# How people with disabilities work to manage the supports that allow them to live independently

## In Costa Rica there is a pioneering independent living center in Latin America that is responsible for managing the service of assistants and other supports so that people with disabilities can decide about their lives. In that country, personal assistance is recognized by law. Legislation of this type and other public policies that support the autonomy of people with disabilities are part of the progress of the independent living movement, which was born in the 1960s in the United States.

## By David Flyer January 25, 2022

The University of California, Berkeley, is one of the most prestigious in the United States. There, in the 1960s, a new perspective on disability emerged that would later spread throughout the world: the independent living movement. It was a group of students with severe disabilities, led by Edward Roberts, who raised their voices with a message: disability should not be a limitation for them to decide on their own lives.

Until then, the concept of independence was tied to a medical model: it was measured in terms of the number of steps someone could take. Roberts, who was in a wheelchair, redefined it and proposed to understand it as everything that someone could do if they had the necessary assistance.

“The philosophy of the independent living movement is that a person with a disability has the right to choose where and how they want to live and to be responsible for their actions. Independent living is increasing control over one's life, over the right to succeed and also to fail”, explains Leah Simmons. She has 23 years of experience at Independence First, an independent living center in Milwaukee, USA, that is a central place for the empowerment of people with disabilities. In Latin America, Costa Rica is a pioneering country that has legislation for people with disabilities to have personal assistance and three independent living centers. In Argentina, the most advanced project is in the city of La Plata.

**Personal assistance and peer support**

“Independent living centers are organizations designed and operated by people with disabilities, which provide services for people with all types of disabilities, based on the belief that each person can live with dignity, make their own decisions and participate fully in life. society,” explains Simmons.

The core services provided by an independent living center, according to the vision of Independence First, are: providing information and referrals, offering independent living skills training, advocating for the rights of people with disabilities, providing peer support and assisting “in transitions,” such as leaving a day center to live in their own home.

“The independent living center is the office that provides a central structure that helps people with disabilities manage the support they require. It is the place from where everything that is support for independent living is generated, administered, trained, monitored, and responded to in emergencies,” complements Elena Dal Bó, director of Asociación Azul, an organization from La Plata that works for the movement. in Argentina and that, with the model of Independence First, has the project of establishing the first center of this type in the country.

One of the central requirements of independent living centers is that more than half of their management staff are people with disabilities. It is not for nothing that the motto that identifies the movement of people with disabilities throughout the world is: “Nothing about us without us”.

“An independent living center has among its main services those related to the personal assistant”, explains Dal Bó. The personal assistant is a formally recognized figure in other countries of the world, such as the United States, Japan, Costa Rica or European nations. This is someone who is at the service of the person with a disability and assists them in what they need to develop their lives independently. In other words, the personal assistant executes the decisions made by the person with a disability. This can be anything from helping her write WhatsApp messages or describing an object or sound to sanitizing her, cooking for her or taking her to the movies.

In the province of Buenos Aires, in 2021 and for the second time, a project of the Blue Association for a personal assistance law that guarantees this service to people with disabilities who require it lost parliamentary status. Today, it is only accessed by judicial means.

**Training for attendees**

“One of the functions of the centers is to train the personal assistant. This training is in human rights and independent living”, informs Dal Bó. But he clarifies that "the training of the personal assistant is completed by the person with a disability, because she makes the decisions and tells him what to do." In other words, what personal assistants need to understand is that the type of work they provide is not about making decisions. This is not usually easy: “It is easy to go over the person with a disability”, emphasizes Dal Bó.

For this reason, he adds, another of the functions of an independent living center is to monitor the personal assistance service and help in the bond and intervene in the event of a conflict. For example: what if a person with a disability asks the personal assistant to buy marijuana for recreational use? Should the person who assists her respect her will if this implies committing a crime?

Although the center for independent living does not yet exist, the Blue Association already offers a four-month course through the trade school of the National University of La Plata.

On the other hand, Dal Bó emphasizes that “the center must also provide support among peers, for people with disabilities, assistants and families. And you have to attend emergencies. For example, making sure that a person has an assistant in case theirs is missing for a day.” Another of the tasks, he points out, is to promote advances in public policies and legislation in favor of the independent living movement.

Once this service floor has been completed, “more can be offered, such as a job bank. But nothing segregated. For example, in Milwaukee they have a wheelchair recycling workshop that works in a prison”, he adds.

**From Japan to Costa Rica**

The independent living movement spread to different places, including Japan. And from there, through the Japanese International Cooperation Agency (JICA), they promoted it, in recent years, in Latin America.

Between 2008 and 2013, people from the region involved in disability rights work traveled to Japan for training.

“In 2010, several people from Costa Rica who had traveled got together to launch the first independent living center,” recalls Wendy Barrantes Jiménez, president and co-founder of Morpho, a pioneering place in Latin America that follows the principles of the movement. The center operates in the city of Pérez Zeledón, in the Brunca region. It was launched in 2012, with the support of JICA.

“From Japan they assigned us a budget, which at first was to pay for the services, including the rental of the facilities. And also for the payment of staff with and without disabilities. Once we advance in the incidence and coordination with other institutions, such as the Municipality, we request the donation of a lot, where we are now installed. The Embassy of Japan financed the construction of the office. The goal is for us to be self-sustaining over the years,” says Barrantes Jiménez.

"Between 2012 and 2017, the first phase of the project took place, whose objective was to achieve a personal assistance system in Costa Rica," he details. The success of this five-year work led to JICA's support being renewed for another five years, which due to the pandemic was extended to 2023 and adding another year is being evaluated.

This success is largely based on the fact that in 2016 the law on personal autonomy for people with disabilities was approved in Costa Rica, which creates the figure of the personal assistant. “We did advocacy activities, marches, forums. And even a walk of more than 283 kilometers in a wheelchair”, says Barrantes Jiménez, who moves precisely with this device.

Based on the law, in Costa Rica you can access a personal assistant with full coverage through the National Council for Persons with Disabilities (CONAPDIS), private companies or NGOs. In this last group are independent living centers (the cost is borne by the State, the centers manage the service).

After the presentation of the certificate of disability and the certificate of poverty, CONAPDIS conducts an interview in which the number of hours of personal assistance that corresponds to a person is determined, according to their needs. Based on this data, and through an app, Morpho organizes schedules to cover the required hours with the personal assistants with whom he works (there are 27 between men and women). "Only in centers like this one work with that degree of organization," he emphasizes.

“Independent living centers charge 20% of what personal assistants earn to cover the costs of the service,” says Barrantes Jiménez. Among the benefits of this intermediation, he says, is that the assistant can take leave more frequently than if they work independently (in the latter case, they must work with the same person for three months and instead with the management of Morpho assistance is rotating) and that users have replacements in case of eventual needs or emergencies.

In the Morpho center there are sixty partners; twenty receive the personal assistance service. In addition to helping people with disabilities and their families process their request for the assistant service, the center advises on similar procedures to obtain items such as wheelchairs.

**The work at Morpho**

Six people with disabilities, three women and three men, work in the first independent living center in Costa Rica.

With "empowerment and a better quality of life for people with disabilities" as a goal, it works on five axes:

* Administrative: with activities such as board meetings, accounting, actions to raise funds and control of the other axes.
* The coordination and training of personal assistants.
* A system of support for people with disabilities. “This includes peer counseling, which is non-professional emotional support, and also a program in which a simulation room is used: a place where the person with a disability lives for a week and where they interact with the personal assistant and they are given a series of talks that have to do with legislation and personal life so that they know their rights”, explains the president of the center.
* Empowerment: political influence is sought, such as by promoting the law, and work is done on disability awareness through talks.
* Replication of experiences, with individual and group internships for people with disabilities and associations.

In relation to this last axis of work, Barrantes Jiménez says that the Latin American Network for Independent Living (RELAVIN) was created last May, which seeks to establish the philosophy of independent living in the region, for this year it plans to give technical advice courses in various countries. Additionally, at the national level, Morpho created two other independent living centers in Costa Rica.

**The project in Argentina**

The personal assistance law would avoid the judicial journeys that people with disabilities go through to access an assistant, after their social works recognize the service as an exception. Also avoid twists and turns with coverage, as it happens, says Dal Bó, "now IOMA [the main Buenos Aires social work] says that it will not recognize personal assistants with the fees that correspond to them."

While fighting to make the rights of people with disabilities visible and for the personal assistance law, the Blue Association seeks to establish the center for independent living. Today, the main obstacle is economic. “We need to have funds to pay salaries, because people with disabilities who work in a center earn salaries. With a telephone and a person per shift to answer the calls is enough to start”, he says.

A small place that functions as an office is also required. "But even without that, you can go to a cultural center or club," admits Dal Bó. One advantage, he says, is that personal assistant trainings are oiled. And he anticipates that the association hopes to obtain financial resources from international private donors. "We don't have any support from the state," he stresses.

For Dal Bó, despite the obstacles that appear, giving up the bill for a personal assistance law and an independent living center is not an option: "There is no other way of life for people with disabilities."