International Training Report

Exploring Medical Care that Promotes Well-Being

for Individuals with Profound Intellectual and Multiple Disabilities:

Five-Country Comparative Study

Hokkaido Ryoiku-en

Facility for children and adults with

profound intellectual and multiple disabilities (PIMD)

Shunkodai 4-10, Asahikawa, Hokkaido 071-8144, Japan

Tel: +81-166-51-6524

Fax: +81-166-51-6871

Email: michiru.j114@gmail.com

Pediatric neurologist

Michiru Sasaki

Table of Contents

I. Introduction

The motivation for applying to this international training program stems from an experience I had approximately ten years ago while working as a pediatric resident. At that time, I was assigned for the care of a boy with profound intellectual and multiple disabilities (PIMD). That year, he repeatedly experienced severe aspiration, in which food and liquids taken orally flowed directly into his lungs, and there was no expectation of improvement. Continuing oral intake was judged highly likely to result in life-threatening pneumonia. After extensive multidisciplinary discussions, our team ultimately proposed discontinuing oral feeding and creating a gastrostomy for long-term nutritional support.

Following careful conversations with the family, the gastrostomy procedure was performed successfully. When the time came to begin administering enteral nutrition through the gastrostomy, I suggested to his mother, "Considering nutritional balance, would you consider blending your home-cooked meals and administering them as well, rather than relying solely on commercial enteral formulas?" However, she replied, "I cannot do that. I have already taken away what my child enjoyed most—eating. That alone fills me with guilt, and I do not want him to smell the aroma of our meals." Upon hearing her words, I found myself at a loss for a response.

Through this experience, I came to understand that what physicians must confront extends beyond the improvement of bodily function or disease pathology. In 1948, the World Health Organization defined health as a state of physical, mental, and social well-being.[1)] More recently, researchers have emphasized the importance of understanding well-being in a broader sense that includes existential dimensions—such as how individuals and their families find meaning in their lives.

What I confronted at that moment was a question: To what extent had I engaged in dialogue with the family and reflected together not only on the child's physical well-being, but also on his psychological, social, and existential well-being? This question became the foundation of my subsequent clinical practice and research.

In pursuit of this question, I enrolled in the Graduate School of Tottori University in 2019, entering the program in Medical Care for Children with Disabilities. While reviewing literature from around the world to identify researchers who shared similar concerns, I encountered the work of Dr. Zaal-Schuller in the Netherlands. Her 2016 study clarified differences between physicians and caregivers in their experiences of end-of-life decision-making for children with PIMD, resonating deeply with my own research interests.[2)] I also learned that she is a specialist in intellectual disability medicine—a medical specialty formally institutionalized only in the Netherlands. From that point forward, I developed a

strong desire to one day observe firsthand the lived realities of children and adults with PIMD and their families, as well as the structures of healthcare and social welfare that support them in countries such as the Netherlands.
In the summer of 2024, I came across a brochure for the international training program sponsored by the Shimizu Foundation. I was convinced that this was precisely the opportunity I had long been seeking and immediately applied.

II. Objectives of the Training

Building on the motivation described above, I defined the theme of my individualized training as “Exploring Medical Care that Promotes Well-Being for Individuals with PIMD”.
For my visits in the United States, I received comprehensive support from Dr. Yamaki at the University of Illinois Chicago. Drawing on his many years of experience and professional network in Chicago, he advised me to extend my stay by an additional two weeks after the joint training program. This allowed me to conduct individualized training through focused visits to institutions of particular interest. This additional period of training significantly deepened my understanding of support systems for individuals with PIMD in the United States.
During my training period, the annual meeting of the Child Neurology Society was being held in Charlotte, North Carolina. I therefore attended the conference to better understand how pediatric neurologists in the United States conceptualize medical care for children with profound disabilities and what forms of support they provide in practice.
Furthermore, through an acquaintance working in healthcare who resides in Augusta, near Charlotte, I was introduced to several facilities. This connection enabled me to visit a pediatric clinic serving low-income populations, as well as a comprehensive support center that integrates education, developmental services, and medical care for children with disabilities.
Regarding the European component of my training, which had been my original objective, I first contacted Dr. Zaal-Schuller in the Netherlands and was granted the opportunity to train in Amsterdam, where she primarily practices as a specialist in intellectual disability medicine. With her generous support, I was also able to access an extensive professional network spanning both the Netherlands and neighboring countries. This made it possible for me to visit affiliated institutions centered around KU Leuven in Belgium and the University of Groningen in the Netherlands, both internationally recognized hubs for research on PIMD. In addition, through an introduction from Dr. Suemitsu, Chair of the Pre-Selection Committee

for the Shimizu Foundation Overseas Training Program, I was able to visit Radboud University in Nijmegen, a core educational institution for specialists in intellectual disability medicine.

I also had the opportunity to visit Bethel, often referred to as the "City of Welfare," in Bielefeld, Germany. This community is known for its history of protecting persons with disabilities during the era of persecution in the Second World War, and more recently for establishing a specialized clinical department dedicated to intellectual disabilities. For these reasons, I was eager to observe the site firsthand and arranged the visit accordingly.

Throughout this training, my objective was not merely to tour facilities and hospitals in each country, but to compare the institutional and structural characteristics of their healthcare and social welfare systems, while also deepening my understanding of the cultural and historical contexts that underpin them.

III. Training Activities

In this training program, as outlined in the program overview, I visited a total of 25 institutions and conducted interviews with more than 100 professionals and stakeholders. Due to space limitations, it is not feasible to describe all of these experiences in detail. Therefore, this report has been selectively organized to focus on the central theme of the training.

1. United States

1.1 *Almost Home Kids*: A Transitional Care Facility Supporting the Shift to Home for Children with Medical Complexity

— An Interdisciplinary Model for Home Transition Support—

On September 23, I revisited *Almost Home Kids Chicago* (hereafter, *AHK Chicago*), which had been included in the joint training program, for an individualized visit and conducted an interview with Ms. Carlson, a Nurse Practitioner (NP). *AHK Chicago* employs three NPs who are authorized to practice independently in areas primarily related to primary care, including the diagnosis and treatment of infectious diseases and the administration of vaccinations. For medically complex cases, a collaborative system is in place in which they work closely with the physician team and seek consultation as needed. Rather than serving merely in an assisting role to physicians, the NPs function as a bridge between medicine and nursing, assuming their responsibilities with a high degree of professional autonomy.

On the following day, September 24, I visited *AHK Naperville*. Whereas *AHK Chicago* is an urban facility located on a single floor of a high-rise building in the city center, the Naperville site is situated in a suburban area, offering a more spacious environment and a structure that more closely resembles a home. The facility has 12 beds and provides two primary services in roughly equal proportion: transitional care to support discharge to home, and respite care intended to provide temporary relief for families.

During this visit, I had the opportunity to participate in a case conference (held in the garden shown in **Photo 1**). Attendees included family members, the primary nurse, an NP, a physician, a case manager, and a social worker, all of whom exchanged views on an equal footing. The role of case manager was fulfilled by a nurse, who coordinated admissions and discharges, supported families, and facilitated the transition back to home from a clinical perspective. Meanwhile, the social worker provided support from a social standpoint, and the two collaborated while maintaining clearly differentiated roles. I also received an explanation from the attending physician regarding the decision-making process for medical interventions, including tracheostomy. These care policies had been determined and documented in advance through discussions between the family and the palliative care team at *Anne & Robert H. Lurie Children's Hospital*, which partners with *AHK*. At *AHK*, support was provided in a manner that respected these prior decisions while maintaining a shared focus on quality of life.

Overall, at *AHK*, multidisciplinary professionals—including NPs—demonstrated their respective expertise with vitality, practicing care centered on the child and family within a framework of mutual respect and professional equality.

Photo 1. The open garden at *Almost Home Kids Naperville*.

1.2. Pediatric Palliative Care Team at *Anne & Robert H. Lurie Children's Hospital* *— A Specialized Team Supporting Shared Decision-Making—*

On September 26, I visited the palliative care team at *Anne & Robert H. Lurie Children's Hospital* upon the recommendation of an AHK physician. The team operates throughout the hospital—including the NICU—and consists of physicians, nurse practitioners (NPs), nurses, and social workers.

What left a particularly strong impression on me while accompanying Dr. Shear during a counseling session was her approach of empowering the mother not as someone to whom decisions are merely entrusted, but as the expert on her child's life. Amid prolonged hospitalization and repeated medical crises, Dr. Shear carefully helped articulate the mother's feelings of the pain of "not knowing why this had happened," listening attentively without interruption. Rather than rushing toward conclusions, the highest priority was maintaining a safe space in which the parent could give voice to her own values.

In a subsequent session, I observed counseling conducted by Mr. Butzen, a palliative care NP, regarding planned extubation in the NICU, where support for more concrete decision-making was provided. Addressing weighty choices—such as how many times reintubation should be attempted if extubation proved unsuccessful, and whether to pursue tracheostomy—Mr. Butzen clearly stated that "the time and information needed to think are the family's right." He also explained that reintubation does not automatically lead to tracheostomy, thereby easing the family's anxiety while supporting their decision-making process.

Equally noteworthy was the team's response when distress arose among healthcare professionals in relation to decision-making. The palliative care team assumes the role of carefully discerning whether such distress stems from insufficient family understanding or from ethical conflict on the part of the clinicians. Only when a disagreement is determined to constitute a genuine ethical issue is the ethics committee convened. This approach demonstrates that the team's expertise extends beyond extensive knowledge of palliative medicine to include the practice of fostering meaningful dialogue between families and healthcare professionals.

1.3. *Marklund Wasmond Center*; A Residential Facility for Individuals with Intellectual Disabilities and Complex Medical Needs

—An Integrated Long-Term Residential Care Model —

On October 1, I visited the Marklund Wasmond Center in Elgin, Illinois, operated by Marklund. The Center is a private residential care facility serving approximately 85 children and adults with complex medical needs.

The architectural layout resembles that of Hokkaido Ryoiku-en, my affiliated institution in Japan, in that it is organized as a “connected-unit” model centered around four nursing stations. Each room accommodates four residents. Medical infrastructure, including built-in oxygen and suction lines, is installed in the living spaces, enabling advanced respiratory care such as tracheostomy management and mechanical ventilation.

The medical system is primarily based on weekly visits by two part-time physicians. Approximately 40 nurses are employed, with eight nurses on duty per shift. An on-site school is integrated into the facility. In addition to educational staff, physical therapists, occupational therapists, and speech-language therapists move flexibly between the residential and school buildings, facilitating seamless interdisciplinary collaboration across medical care, daily living support, and education.

Discharge is generally not anticipated, and end-of-life care can be provided within the facility in accordance with the wishes of the legal guardian. This underscores the Center’s role as a long-term living environment rather than a transitional institution.

Operational funding is primarily supported by Medicaid. However, there is an annual shortfall of approximately $20,000 per resident, which is covered through charitable donations. A dedicated fundraising team is responsible for securing corporate partnerships and major gifts, reflecting the organization’s proactive and structured approach to financial sustainability as a nonprofit entity.

In addition, the attached Adult Day Program serves individuals aged 22 and older, offering vocational preparation and life skills training. Activities such as greeting card production and community-based shopping exercises promote social participation and the development of self-efficacy.

Overall, the Center represents an integrated model of care that combines advanced medical support with educational services, rehabilitation, and opportunities for social engagement within a single institutional framework.

2. Belgium

2.1. *Ter Heide Tongeren*: A Residential Facility for Individuals with PIMD — *Transitioning from a Medical Model to a Social Model* —

On October 15, I visited *Ter Heide* (Tongeren campus), a specialized residential facility for individuals with PIMD located in the Flanders region of Belgium. *Ter Heide* is a long-term residential institution that provides integrated services encompassing daily living support, medical care, nursing, rehabilitation, and leisure activities. Owing to its care model—characterized by individualized support plans and close collaboration with families—the facility is widely recognized for its high level of expertise and attracts professionals from both within Belgium and abroad.

In Belgium, independent community living is generally encouraged for individuals with mild intellectual disabilities. However, for those with profound disabilities, whose support needs are considerably higher, care that combines small-group living with individualized activities is regarded as more appropriate. Children typically remain enrolled in external schools, with educators traveling to the facility to provide instruction.

The Tongeren campus consists of seven "house" units, each accommodating fewer than ten residents, for a total of approximately 65 individuals (Photo 2). Each unit is designed to foster a homelike atmosphere, and residents' rooms can be freely decorated according to their personal preferences.

Particularly striking was the extent to which the framework of care in Belgium has shifted from a medical model toward a social model. Ms. Neessen, who has long been involved in practice at the facility, explained: "In Belgium, I think the focus is more on the behavior and quality of life, to live together, not the medical. The medical aspect is very important, but it's not the most important." Indeed, although *Ter Heide* was once positioned primarily as a medically oriented institution, it has since reexamined this framework and transitioned toward a care model that situates medical care as one component of daily life support while prioritizing quality of life, including social and psychological dimensions.

This philosophy is also reflected in the staffing structure. Physicians do not serve as leaders of the care team; rather, they are external doctors who visit twice weekly. Nurses maintain an ongoing understanding of residents' health conditions and coordinate medical consultations when necessary. Leadership within the care structure is frequently assumed not by medical professionals but by specialists in the behavioral sciences, underscoring a support system centered on everyday living rather than on medicine alone.

Photo 2. A "house" unit at *Ter Heide.*

2.2. *Zevenbergen Service Center*: Residential Services for Individuals with Intellectual Disabilities, Including Those with PIMD

— Residential Care Where Primary Care and Disability Studies Intersect —

On October 17, I visited the Zevenbergen Services Center, a residential facility for individuals with disabilities in Belgium. During my visit, I attended a lecture on disability studies and community-based residential support delivered by Dr. Colliers, a General Practitioner (GP) affiliated with the Department of Primary Care at the University of Antwerp.

Dr. Colliers explained that the purpose of teaching disability studies within medical education is to equip healthcare professionals with practical competencies directly applicable to future clinical practice. She emphasized the importance of moving beyond a perspective that views "disability" solely as **impairment** within the medical model. Instead, healthcare providers must develop a broader understanding of **disability** grounded in the social model—one that recognizes persons with disabilities as citizens and supports their daily lives and dignity.

Zevenbergen has a history spanning more than 50 years and serves a diverse population ranging from children to older adults. The campus consists of 22 small-scale homes organized into units tailored to residents' characteristics and support needs. Residents are free to receive visits from family members, and short-term stays (respite care) are offered flexibly. Portions of the facility are also accessible to local community members; the gardens and farm, in particular, foster an environment of "reverse inclusion," where community residents naturally come and go (**Photo 4**).

The medical system is characterized by the presence of four full-time general practitioners and five full-time nurses, complemented by regular visits from specialists in psychiatry, orthopedics, dentistry, dermatology, neurology, and ophthalmology. As a result, a wide range

of specialized care can be delivered within the facility.

While the management of gastrostomy and suprapubic cystostomy is common, tracheostomy and mechanical ventilation are rarely introduced. Instead, the facility adopts a clinical approach centered on respiratory care through physiotherapy and the use of nebulizers. At the end of life, efforts are made whenever possible to provide care within the facility, including the use of palliative sedation when appropriate. Advance Care Planning (ACP), with a strong emphasis on residents' quality of life, is thoroughly implemented.

During a guided tour led by a nurse, chronic staffing shortages—particularly the absence of physicians during certain weekend hours—were identified as ongoing challenges. Nurses and therapists play central roles in preparing for emergencies, with a system in place to transfer residents to a hospital when necessary.

Photo 3. Physicians and nursing staff at Zevenbergen.

Photo 4. The farm at Zevenbergen.

3. The Netherlands

3.1. Interview with Dr. Bakker, Intellectual Disability Physician

— Expertise Grounded in Qualitative Scholarship —

On October 23, I met with Dr. Bakker, a physician specializing in intellectual disability medicine, at Radboud University in the Netherlands to exchange views on the development of the Dutch specialty training system and the nature of integrated care spanning adulthood through the end of life (**Photo 5**).

In the Netherlands, a formal training system for physicians specializing in the medical care of individuals with intellectual disabilities was established in 2000. Now, approximately 25 years since its inception, the field has become firmly recognized as an independent specialty dedicated to the unique healthcare needs of this population. Currently, only two university medical centers in the country maintain academic departments devoted specifically to intellectual disability medicine, and Radboud University serves as one of the central hubs, playing a significant role in clinical practice, education, and research.

Physicians specializing in intellectual disability medicine are positioned apart from hospital-centered models of care. Instead, they provide long-term, comprehensive medical services in close proximity to individuals' everyday living environments, such as private homes and residential facilities. Their training involves rotational experience across pediatrics, neurology, rehabilitation medicine, clinical genetics, emergency medicine, and psychiatry, among other disciplines, cultivating the capacity to understand physical conditions, development, psychiatric symptoms, behavioral characteristics, and social contexts in an integrated manner. While maintaining a high level of expertise, these physicians function as bridges between primary and specialized care.

When I asked Dr. Bakker about the process through which such professional expertise is cultivated, it became evident that the Dutch system itself has been built upon an academic foundation that places strong emphasis on qualitative research. Dr. Bakker described this starting point succinctly: "Start with qualitative studies to have an impression of what's going on." In other words, to understand what is truly occurring in the lives of people with intellectual disabilities, it is essential to begin with qualitative inquiry.

What has been explored through qualitative research is not merely pathology or diagnostic criteria, but rather the life trajectories of individuals with intellectual disabilities and the contexts in which they require medical and social support. Medical challenges first become visible within the settings of everyday life and relationships. A defining characteristic of intellectual disability medicine in the Netherlands is that its professional expertise has been shaped by careful inquiry into these "healthcare needs arising within daily living."

Photo 5. Dr. Bakker, NP Gijsbers and the author.

3.2. *Care Foundation 's Heeren Loo*: Residential Service for Individuals with Intellectual Disabilities, Including Those with PIMD.

— Care Practices Grounded in "Home" —

On October 30, I visited a residential care facility for individuals with intellectual disabilities, including those with PIMD, operated by Care Foundation *'s Heeren Loo* near Groningen in the Netherlands. The facility is composed of small, dispersed "houses" situated within an ordinary residential neighborhood. Unlike hospitals or large institutional settings, the environment is domestic in character and well-integrated into the local community. Each resident has a private room—many with an en-suite toilet—and is free to arrange personal belongings and photographs, reflecting respect for individual life histories and preferences (**Photo 6**).

Approximately 220 individuals with intellectual disabilities live across the entire campus. Among them, two "house" units are dedicated to residents with PIMD, each accommodating around ten individuals. Particularly noteworthy was the practice of planning and deciding dinner menus at the unit level, with support from dietitians. Residents and staff collaboratively select ingredients and prepare meals, treating the cooking process itself as part of daily living and developmental support. A culture was evident in which residents actively shape "their own table at home."

Separate from the residential "house" units, the facility maintains a medical unit staffed by on-site physicians and nurses. Two to three physicians specializing in intellectual disability medicine are employed full-time. Physicians primarily work during weekday daytime hours, while the on-site team provides initial responses in emergencies and contacts an on-call physician when necessary. In addition, two staff members specialize in spiritual care. Their

role extends beyond religious support to addressing existential concerns such as the meaning of life and what matters most to each individual. Especially in cases of serious illness or at the end of life, they accompany residents and families, supporting the process of grief.

Furthermore, a dedicated remembrance place has been created to honor deceased residents (**Photo 7**). Each leaf on a wooden memorial object bears the name of a departed individual, with a bench placed nearby to provide a space for reflection.

At this facility, tracheostomy for individuals with PIMD is extremely rare. It is regarded as a highly invasive intervention that often entails long-term technological dependence, potentially restricting mobility and activity while significantly affecting quality of life.

In contrast, gastrostomy is relatively accepted as a therapeutic intervention that may help prevent aspiration pneumonia and improve nutritional status, thereby maintaining or expanding opportunities for sensory stimulation and participation in activities. It is also recognized as a more reversible option, as it can be discontinued or removed depending on the clinical situation.

Across all medical interventions, the facility places strong emphasis on evaluating the extent to which a given intervention supports—or limits—the resident's enjoyment of life and personal freedom. Such value judgments are made carefully through collaborative decision-making processes that involve not only healthcare professionals but also families and support staff.

Photo 6. Private room at *'s Heeren Loo*

Photo 7. Remembrance place for deceased residents at *'s Heeren Loo*

3.3. Interview with Professor Vlaskamp, Originator of the PIMD Concept

— A Practice-Led Concept Within a Culture of Continuous Reform —

On October 30, I conducted an interview with Professor Vlaskamp at the University of Groningen. In 2007, together with Nakken, she proposed the concept of PIMD (Profound Intellectual and Multiple Disabilities)[3]. By introducing the term PIMD, they established a shared language that enabled researchers and practitioners worldwide to engage in common dialogue and accumulate knowledge. They also launched an international research network, fostering collaboration and deepening both understanding of and support for individuals with PIMD.

Professor Vlaskamp emphasized that the PIMD concept was not theory-driven but rather represents a form of "bottom-up" knowledge grounded in clinical and educational practice. At a time when children with PIMD often spent their days lying in beds within institutional environments, support began with simple yet transformative actions—"getting them up" and "creating opportunities for activity." Long-term observation of their behaviors and responses became the foundation for the development of the PIMD concept.

She further noted that abstract reforms lacking concrete examples from practice are unlikely to be effective. Instead of compromising with short-term or purely symptomatic solutions, she highlighted the importance of accumulating small yet sustainable changes over time. Transformation, she suggested, should not be pursued as a sweeping overhaul of entire systems; rather, it should be advanced at the level of individual teams and facilities. The key lies in drawing on the strengths of frontline staff while simultaneously engaging organizational leadership in the process of change.

Photo 8. Professor Vlaskamp and the author

3.4. Clinical Practice of Dr. Zaal-Schuller, Intellectual Disability Physician

— Expertise Supporting Open Dialogue in Interdisciplinary Teams —

From November 3 to 7, I had the opportunity to continuously observe the clinical practice of Dr. Ilse Zaal-Schuller, a physician specializing in intellectual disabilities with whom I had been in contact for some time. Dr. Zaal-Schuller is affiliated with the University of Amsterdam, where she conducts research on PIMD, while also maintaining regular clinical involvement with *Stichting Omega* and *Prinsenstichting.* Through these roles, she serves as a vital link between medical care and daily living support.

Stichting Omega is a specialized facility that provides integrated living support, education, and medical care for children with PIMD. Many of the children served do not meet the developmental criteria required for admission to mainstream special education schools; consequently, *Omega* functions as their primary setting for support outside the conventional school framework. The multidisciplinary team is notably robust, comprising not only therapists but also movement specialists, music therapists, and behavioral therapists. Collaboration characterized by mutual learning in everyday practice was strongly emphasized.

In setting goals, parents and staff convene annually to discuss five domains using a visualization tool: (1) physical health, (2) alertness and attention, (3) relationships and connectedness, (4) communication, and (5) meaningful use of time (**Photo 9**). For each domain, participants position their assessment of the current situation along a continuous color gradient ranging from “good” (green) to “challenging” (red), thereby sharing their

evaluations. At times, perspectives converge on the same color; at other times, they diverge between green and red, with such discrepancies themselves becoming the starting point for dialogue. Through articulating why, they perceive the situation as they do, team members gradually align their perspectives and collaboratively construct a shared understanding of the person's present quality of life. This process functions as a common language within the team.

Prinsenstichting, meanwhile, provides residential support and day care for individuals including those with PIMD. Particularly in the domains of aging and chronic illness care, strong attention is paid to care coordination that acknowledges the complexity of institutional systems. Established in the 1970s, the organization was once operated as a cluster of large buildings resembling a "small village." Today, however, an increasing number of private homes for community residents have been incorporated among the facilities, reflecting a transition toward integration within the broader local community.

What was especially striking in Dr. Zaal-Schuller's practice was her approach of not stepping forward as a directive authority, but rather trusting the expertise of each professional and delegating roles so that their capabilities could be fully exercised. During a multidisciplinary conference concerning a young girl with autism spectrum disorder and her mother, the physician spoke very little, instead carefully attending to the psychologist's assessment, understanding of the family, and proposed support strategies. This silence did not reflect passivity; rather, it signaled a deliberate stance of closely observing the flow of discussion and the interactions among professionals in order to discern when a medical perspective was truly necessary. Dr. Zaal-Schuller's manner thus illustrates a model in which the physician functions not as a "leader," but as a professional who sustains and supports the clinical space.

Photo 9. The visualization tool adopted by *Stichting Omega*, the "Goed-Leven-Lint (Good-Life Lint)."

4. Germany

4.1. Medical Care for Individuals with Disabilities at *Mara Hospital* — *The Current Status and Challenges of Inclusive Medicine*—

Mara Hospital (Krankenhaus Mara), located in Bielefeld, Germany, provides medical care primarily for adult patients with intellectual disabilities and severe physical disabilities. In collaboration with nearby municipal hospitals and hospital networks, it addresses a wide range of medical needs, including physical illnesses, infectious diseases, chronic conditions, and psychiatric disorders.

Patients are frequently admitted with aspiration pneumonia related to dysphagia, as well as complications associated with epileptic seizures. The hospital also houses a neurosurgical ward, where highly specialized care—particularly in epilepsy treatment—is provided. In addition, surgical procedures such as gastrostomy placement can be performed, supported by a collaborative system involving both endoscopists and surgeons.

"Inclusive Medicine," a concept that has gained increasing attention in Germany in recent years, aims primarily to improve the quality of healthcare for people with disabilities. It encompasses educational initiatives and systemic reforms designed to ensure that healthcare providers understand disability-specific needs and are equipped to respond appropriately.

Underlying this movement is a shared challenge: medical students and physicians have historically received insufficient education regarding disability. Consequently, Germany has been advancing the development of curricula that enable medical students to systematically acquire knowledge in disability medicine throughout their training. This effort is currently being promoted as a large-scale doctoral-level project.

Regarding physician credentialing, the German Medical Association has formally approved a relatively compact certification titled "Medicine for People with Disabilities," consisting of 50 hours of coursework and 50 hours of practical training. Furthermore, there are ongoing discussions about establishing an additional specialist designation—*Zusatzbezeichnung Inklusiver Medizin* (Additional Qualification in Inclusive Medicine). This credential would be available to already board-certified specialists—such as psychiatrists, neurologists, internists, and pediatricians—after completing two years of further training.

However, institutionalizing this comprehensive additional qualification has proven challenging. The primary obstacle is that some medical societies oppose its creation, maintaining that no special certification is necessary to treat people with disabilities and that all physicians should be responsible for their care.

Proponents of Inclusive Medicine, in contrast, argue that such a stance ultimately results in a situation in which "no one becomes a true specialist," thereby contributing to the persistent difficulty people with disabilities face in accessing appropriate healthcare.

4.2. Observation of Outpatient Consultations by Mr. Oner at *Mara Hospital* — *Patient-Centered Medical Management* —

On November 11 at Mara Hospital, I observed an outpatient consultation on spasticity management conducted by an orthopedic surgeon. The patient, an adult with severe athetosis, demonstrated a remarkable degree of engagement in his own medical care.

What was particularly notable was the extent to which he participated proactively in clinical decision-making, grounded in a sophisticated understanding of his bodily condition and treatment options. While offering critical reflections on both the benefits and limitations of interventions, he conveyed a clear intention to collaborate with healthcare professionals in shaping his therapeutic course.

He also articulated systemic challenges within the current healthcare structure, emphasizing how financial and institutional constraints can restrict access to appropriate equipment and individualized rehabilitation. His experience underscored the importance of trust-based therapeutic relationships and the need for care that is responsive rather than merely procedural.

This encounter illustrates how individuals with severe physical disabilities need not occupy a passive role within medical systems. When equipped with experiential knowledge and communicative agency, they can engage in meaningful negotiation with professionals and institutional frameworks, thereby actively influencing their own quality of life.

Photo 10. From left: Dr. Schmitz, Mr. Oner, and a care assistant.

(Published with persmission.)

5. Summary

Integrating the findings from the above training experiences, a comparative analysis was conducted of residential and support facilities serving individuals with PIMD, focusing on *Hokkaido Ryoiku-en* in Japan, *Marklund* in the United States, *Ter Heide* and *Zevenbergen* in Belgium, and *'s Heeren Loo* in the Netherlands. The results were organized from the perspectives of structural characteristics, staffing configurations, and systems of medical and daily living support, and are presented in **Table 1**.

In addition, the professional roles and institutional frameworks of physicians who play central roles in providing healthcare for individuals with intellectual and developmental disabilities were compared across five countries—Japan, the United States, Belgium, the Netherlands, and Germany. An overview of these findings is summarized in **Table 2**.

Table 1. Multinational Comparison of Residential Facilities for Individuals with Intellectual Disabilities, Including Those with Profound Intellectual and Multiple Disabilities (PIMD)

Country	**Japan**	**United States**	**Belgium**		**The Netherlands**
Facility	***Hokkaido Ryoiku-en***	***Marklund Wasmond Center***	***Ter Heide Tongeren***	***Zevenbergen Services Center***	***Care Foundation 's Heeren Loo***
Structural Characteristics	- Connected-institution model - 6 wards (approx. 45-60 residents per ward / building) - 1-8 residents per room	- Connected-institution model - 4 nursing stations - 4 residents per room	- Clustered housing model (ordinary residential houses; separated from the town) - 7 group homes - 10 residents per house	- Clustered housing model (ordinary residential houses; separated from the town) - 22 group homes - 6-10 residents per house	- Clustered housing model (ordinary residential houses; integrated with the town) - All private rooms - 10 residents per house
Patient lift for transfers	None	Available	Available	Available	Available
Funding	Primarily public funding	Public funding + donations	Primarily public funding	Primarily public funding	Primarily public funding
Number of Residents	320 residents	80 residents	65 residents	240 residents	220 residents (including about 20 individuals with PIMD)
Age Range of Residents	7-84 years	7-57 years	18 years and older	7-70 years	18 years and older

Country	**Japan**	**United States**	**Belgium**		**The Netherlands**
Facility	***Hokkaido Ryoiku-en***	***Marklund Wasmond Center***	***Ter Heide Tongeren***	***Zevenbergen Services Center***	***Care Foundation 's Heeren Loo***
Physicians	- 9 full-time physicians - At least one physician on duty at night and on weekends	- 2 part-time physicians - Weekly visits	- 1 part-time physician - Visits twice per week	- 4 full-time general physicians - 1-2 physicians on-site during weekdays - On-call coverage at night and on weekends	- 3 full-time intellectual disability physicians - On-call coverage at night and on weekends
Nurses	150 nurses	40 nurses	Two visits per day by nurses	five nurses (weekday shifts)	Two nurse practitioners and one nurse assistant
Medical Procedure	- Gastrostomy - Tracheostomy - Mechanical ventilation - Artificial anus (colostomy) - Cystostomy - Nephrostomy	- Gastrostomy - Tracheostomy - Mechanical ventilation - *IV infusion permitted*	- Gastrostomy - Tracheostomy and mechanical ventilator are rare	- Gastrostomy - Cystostomy - Tracheostomy and mechanical ventilator are rare	- Gastrostomy - Tracheostomy and mechanical ventilator are rare

Table 2. Five-Country Comparison of Physician Expertise Supporting Medical Care for Individuals with Intellectual and Developmental Disabilities

Japan	United States	Belgium	The Netherlands	Germany*
Pediatrician Internist	Family Physician General Pediatrician Med-Peds (Internal Medicine-Pediatrics) Developmental-Behavioral Pediatrician (DBP)	General Physician Pediatrician Internist	Intellectual Disability Physician Family Physician Pediatrician	Internist Pediatrician Psychiatrist Neurologist

*In Germany, a relatively compact certification titled "Medicine for People with Disabilities" has been formally approved. In addition, there are ongoing discussions about establishing an additional specialist qualification—"Zusatzbezeichnung Inklusiver Medizin" (Additional Designation in Inclusive Medicine)—which would be obtained after completing two years of further training.

IV. Discussion

1. Differences in the Positioning of Medical Care for Individuals with Profound Intellectual and Multiple Disabilities

During this overseas training, I visited residential facilities supporting individuals with profound intellectual and multiple disabilities (PIMD) in four Western countries—the United States, Belgium, the Netherlands, and Germany—while also considering the current situation in Japan. Through these visits, I conducted a comparative examination of how medical care can contribute to the well-being of individuals with PIMD. Although the comparison of one to two facilities per country presented in **Table 1** cannot be generalized to represent each nation's overall system or practice, it nevertheless reveals substantial differences in the positioning and delivery of medical care for this population.

In Japan, residential facilities for individuals with PIMD have historically assumed both medical and welfare functions, with institutional standards mandating the placement of physicians and nurses.[4)] As a result, these facilities have developed systems capable of continuously providing advanced medical care within the residential setting, including gastrostomy management as well as more intensive interventions such as tracheostomy and mechanical ventilation. As residents' medical complexity increases, more concentrated medical intervention becomes necessary. This has, in turn, led to larger numbers of residents per room and to the emergence of structurally "integrated facilities," in which medical wards are physically connected to residential units. This structural evolution reflects historical

policy priorities rather than a simple preference for institutionalization. *Hokkaido Ryoiku-en* in Japan and *Marklund* in the United States exemplify this model and may be characterized as settings with a high density of medical care.

By contrast, facilities in the Netherlands and Belgium are primarily organized around small-scale living arrangements, typically consisting of "homes" for six to ten residents. Medical consultations occur either when residents travel from their homes—their primary place of daily living—to a medical unit, or when physicians visit each unit to provide care. Nurses, rather than being permanently stationed as "facility nurses," function more like visiting professionals, bringing medical care into the living environment as needed. Underlying this structure is a shared assumption that medical care exists to support a life grounded in everyday living. Consequently, highly invasive interventions such as tracheostomy and mechanical ventilation are approached with considerable caution, particularly in light of their impact on quality of life.

When confronted with these differences, it is easy to fall into binary debates such as "To what extent should medical care be provided for individuals with PIMD?" or "Should Japan pursue deinstitutionalization?" However, the medical and welfare systems in each country have evolved within distinct historical contexts, cultural values, and social security frameworks. These differences should therefore be approached with caution, rather than interpreted through simplistic notions of superiority or backwardness.

What I learned from these four countries through this overseas training is that, in exploring the well-being of individuals with PIMD, it is necessary to reconstruct the very way we formulate our questions.

2. Reframing the Research Question: From "What Should Be Done?" to "What Is Happening?"

At this point, I am reminded of the words of Dr. Bakker, a Dutch physician specializing in intellectual disability. When I asked her how she had developed a field of expertise that remains rare even by international standards, she responded: "Start with qualitative studies to have an impression of what's going on."

In other words, to understand the lives and medical care of people with intellectual disabilities, we must begin with qualitative inquiry that allows us to grasp what is actually happening in the present.

A similar concern has been articulated by the Japanese qualitative researcher Otani, who writes, "Before asking 'What should be done?', we must first understand 'What is happening?'" [5] When we consider Dr. Bakker's statement alongside Otani's, it becomes

clear that we may need to reframe the very way we formulate our questions.

Rather than immediately posing normative questions such as "To what extent should medical intervention be provided?" or "Should deinstitutionalization be pursued?", we must first carefully explore descriptive questions: What conditions currently shape the lives of individuals with PIMD in Japanese society? How do they and their families experience and make sense of this reality? Without engaging in this prior inquiry into "what is," it is difficult to arrive at meaningful answers to the question of "what ought to be."

Indeed, physicians I encountered during the joint training—including Dr. Colliers in Belgium and Dr. Zaal-Schuller in the Netherlands—have incorporated the fundamental question "What is disability?" into medical education while grounding their work in disability studies. For physicians, cultivating the perspective that disability should be understood not only as impairment within the medical model but also as disability shaped within a broader social context is critically important for clinical practice.

Reflecting on my own experience, I recall a boy with profound disabilities whom I cared for during my residency. His recurrent aspiration pneumonia could not be understood solely as a medical risk. It also carried psychological meaning as a source of "enjoyment" for him, as well as social meaning embedded in the life and relationships of his family. Behind the diagnostic label of aspiration pneumonia, the deeper question—What is disability?—was once again brought into focus.

Furthermore, through visits to residential facilities in Belgium and the Netherlands, I was struck by how deeply practitioners engage, in their daily work, with the qualitative question: What does "home" mean for people with intellectual disabilities? At *'s Heeren Loo* in the Netherlands, for example, dinner menus were planned within each housing unit, where residents and staff selected ingredients and prepared meals together. When I heard the casual question, "What shall we have for dinner tonight?", I sensed that the setting functioned not merely as a residential facility but truly as a home.

Similarly, at *Prinsenstichting*, residents put on coats and changed their shoes before heading out to day services or medical appointments—an act that clearly signaled "going out." Upon finishing their activities, they returned to their own home and their own rooms. This simple movement outward created physical, psychological, and social boundaries between home and other spaces, making visible that residents themselves remain at the center of their lives and are the primary agents within them.

These experiences suggest that in Japan as well, there is an increasing need to foster a culture that reexamines questions such as "What is disability?" and "What constitutes well-being?" for individuals with intellectual disabilities, including those with PIMD—not only from physical and medical perspectives but also in psychological, social, and existential terms.

Such perspectives should be systematically and practically integrated into professional education, beginning with medical training.

At the same time, by sharing the question "What does home mean for them?," it is essential to reconsider what existing residential institutions—including *Hokkaido Ryoiku-en*—currently provide, what they sustain, and what they may yet transform.

It is through the steady accumulation of inquiries into "what is" that we may ultimately discover our own answer to the question: What kind of medical care truly promotes the well-being of individuals with profound intellectual and multiple disabilities?

3. Re-examining How We Ask Questions: Beginning with Voices from Practice and Asking Together with Colleagues

I also felt that there was much to be learned from the practices of these four countries regarding the very ways in which questions are framed.

First, a shared feature across these contexts was a consistent commitment to grounding inquiry in the voices of the field—namely, the perspectives of individuals themselves and their families. Professor Vlaskamp, whom I met in the Netherlands, emphasized that the concept of PIMD did not emerge from theory alone but represents a form of "bottom-up" knowledge accumulated through lived practice.

A similar orientation was evident at *Mara Hospital* in Germany. Beginning with the narrative of Mr. Oner, a person with severe athetoid cerebral palsy who demonstrates a deep understanding of his own bodily characteristics and treatment, physicians and therapists collaboratively "constructed" medical care while incorporating his candid reflections on both the effectiveness and limitations of treatment.

Likewise, Dr. Shear of the palliative care team at *Ann & Robert H. Lurie Children's Hospital* of Chicago clearly positioned the mother not as someone to whom decisions are merely entrusted, but as an expert in her child's life, thereby fostering genuine empowerment.

The second insight I found particularly significant was the posture of "questioning together." After returning to Japan, I observed a developmental outpatient consultation at a hospital that left me with a sense of discomfort. A large, expensive chair had been placed for the physician, while the child, family members, and therapists were seated on small stools. The spatial arrangement itself may symbolically reflect traditional professional hierarchies. Such configurations may symbolically reflect how professional roles and power relations have been embedded within everyday medical practice in Japan. In settings like these, even when multiple professionals share the same room, it is not easy to exchange views candidly and think together.

In contrast, I was reminded of a tool used at *Stichting Omega* in the Netherlands (**Photo 9**). Within the "space" created by this tool, individuals, families, and professionals were not positioned within hierarchical relationships; rather, each participant could bring forward their perspectives and insights from a fundamentally equal footing, making it possible to engage in shared inquiry. The deliberate creation of such dialogical spaces—where conversation transcends positional and professional boundaries—offers important implications for future practice in Japan.

Another notable feature across the countries visited was the involvement of a wide range of professionals. As shown in **Table 2**, the expertise of physicians working with individuals with intellectual disabilities was itself highly diverse, including developmental-behavioral pediatricians in the United States, physicians specializing in intellectual disability medicine in the Netherlands, and emerging specialist certification systems in Germany. Moreover, roles beyond physicians were equally varied, such as nurse practitioners in the United States and the Netherlands and spiritual care providers in the Netherlands. A culture had clearly taken shape in which professionals collaborated while drawing on their respective expertise and learning from one another.

This orientation becomes even more critical for individuals with PIMD, many of whom face challenges in verbally expressing their own intentions. Sustained inquiry from multiple perspectives—questioning alongside one's colleagues—therefore assumes particular importance. The answers to such questions cannot be borne by any single individual or profession alone. Rather, this training reaffirmed that the very process of attending carefully to subtle responses and the lived contexts of individuals, while continuing to question and reflect together across diverse forms of expertise, constitutes the foundation that supports medical care and social welfare for people with PIMD.

V. Conclusion

The many encounters and lessons gained through this training have provided an opportunity to fundamentally reconsider the nature of medical care and social support for people with intellectual disabilities, including those with PIMD. Drawing on these experiences, I would like to conclude this report by outlining a personal blueprint for the stance and commitments that should guide my future practice.

First, I intend to continue exploring forms of medical care that promote the well-being of residents at *Hokkaido Ryoiku-en*. In particular, I hope to intentionally create opportunities for

conferences in which family members, direct support professionals, nurses, therapists, and physicians can engage in dialogue on equal footing, transcending professional roles and positional boundaries—especially for those individuals under my primary care.

Furthermore, this training impressed upon me the need to deepen my understanding of palliative care. The posture exemplified by palliative care teams in the United States—regarding dialogue and relationships themselves as areas of professional expertise to be continually refined—offers an important guiding principle for my own future clinical practice.

At the same time, as a physician caring for children with developmental and intellectual disabilities, I aspire to more consciously assume the role of bridging the medical and social models, following the example set by Dutch physicians specializing in intellectual disability medicine. Beyond remaining a professional who provides diagnosis and treatment, I hope to stand alongside individuals and their families, listening carefully to their voices and translating those voices into both medical and societal contexts.

VI. Acknowledgements

I would like to express my sincere gratitude to the Shimizu Foundation for granting me this invaluable opportunity and for their generous support throughout this overseas training.

I am also deeply grateful to Dr. Maruyama, Chairman of *Hokkaido Ryoiku-en*, and Dr. Hayashi, Director of the institution, who received my aspiration to participate in this program with understanding and encouraged me with steadfast support.

My heartfelt thanks also go to the staff of *Hokkaido Ryoiku-en*, who continued to support the residents in my absence and created an environment that allowed me to fully dedicate myself to this training with peace of mind.

During my training in Chicago, I was fortunate to receive thoughtfully tailored lectures and learning opportunities designed around my academic interests. I extend my deepest appreciation to Dr. Yamaki for his exceptional guidance, which made this experience profoundly meaningful.

Finally, I offer my deepest gratitude to my wife, Maho, who supported me unfailingly from afar throughout this nearly three-month journey while caring for and nurturing our three children. Her unwavering support made this endeavor possible.

VII. References

1) World Health Organization.“Constitution of the World Health Organization”, World Health Organization, 1948
2) Zaal-Schuller IH, Willems DL, Ewals FVM, van Goudoever JB, de Vos MA. “How parents and physicians experience end-of-life decision-making for children with profound intellectual and multiple disabilities, Research in Developmental Disabilities 59”, 2016 Dec:283–293
3) Nakken H, Vlaskamp C. “A Need for a Taxonomy for Profound Intellectual and Multiple Disabilities, Journal of Policy and Practice in Intellectual Disabilities 4(2)”, June 2007, pp. 83–87.
4) 岡田喜篤(監修).“新版 重症心身障害療育マニュアル”, 医学書院, 2015, pp.19-23.
5) 大谷尚.“質的研究の考え方 研究方法論から SCAT による分析まで”, 名古屋大学出版会, 2019, p.93.

International Training Sites Visited

United States – Chicago, Illinois Area

Almost Home Kids (Chicago)

A pediatric transitional care facility supporting the transition of children with medical complexity to home-based care (urban model).

Address: 211 E Grand Ave, Chicago, IL 60611, USA

Website: http://www.almosthomekids.org/

Almost Home Kids (Naperville)

A pediatric transitional care facility supporting the transition of children with medical complexity to home-based care (suburban model).

Address: IL-53, Naperville, IL 60540, USA

Website: http://www.almosthomekids.org/

Anne & Robert H. Lurie Children's Hospital of Chicago

A comprehensive children's hospital providing highly specialized medical care.

Address: 225 E Chicago Ave, Chicago, IL 60611, USA

Website: https://www.luriechildrens.org/

UIC Division of Specialized Care for Children (DSCC)

A state organization responsible for care coordination for children with medical complexity and chronic conditions.

Address: 1309 S Halsted St, Chicago, IL 60607, USA

Website: https://sac.uic.edu/expo-homepage/exhibitor-list/uic-departments/uic-division-of-specialized-care-for-children-dscc/

Marklund Wasmond Center (Elgin)

A residential and support facility for individuals with severe and profound intellectual and physical disabilities.

Address: 1435 Summit St, Elgin, IL 60120, USA

Website: http://www.marklund.org/

Illinois Council on Developmental Disabilities (ICDD)

A state council promoting independence and community participation for individuals with

intellectual and developmental disabilities.
Address: 160 N LaSalle St, Chicago, IL 60601, USA
Website: https://icdd.illinois.gov/

United States – Augusta, Georgia

Apparo Academy
A comprehensive support center integrating education, therapy, and medical services for children with disabilities.
Address: 3104 Skinner Mill Rd, Augusta, GA 30909, USA
Website: http://apparoacademy.org/

Christ Community Health Pediatrics
A community-based pediatric healthcare provider improving medical access, particularly for underserved populations.
Address: 1238 D'Antignac St, Augusta, GA 30901, USA
Website: http://www.cchsaugusta.org/childrens-health

Belgium – Leuven Area

KU Leuven – Research Unit Parenting and Special Education
An academic research unit specializing in special education and parenting.
Address: Vanderkelenstraat 32, 3000 Leuven, Belgium
Website: https://ppw.kuleuven.be/pserg

Ter Heide (Tongeren)
A residential care facility supporting individuals with severe and profound intellectual and physical disabilities.
Address: Baversstraat 32, 3700 Tongeren-Borgloon, Belgium
Website: http://www.terheide.be/

UZ Leuven – CP Expert Center
A multidisciplinary consultation center specializing in care for individuals with cerebral palsy.
Address: Herestraat 49, 3000 Leuven, Belgium
Website: https://www.uzleuven.be/

Zevenbergen Services Center

A residential and support service provider for individuals with intellectual disabilities.

Address: Boerenkrijglaan 25, 2520 Ranst, Belgium

Website: http://www.zevenbergen.be/

Center for Developmental Disorders

A specialized center providing assessment and support for individuals with developmental disorders.

Address: Tervuursevest 242c, 3000 Leuven, Belgium

Windekind

A special education school for children with severe disabilities.

Address: Schapenstraat 98, 3000 Leuven, Belgium

Website: http://www.windekindleuven.be/

The Netherlands – Nijmegen

Radboud University Medical Center

Department of Primary and Community Care – Intellectual Disabilities and Health

An academic department specializing in primary and community healthcare for individuals with intellectual disabilities.

Address: Geert Grooteplein Zuid 10, 6525 GA Nijmegen, The Netherlands

Website: https://www.radboudumc.nl/

The Netherlands – Groningen Area

University of Groningen – Academic Collaborative Centre for PIMD (ACC-PIMD)

An academic collaborative center dedicated to research on profound intellectual and multiple disabilities.

Address: Grote Rozenstraat 38, 9712 TJ Groningen, The Netherlands

Website: https://aw-emb.nl/en/about-us/

Care Foundation 's Heeren Loo

A care organization providing residential and daily living support for individuals with intellectual and severe disabilities.

Address: Fazant 15, 9781 XE Bedum, The Netherlands

Website: https://www.sheerenloo.nl/in-de-buurt/onze-woonzorgparken-wijken/bedum

---

The Netherlands – Amsterdam Area

Stichting Omega

A comprehensive support organization offering education, therapy, and residential services for individuals with profound disabilities.

Address: Fritz Dietrich Kahlenbergstraat 66, 1087 LL Amsterdam, The Netherlands

Website: https://stichtingomega.nl/

Prinsenstichting

A comprehensive service provider offering residential support, daytime activities, and specialized services for individuals with intellectual disabilities.

Address: Kwadijkerpark 8, 1444 JE Purmerend, The Netherlands

Website: http://www.prinsenstichting.nl/

Germany – Bielefeld

Mara Hospital – Inclusive Medicine Unit

A hospital unit specializing in inclusive medicine for adults with intellectual disabilities.

Address: Maraweg 21, 33617 Bielefeld, Germany

Website: https://mara.de/epilepsie-zentrum

MZEB Bethel – Medizinisches Zentrum für erwachsene Menschen mit Behinderung

A specialized outpatient center for adults with disabilities.

Address: Maraweg 21, 33617 Bielefeld, Germany

Website: https://mara.de/epilepsie-zentrum

Mamre-Patmos-Schule

A special education school.

Address: Maraweg 29, 33617 Bielefeld, Germany

Website: http://www.mps-bethel.de/

Werkstatt Eicheneck

A vocational workshop supporting employment for individuals with disabilities.

Address: Karl-Siebold-Weg 60, 33617 Bielefeld, Germany

Evangelical Hospital Bethel (EvKB) – Johannesstift (Palliative Care Unit)

A palliative care unit within a general hospital.

Address: Schildescher Str. 99, 33611 Bielefeld, Germany