Katrin Modic, Elena Pečarić,
Domen Retelj

PERSONAL ASSISTANCE

HANDBOOK FOR UNDERSTANDING INDEPENDENT LIVING

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Handbook for understanding independent living

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This handbook is free of charge. However, if you wish to support us in our endeavors helping people live independent lives, you can do so by donating to our bank account IBAN SI56 0400 1004 6471 816, Tax no.: 39692116.

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HANDBOOK FOR
UNDERSTANDING INDEPENDENT LIVING

If you wish to put the ideas contained in this e-book into practice, you are taking full responsibility for your actions. By taking responsibility for your actions, you act in line with the philosophy of independent living.

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Also, special thanks to Natalija Jeseničnik, Vita Nastran Janje, Klaudija Poropat, Barbara Močilar, Andreja Gomišček, Sašo Stojanovič Lenčič, Jonas Žabkar, Lilia Angelova, and Gregor Fajdiga.

We are also grateful to users of personal assistance, personal assistants, and everyone else who shared their stories that cover more than 20 years of personal assistance in Slovenia.

This handbook is dedicated to Emil Bohinc.

Emil had a degree in philosophy and sociology of culture. He founded YHD – Association for the Theory and Culture of Handicap along with Elena Pečarič and Klaudija Poropat, whom he met in the Institution for Disabled Children and Youths in Kamnik. As a key member of YHD, Emil fought for independent living of disabled people and was always an active member of society.

Emil Bohinc while working in the office. (Image: Klaudija Poropat)

> The middle of the photograph shows Emil Bohinc while working in the office. He is visible from the waist up, from the side. He is turned to the right and has a smile on his face. He holds a computer mouse on the table with his left hand and wheelchair‘s joystick controller with the right hand. He uses a breathing apparatus.

“I don‘t know if everybody knows what a great man Emil was and how significant his struggle for independent living was. He is a role model of what is possible to achieve with a strong will and heart in the right place. One day, history will tell about all the pioneer steps of independent living and no sooner than that will Emil get the recognition he deserves.” (Elena Pečarič)

“30 years ago, we refused institutions and started to fight for independent living and personal assistance. This was long before anyone else did it, and long before this became a right enshrined in the Convention on the Rights of Persons with Disabilities. Together with Elena, you proved with your experience and your way of life that personal assistance is possible and can be available TO EVERYONE who needs it and wants to live independent living. You proved that it is a right. A right as well as responsibility.” (Klaudija Poropat)

FOREWORD 1

This new impressive guide to Personal Assistance by the Slovenian Independent Living organisation YHD is a unique contribution to the essential resources of Personal Assistance. What is remarkable about this Manual is that it was developed and designed by one of the most resilient and formidable Independent Living Organisation in Europe.

They have achieved this significant document against all the odds and have transformed the thinking about Independent Living and the equality of disabled people and the importance of disability rights in Slovenia. This is a great achievement and is a “must read” for anybody who embarks upon the journey as a personal assistant user wanting to liberate their lives in finding freedom, self-determination and independence.

Personal assistance did not come that easily for it to be readily available for disabled people in Slovenia and it took many years of constant campaigning and advocacy to get the government and appropriate authorities to fully understand its importance.

I have been lucky knowing the disabled people involved in this organisation for decades and I have been very impressed by their work campaigning to get personal assistance accepted in law. They are a good role model for disabled people in many other European countries.

Now they have produced this appropriate handbook which can be used by others in different countries as well. I wish them every further success with this publication as I am sure it will benefit many disabled people in Slovenia and beyond.

John Evans OBE
Independent Living Expert
January 2023

FOREWORD 2

I have had the privilege of following YHD for a few decades. YHD is a beautiful example of how a few people with extensive disabilities helped each other change their definitions of themselves from objects of care and charity to subjects of their lives, how this enabled them to analyse their situation in society, formulate their needs, design services for meeting them, and tirelessly bombard the government to fund these services.

They used their intelligence and anger, the arts and humor, they formed coalitions with artists and researchers. All this in a post-communist society where the leaders of the national umbrella organization for people with disabilities continued to defend and run profitable institutions from the communist era. YHD is well on its way to success. An incredible feat!

The present handbook on personal assistance is one of the milestones in their long fight toward equal rights and equal opportunities for all. Our fight will never end. We need courage, endurance, and a long perspective.

I wish YHD many more milestones on this rocky road.

Adolf D. Ratzka
Founder and Director, Institute of Independent Living, Sweden
January 2023

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INTRODUCTION

This manual was produced by YHD – Association for the Theory and Culture of Handicap (hereinafter: YHD) – based on its comprehensive understanding and vision for shaping the future of independent living, as well as on the firm foundation of its vast, decades-long experience of providing personal assistance, which reaches back to the 1990s.

Personal assistance (hereinafter: PA) is the most fundamental and most important "tool" available for disabled people, making it possible for them to live independently and ensuring that they can, on a daily basis, perform tasks and engage in activities that their disability would otherwise prevent them from doing. At the same time, it affords them the opportunity to partake in all aspects of social life actively and on an equal footing.

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[1] In Slovenia, the state and institutions, based on the medical model for decades used the term "invalid". This term is still used by many disabled people, traditional disability organizations based on diagnosis, institutions and legislation.
When Dušan Rutar started to develop the theory of handicap in Slovenia, he used the terms "hendikep" and "hendikepiran" which were previously not used at all in contexts related to disabled people in Slovenia and hence had no negative connotation.
The activists for independent living in Slovenia considered the theory of handicap as opposition to the medical model as they saw their identity a product of barriers they faced in the environment, not a result of their own (medical) characteristics. They refused the term "invalid", and used the terms "hendikep" and "hendikepiran" in their work and writings.
The Slovenian term "hendikepiran" is not equivalent and cannot be translated into English as the derogatory term „handicapped". The most accurate translation for "hendikepiran" is "disabled", although the terms are not completely synonymous, as explained in this introduction.
The development of terminology in Slovenia was different from, for example, the one in the UK because of the different cultural and historical context. The English term "handicapped" was for the most part of the 20th century a prevailing term describing disabled people in English-speaking countries. By the 1970s, it became a term used in legislation and social services, based on the medical model, that controlled disabled people's lives. A community of people fighting for self-determination and services, based on the social model, rejected the term "handicapped" in favor of "disabled".

This manual understands disabled people as those who either cannot move or can only do so with difficulty, those who have poor coordination or balance, who are visually impaired or blind, hearing impaired or deaf, or those who have difficulty speaking or are unable to do so. They might even have difficulties with comprehension. In short, YHD understands the term “disability” in a much broader sense, as explained by **Emil Bohinc**: “We understand disability as a theoretical concept. Characteristics are not the basis for labeling someone as disabled. Disability is a symbolic, social status; in a given social network of interpersonal relationships, a universal category such as disability is always embodied in a person who is different on that account. It is thus historically conditioned and dependent upon the individual and upon more or less random circumstances. Awareness that disability is a primarily a symbolic status makes it possible to question our own position, which reveals the old dynamic of strength, and the relationship of subordinate to superior. This lays the foundation upon which we can fight for our rights, above all for our right to be different.”

The chapters herein will explain what independent living and PA are, as well as how these systems help disabled people live independently. “It is crucial that those producing theory be disabled people themselves, who are the ‘objects’ of the experts surrounding us. We want to place our so-called other side alongside those areas whose primary focus or ‘concern’ we are. At the level of theory we would like to define our role and ceaselessly question our place,” added Bohinc.

This manual is written primarily from the perspective of the user, who plays the primary role in this context as holder and exerciser of rights to PA. At the same time, it bears stressing that PA itself would be impossible without the assistants who provide such work.

To better understand the circumstances, we will refer to **true stories** from people who use PA (hereinafter: users), from personal assistants (hereinafter: assistants), providers’ coordinators and PA coordinators at social work centers (hereinafter: SWC), who will remain anonymous in the interests of data protection. All stories in yellow fields are real.

If in the remainder of this manual a gendered noun is used (e.g. actor/waiter instead of actress/waitress), all genders are to be assumed. Technical descriptions under images herein are provided for accessibility to people who cannot see.

The first edition of this manual was published in Slovenian in 2021. Despite the Personal Assistance Act from 2019, the struggle for implementing personal assistance on the principles of independent living is still going on in Slovenia as stereotypes of disabled people and patterns of care persist.

The decision to translate our work into English came after receiving many requests from all around Europe. Hopefully, it will inspire more disabled people and activists in efforts to have personal assistance legalized in every country. We all still have many goals to achieve, also on the level of the European Union. Its regulations and directives should define standards for implementation of this human right on the principles of independent living in all member states.

1. INDEPENDENT LIVING

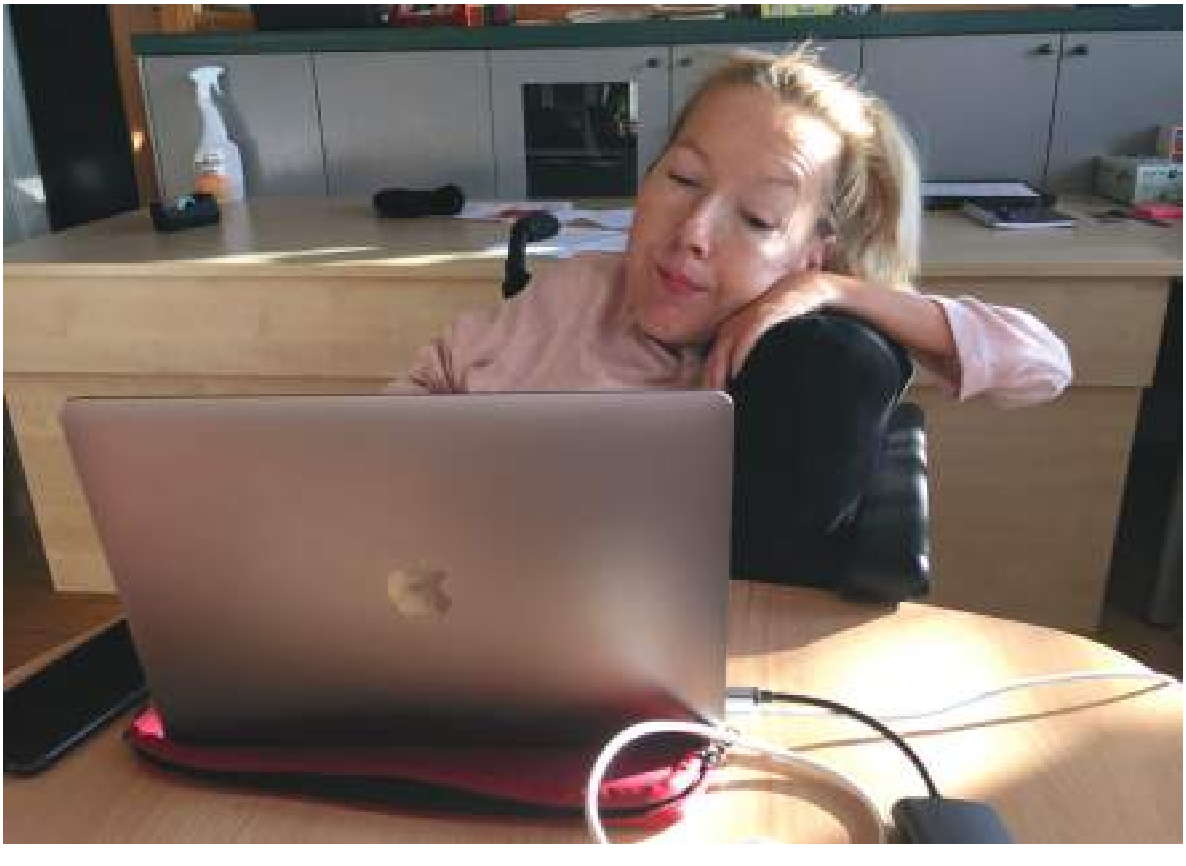
What is independent living?

People most often do things completely on autopilot, either by habit or reflex, without giving much thought to or preparation for it either in advance or in the moment. They turn over in bed, get up, dress themselves, wash up, go to the bathroom, eat something, and set off towards their job or whatever else they have to do. More intimate tasks can be included here, such as shaving/hair removal, scratching, cutting nails, dying one’s hair, etc. It is implied and assumed that they have done such things forever and will continue to do them. In their everyday lives, they generally do not even think about such things, do not second-guess them, and do not concern themselves with them. Things that go without saying for the majority, however, constitute a true challenge for the disabled. In order to live independently, such people must seek a workable solution.

We view independent living as a right that is not self-evident. This right was hard-fought and won in a political sense by the movement for independent living, whose aim is for such services to be recognized and assured as fundamental and universal human rights. The movement combats any form of discrimination, ghettoization, or psychological or physical violence, and fights for equal opportunities in including disabled people in all facets of personal and social life. This means that everyone has the chance to choose from various services. This also includes the opportunity and right to reject institutional forms of living. More than anything, it is a suite of ideas that constitute a challenge to and criticism of lifestyles that force individuals or groups into a less valid, less capable, even more invalid, etc. status, which is distinguished from the “healthy majority” of people who should be caring for them.

Anyone can chose to live independently. Independent living is completely different from living as a dependent, in someone else’s care and under their protection, with limited options and unrealized expectations.

“Independent living is the possibility to live on an equal footing with everyone else: to have the opportunity to make decisions about your life and the chance to manage all your everyday activities, all while having the right to responsibility for your actions. It is closely related to the concepts of self-determination and autonomy. It is the right and opportunity to pursue certain courses of action, and at the same time the right to make mistakes and learn from our own mistakes. Above all, it is the right and responsibility that a person can choose, manage, and thrive in their preferred lifestyle. Independent living is by no means a simple thing, and in some circumstances it can indeed even be risky. You need to step into the abyss, the unknown, as in a familial or institutional context a person's life is shielded, protected, and nurtured through a set of routine measures and forms of care. These actions and forms of care help set order and supervision, but rob the individual of their potential for development, as independent living by its very definition cannot be predictable and even less can it be supervised and controlled. It is essential that the person opting for independent living first conquer their own fear, which is conditioned by years of living within the 'cushions' of an institution or family, and thereupon find the courage to take the necessary step. Their reward is the freedom of decision." (Elena Pečarič)



Elena Pečarič working at YHD (Image: Elena Pečarič's personal archive)

The bottom quarter of the photograph shows an open laptop. Behind it, in the upper part of the photograph, sits Elena Pečarič, as she works in her office. Her head is leaning against her arm, which is resting on a pad on her wheelchair's armrest. She is looking towards her computer.

The principles of independent living are:

- **taking responsibility for your life and actions,**
- **the right to life in a community,**
- **the right and responsibility to speak on your own behalf,**
- **universal design,**
- **access to PA and other services in the community, which facilitate inclusion in all aspects of life (education, employment, culture, sport, politics, free time, sexuality, parenting, etc.).**

Independent living is connected to the disabled person's ability to reject care, accepting help when needed and in an appropriate way.

In this manual the concept of help is not intended as a catchall, but refers to PA. Only this can assure that people can exercise control over their own lives. The principles of independent living make it possible to find the right assistant, set such assistant's schedule, and determine how exactly that assistant will provide help. People with severe disabilities are stressed by constantly having to think about how to manage their intimate everyday tasks without assistance. Such a person does not view their intimate tasks as automation, as something spontaneous and self-evident. They need help for every trivial task, which at the end of the day amounts to a significant cognitive and logistical burden. Disabled people spend a lot of their time, mental capacity, and energy towards planning for the help that they need. Once such an approach is accepted, it becomes second nature. As an example: if a disabled person doses off at night, they might need help simply turning over in bed if they fell asleep in an awkward, painful position. They must then call an assistant and instruct that assistant on how to turn them over. The same applies for trips to the bathroom, or in cases of hunger or thirst, when they have an itch to scratch, a nose to blow, nails to cut, when they need to put on makeup, wash themselves, shave, etc. Several such fundamental needs arise in a given day. Each one requires a certain set of instructions.

The difference between independent living and living a life under care is that, in independent living, the disabled person gives the instructions on how the assistant is to help, while under care the disabled person merely expresses a desire, not the manner in which such desire is fulfilled.

Disabled people living with their families or in institutional facilities who are completely dependent upon family members or institutional staff for assistance generally tend to adapt to those people's lifestyles. If such a person wants to satisfy all their needs, they are forced to delegate such needs among several different people. Often a survival strategy is formed.

Those who need help are most often dependent on the person helping them. The helper has the clout and often conditions such support, leading to something like emotional blackmail, putting (psychological) pressure on the disabled person, either intentionally or subconsciously. Whoever needs assistance must learn patience, waiting for someone to come help them, waiting for it to be their turn, etc. At the same time, the person needing help is expected to show gratitude for that which they receive or whatever is approved for them. As a result, the recipient of care is not allowed to need a lot, or must learn not to request, want, or desire too much, as that which they do receive should suffice. Those who live in complete dependence upon their family (be it parents or partner) or their institution are often subject to various forms of "moral" or psychological blackmail or manipulation. The concept of independent living, in addition to the right to help, i.e. PA, also includes the right to economic independence, to be informed, to mobility, access, and equal inclusion in all areas of social life (education, employment, family life, political and cultural participation, etc.).

The philosophy of independent living

"The definition and practice of providing personal assistance comes from the independent living movement. Independent living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation. Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbors and friends take for granted. We want to grow up in our families, go to the neighborhood school, use the same bus as our neighbors, work in jobs that are in line with our education and interests, and start families of our own." (Adolf Ratzka)

Adolf D. Ratzka (Image: www.federacionvi.org)

The middle of the photograph shows Adolf D. Ratzka from the waist up. His head is supported by his wheelchair's headrest. The right side of his mouth is holding a tube. He is looking slightly to the left. His look is attentive and serious.

The philosophy of independent living, as explained by English writer and activist Jenny Morris, is based on 4 pillars:

- Every human being is valid.
- Everyone, regardless of disability, has the right to choose.
- Everyone has the right to be in control of their own life.
- Disabled people have the right to participate actively at every level of society.

Jenny Morris (Image: www.disabilitynewsservice.com)

The photograph shows a smiling, middle-aged woman from the waist up. She has medium-length, slightly curly, blond hair reaching down to her neck, with bangs on her forehead. She is wearing frameless glasses and rectangular earrings that hang downwards at about the length of half of her ear. She is wearing a dark jacket with a V-neck. To the right of the collar is a light-colored band. At the bottom of the V are seen a white undershirt and a pearl necklace.

By telling their personal experiences, some disabled people began forming a political vision and activist strategy. The personal, augmented by theory, has become the political. Personal experience does not occur in isolation from society, but is always composed of social, economic, and political influence.

The philosophy of independent living includes the following aims:

- encouraging the spread of this philosophy among disabled people, the general public, lawmakers, governments, official organizations, etc.,
- the development of a concept, principles, and definitions of independent living for disabled people,
- encouraging the development of centers for independent living throughout Europe,

- training and raising awareness at the European level,
- representing organizations and the independent living movement at the European level and in various European organizations and official bodies,
- the fight for social inclusion and against discrimination with policies that encourage disabled people’s independent living,
- the end to discrimination against disabled people,
- adopting a social model of disability for independence and self-determination.

The difference between self-sufficient and independent living

In the rehabilitation process, many experts exhort people with certain limitations (e.g. inability to walk, blindness or sight impairment, deafness or hearing impairment, cognitive difficulties, etc.) that they just try, even to do more than they are physically capable of: “Push past your comfort zone, try harder. Practice! Don’t be lazy. Use your regular wheelchair and not your electric one.” It is imperative that people consider to what extent self-sufficiency is useful and appropriate, and at what point it actually starts to become a hindrance. For instance, is it useful for a person to use a lot of time and energy for a task, with the result that they must rest for the remainder or the day, with enough strength only to carry out their most basic life functions, suffering the whole time? Despite the fact that they enjoy being self-sufficient, life is a constant struggle of deciding exactly what should be given priority at a given moment.

Will they ask for help in putting on a sweater, or wear a jacket instead, since they can put that on by themselves? Will they dress themselves, even though it might take them a half an hour and afterwards they might need to rest a bit, or will they seek help for such a task?

Self-sufficient living means that a person performs their own activities. Whenever they run up against a barrier in doing so, they usually change the way in which that activity is carried out, including using a variety of tools or aids. Sadly, due to their limitations, they usually cannot in fact perform every single activity themselves, or doing so would take up too much of their time and energy. As a result, they begin restricting and adapting their own life (e.g. they only wear shirts that are too big so that they can actually put them on, they wear only sandals instead of shoes, females stop wearing bras, etc.).

“When I was first faced with my disability, among other things I lost my coordination and the ability to do much of anything. The rehabilitation center showed me some new ways of handling my own body, the most effective trick being just to concentrate fully on coordinating and managing every motion. I was thus able to do a great many things by myself. I thought only the things I could do myself were valuable, not those things that I could with someone else’s help. Every day I pushed myself to practice as much and do as many activities as possible. I tried all afternoon to sit up straight and not to fall out of my wheelchair. None of that resulted in improved (cap)abilities. Quite the opposite – I was exhausted and needed a lot of rest. It finally dawned on me – there are many paths leading towards the goal, not just the path that no longer works. The things I can’t do myself in the normal way I can still do with a modified approach, using aids or other people’s help. So I asked for help from a therapist, for them to fix my hands in place when doing manual work. This helped me not to lose energy in holding my arms up and helped me keep them from falling onto the table, so I could focus my energy on spinning thread.”

Disabled people often insist on doing certain tasks by themselves. And they have every right to do so. When the content or results of their work is not emphasized, or if they lack clear goals that they wish to achieve with their efforts, their behavior is often self-serving.

“I’m extremely proud that I typed my first poetry collection, which I just recently published, with one finger. Despite having personal assistance, it means a lot to me that I could do that by myself. The typing really exhausted me. When I told my friend that I typed the collection myself, she asked me if it wouldn’t have made more sense to have used my personal assistant for that.”

Independent living means that a person can do all the things important to them without having to limit their options or adjust them to the point where they no longer make any sense. At the same time, they can also perform their activities with someone else’s help, namely that of their assistant. In doing so, there is no need to express gratitude or a sense of debt to the person helping them. Assistants are paid for their work. Furthermore, it is also important for the disabled not to have to adapt to the schedule of the person helping them. They are the ones to choose what to do, when, and who will help them in doing so.

“Before I had personal assistance, I had to ask friends and my family members for help. I soon figured out that I was a burden to them. Nobody actually said that, but I noticed that some of them started ignoring me. I felt a sense of obligation to those who did help me. I often made dinner for those friends who helped me. This worked out for a while, but I eventually realized that I needed help too often, and that I would never be able to pay back every favor."

The barriers to and support for ensuring independent living, and how they are connected to the need for personal assistance

The most common barriers are:

- Patronizing attitude towards the disabled person, who is not given the opportunity to speak for themselves or have their needs prioritized at all steps.

- An insufficient amount of accessible housing: a lack of access to the majority of the housing fund and a prioritized system of various forms of institutions lead to disabled people's segregation (isolation) from the broader community.

- A lack of access to the regular school and education system.

- A lack of access to the job market and a corresponding lack of financial independence and social security (a low rate of employment, insufficient opportunities for employment in ordinary jobs) – PA is essential for helping disabled people access the job market.

"The fairly widespread practice of social workers at the institution where I spent 12 years was such that they simply suggested people with a significant disability should just opt to claim disabled status according to relevant legislation. This status would ensure a minimum amount of permanent and regular financial support. It's meant to offer me a bit of security and should be the most I could hope for. I should have forgotten about work and education, and quit dreaming about the unrealistic. I could have listened to them and given up, but of course I didn't. I was convinced that one day I would be able to support myself with my knowledge, my work, with my own capabilities and talents."

- The inaccessibility of public and private goods and services. Assistants are even more necessary when local options for self-sufficiency are limited and where the public transportation network remains inaccessible (for helping with curbs, opening doors, pushing elevator buttons that are too high, etc.). When there are barriers in communication, PA is all the more necessary.

- Inappropriate systemic solutions, such as adjustments of community services, and a lack of other support measures (education, empowerment).

- Ingrained discriminatory social practices (inflexible behavior from goods and service providers, prejudices from employers and housing providers, etc.).

- A lack of response from institutions that should be watchdogs or fail-safes against discrimination (an ineffective system of protecting against discrimination, etc.).

Some misconceptions that make it impossible for users to live independently:

- “There’s no other option!”

“Since my mother is constantly hovering and ordering me around, I’d like to move out on my own. But even if they found me an apartment, I couldn’t leave, because nobody but my mother will help me.”

- “I need to adjust all my needs to those of the institution.”

“I woke up with a wet diaper. I called my nurse to change it for me, and she just frustratedly snapped that I should wait until the morning when the next diaper change was scheduled.”

- “There are both written and unwritten rules about how to access assistance, and I have no influence over that.”

“In order for people to help me when I need it and not when they just have time, I need to show them endless amounts of gratitude. I’m running out of ideas about how to thank them so that they keep coming the next time I need them.”

- “Assistance is limited to a certain time and a certain amount of hours, activities, locations ... That’s why I need to live in a specific, determined place, instead of living wherever I want.”

“Since I can’t get out of bed by myself, I needed to move into an assisted apartment. That’s the only place they could assure me that someone would help me out of bed every morning, even though it only takes 5 minutes all together.”

- “I need to share my assistant with others.”

“I live in an assisted apartment in a student community. They have an employee there who helps us. But what use is that when, for instance, my roommate and I both have to use the bathroom at the same time? Since they can only help one by one, it takes a bit of time to help us both, and it’s even happened that I couldn’t hold it any longer.”

- “There’s a hierarchy in which we users are at the very bottom of the pyramid.”

“I live in an apartment community, where we have 3 workers who rotate shifts and take care of us. Whenever the first two make coffee, we drink it together. When the third one makes it, she thinks she’s something special and she first pours for herself, then drinks it alone, away from us. Even if we need something, we first need to wait for her, and of course we have to drink cold coffee.”

Support measures include:

- Encouraging users to speak up and handle what they can by themselves, supporting them along the way and providing them an advocate.

- The greater provision of accessible housing for the disabled.

- An inclusive education system where people can study in mainstream environments among their peers, all while having access to assistance and adaptations that provide them with equal opportunities (e.g.: extended time limits for various activities, having instructors with expertise in diverse teaching methods and experience working with disabled students).

- Employment opportunities that offer financial independence or personal social security.

“Specifically because of the general prejudice that I am incapable or unqualified for employment, work is all the more important and valuable to me. It is not merely a means of survival or an issue of necessity. With and through my work I show and prove my equality and establish my financial independence. Work has become a value exactly because it is not self-evident, because I have invested a lot of effort into overcoming prejudices and stereotypes, not to mention the various bureaucratic obstacles blocking my path to employment. And of course then I needed to prove myself on the job with my work itself and the results I produce, which are after all the only indicator of success. My right to work was not gifted to me, but I had to fight for it. Thinking I was going to be an ineffective and thus incapable of working, they didn't want to grant me that right."

- Accessible public and personal goods and services (in addition to PA, other adjustments to community services are necessary – e.g. the ATM must be low enough for people in wheelchairs to use, or must have instructions in audio format, Braille, and simple language); such adaptations for access must be considered in designing e.g. cultural and sports programs, as well as in stores, restaurants, and elsewhere.

- Systemic solutions that include modifications in their design, making it easier for everyone to use, not just disabled people (e.g.: ramps provide access not just to the disabled, but also to children in strollers and people carrying heavy loads).

- Establishing a more effective system of protecting people from discrimination.

- Encouraging people to flag and draw attention to approaches and infrastructure that are harmful to disabled people – just as we have an obligation to respond in the event of physical violence, we are also obliged to respond to discriminatory behavior.

- Education and raising awareness (reducing prejudices, developing new educational methods for various forms of disability and including them in school lessons).

In order to educate, raise awareness, and reduce prejudice, YHD holds interactive workshops called Bontonček (translation: Ettiquette), which are intended for audiences of various ages (preschoolers, elementary schoolchildren, teachers, pedagogic staff, and other support staff).

Multisensory participative leadership after the photo exhibition on independent living at the Ksaver Meško Library in Slovenj Gradec (Image: YHD archives)

The collage is made up of 4 photographs.

The first photograph on the top left has a man with a blindfold, visible from the waist up. His right-hand index finger is extended pointing at his nose, which is also covered by the blindfold. His left hand is holding a canapé chest-high. The photo exhibition is displayed behind him.

The second photograph, top right, shows a person in a wheelchair leading a column of other people with blindfolds on. Half are in wheelchairs and the other half are standing. Each is holding on to either the shoulders or wheelchair handles of the person in front of them.

The third, on the bottom left, shows a mat laid out on the floor, with various aids on top of it. Visitors, all standing around the mat, are looking at the aids.

The fourth photograph, bottom right, shows visitors spread out through the exhibition space. Their arms are extended directly in front of them.

Etiquette workshop (Image: Mavric Pivk)

The collage is made up of 4 photographs.

The first one, top left, shows first-graders sitting in their seats, arranged in a circle in the classroom. In the middle of the photograph and the circle is a woman in a wheelchair. Her right hand is on her chest, her left is on the wheelchair’s frame. She is looking at the ground with her body leaning forward. The impression is that she is frightened. There is a plank on the ground behind the wheelchair, with a student standing at either end. Behind the plank stands a man who is pushing the wheelchair.
The second one, top right, again shows first-graders sitting in their seats, arranged in a circle in the classroom. In the middle of the photograph and the circle is first-grader, seen from the back, who is pushing a person in a wheelchair over a plank, on both ends of which are standing two students. On the right edge of the photograph stands an adult leaning over with their hands at the ready as if to help the student.
The third, bottom left, shows students holding their palms to their eyes mimicking binoculars. They are sitting in a diagonal from left to right and facing the right.
The fourth, bottom right, shows five first-graders sitting in a row. They are all blindfolded. The third from the left is passing an object to the fourth.

The need for PA also depends on how effective support is. The more effective the support, the lesser is the need for PA.

Parental beliefs that prevent children from developing their potentials

Parents often fail to accept their children's disabilities. They often resort to various therapies to fix their child's disability and normalize them. However, it makes little sense to "fix" disabled people and make them "normal". Disabled people have the right to be accepted for who they are and to live in a mainstream environment. In raising a disabled child, it is important not to lower expectations, to provide them the chance to interact with other children, to treat them just like other children and facilitate their development of self-confidence, and not to "cover them in bubble wrap". They must attend an inclusive school (one where disabled students are afforded modifications for cases where they need it), where they can develop a regular command of language, behavioral patterns, and personal traits. They must be encouraged to accept responsibility for their own behavior and be assisted in recognizing their own limitations.

Disabled children have the right to live among their close family and attend daycare and school in their home environment or neighborhood. When they grow up, they are to "move out on their own", get an education, work, and partake in hobbies and other free-time activities. Families with disabled children have the right to a regular life. Unfortunately, however, due to the constant need to care for their disabled child, they often do not have the chance to lead such a life.

It often happens that disabled children become dependent on their parents and on their parents' opinion about what the disabled children need. They do not want to grow up and accept responsibility for their lives, they often unrealistically assess their own capabilities (they believe that they are capable of far less than is actually the case), and they develop inappropriate social skills and linguistic habits (e.g. referring to themselves as crippled), and thus they have difficulty integrating into a normal life. They remain dependent on their parents and siblings. Parents assume the role of caregiver, doing all the work instead of the child and not expecting the child to do that which they are capable of. They often experience burnout by constantly providing care, suppressing negative feelings, which is often expressed by constant states of anger, hatred, and grudge. Siblings are forced to grow up quickly; they often assume too many responsibilities and are too demanding of themselves. The siblings, too, often suppress their feelings so as not to upset their families. They might have the feeling that they themselves are neglected or forgotten, or only receive attention as scapegoats.

Limiting parental beliefs that make it impossible for their disabled children to develop their potentials:

- “I can’t deny my child anything, as their disability already prevents them from having a normal life.”
- “I can’t force my child to do anything, because I feel bad for them.”
- “My child must accept that they are different from the people who will care for them.”
- “I must devote my whole life to my child and ignore whatever I feel and need.”
- “Disabled children require special treatment.”
- “We can’t be too hard on them, and they will remain children forever.”
- “Since other children are so mean, we can’t include disabled children in normal environments.”
- »It is cruel to put a child like mine in a regular school or let them go to school by regular bus.”
- Siblings will take care of the disabled child after their parents’ death.

Strategies that make it possible for disabled children to grow up into independent adults:

- Setting realistic expectations and boundaries for their disabled child.
- Demanding from disabled children that they accept the natural and logical consequences of their own behavior.
- Encouraging the disabled child to take responsibility for their day-to-day activities.

- Defend and advocate for the disabled child in relationships with pedagogic and support staff in school so that the child experience a regular and inclusive environment.

- Ensuring balance for themselves (the parents), including being attentive to personal health, personal free time and free time with their partner, family and friends.

- Devoting enough attention to the disabled child's siblings and, no matter the circumstances, showing them sufficient amounts of love. Devoting attention to the failures and disappointments experienced by the disabled child and their siblings, while encouraging them to accept failure and disappointment as facts of life.

- Encouraging all family members to express their feelings and listen to one another.

The medical and social model of disability

How we address disability depends on what we view or prioritize as the "problem".

The medical model focuses on the individual and their innate or acquired impairment as the problem. Despite the fact urban environments come with their share of barriers, people do not feel responsible for changing their surroundings and do not systematically undertake to remove such barriers. Plagued by their erroneous perception of disabled people, they only see problems in the individual, whose characteristics deviate from the norm. They leave disabled people to experts who decide in their place. The experts treat the disabled person, change them into "normal", "fix" them, or address their problem with some special benefits or "special needs". People live in special institutions and receive their education there. Experts determine the extent of the impairment, how severely their capabilities are hindered and to what extent they cannot, for instance, communicate, move, or work.

They think that disabled people need treatment and care, while at the same time expecting less of them than of others. The medical model seeks to change whoever deviates from "normal". The result of this is that disabled people often feel as if they themselves are at fault for their disability.

The medical model sees the problem in the individual: “What is wrong with me?”

Several disabled professors who were also activists in the Independent Living Movement (e.g. Mike Oliver, Paul Abberley, Vic Finkelstein, and Paul Hunt) worked to develop a theory that became known as the “social model”. This model treats disability as “resulting from a discriminatory environment that disables people with impairment” Impairment is treated by the theorists behind the social model as limitations in a physical, intellectual, or sensory capacities. Impairments become extreme or disabling only in certain special circumstances. Instead of focusing on the impairment, or on categorization and comprehensive understanding of certain problems arising from given viewpoints, such as, e.g., “they can’t see” or “they can’t walk”, the social model studies the actual barriers that truly “disable” people in their daily lives.

The social model does not center on the disabled person but on the limitations in the environment that make it impossible for them to conduct daily activities. Such barriers can be removed or corrected. The disabled person’s circumstances and discrimination itself are conditioned by the social environment they reside in, and are not related to such person’s diminished capabilities.

Unfortunately, many people fail to accept disabled people for who they are. Due to their own fears and prejudices, they often ignore the disabled, discriminate against them, and write them off as incapable. The situation can be improved by removing the systemic barriers and constructing an accessible environment, ensuring appropriate aids, making PA available, educating society about independent living, and by asking more of the disabled – indeed requiring of them the same as of other people, including taking responsibility for their actions.

The social model focuses on society: “What barriers and limitations do you face?”

The social model, at least at the declarative level, facilitates a significantly different way of understanding the individual. Through this model, the individual transcends its role as the object of treatment and becomes the subject, gaining the right to being informed about all processes in which personal rights are exercised. They have the right to refuse a given procedure and express their opinion about it. If the disabled person does not understand or is unfamiliar with a given procedure, it is explained and clarified to them. When they are sufficiently informed about the procedure, they can exercise their right to accept or reject it – their signature confirms that they consent and agree to treatment.

Changes in disabled person’s position and their demand for basic human rights (among other things the demand to live in a domestic environment augmented with support services) has surely led to this change at the service level. In everyday life, the biggest change is in realizing the right to speak on one’s own behalf and to resist having other people speak in their place.

The following table shows the difference between the medical and social model, as reflected in terminology, aspect, and treatment method.

Medical model	**Social model**
1. Terminology:	
• invalid • normal, healthy, sick • incapable, or needing of help • care, protection • medicalization, treatment, rehabilitation, supplemental therapy • professionalization • “family problem”, protection and care • normalization • charity, humanitarianism • adapting • correction • compensation • special needs, limitation, disability • social integration Experts and parents speak on their behalf.	• disabled • discriminated against, deprived of rights • self-determination, emancipation, responsibility, active inclusion, participation, co-determination • active role in forming strategies and policies • inclusion • empowerment • civil and human rights • equal rights and opportunities • options • independence • responsibility • autonomy • solidarity They tell their own stories, express their own desires and needs.

2. Treatment:	
• a committee for determining the level of impairment, experts • focused on the individual (accident, injury, being different, a loss, being limited, incapacity)	• self-determination • focus on social circumstances (prejudices, social conditions, architectural barriers, discrimination, repression, other forms of social inequality
3. Problem-solving approach:	
• charity, treatment, rehabilitation, segregation, modification, supplemental therapy, protection, and care • institutional protection and other institutional forms of assistance	• education, informing the public, examples in practice, direct funding, accessibility • civil rights, antidiscrimination legislation, political struggle • living in a community • personal assistance and other support services that afford people an independent life
4. Rights:	
• derived from legislation protecting the disabled: social rights	• human and civil rights

The difference in understanding disability according to the medical and social model

> “I moved into a completely adapted apartment, which I could only get to from the basement. If I wanted to get in through the main entrance, which didn’t have adjusted access, then I needed help from a personal assistant.”

There are barriers in our surroundings (Image: Katrin Modic’s personal archive)

The right of the photograph shows a door held open by a woman in a wheelchair. A man is pushing her wheelchair over the door’s threshold. There are buzzers to the building’s apartments in the top left corner. In the back of the photograph is a green space where a tree is growing and a building is behind that.

It is clear that the man, who needs a wheelchair for mobility, cannot get into the building without a modified entrance (there are just steps, not a ramp or an elevator). We can attribute the person’s inability to get into the inaccessible building either to the individual (therefore to their personal circumstances that they cannot walk), or to the unmodified surroundings that prevent the person from performing an activity.

How we understand and solve the “problem” depends on what we see as the problem itself and which of its aspects we focus on. All methods, procedures, treatment approaches, and problem solving depend upon that. The problem definitely is not in the individual – the person in the wheelchair can get into any accessible building. They can also get into any building if they have available someone to help them overcome the barriers. It is therefore crucial to recognize where in the environment barriers lie, and then do something to correct them.

Where the focus lies	**Understanding the problem**	**Most likely answers or solutions**
the individual	accident injury being different loss incapacity/inability support/assistance	charity treatment/rehabilitation segregation modifications “supplemental” therapy protection and care
in society	prejudices social circumstances systemic barriers discrimination repression	educating, informing the public, direct funding accessibility civil rights, antidiscrimination legislation political struggle

The Independent Living Movement sparked a revolution in how disabled people are understood and how their circumstances are viewed. In practice, this is seen in the personalization of services and the individual’s empowerment. The key conditions of independent living are access to information, the environment, and all forms of housing, mobility, and especially PA. Users have certain inalienable human and civil rights, equal opportunities for choice, and equality in treatment. Similarly, they are included in all aspects of social life on an equal footing. They can assess their own situation, make decisions about their own life and body, exercise their rights, and take on obligations and responsibility for their decisions and actions.

The “identity” of the disabled

Society often understands disabled people as those who need help from others, as those who are emotionally and intellectually dependent on others. For instance, someone who due to their disability cannot dress themselves as even a small child is capable of doing, and thus people often talk to disabled people as if they were children in other aspects as well. For example: “Do you want me to move your leg?”, “Should we go pee now?”, “What hurts us today?” The results of this belief that adult disabled people are impotent are seen in overprotection, excessive protection, and in decision making without the disabled person’s input.

Questions for consideration:

What is the reason you perceive others as different from you? Are you scared, do you feel awkward, have pity or sympathy, or feel uncomfortable whenever you are around disabled people? Do you perhaps view them as a hero? How and in what ways do you see them as strange or different from you?

“When I first saw a disabled body, I felt very uncomfortable and afraid. When I first began working as a personal assistant I was even afraid to touch my user, for instance in cleaning, getting dressed, helping her into her wheelchair, because I was afraid of hurting her. With time I got used to it and now I do all those things with no problems or fear. And I view her body completely differently, too. It doesn’t cause me any unpleasant feelings; I just see her body as a body, one that deviates somewhat from the average.”

Regardless of what diagnosis people have and with what limitations they live (physical, sensory, intellectual, emotional, mental health, etc.), the common rights they share are that of independence and respectability, of fulfilling basic needs and desires, and of being treated equally in society. Everyone strives for a good life in their own way. People want to exercise their rights to the fullest and be respected members of their community. This means that they absolutely need bilateral, mutually fulfilling relationships with their loved ones, friends, acquaintances, and others. It is crucial that they live and work in normal environments, and use normal services and facilities (shops, schools, clubs, libraries, bars, sports facilities, etc.) in their daily lives, instead of being provided with “special” services and “special” facilities, which are usually segregated from spaces for the non-disabled. To get a better idea: access to halls in cultural institutions for the disabled is often only possible through a service entrance or service areas; in restaurants – through the kitchen or store room; some institutions have elevators for the disabled, but these are usually used to store things; e.g. planned elevator use must be announced in advance so the institution can provide an operator – it often happens that “qualified operators” do not know how to operate the lift, or it might be broken, locked (no one knows where the key is) or intended only for people in a wheelchair (e.g. access to a ramp is locked because it is intended exclusively for the disabled, but not for transporting cargo or for mothers pushing strollers – abandoning the principle of universal design).

The Use of language

We use terms that describe disabled people as capable and responsible for their own lives, and not as passive objects of care. Language reveals our relationships and influences them, which includes our relationship with our own selves. That’s why we use inclusive language that neither insults nor labels disabled people as inferior or incapable.

We avoid negative and outdated terms such as “invalid”, “crippled”, “mongoloid”, “special needs”, etc. The word “invalid” is still often used in legislation in Slovenia, but it is insulting and completely devalues the people to whom it is attributed. Similarly to be avoided are directly mocking terms. These include “gimp”, “cripple”, “spaz”, etc.

When we introduce a disabled person, we always highlight their strong suits (their name, profession, their character, education, hobbies, etc.). We never start introductions by explaining the person’s diagnosis. We never say that a person is “stuck in a wheelchair”, but merely that they use one. We never say that they “suffer” from a certain disease, but merely that they have one.

The history of the independent living movement

In the 1960s, disabled people began taking a stand against the idea that they were a special category of people to care for. Society was of the general belief that disabled people cannot care for themselves. The beginnings of the independent living movement took root in the battleground of the fight for the rights of other disadvantaged groups (women’s rights, LGBT rights, student movements, the fight against racism and xenophobia, consumer movement, etc.), which encouraged disabled people to fight for the right to independent living.

The movement contributed significantly to making a new and different reality, one that meant a departure from categorizing the disabled as passive, helpless, and hopeless patients who need help. To affect their desired changes in nomenclature and treatment, disabled people first needed to develop the concepts that identified their identity and position as completely different. They realized that the legal and political systems would not take their demands seriously, and that their voice lacked clout. Bureaucracy was too slow to respond, and so they decided on more decisive, radical ways of demonstrating their ideas. The result was a direct and effective way of informing and educating the general public about the inequality in which they found themselves. Politicians could no longer ignore the problem when the public realized the discrimination and even violence that disabled people faced on a daily basis. Having exhausted all normal legal avenues, disabled people took a cue from civil rights' movements and tried their hand at other forms of social protest, such as demonstrations, boycotts, traffic blockades, and sit-ins.

UCLA Berkeley was one of the first colleges in the USA to accept disabled students. However, the university administration housed them in a hospital on campus, functionally cutting them off from their peers and thus student life. The students resisted this and forced the administration into providing equal opportunities for disabled students' life and education. The students actively joined efforts to remove barriers on and around campus. They gained the skills and knowledge they needed for performing everyday activities. They learned how to hire and train assistants to provide the physical aid that they needed for everyday life. This group found that living in an institution stripped disabled people of their ability to make decisions about their own body and lifestyle, and along with it stripped their freedom, dignity, and self-respect. Their conclusion is that it is wrong to segregate or institutionalize the disabled, regardless of their lifestyle or disability.

In 1972, a group on campus moved into a collective and opened the first independent living center. They demanded individualized support – not as a luxury, but as a fundamental human right. Their battle was for “the impossible”: the right to housing, PA, and accessible public transportation, buildings, and peer counseling. Throughout the country they opened independent living centers. This earned them the right to determine where and with whom they would like to live, and who would support them in their efforts. It was precisely the activism of these disabled students at Berkeley that stoked the flames of the civil rights movement, which later led to the adoption of the Americans with Disabilities Act, which prohibits discrimination against the disabled in a wide range of settings, including employment, transportation, public housing, communication, and access to municipal services and programs.

While the roots of the independent living movement indeed took hold in the USA, similar ideas and movements were brewing in Europe, especially in England. It was the many English activists who developed the theory known today as the “social model of disability”.

In April 1989, ENIL (European Network for Independent Living) held an international conference in Strasbourg that focused on the services of personal assistance. They identified PA as the very core of independent living, making it possible for disabled people to choose where to live, to be mobile, active, and included in all facets of life (from education to employment, politics to family life, recreational options, and more), and to finally enjoy economic and social security, along with political clout. In this light the attendants decried segregation and institutionalization as a direct infringement on their human rights, calling upon the government to pass legislation protecting disabled people’s rights.

The history of the independent living movement in Slovenia

Similarly, the roots of the Slovenian independent living movement sprouted from the needs of young disabled students, who were forced to live and attend school at a special institution (now CIRIUS Kamnik).

After finishing high school, Emil Bohinc, Elena Pečarič, and Klaudija Poropat had to face the reality that living outside of an institution is impossible for anyone who needs constant physical support. At that time there were neither the structures nor the services or organizations in place to even make this possible. To make matters worse, the only existing associations of disabled people, which considered themselves the advocates of disabled people’s rights and the administrators of programs, were the very entities opposing them and quashing their endeavors.

The first funding for their ideas came from the George Soros Open Society Foundations.

George Soros on a visit to Slovenia (Photograph: Elena Pečarič’s personal archive)

The photo shows people socializing during a banquet. Five of them are standing in a circle and talking. Two of them, on the bottom third of the photograph, are in wheelchairs – one of them is Elena Pečarič. Standing across from her is George Soros, who is smiling at another person in a wheelchair. The other people in the circle are looking at him.

They stood up for equality among unequals and for respecting diversity. They realized that excluding people, regardless of whether based on faith, ethnicity, gender or sexual orientation, disability, or any other circumstance, is always based on the same objectives, namely the desire for power and control. They dreamed that human rights should prove the measure by which legislation would be adopted. The rule of law would provide for justice, equality, equal opportunities, and solidarity, and the actual social nature of society would be fostered. With great hopes and enthusiasm they attempted to leverage their own situations and experience to help formulate creative suggestions for systemic changes.

Psychologist Dr. Dušan Rutar was also instrumental in helping formulate these ideas. His lectures in the institution helped enact a transformation in how they understood their own position in a society of unequal opportunities and injustices. Their struggles and perseverance led to the founding of an informal movement, which they called the **Youth Handicapped Deprivileged** (hereinafter: YHD).

As a movement, they came to the realization that they themselves bore responsibility for changing their circumstances and creating new conditions for their lives. The theory of disability developed by Dr. Rutar, and the resistance to the medical model of disability, were and remain the guiding principle in the creation of all their further projects and campaigns.

Despite the bad experiences they'd experienced when living in an institution, they wanted to go to college and live an everyday life, just like their peers.
They began adopting the ideas they would later dub the concepts of independent living. The Independent Living Movement in Slovenia did not originate in any concepts or models from abroad, but as the result of the firsthand life experiences and actual needs of disabled people who had left their institutions and began living in a normal environment. Only later did they realize that students in other countries were struggling for the same rights with the same set of convictions.

Their desires were extremely simple and humble: all they wanted was to finally experience a bit of everyday normality. They wanted to do the most trivial things, taste life's simple pleasures, which institutionalized living had prevented.

Student life in Ljubljana (Photograph: Elena Pečarič's personal archive)

> The collage contains three photographs.
>
> The first one, bottom left, shows Elena Pečarič sitting in a wheelchair in her apartment. Her mouth is open, as if she were speaking. A woman is sitting next to her. Both are looking at a computer screen on the table between them, located at the far left of the photograph.
>
> The second photograph, bottom right, shows Elena Pečarič in a wheelchair on the left side, bottom quarter. She is holding her chin in her hand and her mouth is open, as if she were speaking. Next to her on the right is a woman sitting cross-legged on the ground. There is a moped in front of the woman. There are people standing at the entrance to the club SOT 24.5, looking as if they are at a party.
>
> In the third, top right, inside SOT 24.5 sit Elena Pečarič, Klaudija Poropat, Emil Bohinc, and one other person around a table with glasses on it. They are clearly having a conversation.

“We wanted to go shopping, decide what to eat and cook, even with the risk that it wouldn’t come out edible. We wanted to come home at whatever hour we wanted, without having to explain ourselves or apologize. To clean and arrange our homes as we saw fit, decorate the walls however we wanted ... We were young on paper, sure, but in many respects quite grown up already. We knew that freedom comes at a price, one that we had been paying the whole time without experiencing it. Despite the belief that we needed to catch up and experience all the things we’d missed out on, we still managed every time to avoid that gray average, established practices, and trendy schools of thought; in a word – a normal life. A normal life that, together with others just like us, both unconditionally and as if it went without saying, distinguished us as different and shut us away in a room, away from our families, friends, and home.” (Elena Pečarič)

Rigid social institutions ensured that this would truly prove to be a fight for personal independence that demanded a high degree of dedication and perseverance. These institutions didn’t even provide a modicum of support in seeking appropriate housing or physical assistance from other people. The only solution offered by social services was to live at the institution in Kamnik, where they could be driven to classes in Ljubljana (about a half an hour’s drive), as the legislation at the time had no mechanisms for financing disabled people who wanted to live outside of an institution. Circumstances, augmented by the dedication of these disabled students, who were determined not to live in an institution anymore, led to an agreement with the social work centers that they would provide the funding for their rents.

Securing necessary physical assistance in everyday tasks (personal assistance, as it would come to be called) also required a good deal of quick thinking and improvisation. Those who were willing to help and provide assistance were offered housing, while some of the assistance was covered by a special allowance, or by their scholarships or stipends. At first they were helped in their tasks and care by a Bosnian friend, who wanted to live in Slovenia.

It was more or less a coincidence that the group learned about a public works program launched at the time by the Employment Service of Slovenia. They got the idea to apply to a tender to cover the costs of hiring assistants. Since they lacked an appropriate formal structure, they were offered support by the Association of Developing Voluntary Work. They became the authors, the implementers, and at the same time the users of the Independent Living for the Disabled project (hereinafter: ILD) within this organization, which, through a public works program, supplied the first two assistants from its ranks of employees. The remainder of the assistance was offered by volunteers, primarily students of Professor Bojan Dekleva, who taught at the Faculty of Education and spread among his students the concepts of independent living. At first, the project mainly just included physical assistance for disabled people, including care, household tasks, and accompaniment on errands and tasks. The project's designers were both its users as well as its facilitators. With that type of help they were able to live independently from institutions and families, regardless of the fact that they were physically dependent on assistance from other people.

“Those girls worked on weekends and all night long. During the day, every 2 or 3 hours, freshman and sophomore volunteers from the Faculty of Education would work in shifts. It was a fascinating experience, and we wanted to pay them back for their physical assistance in some other way, with other means. Roughly 15 volunteers traded off throughout the week in that apartment. We had a weekly schedule of tasks that was to be strictly adhered to. In dealing with the assistants, it was important that we were consistent, fair, and flexible to a certain extent – but not to our own detriment. We had to set an example for them in some ways. This experience was an incredible lesson in how to later structure and handle personal assistance, especially in terms of implementing programs. The whole time we wanted to portray our practical experience as a potential model of independence for others, too, as something that could be scaled and become a part of the system, or an individual right ensured by direct financing.” (Elena Pečarič)

YHD's informal movement joined forces with another network (Mreža za Metelkovo, or MzM), which focused on securing premises for cultural programs, social and cultural groups, as well as individual creators. The idea of working with different people for a common cause fit well with them, and they saw in MzM a potential solution to their own difficulties with finding an appropriate space. In 1994, the movement finally had its own space, which they named SOT 24,5. They immediately began planning lectures, round tables, exhibitions, small concerts, and similar undertakings. In 1995, they began publishing a special social sciences newsletter called AWOL, in which they attempted to develop a theory of disability along with a space for a general discussion of social studies.

The next year, in 1996, YHD – Association for the Theory and Culture of Handicap was founded. And thus 10 like-minded individuals formalized their movement, in large part just in order to secure sufficient funding. They strove all along, through a variety of projects, programs, workshops, conferences, round tables, public discussions, international networking, and informing the public, experts, and policy makers, to codify the right to independent living for everyone. They also strove for the recognition of PA as a fundamental part of ensuring independent living. Their main goal was to help pass legislation on PA that would recognize PA as a human right, ensured for all disabled people who either want or need it.

From the segment Gastroskopija on Radio Študent (Photograph: Elena Pečarič's personal archive)

> Inside the radio studio sit from left to right Stojan Zafred with Elena Pečarič and Emil Bohinc. Behind them, on the right side of the photo, stands a man who is pouring a drink from a can into a glass.

The biggest difference between YHD and other organizations working on disability issues is that the others are organized on the basis of diagnoses, e.g. an organization for muscular dystrophy and one for multiple sclerosis, etc. YHD is utterly uninterested in diagnoses, as these are not what comprises an individual and their identity. YHD's goal is simply to change the position of people with disabilities within society. YHD unites people through shared values and common goals. The social model of disability is at the heart of its philosophy, and it rejects the medical model outright. It interprets disability as a matter of social status and not as a bodily or mental characteristic, not as debilitating, and not as a disorder or special requirement. The urge and need to change their own station came from their dissatisfaction with the predominant way their circumstances were understood in society (as incompetent, as needing care). The association's members rejected all scenarios for their lives that had been written by others and began putting pen to paper writing their own. Similarly, they had no intention of lobbying or applying formal pressure on lawmakers, until, of course, it became clear that there was no other path towards codifying their needs.

The history of providing personal assistance in Slovenia

The turning point came in 1995, when young people from the YHD movement first came in contact with representatives from the Dutch Institute for Care and Welfare (NIZW), or the MATRA project, and received an invitation to help create a 9-year program for developing a model of independent living for the disabled. The program, which they ran as a pilot from June 1998 to June 2000 and then evaluated later, was spearheaded by the Slovenian NGO SINCO. It was entirely funded by NIZW, while the assistants' salaries were covered by grants from the employment service, as well as local municipalities.

The program, as designed, provided PA for 15 people, even 24/7 if needed. For the first and so far the last time in Slovenia, admittance into the program was advertised through a public tender printed in a daily newspaper.

RAZPIS

za "NEODVISNO ŽIVLJENJE HENDIKEPIRANIH"

YHD- Društvo za teorijo in kulturo hendikepa razpisuje prosta mesta za uporabnike projekta "Neodvisno življenje hendikepiranih".

Projekt je namenjen vsem hendikepiranim osebam (ne glede na vrsto in stopnjo invalidnosti), ki hočejo živeti izven inštitucij ali družine, lahko pa je le oblika doseganja večje neodvisnosti znotraj le-teh.

Projekt je nastal z namenom, da posameznik/ca sam upravlja, obvladuje in organizira svoje življenje. Projekt bo v praksi zagotavljal osebno nego, spremstvo in druga fizična opravila, ki jih posameznik/ca zaradi svojega hendikepa ne more sam opravljati. Posameznik/ca si bo sam izbral njemu ustrezne osebe, ki jih bo "izobrazil" o obliki in načinu nudenja željene pomoči. Pomoč lahko obsega tudi 24 ur dnevno, oziroma po potrebi posameznika/ce. Nudena pomoč bo za uporabnike/ce projekta brezplačna.

Prednost imajo mladi (od 18 do 35 let) posameznik/ce s težjim fizičnim hendikepom, saj so le ti najbolj ovirani pri vzpostavljanju lastne neodvisnosti. Stalno prebivališče na območju mesta Ljubljana, državljanstvo, zaposlenost NISO pogoji za prijavo.

Projekt bo potekal na območju MOL, vendar pa smo na voljo za vse potrebne informacije glede vzpostavitve podobnih projektov tudi v drugih krajih po Sloveniji.

Projekt finančno podpirajo program MATRA, OSI - Slovenija, MOL, Ministrstvo za delo, družino in socialne zadeve, Urad RS za mladino.

Informacije in prijave pisno ali po telefonu, do 10. 10. 1998, na naslov: YHD - Društvo za teorijo in kulturo hendikepa, Neubergerjeva 7, Ljubljana in telefon 061/131 20 54, od 10. do 12. ure, vsak delavnik.

Ad in the daily paper Dnevnik – 28 September 1998 (Photograph: YHD's archive)

The photo features an ad with the text: "A TENDER FOR 'INDEPENDENT LIVING FOR THE DISABLED'. YHD – Association for the Theory and Culture of Handicap, is announcing openings for people to join the project 'Independent Living for the Disabled'.

The project is meant for all disabled people (regardless of type or degree of disability) who want to live outside of an institution or their family, and those who nonetheless chose to live at home or in an institution and would have the PA they need to at least increase their independence. The project is formed with the purpose of helping people plan and lead their own lives. In practice, the project will provide intimate care, accompaniment on errands, and help with other physical tasks that the disabled person is unable to perform. Participants will be able to choose the right person to help them and 'educate' them to provide the right form and method of assistance. Assistance can be provided even 24/7, or as needed. The assistance offered through the program is free of charge. Young people (aged 18 to 35 years)

> with serious physical handicaps will be given preference, as this is the group most challenged in trying to carve out their independence. A permanent residence within Ljubljana, nationality, or employment status are NOT conditions for application. The project will be held within the municipality of Ljubljana, but we are eager to provide any information about establishing similar projects elsewhere through Slovenia. The project is being financed by the MATRA program, OSI – Slovenia, the Municipality of Ljubljana, the Ministry of Labor, Family and Social Affairs, and the Slovenian Office for Youth. **Information and registration are available, both in writing and by telephone, until 10 October 1998. Write or call to: YHD – Association for the Theory and Culture of Handicap Neubergerjeva 7, Ljubljana, 061/131 20 54, any working day from 10 AM to 12 noon.**"

The response was muted at first, as people barely understood what it was about. The scope set by YHD proved insufficient by the end of 2 years and the number of people enrolled in the program almost doubled, going from the planned 15 to 27 users, without even increasing the budget. In 1999 the group first applied for a tender issued by the Foundation for the Financing of Organisations of the Disabled and Humanitarian Organisations (hereinafter: FIHO). Traditional organizations supposedly advocating for disability, which comprised a majority in FIHO, were opposed to YHD's ideas, and so at first YHD was excluded. They eventually were forced to change their mind, but YHD still never received sufficient funding for co-financing the IL program smoothly and consistently. Thus began the many years of struggling to stabilize working conditions at YHD, a battle which rages on.

At the end of 1999, YHD published the Manifesto of Independent Living.

The cover of the Manifesto of Independent Living (Photograph: YHD's archive)

On the bottom left of its open orange covers is YHD's logo. There is an illustration on the right side, alongside in both Slovenian and English are the titles: "MANIFEST NEODVISNEGA ŽIVLJENJA" and "THE MANIFESTO OF INDEPENDENT LIVING".

In April 2000, they opened the first Independent Living Center in Slovenia, which also housed the Independent Living program office. Emil, Klaudija, and Elena became employed as the program coordinators. Thus they succeeded in forging job openings and new careers out of what was originally a matter of personal needs in everyday life.

The Ministry of Labor, Family and Social Affairs first published a tender to co-finance long-term (5-year) programs in 2000. The city of Ljubljana also announced 3-year program grants in the same year, and the employment service also first announced a long-term program of financing salaries for jobs within the scope of social security (A Thousand New Opportunities, and later the Disabled for the Disabled, as well as I Will Be an Assistant). YHD took advantage of these grants to permanently employ assistants and provide for the program's stability. Assistants were always employed through public works' programs. FIHO funds were also crucial for the program, along with funding from individual municipalities, and from other small-scale contributions (e.g. donors, out-of-pocket contributions from users, European funds, etc.). Soon other disability organizations also began providing PA.
In 2004, YHD applied to the EU's EQUAL program, which led to the codification of personal assistants' roles and conduct, as well as carving out opportunities

for permanently employing assistants. The project also saw the publication of a Manual for Educating Personal Assistants.

In 2015, the main role in financing was overtaken from the employment service by the Directorate for the Disabled, Injured Veterans, and Victims of Wartime Violence, which, as part of a dedicated tender, provided funding for the majority of assistants in the period from 2015 through 2018. The state's project-based financing of PA was thus ensured through the end of 2018, or until the Personal Assistance Act (hereinafter: PAA) came into force.

The political struggle for the right to personal assistance and the law's adoption

YHD has striven for years to reach a systemic solution for PA, one that would see PA recognized as the right of every disabled person in the country. This would also ensure permanent sources of funding. Until the PAA came into force, disabled people here did not receive PA to the extent that they needed it – assistants were not available as often and regularly as needed. Another problem was that the former system did not recognize the right to PA for everyone who actually needed it.

Politicians listened to YHD and their requests, but it took a long time for them to support them.

A discussion between the president of the Republic Slovenia and president of YHD. (Photograph: YHD's archive)

A gate is in the bottom of the photograph with the word STOP written on it. Behind it, to the right of the photograph, sits Elena Pečarič in an electric wheelchair. She has a protest sign attached to her headrest. Across from her, on the left side, kneels Slovenian president Borut Pahor. He's holding his chin between thumb and forefinger, his brow furrowed. They are facing one another, seemingly in conversation.

The legal basis for PA is guaranteed by Article 19 of the Convention on the Rights of Persons with Disabilities. As a country, Slovenia undertook to put into place a system for assuring the right to independent living in a community or mainstream environment, along with social inclusion and participation, and access to support services in their own homes. Systemic arrangements for PA in Slovenia were also the goal of several strategic documents on social and disability security. Nonetheless, there still was no political interest in codifying PA.

YHD's representatives held many protests and staged public campaigns, which, along with the association's supporters, demanded that the country legislate PA permanently and with it pass a law on the right to independent living. They explained and highlighted the problem of funding and the financial pressures that PA had struggled against for decades already, demanding the fair and equitable distribution of FIHO funds, which should go to programs for independent living and housing outside of institutions.

Protests for codifying disabled people’s rights, as organized by YHD. (Photograph: YHD’s archive)

The collage has 4 photographs: 3 are arranged diagonally from the top left, while the 4th one is in the top right. They show protests for disabled people’s rights.

The first shows a throng of people moving down Slovenska Cesta, with two people in a wheelchair and a goat in the front. Behind them are a person with a megaphone and a mass of people, with people in wheelchairs between them. They are all carrying protest signs and yellow and blue balloons. Zvezda Park and Kazina are in the background.

In the front of the second photograph is Emil Bohinc. A group of people is behind him, most of them in wheelchairs, including Elena Pečarič among them. Their posters bear the slogans: “WE’RE TOO YOUNG TO LIVE IN RETIREMENT HOMES” and “ARE POLITICIANS BLIND OR ARE THEY BENEFITTING FROM THE STATUS QUO?” The protestors have filled the whole road.

In the third photograph a group of people walks down half the road, with many people in wheelchairs among them. Some of them are carrying protest posters; others have them attached to their wheelchairs' headrests. One of them reads: "FIHO'S LOTTERY IS BULLSHIT". Behind them, on the other side of the road, a city bus is driving in the opposite direction.

At the front of the 4th photograph is a column of people moving along the sidewalk and bike lane. A person in a wheelchair is holding a sign saying "ACCESS EVERYWHERE". Behind him protestors carry signs reading "DISABLED CORRUPTION IS HOT BUSINESS".

The protests, staged by YHD, were even attended by British activist John Evans, who in 2013 was inducted into ENIL's Hall of Fame. (Photograph: YHD's archive)

> The collage shows photographs of a protest that the British activist John Evans attended.
>
> Klaudija Poropat leads protestors with a megaphone in her lap in the top photograph. Her right hand is touching John Evans's wheelchair. Elena Pečarič is to her right. The group of protestors has taken up the whole road downtown. Some are carrying balloons, others signs reading: “WHO IS STEALING ALLOCATED FUNDS?”, “GETTING RICH OFF OF THE DISABLED = UNCHRISTIAN”, “FAIR PAY FOR OUR ASSISTANTS”, and “WE DON'T WANT YOUR INSTITUTIONS, WE WANT OUR HOMES”.
>
> In the second photograph, bottom left, John Evans is in an electric wheelchair. He is wearing a light blue shirt and beige pants, with a white hat. He's strapped into his wheelchair, his arms on the armrests, palms facing upwards. His fingers are bent and at an angle that gives the feeling that this is the result of a disability. He has a serious expression and furrowed brow. A sign is behind his wheelchair. There are 3 protestors behind him.
>
> The third photograph, bottom right, is a group shot of all the protestors. In the front on the right is John Evans, on the left Katrin Modic (who holds a sign in her left hand reading, “IS OUR COUNTRY AN INVALID?”). The protestors are holding balloons and signs. One of them reads “NO PERSONAL ASSISTANCE, NO EXISTENCE”.

Many years of experience in implementing and using PA programs helped YHD compose the first draft act on personal assistance. **In 2012, YHD became the first organization in Slovenia to launch a grassroots campaign to acquire the 7000 signatures necessary to submit the draft act to the National Assembly for consideration.** They were unsuccessful in this attempt at legislating, as the majority of deputies at the National Assembly rejected the draft already in its infancy at the Committee on Labour, Family, Social Affairs and Disability - largely due to the open opposition from other disability organizations.

They were unsuccessful in this attempt at legislating, as the majority of deputies at the National Assembly rejected the draft already in its infancy at the Committee on Labour, Family, Social Affairs and Disability - largely due to the open opposition from other disability organizations. These organizations were mostly opposed because of the plan to finance PA through FIHO. Upon the proposal‘s rejection, the deputies and the Committee promised to form a new working group and begin the process of accepting a new draft act before the end of the year.

At the same time, the Ministry of Labour, Family, Social Affairs and Equal Opportunities was working on the Long Term Care Act, one of whose goals was to codify PA. But it became clear that there were two different concepts or approaches to treating individual users. Long-term care focuses on the prevalent medical model, which focuses on ranking users by diagnosis. Taking an opposite approach, PA is based on the social model and on the equal application of human and civil rights. It thus opens up a new dimension of seeing, understanding, conceptualizing, and relating to the concept of disability.

As such, in 2015, as part of the Deinstitutionalization Network project, YHD worked with other NGOs to modify the 2012 draft bill. The chances of leaving an institution are extremely low for the severely disabled if they lack the right to PA. Intensive rounds of coordination and negotiations helped YHD finally formulate a draft act that other organizations advocating for disability supported.

This consensus was part of the ultimatum given by the minister at the time before submitting the draft act to parliament. Despite the fact that the draft act was supported by the Council For Persons with Disability, the ministry did not fulfill its promise.

It was only in 2016 that YHD finally convinced a political party to submit to the National Assembly the harmonized draft of the Personal Assistance Act.

PAA was adopted in February 2017 and began to be implemented in January 2019. PAA gave the significantly disabled in Slovenia the legal right to PA and, as such, the possibility of independent living. PA became available to everyone disabled between the age of 18 and 65 that needed more than 30 hours of assistance per week. This was a huge achievement for Slovenia and the result of YHD’s 30 years of efforts.

PAA is also the fundamental condition for deinstitutionalization and the end of the era when, due to a lack of appropriate care, disabled people were only housed in institutions, which served as their “homes” nearly from birth to death. From its original utopian ideal of “living on their own in a mainstream environment, just like their peers”, PA has become a tangible and actual individual right and systemic solution, even inspiring other EU member states and beyond to create similar programs.

PAA makes it possible for people who need constant support nonetheless to enjoy independent living. First: it is a radical change from “care for the incapable” and “protecting the vulnerable” to equality and equal rights. This is a transition towards more rights, and a departure from the medical model and the social security we were familiar with before. Second: the philosophy of independent living emphasized that the disabled are capable of leading their own lives, that they have the right to choose, to be supported, and to live in a community. If someone chooses to live in an institution or to live at home and have their loved ones take care of them, simply because they do not know or do not have any other option available, then this is not a choice.

2. PROVIDING PERSONAL ASSISTANCE

Who uses personal assistance

Users of PA are disabled people who would like to lead active and independent lives. They must know how to use and manage their own PA, which requires a great deal of responsibility, akin to the role of an informal employer. PA users who are incapable of such a role must have a legal representative who accepts this responsibility on their behalf.

The assistant performs all tasks according to the user’s instructions and in their presence. The service provided or task performed for a given user depends upon that user’s needs and wishes. It is vital that either the user or their legal representative controls or directs the provision of PA. This includes managing their own PA, determining the methods, content, and schedule of work, choosing the right person to provide assistance, and keeping records on the assistant’s hours on the job. As such, the user must actively engage in the provision of PA, deciding on how it is to be administered and acting responsibly towards their assistant as foreseen by labor legislation. PA services are adapted depending on the user’s needs, capabilities, circumstances, limitations, and wishes; in a word, they are individualized.

Put simply: PA means the user has the right and active power to control their own assistance, and therefore their own life. It is important that the term “personal assistance” be used strictly for this type of aid, when the user is actually able to manage and control the services provided, and not for other institutionalized forms of care or community services.

The user (and their legal representative, if applicable) must protect their assistant’s personal data and respect their privacy and personal integrity.

Legal representatives

A legal representative is someone who accepts those responsibilities that the user is incapable of handling themselves due to their disability. It is imperative for the legal representative to understand that their role is to advocate and prioritize the user's needs, interests, and indeed independent life, not their own. The legal representative's responsibility is to help the user manage their PA, or to manage the PA entirely, if needed. The representative must therefore be very familiar with the tasks and manner of aid the assistant will provide, giving instructions and supervising how the assistant performs their work.

The user's responsibility as an informal employer

PA users serve as their assistant's informal employer. This entails the following responsibilities:

- **Finding and choosing the right assistant and taking responsibility for that choice**

- **Training and instructing the assistant for providing individualized PA**

- **Supervising the assistant's work**

- **Recording the assistant's hours and other details concerning formal employment;** the user or their legal representative must record the hours worked by the assistant and submit monthly records, along with the assistant's signature, to the provider of PA

- **Resolving conflicts**

- **Firing the assistant in the event of justified reasons in accordance with labor legislation**

- **Educating themselves about managing PA**

  Many users have only ever lived with their families or in institutions, and so they themselves require the skills and knowledge to manage their own PA (setting schedules, keeping records of the assistants' work, informing the PA provider of any absences, sick leave, vacation, etc.) as they take on the role of informal employers. Users and their legal representatives, if applicable, must take a course on managing PA before their assistants begin working. They must also learn the basics of labor legislation and occupational safety and health. It is extremely important that they acquire this knowledge before PA begins, as this is the only way for them and/or their legal representatives to properly prepare for the new responsibilities they must take on to manage their PA effectively.

User training here is similar in content to the training that assistants themselves undergo, although it is, of course, framed from the perspective of user responsibilities in managing PA. The user and/or legal representative must repeat their training for managing PA once per year. If the user is still insufficiently prepared for managing PA, they can attend the course more than once per year.

Developing the skills to manage personal assistance

Disabled people who want to lead an independent life are suddenly thrust into the role of employer, usually with little to no such prior experience. They require several social skills in order to be a good employer to their assistant, from giving instructions to leading negotiations in the event of a conflict.

Users must adopt an active approach; it is not enough to just leave things to chance and hope they work out. Their very existence requires them to identify their need for assistance and supervise its provision. They must do everything that they can do by themselves, as only that will bring satisfaction with the lifestyle that they have chosen. At the same time, they must consider their assistants’ (both new and former) needs.

Not every user knows from the start how to manage their own PA, that is to be a good, diligent, and most of all responsible employer. Reprogramming the old habits and internalized patterns that the great majority of disabled people live in is the greatest challenge. Whoever has lived their whole life as a passive recipient of care requires a good deal of time and effort to attain the amount of self-confidence to free themselves from that structured role, to truly embrace what for them is uncharted and uncertain territory. The people around them can also present a problem and a barrier; parents and relatives often oppose this sort of liberation and transition to independence, sometimes even directly blocking it. Their excuses are often trivial: the user is incapable, too feeble, or simply incompetent.

Disabled people also often face barriers on the path to independent living in the various social and institution workers, who are trained to advise and provide various forms of social assistance, even though their true responsibility should be to understand their users' needs and wishes.

Choosing the right personal assistant

Preparing for interviews

Before choosing an assistant, the user must know for which tasks they require PA, when they require it, and the manner and place in which it will be provided. It is crucial that they can explain these details clearly and specifically during interviews with potential candidates for personal assistants.

It is equally important for the user to know what they need, what they are looking for, and what they expect to receive. They must know their preferred choices in life, work, and the everyday tasks and activities that they are unable to perform themselves due to their disability .

Before choosing a candidate, the user must determine clear rules about what the assistant can and cannot do, and to what extent they are prepared to compromise and be flexible.

Conducting job interviews

- **At the interview, users first introduce themselves.**

  They emphasize their strong suits: what their job or education is, what they enjoy doing, what hobbies they have (from being active outdoors to attending cultural or religious events, etc.). It is important for the user to make a good impression on the candidate and to demonstrate that disability is not their only defining characteristic. It is unhelpful for the user to begin the discussion with sentences like: "I'm handicapped," or "I have multiple sclerosis," or "I'm a quadriplegic." They should never present themselves as patients seeking a caregiver or guardian. **The user must not try to evoke pity in the candidate; PA is not the right service for someone who wants to be pitied.**

It is crucial for users to present themselves as people with multiple interests and activities. At the interview, they should describe how the candidate could help them lead their preferred lifestyle and achieve independent living. It is best for the user to list and describe specific forms of assistance that they require, beginning with that which is most difficult for and important to them. This is the best and fastest way of determining how willing the candidate is to learn and work with the user to perform tasks according to the user's instructions and needs.

"Finding a new assistant is difficult and demanding, since only with the help of an assistant who does their job well can I lead a rewarding and independent life. Having a conversation with a potential assistant is the fastest way for me to tell if they could be the right person. During the interview, I emphasize what's important to me when providing me with assistance. Despite a serious disability, I'm still active in a lot of aspects. I need help with things like bathing, getting from my bed to my wheelchair and back, household chores, computer work, editing videos that I also record along with my assistant, and accompaniment whenever I have a meeting. I give the candidate an approximate schedule and explain that the schedule could change if my other assistant is absent. The candidate must arrive promptly at the time we agree, because my husband leaves for work early and I can't be alone. They must be willing to follow my instructions. I know that some people are incapable of this, or it stresses them out, so they should really think about how this would affect them and decide whether they are willing to accept it. I also want to know whether the candidate has any back problems, because even though I have everything adapted with all the equipment I need, including a lift and everything else, you still need a bit of strength for some motions. I'm also curious how flexible they are with working hours, and whether cats are a problem, since I have three. If the candidate is a vegetarian, I want to know whether they have a problem cooking meat."

If the user has a severe disability that requires complicated forms of assistance (e.g. operating a breathing apparatus or aspirator, catheterization, cleaning wounds, etc.), it is essential that the user shows or explains all such procedures to the assistant. If they cannot explain and/or show the assistant themselves, users can have another trained person or assistant provide instruction. If users themselves are unfamiliar with these procedures, then they too must learn them at a place where they are already provided (e.g. hospital, clinic, etc.). Users should explain these tasks to potential assistants in ways that are neither frightening nor uncomfortable. Instead, they should be explained as something simple, easy, routine, and unproblematic. For instance, the user could explain aspiration as a way of removing fluid from the lungs. This helps relieve the fears and pressures that people generally experience when meeting disabled people. The user should also explain when they need aspiration or any other procedure. Sometimes the user might not be able to speak; in this case, they will use non-verbal communication and facial expressions/ eye movements to indicate that they need something or that something is wrong. The user should inform the assistant as such in advance, so that, whenever in doubt, they can ask the user something and the user can respond by nodding or shaking their head, blinking, or any other agreed upon sign.

- **Users must verify whether their interests and views significantly differ from those of the candidate.**

- **They set an approximate schedule for the assistant.**

  Users with multiple assistants must present a work schedule and explain that potential changes to that schedule might occur in case of other assistants' absence. The user must not allow assistants to make an agreement among themselves, merely informing the user as to what they decided. Assistants who need to change the schedule must inform the user, who then comes to an agreement on such changes with another assistant. This is the only way for users to control the provision of their own PA.

- **They check for the characteristics sought and required of the assistant.**

  For example, punctuality, following instructions, keeping agreements, and having a fair attitude towards the arrangement. It is crucial that the user's privacy is respected, meaning that the assistant should not relay information about the user or the user's condition to anyone else (friends, relatives, acquaintances, etc.). The assistant should be honest (e.g. should inform the user of any health issues or beliefs that might make it impossible to provide assistance, should work according to the schedule that the user sets, etc.), respectful, and professional. The same is expected of the user.

> "Usually I hold interviews with more than one candidate. With some of them, I know immediately that things wouldn't work out. For instance, one time a young lady came, quiet, moody, cold, no energy ... even her answers to my questions were hardly intelligible, and with candidates like that I simply don't feel like explaining everything I need and what personal assistance would be like with me. We finished that conversation very quickly. I had the feeling that I could rather be

her personal assistant, to help her get some life in her."

"One candidate came for an interview and was all happy that she would be able to help me, since helping and doing good deeds fulfills her, and she was looking forward to going for coffees with me. My blood pressure rose and I had to take a deep breath before trying in a calm voice to explain to her that I wasn't looking for company, as I have my own friends, that I don't like pity, and that this isn't some humanitarian mission. Assistants are paid for their work, which is why I have no interest in explaining exactly what I need and expect from them."

"I had a case where the candidate said her husband lived and worked nearby, and that he could come check in on us and help us out. I had to tell her that wouldn't work, as PA was her job and not her husband's. I am the only one who decides who can come to my place for a visit."

- **The user must set boundaries.**

  Users should say clearly up front if there is something that they absolutely will not tolerate, for instance smoking or using a telephone for personal communication during working hours. They should check whether candidates have any health problems, such as an allergy to animal hair (if the user has a pet, then employing an assistant with an allergy is pointless) or problems lifting heavy loads, etc. Rules must be set firmly in advance (requiring the user to be strict and consistent) and the user must verify that the candidate understands at the beginning, instead of trying to resolve potential misunderstandings or push the boundaries of tolerance later. The user should clearly state what bothers them and what they find unacceptable. It is precisely because things go unspoken and because users are often too flexible, largely on account of their inexperience and lack of confidence, or because of their need to choose an assistant quickly, that users often choose an inappropriate candidate. The user sets the rules that apply in their own home, rules that the assistant will need to respect (e.g. the assistant will not be allowed to go rummaging through drawers or folders, to borrow items without asking, use the user's telephone for personal purposes, etc.).

- **Work is different with every user.**

  Even if the user is interviewing a candidate who has already provided PA for someone else, it is imperative that the user conducts the interview as if it were the assistant’s first time. The user should act as if the candidate has no prior knowledge or experience, as indeed the PA process differs from user to user, since it is such a personalized service.

- **The user makes it clear that new rules can be determined in the event of unforeseen situations.**

  If something unexpected arises, the user will say how the assistant should react and to what they should be attentive.

- **The user must tell enough about them so that the candidate knows how to react, with confidence and with no fear about working with the user.**

What can help the user decide whether a candidate is a good choice as a personal assistant

Often the user has a hard time choosing the right person among several candidates for personal assistant. In that case, it is important to reflect on previous experience to determine in what areas the user is lacking or where they have insufficient knowledge. Perhaps the user took the wrong approach to finding an assistant, or perhaps presented themselves in the wrong light. In deciding whether a given candidate is the right choice, the user can study **their nonverbal communication** during the job interview; oftentimes it speaks much louder than the words themselves. If the user recognizes nonverbal cues, they can guess what the candidate is hiding or not being up front about.

Nonverbal communication clearly conveys information about our thoughts and feelings. Over 90% of our communication is non-verbal. The majority of nonverbal communication is found in visible cues (facial expressions, hand movements, posture, etc.), a lesser amount in auditory ones (pitch and tone of voice, volume level, etc.), and tangible cues make up a minimal amount.

We make first impressions very quickly (in the first minute or even seconds after meeting someone), changing them or augmenting them only rather slowly after that. It is important for users to recognize candidates’ nonverbal reactions, using them to inform their decision about employment.

If choosing from among several candidates, users should consider their priorities (e.g. flexibility in scheduling, the candidate’s proximity to the user’s home, whether the candidate has a driver's license, their age and physical fitness, potential mutual common habits and interests, etc.).

Practice often shows that the best assistants are people that do not have backgrounds in social work or medicine and do not have previous experience working in residential or other institutions. Such people are more open to new approaches since they have no prior perception of "what must be". This makes it easier for them to consider the requirements of each individual user anew. They are unconcerned with established industry guidelines, codes of conduct, and the user's medical diagnosis.

"I know immediately when I'm dealing with someone who 'already knows everything' and thinks 'everything's clear immediately', who 'would like to help', who 'would like to work with people like me', or who 'has many years working in this field'. Usually these types of people have a superiority complex, or better they give off the impression that they are happy because they have more opportunities and they aren't lacking anything. Because they are convinced that I am their polar opposite, they need to 'help' me or even 'give my life purpose'. I personally find that approach and behavior completely off the mark, insulting, and humiliating, and so I never pick such people to provide me personal assistance."

What can happen at an interview that immediately gives the user reason not to hire a candidate

- The candidate is late to the interview, or far too early.
- The candidate tries to lead the discussion, asking many things, especially things unrelated to the work.
- The candidate comes unkempt or ungroomed, potentially stinking (including from alcohol).
- The candidate starts asking about pay, benefits, and vacation too soon.
- The candidate complains about personal or family problems, current crises, mood, or illness.
- Behaves in a patronizing manner towards the user.
- Shows insufficient interest.

- Behaves in an arrogant manner.
- Criticizes former coworkers or employers.
- Behaves in overly friendly and accommodating manner.
- Has medical limitations or injuries (e.g. chronic back pain).

“One candidate came to try out the job covered by a big hat and wearing a long, black dress, over which she had a shawl with long tassels. She was wearing high heels. After welcoming her politely, I asked if she was ready to help me go to the bathroom. She was ready immediately. She didn’t even take off her hat before we went to the bathroom. It all seemed a bit odd to me with all those clothes. Everything was fine when she helped me use the bathroom, only she got my legs stuck a bit as she put them back on my wheelchair. After that, still dressed the same, she washed the dishes. All I could think the whole time was that the shawl, which really had long tassels, was going to be soaked in the sink. When she had finished the day, I asked her if she really wanted the job. She answered honestly that she had never heard of personal assistance before and she didn’t really have any idea what the job entailed. As we talked, it turned out that she wouldn’t be able to work with me, as she had a knee injury that prevented her from kneeling.”

“As soon as he walked through the door, I could see the candidate was surprised, confused, and not even ready to see a disabled person. He almost stretched himself out on the couch when I invited him to sit down. As I asked him various questions, he seemed uninterested, and just stared off into the distance. He mentioned many times that he had done many different things for work, but he had no experience with this. I then explained to him what tasks an assistant would have to perform, and when it got to personal care, he said he wouldn’t do that.”

“At the interview, the candidate first listened attentively as I explained what personal assistance was and for what things I would need help. When I asked if there was anything else that interested him, he ‘filled in’ the list of all the things he could do with me. He told me that he had a car and didn’t have a girlfriend at the time, so we could go somewhere together. Of course, I decided against him. I told him that my assistants only drive my car. He insisted that he’d rather drive his, since he was more familiar with it. He even wanted to hang out with me in his free time.”

“Ten minutes after we had agreed to meet, a candidate for personal assistant sent me a text message saying he couldn’t find my address or entrance. I called him and asked where he was. I was bothered by the fact that he didn’t answer, he just told me that he’d be there in 5 minutes, which didn’t answer my question. In another 10 minutes, he rang my doorbell. When I opened the door, I asked him if he had come for the job interview. Again he didn’t answer, just confidently told me his name and went in for a handshake. I was surprised that he would be so condescending and that he had no professional demeanor – the employer is the one who decides if they’ll shake hands, not the other way around.”

“I invited the candidate into my kitchen, where I wanted to conduct the interview. When we were sitting, I asked why he had arrived late. His confession came pouring out: ‘I was at my old job, talking to the boss. I had to sort some things out, because he didn’t pay me as much as we had agreed. My boss isn’t honest, you know. He always promised when there was a lot of work that the paycheck would be great, but he never followed through. While I was there now, he kept making excuses, and we couldn’t agree on anything, and I was even late because of him. Well, I’m here now, and I hope I won’t have any more experiences like that.’ I was surprised that he was so up front, but I held the interview with him anyway.”

“One candidate came for an interview who had been employed already as an assistant to someone else, who then reduced the amount of assistance they needed. At the interview, he quickly tried to ‘take the reins’ into his own hands. First, without asking if he could, he closed the window in the kitchen where we were talking. When I set the firm boundary that he had to ask me if something was even necessary before doing it, he offered to make me coffee if I wanted. He talked to me on a personal, first-name basis. Despite me telling him that we weren’t friends, he continued in the same vein. He explained that he was on a first-name basis with everyone except his landlady. Of course, I decided that he wouldn’t work for me. Unfortunately, a few days later my other assistant fell sick and I had no one to help me. Luckily, I got a replacement, but he was extremely difficult to work with. It was the assistant who had come for an interview a few days before. When my partner came home, my assistant stood up and began to greet him, offering to pour him some of the coffee he had just made for us. He talked to my partner on a first-name basis as well and acted like he was the one at home here and that my partner and I were the visitors. For every boundary I set, he found a reason not to respect it. It was a really hard day, that one and all the ones that followed until my regular assistant returned. Even while he was here, I kept his hours to a minimum. I found that it was easier to live without assistance than to have the assistance he was providing, although neither of the two options was an actual solution.”

“Before my assistant left for retirement, 7 different candidates came for an interview, sent to me by the Employment Service. The weird thing is, I didn’t pick any of them. The first one told me immediately upon arrival that she already had a job picked out and she just came because the Service sent her. I told her she could have mentioned that instead of even bothering to come. We parted almost as soon as she had come. It was even shorter with the second one. She just poked her head in to say, ‘My husband is waiting outside, I don’t have time for any discussions, call me when you need me, and we’ll sort it out as we go along, right?’ I answered simply, ‘I don’t think this is going to work out!’ The third one said when she got there, ‘I’m a nurse and I can tell you right now, I won’t work nights because I have a 9 year-old daughter at home and I won’t leave her alone. I follow the profession’s rules in my work and I don’t intend to follow any other instructions.’ I happily informed her that I don’t need any help at night and that in any case I had no intention of changing her style of work! And we parted ways soon thereafter. The fourth interview was perfectly normal, to the point where I thought we’d even be able to agree for a trial day. I said that I had three more candidates to interview and that I’d contact her the following week for a trial day. And the following week she answered my third call angrily and blurted out, ‘Ma’am, I’m not in Ljubljana right now, and I won’t be for a while. I’ll call you when I get back.’ And she never did! The fifth candidate was the most interesting. She showed up promptly the first time to the interview. She looked like a nice older lady, dressed in all white, with a huge hat, and a huge shawl that trailed behind her on the floor. After formal introductions, I invited her into the kitchen. I asked her immediately, ‘Do you have any similar experience in this line of work?’ Her answer surprised me: ‘No, I don’t have any work experience, not a single day.’ Since she was a bit older, I asked her in surprise, ‘So why are you looking for a job now?’ She answered me, ‘I always stayed at home because my son has behavioral and mental disorders. Now he’s older and he joined a musical group through the church. They travel a lot and I realized that I don’t have anything to do sitting at home all day.’ I told her that I had a generally fixed schedule during the day, including Sundays and holidays. She would trade off with my other assistant during the week, one in the morning and one in the afternoon, and each one every other weekend. I told her I needed help with personal care, household chores, and accompaniment when I went out. After all that, I asked her if she really wanted to work for me. She answered yes. We agreed for a trial day the following week. Before then, two other candidates came for an interview. The sixth arrived when my assistant and I were in the bathroom. I expected her at least 10 minutes later. I invited her to join us if she had already arrived. She would at least see what kind of help I need. Indeed she did come to the bathroom, turned to the opposite wall, and found that I have really nice paintings on the wall. Immediately after that, my assistant dressed me and helped me into my wheelchair. We continued the conversation in the kitchen: ‘I’m a nurse and I know everything you want to show me. I worked at an elderly home and at a care institution.’ So I asked her why she didn’t stay there. ‘I was wrongly fired for commenting about the work conditions,’ she shot back. I said a few polite words and then we parted ways. The seventh candidate arrived. We had a formal interview and this woman, too, was looking forward to a trial day. But there was no end to the surprises. She came finally one week after we had agreed. I first asked her if she realized what would happen to me if I didn’t have anyone and had to just wait for her. Feeling guilty, she told me some story about a robbery at her house, the police, her son the drug addict, her younger daughter, her mom, and a bunch of other things to the effect that she couldn’t come sooner. I was ready to end the discussion when she started begging me to give her at least one more chance. ‘I’ll show you I know how to work.’ I didn’t want to promise her anything, but I suggested that we try seeing how she would help me go to the bathroom. I have to say, she was quite useful, but when she helped me into me wheelchair, she stank of alcohol, and it was only 9 in the morning. My patience was running out, so I just ‘told her nicely’ to leave, because there was no way I’d hire her.”

It makes sense for users to avoid candidates who act patronizing to them, who want to help at all costs, and those who already know everything. It is crucial that users present themselves as informal employers who determine what and how the assistant will work, without the assistant commenting on what is healthy and what is not. Similarly, users should not tolerate criticism about their lifestyle (e.g. the user is a smoker).

How should the user structure a trial day and what should they look for during the test

The user and the candidate for assistant should use the trial day to try the task that the user finds most important. The test is also a chance to observe characteristics that the user finds important, such as dexterity, listening skills, ability to follow instructions, responsiveness, flexibility, precision, respect, sense of humor, etc. Some users and assistants try out a trial day immediately after the interview, though we recommend waiting until the next day. This helps them clearly distinguish between their impressions from the interview and from the actual trial, and gives the opportunity to ask questions they might not have remembered to enquire during the interview; if the candidates comes twice, users will certainly end up knowing more about them. Deciding on a candidate is a serious matter for both parties, so all decisions should be thoroughly premeditated. Users should not rely on the fact that, during the trial period, which usually lasts 6 months, they can terminate their relationship with the potential assistant at any time. This should be a last resort, not a starting point.

A trial day with a candidate for personal assistant (Photo: personal archive of Martina Piskač)

The bottom right of the photograph shows a woman in a wheelchair with her head leaning against the headrest. In the middle of the photograph, to the left, is a woman tilting a plate full of spices towards the first woman. The plate is above a pan on a cooker in the center of the photograph.

"After every interview with a candidate, I tell them that I'll think things over and that I'd like them to do the same thing, and that I'll call them within a day or two. I set up a trial for those candidates that seem best. They then come to my home so they can see for themselves what it's like to work with me."

"My assistant and I greet the candidate, who then spends 4 hours with us. During that time, they get to see how I give instructions and they can try their hand at a task or two. We use a lift to help me move from the bed to my wheelchair, and it takes a little practice to get used to, and the same for going to the bathroom. Of course the candidates can try everything for themselves."

"The trial day is important for me, as it helps me see how close the things the candidate said in the interview are to how they unfold in practice. I want to see how the candidate responds to my instructions, whether they respect my decisions or try to force their own upon me, how they react to the environment, and most of all whether they are taking on the role of assistant and not guardian. One of the things I need from a personal assistant is accompaniment, such that they push my wheelchair and give me information I can't sense myself due to my blindness. I went with a candidate to a shopping center to buy some food. When she parked, she brought my wheelchair around just as I instructed her, and helped me sit in it. I told her how to push the wheelchair, what obstacles to be aware of, and where we were headed. In the middle of the first roundabout she let go of my wheelchair. 'Just because you can't see,' she said, 'doesn't mean I have to push you. You push yourself, I'm not going to support your laziness. I'll tell you where to go, but you push yourself.' Despite being angry, I told her in a calm tone that I also have difficulties with coordination in my hands, so I need physical help to push my wheelchair. She grabbed the handles again and we continued on our way. Despite that incident being really unpleasant, I decided to employ her as my assistant. But it soon proved that was the wrong choice. Instead of supplying me with the information you can only get through sight, she just told me what I had to do, or instead of helping me with what I needed, she tried to find someone else to do it instead of her. When I finished showering, I told her to bring my wheelchair and help me sit in it. I found it odd that she just disappeared from the bathroom. A bit later, my partner came in and told me she had gone to tell him that he should help me. He thought that I was sick and the assistant didn't know what to do. We were both perplexed, as there was no reason for him to have to come. The assistant should have done that herself. It was even more disturbing when she began interfering with how I raise my son and demanding what he should do and how he should act. Despite me setting boundaries, she didn't respect them. I let her go even before her trial period was over. Luckily, she was employed with me only part-time. When I spoke with another user who had also worked with the same assistant, she told me that she didn't want to keep her either, as she had figured out the same as I did already on the trial day, that this probably wasn't the right person for the job of personal assistant. At her trial day, she had told the candidate how to accompany her: 'Walk a half step in front of me and I'll hold your elbow.' The candidate replied, 'You're not going to hitchhike. I'll teach you how to walk with a cane by yourself.'"

Accompaniment (Photography: Klaudija Poropat)

The scene is a crosswalk on the road, in the bottom of the photograph, with a man and woman crossing. The man is holding a white cane in his left hand and with his right hand he is holding onto the left elbow of the woman, who is walking a half step in front of him. There are cars parked on both the left and right sides of the streets, with trees planted along the sides and apartment buildings in the back.

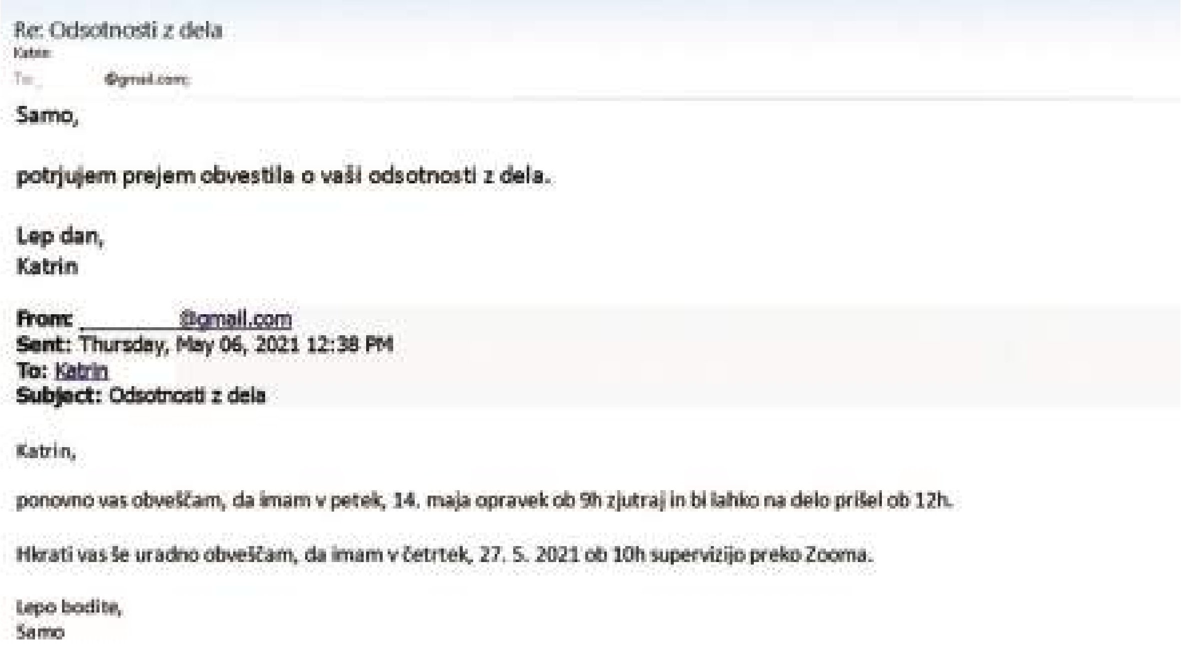
"When I said what I like to do and what kind of help I need, I found that the candidate and I even had common interests, like gardening and shopping. Despite being angry that he was late to the interview and he didn't tell me the real reason for being late, I still decided that we would have a trial day. He did great during the test: he followed my instructions, asked whether or not he had understood me correctly, and was precise and quick. Of course, I decided he would work for me. When he received his employment contract, he studied it carefully and took two days to think it over before signing it. He was concerned about the amount of money. When he signed the contract, I breathed a sigh of relief, convinced I'd found the right assistant. After a few weeks, he suggested that he could raise his salary by being paid a higher travel allowance. I was shocked at his suggestion and I rejected it. Soon, I started noticing changes: he began coming to work late, and he started calling in sick right before he should have arrived, and then he was on sick leave."

It is good to have several candidates to choose from. Sometimes, though, the user might only have one available.

It happens that users determine during the interview or trial day that the candidate is not the right choice for them, but they nonetheless decide to employ such a candidate, because they urgently need PA. They usually find out quickly that that it is impossible to work with that candidate. Often they complain to the PA provider for not having sent more candidates to choose from. Users always have the option of rejecting an ill-suited candidate and continuing to search for a better one.

Setting a schedule

Users should set schedules according to their own needs, specifically when they need PA and for what tasks, always keeping in mind labor legislation. It is important here, if at all possible, to consider the assistant’s needs in setting a schedule (so they can, e.g., visit their doctor, run errands when necessary, etc.).



Re: Odsotnosti z dela
Katrin
To: @gmail.com;

Samo,

potrjujem prejem obvestila o vaši odsotnosti z dela.

Lep dan,
Katrin

From: _________@gmail.com
Sent: Thursday, May 06, 2021 12:38 PM
To: Katrin
Subject: Odsotnosti z dela

Katrin,

ponovno vas obveščam, da imam v petek, 14. maja opravek ob 9h zjutraj in bi lahko na delo prišel ob 12h.

Hkrati vas še uradno obveščam, da imam v četrtek, 27. 5. 2021 ob 10h supervizijo preko Zooma.

Lepo bodite,
Samo

An example of communication between a user and their assistant (Image: Katrin Modic’s personal archive)

The screenshot shows an email with the following content:

> Re: Absence from work
> Katrin
> To: …@gmail.com;
>
> Samo,
> I’m writing to confirm that I’ve received your email about being absent from work.
>
> Kind regards,
> Katrin
>
> To: …@gmail.com;
> Sent: Thursday, May 06, 2021, 12:38 PM
> To: Katrin
> Subject: Absence from work
>
> Katrin,
> I’m just reminding you that on Friday, 14 May, I have an errand at 9 a.m. and I can come to work at 12 noon.
> At the same time, I’m reminding you that on Thursday, 27 May 2021, I have a Zoom meeting at 10 a.m.
>
> Be well,
> Samo

“My assistant tells me that they have something to take care of at an office that is only open during our scheduled time, so they will come two hours late one day next week. The assistant’s initiative in setting of the schedule surprises me. Since I want to have a professional relationship, I write back: ‘It is unacceptable to me that you decide to come to work late due to a personal errand. I’ll let it slide this time, but I will decide which day it is when I see which of my obligations I can reschedule. The next time you need me to adjust our schedule to your needs, first ask me if it’s even possible.’”

The user must consider labor legislation when setting schedules. This manual was written with Slovenian legislation in mind, so be sure to check how legislation varies in your home country. Employment contracts for assistants stipulate that they must work 40 hours per week. The user must allow the assistant daily and weekly rest.

One vacation day per year may be used at the assistant's discretion without the user's approval, while all other vacation days must be set in agreement with the user. It is also the user's obligation to allow the assistant annual leave of 10 consecutive working days.

If there arises a period in which the user does not require PA, the user may not determine that the assistant should use their vacation days for that time. The following options are available: the assistant can reschedule those hours at a later time, suggest that the assistant indeed take vacation (which the assistant can deny), or the provider of PA can put the assistant on furlough during the user's absence.

The user can also share the assistant's time with another user (e.g. the assistant works 10 hours for one and 30 for the other). In this case, the users first come to an agreement about for whom and when the assistant will work, and then they submit this plan to the assistant.

If the user employs more than one assistant, they must consider the fair and equal treatment of all in scheduling. This includes rotating shifts. The user should inform assistants during job interviews that they will be working in shifts. It is not acceptable, for example, to have one assistant in the morning and then look for one to cover afternoons and weekends. There can be an exception here if the assistants actually prefer such an arrangement (if, e.g., it is easier for one to find a sitter for a small child in the afternoon, etc.). But assistants should accept that the nature of the job entails that work is not likely to be so evenly divided. It is good for the user to set a time (e.g. after a year) to determine whether the schedule still works for all parties, or if it is time to make a change. Nonetheless, it must be clear the whole time that it is the user who sets and changes the schedule. Regardless of the agreed upon general framework of the schedule, the user always has the right to announce a slightly changed schedule for the following week, as nobody's life is perfectly and perpetually predictable.

In the many years of PA's existence, sending a schedule out at least a week ahead of time has proven to be the best practice (both user and assistant have a difficult time planning their obligations more than one week ahead of time). The user sets the schedule and gives it to the assistant. If assistants need a day off or need to adjust the schedule, they must inform the user by the deadline set in order for that request to be considered. Users striving to maintain a good relationship with their assistant will try to accommodate a request made by the deadline, but it is not always possible to do so.

The user determines how the assistant takes their statutory meal break, namely whether the assistant can leave the user's home and how long the break can last.

Here they must consider labor legislation, which stipulates a 30-minute break for an 8-hour working period. The user sets the length of the assistant’s break with respect to the length of time they are working that day.

The user sets up front the methods in which to communicate information regarding schedules, vacations, and the assistant’s wishes in terms of the schedule. It is recommended that communication should be sent in writing through email or text message. This prevents either party from forgetting agreements and helps resolve conflict through records of responsibility.

“My assistant didn’t come when we had agreed, so I called him on the phone. He assured me that the note where I had written the schedule said an hour later than what I believed. When I told him to bring the note so we could check what was really written, he said he had lost it. Since then I always send the schedule by email.”

Training personal assistants and monitoring their work

The user conducts the assistant’s practical training. This ensures a highly individualized approach, which is essential for providing personalized and excellent services for each user. If the user wants a good assistant, they must teach that assistant to provide the aid and services that they need.

It is not self-evident that users will know how to instruct their assistants. Some assistants think that users do not really do much of anything and fail to recognize that many users put a lot of energy just into giving instructions. It is crucial that instructions are such that the assistant understands them and carries them out. Giving instructions well requires training, most often acquired through a formal program and practical application. Above all, users learn from their mistakes. It is important here that the user has support to help them evaluate the process of training their assistant. Peer consultation is an effective method of obtaining such support.

The following recommendations should be considered in training an assistant:

1. The user tells the assistant what, when, and how to do things, sets rules and boundaries, and verifies whether instructions are clear.

The user gives feedback as to what the assistant is doing right and wrong, explaining how to correct what is wrong. It is inappropriate for the user to think that the assistant should just know what to do by themselves (e.g. how to lead someone who cannot see). The assistant will only do their job if they know what the user expects of them, what they can and cannot do, and what they have already done well and what poorly.

Assistants want and need more than just general “complaints”, “bad moods”, “ecstatic gratitude”, or “silent treatment” from the user; they want to do their job well, and for that they first need the user’s instructions and then their feedback on whether the job was done well or not.

“When I started using personal assistance, I didn’t have the courage to tell my assistant that she wasn’t helping right when bagging things we bought at the store. The items were thrown in the bag haphazardly such that the packaging was already damaged and torn when we got home. Whenever I put things away at home, there was something leaking in the bag. I was angry, but I didn’t say anything. One time it was clear that I was in a bad mood, so she asked me what had angered me. But I still didn’t tell her. I just said it was nothing important. I could hardly wait for the year to pass, as I knew I wasn’t going to extend her employment. At the time, assistants had contracts for one year. As the reason why I didn’t extend, I listed carelessness as the reason. I got a new assistant, who was careful and who put things in the bag such that nothing was damaged at home. But I was bothered by her lack of initiative, as she didn’t lift a finger unless I said something. Waiting a year would be too long. When I thought about what to do, I realized the responsibility was mine.”

“I didn’t give my assistants instructions about what and how to do it, but I just expected them to know. When I learned at a training course that it was my responsibility, I stopped getting mad at them and started giving them clear instructions about how and with what I want them to help.”

2. It is the user’s responsibility to give clear and realistic instructions.

The assistant must work according to the user's instructions, provided that they are clearly given and are possible to follow. It is a common occurrence that an instruction can seem at first glance clear and easy, yet nonetheless requires a lot of words and energy to put into speech. This is especially true at the beginning, when the user and assistant do not know each other that well. Unclear instructions and accusations are unhelpful for assistants:

- "You know what needs to be done."
- "I've already told you and you're still not doing it."
- "You should already know what's wrong."
- "Doesn't it seem like your job to watch for what station we're supposed to get off at?"

Personal assistants notice about users:

- an incomplete, imprecise description of their job tasks
- a lack of objective feedback (constructive criticism)

3. The user does not ask nicely if the assistant can do a certain task. Rather, in a respectful manner, they tell the assistant what to do.

Asking too nicely sounds like: "Is it possible for you to maybe take out the trash please?" It is much more effective to say: "Please take the trash out."

4. The user is consistent with the assistant.

Users who allow their assistants too much leeway are only harming themselves.

"One of our users called me into the office and began complaining about all the things their assistant wasn't doing that the user wanted them to do. As the coordinator of personal assistance, I first asked if the user had given the assistant clear instructions for everything. He answered me, 'My heart is too soft to give orders.'"

Assistants must respect users' decisions and not try to force their own solutions and viewpoints on the user.

5. Assistants may refuse to do work that makes them feel unsafe or unsecure, or if a device that they are supposed to be operating is not

sufficiently safe. They can also refuse work that does not align with their moral convictions.

“The user asked me to clean the overhead light above the door. I was to use their ladder. But when I saw the ladder wasn’t stable, I refused. I assessed that the ladder could break and that using it simply wasn’t safe.”

6. The user should explain a given procedure a few times and then expect that the assistant will master it. However, it is useless to explain the same thing over and over. If the assistant fails to understand something, they should say so. Then the user can verify whether the procedure was understood.

Over time, communication between users and assistants becomes routine. For instance, sooner or later assistants learn where the spoons and forks are and do not need to be told from which drawer to take them. Or if the user prefers the table first cleaned with a sponge and then with a dry rag, it will soon be necessary just to say “clean the table”, without explaining the procedure.

7. The user even requires the assistant to perform tasks that they might not be comfortable with. The sooner the assistant learns to follow instructions and requests for tasks they see as less pleasant, the better the relationship between user and assistant in the future.

“During working hours on a holiday my assistant was unhappy when I instructed her to do a task that in her opinion shouldn’t be performed on Labor Day. I insisted, despite her beliefs that vacuuming and washing shouldn’t be done on a holiday, that she do it anyway. She really had to force herself to do those chores. For every boundary I set, that assistant sowed silent grudges and on that basis found sophisticated ways of exacting her revenge. I stopped working with her quickly after that.”

8. The user should not insult the assistant and vice versa.

“One time, my assistant didn’t understand how to follow my instructions, so I said, ‘What an idiot you are!’ I was surprised when he responded in a serious voice: ‘It makes me feel bad when you call me an idiot, so if I don’t do something the way you want me to, then explain to me once more how I should do it. Never call me an idiot, moron, or dummy again, as you’ve already done!’”

9. The user can allow the assistant to take an active approach by asking if there is anything else they can do or anything the user still needs.

Users cannot expect that assistants will see by themselves what all needs to be done and then do those things (e.g. the vase with flowers needs its water changed, a certain ingredient still needs to be bought for lunch, etc.). If the assistant does notice something that the user has not, they can tell the user. E.g. "I see that the trash can is full. Should I take the trash out?" However, they should never just do that by themselves.

Assistants should be told to inform the user if they notice anything that the user is unable to observe due to their disability (e.g. if while administering personal care the assistant notices any changes to the user's skin).

"My assistant and I were climbing a hill nearby and a woman coming the other way said hi to us. I wasn't sure whom she was talking to, so I didn't return the greeting, and my assistant scolded me immediately, saying that I could at least say hi back if someone does so to us. Soon after that another woman near us said loudly, 'Well hello, look where we run into each other.' So as not to come across as impolite, I said hello back just as loudly. Again my assistant was cross, saying, 'Who said anything to you?' When I thought at home about what had happened, I realized that my assistant should have told me when or whom we had run into, but she shouldn't tell me how to act or whom to greet. Since I can't see, I can't always tell if someone's approaching. I told my assistant in the future to tell me if someone was approaching us, and that I would decide myself afterwards if I say hi or respond to them."

10. The user and assistant uphold agreements.

"In the morning, when my assistant came to work, she asked if she could leave 15 minutes earlier, at 1:45 p.m. I answered that, despite having obligations I couldn't put off, I would try to make it happen. By the time she and I came back home, it was 2:15. Before leaving, she commented accusatorily, 'People can't rely on you at all, because you don't hold up your end of the deal. This morning you said you'd try to make sure we were done by 1:45. But you did the opposite; you actually extended my working hours!'"

The user cannot decide unilaterally to extend the assistant's working hours. If the user wants to change the assistant's working hours, they must do so in agreement with the assistant. The same applies in reverse, as the assistant must ask the user if they can change their schedule. It is not acceptable for the user to shirk responsibility with phrases like "I promise" or "I'll try", or not to extend an assistant's working hours when the assistant asks to finish early. This sort of behavior causes the assistant to lose trust, and thus the relationship between user and assistant deteriorates.

11. Minor dissatisfactions should be dealt with immediately, so frustrations do not pile up. When things reach a breaking point, the user soon finds that it is impossible to continue working with their assistant, as it is very difficult to patch things up after the fact. The providers of PA are powerless to help if the user does not inform them about unresolvable situations with their assistant as they arise.

"A user sent me a video that he shot with his phone of one of his assistants not responding when the user was giving him instructions. He demanded that we fire him. When I called the user, I first explained that he shouldn't have filmed his assistant and sent the video. Then I asked what was going on. He said he had noticed for a while now that his assistant didn't respond to his instructions. He also noticed that the assistant had been taking pills that made him unresponsive at work. When I asked if he had talked about it with his assistant, he just told me, 'I know he had a lot of problems at home, and I didn't want to make things worse. I know he doesn't feel good in his own skin.'"

12. The user must know the right procedures for the things that they do and give assistants instructions about how to help them with such things.

A user is giving her assistant instructions on how to use a hoist (Photograph: Klaudija Poropat)

> On the left side of the photograph is a woman, visible from her neck to her waist. She is operating a hoist with her right hand, with her left hand reaching towards a woman who is surrounded by the straps of the hoist and is sitting in a wheelchair. The woman in the wheelchair is looking upwards, towards the first woman.

If the user, for example, requires help with cooking, they must know how to cook themselves, or be able to give precise instructions about how and what to cook. It is unacceptable simply to ask the assistant to cook a stew and potatoes. The user must be present during the cooking and give exact instructions for every step: where the potatoes are located and how many of them to boil, which pot to cook in, how much salt, how much meat, vegetables, onions, etc. Users should not seek a good cook in their assistant, but should learn how things are cooked if they want to eat something. If the stew is spoiled, that is the user's responsibility and not the assistant's, who does not know how to cook or who cooks in a way that is not to the user's liking. The user is not allowed to just leave their assistant to fend for themselves. Therefore, the user's physical and mental presence are required for every activity.

"Since I've been disabled since birth, I had to learn a lot in order to manage my personal assistance. When I decorated my apartment, I wanted to have as many plants as possible to decorate my house. It all started out well. 'Please water my plants,' I said to my assistant every day, happily repeating the same sentence. Soon the plants by the window, the ones turned towards the sun, were doing well, but the others had started to wilt. The more she watered them, the more they started drooping. The disappointment was immense. I went to the garden shop where I'd bought the plants and I asked them why the plants were dying even though I was watering them. 'You can't water plants too much, water them as little as possible,' they explained. I heeded their advice to the point where my assistant started asking me, 'Should I water the plants?' I taught her what they had told me: 'As little as possible.' But it was no different, as the plants just kept on dying. Even the ones on the windowsill withered. I was confused and I asked my assistant, 'Did you really follow my instructions?' She replied, 'Of course, but I have no experience, so you need to tell me how much water each plant needs, too.' Since she didn't have any experience with plants, she needed exact instructions about how much water: 'Too much, too little, which one is it?' I was about to give up. But I started reading, asking, observing. I learned that different plants need different techniques, each one with its own requirements. It took me quite a while to learn how to care for them so they grew to be lush and beautiful. I also learned how to give my assistant instructions: 'Please touch the soil to see if it's dry. Did any dirt get stuck on your fingers?'"

13. Users who need PA at night must set a bed for their assistant and tell them how they will be contacted if needed (e.g. the user can get a horn to blow, if they cannot speak but can squeeze their fist). The user cannot require the assistant to be awake through whole the night and, e.g., cover the user if the blanket falls off. This behavior would be typical of a child or someone in institutional care.

“Before I fall asleep, I need to be hooked up to a respirator, and sometimes I need aspiration during the night, and most of all I need to be turned in bed, usually from my left to my right. My assistant sleeps in the same room with me, and I call her when I need her. If I cannot speak a word at the time, I make a clicking noise with my mouth, and my assistant knows this is the sign that I need her.”

14. The user assesses the assistant’s work skills.

“I had an assistant for whom this was her first job. She had held volunteer positions at various organizations and thought that working as a personal assistant was similar to volunteering, just a little bit better paid. The first day she came to work, she was already tired. She came straight from the train station, as she had just come back from traveling. It’s a good thing that my regular assistant was there to help us with more complicated tasks that require a little practice. I told her that this is a job that requires full focus. If she’s tired and hasn’t slept, that’s not my problem, so she shouldn’t do that. I needed someone who would come on time. My assistant received my keys on the first day. It’s important to come on time, especially in the morning, when my husband goes to work. And a couple of days later she came without the keys. Good thing I didn’t quite trust her yet and that my husband was still at home. Otherwise I’d be in big trouble. While I was lying in my room, my daughter asked me if I knew that my assistant was on my computer. I called her and asked her if she really was using my computer. She didn’t think it was a big deal, she was just looking something up. But I was really angry, and I asked her how she would feel if I had been scrolling through her phone. It was only then she realized that maybe it wasn’t OK what she was doing. It would have been totally different if she had asked me beforehand. One day she told me that one of her friends would be coming for the keys. I was a little surprised that her friend knew where I lived. Since we live in an apartment building, I thought he would ring the buzzer downstairs. About an hour later, two people showed up outside of my garden, which is on the back side of the apartment building, and began calling her. I didn’t like that they knew which flat was mine. My assistant knows about my personal life, and also my financial life. Usually I quickly tell my assistants my bank card PIN, but I couldn’t trust her at all, as I just felt it wouldn’t be a good idea. An assistant can’t work for you if you don’t trust them. Even when I gave her instructions, she had a hard time following them. She was always tired, and her private life affected how she worked for me. She worked for me for two months, then we decided that it wasn't the job for her."

The more precise the user is in giving their requirements and needs at the beginning, the less the chance there is of misunderstanding and conflict.

All that an assistant needs to learn is a matter of routine and familiarization, where practice and information are key. Thus the user's presence is required, as they must observe the assistant's work attentively and know how to assess it. If it is already clear during the trial period that things are not going well and that the candidate is not doing their work well, it is usually a sign that the user's choice of assistant was the wrong one, and it is useless to waste further energy and time.

Practice has shown that it is good to condition an assistant's employment contract on a trial period (of a maximum 6 months). During the trial period, the user and provider must monitor the assistant's work and training. The user should make a monthly report during the trial period, evaluating how the assistant is performing their tasks, along with their punctuality, reliability, and attitude. Similarly, the assistant evaluates how the user is managing their PA: how the training is going, whether they are receiving schedules on time, and whether instructions are intelligible and feasible. Thus, both the user and the assistant have a view of each other's reports.

Since PA is paid for by the state, the user must take it for granted that the provider of PA, the coordinator, and even the ministry might at times check how it is being administered. In this case, users must share parts of their personal lives.

Setting boundaries

The user sets boundaries for the assistant at the job interview or as soon as possible thereafter.

1. The assistant must come to work on time. Whenever force majeure prevents this from happening, the assistant must inform the user as soon as possible.

"My assistant was regularly late. Since it made me feel uncomfortable, I let her know after several times: 'Please start coming at the time we agree upon, as it's important to me that I'm not late to my appointments.' The assistant started defending herself: 'I do come on time. Sometimes the bus is late, though, or there are traffic jams, and it just takes too long.' I persisted: 'Please figure such things out in advance or organize your day so you can come on time. It's extremely important that you stick to the times we set, as that's the only way I can meet my obligations.' The assistant agreed: 'Ok. I will try harder in the future.' I responded: 'I need a guarantee that you will be on time, not that you will just try.' From then on, my assistant always came at the time we agreed upon."

2. Assistants must respect users' decisions and not try to force their own solutions and viewpoints on the user.

"When my assistant arrived, we made the deal that we could have lunch at my place when she cooked for me, as there was enough for both and because the store was a long way away. We made food according to my instructions. After a while she said, 'You know, I was thinking today that you could eat tripe, I love tripe.' I like tripe, too, so I agreed, but then that started to become a common occurrence, until one day she just made lunch the way she wanted to. I didn't like that, so I reacted immediately, saying, 'Look, I really don't like what you did today, and I don't want it to happen in the future. I would like you to make food according to my instructions and always ask me what I would like to eat on a given day.' And that's how I resolved that problem with no conflicts."

3. When the user meets up with other people, the assistant should not speak with them, even if they speak to them. The assistant should redirect the conversation towards the user. The user should speak with the assistant about possible situations, telling them ahead of time how to react if people address the assistant instead of the user. If the user has difficulties speaking or their speech is not intelligible, it is best for the assistant to help them with communication. The assistant does this by repeating the user's words, so other people understand what they wanted to say. The assistant may not, however, change the words that the user speaks.

"My assistant and I went to the doctor, and I made it clear that their job at the hospital was to help me. So, they should help me open doors, take out my medical card from my wallet, hold my file if necessary and giving it to the nurse, and that's it. I go into the office by myself, and do all the talking and discussions by myself. Then I come out, my assistant takes my medical card, and we're off."

"My assistant and I went for a walk. My neighbor who walked by, said something to my assistant: 'How is she feeling today?' My assistant replied, 'I have no idea.

Ask her yourself, and I'm sure she'll be able to answer your question.'"

4. The assistant must adopt the principle of trust, mutual respect, and privacy with the user, and protect confidential information about the provider.

"I had an assistant who took a lot of personal calls on the clock. It turned out that it was her boyfriend. He was constantly monitoring her, where she was and what she was doing. She always explained everything to him in detail, which really made me mad, since in doing so she was also exposing my private life. I reacted strongly to such repeated behavior. I prohibited her from using her phone during work, which still wasn't enough, as her boyfriend soon started monitoring the premises. One time, he cut us off on our way back from the store, demanding to know why she wasn't answering her phone."

5. The assistant must work according to the user's instructions and in their presence. They should not try to help until instructed by the user. They can ask the user if they need anything or suggest how a certain task might be completed, and the user can accept or reject this recommendation. Some users find it acceptable for the assistant to ask them how to perform a task or suggest a methodology. Others only find it acceptable when the assistant does exactly what the user has instructed, then waits for instructions for the next task.

"While I was lying in bed and had visitors over, my assistant was sitting in the kitchen, drinking coffee and waiting for my guests to leave. When a friend came over the next day and started washing a dried out plate, I was really mad that my assistant hadn't washed it the day before. But soon I redirected that anger at myself, as after all I never told her to wash that dish."

For minor tasks, it is unnecessary for the user to follow the assistant like a shadow (for instance in taking out the trash, getting the mail, making a cup of coffee, etc.). Of course, this does not obviate the user of responsibility. It is unacceptable for the user to send the assistant to the store by themselves, or leave them to cook everything as if they were a personal chef while the user does something more enjoyable (e.g. watches television, plays on their phone or computer, or drinks coffee with a guest, etc.).

6. The user determines what they will do and what their daily rhythm will be like. The assistant may not determine how the user's day will go.

Personal assistance in getting dressed (Photography: Klaudija Poropat)

On the left third of the photograph is a woman, visible from her knees upward. She is looking at her palms, in which she is holding the sleeves of a coat up for the stretched out arm of a man who is sitting in an electric wheelchair on the right side of the photograph. He is leaning towards the right and he has a smile on his face.

7. It is important before events like meetings, educational lectures, doctor visits, or social gatherings, etc., that the user and assistant agree as to whether the assistant will be present or merely nearby in waiting. It is not necessary for the user and assistant to spend all of the assistant's working hours together.

For instance:

- "You will drop me off at the spot where we agreed. When the guy I am supposed to be having a meeting with arrives, then you can go."
- "My meeting will last about an hour, be somewhere nearby."
- "Have your phone nearby, and I'll call you when I need you."

8. If a user requires 24/7 PA because of the nature of their disability , it is imperative that the assistant spends all their working hours with the user and does not leave their home or premises. While waiting, the assistant can attend their own matters (e.g. read a book, use their phone), but must respond immediately when the user calls them. If the assistant gets too absorbed in their private business and fails to respond when the user needs them, the user can forbid them from doing such things.

“One of my assistants didn’t understand that it’s necessary to wait sometimes and be ready for me to call when I need him. Usually he spent the time when I was at meetings in bars and coffee shops. One time my meeting finished sooner than I expected, so I called my assistant to come get me. He told me he was at a bar that was a good half hour’s walk away. And he had just ordered a coffee, so he would need at least 45 minutes to get there. That experience taught me to tell assistants that while they’re on standby they need to be available on their phones, and they need to come within 10 minutes of me calling them.”

9. In unforeseen circumstances, the user sets boundaries as they go along.

“When I began using personal assistance, I told my assistant at the beginning of his shift what we would be doing that day. It happened several times that plans changed, usually because of external factors, and that always threw my assistant off completely. When the meeting to which my assistant was supposed to accompany me was cancelled, he freaked out, since then he wouldn’t be able to meet up with his friend. They’d had a plan to get a cup of coffee during my meeting. That experience taught me to give my assistants instructions as we go along, and I announce the things I plan to do with my assistant’s help that day right before we have to do them.”

“I’ve even had it happen that my assistant’s partner has shown up unannounced at my home and began in her name trying to make agreements and negotiations about her job, working conditions and schedules. I firmly made it clear that we wouldn’t be discussing that. I also told him that I understood his arrival at my home as an act of aggression and an insult to his partner, whom he had reduced to mere physical property.”

In such cases, it is necessary to firmly forbid assistants’ partners from interfering with the work process in any way. Assistants must also be informed in no uncertain terms that such incidents will never be tolerated again.

“I was getting ready to go to the doctor, when my assistant told me that he had to go to the bathroom first. A bit of time passed and, since my assistant knew what time I had an appointment and that I was already in a hurry, I awkwardly asked how long he would still be in there. There was no answer. A few minutes later he came storming angrily out of the bathroom, and blurted out that he didn't need to tell me how long he would be in the bathroom. I answered calmly, 'I wasn't trying to rush you, but I told you even before what time I needed to go to the doctor, because I had an appointment.'"

"I was at the store with an assistant who had just started working for me, and we'd almost gotten everything we needed. Milk was all that was left. The assistant offered to go grab it herself to make things faster. I agreed and she hurried off to find the milk. Quite a bit of time passed, so I called her, but she didn't answer. I was angry when she finally returned. I asked her, 'Where were you this whole time?' She nonchalantly replied that I shouldn't get upset, that she simply shopped for a few things for herself along the way. I told her that during her workday she wasn't allowed to run any personal errands. She was a bit surprised, as she hadn't realized she wasn't allowed to do that."

10. Potential conflicts are first to be resolved by the user and assistant. If this fails, only then do they turn to the PA provider.

"My assistant avoided work during weekends and holidays, was not interested in working more than 8 hours a day, took long smoke breaks, and wasn't as focused on his job as he was at the beginning. When I spoke with him after every such incident, he told me, at first coyly and then later rather directly, that working for minimum wage just wasn't worth it, and that he would resort to any legal means to fight for his rights and for a better salary. When I set boundaries for him, he – even during his shift – would call his lawyer and ask what he should do. I informed the PA provider every time something like that happened. Based on what I said, the provider gave the assistant a formal warning about being late, which did help. But he kept taking more and more sick days, right when he was scheduled to work at the times he didn't prefer."

11. The user must determine what the assistant is allowed and not allowed to do during working hours (e.g. watch TV, use a computer, charge their phone, put food in the fridge, make a cup of coffee, etc.).

"It became more and more annoying that my assistant's phone was always ringing, and then she'd go on and on about all sorts of things on the phone. One day I wanted us to go to the store, but her phone rang again and her conversation lasted more than half an hour, and by that time the store was closed. When I asked her how she explained that behavior, she told me that we would just go to the store the next day. I was furious, so I told her, ‘With all due respect, I have to tell you that your constant telephone conversations really bother me, I’m really not interested in you and your friends’ business. She tried to defend herself, asking, ‘But I can still answer my phone if it rings, right?’ I persisted, saying, ‘Yes, but this has gotten out of hand and become very bothersome; you’re at work after all! Let’s make a deal just like we did for smoke breaks: every hour you can take a break for a cigarette, and during that time you can use your phone all you want, but you can’t chat during work. I hope we have an agreement; otherwise, I’ll have to ask for mediation from the PA coordinator. But I hope that won’t be necessary.’ The assistant accepted my boundary: ‘OK, I’ll follow your instructions and you don’t need to inform anyone of anything.’”

Users must set boundaries as regards the use of telephones during working hours. While the user requires assistance, the assistant may not use their phone. Of course they are allowed to use their phone during breaks or when on standby and the user does not require assistance. The user may not require the assistant to keep their phone turned off for their whole shift. For instance, if the user is resting, the assistant is allowed to go online, provided this does not cause any noise.

12. If the assistant ever acts dishonestly, the user must confront them about it.

“I had two envelopes in the basket of my walker. In one of them, I had money for the month’s expenses, and in the other I had money saved for a rainy day. Before I went into the store, I asked my first assistant to check the balance in the envelopes. It turned out that the rainy day envelope was missing €100. I had the balances written down in a file saved on my computer. I was quite surprised, as this was the first time there had been less money than I’d had recorded. My second assistant and I talked about it, and she was surprised too, denying having taken anything without me knowing it. We went through the numbers one more time together, and sure enough €100 was missing. The next day, the first assistant volunteered to check the balance in the envelopes again. And when she opened them up in front of me, suddenly, miraculously, the missing €100 was back in there. I had to face the reality that she had put the money back in the envelope herself, as it hadn’t been in there in the morning before she arrived at work. I warned her in no uncertain terms that such a thing must never happen again, or we wouldn’t be working together anymore.”

“I had an assistant with whom I was really very satisfied, as she learned quickly and was great at providing personal care. But after a few months I started noticing that things were going missing around the apartment. Small things at first, like hair dye, which I always bought two at a time, then I couldn't find my mascara, hair lotion, etc. Then one day I had some money set aside in my office for a birthday present. I kept it in my wallet in my backpack. It was gone the next day. I couldn't shake my suspicion, so I decided to talk with my assistant. When confronted directly, she admitted to stealing. Despite her doing that, she nonetheless had always provided great assistance, so we resolved things by me giving her one more chance, which she then respected forever until she stopped working with me. She never stole anything again."

13. The user must explain to the assistant that PA does not mean entertaining the user. Even if they get along well, they are in no ways friends. This boundary must be firm and clear. If it is not respected by either party, then a string of accusations can begin (e.g. who did what for whom, who overlooked or forgave whom for what, etc.) This can build to the point of unnecessary yet unresolvable conflict, which usually ends with the assistant leaving, or in worse cases with a formal complaint to a supervisory body (Social Work Center or Ministry, etc.).

"A user called me and told me that his assistant hadn't come to work all week, and wasn't answering their phone. I called the assistant and asked where he was. He explained, 'I had some things to take care of and I'm on vacation. My user knows that I took off.' Further conversation with both of them showed that they had adopted a 'relaxed attitude' towards personal assistance. The assistant had often done things for the user, like coming over to help when he wasn't on the schedule, painting the user's apartment when he was absent, driving the user around with his personal car, etc. On the other hand, the user told me that the assistant sometimes worked less than scheduled, as he often let him go home early, and the assistant even ran personal errands during working hours ... Since both figured that they had done the other favors, both were convinced that they were right. It turned out that they hadn't precisely agreed on how long the assistant would be off duty. The user thought that the assistant had unilaterally extended their vacation, and was sure that, since he had done the assistant so many favors, such a long vacation was out of the question, and furthermore that all this should be obvious. Even though they had worked together great before then, this situation caused such a mass of grudges and accusations that they ended up parting ways."

14. The assistant may not seek other people's attention. Assistants who require attention often seek out interactions with other people such as greetings, responses, or eye contact. These behaviors attract attention, which, if done during their shift, prevents the user from living an independent life, as people interact with the assistant instead of the user.

“My assistant and I were going for a therapeutic walk down the street. In a driveway at the end of the street, a man was unlocking his car. I greeted him with a warm hello. Despite not even knowing him, my assistant said, ‘And where are you going today?’ I was completely surprised, as this neighbor and I were used to just exchanging pleasantries. He looked at the assistant in surprise, too, answering, ‘Don’t worry, I told my wife already.’ Later I told my assistant that it had made me very uncomfortable, and in the future she should keep her communication at a more formal level.”

15. The user has the right to privacy. In some circumstances, the user will not want the assistant to be present (signing official documents, reading personal correspondence, communicating with other people, etc.).

For instance, at the doctor’s office the user might tell the assistant to accompany them inside, perhaps help with something once there, but then to wait outside before the user begins speaking with staff. When the discussion is over, the user then asks the assistant to come back or has one of the staff members fetch them.

The user will be able to set clear boundaries when they can clearly articulate their values and their needs. It is crucial to be firm, not to just ask or complain all the time.

Weak, unclear, or oft trampled boundaries are reflected for example in unnecessary physical contact, socializing outside of working hours, extended shifts, excessive familiarity (e.g. borrowing money or clothes in either direction, conversations about banal and trivial things, etc.).

How the user reacts to boundaries that have not been respected depends largely on the particular boundaries, and how breaking them affects their relationship with the assistant. The user can try to set boundaries anew. Sometimes this proves impossible, to the point where it is necessary for the user and assistant to part ways (e.g. in cases of sexual harassment, threats, abuse of trust, consumption of illicit substances, violations of personal information, etc.).

When resetting boundaries, it is important that the user acts as soon as possible. The user apologizes and expresses concern for the crossed boundaries. The user further expresses concern that the current state of affairs is affecting their working relationship. It is expected that whoever crossed the boundaries apologizes and admits to their mistake. If it is possible to come to an agreement about changes and objectives, then they set a date upon which to verify whether they are keeping true to their agreement. The user clearly indicates that they will not tolerate that things return to the way they were. If the boundaries continue to be crossed even after this meeting, the user and assistant will be forced to part ways.

Success in resetting boundaries does not depend merely on the user, but on the assistant as well. Both are responsible for their behavior and for their mistakes.

How to fire a personal assistant

If during the trial period users determine that they have not been successful in teaching their assistant all the necessary tasks, or that they do not get along with their assistant in terms of character and personality, or that the assistant does not respect boundaries, fails to work according to instructions, is late to work, or if for any other reason the user loses trust in the assistant, they can choose to part ways. First, the user speaks with the assistant, explaining which parts of the assistant's work or behavior are unsatisfactory. Then the user informs the assistant that they will let them go because of those reasons. The user explains their decision in a report to the provider of PA, who can then formally fire the assistant.

It is harder to fire the assistant after the trial period, so it is all the more important during the trial period to monitor the assistant's behavior and identify anything unacceptable. Some examples:

- Pressuring the user to rearrange schedules so the assistant's working hours are remunerated at a higher rate
- Not wanting to work when the user requires it
- Having a warped perception of what PA is and what its provision makes possible for users
- Needing attention from others, as reflected in their speaking with other people in the user's presence about things pertaining to the user
- Not wanting to perform the tasks outlined in the job interview
- Going through the user's things

- Giving erroneous or untrue information about the surroundings when reporting to the user
- Not taking responsibility for any damages caused through negligence
- Being unkempt or stinking (body odor, cigarettes, alcohol, etc.)
- Coming to work under the influence of illicit substances

If the user notices any of the things listed above, they must both discuss it with the assistant and at the same time inform the provider. If the assistant is not willing to change their ways, then they can be fired for failure to complete their trial period satisfactorily. Even after the trial period expires, the user must speak with the assistant immediately after noticing one of these things, setting boundaries immediately. Incidents are to be recorded and then reported to the provider of PA. If the assistant does not provide the services that the user requires, or repeatedly engages in behavior that the user finds unacceptable, then the user can begin the process of firing the assistant. Since labor legislation regulates formal firing and related process, the user must realize that it is impossible to fire their assistant in the instant that things become insufferable.

“When my assistant was late to work the first time, she gave the excuse that the bus was late. She apologized and that was that. It happened again, with the same excuse and apology. I started to become suspicious, but I was nonetheless a bit hesitant about how to react. I was afraid that I would come across as the bad guy if I set a boundary. But since it happened again, or even a third time, I told her not to be late anymore. She was superficial in her work and had a hard time following instructions. Nonetheless, we had a good relationship. She also told me that she regularly used marijuana. Even though she didn’t use drugs during working hours, it still slowed her down at work. As a user, what an assistant does in their spare time doesn’t even interest me. But it was clear why she had so much trouble following directions. She was also quickly insulted over nothing. And my requests that she come to work on time had no effect. Since at the end of the day a good relationship between me and my assistant wasn’t enough for the fundamental point of personal assistance, I had to let her go.”

Behavior types and communication styles

There are 4 types of behavior and communication: passive, manipulative, aggressive, and assertive. What follows are examples of each type of behavior, portrayed from the same starting situation: After lunch, the user wants an assistant, who is substituting for another assistant for the day, to vacuum, clean the windows, and take the garbage out. When the assistant returns after a break, the user tells her what to do.

Passive behavior

"I told the assistant, 'Please see to it that floor and windows are clean, and the trash is taken out, so the assistant who comes after you doesn't complain.' She replied, 'I can't work on a full stomach. I need a little time, then I'll see if anything needs to be done.' I asked her, 'How much time will you need?' She said just a few minutes, so I acquiesced. But 10 minutes went by, and the assistant was still sitting there. I then began thinking about what would happen if this substitute assistant didn't vacuum or clean the windows, like my other assistant does every Tuesday. I'll need to apologize to her, as she'll be angry that, yet again, chores scheduled for every Tuesday morning are waiting for her when she gets back. I thought about the bad luck I had to always get that kind of assistant that doesn't see what needs to be done and whom I have to expend a lot of energy in convincing. It seemed unfair to me that my better assistant often got sick right when I was having unusually difficult periods. I am so good to my assistants and this is what I get back. To encourage my assistant to notice that it was necessary to vacuum, I asked her, 'Wouldn't you want to check now if the floor is dirty?' She shot back, 'The floor isn't dirty, there's just a little bit of trash on the counter. At home, I just throw out the bigger pieces of trash real quick, and I vacuum when the floor is dirty. I'll do the same at your place.' I gave up: 'Well, OK, I guess.' I hoped that the assistant would end up noticing anyway that it was time to vacuum and to clean the windows, which had gathered dried up rain drops already. Instead, she suggested, 'I'll make us some coffee.' Even though I don't drink coffee, I agreed: 'All right, I'll keep you company.' And so she made coffee. By the time she had drunk it, her substitute shift was already over, so she went home. When my regular assistant came back, I felt guilty, because the other assistant had taken advantage of my good nature and had not done her job. Now my regular assistant would have to do it."

Passive behavior is often used by people who have insufficient self-respect, who are in denial about their true needs, and who only rarely actually express their desires and viewpoints. Predominantly passive people will never show what they are truly feeling or experiencing in a given situation. Most often, they seek recognition from others and avoid conflict and responsibility.

Passive people often come across as kind and friendly. You can only fight with them for a brief time, as they will make sacrifices and go along with whatever causes the least fuss. They are “satisfied with everything”. Such behavior is only pleasant for a limited amount of time, as such people are also often silent, as they do not dare to express their own thoughts and desires. They are often actually aggressive under the surface. They lack vital energy, because they use all of it to persist in being humble. They are uncreative and let themselves be led by others. Since they rarely express their own feelings, they tend to have superficial relationships with others.

Passive behavior in others often leads to anger and bad moods, accompanied by feelings of guilt, as it is difficult to explain:

“Why does this person get on my nerves if they’re so nice and harmless?”

Manipulative behavior

“I told my assistant, ‘Ugh, surely you can smell how much the dirty dishes stink. You should check to see whether the food stuck on them is already dry by now, even.’ She replied, ‘My stomach is full right now and I need a little while for my food to settle before I can clean the kitchen.’ I responded, ‘Well you aren’t the most meticulous person, and don’t seem to be bothered by bad smells.’ She continued calmly, ‘I’ll make us a cup of coffee and then I’ll start cleaning the kitchen.’ Because I wanted her to do things exactly as I like them done, I replied in a whimpering voice, ‘This air is suffocating me, I can barely breathe. And what an awful smell there is, like burnt food!’ She still wouldn’t do what I wanted, so I started crying: ‘Nobody understands me, nobody knows how hard it is, when I’d like to wash the dishes but I can’t. Until it happens to you that you can’t do something, you have no idea how terrible it is. You know how much I respect you for being willing to help those who can’t help themselves?’ The assistant turned off the stove where she was boiling water for coffee and said, ‘I’ll wash the dishes first.’”

Manipulative people want other people to do the things they did not do themselves and mitigate the force of their own actions. They are willing to humiliate themselves, make other people feel guilty, and keep forcing until they get what they want. They trust neither themselves nor other people. They complain excessively. They only show respect to others if they can get something out of them. They do not say anything directly, but only hint at it. They feel powerful and satisfied briefly, as they blame others and achieve their aims. In the long term, they become dependent on others.

Other people in their company feel used and taken advantage of, and so they tend to distance themselves from them.

Aggressive behavior

"'Vacuum the apartment, now, and clean the windows and take out the trash! The vacuum is in the closet in the hall, clean the windows with the detergent on the counter and the rags next to it, and then take out the trash,' I told my assistant, who complained, 'I can't work on a full stomach. I still need a bit of time.' I was adamant, 'You're not going to be lazy here, do it now!' The assistant said that she didn't feel well and she still needed a few minutes. I was relentless: 'You're at work now, and if you can't do your job, then go on sick leave! There's no sitting around here on my watch.' The assistant kept resisting, asking, 'Why is it necessary to vacuum, wash the windows, and take out the trash right this second? I can do it a little later, it's nothing urgent. I still need a few minutes for my food to settle, then I can work. Everything you asked me to do can wait.' I freaked out. 'What?! You're even going to talk back at me, you lazy brat? Here you need to do what I say, and be quick about it!' But the assistant didn't give up. 'I'll do it in 5 minutes.' I absolutely lost it. 'No! Do what I ordered you to do, immediately!' The assistant kept pushing her side. 'I'll clean up if it's so important to you, but only after we finish our coffee.' I saw red. 'Who do you think you are not to obey me when I talk to you? I'm going to call the PA coordinator to replace you immediately, because I don't want you working here anymore!' I called the coordinator right away, and said with a sharp tone, 'What a lazy assistant you sent me. Send me a different one right away, one who is willing to work, not just sit around here.' Mad as can be, I listened to the coordinator ask me not to yell. 'It's her fault if I'm screaming, because she's trying to avoid her job,' I explained to her."

Aggressive people view their needs, emotions, and opinions as more important than those of the people around them. They think that their needs must come first. They do not care what other people think, and their remarks are loud, cynical, crass, and sarcastic. They often criticize others and give off the feeling that only their points of view are important. Though it may seem on the surface that they freely express their feelings, in truth they hide them, because they figure people would not understand anyway.

Aggressive people can achieve short-term success, as they are loud, fun, and entertaining company. Thus, they usually get what they want. They supervise their own lives and the lives of others.

Over the long term, aggressive people foment aggression in other people, and they themselves have feelings of guilt, isolation from others, and the feeling that they have many enemies. They do not have real friends and have a narrow view of what friendship means; they feel vulnerable and scared. They often feel like they are losing control over their lives and losing the confidence of others.

Assertive behavior

"When I told my assistant to vacuum, she replied, 'I can't work on a full stomach. I still need a bit of time.' I asked her how much time she needed, and she said a few minutes. I agreed. 'OK, you can do it in 5 minutes.' When she was still sitting at the table 7 minutes later, I got angry. 'Seven minutes have passed and you haven't begun to vacuum. She tried to defend herself, asking, 'Why is it necessary to vacuum right this second? I can do it later, there's no rush. At home I just sweep, and only vacuum once in a while. It's easier that way. I'll do the same here and just sweep up real quick.' I explained to her, 'We don't sweep here because I have allergies and when the swept dust is in the air, I have a hard time breathing. Please vacuum the kitchen, living room, hall, and balcony.' She answered me, 'Well, if you insist. But I'm just going to sweep the balcony, not vacuum it.' I persisted, 'No. We don't even have a broom. We even vacuum the balcony.' To that she responded, 'If it's so important to you, OK, I'll vacuum as soon as we make and drink a coffee.' I was firm: 'No. Begin vacuuming now.' When she finished vacuuming, I gave her the next instructions: 'Please clean the windows in the kitchen and living room. There's some window cleaner and paper towels on the counter.' My assistant didn't say anything else, she just began washing the windows. She figured it out that she wasn't going to be able to shirk her responsibilities like she had with her previous user. When she finished, I then told her, 'Please take the trash and come with me, so I can show you where the trash cans are.'"

Assertiveness is the most important skill that both users and assistants need to effectively manage and provide PA. It is both a behavior and a means of communication. Assertiveness is founded on self-respect, on creating equitable relationships, accepting personal responsibility, and being aware of both personal and other people's rights. Being assertive allows you to express what you feel, what you need, and what you want. It increases self-confidence without humiliating others. The result of assertive behavior is not that one wins and one loses, but that both sides have the feeling that their needs and desires were both heard and heeded.

Assertive behavior is a social skill that enables disabled people to stand up for their rights. Disabled people need this knowledge for:

- Expressing their needs in a respectable way
- Reducing feelings of stress and fatigue related to the frustrations of low self-esteem
- Being honest with themselves
- Respecting themselves and others, treating them as equals
- Saying no, if necessary
- Expressing points of view honestly and without fear
- Asking for assistance when needed
- Having the confidence to starting conversations and finishing them
- Socializing with the people they choose to
- Expressing positive and negative emotions
- Not being aggressive when angry, and expressing anger in a way that the other party can accept
- Not feeling “small” and humiliated when they do not get what they want
- Not feeling less worthy when not receiving recognition from others

Assertive behavior does not include:

- Profiting at other people’s expense
- Winning and getting your way at all costs

- Controlling others to achieve personal goals
- Being physically or verbally abusive
- Thinly veiling comments or sending mixed messages, emotionally exploiting others, criticizing, and humiliating others

The relationship between user and personal assistant

The user considers their assistant to be their “right hand”, an extension of their own capabilities. It is crucial that the user is professional and respectful towards their assistant, and that they require the same of their assistant. It is important at the beginning of their relationship for the user to check up on the assistant often, asking how things are going and whether everything is all right. The user should be attentive to the feedback the assistant gives about how difficult it is to perform certain tasks.

Personal assistance at work (Photography: Klaudija Poropat)

> On the bottom right quadrant of the photograph sits a woman in a wheelchair. She is touching an opened folder, which another woman is holding in her hands on the left side of the photograph. She is visible from the knees up and is leaning towards the folder. In the background are shelves storing other folders. There is also a refrigerator in the background and a microwave oven on top of it.

The user must abide by labor legislation.

In its Article 7, the Employment Relationships Act forbids sexual and other types of harassment at the workplace.

Sexual harassment is any kind of undesired verbal, nonverbal, or physical action or behavior of a sexual nature with the intent or even unintended effect that the target's dignity is damaged, especially when the behavior contributes towards an intimidating, hostile, humiliating, or offensive environment.

Harassment is any undesired behavior of any personal background with the intent or even unintended effect that the target's dignity is damaged, or that an intimidating, hostile, humiliating, or offensive environment is created.

Bullying at the workplace is any repetitive or systematic, reprehensible, blatantly negative and offensive conduct or behavior directed against specific workers.

"I liked my assistant, so I wanted to compliment her: 'You really have some nice tits, babe!' I couldn't understand why she started screaming at me: 'That's the first and last time you harassed me. If that ever happens again, I'll quit immediately!'"

The following types of relationships can develop between users and assistants: friendly, protective, and professional.

"When I decided to leave the institution I was at, a retirement home, the personal assistance provider and I started looking for an assistant earnestly. One candidate applied who was also my friend, one who had often come to help me when I was living in a home. Even then, he had complained to me how desperately he needed a job. Since we were friends, I was a little skeptical, but nonetheless I decided to give it a chance and see how things worked out. Up to his employment, everything went just fine, but when he started, he called me one day at 4:30 in the morning saying he was sick and wouldn't be coming into work. Over time, things just got weirder and weirder, as he even stopped picking up the phone. I wanted to ask him until when he was going to be on sick leave and how he was feeling. At the end, the situation resolved itself with him quitting. And our friendship was lost forever. I found out that it isn't a great idea to consider your assistant your friend."

"I had an assistant working almost a whole year, and I was really satisfied with her. She was diligent, clean, kind, hard-working, in short everything I could have imagined. But she was sent to another user, who needed a little more attention. I was sent a replacement. My old assistant and I kept in touch. Nearly every day after work she stopped by for a coffee. In a few months, the user she was working for no longer required assistance for 8 hours a day. The PA provider offered that the assistant could return to me for a few hours a week. I was thrilled to have her back, but that soon turned to disappointment. She now considered me a friend and had become too comfortable in my home, making coffee and then sitting and chatting with me for a few hours, but neglecting her work. When her contract expired, at my request the provider didn't extend it. Since then I only maintain a professional relationship with my assistants and don't try to make friends."

Sometimes a friendship forms between the user and assistant; there is nothing wrong with this as long as it does not affect the provision of PA. The transition from a worker/employer relationship to a friendly one can occur very quickly, and so it is better for the relationship to be respectful, but not quite friendly. If a conflict of interests or viewpoints arises (one likes something that the other does not), the parties might try to engage in haggling or bargaining to get their side if clear boundaries are not set and respected. PA loses all value if the assistant, under the guise of friendship, limits the temporal or physical extent of the PA that they provide.

A protective relationship develops when the user allows the assistant not to work according to the user's instructions, allowing the assistant to plan all activities. Usually the reason for such a relationship is a lack of self-confidence in the user. This kind of relationship can form when users are convinced that they are helpless, that other people must take care of them, and when they simply relinquish control over their own lives to someone else. If the user allows the assistant to run the user's life, then both parties are responsible. If the user sets boundaries and the assistant does not respect them, then the assistant is responsible.

In a professional relationship, the user is respectful and expects respect from their assistant in kind. The user must ensure the assistant a safe environment as well as tools and devices to make work safe (e.g. using

a hoist, etc.). Having a good relationship with an assistant requires considering their needs when making schedules, for instance accounting for their personal errands (bank, doctor, etc.) and requires making allowances for statutory meal breaks, bathroom breaks, etc. The user should not hover over the assistant and disparage them. Instead, they just monitor their assistant's work and give constructive criticism.

The user decides if they will be on a first-name basis with their assistant. In cultures where this is relevant, this includes deciding about the dynamic of the T–V distinction in addressing one another. The user makes and justifies their suggestion in this regard to their assistant. Some decide to continue with formal addresses to maintain a professional relationship, and some decide upon a first-name basis to forge a more relaxed and equitable relationship where the assistant does not feel bad. It is unusual and inappropriate for one party to be on a first-name basis and the other to use formal address. It is also inappropriate for the parties to be on a first-name basis until a conflict arises, after which they continue with formal speech.

The user endeavors to make an appropriate and congenial relationship between them and the assistant, one where they both feel comfortable, trust and respect one another, are honest with each other, feel comfortable discussing anything with one another, including sensitive topics, and that they both feel like their needs are heard and respected. Above all, though, the relationship may not include any sort of violence. They resolve their conflicts as they arise.

It is important for the user to be able to recognize poor or inappropriate relationships.

The user does not feel comfortable (physically or emotionally). They feel either unaccepted or poorly understood. The user is afraid to speak about pleasant and less than pleasant things. Both hidden and overt conflicts arise that the user fails to resolve with their assistant. The user is tired and deflated. There is no leeway for individual needs in the relationship. Manipulation, extortion, and violence are mainstays, and the user fears the assistant's reaction to certain questions, comments, or suggestions.

Sometimes the user takes on the role of victim and self-pity. They think that they experience difficulty because of something the assistant did. The user has the feeling that they lack any influence or control. Often it seems that the user can do nothing to change the situation, usually not even knowing how to begin a conversation about that which causes dissatisfaction. They feel powerless.

Without the assistant’s cooperation, the user can do nothing to improve their relationship. It is not enough for just one of them to be prepared to change their behavior. Often when the user changes their own behavior, the assistant is “forced” into changing their own. If the user notes that something is wrong in their relationship, they can also change their own behavior. It is important in such circumstances for the user to ask:

- “What can I do by myself in this situation?”
- “What have I done so far?”
- “What else could I do?”
- “What or whom do I need to support me (knowledge, experience, another person, etc.)?”

The user also accepts part of the responsibility. If the assistant does nothing to change their own behavior, then it is impossible to keep working together.

Examples of good behavior on the part of the user leading to a good and professional relationship with their personal assistant include:

- Respecting themselves and others. It is inappropriate for them to consider themselves as patients, as wards, or as handicapped.
- Respecting and protecting their assistant’s privacy and personal data.
- Striving for a non-patronizing relationship. This means that assistants must respect the user’s decisions and not try to force their own solutions and viewpoints on the user.
- The user tells the assistant how to (re)act when meeting other people in the assistant’s presence. If people interact with the assistant instead of the user, the assistant may not respond or make eye contact with them.
- The user gives clear and feasible instructions. Adjectives such as “nice”, “diligent”, or “fast” do not communicate anything. If the assistant is to do things as the user wants, then instead of saying something like “You didn’t mop the floor diligently”, they should rather say “Please mop the floor so that you can’t see any cleaner left on it.” Instructions should be given right

before a given chore, and not at the beginning of the day for the rest of the day. Giving unclear instructions, accusing the assistant, and being patronizing or insulting are all examples of poor management of PA.

- The user monitors the assistant's work without hovering or being accusatory; instead of saying "Why didn't you do it?" say "Please do it."
- The user sets boundaries for all foreseen situations, and for unforeseen ones as they arise.
- A user's disability might deteriorate, and the user's self-sufficiency along with it, meaning that the user might later need help with certain activities that they can nonetheless perform now. At that point the user will set a new boundary in light of what they will be able to do by themselves and for what they require assistance.
- They come to agreements.
- They maintain a professional distance from their assistant. The user can insist that they use formal addresses. A personal assistant is not a friend.

User behavior and mindsets that lead to poor relationships include:

- Not setting boundaries and requirements. Putting themselves in a victim role, dwelling on what the assistant has done to them, and blaming the assistant for their own bad feelings. Refusing to stand up for themselves out of fear that the assistant will no longer want to work for them. Being convinced that a friendly relationship and leniency are necessary for good working relationships with their assistant.
- Seeking emotional support or confirmation of viewpoints whenever unsure of themselves.

"My assistant and I were at a meeting with my employer. 'Is it possible to extend the deadline by which I have to inform you of my decision regarding continuing with work?' I asked, and got the answer: 'No.' I had expected a different answer and since I wanted to delay a little longer, I turned to my assistant, who I hoped would support me: 'Wasn't he rude to me?' But my assistant didn't have my back, and replied, 'No, he just told you firmly about the deadline by which he expects your answer.'"

- Expecting the assistant to know what to do without being told. For instance: “You know what to do!”, or “You should already know without me telling you!”

“My assistant didn’t do anything by himself. I was angry because he didn’t even tell me the table was dirty. I would have just wiped it myself, despite not being able to see.”

- Giving unclear, unintelligible, or unfeasible instructions.

“Every family has their own way of putting away the dishes. Ours puts the pots and pans in two large drawers under the counter. If they aren’t put away such that the smallest is on top and the biggest on the bottom, then you can’t shut the drawer, which puts me and my family, especially my husband, in a bad mood. One of my assistants put stuff away in a way that made it almost impossible to shut the drawer. At first, I thought she’d figure out for herself that something was wrong with her way of doing things. After a few days, nothing had changed, so the next time she was putting the dishes away, I sat next to her. She put them away according to my instructions and there were no more problems after that. It was the same with putting dishes into the dishwasher, putting groceries away, and sorting the pantry.”

- Not checking whether the assistant understands instructions. Not checking whether the assistant is working as the user intended

- Not reacting when the assistant does something the user does not like or that the assistant was not instructed to do

- If the user finds that the assistant has done something differently than the user expected, the user should not ask them why they did it like that, as this leads to feelings of guilt. Instead, the user says what they did not like, as well as what to fix and how.

Effective communication that leads to a good relationship

Replace “**Why** did you do that?” with “**What** made you do that?”

The word **must** or **have** is often interpreted as coercion and should be replaced with **I’d like**. So, “You have to clean the table” should be replaced with “I’d like you to clean the table.”

Avoid words with negative connotations that are likely to cause subconscious stress. This includes words like **stress** itself, as well as **problem** or **difficulty**. Instead, use the word **challenge**.

"Instead of saying, 'I have a problem, since my assistant got sick and is on leave,' say 'Since my assistant is on sick leave, it will be a big challenge to find a replacement.'"

Generalized and impersonal speech makes it easy to shirk responsibility. Such sentences focus on everyone, or on you. Better relationships are built through the use of I/me. For example, instead of saying, "Why don't you respect my instructions when you're driving? Once again, you braked sharply for no reason, despite knowing that you're not allowed. It's your fault that I was scared," say "Whenever you brake sharply, I become frightened. So I'm asking you to please respect my instructions and don't turn sharply if it's not necessary."

It is the user's responsibility to tell the assistant in a respectful manner what to do and what to correct. The relationship that the user builds with their assistant is extremely important, and it is just as important to address dissatisfaction and resolve conflicts immediately. Users can also seek aid from the PA coordinator, use peer counseling, or resort to their own advocate. Sadly, often dissatisfaction piles up until the point where one of the parties finds that they can no longer work with the other. It is very difficult to change a relationship for the better once it has deteriorated. PA providers cannot help if they are not informed about irregularities occurring in the user/assistant relationship. In cases where both the user and assistant engage in mediation with the PA provider, they often merely blame one another, which does not repair the relationship.

Giving constructive criticism

Constructive criticism means commenting on and assessing the work done and not on the assistant who did the work. Always address the person's behavior and not their immutable characteristics. **When giving criticism, first address the incident, then how it made you feel, or alternatively address the emotions that led to the incident in the first place. Finish by saying what the person could do differently in the future**. If necessary, increase the level of criticism. Give criticism as soon as possible.

"When you drive recklessly, I feel powerless, as I can't control my body, so I have to lean on you, which can be dangerous. Please keep a longer distance between you and the cars in front of you, don’t weave in and out of traffic, and only brake sharply when necessary.”

If the assistant changes or completely stops their inappropriate behavior for the better, this should be complimented.

Preventing and resolving conflicts

The ability to prevent and resolve conflicts between the user and the assistant is an important skill that both parties can learn. They learn to recognize the miscommunications that lead to conflicts. Thus, they avoid unpleasant situations and complications that result from conflicts that might otherwise destroy their relationship. They recognize bad moods and tension. Tense workplaces are nerve-wracking for both parties.

At first, they must establish a professional relationship, be respectful to one another, and set boundaries for one another. If the user and assistant are both the sort that makes fast friends and does not maintain professional distance, they can also end up being disrespectful and inappropriate. The user’s role is the most important, as they are the one managing their own PA. If the user knows how to learn from their own mistakes, they will become more and more versed in the necessary skills.

Causes of conflicts

- The user regularly makes exceptions and compromises, wanting too much to accommodate all the assistant’s requests.

- The user is too unsure of themselves, adjusting to the assistant’s wishes instead of the other way around. The user becomes lenient and uncritical, not solving their own needs with PA and harming themselves in the long run. For example: the schedule is set for the time slots that suit the assistant, not at the times when the user requires help. The assistant wants more and more (e.g. expecting to have vacation approved whenever requested). PA is the assistant’s job, and they are compensated for it. They have a set number of hours to work per week, and a schedule set for them by their employer, the user. When users are insecure, they tend to adjust to their assistants rather than the other way around.

- The user begins treating their assistant as self-evident (e.g. like a machine or robot to be turned on whenever necessary, like a mere servant, hired for a particular service – like physiotherapy, repairing a wheelchair, painting an apartment, or handiwork around the house).

- The user and assistant develop a “utopian” relationship, where each is euphoric and gushing about the other. They are satisfied in all regards, without any critical distance. The user forgets about the necessity of a professional relationship. The assistant does all chores, even those not included in PA, and hangs out with the user outside of regular working hours (concerts, free time, recreational activities, etc.). This “utopia” is shattered sooner or later by a conflict.

- The assistant acts in a patronizing or condescending way towards the user.

“One morning, before going to work, my assistant, who hadn’t been working with me for very long, asked if I was going to have breakfast. I don’t usually eat breakfast and I wasn’t feeling very well, so I declined. When I came to the living room, he asked the same question again. There were still some crêpes covered on the table from the day before, so I said, ‘Ok, I’ll have one real quick.’ Then he cheekily commented, ‘Ooh, naughty naught, you know that’s bad for you!’ I didn’t react to that comment, because I was still thinking about what to say. More than anything I was bothered by his condescending tone, as we had already gone through similar situations. I thought to myself, ‘That’s none of your business.’ He handed me a crêpe without saying a word, then sat on the couch and waited. While I was eating it, I asked him, ‘So this is bad for me, huh?’ He replied, ‘You know, your pancreas.’ I answered calmly, ‘Yeah, well, you have to die from something. We put worse things into our body and still manage to live. Otherwise, that doesn’t even concern you.’ He was insulted by this and replied, ‘How can you dare tell me to mind my business?! Nobody has said anything that rude to me for a long time!’ Keep in mind that I didn’t even use the words ‘mind your business’. Then we both got rather irate. I admit that perhaps I somewhat provoked his reaction, as he had previously entertained similar thoughts as if he were my guardian. But I wanted to make it clear that the contents of my diet were not his responsibility, which he found hard to accept at first. There followed a few moments of intense debate. At the end, though, we resolved it, and it hasn’t ever happened again.”

- When things go unsaid between user and assistant, and those things start to pile up, the relationship quickly sours and turns into a conflict. Each begins accusing the other for things that have already transpired. At this point, it is usually too late to repair the relationship and the only thing to do is for the user and assistant to part ways. It happens often that the user and assistant either fail to heed or do not realize the relevance of the advice and warnings given to them by the provider of PA. Some even perceive it as “nagging”.

What the user can do to avoid conflict

- Know what they want in life and know for which tasks they require assistance. Realize that an assistant is neither a companion nor a guardian.
- Choose the right assistant and train them properly.
- Set boundaries for the assistant for foreseen situations as soon as the assistant begins work.
- Have a professional relationship with the assistant. This includes trust, respect, discussion, regular conflict resolution, checking whether the assistant understands instructions, recognizing dissatisfaction and tension, and resetting boundaries that have either become too flexible or have been trampled entirely.
- Respect the assistant’s needs if possible (schedule, private life, errands, etc.).
- Allow for exceptions and compromises (either the user or the assistant) and strive to accommodate the other party, but being prudent about this.

What the user is not allowed to do

- **The user may not act condescendingly towards the assistant, nor insult or psychologically blackmail them.**

“My user was condescending, insulting, rude, and acted superior. It was very rare that he acted in a friendly manner. Maybe at the beginning. One time, because of my own moral convictions, I wouldn’t sign the record of my working hours because it didn’t match the actual hours I’d worked. Apparently, that ruined his well-calibrated system, and I began to represent a threat. He treated me like an enemy. Almost every time I went to work, I had to listen to several hours of lectures about how, in his opinion, I was doing everything wrong and how I always had to be available to him. Sometimes this lasted up to 3 hours, and I had to sit there calmly and stoically listen to his insults and criticism. If I had left the workplace, it would have been irresponsible behavior. I was never rude to him and never returned his insults.”

- **Abusing the power of informal employer**

“Almost every single day my user ‘told’ me that HE was my boss. That HE was supporting me and my family. That HE was putting food on our table. That without HIM we’d all be poor. That HE was our benefactor.”

- **Unilaterally changing schedules and forcing assistants to work when they are not scheduled to do so**

“My user expected me to come in the middle of my already booked vacation, and that I would even leave my family there. I resisted and told him that he didn’t put me on the schedule that day, and then he exploded, telling me that he needs me and can’t live without assistance.”

“While I was on vacation with my family at the seaside, my user called, saying that she desperately needed me and that I needed to come to work the following day. I fought back, as I really needed a break, and I didn’t have a sitter for my kids, either. The same user did something similar last year, too, so there was no way I was going to cancel the vacation that she had already approved. When at the end of my vacation I returned to work, my user handed me a printed notice of firing and insisted that I sign it, and she would then take it personally to the PA provider. Of course, I didn’t sign it. I insisted that we go to the provider together. But she didn’t want to do that, and so she had no other choice but to throw the notice into the trash.”

- **Abusing a disability to pressure an assistant or sexually harass them**

“As soon as I signed the employment contract, my user told me that he has a potentially life-threatening diagnosis, and thus he might need me at any time, and so I needed to be available 24/7. Without him knowing it, I’m not allowed to go anywhere.”

“When I helped my user sit down, his hand would ‘always just flop’ and land on my breasts or butt. When I told him that I wouldn’t tolerate that anymore, he blamed his behavior on poor coordination. Since he can’t hold his hand up, it’s ‘logical’ that it would flop around uncontrolled.”

- **Demanding that an assistant is always available, and thus preventing them from fulfilling their own needs**

“I asked my user if I can switch out my morning shift one day, so my father, whom I look after, won’t be alone, since my mother was in the hospital. For one day, I would ask the neighbor for help. The user asked me, ‘So did you mean to always substitute that shift?’ I answered, ‘No, but you know what the situation is right now. When my mom comes home, they’ll be together and everything will be easier.’ She continued, ‘Ok, but work comes first.’ To which I replied, ‘Not really, not if health and family are involved.’ But she wouldn’t give up: ‘You knew what kind of job this was when you signed up, that I always need assistance.’ My mood started to sour, and I said, ‘And I told you at the interview that I have obligations at home.’ She fired back, ‘Well that’s not my problem!’ I was speechless, and now I only communicate with her about urgent matters.”

“My user was constantly changing up the schedule. If I mentioned upon such a change that I already had a commitment at the time, a barrage of emotion and vitriol would be waiting for me the next time I came to work about how I always need to be available. As a result, I often had serious problems, as I have a big family with plenty of obligations.”

Managing personal assistance when the user lives with other people

If the user lives together with other family members or roommates (parents, partner, children, friends), then these people, too, must deal with a “stranger” coming into their home and private lives. Users in this case have additional responsibilities. They must ensure that the people living with them do not interfere with their relationship with their assistant, nor with managing PA. Above all, they must not try to supervise PA and put conditions on when, how, and for what the user can request PA.

It happens often that the relationship between user and assistant is unprofessional, and so the assistant acts like a family member, forming personal relationships with others in the same home. Assistants who feel like family members make independent living impossible for the user (instead of the user’s instructions the assistant listens to other family members’) – this can also lead to the assistant forfeiting their right to privacy before other family members.

Parents are often overprotective and patronizing. They treat adult children as if they were toddlers who need their care and upbringing. Often they fail to teach children how to do certain things, always doing them instead of their children. This behavior often continues into adulthood. In such instances, parents deprive the user of the opportunity to learn life skills. Not only do they do things instead of the user, but they also hover, preventing them from experiencing the freedom that PA provides.

“My mom moved into my room so she could be available all the time. She convinced me to send my assistant away, as she wouldn’t even have anything to do.”

Some users are used to their parents doing things that they should be doing themselves. They live with their parents in “symbiosis” and do not see the need for change. When parents take over the management of PA, the user does not react. Parents track and follow the user’s activities and the user does not see anything wrong with this. Instead of talking to their adult child about the division of chores among family members, they instead tell the assistant what to do. For instance, they often do not allow the assistant to cook for the user, who wants to eat a specific meal. They rather force something else, insisting that it is healthier for the user. Sometimes parents tell the assistant not to tell the user what is in the meal (e.g. the user does not like meat, so the parents mash it up and sneak it into minestrone). They similarly like to charge the assistant with obligations that are not directly related to the user (e.g. caring for an elderly grandmother who lives in the same home). Both parents and the user view the assistant’s work as the user’s “contribution” to the household chores, making up for what the user cannot perform on their own.

Users who have their own family often expect the assistant to assume management of the whole household, including raising and babysitting the children. Often their partner and children give the assistant instructions (the child tells the assistant to put away their toys). During training, the assistants learn that when other family members manage PA, the user is deprived of their opportunity for independent living. After receiving training organized by PA provider, assistants often resist and no longer want to work according to the instructions given by parents or other family members. That is when above all parents complain that the assistant is “lazy”.

The user must not allow parents to hover and control the user’s household matters, and not allow them to instruct the assistant. It is imperative that the user and parents agree on how household chores are to be divided. Once they agree, then the user contributes their share with the help of PA. On the other hand, it is unacceptable that the assistant assumes management of the whole household and performs the chores instead of family members. This happens often if the user lives with their partner, or if the user has children, even if the children are adults. Unclear divisions of responsibility in the family and family members' interference in the user/assistant relationship are the most common causes of misunderstanding and conflict. It is crucial that, in addition to the user, other family members also understand and respect the assistant's role, what the assistant's job is, and what their responsibilities are within the family.

Only the user gives instructions to the assistant. If the user needs help in doing so, they have a legal representative to instruct the assistant on the user's behalf. If the user fails to provide adequate instructions for specific tasks, they must accept responsibility for poorly done work. The user's spouse or partner does not give instructions to assistants, nor do parents or other relatives living with the user.

"My user asked me to vacuum the flooring and seats in her car. The next day, her husband, in the presence of both his friend and my user, commented, 'Well, the car isn't exactly clean. I worked at a carwash and I learned there what a clean car is.' 'The dashboard is really dusty.' I thought to myself, 'Really, the first time when I follow the user's instructions to the letter ... She can't see and I didn't tell her the dashboard was dusty, and then this happens.' As feelings of guilt started gnawing at me, my user calmly responded to her partner, saying, 'I didn't ask her to clean the dashboard, just to vacuum the flooring and seats.' That made me feel like my user respected me and wasn't just using me like some old rag to wipe the floor."

Personal assistance in using a car (Photo: Klaudija Poropat)

On the right side of the photograph stands a woman, visible from her knees upward. She is holding a folded wheelchair with both hands, putting it into the trunk of a car in the center of the photograph. On the left side of the car stands a man, whose back is visible. In his left hand, he is holding the driver's side door, and his right hand is on the car's frame between the front and back doors. The impression is that he is getting into the car.

The assistant can do some chores for other family members, as long as the family divides up responsibilities fairly (e.g. the assistant makes lunch for everyone while one other family member does the laundry and ironing, including the user's clothes). It is a must that there is a clear agreement within the family about the allocation of chores and tasks. It is unacceptable for the assistant always to make meals for the whole family, do all the ironing, all the cleaning, etc. Even children should be included in the household chores, undertaking age-appropriate tasks. PA is not household assistance per se, but aid for a person who cannot perform certain tasks that allows them to fulfil their part of household responsibilities.

User obligations in managing PA for users who do not live alone

- Informing other members of the household that PA will begin, meaning the entry of a “stranger” into their personal space. The discussion should focus on what it means for other household members to accept and adjust to the new circumstances.

- Helping other household members find solutions for personal privacy in light of the assistant’s arrival. The user can even ask whether other household members are willing to take on a part of the assistance that the user requires in order to maintain privacy in the family.

- Setting boundaries for other household members, so they do not interfere with managing PA. They should not monitor, limit, or condition the user’s needs.

“I have my own business and I live with my parents. My assistant helps me with my everyday tasks, like typing and changing clothes, or she accompanies me if I need to go out and arrange any paperwork, go to meetings, buy any essentials, etc. Usually I plan all these things myself, but it still often happens, especially for the shopping, that my mom takes the initiative. She just takes my assistant, without asking my opinion or permission. A lot of times when I’m working, she just barges into my room and starts telling my assistant what all needs to be done. I interrupt then and tell her that any such orders must be given to me, and I’ll take care of it with my assistant after I’ve already done my most pressing tasks. My mom thinks this is just wasting time, but for me it means that I can maintain my independence, as after all my assistant isn’t my mom’s slave, but my personal assistant. That’s why I insist that my mother first tells me everything that needs to be done, and then my assistant and I will take care of things in the way and at the time that I decide. Despite me being stubborn about this, my mom is stubborn too, and so I often need to stop her.”

- It is crucial for the user, despite living with family members, to insist that the assistant perform tasks only at the user’s request and instruction, and not respond to other family members’ instructions. Otherwise, the user is no longer independent, and the point of PA become diluted.

“Since I live with my parents, it often happens that my mom asks my assistant to do something. It has even happened that she sent my assistant to the store without telling me, and I was waiting for her. I asked my mom, ‘Well, where is my assistant, I’ve been waiting for her half an hour?’ My mother answered back nonchalantly, ‘Oh, right, I forgot to tell you. You were on the phone and didn’t need her, so I sent her to the mall.’ My blood seethed. ‘What?! You didn’t even say anything to me!’ My mom kept acting like nothing serious had happened. ‘Yeah, I forgot.’ I persisted, saying, ‘She is my assistant, not yours. She’s here to help me, not to go run errands whenever you see fit.’ But my mom refused to give up. ‘Yeah, well, I needed something urgently, what’s the matter? You can wait a little bit.’ This really outraged me, as I’d told her time and time again to let me know if she needed anything. ‘No, this is far from OK. You can’t use my assistant for your needs. I have work now and I have to do it by myself, and I’m a lot less efficient than when I work alongside my assistant.’ Cold as ice, my mother replied, ‘Ahh, you’ll get it done, there’s no rush.’ I almost screamed. ‘No! Please, never use my assistant again and never send her out on your errands!’”

- **Despite insisting, the user only rarely convinces family members not to use PA for themselves. It is essential to come to an agreement with the assistant not to respond to requests from family members; if that occurs, the family members should be directed to discuss it with the user. If the assistant does not respond to instructions given by family members, they will soon realize there is no use giving them.**

  The user is to make an agreement with other household members about the division of tasks and then use PA to contribute their share. It is not just the user who performs household tasks, but all family members, including children, respective to their capabilities and in the presence of an adult. As children grow older, so too changes a user’s need for PA, as children must take on their share of responsibilities in the family. If the user has assistance for personal care and for caring for the user’s infant child, it is understandable that the number of PA hours lowers over time. The child will grow and eventually take on more and more of the household chores. PA is not household assistance, but aid for a specific person who is unable to perform all tasks in one of their given roles (e.g. wife/husband, mother/father, or child). The user requests that their family members perform their share of the household chores and not engage the personal assistant for such reasons. Users often employ their assistants as domestic servants. Example: The user leaves the home with other household members, while ordering the assistant to stay at home and clean everything up.

Personal assistance in caring for children (Photography: Klaudija Poropat)

On the left of the photograph, a woman with sunglasses on is carrying her baby in a harness. She is holding a white cane in her right hand. Her gaze is focused on another child who is walking on a diagonal log. She is holding the child's hand with her left hand. The child's other hand is held by a woman on the other side of the log, on the right side of the photograph. Tall trees are in the background.

"Complications with my assistant began when my daughter's partner began spending the majority of his time around our family. It became unbearable, as there was all of a sudden far more laundry, dirty dishes, and other things that neither my daughter nor her partner noticed, and thus the lion's share of work remained for me, or consequently for my assistant to do. I could sense that things weren't OK, but I didn't know how to set boundaries and demand that the others do their share of household chores. I tried several times when we were alone, when my assistant wasn't around, to resolve things, but it never worked. After a while, my assistant herself told me that she didn't think things were fair. I of course agreed with her and again tried with new requests. Soon I realized that the problem would not resolve itself and that, if I wanted to have PA and do what is right and fair, my daughter and her boyfriend would have to move out on their own. And they did so. Since I'm usually home in the morning and I cook for myself, my husband, and my assistant, I decided to cook for them too, and my daughter would take the meal home. Then came the news that I was going to be a grandmother, which thrilled me. When my assistant found this out, she asked me if now I was planning on cooking every day for grandkids, too. I replied, 'Yeah, I'd like to have them around, and I don't know what the problem is to add 5 potatoes and 2 filets.' My assistant fought back, saying that cooking daily for an extended family is not personal assistance. Since we couldn't come to an agreement, we called the PA coordinator, who agreed with the assistant that cooking for an extended family every day is not personal assistance."

"I worked for a user who had a 16-year-old son. He lived on the house's top floor. Every day I helped my user cook for the whole family. Their son used to always take his lunch into his room and then leave his dirty dishes there. According to my user, the next day I'd have to go get the dirty dishes from his room and then wash all the dried-up bits. When I balked at that, she replied, 'I would do it myself if I could.' I persisted, 'If you got everything all dried up like I do, you would not!'"

- Only the user or their legal representative gives instructions to the assistant. The legal representative only gives instructions if the user cannot do so themselves, or only gives such instructions that the user cannot give.

- The user sets boundaries about not interfering with family relationships. The user introduces family dynamics to the assistant and explains any idiosyncrasies. Further, if needed, the user teaches the assistant about any specific techniques (e.g. in caring for a disabled child).

Personal assistants only accept instructions from the user and/or their legal representative, and not from their spouse/partner, never from their parents, and never from any other household members living with the user.

The relationship between the broader environment and the user and their personal assistance

People who depend on others' assistance for their most basic needs often face significant discrimination. Often people who require other people's help are viewed as emotionally and intellectually dependent. This results in overprotective practices and decision-making on the disabled person's behalf.

People who do not have a disability are often insufficiently informed, and so their prejudice turns into inappropriate approaches.

- They try to predict what the disabled person can and cannot do.

"When my assistant and I arrived at the clinic, I gave her instructions: 'When they call me into the room, you will accompany me to the doctor and then wait in the hall for them to call you.' When we came inside and she was about to leave me with the doctor, he turned to her all worried and stammered, 'Umm, where are you going? Who will undress her?' The assistant replied, 'Ask her yourself.'"

- They speak with the person accompanying the user (assistant, interpreter, volunteer, family member) instead of with the user.

"Before my operation, the dental surgeon was talking to me about possible complications. One of them was that I wouldn't be able to talk for a few hours after surgery. I told him, 'If that happens, call my assistant, who is waiting outside the operating room. He'll know what to do.' Luckily, nothing like that happened and the surgeon and I were able to communicate so we could discuss caring for the wound. When the surgeon finished, he placed a cotton swab in my mouth and told me to bite down hard for another 20 minutes. Of course, I wasn't able to speak during that time. As we had agreed, he called my assistant and told him to take out the cotton in 20 minutes, then began talking about the healing process for the next few days. My assistant noticed immediately that there hadn't been any complications, and so he interrupted the surgeon: 'She'll be able to talk in 20 minutes, and then she'll tell me what to do herself.'"

"When my assistant went with me to the dentist, we couldn't get in because someone had chained their bike on the access ramp. I couldn't do anything else but to ask my assistant to push me up the stairs. I didn't feel good about that since I'd been forced to bother my assistant. When I had calmed down a bit, I ran into

> the next ‘landmine’. While I was feeling around for the chair that I was planning to move onto from my wheelchair with my assistant’s help, the dentist asked my assistant, ‘Is she blind?’ I responded with a direct voice, ‘Yeah, I’m blind.’ When I’d sat down, she continued, ‘Sir, what tooth is hurting her?’ My assistant answered her, ‘Sorry, I have no idea, ask her yourself!’”

- Due to fear, they either freeze up or try to escape when a disabled person asks them for help.

> “Sometimes my assistant accompanied me to some records office. Sometimes the attendant there would interact with my assistant instead of with me, or only give my assistant information when I wanted to be the recipient. To avoid that, I decided to walk into the office by myself, with just my cane for help. When I asked an official where to go, they usually invite me to ‘sit over there’, pointing with their finger to a chair, even though I clearly use a cane to move around. Then I usually ask the official to describe how to get to the chair, or I ask them to accompany me. Usually the official freezes up and is unable to help me.”

- They want to help, even when the disabled person does not require help.

> “My assistant and I got onto the bus through the middle door. A woman came up and asked if she should help us. Even before I could answer that no, we don’t need help, she was already reaching for the wheelchair’s footrests. One remained in her hands, but I and the wheelchair fell a good 30 centimeters. Good thing my assistant was holding the wheelchair and I didn’t tip over, as one of the footrests fell off before the other. It hurt, but thankfully there was nothing serious. The woman who had wanted to help at all costs was even more surprised than my assistant and I were, as we’ve had similar things happen before, and the woman just froze. The bus couldn’t drive off, and we couldn’t get on, because the woman was standing between the doors. Since she had frozen so thoroughly, I even had to say to her, ‘Sorry, but could you move, please?’”

- They are insulted whenever a disabled person refuses their help.

> “On the way home, my assistant pushed up to the ramp onto the bridge, where you really need to push the wheelchair a bit harder. A second later, she said in a serious tone, ‘You don’t need to push me!’ I realized something inappropriate was going on, as usually my assistant was quiet and reserved, and it was unusual for her to react so intensely. Then I heard another woman’s voice, ‘Push already!’ I asked my assistant, ‘What’s going on?’ She answered back angrily, ‘This lady is pushing on my butt!’ Since I knew my assistant could push the wheelchair by herself, without any help, especially not that kind of help, I said, ‘Thanks for

wanting to help, but my assistant can push the wheelchair herself up this ramp and doesn't need any help.' An insulted voice answered back, 'Wow, all I wanted to do was help, and that's the thanks I get!'"

What disabled people can do when other people act inappropriately:

- Insist that people interact with them directly instead of with their assistant, interpreter, or other companion.

"My assistant and I arrived at the counter at the bank. I gave the worker there my card and ID, and said how much money I wanted to withdraw. After a while the teller asked my assistant, 'How much money does she want to take out?' I answered, 'He's only accompanying me because I can't see. I'm the one withdrawing money and I can answer for myself, so please talk with me.'"

- Take a stand when confronted with pity or ridicule, when people point and stare, or when people are insulting or abusive.

"I was buying a ticket on the train. I had barely said what I wanted when the conductor spat back in contempt, 'What's up, brat, are you a little drunk?' I gathered up all my strength and energy. 'Pardon, but I'm not a brat. And I'm not drunk either. I merely have speech impediment, which hardly gives you the right to be disrespectful!'"

"Soon after I needed to start using a wheelchair and there were still plenty of barriers around me, especially sidewalks without onramps, my assistant and I went to the nearby store. I was having trouble angling the wheelchair the right way to get onto the sidewalk, I asked my assistant to push the wheelchair along the edge of the bike lane. I heard a bike riding by. And a few moments later I heard a man's voice complaining, 'Crazy lady! What are you doing in the bike lane? Stay at home if you can't walk and stop blocking the lane for others!' Even more than me, the incident affected my assistant, who began thinking that it really would be better if we didn't go out walking. We talked later and she realized that there was no point in hiding at home from hate speech and intolerance."

- React when people effusively praise them for banal tasks, showing that they do not consider them as equals.

- If people do not know something about a person with a disability, they should ask them directly.

“When I went down the stairs, I felt that someone was sitting there. I heard a child’s voice ask, ‘Mom, why doesn’t that guy have any arms, and why can’t he see anything?’ I stopped and explained to the child, ‘You just sit here, OK? I know exactly where you are. I don’t have any arms because when I was a child I was careless, and I kept hitting an old bomb until it exploded. At the time I didn’t know it was dangerous. If you want to know anything else, just ask!’”

- Request that people respect disability-related accommodations (extra time, different approaches, use of tools and devices, help from assistants or others, dedicated parking spots, etc.), that they do not contribute extra barriers on sidewalks and other walkways, and that they offer their seats on public transportation.

“When the lady at the cash register told me the total, I gave her my money. I held my hand out for the change, holding my cane in my other hand. I didn’t feel anything, so I asked if I could get my receipt and change. She replied frustratedly, ‘I gave it to you already.’ I persisted, ‘Sorry, but you didn’t give me anything. Please put it in my hand.’ I could sense her gathering up the coins, which she then put in my hand.”

“While my assistant was getting my wheelchair out of the trunk, somebody knocked on the car windows. I didn’t know what they wanted, so I opened the door and asked what was going on. But he was already rushing to answer, ‘Are you blind? You can’t see this is a disabled spot? Get out of there immediately! So young and already parking here!’ My assistant, who was pushing the wheelchair around for me, replied, ‘I drove a woman in a wheelchair here.’ I just heard the voice fading as it left, ‘So young...’ Before I sat down, I asked my assistant to tell me what had happened. First an older lady came up to him, demanding that he leave the reserved spot. He replied that he had driven a woman who needs a wheelchair, but she didn’t believe him and so she knocked on my door. Usually when people act poorly, they apologize for it. But not this time. The older lady must not have believed that such a young person could need a wheelchair.”

3. PROVIDING PERSONAL ASSISTANCE

The personal assistant

The Personal Assistance Act (PAA) defines an assistant as a natural person who carries out PA either on the basis of a contract with an organization providing PA or as a sole proprietor. Such a person must further:

- be 18 or older
- have the legal capacity to provide work
- not have any prior criminal convictions related to physical violence, sexual inviolability, or discriminatory behavior based on disability as prescribed by other regulations
- have appropriate training according to the Personal Assistance Act

The assistant works for the user, according to the user's instructions, and in the user's presence. Assistants can be of varying ages and backgrounds. Above all they must be reliable, responsible, punctual, careful, honest, flexible, patient, and discreet. They must respect the user and the user's decisions. They must be capable of understanding, following, and carrying out the user's instructions. They must be willing to substitute for other assistants. They must not be patronizing, and must not pity the user or treat them like a patient. They help with those tasks that, for reasons of physical, sensory, intellectual, or mental disabilities, the user cannot do alone.

Personal assistance while eating (Photography: Klaudija Poropat)

On the right side there is a smiling woman with a tattoo on her left arm. She is facing to the left, visible from the chest up. Her left hand holds a cup of ice cream, and her right hand a plastic spoon for it. Her gaze is centered on the spoon in the center of the photograph. On the other side of the spoon, on the left of the photograph, is a man visible from his chest up. His head is turned slightly to the left and his facial expression hints that he is holding back a smile. His right hand is bent downward in front of his chest, under the cup. The background has green shrubbery.

Assistants, employed by the provider of PA either part or full time, carry out PA for users. As such, they must undergo basic training with the provider. The user then instructs the assistant about specific tasks.

The assistant’s attitude towards the user

- The assistant should not refer to the user as a ward or as a handicapped person, but as a regular person with interests, talents, and capabilities. This means their attitude should not be patronizing.

- The assistant respects the user’s privacy. Unless necessary, they should stay out of the user’s personal space.

- When the user is speaking with other people, the assistant should not speak with their interlocutors, even if they address the assistant. Similarly, the assistant should avoid eye contact with them. The assistant is to stay out of the user’s personal choices.

- Assistants should not respond to instructions given by other family members with whom the user resides.

- They should not take offense if the user, for instance, says that they made lunch, even if the user merely instructed the assistant in how to make the meal. Even the greatest architects had construction workers build their buildings. It was the architect’s brainchild, although physically completed by someone else. The user can therefore claim with all legitimacy to have come up with the meal, instead of it being the assistant’s idea. If the assistant understands the concept and point of PA, then there is no reason to take offense.

The personal assistant’s responsibility

- The assistant makes it possible for the user to live like everyone else (e.g. by contributing their fair share to family dynamics and the household, pursuing education and employment, enjoying free-time activities, etc.). The assistant’s role is not to react or respond instead of the user or on the user’s behalf. For example: when in answering other people like nurses or salespeople the assistant says, “I’m just the assistant, please ask the user instead,” they should not feel like a robot or like a child who is not allowed to talk. Instead, they should realize that in such a response indeed lies the assistant’s greatest value. This ensures that the disabled person, who in even the most trivial of everyday circumstance often finds themselves ignored, is not stripped of their voice, but is afforded as equitable a life as possible.

- The assistant works according to the user’s instructions and in their presence.

- They speak up when they do not understand something and ensure they understand the instructions.

- They say something if work conditions are unacceptable.

“In the fall, when it was already cold outside, my user asked me to cover the window flowers with a plastic tarp. I tried, but I complained under my breath the whole time. It was hard because my hands were freezing. They wanted me to cover the whole windowsill carefully, but didn’t tell me exactly how to do it. When I had finished, kind of, you could say, she and I discussed things. She told me that she hadn’t realized that my hands were cold and that she was giving unclear instructions. Thinking it was obvious that I can’t do a great job in such cold, I didn’t tell her that. We agreed that we would do that task when it was warmer outside.”

- The assistant rejects work that is unsafe and refuses to use a device or tool that is insufficiently safe. They can also refuse work that does not align with their moral convictions.

- Conflicts and points of dissatisfaction should be cleared up with the user as they arise.

“My user and I were downtown. As my shift was coming to an end, I said that we needed to start making our way back to the car. When I first said this, he pretended not to hear me, expressing interest in stopping at one more place while we were out. I responded negatively and once again asked if we could head to the car. In a bad mood, he started moving towards the car, but still looking for any excuse to extend his outing to the city center. On the way to the parking lot, he complained about being tired a few times, asking if we could stop. Before that day he had never said anything like that to me. Often it was just the opposite, that he was always trying to push past his actual abilities and not admit his limits. Despite knowing this was just a tactic of his to get what he wanted, I acquiesced. After all, he’d begun loudly moaning and seeking solace from passersby, who would see me for the “evil” person I was, torturing someone with a disability. We’d almost reached the parking lot and he tried once again to “extend” his trip downtown by talking up people on the street and chatting with them, while my shift had already been over for 20 minutes. I got into a bad mood, knowing that we still had another 25 minutes’ drive to his house even if we didn’t hit traffic, which is a rarity in Ljubljana. A hundred meters from the car, he tried again. In the lot where the car was, an Italian family with 2 young children had stopped. My user decided he wanted to talk to one of the girls. Of course not knowing any Slovenian, the girl didn’t understand and she tried to move away from him. So he changed his communication tactic and reached out with his arms towards her. I saw that the situation had gotten out of hand. When the user reached out, the girl’s father reacted and quite protectively moved in between the two of them. In my rudimentary Italian, I began apologizing to the girl’s father, who soon realized that it was all a miscommunication and that we had no ill intentions. We continued to the car, where the user went from an adult ego state to a completely childish one. He began crying and lamenting his woes, devoting a few words my way with the gist that, ‘You’re paid for this work, all you want is money.’ At the same time he threatened that he was going to call the PA provider and decry my ‘inappropriate behavior’. I took his phone out of his backpack and handed it to him, waiting to see what would happen. In his rage, he could barely keep ahold of his phone, which fell out of his hands a few times. He calmed down a bit after a while, giving me the opportunity to try and smooth things over. It became clear that this was a conflict that I needed to resolve immediately. My user had a head injury, so resolving the conflict after the fact could lead to a big lack of clarity and a range of interpretations. With a serious and stern voice, I explained to him that the time I spent with him was set by the schedule that he sent me. My responsibility as a personal assistant ends at the time written on the schedule. Since I had the feeling that my user didn’t realize that I, too, have rights in this relationship, I explained to him the whole concept of personal assistance and its end goals. We finally made it home more than an hour after my shift had been scheduled to end. His mother noticed right away that something was up, as we had returned late, and she could immediately see on his face that something wasn’t right. Since I was already quite late, I expressed my desire to have a conversation the following day with everyone in the house, to which his mother agreed. We talked the next day. At first, he wanted to emotionally manipulate us and he began crying uncontrollably and feeling sorry for himself. His father ‘calmed him down’ quickly and we resumed our discussion. I once more explained what personal assistance is and what it’s for, and that I have my own rights in this relationship. The whole conversation ended with the user finally realizing his mistake, with his apology, and with the promise that he would respect my rights, and I his. I learned that the greatest fault was my own; surely the fact that I let the initial conflict, namely his desire to stay in the city longer, escalate into several other conflicts, like my disapproval of his time wasting, the incident with the Italian family, etc. If I had immediately reacted when he started with his ‘evasive maneuvers’ and made it clear in an understandable way that his behavior was violating my rights, we could have avoided all further escalation. The user would have understood that his emotional manipulation has no effect on me. Since we resolved everything the following day in our discussion with all the family members, we didn’t need to escalate things to the PA provider. I was a little worried that his mother, who tends to be overprotective and patronizing, and who spoils her son rotten, would make it impossible to resolve the conflict amicably, but thankfully that didn’t happen. Since that incident, my user and I have, as I see it anyway, a good and professional relationship. And precisely because of this incident, such conflicts are really rare between us. If one does come up, we resolve it immediately.”

- The assistant assumes no responsibility for liabilities resulting from the user's actions or decisions.

- The assistant's role is not as household servant.

- The assistant can reject the user's request that the assistant find a replacement during their vacation, as this is not the assistant's job.

- The assistant protects the user's privacy.

"People often ask me, 'What's wrong with her?' When I answer that nothing's wrong with her, they persist, asking, 'Well, then why is she in a wheelchair?' When I say that I'm not allowed to talk about it, they still won't give up. 'What's so important that you can't talk about it?' To which I reply, 'How would you feel if I were your assistant and I told the whole world the intimate secrets you confided in me? Is it not your business and yours alone how much money you make, or whether you have a certain disease, like cancer, for instance? If you're so curious, go on up and ask her yourself.'"

At most jobs, it is expected that employees arrive at their jobs and immediately begin working. It is preferable if they see and find work that needs to be done, even if their employer does not expressly ask them to do it. Perhaps they can independently start a task that no one had found time for yet. Things are different with PA. When a personal assistant arrives at work, they do not do anything until the user gives them instructions. This helps the user pursue an independent life. Therefore, the assistant's value is found in facilitating this independent living for the user, not in doing everything for and in place of the user.

What a personal assistant does

The assistant helps a person with a disability, and so their specific tasks vary according to the user's needs. Perhaps they might need help moving around the house, in lying down to rest, in switching seats, personal hygiene, dressing and undressing, or eating and drinking.

Personal assistance in putting on makeup (Photography: personal archive of Klaudija Poropat)

On the left side of the photograph is a woman leaning on a chair's headrest, visible from the chest up. At the height of her chest, she is holding a makeup kit. Her knuckles show an impairment in the hands. She has her head up and her eyes closed. Another woman, on the right side of the photograph, is holding her head up underneath her chin and leaning over her. Her left hand is holding eye shadow. Her facial expression shows attentiveness and satisfaction. In the background on the left are the branches of a blossoming tree, and the right side has a parked motorcycle, with the house way in the back.

They might need help with everyday activities, such as household chores (cooking, cleaning, grocery shopping), taking care of pets, and engaging in recreational activities. They might need help with studying or their jobs.

Personal assistants can help with communication or with schedule planning. They convey information from the surroundings (e.g. reading or describing photographs or the environment to people who are visually impaired) and accompany the user. They make it possible for users to use public transportation and they can also drive the user's car.

If the assistant is working for someone whose disability prevents them from identifying and responding to dangers and risks, the assistant helps or alternatively identifies such risks and dangers themselves, and encourages or guides the user in responding to them.

Often personal assistance involves basic healthcare, e.g. in catheterization, aspiration, taking medication, administering insulin, etc. The user teaches the assistant about such procedures and trains them to perform them how and when the user wants and needs. The assistant is not responsible for the potential medical consequences of the user's instructions. It is the user who is responsible for their decisions and their body, and the assistant merely respects their instructions. Practice has shown that the user knows what they want and thus they teach their assistant how to react appropriately to their needs. As a result, users tend to trust their assistants even more than they trust medical staff to act appropriately in a given moment and react to a given situation. While they may be well trained otherwise, still, medical staff do not intimately know the user's needs, and thus can even potentially harm the user when helping with simple, everyday activities like moving, getting dressed, lifting things, etc., if not done the way the user prefers. The same holds for actual medical procedures. An assistant who has been trained well by the user knows their specific needs and does their job as a matter of routine, specifically in a way that suits the user. Often established medical doctrine drastically differs from the user's actual everyday needs and practice. Hospital care, protocols, and standards are often significantly different from everyday domestic care. Accordingly, the assistant does not require any special formal education for performing their work.

> "Despite me telling them before the operation how the nurses should help me out of my wheelchair and onto the operating table, as well as where they shouldn't grab me, they didn't listen to me. Even while they were moving me, I could no longer feel my arms, and I couldn't move them, either. The next time I went in for an operation, I insisted that my assistant help me instead."

Personal assistance in aspiration (Photography: personal archive of Klaudija Poropat)

The left side of the photograph shows a man in an electric wheelchair, visible from the waist up. His right hand is resting on the wheelchair's controls. He has a cannula on his neck, attached to a breathing apparatus. Another man, on the right half of the photograph, is kneeling across from the first man. He is holding a tube with both hands, pushing it into the cannula.

What a personal assistant does not do

- **Massage and physiotherapy are not part of PA**

If the user gets a cramp or a neck spasm, which does happen sometimes, the assistant may massage the affected spot. This is only briefly, a few minutes at most. The user would do the same for themselves if not for their disability. The same applies to stretching. The assistant may help the user stretch or exercise if the user knows well what kind of help they need. For instance, they might say, "Please help me put my arms out in front of me and keep them there for a few seconds." While such assistance is part of PA, long massages and physiotherapy are not. Nobody massages the assistant for free or provides physiotherapy, even if their back hurts and a massage would feel nice. Often users justify their request by saying that the assistant wasn't doing anything else, so why not massage them. What it means in truth, though, is that the assistant is employed for too many hours if they have done everything necessary for PA and have nothing else to do.

"On the first day when my user returned from the hospital, her legal representative told me that, from then on, physiotherapy would be added to my duties alongside intimate care, and that I would need to provide physiotherapy twice daily. I resisted and said I wouldn't do it, after all I didn't even know how. She told me that if I wanted to keep my job, I would be doing that, too. I insisted, but we couldn't resolve the conflict. The legal representative called the PA provider and demanded they replace me."

- **PA does not include heavy maintenance work** such as painting walls, laying tiles, farm work, driving a tractor, or working in the service sector, etc.

- **PA does not include doing chores for the whole family**, for instance cleaning the rooms of the user's teenage or adult children. Despite the user saying that they would do it themselves were it not for their disability, the assistant should refuse such requests. The user should not use as their starting point everything that they would do if not for their disability. It is imperative that the user share household chores with other household members and not use their personal assistant to do the work of everyone else.

- **PA is not socializing**

"Since my user often wanted to talk to me when he didn't have anything to do, I got the feeling he was looking for a companion in me. I didn't want to converse with him like that, so whenever he started talking to me about his life, I just scrolled on my phone instead."

The personal assistant's qualifications

There is no requirement as to type or level of formal education for personal assistants, but they must have certain work qualifications. This includes a combination of abilities, theoretical knowledge, skills, values, and viewpoints. Assistants in large part learn the skills required for PA during their training by both the provider of PA and the user. Such skills are demonstrated by how effectively assistants work, and they comprise the principal reason for their employment. During their work, assistants gain the following:

- Understanding that PA is a service that helps the user pursue an independent life.

> Personal assistance in lighting a cigarette (Photography: Klaudija Poropat)
>
> On the right edge of the photograph is the profile of man seen from the back, from his left shoulder up. In front of him, at the height of his chin, he holds a cramped hand. He has a cigarette extended between his lips and the woman on the left of the photograph, who is sitting across from him, is lighting the cigarette with a lighter. There are cups on the table. In the background is a stone facade.

- Knowledge on using technical aids (e.g. wheelchair, breathing apparatus, etc.)

- Social skills of understanding personal space

- Protecting the user’s personal data and privacy

- Respecting the user as an employer, respecting the user’s ethical principles, decisions, and independence, as well as the principles of independent living

- Respecting other mutually accepted rules, agreements, and contractual obligations

- Familiarity with the principles of independent living and PA, with the responsibilities of both user and assistant, with effective communication and behavior, with the basics of intimate care, and with techniques to carry someone while protecting their spine

The personal assistant’s responsibility

- The assistant’s signature on the records of hours worked confirms that the records are accurate. This means that the assistant received a schedule and then worked during the hours recorded.

“I didn’t have enough hours one month, so my user suggested writing it off as vacation. I told her that such a lack of hours wasn’t my responsibility. I told her I didn’t want to use vacation to make up for missing hours. ‘You set the schedule, so I don’t feel responsible for the missing hours. I’m willing to make them up. You can schedule me back-to-back, or I can stay a little longer sometimes. She insisted that she would write it off as vacation, even though I refused. At the end of the month when she gave me the time sheet to sign, I saw that she had nonetheless written down vacation. I didn’t sign it.”

- The assistant communicates changes in any pertinent information immediately to the PA provider as formal employer, to facilitate bookkeeping and paying salaries.

- The assistant informs the user and then the PA provider immediately about any sick leaves, and then brings a doctor’s note by the end of the month.

- If any accident occurs on the job, the assistant immediately informs the PA provider. There is a special form for such reports.

- The assistant also informs the PA provider of any potential conflicts with the user, especially those that they cannot resolve by themselves.

- If the assistant needs a day off or needs to readjust working hours, they must inform the user as soon as possible, before the next schedule is sent out. The user will endeavor to honor this request, but it is not guaranteed. It is inappropriate to express displeasure with a schedule after it has already been sent out. For instance: the assistant knows they have a dentist appointment and so merely hopes they will not be put on the schedule for that time slot. Then the assistant receives the schedule and sees that, in fact, they are indeed scheduled for that slot, and only then asks the user to change it.

Inappropriate behavior among multiple assistants working for the same user

When they have situations or conflicts they cannot resolve with their user, assistants often seek support from (an)other assistant(s) who work(s) for the same user. Assistants who are contacted by their colleagues in this way, especially when this happens during their free time, often experience such behavior as excessive pressure. Most often, they can do nothing to help the situation and/or they do not want to get involved.

- Some assistants even go as far as agreeing on substitutions without the user's knowledge.

"I was in my bed in the morning waiting for my assistant to arrive. I was surprised when the front door opened and I heard the voice of my second assistant. The point is, a different assistant came to work than the one who was scheduled. I was a bit shocked, so I asked her before she began lifting me: 'Aren't you off today? Why did you come in, then?' She shrugged her shoulders and answered, 'The other assistant called me last night and asked if I could sub for her because she had some errand to take care of. I had time, so I was happy to do her a favor. She'll return the favor when she gets the chance.'"

- Some assistants monitor their colleagues' work and give them tasks to do without the user's knowledge.

"When I got to work, in the closet where we assistants leave our personal belongings there was a list waiting for me from the assistant who had worked before me. It had all the tasks that I needed to do during my shift. While I helped the user with the things she needed, the assistant who had left me the list called and asked, 'Did you already clean up the dust you forgot yesterday? After all, you know that Tuesday is dusting day.'"

- It also happens that assistants attempt to manipulate the user into changing the other assistant's behavior, pressuring the user into doing what they want.

“My assistant often resisted helping me do the grocery shopping, because she doesn’t like going to stores, as she finds them unpleasant.
She wanted me to make the decision not to go shopping with her, as that was a task I could do with the other assistants.”

- Assistants may not influence the user’s relationships with other assistants or engage in mobbing, violence, harassment, or other forms of pressuring the user or other assistants.

“During my shift, the user called the other assistant who was working for him, and they both ganged up on me. I didn’t stoop to their level, even though inside I was screaming because of how powerless I felt. I begged them to stop that, to stop the violence and aggression, or I would leave. But they didn’t stop. Despite the fact that I was used to it by then, as I had always stayed and listened to the accusations, the criticisms, and the insults, that time I just couldn’t take it anymore. I was suffering and experiencing indescribable anxiety and feelings of impotence, so I had no problem leaving the job. The other assistant continued yelling at me and continued verbally abusing me in front of the whole neighborhood. I didn’t say a word back to her. When I left, I was shaking and started crying along the way. That was the last straw, and from then on I couldn’t sleep, eat, or function normally in my everyday life. I went to a doctor who sent me to a psychiatrist that same day. The psychiatrist prescribed me a lot of anti-depressants and anti-psychotics. She suggested I get some rest and change my lifestyle.”

A comparison of personal assistance in Slovenia and the UK

“I was hired as a personal assistant in Ljubljana by an organization that took the Personal Assistance Act very seriously. There was creative and interactive onboarding for newly employed assistants. The woman I was helping was extremely active, with a well-developed work ethic and a clear picture of what personal assistance is. I can say this was the first time I enjoyed myself in a full-time position. Every bit of help I offered had a point to it, and I never deprived my user of their personal strength. And even if I had, she would have alerted me immediately. My provision of personal assistance was grounded in human rights, not in social transfer.

She was active in raising awareness. She held workshops for children as part of the Bontonček (Etiquette) Project. Only after the twentieth time that I heard from the students that you can’t play chess if you can’t see, or that someone in a wheelchair can't go to gym class, I realized how fortunate I was to have been in contact with disability in my family. Until then I had no idea that so many people had such misconceptions. Since we had an example of disability in the family, it was only logical that I considered disability as ordinary.

One of my uncles is actually an elite athlete. Even though you can't tell at first glance, he can't see very well. Both he and my aunt, as well as my father, were teachers at youth facilities for disabled children, and I spent a lot of time there growing up. Despite the fact that my other uncle hasn't been able to feel the lower half of his legs since birth and uses a wheelchair, he's extremely independent. I was happy that the word "invalid", even though still present in some legal contexts, is gradually fading in 'popularity' – also because of the work my user did with young people. The only path towards the equitable inclusion of people with disabilities in all facets of society is direct contact, the freedom for everyone's voice to be heard, and the broad dissemination of people's stories.

Assistance only makes sense if the user requires it. And at times it is indeed needed! Our society tends to place an enormous value on altruism and helping out those in need, but the type of help that would actually be reasonable is seriously lacking. Meanwhile there is even too much of the sort of people who like to show their good character through charity for 'the poor and the meek'. Unfortunately, they don't even realize, or if they do, it's even worse, that the majority of their efforts result in personally limiting the capacity for independent living and decision-making of the person they are 'helping'. No matter what the decisions, the most important thing for independent living is that everyone is prepared to accept responsibility for their actions. My job supported this understanding 100%, and I was proud of the work I was involved with.

After 6 months, I moved to London to try living with my girlfriend, who was studying there. This was a quantum leap that I jumped into with meager financial support. Even though I was open to any sort of job, I managed to find 2 jobs as a personal assistant in my first week, as there was a real lack of workers in this sector over there. I began working at a small organization that attracted my attention with their pamphlet, which read, "We don't care!"[2]. I found myself in a very similar environment, which gave users complete independence in choosing and managing their personal assistance, and which sharply criticized the UK's existing policies. In 2 weeks, I worked two or three times a week with a person of my age and helped them study virtual reality at college.

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[2] A clever play on words suggesting the organization did not have a patronizing attitude, e.g. "we provide PA not 'care' per se".

It was incredible to sit there and receive the knowledge that other people were paying a pretty penny for, and there I was on the clock, getting paid well just to be ready to type or handle objects if the user required it. If you work for someone who is a graduated director and music producer, and at the same time has been dealing with his own marginalization since birth, then you have a user who knows exactly what kind of help they need, and how that help is to be provided. I was there for the most crucial things, and the user did the rest by themselves, and was socially active. For example, while he was working in Uber's offices he managed to make sure that Uber in London doesn't charge extra for electric wheelchairs. This gave me good insight into the demographic of disabled people living an independent life, which is very, very rare in London, as I noticed at other jobs and during training.

I got my second job at a company that specialized in complex spinal injuries. At an intense training module, which lasted all week outside of London, in a building that was absolutely inaccessible for people that use a wheelchair, I became familiar with almost every tool and device that I could use on the job. I didn't, however, hear anything about users' independence. When I spoke up about that, everyone agreed, but the lecturers weren't interested in developing any concepts that transcended caregiving. Even though I was happy to have new knowledge, I nonetheless had the feeling that most of the training was focused on the legal aspects of caregiving, explaining in detail what our obligations are and what we can and cannot do. E.g.: we can't lift a user if they've fallen, we can't replace light bulbs or fuses. Every deviation from the routine spelled out in their "Care Plan« must be recorded, every single thing that the user does or has happened, e.g. falling or having high blood pressure, how much they eat and drink, how they feel, any emotional outbursts ... All this of course prevents both the user and assistant from filing lawsuits, and at the same time helps both users and the company itself refer to "facts" in the event that other social services get involved. Thus, the personal assistant's job is bogged down by a whole heap of bureaucracy. I learned why that is soon thereafter. After finishing training, because of which I had to live in a hotel outside of London, I learned that I needed to work for 3 months if I wanted the company to cover my accommodations. As is standard in this industry, of course nobody had told me that before I left for the training module. They assigned me a user who had jumped off the balcony of a mental institution and broken his neck. I already had some experience working with such cases, so we had a great working relationship for the first 2 months. I told myself that I would make it 3 months, after all I needed the money to cover my cost of living in the absurdly expensive London, where all of a sudden I was forced to work between 50 and 84 hours per week. We were both professional and personal, but soon he started applying his, as I later noticed, classic approach to each and every assistant. He always demanded undivided attention and care. If he didn't get that within almost every moment of a 12-hour shift with no breaks, he resorted to self-harm. Since I could 'read' him fairly well and was up front with him, and since I didn't make any excuses to take various breaks, he responded well to me. It was tough, but it worked. We had a period where he even started revisiting things he hadn't done in a while. He said he was excited that he could live so well given his condition. That he couldn't have even imagined this before then.

Honestly, his personal story was far from rosy. He was the son of a prostitute. He ran away from home twice and from his foster parents, and he led a wild life with the wrong crowd. Soon I noticed that he was quite keen to change his story for each assistant, adding bits that would earn him more sympathy. As if he wanted people to pity him. Since all of his income came from a trust following his lawsuit against the mental facility where he threw himself from the balcony, he was only given a portion of the funds, and he wasn't allowed to spend it himself. The money went to the rent on his huge, luxurious loft apartment, and for 3 full bags of medicine a week. And so I would walk the streets of London carrying over 1000 pounds worth of medical morphine. A lot of money went to pay his army of assistants, managers, doctors, and technicians, but not to a psychiatrist who could actually help him somehow. The healthcare system was somehow financing itself through him; us assistants, 2 every 12 hours, were there to make sure this situation could continue, to make sure he wouldn't put an end to the spending by committing suicide, which he tried often. The guy had his own routine, though he had some very funny moments, too, but his addiction to morphine and alcohol definitely didn't help anything. He often suggested to his assistants that we take some morphine or drink something with him, which we always refused. Even now, I ask myself how much he himself was to blame for his own situation. If I am to consider him as independent, then I of course must attribute responsibility for how he leads his life to him. But is he really completely responsible for his situation, or is the system he's trapped in responsible for it? Even if his assistants tried, they couldn't solve his circumstances for him until he decided to do so himself. It was as if his greatest strength was found in his ability to lodge complaints, both in the sense of complaining about his woes and tribulations, as well as in formal complaints in the form of legal pressure.

It was an interesting winter, in which I learned just how correct that other organization was where I had worked my other job. That organization was a brutal and relentless critic of the 'industry of caregiving' – a form of exploitation, which makes people dependent on the system, calls those who provide assistance "care workers", while users are called "clients". It keeps the subordinated disabled people in constant fear that something truly bad will happen, either legally or medically, while the industry "gently suffocates" them with care. It certainly doesn't help that there are so many actually counterproductive services available. And I really had the feeling that my work in such environment served to strip the user from his own power to decide, and the only thing fighting against that system was just a small organization with increasingly less help from the state. Many other users that I met or heard about seemed like but a cog in the machine for all of the institutions that provided them with aid. Primarily they are just recipients of care, and they are socially less active on purpose, as they are usually overcome with shame at every interaction with the public. They do not feel adequately equipped for a social life. This makes the job more like that of a nurse, or a security guard, than that of a personal assistant, as in that system the assistant is, alongside everything else, also legally responsible for the user taking their medication, even if they decide to overdose by themselves.

When the pandemic forced me back to Ljubljana, I finally realized that Slovenia is far more advanced in its understanding of disabled people's independent living. It seems that in London there are fewer people that understand the independent living approach, and even fewer people who actually lead independent lives with the help of their assistants. After returning to Slovenia, I began seeking employment as a personal assistant and I went to every interview, as I really wanted to know what the situation was like here. Several providers sadly left a very bad impression on me. Even though it should be proper personal assistance, in Slovenia, just as in London, it often takes the form of caregiving at home.

I found a weekly job working for a man who lived alone. His condition deteriorated suddenly, but he didn't have a diagnosis. Since everything happened so quickly, there was no legal framework for the help that he needed, and so he paid for his assistant out of pocket, and paid them handsomely. This is a tremendous expense for someone who pays for everything from their own savings, and it doesn't make things better for the assistant than in an actual full-time job, so I explained the law to him and helped him formalize his situation. Meanwhile I figured out that he wasn't interested in assistance as help with his everyday life, as he hadn't actually accepted his disability yet. As such, every second of his time and my work was devoted to curative practices. As people with more experience told me, it will probably take a bit of time before he can imagine a good and active life despite his disability, which in all likelihood cannot be "healed" more than it is already.

Among the providers of personal assistance, he chose one whose system was akin to institutionalized care for the elderly. I had the feeling that I would yet again be silently fighting against the company I worked for, while the user above all desired respect for his beliefs and help with curative measures, cooking, and personal hygiene. He didn't want to waste energy on anything else, and I respect that as his independent desire. I did decide to seek regular employment elsewhere.

In the meantime, I found a part-time job working for another man who lives alone. He spends his whole time at home, but he has a sharp mind and an honest smile. He needs help taking medication, getting dressed, eating ... Despite the fact that he only gets out of bed once a month, he has accepted his situation and he does everything that interests him. He has a lot of time to think about everything he likes. He enjoys spending time by himself. I can say that he is an excellent example of independent living, with a well-defined structure for my work, too. He told me recently with satisfaction that he never thought he'd live to see 50. He's one of those people who might not do a lot, but he lives as actively as possible within his limitations. He says that he'll keep on living like that for as long as he can. Then, more quietly, he added that the only thing he doesn't want is to become poor and pitied upon. The silence that followed makes everything clear. Poverty doesn't mean having a small apartment and advanced multiple sclerosis, you know? Poverty means no longer being able to make decisions about one's life, but just passively observing the world rushing by. I can do my job easily, as I just make it possible for him to be active in the things he has chosen to pursue. He does not need care per se, and he rejects it, but if that suits someone else, he doesn't get too mad. His choice to lead a private life is exactly that, his choice. His life is independent and active regardless of his illness or other people. And it really shows when someone is satisfied with their situation, including with their health."

Providers of personal assistance

Based on decisions issued by the Ministry of Labour, Family, Social Affairs and Equal Opportunities (herein MDDSZ), providers of PA must be registered as such. Competent providers require knowledge and specific skills to help them allocate and supervise the provision of PA, train assistants and users, respect rights and responsibilities, resolve conflicts, mediating between quarreling parties, and reporting instances of abuse.

Characteristics of a good provider

The providing organization must be familiar with the philosophy and concept of independent living. It is imperative that their understanding of disability center on human rights and the social model of disability.

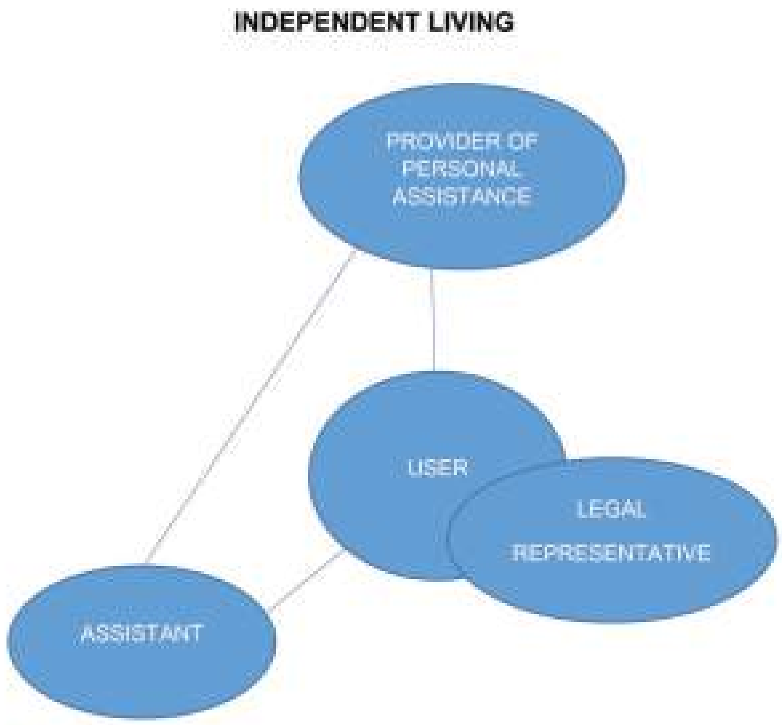
Providers of PA require the following knowledge:

- What independent living means and how it can help users lead their lives
- The principles of PA
- The difference between true PA services and other services
- The responsibilities of users, assistants, and providers of PA
- Effective behavioral and communicative practices
- Social skills of closeness and distance
- How to protect the personal data and privacy of both users and assistants
- How to respect ethical principles and the principles of independent living, along with the user's decisions and independence
- Knowledge of labor legislation

It is also important that providers of PA undergo training before they start providing PA.

The responsibilities of providers of personal assistance

The provider must be, above all, responsible for ensuring that users receive PA that helps them live independently. This makes it essential that the focus is on the user, that the user tells what PA services they need, that they choose the right assistant for themselves.



A diagram of independent living

At the top of the diagram is the title INDEPENDENT LIVING. There is an oval towards the bottom reading USER. That oval is partially covered by a circle that reads LEGAL REPRESENTATIVE. Two lines are coming out of the oval, the one on the left leading to a circle that reads ASSISTANT, and the one on the top to a circle reading PROVIDER OF PERSONAL ASSISTANCE. The circles for PROVIDER and ASSISTANT are connected by a line. The oval is as wide as 2 circles.

Similarly, the provider is responsible for PA's quality and professional nature. The provider's tasks are primarily based on their knowledge of the field. They offer users aid in managing their PA, they are responsible for the quality of that PA, they monitor their employed assistants, and they provide assistants with the help and support they need. All providers must employ a well-qualified manager. In addition to such a manager, large-scale providers also employ one or more PA coordinators, depending on the number of full-time assistants that they have.

Before they begin working together, the provider has an interview with potential users, explaining to them the principles of PA. Together with the user or their legal representative, a plan is made for how PA is to be administered, and the provider sticks to that plan. This action plan is a record of the specific PA services that the user estimates they will need, and the number of hours per week they will require assistance. It includes a very specific outline of the extent, type, and temporal distribution of the help they will need, as well as the number of assistants required. It is a framework that guides the user or their legal representative later to draw up a specific schedule for their assistant(s). The provider also conducts interviews with potential assistants, and then chooses the best ones, sending them to interviews with the user.

An integral part of the action plan is an agreement on the rights and responsibilities of users, assistants, and providers, which is signed by all parties before PA begins. It is important for the provider to ensure that all of these rights and obligations are understood and accepted by everyone. The provider sends to the competent Social Work Center (SWC) this plan before PA begins, as well as upon any subsequent change.

The provider must report to the competent ministry once per year on the implementation of PA per individual user, or as needed upon potential changes to its course. These reports are intended for evaluation and ultimately improving the quality of the services provided. After a certain amount of time, the provider checks whether the user actually needs all of the approved hours of PA. If not, the provider recommends changing the action plan.

The whole time, the provider supervises the process to make sure that the assistant is offering the user appropriate PA, and whether the user is managing their PA according to its integral principles. The provider requires the user to ensure the assistant has a safe working environment and also to ensure the right tools and devices, as well as the use thereof. Sometimes a user does not like to rely, for example, on a hoist, and the assistant agrees, thinking that it is indeed faster and easier not to. Even though they might both agree, it is unacceptable not to use such tools.

A user providing the assistant with technical tools and a safe working environment. (Photography: Klaudija Poropat)

This photograph was taken in a user's driveway in front of their house. On the left side is a man leaning forward, holding the handles of an electric wheelchair with both hands. He is looking up towards the top of two collapsible ramps, up which a woman in an electric wheelchair is riding into a van, which is on the right side of the photograph. Between the back of the van and the wheelchair is visible a boy's head, tilted towards the wheelchair's wheels on the ramp.

The provider needs to know what tasks the assistant performs, e.g. whether the assistant and user go to the store together, or whether the user sends the assistant by themselves. The provider is not interested, however, in what store they go or what the user buys. They are nonetheless interested in what kind of dynamic the user and assistant have, e.g. whether or not the assistant leaves the room if the user receives a guest, and whether they have such an agreement in place ahead of time. The provider is not interested in the personal aspects, e.g. in who is coming over in the first place or how often.

The provider's manager or PA coordinator verifies the state of things by observing PA at the user's home, i.e. by coming for a visit and observing what happens. One immediate red flag that PA is not being administered according to the principles of

PA is when, e.g., the assistant asks the attending manager or coordinator if they should make a cup of coffee, or if the assistant offers cookies that are on the table. The user should offer their own things, and should be the one to remember that this is the polite thing to do if they so desire. Then they can ask the assistant to make a cup of coffee. For such a minor task, it is not necessary for the user to be present. But then the assistant is not at fault if the user does not like the coffee.

If the provider suspects that the assistant is abusing sick leave, they can verify such leave with the assistant's doctor to see whether the assistant can move freely or must remain at home. Other measures might include visiting the assistant's home. In the event the assistant is not there, it could be considered a violation.

> "I had an assistant who was often on sick leave, especially when they weren't pleased with the schedule. One day, when my assistant had come back from sick leave, he was furious because the PA provider had asked his doctor about what kind of illness he was suffering from. Miraculously, he was never sick again from that day on."

The provider ensures the user support for improving self-esteem and education about managing PA. It is crucial that the provider makes peer support available to users, who can take advantage of such support whenever needed. Users can join peer support groups or rather benefit from individual support.

Peer support features a qualified peer counselor who has personal experience with disability, who listens, and who puts themselves in the shoes of the user, who is struggling with a circumstance in life for which they cannot find a good solution. Often the peer counselor has had similar circumstances and can relate to them, telling the user how they felt in the same situation and what they did about it. When the user finds that the counselor, too, is in a similar situation and has experienced the same struggles, the user learns that it is common and thus sheds some of their burden. The feeling that "something is wrong with the user" is precisely the sentiment that prevents users from seeking effective solutions. When the user finds the words to describe their situation, they can begin searching for possibilities that never occurred to them before. Talking with the peer counselor can shed light on and dissect aspects of the problematic circumstances that they never thought of before. The counselor helps them outline specific steps and find a path towards resolution. The peer counselor will guide whoever asks them for help towards seeking out their own options and limitations. This aids them in understanding their own circumstances and in making decisions about what to do differently.

The provider ensures the assistant a safe working environment, education on administering PA, and if necessary also supervision.

Personal assistant group supervision is a process by which people learn through reflection on their work experience. It is a method of encouraging employees' professional and personal development, especially among those who must often work with people. By working with the supervisor, the assistant learns from their own experience, seeking out their own solutions to problems they encounter on the job and seeking out ways of handling stress. In the process, assistants internalize the user's circumstances and their relationship with the user, while increasing recognition of their own thoughts and feelings. Corollary goals of the process include improving self-image and self-assessment, reducing risks of burnout, and strengthening interpersonal relations.

The provider may request that the competent SWC excuse them from providing PA to a specific user in the following cases:

- The user or their legal representative makes demands that cannot be fulfilled, e.g. regarding specific character traits from their assistants.
- The user does not provide the assistant with suitable working conditions (e.g. refuses to use a hoist), making the working environment unsafe.
- In their relationship with their assistant, the user does not act according to the action plan or otherwise violates labor legislation.
- Due to objective reasons, the provider cannot ensure the user PA.
- The provider finds that the user has submitted false information regarding the assistant's working hours.
- The provider loses faith in the user.

If the provider decides to stop providing PA, they must first inform the user or their legal representative as such. In the period between informing the user as such and actually ceasing to provide PA, the provider discusses and decides with the user how PA is to be administered in the meantime.

Circumstances where PA providers must intervene

- **Verifying information submitted by assistants or users**

"Two assistants reported their suspicion that their user was storing weapons at home. Despite being instructed to have a frank and open discussion with the user about that, neither one did anything about it. The user had to find out from me what the assistants were saying. When I did discuss it with her, she told me she has a plastic toy. But both assistants insisted that we needed to inform the police. When I visited the user at her home, it turned out that it really was a plastic toy."

- **They monitor how PA is provided and set boundaries for users and assistants if they have not done so already, and they offer support at the same time.**

"A new user was looking for 2 assistants. Finding the right ones and holding interviews with them proved a huge burden for her. She wanted to find 2 that could cover the whole week for her. After a few interviews, she found a candidate that assured her she was available for work anytime; she could work weekends and sometimes even in split shifts (i.e. a few hours in the morning, then again the same afternoon). As soon as we hired her, she started putting conditions on her schedule. She started work at 7 AM, even though the user needed her only at 10, when she woke up. After I stepped in, the user began controlling the schedule. She picked a different assistant so she could set the schedule she required to cover all her needs."

"When observing PA, I found that the assistant often expressed her dissatisfaction to the user with regard to her work and pay. The user was willing to put up with anything, just that she wouldn't need to look for a new assistant again. Despite me informing both of them that the assistant had crossed a line that could lead to her being let go, neither one of them realized it. The user was afraid of change and of ending up alone. After a few months, we needed to let the assistant go anyway, as her behavior was not helping the user lead an independent life, which is the whole point of PA."

"The user, who had 24/7 personal assistance, wanted assistants to stay awake and cover him if his sheets slid off. That's how it is at therapy centers, where the staff does rounds at night. The assistants said that pulling all-nighters in the dark was just too difficult. At an assessment meeting I told the user in front of the 2 assistants that our assistants would not be holding vigils over him, as that was not part of their responsibilities. If he gets cold enough, he'll wake up and ask the assistant to do something about it."

"The user's legal representative contacted me, saying that it was hard to work with the assistant because she was always insisting that she couldn't work at certain times. I asked the assistant, who confirmed that she did indeed have a few requests about the schedule, but that the legal representative had confirmed everything in writing. I said that compromises about the schedule are not self-evident, but they depend on the user's consent. I told her legal representative that she needed to use her own discretion to approve or deny a request, and to send the assistant a schedule that suited the user's needs."

- **If the user wants to replace an assistant, the provider must insist that the user explain what services the assistant was not providing or explain what the rationale is for such a change.**

"A young user chose an older assistant who acted more fatherly. The candidate also completed a trial period. After a while the user realized that the assistant got tired quickly and had no energy, and that with that kind of assistance he could not do the things that he needed to. He wanted to switch assistants but he didn't know how to list his reasons. He knew he couldn't meet all his needs with his current assistant, he had in mind a younger woman whom he was ready to employ. Since the user had requested that his assistant be a younger woman, at first glance it seemed like he was looking for a partner under false pretenses, as he stopped discussing it with me when I said he had to express his dissatisfaction in words and explain it to the assistant.
When I insisted that he explain to the assistant why he wanted to replace him, he dragged his feet for a while, and then told the assistant the real reason he didn't want to work with him anymore. During their conversation, the assistant also admitted that the user was right and agreed to parting ways."

- **The provider intervenes in cases where schedules are unfavorable and helps form schedules that both cover the user's needs and are also acceptable for the assistant.**

"The assistant told me that she works 13-hour shifts and is not allowed to leave the user alone during breaks to, for instance, go out when the user doesn't need her, for example during meals. Meals are made by the user's mother, who is also her legal representative; the user doesn't need help to eat, but she wants the company. This makes the assistant unhappy and makes her think about quitting, as it is difficult to spend 13 hours straight with the user. A conversation about how work was going showed that the user's mother was usually in the house during the assistant's shift, just in a different room. When I asked if it were possible for the assistant to leave the house during her break, the legal representative said yes. She added that the assistant had never asked for that before. After that, the assistant left the house during her breaks. Since a lack of communication can quickly lead to conflicts, I told both of them that they needed to have better communication in the future."

- **Unresolved conflicts, a loss of faith, and violence or abuse all constitute reasons for terminating the relationship between user and assistant.**

"The user needed 4 personal assistants as soon as possible. We told the first one at hiring that he could work no more than 40 hours a week and 6 days a week; the user would need to find help elsewhere for the remainder of the time. It's possible that the user might nonetheless ask for more, but it's necessary to set a clear boundary, or to refer the user back to us. He replied that there was no problem, that he'd be able to spend more time with the user since he needed help so much. I explained that this would violate labor legislation and that PA was a working relationship and not humanitarian aid. Disregarding instructions leads to problems, to being fed up with work, and to conflicts between assistants and users. I asked the assistant to think of the user just like an employer, not like somebody who would die without them. The assistant did not follow these instructions. Their relationship wasn't ideal. Soon several conflicts arose between them, including hatred, so we needed to separate them after a couple months."

Despite having PA available, many users limit themselves and do not dare to request that their employed assistants help them, as the users have a bad conscience and do not want to trouble their assistants. Then they apologize for having asked for help with a task that other people can do without even thinking about it, but at the same time they are unwilling to take responsibility for their own actions.

Changing the provider of personal assistance

The user has the right to change providers. They must justify this decision with specific reasons and references (e.g. listing what obligations the provider failed to meet). Practice has shown that users often want to fire assistants to avoid fulfilling their own obligations and to justify their decision. Changing providers is often just a cover-up for their desire to fire assistants who stick to the principles of PA for independent living without wanting to be the users' guardians or house servants. Some users want to change providers just to get rid of an assistant they do not like, even though there are not any actual reasons for firing them based on labor legislation. Some users want to change providers to one that does not require the user to take an active role, and that does not remind the user of their obligations. In this category are users who do not want to use a hoist or other devices to help their assistant have a safe working environment, or those who several times a day call their assistant to come over for a brief time, or those who otherwise do not adhere to labor legislation (e.g. regarding the structure of working hours).

"The user's legal representative wanted to give up her status as a retiree and secure a job as her adult son's assistant. Since the provider of PA didn't agree due to the conflict of interests, she decided to choose a different provider and didn't think anything was wrong with that."

Sometimes the reason for changing providers is that the user wants to avoid their debt from not having co-paid for PA[3]. It is imperative that providers in such cases return the user's voucher[4] after the user pays off their overdue fees.

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[3] Personal assistance users who are entitled to care allowance have to make monthly payments in the amount of half of their care allowance to their PA provider to help cover PA costs.

[4] This voucher is given to users, granting them the right to PA. They must present this voucher to the provider of PA.

4. SUPERVISING PERSONAL ASSISTANCE

Coordinators of personal assistance

In its Article 23, the PAA specifies that the coordinator of PA must be a SWC employee who is qualified and responsible for organizing PA for a specific user. This employee helps the user assess their own needs for PA for approval by the committee, and also supervises the provision of PA. They must have undergone training and must not have any prior criminal convictions related to physical violence, sexual inviolability, or discriminatory behavior based on disability as prescribed by other regulations.

After reviewing the potential user's application and finding unfulfilled conditions, the coordinator can deny the right to PA. If they determine that the conditions are fulfilled, they can name a two-person committee from the register of qualified experts, who then submit an opinion on the extent of time and range of PA services the user is entitled to. Based on the committee decision, the competent SWC issues a decision on the right to PA, determining the extent and type of PA services, also indicating who the legal representative is, should the user have one.

If the coordinator determines the user's PA needs have changed, they can recommend a reevaluation.

At least once per year (or as needed), the coordinator visits the user's home to observe the provision of PA. Part of this includes checking whether the user, their legal representative (if applicable), their assistants, and their family members are all doing their part in line with their responsibilities. If not, the coordinator once again explains each party's responsibilities and sets a new date to again verify whether each party kept their end of the deal. Another of the coordinator's tasks is to read the PA provider's annual report on PA for specific users, following up with the provider and/or user in the event of any lack of clarity.

Coordinators should undergo training before beginning their jobs. The expertise a coordinator needs include knowledge of:

- the philosophy of independent living and principles of PA
- the responsibilities of users, assistants, and providers of PA
- effective methods of communication with users.

5. ABUSE

Reasons why disabled people are abused

- **Financial, physical, and emotional dependence on others**

Many disabled adults, especially those with severe disabilities, do not work and do not have sufficient financial means to support themselves, and thus live in dependence on their relatives. Some even depend 24 hours a day on others for physical aid. Due to the need for constant care, most of them cannot construct for themselves the sense of intimacy or appropriate self-confidence and belief in themselves that would allow them to stand up for themselves in the face of painful or otherwise undesired physical contact or communication. They are too patient and passive in expressing their own needs and desires.

- **Communication obstacles**

People with an intellectual disability are often unable to express clearly what has happened to them. They also struggle with people not believing what they say. Due to a lack of proper social experience, many are even unequipped to recognize abuse. Some have only a limited vocabulary or limited possibilities for communication; others use substitutes for communication (computers/phones, pictures and symbols, sign language, etc.). Most forms of electronic or visual communicators and adapted forms of communicating do not use words, phrases, or pictures that would allow a disabled person to express their abuse or other form of victimhood.

Coordinators in this case suggest arranging for a direct advocate or spokesperson for the user, who can help in exercising their rights. Disabled people who live in centers for training, work, and care (hereinafter: CUDV) and have PA approved are often ignored and are rarely asked what services they actually want.

- **Neglect is not limited just to institutions, but can also occur within the family**

Many disabled people are excluded from the mainstream social environment and spend their school years in institutions. Their social neglect or segregation in schooling, employment, and housing translates to limited opportunities for participation in mainstream situations where they would otherwise typically meet and interact with people (their social interaction is limited to caregivers, therapists, and other professionals). Those who live in institutions are, statistically, often victims of abuse, especially to repeat offenders. In institutions, they often lack access to a telephone, and their friends and family members who might otherwise protect them similarly are not nearby; there are no police officers or other advocates, either. The hallmark of institutionalized care is disparity in power hierarchies between service providers and users.

- **Social aspects and myths**

Society tends to think of disabled people as less worthy than others. Their disability has the effect of robbing them of value. It ascribes to them just one “identity”, namely that of a “crippled person”. At the same time, few believe that disabled people can be abused. Further, society assumes that disabled people are asexual beings who are immune to pain and suffering, and that they do not feel things the way others do. This leads to the belief that abuse does not harm them to the same extent.

How to recognize abuse

Aggressive behavior, self-harm, and stubborn behavior are often the result of previous or ongoing abuse. However, many professionals working with PA do not recognize such reactions as stemming from abuse. Often they are just considered as general behavioral problems, and the recommended treatment is medication. It is easier to calm a person down by medicating them to the point of passivity than it is to strengthen them to the point where they can stand up for themselves and for their rights.

Abuse within the family

Regardless of how well a family has adjusted to everything that caring for a disabled person entails, still every now and again there arises some stressful incident. Any family member, most often the mother, can be exhausted from constantly caring for their disabled child, which increases the likelihood of abuse.

Stress factors can include financial status and changing material needs (e.g. growing children), social isolation, and transitional periods (starting daycare, school, new job, etc.). Parents feel shame and guilt for “having that kind of child”. Convinced that their disabled child will perceive their situation negatively (with fewer options and a lower quality of life than other kids), they are often extremely frustrated. These frustrations from the period where the disabled child is still young can continue into adulthood.

It is common that parents are far too overprotective with their “special needs” children. It is understandable that they want to protect their child from the “cruel and dangerous” world. But that can often lead to overprotectiveness.

Caregiving is strongly intertwined with violence towards users

- When someone gives care to a user instead of just offering them help when needed, the user has no way of choosing their own daily routine (when to go to the bathroom and how, when to bathe, eat, sleep, turn over in bed, wake up, etc.) or how that care is administered. Further, such users have no privacy and no control over their own body, nor over the medical procedures applied to them.

- People live in places where physical and psychological violence occurs with no witnesses.

“One PA coordinator asked me if I could offer some help with one of their users. She was acting rudely to her assistants, screaming at them or crying all the time, and so nobody wanted to work with her. The coordinator told me that due to the unacceptable behavior even social services had to get involved. He recommended holding a meeting together with the user, her assistant, mother, and the social worker, to help familiarize me with all the details. When the assistant who was filling in that day tried to help the user move her body into her wheelchair, the user began crying as soon as the assistant touched her. The social worker stepped in, saying she should stop crying, as that was inappropriate behavior. Her mother then complained that it was impossible to find a good assistant, and so she needed to help her daughter all the time, as she didn’t have enough assistance. She mentioned that everything was easier before when her husband could still help her. She told us how hard it was for her, since she now needed to take care of him, too, as he had fallen seriously ill. As soon as the mother mentioned her husband, the user began screaming even louder, and then burst into tears again. The social worker set boundaries for how she should act, which came across as very patronizing. I got the feeling that she was defending the parents. At the meeting, the coordinator, social worker, and user agreed that the user would change her behavior, otherwise the provider would stop sending assistants. She accepted the possibility of peer counseling, where she told me at the first meeting that her father had often abused her. She was also abused by one of the workers providing care at home, which triggered criminal investigations, which ultimately showed the worker's guilt. She also told me that social worker was a family friend of her parents. This also confirmed my suspicion that she was involved somehow, covering up a fact that she should never have ignored – what is even more, she was obliged to report the abuse. The user ultimately took advantage of peer counseling to process her experience. This was made possible because the counselor had also suffered abuse. This was a precondition for her even sharing her traumatic experience."

How to act in the event of violence

Disabled people: Build up a network of friends, join groups for self-help or other advocacy groups, engage yourself in hobbies, and pursue activities that bring you joy. Do not tolerate violence or abuse, and keep in mind that physical, emotional, and sexual abuse are all criminal offences. If any of them happen to you, you must tell someone. Remove yourself from environments where you feel threatened. There are options available for independent living within a community (some organizations have halfway houses, where users can live with PA until non-profit housing becomes available).

Parents, guardians: First, take care of yourselves, so you can then help your children. Use the services available (PA, help at home, OAC), realize your own needs, take care of yourselves, and find a way to relieve your burden. Rekindle or strengthen old friendships, make new ones, and do not isolate yourselves under any circumstances. Anger, depression, shame, and guilt may come and go; when they do, turn to a friend, counselor, or self-help group.

Assistants: Keep in mind that the users you are working with (or their family members) can indeed act abusively. As soon as you recognize any signs of violence, contact the PA provider. A good provider will protect the personal assistant even if users who violate the rules threaten their assistants and the provider themselves with replacing or changing providers.

Family members and users are capable of mobbing, harassing, or sexually harassing personal assistants.

“Sometimes my user’s husband has inappropriate comments: ‘Oh, how cute are you,’ or ‘what a nice ass you have’. The user then gets jealous, and instead of on her husband, she takes it out on me. Whenever I arrive at work in leggings, which I wear because they are comfortable and I can work more easily in them, she accuses me, ‘Why are you dressing so provocatively, that we can see all your curves? It’s your fault my husband isn’t paying attention to me, because you’re seducing him.’”

6. CHALLENGES IN PROVIDING PERSONAL ASSISTANCE

Before the PAA was adopted, YHD warned the ministry and the public about the traps, dangers, complications, and dire practical and financial consequences that nobody else had foreseen or planned for.

Since they lack other forms of assistance that would suit the diverse needs of a wide range of users, and since they lack a useful filter to sort out which service is appropriate for whom, some people receive PA despite it not being the right service for them (e.g. users who are not active and who have no desire for an independent life)[5].

YHD, which has been striving for over 25 years to promote independent living and enact legislation regarding PA, was hardly neutral in its expectations of what the adoption of the PAA would bring. For years the organization had worked intensively on the delineation, substantive difference, and legislative definition that PA (and the associated right to independent living) would be an individual right. As PA is outlined in **Article 19 of the Convention on the Rights of Persons with Disabilities**, we must not allow it to be reduced in its content to merely a bit more than just a long-term caregiving service. After all, this is a modern and independent legal act that is founded on the social model, entailing paradigmatic shifts in social welfare and not on the medical model, involving the patronizing practices of formal and institutional care. PAA stresses the user's activeness as one of the principle factors in determining the estimated extent of PA that they need. The conceptual founding of PA centers on the user living independently and actively, as a member of society on an equal footing as everyone else, which is enshrined in the Act's Article 2.

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[5] On January 1st 2019, when the PAA came into force, there were 311 users of PA. In December 2022, there were 3970 users of PA.
According to PAA, the right to PA can be obtained by people aged 18 to 65 who have permanent residency in Slovenia, do not live in an institution, and need at least 30 hours of assistance per week because of their disability. Users who used PA before reaching the age of 65 can keep the service after that age.

Inappropriate methodology in assessing the need for personal assistance

The methodology used to assess the need for PA, as outlined by the Social Protection Institute of the Republic of Slovenia (hereinafter: IRSSV), had already proven ineffective before the act's adoption. Based on its decades-long experience in providing PA, YHD suggested that, instead of the inappropriate medical model, the institute use the much more useful social model, which considers the user's activeness as a factor. They nonetheless pursued methodology primarily based on the medical model, which has proven to be a conceptual mistake. In formulating a tool, they adapted the German model of long-term care, which, based as it is on the prevalent medical model, focuses on ranking users by diagnosis and measuring their physical capabilities. Taking the opposite approach, PA is based on the social model and on the equal application of human and civil rights. It thus opens up a new dimension of seeing, understanding, conceptualizing, and relating to the concept of disability.

After a year and a half of providing PA according to the PAA, the IRSSV assessed its tool as ineffective, and so they undertook to develop a new one, whose primary focus was on daily activities.

Their existing assessment tool only evaluated users' "self-sufficiency" instead of **their actual need for PA**. As such, assessments of users' self-sufficiency were often arbitrary and inconsistent. Those who are of a pessimistic nature a priori view themselves as less self-sufficient than others. Other people who are in fact far less capable or even entirely incapable but are more optimistic by nature can feel completely self-sufficient with PA. A similar trend is observed in assessing work capacity. Many users were assessed as incapable of work, but with PA plenty of them were able to work with no problem, even in demanding responsible positions. It is clear that the first assessment tool rewarded passivity. It seems as if it was punishing those who tried their hardest to accomplish as much as possible by themselves.

It would be best to modify this tool so that it assesses the necessity for PA based on the user's actual needs in performing everyday activities, and not just what is necessary for survival or for leisure time. The emphasis should be on education and work.

Personal assistance at the workplace (Photography: Klaudija Poropat)

The left side of the photograph shows a man visible from the waist up. His head is leaning on his wheelchair's headrest. He holds a brush with his teeth, using it to paint the canvas on the right side of the photograph. In the background between him and the canvas stands a woman who is looking at the brush's tip. She is holding a palette in her left hand and a cup with traces of paint on its edge in her right. Behind them is the brick wall of the atrium where they are painting.

Let's use two blind people for an illustration: the first is at home most of the time and only ventures out in well-known places. The other is quite active and enjoys exploring the unknown. If self-sufficiency is our only metric, then neither of them is self-sufficient in unfamiliar places. If the need for assistance is the metric, then the person who spends all their time at home needs little, while the active person who heads off to new places requires PA for accompaniment.

It is crucial that, instead of the medical model, we begin asking socially based questions, the sort that apply equally to those with and without disabilities. These questions should target access to education, employment, romantic partnerships, access to medical services, protection from violence, participation in society, etc. Sadly, though, far too often disabled people are viewed as poor souls who need a "good-hearted helper" instead of rights and true support.

Unqualified evaluators of the need for personal assistance

In a very short period of time after the adoption of PAA, Slovenia gained more than 100 “experts” in “social protection and health” who considered themselves “representatives of users based on their diagnosis”; these people determined who had the right to PA. It is impossible in such a short period to properly train “experts”. Furthermore, it was clear at the beginning that we did not need that many. Even the idea of “representatives of users based on their diagnosis” hints at application of the medical model of PA, which is incompatible with the idea that users aiming for an independent life need specific types of support regardless of diagnosis.

Some evaluators failed to understand how important their role was. They often ended up pitying users, giving them access to more hours of PA than other people who needed it in a greater extent; some were allocated their share of PA just based on their appearance or on the user’s family’s general social status. Some users even exaggerated their disability to garner more sympathy before the commission. As an example, there was even a person who could walk just fine who attended their evaluation in a wheelchair. That helped them even earn the right to multiple assistants, even though their actual need for help was so insignificant that it should not have qualified for any assistance.

Cases like this could happen because the commission was not authorized to check any medical documentation of the applicants. Since the PAA was amended in October 2021, this has not been the case anymore. The amendment also defined the Social Protection Institute of the Republic of Slovenia (IRSSV) as an institution that carries out evaluations with their professional team of experts. The amended law also mandates that reassessment should be made in no more than five years after the applicant has obtained the right to PA. However, so far no reassessments have been made.

Unqualified providers of personal assistance

Providing PA became a business opportunity for many sole proprietors after PAA came into force in 2019. Some of them even had borderline absurd job descriptions in the register of legal entities, like “tailor, cabinetmaker, taxi driver, textile worker, tutor, babysitter, and caregiver for the elderly”. We noticed that even social protection became commercialized and commoditized. For instance, someone who considers themselves “handicapped” expects their assistant to do all the things that they themselves dislike doing, even if they are physically capable. The user avoids unpleasant tasks, insisting that it would take them too much time, and therefore would not have time for pleasant things. For a better illustration: if the user does not like to vacuum, clean the sink, or make meals (e.g. not even spreading jam on bread), they believe that it is the assistant’s job to perform such tasks. While the assistant is occupied with such tasks, the user does whatever they want, from sleeping to idling online, etc.

It seems that, more and more often, the crafters and implementers of social policy are systemically uninterested in limiting such opportunistic approaches and in setting clear criteria for approving providers. Only this would help them ensure high-quality provision of PA. Similarly, several new providers popped up who succeeded in attracting a large number of users rather quickly. Such users are of the opinion that these providers “do not complicate things”. This means that they do not demand things of assistants and users that the PAA requires them to. They are not interested in the users’ independent living and they do not understand the difference between caregiving and assistance.

After almost three years, PAA was amended. The amendment enforced the conditions that providers must fulfill to some degree. Sole proprietors can no longer be PA providers, a provider needs to provide PA to at least 10 users and needs to employ a director with required professional certification in the area of social care, otherwise it is struck from the register of providers at Ministry of Labour, Family and Social Affairs. Consequently, the number of providers decreased from more than 200 to the current 107. Alongside the humanitarian and disability organizations that obtained such legal status, the majority of providers are currently private institutes.

Family members as personal assistants

Users all over the world have stressed how PA provides them with significantly more freedom and independence than they would have if their parents, partners, or other relatives were to provide care. Family members are often too patronizing in their approach. Some families are even guilty of abuse, preventing the disabled person from joining social activities that interest them (for instance, excluding them from the OAC to secure their own employment and social security).

Independent living centers worldwide thus do not employ family members, but people from outside of familial circles. Family members can be useful in a pinch for substituting, as they are usually available when the user needs them. But it has been clearly shown that it is not appropriate for family members to be full-time providers of PA (see Chapter 2 on the point of PA). The purpose of the PAA was to take the burden off of family members, meaning that they would not provide PA themselves, but the user would choose an external assistant. Exactly what was not supposed to happen did indeed occur in Slovenia – in some families whopping three members became assistants. Would a college student in a wheelchair want to go clubbing with her mother? Would a young man want to go visit his girlfriend with his father?

After 2004, many unemployed family members of disabled people and those who had left their work to care for them now became family care providers. When the PAA was adopted, many of these people changed their status from family to personal assistant to ensure a better social standing (higher pay, vacation days, sick leave, etc.). This practice is directly at odds with the philosophy of independent living, which YHD stressed before the act's adoption. An assistant is, after all, employed by the user, who acts as an informal employer. Their work, which is detailed clearly by a contract, is compensated. Users can fire assistants who do not work up to standard. Under such conditions, PA affords people more independence, more social options, and more choice. Can we fire our mother, replace our husband, or report abuse from the brother we depend on? Or can we report a family member for poor work results, a family member who, due to the sheer indifference of planners and responsible social security organizations, has become both legal representative and assistant all in one? This is similar to an outdated practice that we overcame with years of hard work, where the director of an institution where a person was living was also said person's official guardian, leading to a serious conflict of interests.

If family members can become assistants, then users of PA do not have the same freedom they would have if someone outside the family circle were employed in this role. Sometimes the PA provider and assistant are the same person. For instance, take a father who has registered as a provider of PA and who then becomes assistant to his adult son, for whom the court has awarded the father custody. The same father as provider of PA then becomes employer to his son's 3 other assistants, in this case the son's mother and sister, and one other person as well.

Who, then, in such a precarious system is responsible for following how PA is being carried out and what actions can be taken in the event of violation of the legal acts that constitute PA? Who will even flag discrepancies and report them, as after all the users themselves are dependent upon their family members? If PA is an essential condition for independent living leading to freedom and choice, then the examples above lead in the opposite direction, as the currently established social system lacks any mechanisms to prevent and mitigate such situations.

Having a disability does not mean that others get to make decisions for you, that you are incapable of making normal choices, or that you are not allowed to have desires just like everyone else. Those who view disabled people just as those who require “care” also tend to view PA as a way to earn money, ergo as a good business opportunity. They lack true awareness about what PA is in the first place.

The essence of PA is ensuring users an independent life. This helps realize the fundamental purpose of the Convention on the Rights of Persons with Disabilities, namely to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all disabled persons, and to promote respect for their inherent dignity. PA gives such people the option of changing their station in society, from that of a passive recipient of help to the active forger of their own lives. If assistants are not related to the user, then the user has more options for socialization and participation in society, which is obviously to their benefit and in line with the principles of PA.

Personal assistance in recreational activities for a woman who cannot see (Photography: Klaudija Poropat)

> On the right of the photograph are 2 women cycling on a tandem bike. They are visible from the side, facing towards the left of the photograph. The first is leaning forward and looking at the bike path, while the other is sitting up straight with her eyes closed. Woods are in the background.

From 2019 to the adoption of the amendment of PAA in October 2021, there was no limit to what extent family members can carry out PA, nor was there a mechanism to verify whether family members are appropriate providers. The amendment limited the number of relatives as user's assistants to two. The relatives mentioned in the PAA are parents, children, spouses and out-of-marriage partners and their children and parents, brothers and sisters, uncles and aunts, grandchildren etc.

Practice has shown that users achieve the highest degree of independence when they have at maximum just one family member employed as a personal assistant. It is thus crucial to limit the employment of family members as personal assistants – they should only provide PA in reserved amounts. For instance, a user with 40 hours of approved PA should under no circumstances employ a family member for all of those hours. A user with even more hours approved could employ at most one family member.

Findings of PA coordinators at the SWC

After conducting supervision in 2020, coordinators of PA at social work centers listed as the benefits of PA the users' increased independence and the relief felt by users' informal networks that provide the aid that users need.

They also found negative effects: user aggression, more unsuitable working environments for assistants, users' family members preventing assistants from entering. When assistants' work is performed by family members, PA often fails to achieve its purpose – the user is not ensured better chances at a more active and more independent life.

Coordinators also face the following challenges in providing PA:

- The roles of family members must be clearly delineated (the mother may not simultaneously be assistant, legal representative, and provider of PA).

- Because families often act in a patronizing and overprotective way towards their disabled members, the user's relatives may not be primary providers of PA, but just part-time assistants. Only external assistants can truly help users lead active and independent lives.

Personal assistance at the supermarket (Photography: Klaudija Poropat)

At the store in front of shelves containing canned fruit stand two women, visible from the knees up. The first, in the lower left quadrant, is sitting in a wheelchair and holding a shopping basket in her lap. She is facing the other woman, who is on the right side of the photograph. The other woman is putting a jar with olives into the basket.

- Family members often limit or even entirely render impossible the user's participation in other services (e.g. OAC) in order to employ as many family members as possible and ensure the greatest possible income. The rationale here is that the number of hours that users spend at OACs are deducted from their weekly quota of PA.

- When assistants are family members, the user has little influence on the choice of PA provider. If the user has an intellectual disability, then that influence is usually reduced to none.

- Family members who are also assistants often demand schedules at hours when there is less work and more money (e.g. at night). If the PA provider requires all assistants to split up the schedule equally, then the parents/legal representatives, who are also assistants themselves usually, demand the provider's replacement, seeking one that will accommodate their request.

- Users who attend centers for training, work, and care (CUDV) do not have the right to PA according to the PAA. Experience has shown that the service is redundant, which means that, despite being at a CUDV, the user still could use PA. Thus, they benefit from what should be two mutually exclusive services.

- PA is not appropriate for everyone. Users who are not active will have better benefit from long-term care. Since such a service does not yet exist, people take advantage of PA in its stead.

Parents or other family members providing PA to their adult child/family member are often at the advantaged end of a power dynamic, a position that they can ultimately abuse. It is common that parents are far too overprotective of their disabled children. Parents prevent them from acquiring social skills through contact with their surroundings, and thus depriving them of life experiences. Thus, they miss out on the chance to develop skills and capabilities that they would otherwise be able to if they had an assistant who was not a family member. If family members take on the disabled child's tasks without good reason, they force such a child into a submissive and debilitated role, ultimately harming them much more than helping. As a result, such children form a negative self-image, believing in their own impotence and dependence. In short, the user becomes the OBJECT of care and supervision.

Harmful practices, abuse, and violating the Personal Assistance Act

- **Both user and assistant falsify the true nature of things, not adhering to PA as its principles describe**

"When I began working, my user often reminded me that things weren't always what they seemed. He made it clear that he was the boss. At his home, it was his rules that applied, not the rules of the PA provider who was employing me. He said that he had his own needs and expectations, and as long as I respected that, everything would be fine. Otherwise, we'd have problems. He informed me that I should forget everything I had learned at training, because he found it all ridiculous nonsense. He added that I should never contact the provider for anything. If the provider ever called me, I wasn't allowed to answer, but I had to call the user first so we could 'get our stories straight'. The PA coordinator called me often, but I wasn't allowed to answer. I had to first call the user, then I could call the coordinator back. He was treating me like some risky link in the chain, as I kept telling him that we needed to inform the provider about some things and that I disagreed with what he was doing. The other 2 assistants had years ago agreed to the user's conditions, as everyone had their own benefits from the arrangement. My objections got on his nerves, and he kept repeating that I needed to watch out. The other 2 assistants were complicit, but he was afraid that I would say too much. He said I was going to ruin everything, that he would lose his personal assistance, along with all 3 assistants and even his job. And that it would be all my fault! The provider couldn't find out what was happening, how we were working, and how we were providing personal assistance. What was being submitted to the provider – schedules, work records, reports on trial periods – was not what was actually happening. The provider was just a necessary evil so the user could even have PA in the first place. The work I did for him wasn't even personal assistance."

"When, after training, I returned to work, my user told me that for her personal assistance wasn't even close to that which they explained to us during training. Working for her always meant that she would tell me in the morning everything that needed to be done for her and for her husband: cleaning their apartment, changing their bed, hanging the wash, and making lunch, while the whole time she was on her computer, watching TV, or talking on the phone."

"As soon as I started working, I was informed that, even since before my arrival, 2 different schedules were in place; one for the provider and one for our purposes. The official schedule and records for the provider were to be stricter and greater in their extent, such that they listed significantly more hours than we were actually present and working for. The user's excuse was that he didn't actually need so much personal assistance. What he did need was for me to be completely flexible and cover all holidays, weekends, and any other times his other 2 assistants couldn't work."

“When I found that the work records didn’t match the hours I had worked, I objected and refused to sign. I later found the user had exploited my electronic signature and just signed off on the schedules by himself. I even had to work when I was officially on vacation.”

- **Users abuse the power they receive as informal employers**

“My user called me on the phone and said I’m obviously stupid since I don’t understand his schedules. That he’s my boss after all and I need to come whenever he says, no matter what the schedule said. I needed to be available regardless of what he himself scheduled. Without him knowing it, I wasn’t allowed to go anywhere.”

“One time I pushed back against my user, and afterwards, when I came to work, a printed letter of resignation was waiting for me, which he had written himself. He demanded that I sign it and that he would then take it to the provider. I told him clearly that I wouldn’t be signing anything, after all he wasn’t my employer. I also made it clear that, were I to resign, it would be to the provider and that had nothing to do with him.”

- **The user abuses their subordinate position that their disabled status affords them**

“My user often demanded that I change schedules despite my protesting that I already had other obligations booked. He told me that I can make adjustments more easily since I’m healthy and nothing’s wrong with me, unlike him, a handicapped person.”

- **Instead of seeing PA as an opportunity to take the burden off of them, families abuse it to increase their own financial circumstances.**

  Often disabled people first want to employ family members. When a user has more hours of PA approved than family members to cover it, then they look to external assistants. That external assistant will then provide other services that other citizens usually have to pay for – more or less acting like a maid or servant. In such an environment, users will never be able to realize their own independence. Their assistants, who are at the same time family members, tend to place conditions on everything they do, making the user a prisoner. At the same time, they are financially dependent on the user, receiving money through them for their (lack of) work.

PA is not a social transfer. Its purpose is to give people with serious disabilities an active and independent life. It was not designed to facilitate disabled people continuing to live with their “handicap” in an inactive and ineffective way, only doing things that they like. They know their “rights” well, and exercise them. On the other hand, they do not realize their own civic responsibilities and obligations to be active with the help of PA, to find a job, and to participate in various ways in society. Too often, they fail to take advantage of such opportunities. They prefer persisting in their powerless, passive, and patronized role. They even abuse PA such that assistants do for them the tasks they find least pleasant, using their own time for enjoyable things that do not contribute back to society.

Many PA coordinators at SWCs can attest to the attempts at extortion on the part of family members employed as assistants. They pressure the provider to schedule hours that are paid the most (night shifts, Sundays, holidays). The worst part is that life does not improve for the user.

“I went to supervise PA for a 48 year-old woman who could hardly speak and, after a severe stroke, could no longer read or write either. Her personal assistant was her partner. I soon found that he wasn’t providing her with assistance, as he had problems with alcohol. As a result, she was locked up all day, since she couldn’t come out by herself. She needs assistance, sure, but with a person who will actually provide what she needs. The current arrangement just means her partner has even more money for alcohol.”

Instead of the user becoming more active in a range of senses (e.g. finding a job and even becoming financially independent), they remain a captive to the old, outdated restraints of “handicap”.

“During training for assistants and users, one user’s mother came up to me and asked me what she needed to do to get another 10 hours a week approved, as then she would have a full-time job. During a coffee break, though, the user himself asked me what he needed to do to be able to leave his home and begin living ‘on his own’.”

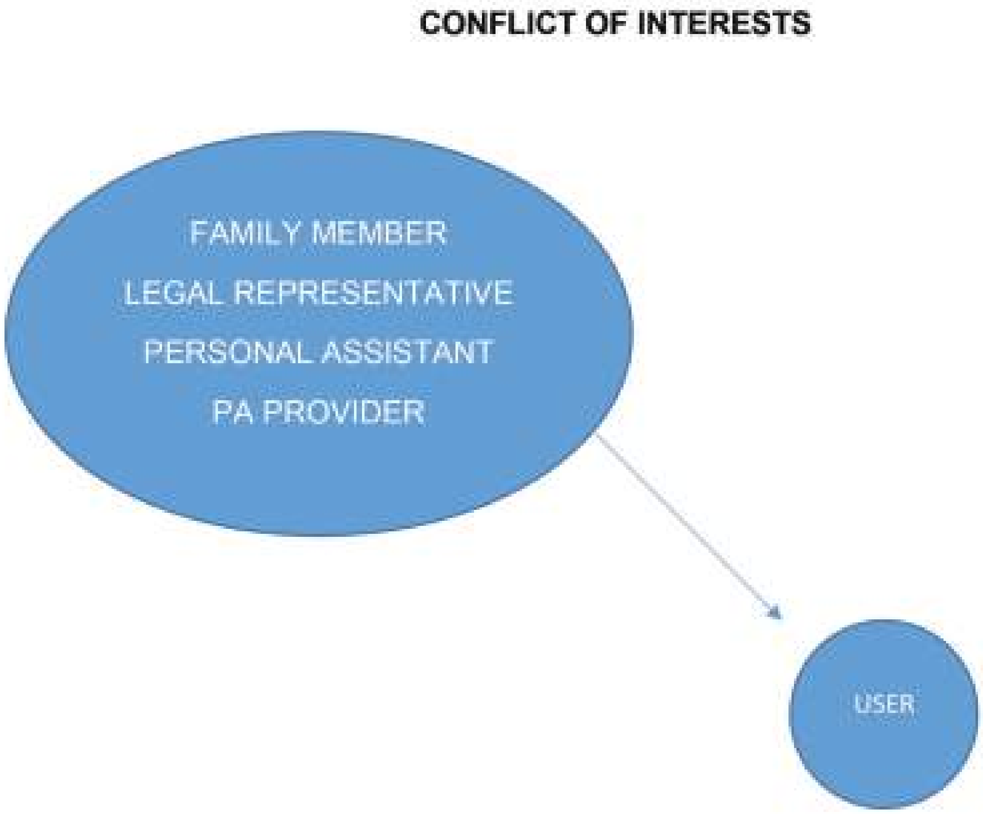
- **Many newly created providers latched on to PA as a new business opportunity.** Overnight there was a whole heap of new sole proprietors, organizations, and associations providing PA without the appropriate expertise, training, references, or even understanding of the PAA’s principles and objectives.

- **It often happens that the user becomes the focus of all attention and people see the “problem” in them.** It should be that the user expresses what they want and need. The legal representative, assistant, and provider of PA should respect that and make it possible for them to live independently.

- **Being the user’s legal representative and assistant or even provider of PA at the same time is an unacceptable conflict of interests.** In this case, the user tends not to receive anything from PA, but sooner loses something. When the user’s interest becomes secondary, abuse becomes a consequence of incompatible interests. At that point, the interests of the family member or legal representative, namely for their own personal social security, or even for the personal need to be a care provider, become paramount. Ultimately, the disabled person does not have a chance at deciding for an independent life.

“In my opinion the biggest problem is when the user’s legal representative is at the same time their provider and personal assistant. Or even just their assistant. I see that, almost as a rule, they do not understand the concept of personal assistance, namely to give users the power to make decisions for themselves. They isolate their own kin, preventing them from participating in a social environment at an OAC just to increase their own working hours. It has happened that we’ve gone for second assessment to a user whose grandfather, in addition to his mother who is already employed as a personal assistant, would like to come out of retirement and work as an assistant, too. The whole time, the boy wanted to say that he’d like to have a girlfriend and move out on his own, but his parents didn’t want to listen to him, not even letting him speak up to tell us that himself. They hadn’t let him go to the OAC for a few months now, ever since his mother became employed as an assistant. And now they want to secure even more hours for the family, so the user’s father could become an assistant, too.”
(PA coordinator at a SWC)

“A user’s mother, who is also his legal representative, called me and said they would no longer be using us for personal assistance. Since we wouldn’t allow her to become her son’s personal assistant alongside the already employed father, she would open her own business and employ herself as his assistant. I asked her, ‘If something happens to you, what will happen with your son?’ She coolly replied, ‘I hope my son dies before I do.’”
(PA coordinator at a SWC)



A diagram of overlapping interests

At the top of the diagram is the title “OVERLAPPING INTERESTS”. The top left has an oval reading “FAMILY MEMBER”, “LEGAL REPRESENTATIVE”, “PERSONAL ASSISTANT”, and “PA PROVIDER”. A diagonal line leads to the bottom right corner with an arrow to a circle reading “USER”. The circle is about a 5th of the size of the oval.

- **For users who have a legal representative and cannot act as their assistants’ informal employer, their parents or guardians often end up using PA services for themselves.** This means, e.g., that assistants clean their homes instead of helping the user for whom PA was approved. It also happens that the user gives assistants tasks that the user does not feel like undertaking, even though they could complete such tasks without help.

“When I got to work, the user’s mother, who is also his legal representative, wouldn’t let me in the same room as the user because of the coronavirus pandemic. Instead, there was a whole heap of dishes to wash from the day before when they slaughtered and dismembered an animal.”

AFTERWORD

The fundamental condition for managing and providing PA is understanding the principles of independent living. This means that both assistants and providers require appropriate training for administering PA, and users require training for managing it. This training comes in the form of educational/training modules and sessions, which are imperative. Just briefly familiarizing oneself with the field is far from sufficient, even for users.

Independent living is the fundamental right for anyone to choose where they live and what they do. If they require assistance in performing any of their activities, they have the option of receiving that help. The option in question is PA, which helps disabled people to the same starting point as others in their ability to pursue and fulfill all the roles in their lives. In short, disabilities can no longer serve as an excuse for being inactive or feigning inability.

Society often treats disabled people as incapable people instead of focusing on the skills and capabilities they do have for various societal roles, for which they might every now and then require accessible options. Accessibility does not count as a special need but is a universal one! It is crucial that we treat disabled people just as we would anyone else – respectfully and, if necessary, with compassionate flexibility.

Above all, independent living imposes upon the user responsibility for their own decisions, upon the provider and assistant for helping the user lead their life independently. This means that they must respect the user’s decisions. Listening to users is the most important part of providing PA, hearing them specify themselves what kind of help they need and how that help is to be carried out. The assistant and providers should not regard their aid from their own perspectives, especially in terms of what they imagine a person should be capable of, what a person needs, and how a person can be helped. If they truly desire to ensure an independent life for the user, then it is imperative that they learn about the user’s needs, respecting them and respecting whatever modifications are necessary. If the provider and assistant help the user according to their own suppositions, then their aid is not PA but is actually caregiving, which is known for its patronizing and condescending nature.

The user is responsible for their own decisions, and the assistant for respecting them. Confidentiality, trust, and respect are not self-evident; the user and assistant must both work to establish and maintain these qualities. If they intend on having a good relationship, they must invest time and energy. They must have frank and open conversations about their needs, expectations, and various viewpoints.
It is a reciprocal relationship, in which the user also respects the assistant's needs (safe and appropriate working environment, working hours, personal life, etc.). The user and assistant discuss matters, but it is fruitless to just complain about one another's behavior. It is the assistant's right and responsibility to set firm boundaries and to even reject work that would potentially harm their health, or work that violates their ethical principles. Respect is built through clear communication about needs and through agreements on how to realize those needs. Sometimes they will think these things go without saying that they will be able to "read each other's minds" or intuitively understand one another without explicitly expressing what is on their mind. Until an open conversation is had, they cannot demand respect from one another. Sharing responsibilities leads to good cooperation, where both parties know and exercise their rights. One party's rights end where the other's begin. This leads to independent living for the user, and a safe and healthy workplace for the assistant.

It is key that users transform their perceived rights to independent living – they must realize that PA is not merely a right, but that managing it is a huge responsibility.

If they want to see for themselves how much PA can help them live independently, they must take an active approach to observing the results of PA and of determining what stands in the way of fully independent life. Once those barriers are identified, possibilities for overcoming them must be sought. As such, it is important that the provider monitor how specifically the individual's life has been improved by PA:

- Do they have greater influence, more options, and more opportunities?
- Have they moved into their own home?
- Were they able to find a job?
- Do they actively participate in that which is important to them?
- How has their life actually changed since exercising their right to PA?

- What can they do with the help of PA that they couldn’t before?
- How has their life changed due to their newfound independence from family members?

Here the user should, when reflecting upon their own PA and their assistants, focus on these questions: What do assistants make possible for them? What all used to be impossible and is now possible thanks to PA?

Commonly used abbreviations

PA – Personal Assistance

SWC – Social Work Center

CUDV – Center for Training, Work, and Care

ENIL – European Network for Independent Living

FIHO – Foundation for the Financing of Organisations of the Disabled and Humanitarian Organisations

IRSSV – Social Protection Institute of the Republic of Slovenia

MDDSZ – The Ministry of Labour, Family and Social Affairs

NŽH – Independent Living for the Disabled Project

PAA – Personal Assistance Act

ZRSZ – Employment Service of the Republic of Slovenia

YHD (Young, **Handicapped**, Deprivileged) – Association for the Theory and Culture of **Handicap**

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**This new impressive guide to Personal Assistance by the Slovenian Independent Living organisation YHD is a unique contribution to the essential resources of Personal Assistance. What is remarkable about this Manual is that it was developed and designed by one of the most resilient and formidable Independent Living Organisation in Europe.
They have achieved this significant document against all the odds and have transformed the thinking about Independent Living and the equality of disabled people and the importance of disability rights in Slovenia.**

This is a great achievement and is a "must read" for anybody who embarks upon the journey as a personal assistant user wanting to liberate their lives in finding freedom, self-determination and independence.

**John Evans OBE
Independent Living Expert**

**I have had the privilege of following YHD for a few decades.
YHD is a beautiful example of how a few people with extensive disabilities helped each other change their definitions of themselves from objects of care and charity to subjects of their lives, how this enabled them to analyse their situation in society, formulate their needs, design services for meeting them, and tirelessly bombard the government to fund these services.**

They used their intelligence and anger, the arts and humor, they formed coalitions with artists and researchers. All this in a post-communist society where the leaders of the national umbrella organization for people with disabilities continued to defend and run profitable institutions from the communist era.

**YHD is well on its way to success. An incredible feat!
The present handbook on personal assistance is one of the milestones in their long fight toward equal rights and equal opportunities for all. Our fight will never end. We need courage, endurance, and a long perspective.
I wish YHD many more milestones on this rocky road.**

**Adolf D. Ratzka
Founder and Director, Institute on Independent Living, Sweden**

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