sustainability in value co-creation through service inclusion for the wellbeing of people with IDD, we expand on the contexts of healthcare (SDG 3) at the individual level, where the service ecosystem must ensure access to health to promote wellbeing, for example.

The concept of socio ecological context then extends towards the “meso-structural levels” to enhance the resilience and sustainability by providing inclusive and quality education (SDG 4) for valuable interaction and social equality, through equal opportunity (SDG 5), where the actors in the value exchange are schools, educational institutions, family, and the close societal structure. At the community level, we can then rely on the community level interaction, where those actors such like technology, public resources and community institutions assimilate into creating smart cities, peaceful and inclusive societies (SDG 16), to reduce inequalities (SDG 10) aimed at incorporating the needs of people with IDD.

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4 https://sdgs.un.org/2030agenda
Further, institutional production sources, transportation, telecommunication, financial resources, for example, become value exchange actors, with the potential of elevating the socio economic status (e.g. social determinants of health) of people with IDD, including reducing the financial burden (SDG 1), providing good nutrition (SDG 2), with access to affordable energy and sustainable sources (SDG 7 & 12). Finally, our framework in figure 1, recognizes that a focus on sustainable management of water, sanitation, natural environment and terrestrial ecosystems, by public services, governmental agencies, legal and governance entities, can ensure a better quality of life for people with IDD, leveraging the enabling role of resilient and intelligent infrastructures (SDG 9).

### 3.4 Sustainable Health Care to Promote Well-being of People with IDD (SDG 3)

Ensuring healthy lives and promoting wellbeing remains a primordial goal to achieve for people with disabilities and particularly youth with IDDs. Young people with IDD have different healthcare requirements than the general population their transition from pediatric to adult healthcare constitute an important phase in their healthcare plan [27]. Difficulties to access health services and transition from stages of care [27] reduce their potential of healthy lifestyles [13]. Major obstacles still include a lack of financial resources, difficulty accessing and using medical facilities and transportation, and insufficient training of health professionals to provide for the needs of people with disabilities have caused ~50% of people with impairments have a need for health care services that are not being supplied [28]. In an inclusive service, treatment must be provided without disruption caused by numerous health, personal, and environmental factors that may influence the sustainability of the service [29]. For instance, a lack of access to affordable nutrition and opportunity for physical activity are disruptions that must be considered in designing an inclusive service for people with IDD [13]. An IDD inclusive service ecosystem must incorporate competitive and recreational sport activities as means of enhancing self-esteem and healthcare [30] and create value in the well-being of people with IDD.

### 3.5 Sustainable Education to Promote Well-being of People with IDD (SDG 4)

People with disabilities continue to be less likely to attend school and finish their elementary education. Youth with IDDs still experience many challenges including educational disparities due to stigma regarding their reduced abilities to transition through the phase of their lives [31] and a lack of opportunities and accommodations in higher education [32]. An
inclusive and sustainable service in education must promote lifelong learning opportunities for the most vulnerable, including people with disabilities, with equal access to all levels of education and vocational training, addressing their fundamental challenges of moving on from high school into the next stage of their lives [32]. The educational socio ecological spheres are not prepared for the challenge to work with students with IDD and teachers express negative attitudes about their ability to teach in inclusive classrooms, therefore falling short from assuring a sustainable education service and substantially contributing to the less than optimal student results [33]. A sustainable educational service for IDD must reform and transform the educational ecosystem to engage with pupils who have disabilities, potentially enhancing inclusive practices in pre-service teacher education programs [34], to improve sustainable value co-creation within the education ecosystem of people with IDD.

3.6 Resilient and Intelligent Infrastructures to Promote Well-being (SDG 9, 11)

Despite the significant progress in the past ten years to emphasize services that provide inclusive opportunities for employment to those with intellectual and developmental disabilities, employment results have barely changed [11]. Social welfare and service delivery people with disabilities seek to ensure access to better services, employment possibilities, and greater assistance [26]. In particular, young people with disabilities need to have full access to excellent services in inclusive settings in order to optimize their chances of leading independent lives and finding work in the future. Unmet needs for support may relate to everyday activities – such as personal care, access to aids and equipment, participation in education, employment, and social activities, and modifications to the home or workplace. The literature suggested technology accessible services designed for users with disabilities to improve inclusion by improving access [35]. However, technology literacy among people with IDD continues to be a significant barrier [36]. Service innovations that include smart technologies, emphasize inclusion of individuals with disabilities with person-centered models of care, for example, have improved the ability of patients to take ownership of their health, availing them intelligent systems to help them make knowledgeable decisions about how to manage their health requirements, without disrupting their capabilities [37]. These inclusive services co-create value for the IDD population, by promoting the customization of treatment and demonstrate an understanding of the necessity of humanizing principles as the cornerstone of care practices, such as empathy and respect for people's dignity, agency, and uniqueness, sense of place, personal journey, and holistic well-being [38].

4 Closing Remarks and Contribution

Social-ecological systems theories and sustainability science share a common goal of fostering transformation toward the sustainability of well-being [39]. Sustainability science provides the adjustments required to achieve a sustainable well-being, through an approach that taps local stakeholders in the co-production of knowledge and active interventions to transformation services to inclusive services. Numerous activities across the globe are contributing to these transformations. For a service to be inclusive, extensive planning is required [40], and a focus on building awareness is essential [41]. We can expect that a successful service inclusion roadmap for people with IDD will not be possible without taking transformation to the levels of inclusive policymaking, and governmentally supported funding [42, 43].

The ability to maintain and increase wellbeing of people with IDD depends on having a connection to and sense of belonging in a socio-ecological context; it is relevant not only at the individual level but also at the communal levels of society. Services like education and
health care, for instance, may have also a significant influence on family units and local communities. There is therefore a need for mobilization of unprecedented levels of resources to support the realization of the Sustainable Development Goals (SDGs), targeting sustainable and just economies, food systems and healthy nutrition patterns, universal access to energy, sustainable urban and peri-urban development for strengthening human well-being, inclusion and capabilities [44]. The SDGs can offer a normative framework for the developing field of sustainability research into practice. Costanza et al. [45] have associated the success of the 17 Sustainable development goals (SDGs) with the efficient allocation of resources, in a fair distribution and at a sustainable scale. Based upon our paper’s reasoning, this translates in the acknowledgement that, for a service to be IDD inclusive, i.e. provide an ecosystem for sustainable wellbeing (in the form of value co-creation), it must embed approaches for fair, efficient and scalable allocation of resources.

We established foundational concepts of service inclusion for the wellbeing of people with IDD, grounded in service science and socio-ecological theory and intersecting with the 2030 sustainable goal agenda of practice. With this work, we extend the potential for a wider research agenda on service inclusion for the wellbeing of people with IDD, especially the youth. We tied the concepts of service continuity and sustainability to value realization through service design practices that focus on the priorities for the people with IDD. We have also connected the socio-ecological context to suggest that future research takes into account the wider context of inclusive service design. Our conceptualization in fig 1. ought to be an inspiration for researchers to consider elements of each ecological context in their research.

References


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