Smart Cities for People with IDD - Foundations for Digitally Inclusive Healthcare Ecosystems

Nabil Georges Badr*

Higher Institute for Public Health, Saint Joseph University of Beirut, Beirut, Lebanon

Abstract. Smart cities require smart healthcare. In a smart city, the purpose of citywide efforts has the fundamental objectives of livability, sustainability, and productivity. Some well-intentioned smart city programs unintentionally worsen inequality when they lack transparency, fail to involve the community or ignore the varied requirements and preferences of residents. To address ongoing health disparities among persons with intellectual disabilities, patient-centred preventive healthcare that considers both their physical and mental health needs must be prioritized. Engagement and inclusion must at the forefront of smart city initiatives that shift from being technology-centric to citizen-centric. We bring attention to pillars of interaction in inclusive smart cities in the context of care for people with intellectual and developmental disabilities. We explore the fundamentals of a digitally inclusive healthcare service ecosystem for people with IDD through the lens of the Actor for Actor framework to learn about the foundational facilities for IDD patients' to engage an establish care pathways.

1 Introduction

The notion of inclusive healthcare ecosystems is strongly represented within the sustainable development goals identified by the United Nations. These goals strengthen the resolution of the Convention on the Rights of Persons with Disabilities adopted in 2006. Thus, the subject of disability is an essential component of sustainable development and integral to at least five of the 17 Goals as SDGs. Specifically related to healthcare (Goal 3) education (Goal 4); growth and employment (Goal 8); social, economic and political inclusion of all, including persons with disabilities (Goal 10); to inclusive safe and sustainable cities (Goal 11); as well as the overarching goal of data collection and monitoring of the SDGs (Goal 17). Healthcare is an essential component of the 2030 agenda of the United Nations’ Sustainable Development Goals (SDGs). Concerning "Good Health and Well-being", SDG 3 has the

* Corresponding author: nabil@itvaluepartner.com
2 https://sustainabledevelopment.un.org/content/documents/2738sustainabilityfinalweb-.pdf

© The Authors, published by EDP Sciences. This is an open access article distributed under the terms of the Creative Commons Attribution License 4.0 (http://creativecommons.org/licenses/by/4.0/).
objective to ensure healthy lives and promoting well-being for all at all ages. Guiding principles for SDG3 define the scope of equitable access to care for persons with disabilities and the removal of discriminatory barriers that prevent full access to health-care services. In order to support the SDG 2030 agenda, individuals, companies and governments must invest in digital accessibility, proposing initiatives that encourage inclusion and social wellbeing. Digital accessibility is a cornerstone to removing barriers that prevent interaction with, or access to digital tools and technologies, by people with disabilities. Leadership in digital accessibility can inspire much needed transformational change for people with intellectual and developmental disabilities. Digital inclusion and fairness should be considered while designing cities to promote a barrier-free, digital urban logic. That is, smart cities need to get smarter to include the underserved populations, in our case, people with intellectual and developmental disabilities (IDD), especially in providing access to equitable care.

Inclusion of people with intellectual disability in cultural and civic activities is an important point for discussion, particularly in the context of supporting the social sustainability of our local communities and cities. While inclusion is the idea that everyone should be able to use the same facilities, take part in the same activities, and enjoy the same experiences, including people who have a disability or other disadvantage. People with intellectual disabilities may find it difficult to participate in community activities, despite their best efforts. The literature provides chances to investigate how persons with intellectual disabilities' particular preferences might be correlated with structure and degrees of involvement to increase social inclusion in their local communities and to develop inclusive cities. Critical studies and discussions of inclusion and accessibility have been offered, not least on topics such as universal service, digital divide, community networking, information technology development, and technology accessibility design. Although there has been much work over the past two decades in understanding disability and in conceptualizing and critiquing inclusion and how it is produced through policies, practices, and technologies, we still lack answers to, and indeed workable strategies for foundations for digitally inclusive healthcare ecosystems.

1.1 What are Intellectual and Developmental Disabilities (IDDs)

Intellectual and developmental disabilities (IDD) are characterized by differences with both intellectual functioning or intelligence, which includes the ability to learn, reason, solve problems, and other skills, and adaptive behavior, which includes everyday social and life skills, and can begin at any time in early childhood.

IDDs are variations that are typically present at birth and that have a particular impact on how a person develops physically, intellectually, and/or emotionally. Many of these ailments have an impact on numerous organ systems or body parts. It may be degenerative. A larger range of frequently lifelong difficulties that might be intellectual, physical or both is referred to as "developmental disabilities." IDD sufferers frequently experience neurological disorders, which can impair cognition and learning. Additionally, these disorders may result in behavioral problems. IDD users frequently experience neurological disorders, which can impair cognition and learning. Other problems including behavioral disorders, speech or language challenges, seizures, and mobility problems can also be brought on by these illnesses. IDDs with nervous system issues include cerebral palsy, Down syndrome, and autism spectrum disorders (ASDs). Others with IDD report that these illnesses have an

5 https://sdgs.un.org/goals/goal3
6 Cambridge Advanced Learner's Dictionary & Thesaurus © Cambridge University Press.
impact on their metabolism, senses (sight, hearing, touch, taste, and smell), or how the brain processes or interprets sensory data.

1.2 Motivation

The future of kids with IDD enjoying a full life and thriving depends in large part on health equity. It is evident that, to do this, a number of contextual elements that affect health outcomes must be taken into consideration. The demand on currently available services for this population of children with severe medical requirements is increasing, which puts more strain on families to provide intensive, continuing care at home with no assistance or respite. There was some worry about the rise in children presenting with IDD as well as the rise in children with more complicated medical demands or illnesses with a shorter lifespan. The already overburdened services for children with disabilities are coming under extra strain as a result of these population patterns.

“It is more important to know what sort of person has a disease than to know what sort of disease a person has”. A quote that was attributed to Hippocrates, the father of medicine, more than 2500 years ago, is never more important than in our present day.

To address ongoing health disparities among persons with intellectual disabilities, patient centered preventive healthcare that considers both their physical and mental health needs must be prioritized. Finding specialized professional services can be difficult, and the rising cost of living has put a financial pressure on many people [6]. In the literature, inclusive smart cities must be “accessible,” “adaptable” as well as “affordable” [7].

We ask ourselves the question of “What does that mean for people with IDD — what services must health ecosystems provide for inclusive care in Smart Cities? This paper explores potential service and social innovations for IDD inclusive smart cities.

For this work, we start by introducing the concepts of smart cities, equitable care and people with IDDs to lay the conceptual foundation of inclusive smart cities and care journey for people with IDD. Then, through the grounded in the theory of value co-creation and service dominant logic [8], this manuscript proposes a conceptual framework for expressing the complex dynamics that are shaping actual conditions in healthcare for people with IDD.

To understand the engagement model of an inclusive health care service ecosystem, we look for answers through the Actor-for-Actor (A4A) lens to unpack a potential for IDD patients' to engage, through meaningful interaction to establish adaptive care pathways [9].

2 Background

2.1 Smart Cities, equitable care and people with IDDs

In a smart city, the purpose of citywide efforts have the fundamental objectives of livability, sustainability and productivity. Livability is in the interest of all key actors, residents and end users, urban professionals, technology and other firms central and local governments benefit from enhanced livability. Although livability is broad in concept, safety, quality of built environments, the convenience of public facilities, accessibility to services including healthcare are keys to livability [10]. Further, the sustainability of smart cities is often assisted by new technological inventions that provide the basis for renewal, continuity and equity in the services that drive social innovation ideas, concerned with improving and empowering underprivileged groups [11]. For a sustainable smart city, an adaptive capacity is becoming more and more important, requiring timely innovation technological and social innovation [12]. This leads to improved productivity where all actors, including the underprivileged can produce higher values that can be reflected in citywide economic
growth. When cities attract skilled knowledge workers, they can bring new ideas, innovation, and prosperity [13].

Cities are using digital technology to regulate urban life and facilitate urban experiences for the benefit of the inhabitants and business. New technologies and digital services, together with the enthusiastic participation of interested individuals, have been viewed as essential elements in smart cities because they connect service providers, consumers, infrastructures, and communities in a single ecosystem to facilitate value co-creation. Some well-intentioned smart city programs unintentionally worsen inequality when they lack transparency, fail to involve the community, or ignore the varied requirements and preferences of residents. Engagement and inclusion are at the forefront of smart city initiatives that shift from being technology-centric to citizen-centric; enablers include data and security, digital and technology, ecosystem, money and funding, internal structure, and policy and regulation. Modern smart cities combine data, digital technology, and human-centered design to encourage decision-making among all local stakeholders, including people, businesses, and other interested parties as well as by the government. Taking this democratization of urban development a step further, some communities are encouraging locals to co-create solutions to neighborhood issues by providing them with the necessary tools, training, and information.

By standardizing digital access, promoting digital inclusion and fairness, building shared, multifaceted stakeholder commitment, improving regulatory urban performance, and putting persons with disabilities (e.g. people with IDD) at the center of smart projects, cities may become more inspirational, livable, and compassionate [14].

### 2.2 Inclusive smart cities and care journey for people with IDD

Smart cities require smart healthcare. Medical care is critical for smart city growth, so assuring high-quality (equitable) medical care for all constituents is the most difficult goal for city governments to achieve [15].

Healthy people must have access to primary care, healthy food and environment, transportation, income levels, social support, health insurance coverage, and health literacy. People who haveIDDs face obstacles to health care access, such as problems with communication and a lack of participation, making it challenging to deliver this type of treatment to a high standard, often leading to a shortened lifespan. Therefore, it can be challenging for young people with intellectual and developmental disabilities to move between phases of care, navigate the healthcare system, and find support. Key findings of studies about people with intellectual disabilities have indicated an overwhelming difficulty in articulating emotions. They require additional assistance to navigate the system and access proper care. Practitioners are developing tip sheets for engaging people with IDD, recommending keeping communication simple, using visual aids, respecting the person’s choice of language or terminology.

The literature recommended technology accessibility design for users with disabilities, where persons with disability, are included in the design process. However, technology continues to be a major obstacle for many individuals with disabilities in accessing the digital city. A more person-centered, humanizing approach of healthcare delivery has lately emerged shifting the paradigm of care, focused on people with disabilities. Person-centered or patient-centered models of care enable patients to make educated decisions about how to manage their health requirements, improve the customization of care, and empower patients to share responsibility for their health. This reflects a realization of the

---

significance of humanizing values, such as empathy and respect for people's dignity, agency, individuality, sense of place, personal journey, and holistic well-being, as the foundation for care practices [21].

### 3 Methodological Approach

Service Science is an interdisciplinary effort to understand how service systems interact and co-create value [22]. Value co-creation is therefore conceptualized through the exchange of services among configurations of actors, focusing on service ecosystems [23], including institutions, humans, societies and those technological actors. This Service-dominant (S-D) logic bears the fundamentals that logic that humans apply their competences to benefit others and reciprocally benefit from others' applied competences through service-for-service exchange [8]. The development of this ecosystems perspective allows a more holistic, dynamic, and systemic perspective of value creation, emphasizing the contribution of all actors in the S-D logic. To that effect, service-dominant ecosystems, such as healthcare ecosystems, look at value as something created by multiple actors in an integrative approach and coordination of services for value exchange with the premise that service is the essential component of the exchange [24]. Ecosystems include human and non-human actors (such as technology) that integrate resources and exchange of service, establishing a foundation for dynamic adaptation [9].

Healthcare may be envisioned as a complex ecosystem based on the interactions of many entities [25]. It must adjust its agenda to the community's unpredictability and include the anticipated value creation from all players, including those with IDD. The difficulty is in adapting particular characteristics to cope with the alignment to given services and service procedures for diverse demands [26]. The same institutional logic that underpins healthcare ecosystems promotes resource integration and re-bundling processes as a means of assuring sustainability and the well-being of all stakeholders [27].

Therefore, our topic under investigation is around essential technology based services that health ecosystems must provide for inclusive care in smart cities. We set the stage for our work on the concept equitable care and people with IDD. Then use the Actor-for-Actor (A4A) approach to uncover the potential for IDD patients' to engage, through meaningful interaction and establish care pathways [9]. We believe that the A4A model establishes a contract within the healthcare ecosystem for value co-creation based on actors integrating their resources and acting with intention to obtain value by providing benefits to each other, thus including each other into the value delivery.

#### 3.1 The Actor-for-Actor (A4A) relationships

The A4A relationships involve value co-creation based on actors integrating their resources and acting intentionally to obtain value by benefiting other parties and by being a part of the emerging viable system; actor acts for other actors directly involved in the relationship generating positive effects for the entire system in which it is contextualized. To comprehend this value chain, the A4A model represents interactions among ecosystem participants, in a cyclical of A4A stages (Fig. 1), while concentrating on the structural prerequisites for actors' connections and involvement as well as the system determinants and their commitment to the value of delivering equitable care for the underserved patients with IDD.
Fig. 1. A4A relationships [9].

The A4A cycle starts with a situation where each actor becomes interested and 'engaged' in a given role within the care ecosystem (A4A - Actors’ Engagement). It is possible to see continual interactions that are initiated by the alignment of objectives and shared purpose among all parties engaged after the first "connection" of significant players has resulted in the beginning of the engagement.

This knowledge contributes to the process of identifying the numerous spheres of interaction that may have an impact on the outcome of the interaction (A4A - Subjective Awareness).

The development of these should result from an understanding of the differences that affect each actor in terms of inclusion, equity and ethical limits so that there is empathy, trust, and support for all parties engaged to maintain focus on the shared objectives and purpose (A4A - Shared Intentionality).

When all parties involved collaborate, out of a sense of mutual satisfaction (implicit or explicit), they can work toward shared objectives and close potential gaps (A4A - Alignment of Finality).

During the subsequent stage of service transformation, every aspect of the healthcare system, including practitioners, patients, caregivers, information systems, governments, law and payment systems, delivery design, assessment, patient engagement/democratization, training, and research, cooperate to enhancing the value and equity of healthcare (A4A – Resource Integration).

Regardless of difficulties, capacities and social challenges, or other factors that may restrict a patient’s ability access care, resources must be integrated to offer continuous and accessible care to all groups of patients once a care choice has been made.

Finally, the integration of resources is essential for a system of actors to produce an outcome that cares for the ever evolving patient’s case (A4A – Emergence in Action). The cycle of engagement starts again with a new context to support the transformation strategy needed for sustainability and continuity until the outcome is recognized.
4 Looking through the Lens of Actor-for-Actor (A4A) Approach

4.1 Actors’ Engagement

The roles of the actors involved in healthcare processes are continuously being redefined from the standpoint of new dimension of value-based healthcare, the inclusion of patients with IDD. Actors of the inclusive smart city must emerge with a barrier-free, digital urban logic intended to close the digital gap and create a digitally inclusive ecosystem. Consequently, actors in an inclusive equitable healthcare ecosystem, become interested in the connection between all people’s access to and understanding of health services and their own health. Actors must participate in building inclusive cities by collaborating to create a shared experience of inclusion, with the goal of delving into the processes and experiences of people with intellectual disabilities, as well as community group leaders, and mapping pathways to a continuum of participation [28]. The emergence of a shared intentionality and evidence based decisions for action aim to sustain inclusive societies. Consequently, value co-creation within the ecosystem contributes to mainstreaming and building inclusive public services that are welcoming and accessible to people with intellectual disability throughout the city [5]. Capacity-building initiatives that build inclusive cities for and with people with intellectual disability are therefore possible10.

4.2 Subjective Awareness

Including people with IDD in a smart health service system, requires a better understanding of how to promote health among those in the IDD population, which often linked to the ability to monitor the life and risk factors of the youth among IDD sufferers [29]. Healthcare providers must be aware about the needs of people with IDD, some literature even advocates establishing systems of care that integrate acute healthcare with long-term services and support, developing IDD medicine as a specialty [30]. After the first 'connection' of important actors has led to the start of the engagement, it is imperical to observe ongoing interactions, which are triggered by the alignment of aims and common purpose among all parties involved. Substandard access to care (leading in insufficient treatment and a higher risk of complications), lower quality of care, and poorer self-care practices, for example, are all part of a postulated causal link between lower socioeconomic level and poor health care outcomes (including diet, exercise). When the context in which this engagement takes place is populated by multiple actors whose behavior can directly or indirectly influence (on the other hand, in a reciprocal manner) the engagement, such awareness becomes a part of recognizing various spheres that can influence the success of the engagement. Therefore, clinicians, payers, and other healthcare stakeholders must be able to comprehend how non-clinical variables influence the health trajectories of the patients they care for if population health and cost management are to be successful and equitable. This awareness becomes part of recognizing various spheres of equity that can influence the success of the engagement.

4.3 Shared Intentionality

A focus on health-care equity ensures that a health-care system is designed to decrease inequities in health-care processes and outcomes, especially for people from low-income families. All aspects of the health-care system, from law and payment systems to delivery design, assessment, patient engagement/democratization, training, and research, should be

aligned with improving health-care value and equity during the next stage of transformation [31]. For the care of people with IDD, the necessity for caregiver respite is well-documented. For example, through “complementary caregiving” activities that encourage involvement and educational possibilities for a care recipient (CR) with IDD, Social Assistive Robotics (SAR) hold promise in alleviating the need for caregiver respite [32]. In other cases, the use of robots could be an agent of personal privacy and dignity for those with intellectual disabilities, who need ongoing assistance with everyday activities [33]. Recognizing the distinctions that influence each agent in terms of equity and ethical boundaries should lead to developing these so that there is empathy, trust, and support for all parties involved to keep focused on the common goals and purpose. A human-centered approach to healthcare service design builds on transformative service research and emphasizes the notion of service inclusion to highlight the necessity for improving the welfare of people with restricting biophysical or psychological features [34].

4.4 Finality Alignment

The potential for certain interventions to improve health care outcomes by addressing patient resource, communication, and navigation barriers; these interventions are often facilitated by technology and are dependent on (1) disease or condition type; (2) phase of the care process; and (3) technology accessibility in many cases [35]. Studies reveal that medical professionals do not believe they are sufficiently trained to assist people with an intellectual impairment issue [36]. The training and equipment required to meet the needs of persons with IDDs in an equitable and empowering manner may not be available to health care professionals who provide some kind of health or social care assistance to people with IDDs [37]. Complexities include short consultation times, multi-morbidities (which can also make the care needs of people with IDDs more complex), a lack of health education, inadequate training for healthcare professionals [38], their negative attitudes [39], and the requirement for complex patient-caregiver-physician interaction [40]. Health care providers must have the skills and ability to initiate change and define the future of their discipline and practices for developing high-quality care inside the digital ecosystem in order to help shape these new practices [41]. When all parties involved cooperate because they believe that working together will result in mutual satisfaction (real or perceived), they can work toward common goals and bridge gaps.

4.5 Resource Integration

Once a care decision has been made, resources must be integrated to provide accessible and ongoing treatment to all patient groups, regardless of location, social issues, or other limitations that may limit patient movement to the point of care. The measures suggested by studies to decrease health inequalities for persons with IDD include developing a better method and systems to monitor and treat chronic illnesses common in the general population that are also experienced by people with IDD [42]. In the bulk of these systems, communications technology is the underlying facilitator for patient-clinician connection, which, due to its relative ease of use, low cost, and ubiquitous nature, has the ability to create health care solutions that transcend socioeconomic class. For example, using telemedicine to treat numerous contagious diseases promotes continuity of care while preventing physical contact, allowing all actors to participate, reducing the access gaps and improving patient outcomes [43; 44]. However, the technical gap in the patient population must also be addressed [45]. Patients who do not have cellphones, for example, can still communicate with care professionals via SMS. Older people, on the other hand, have restricted access to internet-based services due to their low socioeconomic status and computer capabilities; this disparity around telemedicine may exacerbate mental health issues and widen global health
disparities [46]. Trust in technology, design, cognitive impairment, and physical limitations such as poor vision, hearing, or sensory impairment are among issues that telemedicine for the elderly faces [47].

4.6 Emergence in Action to Adapt and Refine

Service inclusion gives service-seeking actors equal access to the service, safeguards must be developed against “deliberately or unintentionally failing to include or to adequately serve customers (patients and caregivers) in a fair manner” [48]. That may induce intentional misbehavior from the part of the people with IDD, due to perception of threat and need of attention [49], thus leading to exclusion. People with IDD want their support teams to be trained in activities that enhance navigation and communication between the IDD and the care ecosystem, while integrating their families and caregivers to reduce the risk of isolation and emphasize public awareness for inclusion, better understanding and compassion. To improve their chances of integration, calls to support inclusive educational experiences for students with intellectual and developmental disabilities (IDD) have been longstanding [50]. Technology could improve the vocational inclusion of people with disabilities, thus increasing their wellbeing and competence development [51]. Research much enrich data sets and data analysis focused on people with IDD to determine patient centered approaches and align their outcome [52].

5 Summary and Call to Action

A health care ecosystem’s largest value proposition is to support a healthy lifestyle, including illness prevention and general health, in all facets of life, and for all its beneficiary stakeholders. Our investigation shows that a health ecosystem must enable patients and other public and private actors—including private businesses in the fields of diagnostics, pharmaceuticals, medical devices, healthcare delivery, support services, and technology — to interact actively in order to be inclusive of IDD patients (Fig. 2).

Fig. 2. Fundamentals of a Digitally Inclusive Health Service Ecosystem for people with IDD.
For people with IDD to engage with their health ecosystem and enable their care pathways, they must easily understand what health services are available to them and have ready access to these services. This demands increased communication and participation from all actors in the ecosystem to provide assistance in navigating the system and access proper care. Special attention must be provided to keeping communication simple, potentially using visual aids, etc.

Actors in the ecosystem must gain better understanding of how to promote health among those in the IDD population. Systems must be in place to monitor the life and risk factors of the youth among IDD sufferers, especially, so that they get a better chance at a quality of life. Then, to address their ongoing needs, healthcare providers in the ecosystem must integrate acute healthcare with long-term services and support for people with IDD, to better learn how non-clinical variables influence their health trajectories. This will establish a common purpose and promote better inclusion. With that, all aspects of the health-care ecosystem should be aligned during all next stage of care.

6 Conclusion

6.1 Results and Implications

This paper is a conceptual exercise to propose essential activities for engaging people with IDD in a digitally inclusive healthcare ecosystem. Looking through the A4A lens has identified that a positive outcome of an inclusive healthcare service must be rooted in the design of the ecosystem in a way to assure that patients are central to communication. While integrating their families and caregivers, surrounding them with teams that are trained in activities that enhance navigation and communication, the ecosystem must provide foundations for tailored and human centered digital accessibility while emphasizing better understanding and compassion. Fundamentals of a digitally inclusive health service ecosystem for people with IDD must be tailored to engage them and understand their needs, so that all actors in the ecosystem become aware, converge and align their resources as they refine and adapt care pathways, increase care satisfaction and improve outcomes through an inclusive healthcare ecosystem, in an inclusive smart city.

In context, digitally inclusive healthcare ecosystems must have ways to understanding and address the capabilities of the caregiver and availing technology aides for their respite. Robotics and data driven facilities ought to be included to provide tailored and smart healthcare that can adapt to the stages of needs. A human-centered approach to healthcare service design should be considered; one that maintains empathy, trust, and support for all parties involved to stay focused on the common goals and purpose. Medical professionals must be sufficiently trained to assist people with IDD, facilitated by technology, with sufficient data on disease or condition type, phase of the process, with as continuous focus on communication and removing the digital accessibility barriers for the patients. Thus, when integrating the resources available, patients, caregivers and other ecosystem actors all included in the process, engaging with the patients with IDD. Since the fragile trust in technology of patients and other physical limitations that may be present (poor vision, hearing, or sensory impairment), can be hindering, tailored care must be provisioned with a thorough understanding of the patient needs, placing technology at work for monitoring the progress of the treatments.
6.2 Limitations and Future Research Paths

High quality, equitable and inclusive care is about providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status [53] and disabilities [54]. With our work, we identify stages of capability integration in a systems approach to co-create value for people with IDD in an inclusive approach. In public health research, service design for inclusion is about patient engagement and ‘empowerment’.

Our discovery on fundamentals of a digitally inclusive health service ecosystem for people with IDD has just begun. Our review contributes a new conception of an ecosystem for Healthcare for IDDs in terms of developing an inclusive service system, in addition to adding to the literature on transformational services, social innovation and service inclusion. We therefore encourage using this work as a spring further research paths to evaluate the potential of IDD patient enablement in our ever-evolving quest for an inclusive, sustainable and smart healthcare ecosystem.

References


42. C. C. Zwack, R. McDonald, A. Tursunalieva, G. W. Lambert, and E. A. Lambert, “Exploration of diet, physical activity, health knowledge and the cardio metabolic


