

Community Living for People with Disabilities in Japan: A Case Study of Sousou no Mori

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Abstract

Community living gained traction alongside disability after the Convention on the Rights of People with Disabilities was created. Although the Convention did not provide any strict definition, it catalyzed the spread of it worldwide. Japan, with its rich history of disability activism and self-advocacy movements, offers a distinctive perspective on community living and its progression.

This research examines Japan's innovative community living model, Sousou no Mori. Sousou no Mori represents a promising paradigm shift in disability care and offers valuable insights into the social parts of community integration. Moreover, it focuses on inclusivity, empowerment, and holistic support of individuals with disabilities. This research note summarizes key findings and insights derived from a case study of Sousou no Mori, highlighting its significance in the broader context of disability care in Japan.

The initial section of this research examines the historical trajectory of the disability rights movement in Japan, with a particular focus on the role of self-advocacy. Subsequently, it elucidates how Sousou no Mori embodies the principles and practices that redefine the landscape of disability care in the country. Further, I will provide the methodology used for this case study. Finally, I will introduce my findings and conclusion.

Keywords: disability, independent living, community living, people with disabilities

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1. Introduction

Since the Convention of the Rights of People with Disabilities was created in 2006, community living for people with disabilities was promoted for the first time. Although it does not provide a clear definition or mention community living, Article 19 on Living independently and being included in the community promotes and supports community living by facilitating access to a range of in-home, residential, and other community support services. It contains personal assistance necessary to support living and inclusion in the community and to prevent isolation or segregation from the community (United Nations 2006).

Community living is a transformative approach to caregiving and social insulation for people with disabilities derived from traditional care models that segregate people in institutions and make them dependent on others' lifestyles. Community living is a better alternative for PWDs (People with Disabilities) in terms of cost-effectiveness (Mansell 2010) and a better way to sustain their social connection and relationships outside the institutions or family and staff (Partington 2005). However, much research examines community living from the point of quality of care and long-term effects on patients, proving it superior to institutionalization (Mansell 2010). The previous research on community living concentrates mainly on the accessibility of facility care, and there is a need to pay attention to social aspects such as the community itself and community integration.

Sousou no Mori is one endeavor that supports the community living of people with disabilities. It can be the perfect platform to explore how community living is in Japan, with particular attention to community integration. Sousou no Mori is a welfare corporation in Joto-Ku, Osaka, that supports every aspect of everyday living, from care to employment, housing services, daycare, etc., through 15 different enterprises they have. Therefore, such a holistic community living support center as Sousou no Mori is a beacon of hope and inspiration for promoting community living in Japan. This case study sheds light on a distinctive approach that offers PWDs all the services to live in the community: inclusivity, person-centered care, and community integration.

After the introduction, I will delve into the context of Japan and how the disability

living paradigm developed to understand the background behind the idea of community living in Japan, which is essential to understanding Sousou no Mori and its uniqueness. Subsequent sections will focus on Sousou no Mori, detailing its history, services, and unique features. The methodology section will elucidate the research approach employed in this study, and the findings will present critical insights gleaned from the case study. Finally, the paper will summarize the implications and contributions of Sousou no Mori's community living model to disability care.

2. The Evolution of Disability Living Models in Japan

Japan's history of disability rights activism can be divided into multiple waves, each influencing the lives of people with disabilities. The initial wave emerged shortly after World War II in the 1960s and 1970s (Heyer 2000; Nakanishi & Ueno 2003). According to Nakanishi & Ueno (2003), during that period, the needs of people with disabilities were largely unrecognized, and support systems and policies were almost nonexistent. That wave was primarily focused on meeting the medical needs of individuals with disabilities and involved medical and social workers advocating for change. It allowed people with disabilities to have institutions and support systems in general. This established numerous networks and institutions to help individuals with disabilities (Nakanishi & Ueno 2003).

In the subsequent wave, Aoi Shiba no Kai, activists sought to transition individuals with disabilities from institutions and family care into communities (Nakanishi & Ueno 2003). They also advocated access to limitless personal assistance services, especially for individuals with severe disabilities, and overall accessibility for people with disabilities in Japan (Nakanishi & Ueno 2003). This movement, which coincided with the introduction of the Independent Living model, originated in the United States during the 1960s. That model supported deinstitutionalization through **self-advocacy groups, peer counseling, barrier removal, and consumer control** (Mansell 2010). In the Independent living paradigm, people would gain independence from their families and institutions by utilizing helpers' services and paying them money. A monetary relationship

guarantees the equality of the relationship and helps PWDs not to form a dependent relationship. Another promoted point was peer counseling, which was supposed to save people from ‘professional paternalism’ and allow people with disabilities to learn from peers and centralize the people with disabilities’ voices (Nakanishi& Ueno 2003).

Nakanishi and Ueno (2003) provide an outlook on how self-advocacy groups became instrumental in driving progress toward improved living conditions for people with disabilities in Japan. For instance, DPI (Disabled People International) organized a significant protest in 1991, with 2,000 people with disabilities across 20 cities going to stations and proving that those were not accessible. It made inaccessibility issues visible and started the conversation between self-advocacy groups and the government.

The establishment of the first Center for Independent Living (CIL) in Japan in 1986 marked a significant milestone in this movement. In the beginning stage, community activities were “Kuron” (empty theory) since no services were available in communities (Nakanishi & Ueno 2003). CILs began providing care services for people with disabilities, addressing the absence of community-based care services (Nakanishi & Ueno 2003). CILs also became central in advocating for changes in government policies, notably challenging the 18-hour-a-week limit on caregiving hours. Self-advocacy groups gained the power to negotiate with the government and used it to better the lives of people with disabilities. The prevailing belief at the time was that individuals with disabilities required assistance around the clock, a perspective that ran counter to true independence, which the self-advocacy groups championed. Moreover, it was believed that people should receive care from their families, not public policies.

Despite the advancements achieved by the Independent Living model in the world, researchers criticized it, arguing that it primarily addressed basic needs like housing, daily living, and employment, falling short of ensuring full social integration (White et al. 2010). Living independently in the community and accessing these services does not guarantee social integration.

While the Independent Living model played a pivotal role in enabling individuals with disabilities to live outside institutions and access education, employment, and

an accessible environment, it primarily addressed material aspects of life. It laid the foundation for community living but only guaranteed partial social integration. A different model that incorporates community integration is needed.

As defined by Mansell (2010), community living encompasses a range of accommodations and arrangements that facilitate social, economic, and cultural participation in the broader population. Achieving community living necessitates access to services and a barrier-free environment. The success of the Independent Living movement, with the support of CILs and self-advocacy activists, paved the way for community living to become a reality. However, the extent of authentic community living remains unclear, as it also depends on the responsiveness of the community to individuals with disabilities. The Sousou no Mori case study provides an exciting outlook on community living since most people with intellectual and mental disabilities are customers there.

In the following section, I will delve into the development of Sousou no Mori within the community, shedding light on its unique approach to community living.

3. SouSou no Mori: A Case Study

SouSou no Mori traces its roots back to 1995, when it began with just one customer and one helper without approved qualifications (Arakawa et al. 2021). It officially became a social welfare corporation in 2001, with 30 customers and 13 part-time helpers. By 2021, Sousou no Mori served 187 registered customers daily and provided home helpers to 300 customers. By 2018, it had welcomed over 100 individuals with intellectual disabilities. Recognizing the risk of group homes potentially transforming into institutions, Sousou no Mori established home helper services as a separate agency to provide tailored support for community living. The other important policy was to accept everybody, no matter the type of disability (Arakawa et al. 2021).

The center houses 15 services and companies supporting community living for people with disabilities, with a predominant clientele of individuals with intellectual disabilities. Sousou no Mori has diversified its services to support community living comprehensively. These services encompass various aspects of life for people with

disabilities. Here are some of the critical services offered by the organization.

3.1 Day Care Services

The organization provides daycare services where individuals with disabilities can spend their days in a safe and supportive environment. These services often include arts and crafts, recreational activities, and skills development, all tailored to the individual's needs and preferences.

3.2 Residential Support

“Sousou no Mori” may offer residential support for individuals who require assistance with daily living activities. This could involve living in group homes or supported living arrangements, where trained staff members provide care and support. A great example of this is “En” and “Sou.” There are 5-6 people in each of those, and there are helpers that come only from evening to morning and provide staying services while helping customers to cook, do laundry, take their medicine, and prepare for the following day.

Some services rent apartments that people with disabilities have trouble renting, and Sousou no Mori does it for them. Customers of that apartment have a higher level of independence, and helpers only come once a day in the evenings and sometimes do not come during weekends. Depending on the case, they also provide the service of managing finances for some customers.

Sousou no Mori also offers group home services for individuals with severe mental and physical disabilities, such as Kura (the group home), where people require assistance 24 hours, seven days a week. Another service provided is daycare services for people with heavy mental and intellectual disabilities, such as Gengen (day-care center), where people spend their time from 9 a.m. to 4 p.m.

3.3 Vocational Training

The organization offers vocational training programs to help individuals with disabilities acquire skills and knowledge that can lead to employment opportunities. This may include job training, resume building, and interview preparation. Moreover, after their employment, they still provide consultation and support services to

employees and employers.

3.4 Community Integration

A core focus of “Sousou no Mori” is community integration. The organization ensures that individuals with disabilities are actively involved in their local communities. This can include participating in community events, volunteering, and building social connections.

3.5 Person-Centered Planning

The organization employs a person-centered planning approach, which means that services are tailored to the unique needs, goals, and preferences of everyone. This approach promotes independence and self-determination. An individualized support plan prioritizes the customer’s choice of how to proceed regarding living arrangements or employment in the community.

It can be concluded that Sousou no Mori’s journey from its humble beginnings to its status as a comprehensive support center for community living is a remarkable testament to its commitment to inclusivity, person-centered care, and holistic community integration. The constant change in services shows SouSou no Mori’s commitment to meeting and prioritizing the needs of its customers.

4. Methodology

This research note employs a qualitative case study approach to comprehensively explore the community living model of Sousou no Mori and its impact on the lives of individuals with disabilities in Japan. A case study design is well-suited for examining complex phenomena within real-life contexts. It allows for an in-depth investigation of Sousou no Mori as a holistic entity.

4.1 Participant Observation

Extensive participant observation was conducted within the Sousou no Mori community over an extended period from May 2023 to August 2023. Participant observation was performed once a week and with Ethical Committee approval. This

approach allowed for an immersion in the daily life of residents and staff, providing valuable insights into their routines, activities, and interactions within the community.

4.2 Data Analysis

Data analysis followed a thematic approach. Field notes from participant observation were organized and coded to identify recurring themes and patterns. An iterative coding and constant comparison process was employed to refine themes and extract critical insights. Moreover, the article published by SouSou no Mori's director is also used as the source (Arakawa et al. 2021).

It is important to acknowledge certain limitations of this research. While the case study approach is valuable for in-depth exploration, it may limit the generalizability of findings beyond the specific context of Sousou no Mori. Additionally, the research was conducted within a defined timeframe of May 2023 to August 2023, and the evolving nature of the community may have introduced variations over time.

This methodology lays the foundation for a comprehensive examination of Sousou no Mori as a case study of community living for people with disabilities in Japan. Utilizing a mix of qualitative data collection methods, this research aims to capture the multifaceted nature of community living at Sousou no Mori and its potential implications for disability care and support more broadly.

5. Findings

Sousou no Mori is a comprehensive community living center in Joto-ku, Osaka, with enterprises along the shopping street. My initial encounter with this community occurred on May 5th, 2023, when I volunteered for Children's Day, a traditional celebration involving various games and prize activities. The event drew participation from residents in the Joto-Ku ward and customers of different Sousou no Mori establishments, fostering a sense of inclusivity. Notably, individuals with significant disabilities also partook, with the assistance of caregivers, offering me valuable insights into the lives of PWDs and their caregivers. Subsequently, I engaged in weekly volunteer work at various Sousou no Mori enterprises, further solidifying the connection between the Joto-ku community and Sousou no Mori,

where everyone is regarded as equal community members.

Moreover, Sousou no Mori contributes to the community in multiple ways, such as having retail sales, including crafts and agricultural goods, sold to the public. This provides a source of income and promotes the integration of participants into the community as contributing members. They also have different enterprises, such as Kawasemi (café) and Boulangerie, that serve food in the Joto-ku area. Those endeavors also allow customers of Sousou no Mori to find employment in a mixed environment, with non-disabled people, along with the support. Furthermore, participating in those activities enables the community to see the customers as essential to their community. However, during my participant observation, I noticed tension between the community and their reaction to Sousou no Mori's customers. For instance, the most obvious example would be constant ignoring of their greetings and occasional hostile expressions on their faces.

Moreover, some helpers mentioned that there are semi-constant complaints to the police station from residents living nearby regarding noise made by customers of Sousou no Mori. The tension was acknowledged by Sousou no Mori in their article (Arakawa et al. 2021). Still, they emphasized their commitment to keep investing in the community more for smoother social integration of their customers.

Another instance that should be mentioned is volunteering in the community; customers provide services such as sweeping streets, organizing different festivals, and any other help the community needs. Moreover, the article published by Sousou no Mori acknowledged that due to Japan's rapidly aging society, they recognize their role as the ones who must pick up the slack. They are not waiting for the community to include or invite them to be a part of it; they are already functioning as a part of it (Arakawa et al. 2021).

At Sousou no Mori, caregivers refrain from assuming teaching or advisory roles, aiming instead to establish equal customer relationships and avoid overmedicalization. An example from 'Gengen,' a daycare service for individuals with severe intellectual disabilities, illustrates this approach. Take K (a made-up name for the customer), for instance; she can comprehend how to eat with a spoon but struggles to put food on the spoon herself. Here, caregivers patiently insert the spoon into the food, allowing K to grab and eat it, even though this method takes

longer. This person-centered care approach prioritizes nurturing and sustaining their customers' long-term independence, even though it requires double the time.

Furthermore, their article addresses the risk of becoming mere providers of welfare and reducing their customers to mere recipients of services. They prioritize investing in the community's sustainability and customers' well-being over immediate profits. For example, they discuss providing scutum suction services, which demands substantial resources, including caregiver qualifications and training. To cater to just three patients, Sousou no Mori trains sixty individuals for three customers using that service. While economic viability is essential, Sousou no Mori is committed to the long-term satisfaction of their patients.

There is a strong emphasis on equal participation in various daily activities, such as dancing and other non-essential activities. Caregivers and customers engage as equals, going beyond the independent living model. Sousou no Mori promotes **self-determination**, allowing individuals to choose their daily activities. Facilities like Tsumugikan (Support for continuous employment Type B) offer flexibility in deciding how many hours customers want to work. At the same time, Prife (Support for continuous employment Type B) mostly emphasizes work itself and provides opportunities to earn extra income while being more rigid with their schedule. That allows customers to have multiple options, and they can switch their place of employment anytime in accordance with their needs.

It can be concluded that Sousou no Mori addresses basic needs and communal participation and presents a more holistic approach. It marks the third step beyond self-advocacy groups and community living. This step involves long-term investment in building relationships and social capital, enabling people with disabilities to integrate as active community members fully.

6. Conclusion

In this research note, I explored the innovative community living model exemplified by Sousou no Mori in Japan, shedding light on its transformative impact on the lives of individuals with disabilities. My study aimed to uncover the distinctive features of Sousou no Mori's approach, its implications, and its

significance within the broader context of disability care in Japan.

The journey began by acknowledging the evolving paradigm shift from independent living to community living for people with disabilities in Japan. While Independent living and self-advocacy groups paved the way for people with disabilities to be able to live in communities, it was only the first step. The broader goal of full community integration should be prioritized. Sousou no Mori, however, emerges as a beacon of hope, embracing individuals with disabilities in all facets of community life, with particular attention on social integration.

From 1995 to its current role as a comprehensive community living support center, Sousou no Mori's journey is a testament to its unwavering commitment to inclusivity, person-centered care, and holistic community integration. It extends beyond fulfilling basic needs to foster meaningful participation, self-expression, and individual growth. Moreover, its long history shows that it constantly diversifies its services to satisfy the needs of its customers and overcome the challenges of social integration in the community.

The investment in specialized services, such as sputum suction care, reflects Sousou no Mori's dedication to long-term perspectives and the well-being of its clientele, prioritizing it over immediate profit. With over two decades of service, the center has touched hundreds of lives and trained and empowered a significant workforce, investing in the broader community.

However, despite Sousou no Mori's constant investment in the social integration of their customers, there are still specific challenges that are constantly addressed by continuous volunteering activities.

As I conclude my exploration of Sousou no Mori, it is evident that this case study offers valuable insights into a holistic approach to community living for people with disabilities. However, I acknowledge certain limitations in my research. The findings presented here are specific to Sousou no Mori and may not be directly transferable to all community living initiatives. Further research and comparative analyses are warranted to understand community living models in diverse contexts better.

In closing, the story of Sousou no Mori is a testament to the power of the community, self-advocacy groups, and care workers who invested years of work in making community living possible for people with disabilities. It invites us to

envision a future where community living is not just a model but a way of life, where every person, regardless of ability, finds their place in the vibrant tapestry of society.

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