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Living as Human Beings: A Report on Practical Approaches to Living in the Community Regardless of the Severity of Disability

Hiroko KOIZUMI and Mitsutoshi OYABU *

* *Japan Center for Independent Living*

Koizumi: Hello. Thank you for the opportunity to speak at this kind of event today. I belong to the Kyoto-based Japan Center for Independent Living (JCIL), an organization through which persons with disabilities themselves work to make the lives of persons with disabilities better.

Regarding the JCIL's basic philosophy, JCIL was established in 1987 by the late Eichi Nagasaki who set down its "fundamental idea." The first sentence of this text is as follows: "People are born as human beings and die as human beings. When it comes to birth and death, there is no difference between non-disabled persons and disabled persons (persons who have received a disability because of dysfunction in their mind or body). However, when it comes to disabled persons 'living as human beings,' the disparity in comparison to non-disabled persons is enormous." The entire text of the "fundamental idea" is available on JCIL's website (http://jcil.jp/eng/e-index.htm).

I have been involved with JCIL since around 1991. I lived with my parents in Fukui Prefecture until I was 18 and suffered constant bullying at school.

I have cerebral palsy, which causes difficulties in speaking as you can see. I also have deformities in my body and face, and an unpleasant appearance. I have had various thoughts and feelings in this situation. Even when I had something I wanted to say, I gave up without being able to enter the conversation. At school I was subjected to cruel words and violence.

After graduating from high school, I came to Kyoto and tried working in an ordinary workplace, but even there I felt isolated; the message I got was, "You are an unnecessary, unwanted person." Our society exists within the context of "eugenic thought." Those of us who have disabilities are seen as “inferior,” and “persons with disabilities are people we don’t need” - this is the kind of unspoken message I received.

When I was 28, I met a member of JCIL. They profoundly influenced my way of “living.” They helped me believe that I am a “being worthy of existence” who “can be of use to others,” and that as such a being I am “a being worth caring about.”

We want to be treated “as human beings” too. This is the idea behind what we do.

Here we will introduce JCIL’s activities.

Oyabu: I’m Mitsutoshi Oyabu from the JCIL center. Thank you for giving me the opportunity to speak at this kind of event. To briefly introduce myself, I have a disability called “spinal muscular atrophy (SMA).” I live with intensive 24-hour in-home nursing care, and work as a staff member with a disability at the JCIL, mainly engaging in activities such as peer support. I would like to introduce the JCIL’s activities and our activities with the “Project for the Future Liberation and Deinstitutionalization of Muscular Dystrophy Wards” that has already been introduced.

I’ll begin with “what JCIL values most.” I think this is the same for any independent living center, but first is “No matter what kind of disability you have, everyone should be able to live in the community, just like anyone else!” Next is “People with and without disabilities are all equal as human beings — we should recognize and respect that.” There are various barriers in our society. These barriers are both physical and mental, and persons with disabilities should raise our voices and “Break down barriers – physical, social, and emotional.” Finally, “Persons with disabilities should take the lead in activities that support others with disabilities!” With these four basic tenets driving our activities, we take on various problems on a daily basis.

This photograph shows a meeting at the JCIL office. The office is near Jyujo in Minami Ward, not far from Kyoto Station. JCIL is a caregiver dispatch office and collaborative workspace, but since its founding in 1984 its office has also been a base for activism by persons with disabilities.

We engage in various activities every day, and first among these is “peer support.” Our office provides a venue for persons with disabilities to counsel each other, and I think it is a place where they can comfortably discuss the many difficulties they face, such as utilizing independent support and nursing care and dealing with problems that arise when a caregiver is not available. The staff can consult each other, and they also visit persons with disabilities at their homes to provide counseling.

There are many independent living centers that provide “peer counseling” in the form of counseling or discussion, but here we offer “peer support” in daily life without strictly adhering to the paradigm of “counseling.”

“Community building and accessibility advocacy.” When we go out in our community, as everyone knows there are many things that are not accessible, but when we encounter an issue in the community for people using a wheelchair, we share this information on social media like Facebook and demand improvements from Kyoto City officials. The photographs may be hard to see, but looking at the one on the bottom left, recently “T” barriers have been installed in places like institutions for the elderly. These are intended to prevent vehicles like motorcycles from entering, but they also end up blocking wheelchairs. It may be possible to get through them in a small wheelchair, but the large ones we use cannot fit. Persons without disabilities may pay them no mind, but many such barriers do indeed exist, and we are working to remove them.

We have been engaged in training Kyoto City transportation bureau staff for many years. Four or five times a year we provide training to city employees such as subway drivers or attendants in the form of classes, practical guidance, and group work centered on the message “Please treat us like other passengers.” We explain things like how to handle wheelchairs, but the training is centered on persons with disabilities themselves, including things like drivers learning to understand a person with a speech-related disability when they say where they want to go.

To discuss a recent event, in 2019, Yuri Hayashi, a person with ALS, asked a doctor named Yuichi Okubo to “please euthanize me.” This led to an actual incidence of euthanasia. When this occurred, some people in our society spoke out in defense of Dr. Okubo. There were even some who said, “He killed her because she wanted to die, so his sentence should be reduced.” As persons with disabilities ourselves, this gave us a strong sense of crisis. People do indeed think, “Persons with disabilities are dispensable beings.” There was a broad debate over euthanasia regarding such issues.

Today’s theme is “to live as a human being,” and “transitioning to living in the community” is important no matter what disability one may have. Even today there are many persons with disabilities living in hospitals or institutions, but JCIL has been providing support for “community transition” for many years. I myself have been involved in the transition from Utano hospital to the local community in Kyoto. JCIL is an organization that offers support for “community transition” not only from this hospital but also many other institutions.

There is a Japan-wide project dealing with “community transition” called “Project for the Future Liberation and Deinstitutionalization of Muscular Dystrophy Wards.”

Some of you may have heard of “muscular dystrophy wards,” but for those who have not, there are wards within the National Hospital Organization where persons with muscular dystrophy and other forms of neck failure are institutionalized. There are 26 of these facilities throughout the country. It is said that they contain a total of 2000 beds. There are various hurdles facing the people in these facilities who would like to leave them and pursue a “community transition.” While the person themselves may want to live in the community, their doctor may object, saying, “I cannot let you do something so dangerous.” While the person may say “I want to transition to living in the community,” circumstances are such that doing so is not easy. It has become clear that this is not only the case in Kyoto; there is the same “difficulty in community transitioning” in Ishikawa Prefecture, Ōita Prefecture, Akita Prefecture, and all over Japan. Amid such circumstances, like-minded people who want to “make muscular dystrophy wards better known in the community” came together as a national movement and established the “Project for the Future Liberation and Deinstitutionalization of Muscular Dystrophy Wards.” JCIL has been involved in this project from the beginning, and it has been set up and expanded through discussions with all concerned.

Thus far we have engaged in a wide range of initiatives. When it comes to “promoting community transition support in each locality around the country,” the first community transition in any locality is always difficult. By sharing things like “this is how community transition was achieved in Kyoto” or “this is how community transition was achieved in Akita Prefecture” with the project as a whole, little by little “community transitioning” is becoming possible throughout Japan.

There is also something called “multiple discrimination” or “intersectionality.” On top of having a disability, there are people who also face additional pressure or discrimination because of the attribute of “being a woman.” We facilitate empowerment and information exchange between women, and every month we hold an online exchange meeting. Once a month, patients in wards and persons with disabilities living independently in the community engage in various forms of exchange and interaction. There are discussions of topics like “how can I transition to the community?” or “what is living in the community really like?”, but there are also more mundane discussions of coping strategies such as, for example, “how do you deal with the cold?”

because in winter persons with muscular dystrophy struggle with lower temperatures. Patients discuss these things with each other online.

When we first launched this project, we put most of our energy into a “fact-finding survey.” We visited the bedsides of patients in the wards, conducted 58 interviews about the actual circumstances of their daily lives, and put together the results in a press release to inform the public. The patients shared various opinions, but it was clear that there was a closed-off environment within the wards, and we took action to make this fact more widely known.

We also exchanged opinions with Ministry of Health officials once or twice a year. Recently “different gender nursing care” has become an issue within the wards. For example, there are circumstances in which male staff assist female patients with bathing or toileting, and while we who are living in the community would say, “Surely this is no good,” such practices are taken for granted in the wards. Every year we submit a request to the Ministry of Health to “end unwanted different gender care as soon as possible.”

This project has succeeded in connecting people online. During COVID-19, people in the community did not meet up in person, but the flipside of this was that connecting to people in the wards became easier thanks to online [communication tools]. And thanks to not only persons with disabilities but various other people such as researchers, journalists, and other concerned parties becoming part of the network, it has become possible to proceed with “community transitioning” while sharing information and experiences no matter where you live.

I am a member of this project, but recently patients in the wards themselves have become the core of this movement. Within the “Project for the Future Liberation and Deinstitutionalization of Muscular Dystrophy Wards” there is something called the “Virtual Patients’ Association,” and through it people in the wards are advancing this movement while discussing their own daily lives and “community transitioning.” Calls for “nothing about us without us” are growing within the wards. While I spent a short period in a ward myself, I am not truly one of the people in question here. But I think that for people spending their daily lives inside the wards, becoming able to send a message to society through online tools is something that could not have happened in the past. Today, however, this is indeed being accomplished.

Right now, we are engaged in activities to advance “community transitioning,” but this is only possible because of the availability of 24-hour intensive in-home nursing care. 24-hour nursing and medical care is indispensably important to persons with disabilities, and it is because we are now living in an era in which it is possible to access this care in the community that we are pushing to steadily increase “community transitioning” going forward.

“Community transitioning” definitely seems to be increasing in other parts of the country as well. At the UN there is talk about “deinstitutionalization,” and in order to pursue “deinstitutionalization” in Japan “community transitioning” initiatives of this kind need to be further expanded throughout the country. We are also living in a new era in which people with severe disabilities living in institutions and wards can participate in projects using ICT and online [tools].

Finally, as an aim of the “Project for the Future Liberation and Deinstitutionalization of Muscular Dystrophy Wards,” various people are participating in this initiative in various ways, so rather than “as a whole,” I think each can take up initiatives with their own content. When this project started, I thought that “community transitioning” should progress and hospitals should disappear. But in my interactions with patients in the wards, some patients themselves said that wards are needed, and that while it is better for wards to exist, at present there are many oppressive limitations within them, so to begin with they would like to make the environment within the wards one in which they can live the way they want. We want to get rid of absolute restrictions and change the fact that different gender care is being carried out to ensure the safety of patients. We also need receptive communities in order to increase “community transitioning” throughout Japan. Under the current circumstances there are some communities that are not fully accepting, and to promote “community transitioning” it is important to increase community resources.

So far, I have introduced the kind of community transitioning initiatives we have been conducting. I will now hand the microphone over to Koizumi-san to continue her discussion from earlier.

Koizumi: There are many people who are “living in the community” amid the activities just discussed. But successfully establishing a life in the community is not the end [of what can be achieved]. I myself manage a nursing care dispatch office. In this role I encounter persons with various kinds of disabilities and engage in battles every day.

This office was established in 2003. At the start, the style of caregiving adopted involved persons with physical disabilities such as cerebral palsy or cervical cord injuries directing the caregiver and the caregiver waiting for instructions.

Later, situations in which “waiting for instructions” was not feasible arose, such as when caring for people with ALS, intractable illnesses (*nanbyō*), and mental disabilities, and collaboration with medical care [providers] and interactions with parents increased. Now we have 24-hour communication via email or messaging apps like “line.” There are persons with progressive intractable illnesses and changes caused by aging, and the person in question cannot always keep up with their own changes.

There are also cases of physical pain in which the response of the caregiver cannot keep up. There are situations in which everyone is suffering.

There are moments when people think, “Wouldn’t it be better to go back to living in a ward or institution?”

Even though there are people suffering in this way, we move forward with living in the community. This is because we are pursuing the aim of “living as a human being.”

I would like to share a final story about a woman with muscular dystrophy. She lived in a hospital until around the age of 40. In 2015 she left the hospital and began living in the community with 24-hour nursing care. The progression of her disability brought physical pain, and there was a time when she would lash out at caregivers. Several caregivers quit because they were unable to endure this. There were others at whom she became angry and said, “You cannot care for me.” At the end it was a truly severe caregiving situation.

She passed away at the age of 65. Many people came to her wake and funeral, and among them were caregivers who had quit or been dismissed from taking care of her. Many such caregivers attended her wake and shared their memories of her. One by one, each told their own story, and I felt something I cannot put into words.

I thought, “This is what it means to ‘die as a human being.’” I don’t think such stories would have been created while living in an institution or hospital. Living in the community is not easy, but nevertheless we aim to live here rather than in hospitals or institutions.

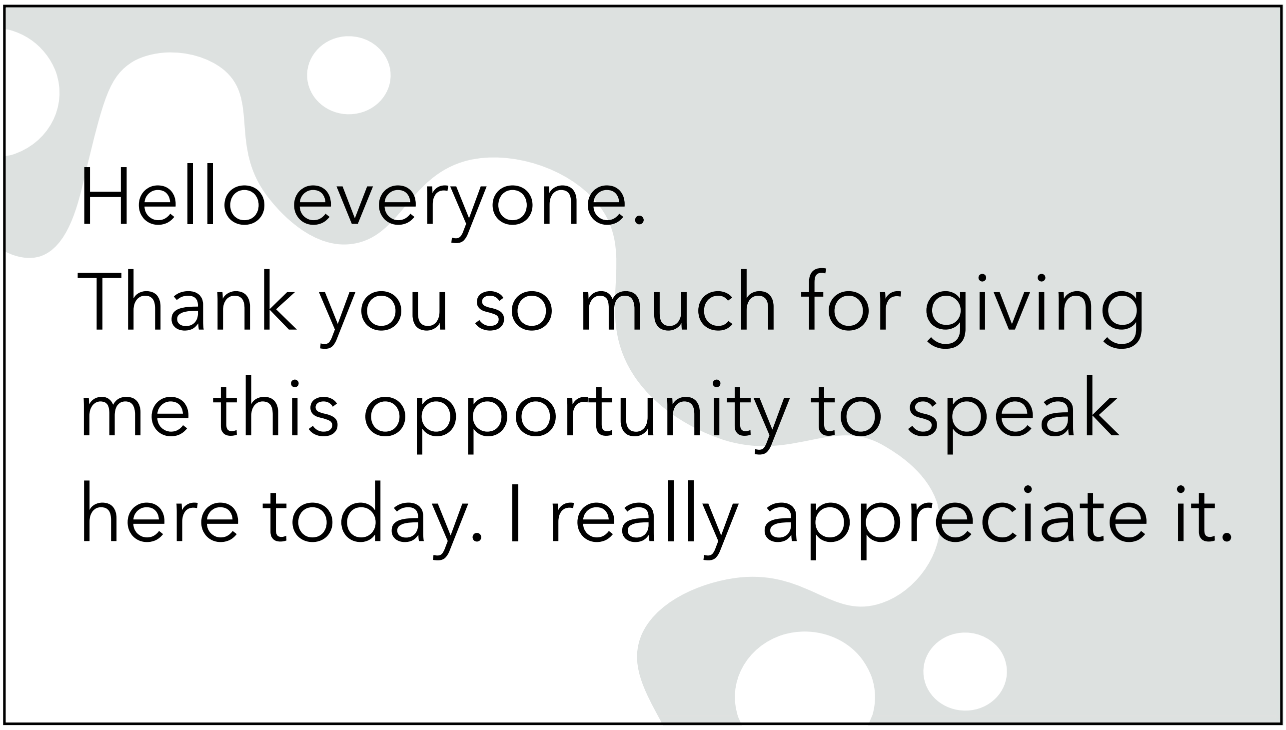
To live “as a human being” is impossible within the limited relationships of an institution or our parents’ homes. I want to keep searching for ways to connect with society.

We want to live as human beings. Please also enable us to meet our end as human beings. Thank you.

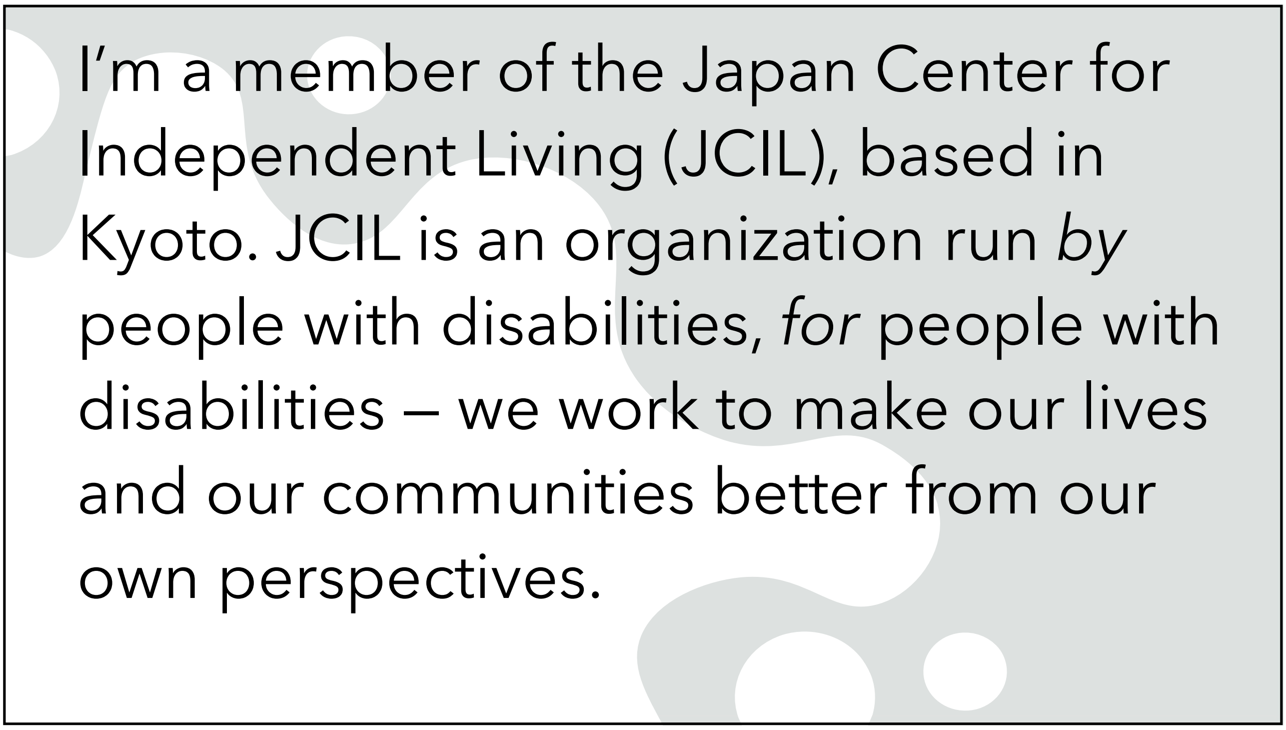
Living as human beings: A report on practical approaches to living in the community regardless of the severity of disability

Hiroko Koizumi, Mitsutoshi Oyabu

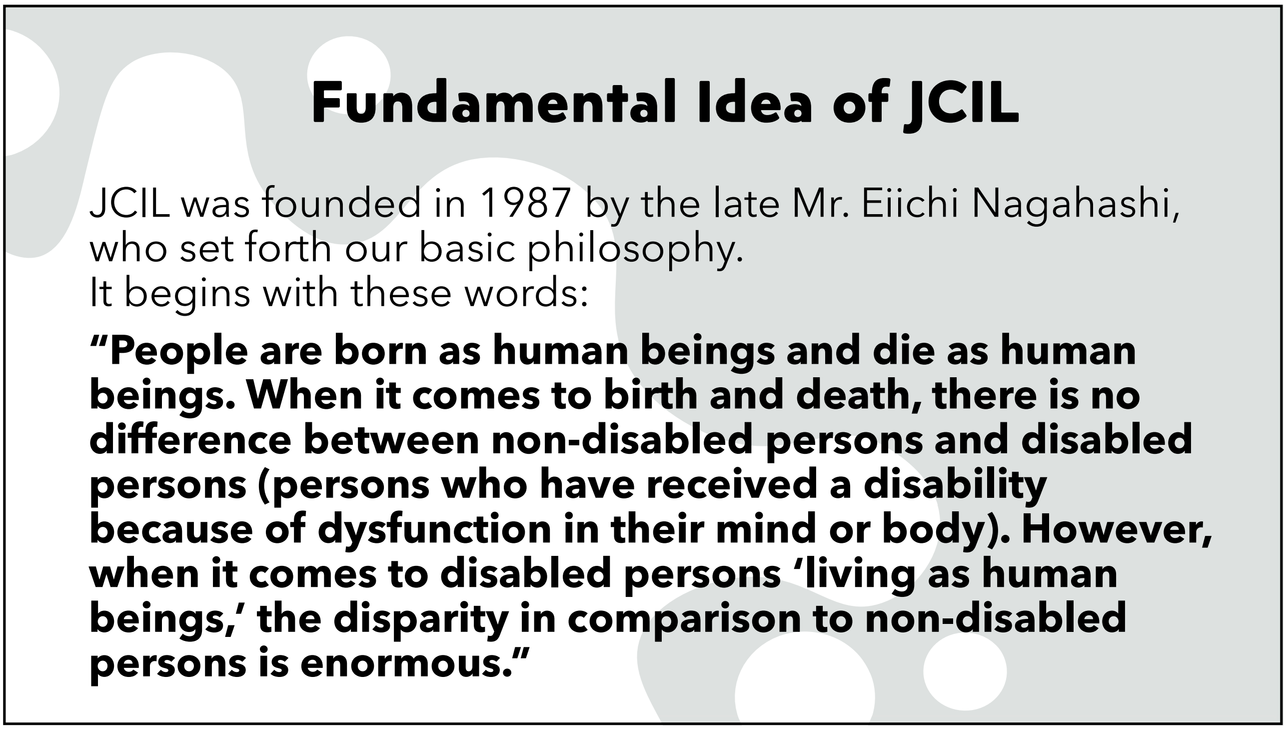
Japan Center for Independent Living



Hello everyone.
Thank you so much for giving me this opportunity to speak here today. I really appreciate it.



I'm a member of the Japan Center for Independent Living (JCIL), based in Kyoto. JCIL is an organization run *by* people with disabilities, *for* people with disabilities – we work to make our lives and our communities better from our own perspectives.



Fundamental Idea of JCIL

JCIL was founded in 1987 by the late Mr. Eiichi Nagahashi, who set forth our basic philosophy.
It begins with these words:

"People are born as human beings and die as human beings. When it comes to birth and death, there is no difference between non-disabled persons and disabled persons (persons who have received a disability because of dysfunction in their mind or body). However, when it comes to disabled persons 'living as human beings,' the disparity in comparison to non-disabled persons is enormous."

基本理念

”人は人として生まれ、人として死ぬ” その誕生と死については健常者であれ障害者（心身の不全によって障害を受ける人）であれなんら変わることはない。

しかし、障害者が「人として生きる」ということについては健常者と比較して天と地ほどの差が存在する。我々は障害者であっても人として生まれ人として死ぬのでありそれと全く同じ「人として生きる」ことを希求しているのである。　しかるに、現代の社会は、経済的、社会的効率の作り出した虚構として障害者は生かされて生きながらえる存在にしてしまっている。国や地方自治体が行う「障害者への施策」は自立しようとする者の主体性を認めるものではなく、本当の意味での援助にはなり得ていない。また一般的に障害者が自ら高めようとする自立への意欲に対しても、はじめから不可能と決めつけ、「人として生きる」上で悩み傷つくことさえも健常者となんら変わらないことを理解しようとはしない。「人として生きる権利」すなわち「基本的人権」を完全に歪めているのに気が付かないのである。その健常者優位の社会が作り出してきた歪みを表現する「障害者は隔離して庇護をする」という既成概念は「障害者はやっかい者として扱う」という一方的なものであり、そこに基本的な誤りが存在してきたのである。

そうした基本的誤りのある既成概念を障害者自身も容認して、「隔離的で庇護的な環境」すなわち依存した生活を送っている限りにおいては、本来、自立生活能力を必要としないのであり、また、この社会の中で「独立して」自立生活をしていく方法を始めて学ぶ機会は決して訪れないのである。

今、障害者自身は「隔離的で庇護的な環境」すなわち「依存」から脱却して「自立生活」へ移行する主体として最大限の努力が必要となったのである。

ここに、人権意識のある多くの人たちの願いと協力を背景として「対等・平等に生きる権利」を行使して社会に大きく貢献する自立生活運動を推進することの責任が課せられたことを自覚し行動しなければならない。

我々は、既成概念の変革を怠けて放置することは許されない。それは、単に障害者の「人としての尊厳」を奪うに止まらず、この社会の総ての人間にとっても完全な敗北を意味することになるからである。この誤った既成概念を容認して済ます時代は既に終わり、自立生活を希求する障害者の人権を擁護し総合的な援助サービスを提供する機関が要求されるに至ったのである。

障害者の社会的ハンディに対して援助示唆する機関である『日本自立生活センター』（Japan Center for Independent Living）は、障害者による障害者のための自立生活運動の拠点として設立の意義を有するものである。

一九八七年六月　日本自立生活センター

代表　長橋栄一

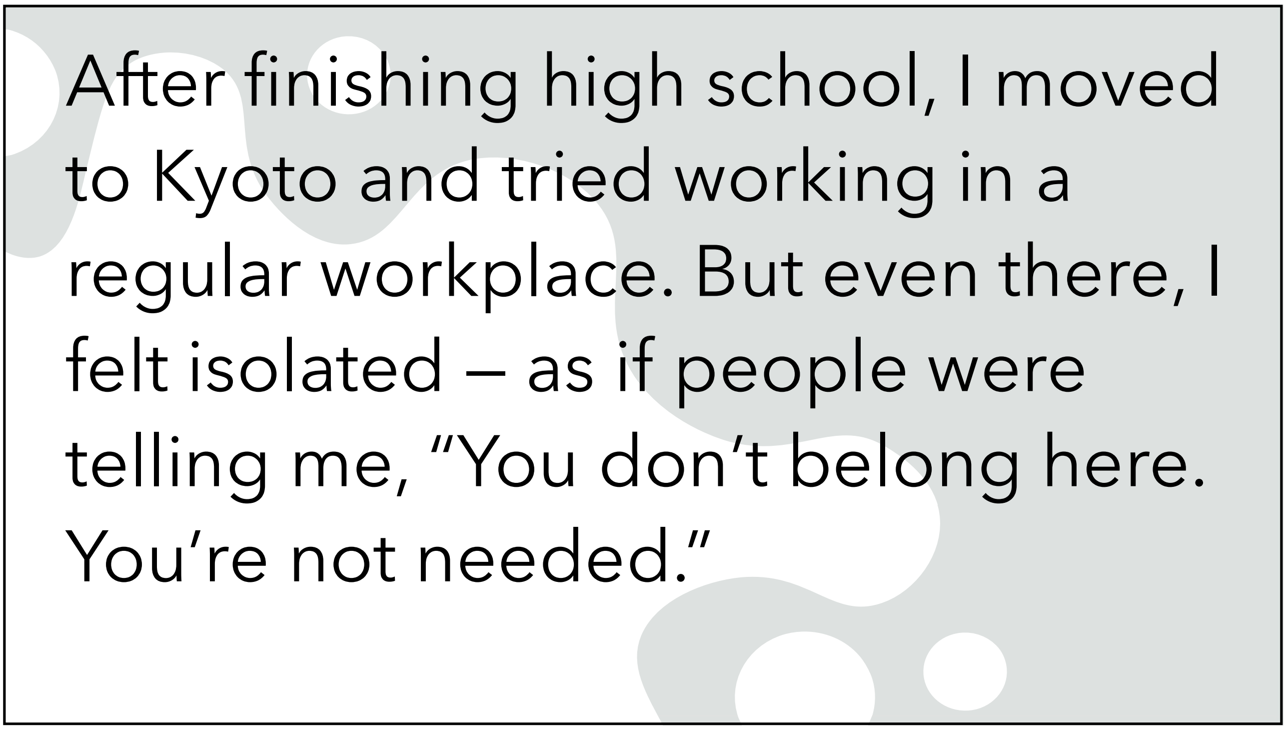
I started getting involved with JCIL around 1991.
Until I was 18, I lived with my parents in Fukui Prefecture, and during my school years, I was constantly bullied.

I have cerebral palsy, which affects my speech. I also have some physical deformities – my body and face are a bit asymmetrical – and for a long time, I struggled with how I looked.

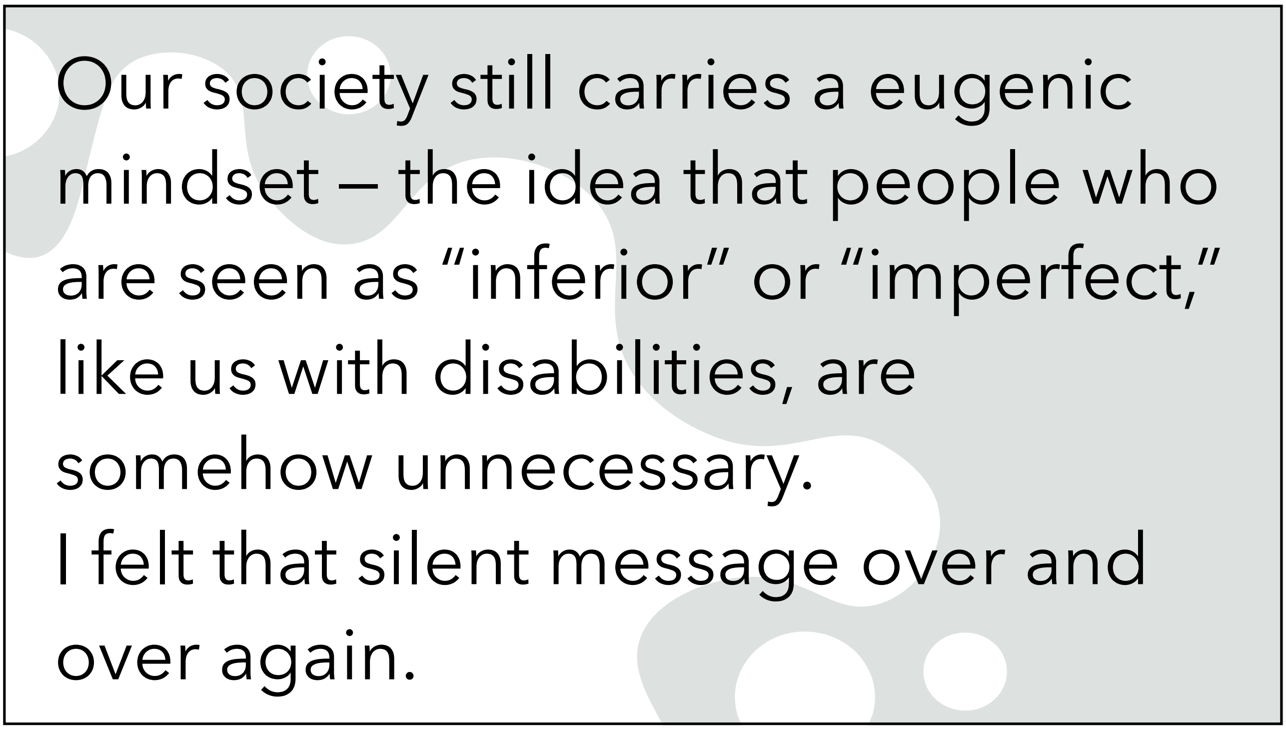
Because of that, I went through a lot emotionally.

I often couldn’t join conversations, and even when I had things I wanted to say, I just gave up trying.

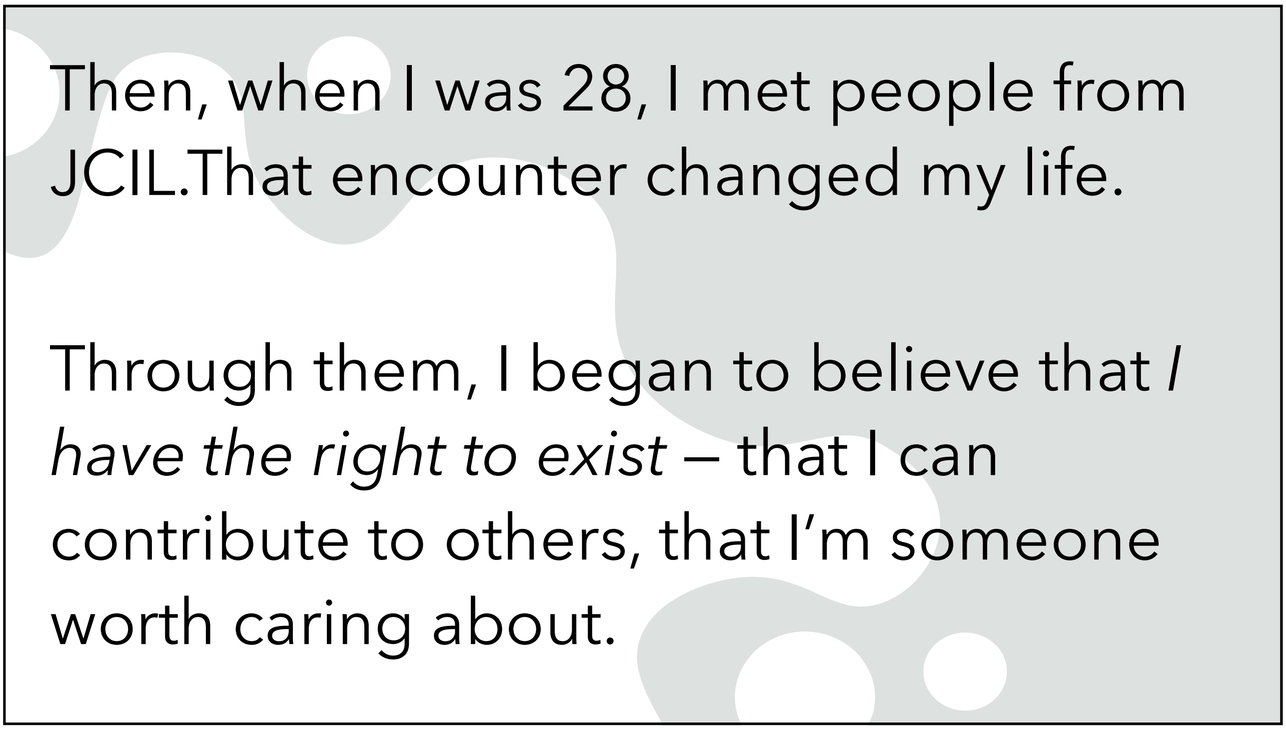
At school, I faced both physical and verbal abuse.



After finishing high school, I moved to Kyoto and tried working in a regular workplace. But even there, I felt isolated – as if people were telling me, “You don’t belong here. You’re not needed.”

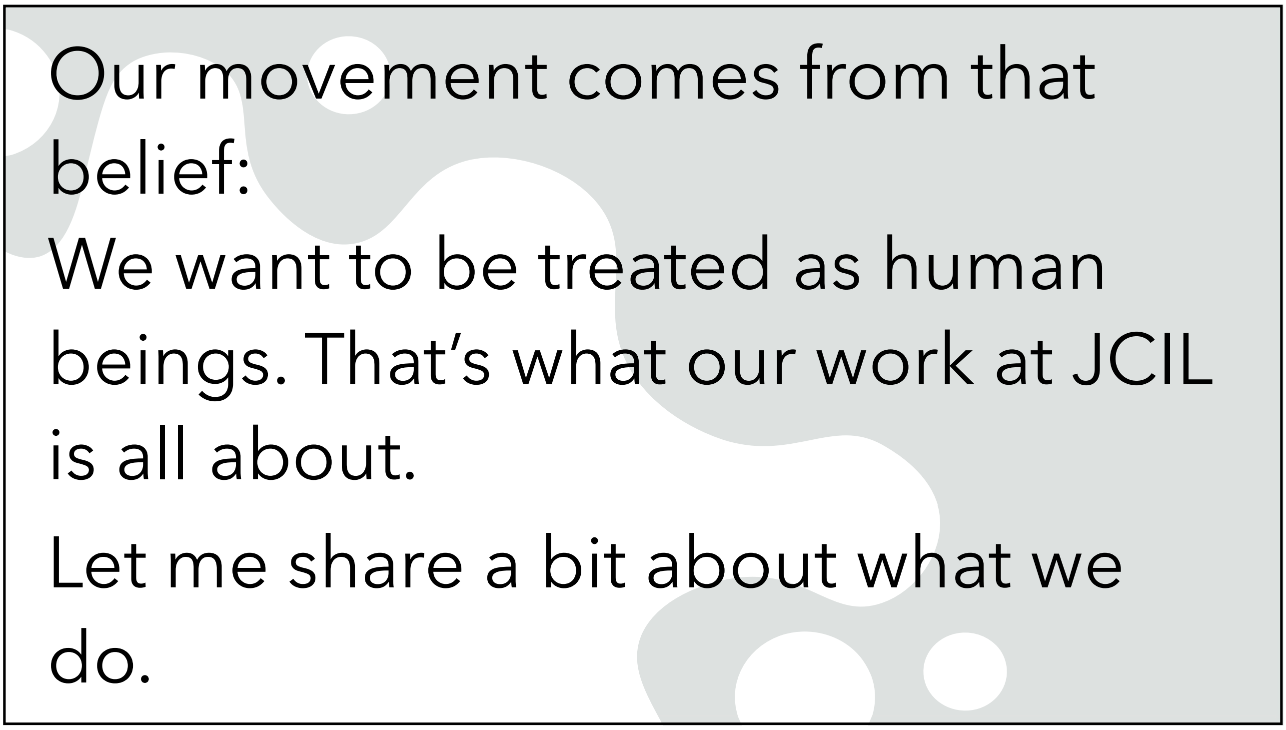


Our society still carries a eugenic mindset – the idea that people who are seen as “inferior” or “imperfect,” like us with disabilities, are somehow unnecessary.
I felt that silent message over and over again.



Then, when I was 28, I met people from JCIL.That encounter changed my life.

Through them, I began to believe that *I have the right to exist* – that I can contribute to others, that I'm someone worth caring about.



Our movement comes from that belief:

We want to be treated as human beings. That's what our work at JCIL is all about.

Let me share a bit about what we do.

What JCIL Values Most

- No matter what kind of disability you have, everyone should be able to live in the community, just like anyone else!
- People with and without disabilities are all equal as human beings — we should recognize and respect that.
- Break down barriers — physical, social, and emotional.
- People with disabilities should take the lead in activities that support others with disabilities!

Activities of the Japan Center for Independent Living

Peer Support

One-on-one peer support by people with disabilities

Practical advice before starting independent living

Home visits to see how senior members live independently in the community

Community Building & Accessibility Advocacy

We're always doing on-the-ground research to make our city more accessible. We even checked the accessibility of "Universal Design" taxis ourselves!

Training for Kyoto City Transportation Bureau Staff

For over 10 years, we've been running workshops for public transportation employees.

We share one key message:

"Please treat us like any other passenger."

The training includes lectures, hands-on practice, and open discussions with people with disabilities.

The ALS Assisted-Suicide Case and Our Lives

At JCIL, we reflected deeply on this case – to share our feelings and concerns, and to discuss how society can better support people with severe diseases and disabilities to live fulfilling lives instead of giving up on life.

We studied the 2019 ALS assisted-suicide case in Kyoto, where Yuichi Okubo killed Ms. Yuri Hayashi, who had ALS, at her own request.
This case was widely reported in the media and sparked national debates about euthanasia and the value of life.

Supporting Transitions to Community Living

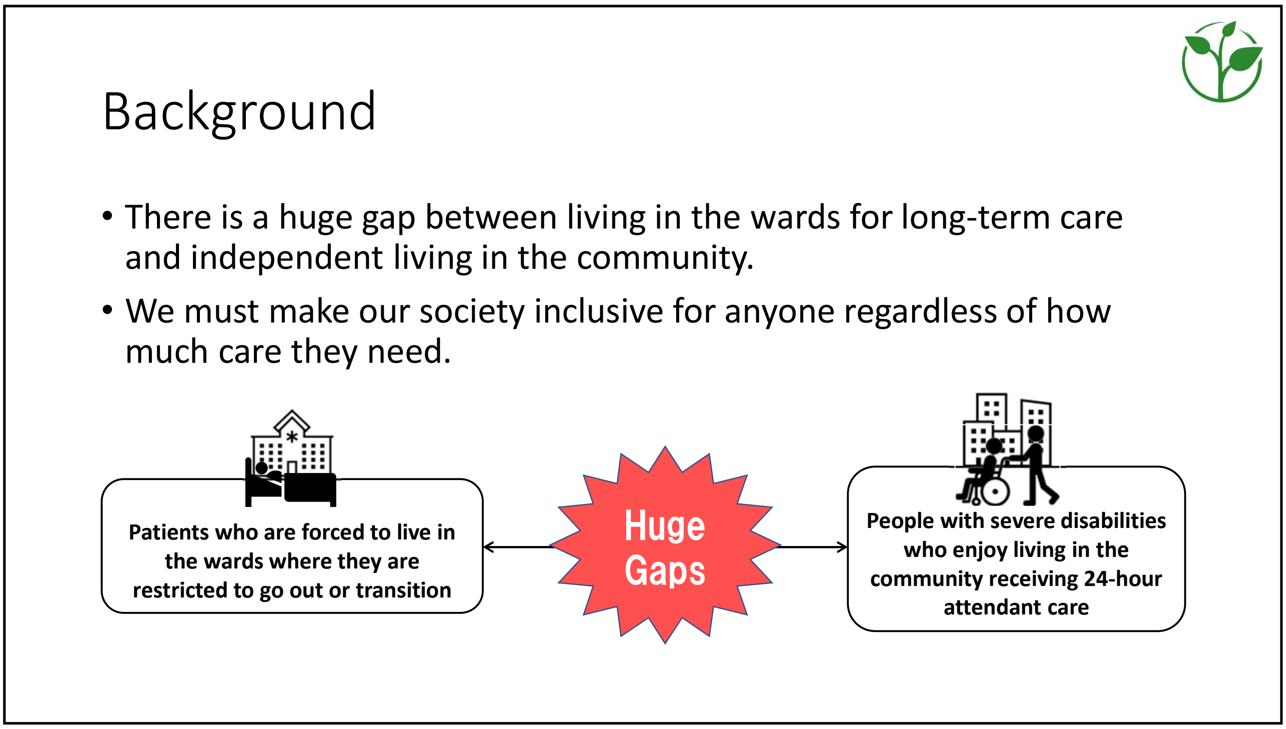
We continue to help several people who want to move out of hospitals or nursing homes into community life.
The last transition from Utano Hospital happened in the fall of 2020 — just before COVID-19 cut off many of our connections.
Now, we're working hard to rebuild those networks.

We've also set up a "Community Transition Team", a joint effort between JCIL's main office and our other departments.

筋ジス病棟の未来を考えるプロジェクト

Project for the Future Liberation and Deinstitutionalization of Muscular Dystrophy Wards

Project for the Future Liberation and Deinstitutionalization of Muscular Dystrophy Wards



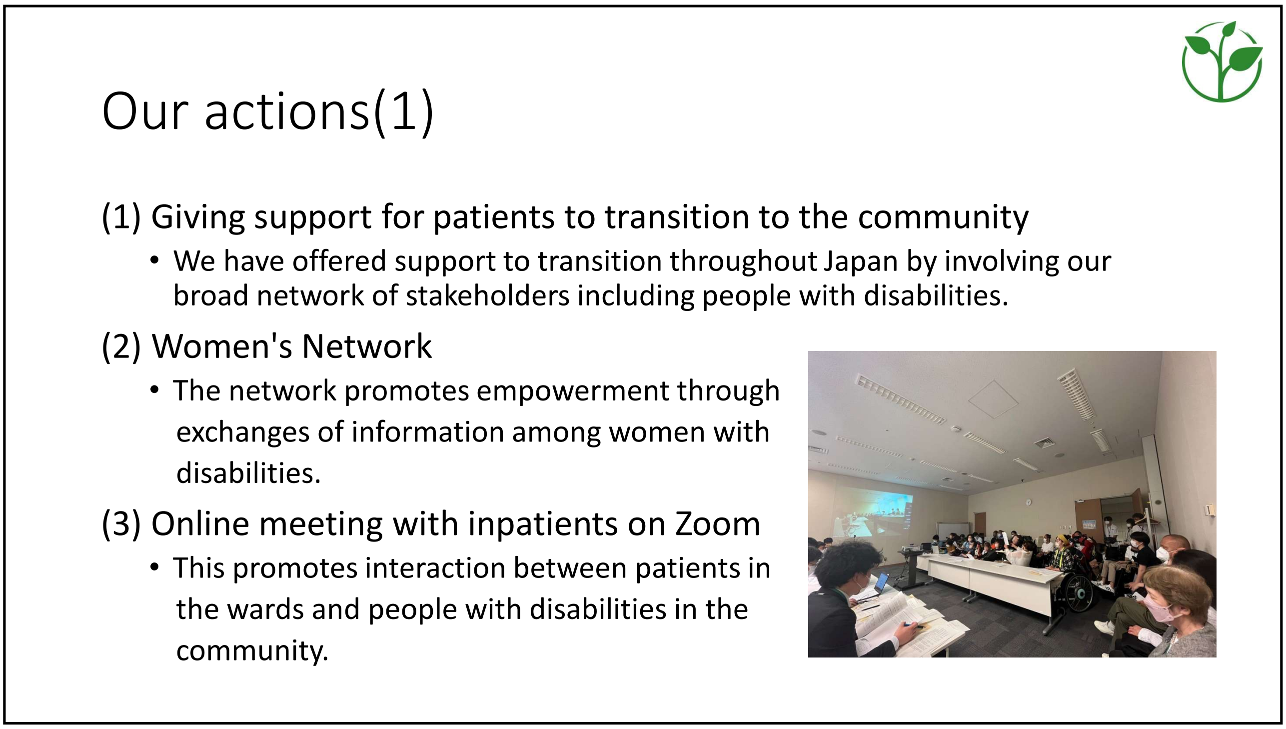
Background

- There is a huge gap between living in the wards for long-term care and independent living in the community.
- We must make our society inclusive for anyone regardless of how much care they need.

Patients who are forced to live in the wards where they are restricted to go out or transition

Huge Gaps

People with severe disabilities who enjoy living in the community receiving 24-hour attendant care



Our actions(1)

(1) Giving support for patients to transition to the community

- We have offered support to transition throughout Japan by involving our broad network of stakeholders including people with disabilities.

(2) Women's Network

- The network promotes empowerment through exchanges of information among women with disabilities.

(3) Online meeting with inpatients on Zoom

- This promotes interaction between patients in the wards and people with disabilities in the community.

Our actions(2)

(4) Survey of the State of Muscular Dystrophy Wards

- Our project members with disabilities directly interviewed the patients at their bedsides in the muscular dystrophy wards.

(5) Initiatives for policy recommendation

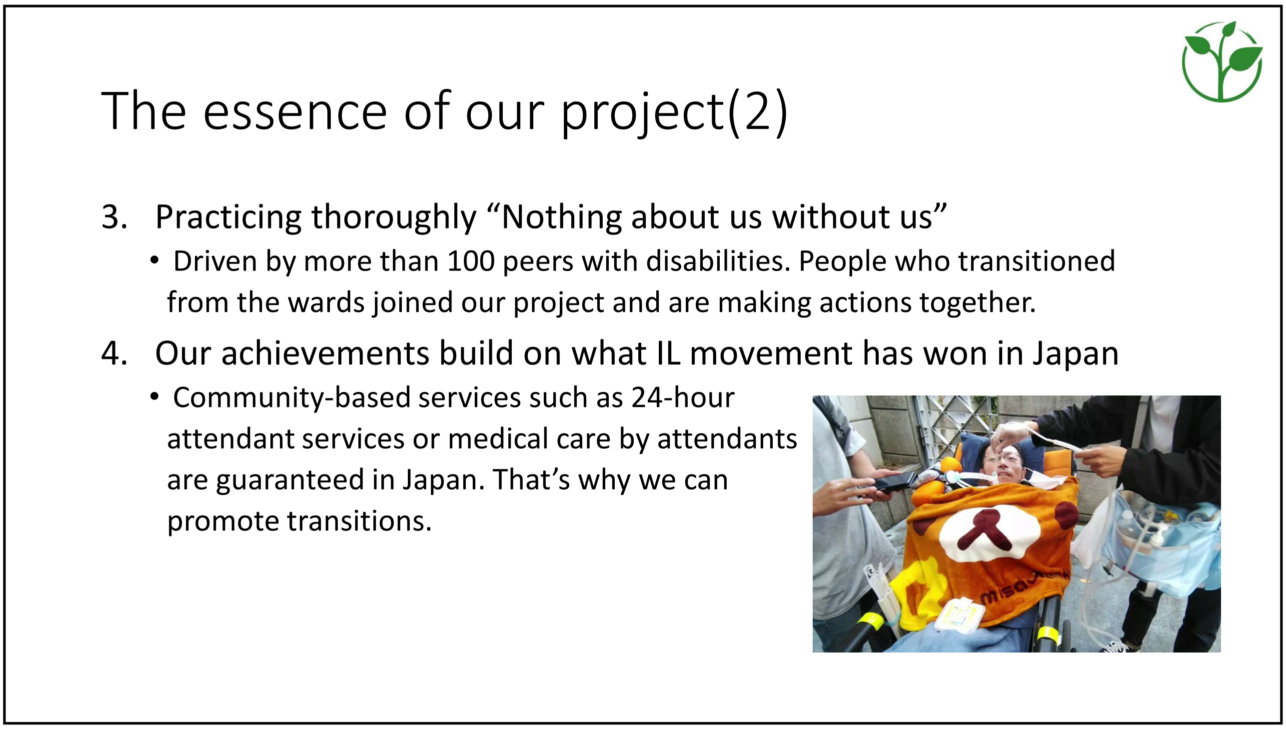
- We have exchanged opinions with the Ministry of Health, Labor and Welfare several times.

(6) Lobbying in Geneva about CRPD

The essence of our project(1)

1. Making full use of online tools
   (Zoom, Messaging apps)
   - Enabled us to communicate with patients in the wards beyond place and time.

2. Involving various stakeholders throughout the country
   - Enabled us to support transitions everywhere by sharing information and experiences wherever they live.

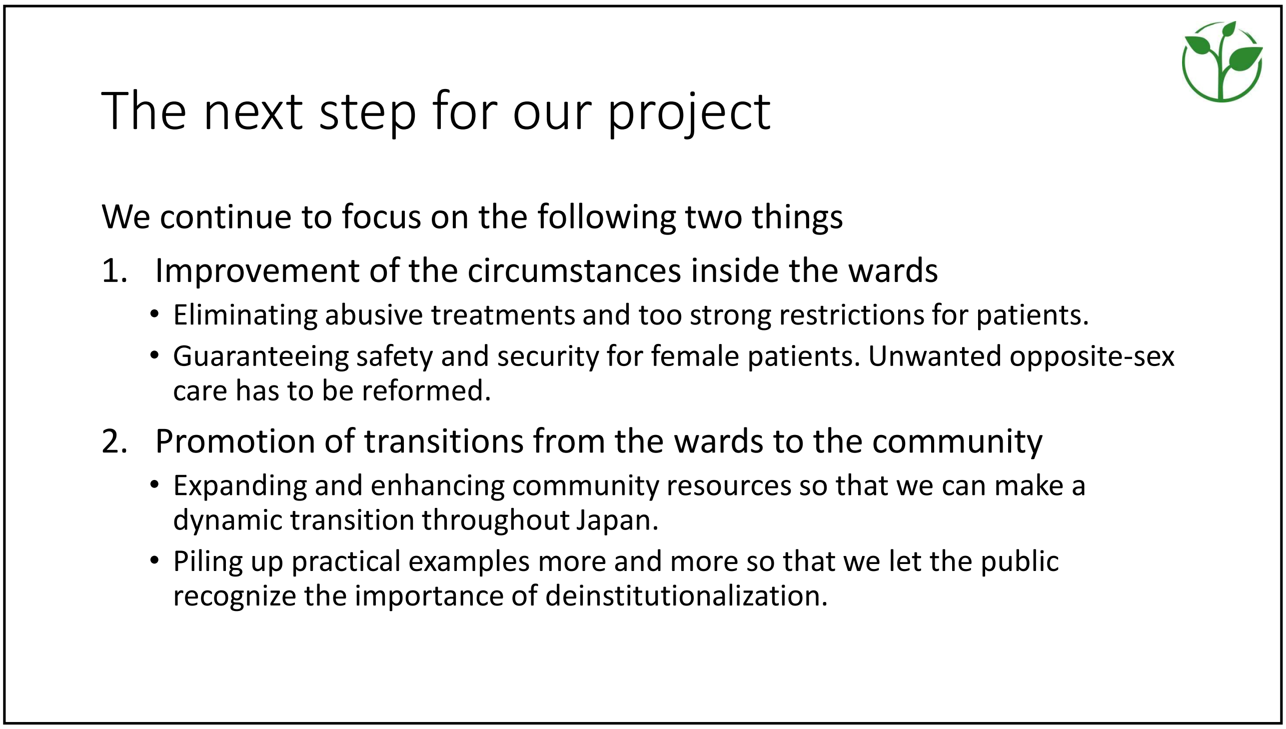


The essence of our project(2)

3. Practicing thoroughly “Nothing about us without us”
    - Driven by more than 100 peers with disabilities. People who transitioned from the wards joined our project and are making actions together.
4. Our achievements build on what IL movement has won in Japan
    - Community-based services such as 24-hour attendant services or medical care by attendants are guaranteed in Japan. That’s why we can promote transitions.

The impact we made

- Succeeded in transitioning more than 10 people from 5 muscular dystrophy wards.
- Made the public know about the inhumane situation inside the wards and the importance and possibility of deinstitutionalization.
- Created a new stage of IL movement that people with severe disabilities or even in institutions can join by using ICT.



The next step for our project

We continue to focus on the following two things

1. Improvement of the circumstances inside the wards
    - Eliminating abusive treatments and too strong restrictions for patients.
    - Guaranteeing safety and security for female patients. Unwanted opposite-sex care has to be reformed.
2. Promotion of transitions from the wards to the community
    - Expanding and enhancing community resources so that we can make a dynamic transition throughout Japan.
    - Piling up practical examples more and more so that we let the public recognize the importance of deinstitutionalization.

Through JCIL's movement, many people with disabilities have started living in their local communities. But moving into the community is not the *end goal* – it's just the beginning.

I also work as the manager of a personal care attendant service for people with disabilities.
Through that work, I meet all kinds of people and face new challenges every day.

We started the service in 2003.
At first, we mainly supported people with physical disabilities such as cerebral palsy or spinal cord injuries.
The system was simple: the person with disabilities would give instructions, and the attendant would follow them

But as time went on, we began supporting people with ALS, rare diseases, intellectual and psychiatric disabilities – and that model no longer worked. We had to collaborate with doctors, families, and others.
Messages and calls now come in through email or LINE –even 24 hours a day.

Some people have progressive diseases or age-related changes that make things even more difficult.
They may be in pain, and attendants can’t always keep up

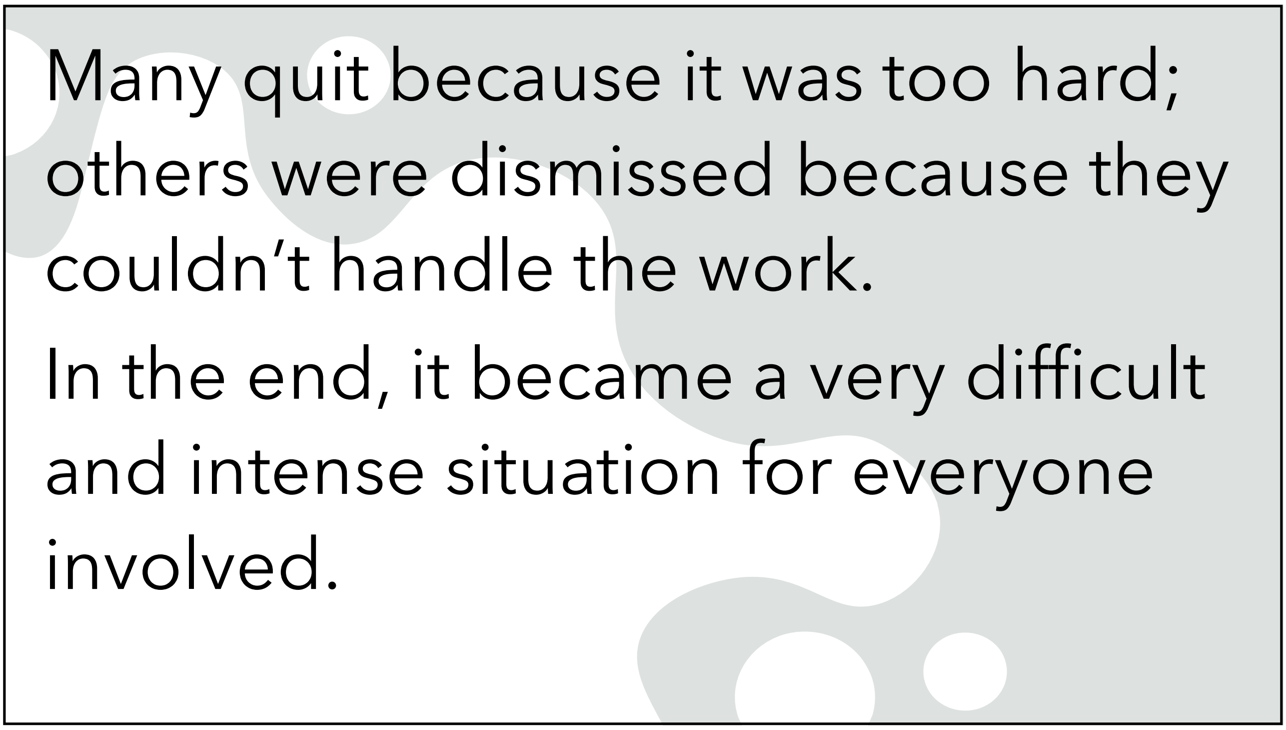
There are cases when everyone suffers.

Sometimes, I even catch myself thinking, *“Wouldn’t it be easier if they just went back to a hospital or a nursing home?”*

But even when life in the community is tough, we keep going – because what we’re aiming for is a life with dignity, a life as a human being.

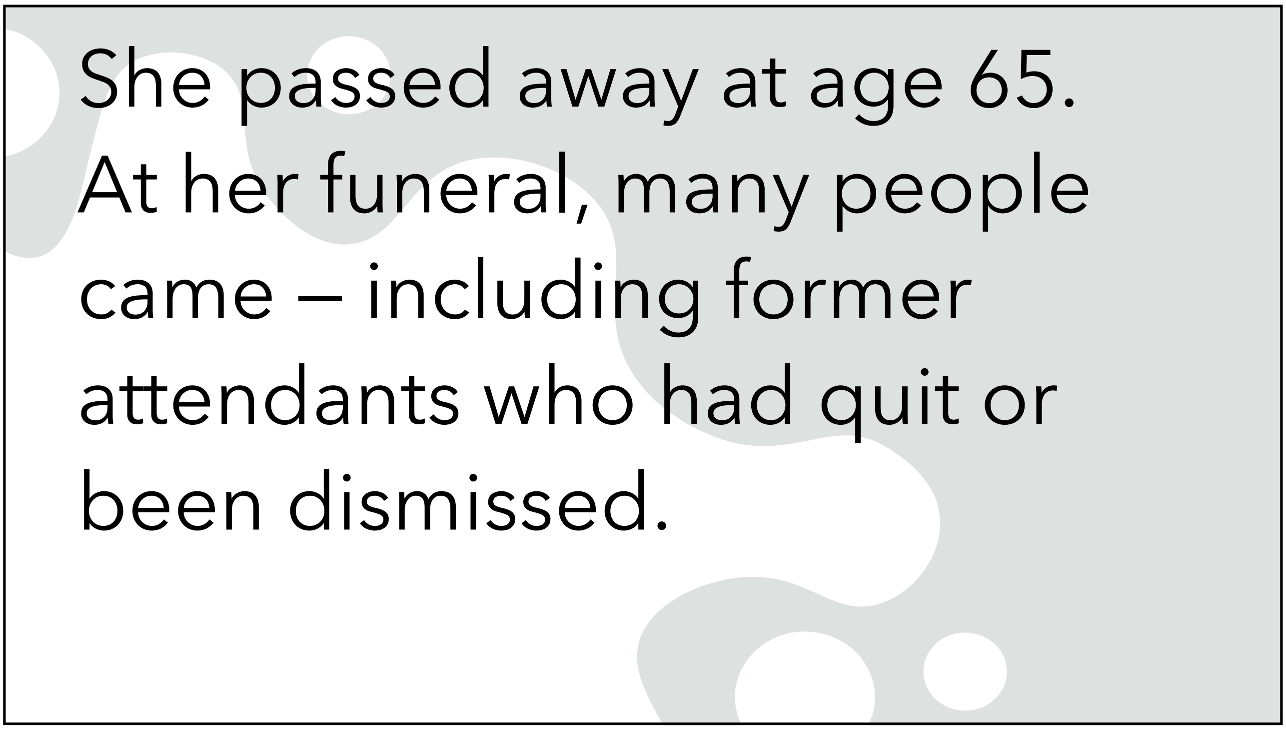
Let me tell you about one woman I’ll never forget – she had muscular dystrophy.
She had lived in a hospital until around age 40. Around 2015, she finally moved out to live in the community, with 24-hour personal assistance.

As her condition worsened, she was often in pain and sometimes lashed out at her attendants.



Many quit because it was too hard; others were dismissed because they couldn’t handle the work.

In the end, it became a very difficult and intense situation for everyone involved.



She passed away at age 65.
At her funeral, many people came – including former attendants who had quit or been dismissed.

Each one spoke about their memories with her, their feelings, their own stories.

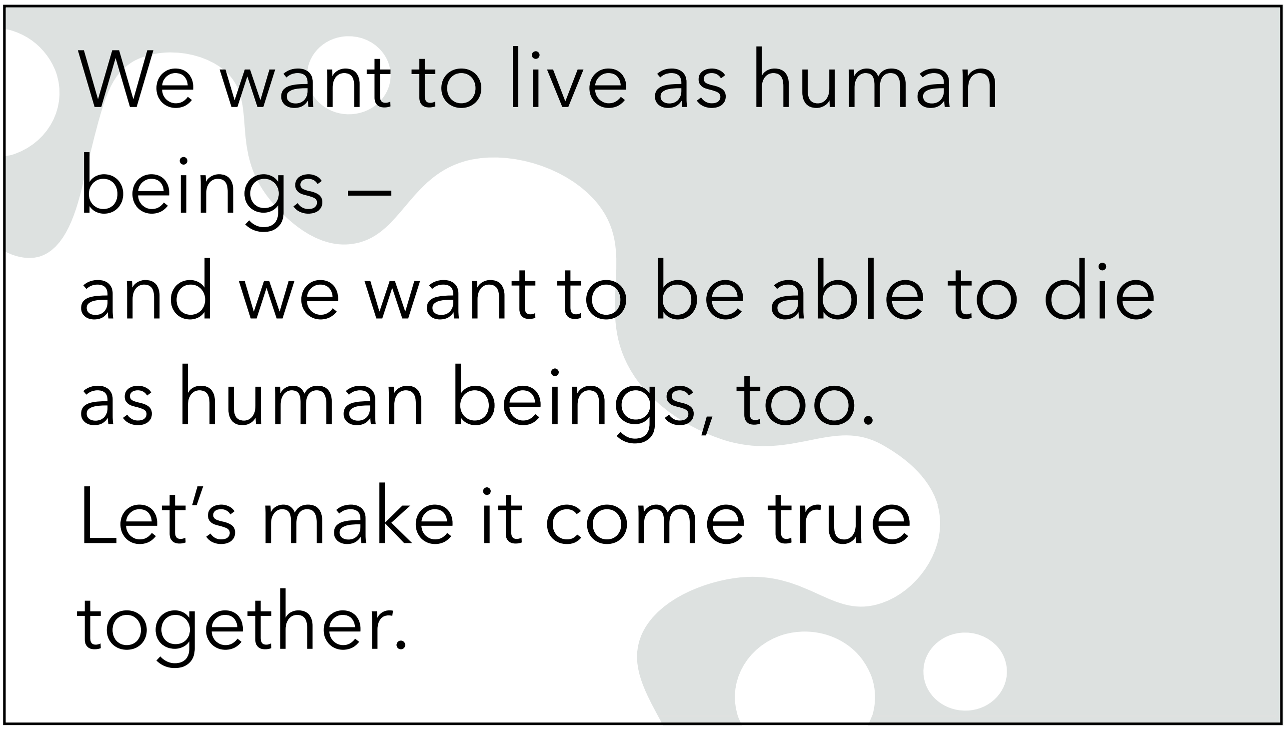
Listening to them, I felt something I can hardly describe.

And I thought – *this is what it means to die as a human being*.

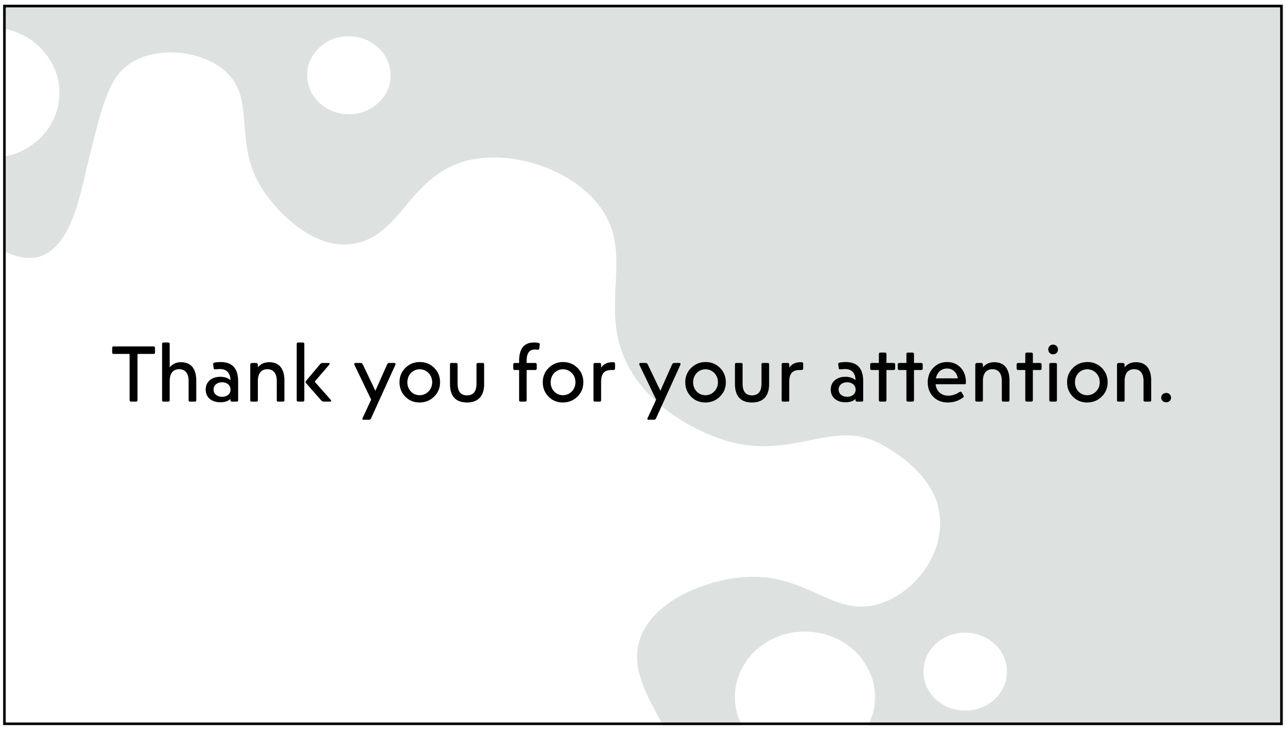
These stories, these connections – they could never have been born inside a hospital or a nursing home.

Living in the community isn’t always easy. But still, we choose it – because we want to live as human beings, not just exist under someone else’s control.

To me, *living as a person* means having real relationships, beyond family or institutions.
It means being part of society, even with all its challenges.
That’s what I want to keep searching for.



We want to live as human beings –
and we want to be able to die as human beings, too.
Let’s make it come true together.



Thank you for your attention.