

Towards a National Personal Assistance Policy in Portugal: What Requires the United Nations Convention on the Rights of Persons with Disabilities?

Colloquium “Deficiência e autodeterminação: o desafio da Vida Independente”,
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I'm delighted to be here again with my friends from the Portuguese Independent Living Movement. It has been a privilege to watch the origins and growth of your movement. I am honored to have known Member of Parliament Jorge Falcato Simoes since 1994. And, I am proud about being the first honorary member of your Centro de Vida Independente.

I'm happy to be here with my friend Kapka, the present chair of ENIL, the European Network on Independent Living. I was ENIL's founding chairperson in the years 1989 – 1992.

Today's conditions of Portuguese who require personal assistance

Today's colloquium is about your pilot project for personal assistance and its implications for a future Portuguese national policy for personal assistance and Independent Living. As I understand, this new personal assistance policy is to be adapted to the conditions of your country and to Portuguese traditions and values. So what are these traditions and conditions on which you intend to base your national personal assistance policy?

Deficiencia, invalido are common terms

Common terms for a disabled person in Portuguese seem to be “deficiencia” and “invalido” which in Latin literally means “without any value”. Are these terms indicative of how Portuguese society values our lives and determines the quality of life to which we are entitled?

Dependence on family

Persons with extensive disabilities, persons like myself, require assistance by others for the activities of daily living, such as getting up in the morning, managing their personal hygiene, getting dressed and eat, for work and leisure, for being full members of their families, communities, and society. The majority of these people in Portugal receive this assistance from family members. That may work as long as we are children, keep a low profile and don't demand a regular life. After our brothers and sisters have moved out to start families of their own, we are left with mum and dad. Soon we are 40 and still need mum and dad for going to the toilet. What happens when mum and dad are in their 80s and need help themselves? The family as provider of assistance limits everybody's life opportunities, gives everybody a bad conscience: we feel bad about asking for too much, our families feel bad about not doing enough. Depending on family is a ticking time bomb, not a sustainable solution. Is this Portuguese tradition to be the standard for your new personal assistance policy?

Institutionalization

Last week I saw a video on YouTube about Eduardo Jorge who struggled to stay in his own house but in the end had to move to an institution. In his house the government paid him 88€ per month to hire a helper, residential institutions got 10

times as much for each of their residents. Again, is this practice to be a guideline for the new assistance policy?

As a teenager, I lived for five years in an institution. My mother was unable to assist me, our house was not accessible. Besides, I was considered to be too sick to live outside an institution. Sure, in the institution they fed me, helped me to the toilet and kept me warm. But is that what life is all about? Everything was planned by the staff: when to get up, sleep, eat and go to the toilet. I had to accept help with the most intimate things from people I did not get along with. I survived, but had no life. The video about Eduardo made me cry.

Abandonment

A few years ago, I was confronted with the story of a young man, living by himself. He had a high spinal cord injury and required much assistance but had only friends and volunteers who occasionally could help him. As a result, he hardly left his bed. He was living in an apartment on the second floor without elevator. As a result, he hardly left his apartment. Somebody from the local government came twice a day with food. That was all the support he received from society. That was how much his life was worth in the eyes of the government. This took place not in a remote village in a developing country one hundred years ago, but in Lisbon, in Portugal, in the EU, in the 21. Century. Will your national policy be based on such practices?

Portugal ratified the UN Convention

Given these practices in your country, a national policy for personal assistance must obviously be radically different. But you do not need to start from scratch when formulating the policy. You need not re-invent the wheel. Portugal ratified the Convention on the Rights of Persons with Disabilities, the CRPD. Your country cannot adopt a policy that violates the Convention. General Comment No 5 on Article 19 of the CRPD contains clear guidelines and operational definitions of what a national personal assistance policy is to consist of. You have no choice. If you want that all Portuguese live in dignity, if you want a sustainable solution that will hold up in the European Court of Human Rights in Strasbourg, you'd better comply with the Convention.

Here are the main features that the CRPD requires your personal assistance policy to have.

CRPD on Personal Assistance

According to CRPD, Independent living means that individuals with disabilities are provided with all necessary means, including personal assistance. Personal assistance as defined in CRPD Article 19 and General Comment No 5 is a person-directed, user led, support service intended to enable persons with disabilities to exercise choice and control over their lives, and live independently and be included in the community, equal to others.

"The service is controlled by the person with disability, meaning that he or she can either contract the service from a variety of providers or act as an employer. Persons with disabilities have the option to custom-design his or her own service, i.e. design the service and decide by whom, how, when, where and in what way the service is delivered and to instruct and direct service providers." (GC 16 d ii)

To achieve this goal, personal assistance services must have the following features:

Eligibility

According to General Comment No 5, all persons with disabilities are eligible who require personal assistance services for living in the community and for exercising their culturally expected functions in family, community and society; with the same degree of individual choice and range of options enjoyed by others; regardless of medical diagnosis, age, gender, income or wealth, intellectual or psychiatric impairment; regardless of the percentage of a medically certified impairment.

In some countries, eligibility for direct payments for personal assistance is limited to low-income persons and households. As a result, a family might be forced to sell their home using the proceeds for personal assistance until they reach the poverty line and become eligible for direct payments from the government. This is a violation of the Convention.

In some countries, only persons with physical but not cognitive or psychiatric impairments are eligible. Or only certain age groups, for instance, persons above the age of 12 and below 80 years. Such limitations are in violation of CRPD.

The minimum age for participation in your current pilot project is 16 years, as I understand. CRPD Article 19 explicitly refers to all persons with disabilities. Thus, you cannot have a personal assistance policy in Portugal that excludes children. For children's personal development it is extremely important to do things on their own without the assistance and supervision of their parents, like hanging out with their friends, skipping school or experimenting with cigarettes. How will children with extensive disabilities manage to go to regular, mainstream schools without assistants? Apparently, you assume that they will go to special and segregated schools exclusively for children with disabilities. All that violates the CRPD.

Funding

According to General Comment No 5, funding of personal assistance is to be based on personalized criteria and is to guarantee decent employment conditions for personal assistants. Also, funding goes directly to the person with disability in the form of direct payments for paying any assistance required. As I understand, in your future national personal assistance policy, funding is not through direct payments but to so-called Independent Living Support Centers. Why? Don't you trust the ability of persons with disabilities to handle money? How shall we choose among different service providers, how shall we employ our assistants ourselves, if not we, but an agency is to receive the money? Does your government pay old age pensions to an agency or directly to the retired people? The more middle men are involved, the less money reaches the recipient.

Where no direct payments are in place and an agency and not the service user administers the money, the individuals requiring the services will not be able to custom-design their services according to their individual and personal requirements. Users are likely to be seen as passive recipient and object of care rather than the boss, supervisor or customer who makes the decisions and sets quality standards. Direct payments enable the person to be in control, direct payments empower.

Article 19 and General Comment No 5 do not specify from which level of government funding should come - local, regional or central - although this has far-reaching consequences for the user's geographical and social mobility as well as social status in the community. Where central government is responsible for funding, costs are geographically evenly distributed in the population which enables individuals to relocate and move within the country without any fiscal consequences for local governments. When local governments are responsible for funding personal assistance, they sometimes restrict the use of the service to the geographical area of their jurisdiction. This affects personal assistance users'

opportunities for travel and moving to other parts of the country for educational, occupational or family reasons.

Assistance policies that require the user or the family to pay any part of the service's costs violate Article 19. In some countries, users have to pay a percentage of the total assistance costs. In practice, this amounts to a tax on disability - the more extensive the impairment and service requirements, the more one has to pay.

Direct payments for personal assistance that decrease as the person's or the family's income increases represent severe disincentives to education and work.

When assistants do not earn competitive wages, when payments are not adequately adjusted over time for rising wages and inflation, persons requiring personal assistance will have difficulties in finding competent assistants or cannot afford as many assistance hours as they require. Payments must cover the service provider's total costs, for example employer's contribution to social security or administrative costs including movie tickets, travel costs or hotel accommodations when assistants accompany us.

Respect, punctuality, and an attentive attitude are difficult to expect from volunteers without payment or from personal assistants who know they could earn higher wages elsewhere.

Whenever personal assistants are not remunerated with conditions that are in line with those for similar work, assistants expect gratitude from service users and work for ulterior reasons, for example, ideological or religious motives. In such cases, the person who requires the service does not have the same degree of control as someone who pays full market wages when it comes to setting quality standards and customizing one's service.

Below-market wages for assistants are likely to promote our image as helpless persons who depend on charitable persons for survival which is diametrically opposed to the vision of CRPD, of living independently and being included in the community, equal to others.

Needs assessment

Needs assessment has to take into account personalized criteria and individual life circumstances. It has to result in the quantity and quality of assistance required for living independently and being included in the community, as others. The services' quantity and quality must enable the person to take on and exercise the culturally expected functions in family, community and society, regardless of medical diagnosis, age, gender, income or wealth, intellectual or psychiatric impairment, with the same degree of individual choice and range of options enjoyed by others.

Independent living is not compatible with the promotion of "predefined" individual lifestyles. The assessment should be based not on the medical model where persons with the same impairment would receive the same personal assistance in terms of quantity and quality but on the human rights approach to disability where the focus is on the requirements of the individual because of barriers within society and the person's different roles in life, as interpreted by the person. Assessment must follow the person's will and preferences, and ensure the full involvement of persons with disabilities in the decision-making process.

Needs assessment based on medical diagnosis cannot take into account the person's background, expected functions in family, community and society. Neither can medical criteria reflect the interplay between a person's impairment and obstacles in the person's attitudinal and physical environment, a process that

differs from person to person and over time. Without respecting the individual's unique combination of personal resources, preferences, and aspirations, assessment denies us our uniqueness as human beings.

There are personal assistance schemes where only a minimum standard of comfort is supported. For example, instead of supplying sufficient number of hours to enable the person use the toilet when needed, diapers are provided and changed once a day. This practice violates the Convention.

A country's personal assistance policy can become a self-fulfilling prophecy when assumptions about persons with disabilities with a given impairment or age determine how many hours of personal assistance they will receive. As an example, in a culture where persons with disabilities are seen as asexual beings, personal assistance hours might not be granted for child rearing, and consequently, few persons with extensive disabilities will be parents.

Limiting the maximum amount of hours of personal assistance for all users to a certain number of hours a week, for example 40 hours, or to weekdays but not weekends and holidays, does not promote living independently in the community, equal to others. The number of hours may not support a young person in leaving the parental home and establishing a household, it may not enable somebody to take on full-time work on the open employment market, or may not provide sufficient support with the physical tasks of raising small children.

With 40 hours a week I could not even survive. 40 hours a week would enable me to employ two part-time assistants, at most. Even if I had all the hours I require, having only two assistants would make me extremely vulnerable. Assistants get sick, need vacations and time off. With 40 hours a week and two assistants only, I could not hire parents with young children - they are often on sick leave – and I could be taken to court for discrimination. Now you might say, your system can provide you with more than 40 hours a week - in exceptional cases. In Sweden, the average number of hours per week is close to 120. The average! Not the exceptions! So, whoever suggested these limitations for your pilot project has not much experience of personal assistance, to put it mildly. In my case, I have 18 hours a day. 40 hrs a week would make me totally dependent on my wife. She has her own life, with job, interests, friends and travel. Being glued together like Siamese twins would be disastrous for her, for our relationship, for me.

Control

According to General Comment Nr. 5 on Article 19 of the Convention, the services need to be controlled by the person with disability such that the individual can either contract the services from a variety of providers or be the employer of assistants. In both cases, the persons with disability needs to be able to custom-design the service and decide by whom, where, when, and in what way the service is delivered, and to instruct and direct service providers. Persons requiring personal assistance are free to choose their degree of personal control over service delivery according to their current life circumstances and preferences. Even if the responsibilities of the employer are contracted out, the person with disability always remains at the center of the decisions concerning the assistance. In the case of persons with cognitive or psychiatric impairments, the control of personal assistance can be through supported decision-making.

Direct payments equip the person with the purchasing power that is necessary to employ one's assistants or buy services from service providers. The purchasing power is the prerequisite of a market for personal assistance services where users and service providers meet. A market with a multitude of competing actors is necessary, if there is to be choice and self-determination for personal assistance users.

With the necessary purchasing power, it is the person who requires the service who has the final word on everything related to the service. This degree of control is indispensable in custom-designing one's own individual personal assistance scheme that suits one's changing requirements and preferences. Unfortunately, very few personal assistance policies exist today that allow the person who requires the service that degree of control.

Control over the service requires a one-to-one relationship between the person and his or her assistants where personal assistants must be recruited, trained and supervised by the person granted personal assistance. Personal assistants should not be "shared" without full and free consent by the person granted personal assistance. Sharing of personal assistants limits and hinders the self-determined and spontaneous participation in the community. Aspects of cost-efficiency must not override the core of human right. So far the General Comment.

I hope your pilot project and any resulting national personal assistance policy does not force participants to share assistants. Because the sharing of assistants is the single most decisive feature that turns any housing arrangement into a residential institution, whether two persons live there or 200. If you need personal assistance often during the day, as soon as you share your assistant with one or more users, you will be limited as to where you can go and what you can do. Sharing personal assistants takes away your self-determination. You have only two alternatives: either you go out together to the same place or you stay at home together.

In some countries, personal assistants are employed, trained, supervised by a government or private agency that has a monopoly position. This solution cannot be called "personal assistance" according to General Comment No 5 of the CRPD, since it undermines the ability of the individual person to control his or her services. For example, individual users cannot select workers they like as persons, cannot train them in their own particular routines which they developed over years of living with their disabilities. When an agency takes over these functions, service users have to admit people into their homes and families whom they may hardly know. These agencies might even call themselves Independent Living Centers or, in your case "Independent Living Support Centers". But how could they possibly know and understand your requirements, preferences and aspirations better than yourself? I have used personal assistance for over half a century. But even if people like myself were working for such a center, how could they know the way you like your assistants to help you take a shower without hurting you or how you want your assistants to relate to your family? There is no way for me to train somebody else's assistants in such tasks. My guess is that the people working in these centers would not even have a disability themselves. My point here is that no matter how much direct experience of personal assistance they might have, the fact that you are not the person who selects, trains and supervises your assistants will reduce your authority in the eyes of your assistants, will severely diminish your possibilities to optimize the quality of your services, and thereby, the quality of your life.

As I understand, according to your planned national personal assistance policy, your personal assistants must undergo a formal training by an Independent Living Support Center before they can work. I can see that persons with cognitive and psychiatric impairments can have difficulties in training their assistants themselves. They might need supported decision-making to do this. Many Centers for Independent Living offer this service where staff who themselves require personal assistance, together with the assistance user, instruct personal assistants in how they prefer their assistance services. For assistance users without cognitive or psychiatric impairments it would be much better to train their assistants themselves. This is not easy for everybody. So, if there is anybody who needs training, it is the personal assistance user. Most Independent Living Centers

around the world offer courses for personal assistance users where, among other things, they learn how to train their personal assistants.

If personal assistance is truly to be personal, users must have the opportunity not only to recruit, employ and supervise but also train their assistants themselves to make sure that assistants work according to the respective user's personal requirements and preferences.

Deviation from the CRPD

In summary, from the information I received about your pilot project and the planned national personal assistance policy, I see several important areas where they deviate from Article 19 of the CRPD.

- eligibility is determined by medically certified impairment,
- children under 16 years are excluded,
- no direct payments,
- limited to 40 hrs/week,
- recruitment, employment, training, supervision of assistants by an agency and not by the individual user

Given these decisive limitations, your solution does not comply with CRPD Article 19 as clarified in General Comment No 5. It does not give taxpayers the best value for their money. More importantly, it does not give users the means to control and optimize the quality of their services and, thus, the quality of their lives.

What personal assistance can enable us to do

Real personal assistance can do wonders, can be key to "living independently and being included in the community" for persons with extensive disabilities who otherwise would have no future. Personally, I was extremely fortunate to have had personal assistance since the age of 22. Here is the story of my life which has been based on personal assistance.

Personal assistance for university studies

I was hospitalized with polio at age 17. At age 22, I was able to leave the residential institution in Germany to attend university in the US with the help of personal assistants. I didn't know anybody there, none of my family could come along. I lived in a regular student room in a dormitory on campus and in regular apartments. My personal assistants got me up in the morning, helped me with bathing, toileting and dressing. They did the shopping, cooking, cleaning and other household work. They helped me with my ventilator, carried my books. I hired fellow students who needed some income as my personal assistants, I trained them, paid their wages and supervised them. I was their boss. I could afford to hire them because, as part of my scholarship, I received monthly payments from the German State for this purpose.

Personal assistance for work

After eight years in the US I moved to Sweden to do research - with the help of personal assistants whom I hired with money from my research grant. Again, my personal assistants helped with everything I needed to concentrate on my work. They drove me to work, helped me at my workplace, came along when I wanted to go out and spend time with friends.

Personal assistance for a career

After finishing my Ph D I stayed in Sweden, worked as researcher at the university, got involved in disability politics, introduced the Independent Living movement and the concept of personal assistance to Sweden, was founding chairperson of the European Network on Independent Living. I started the first personal assistance user cooperative in Europe, founded the Independent Living Institute whose director I was until half a year ago. I have worked and lectured in many parts of the world, made friends with many special, kind, and interesting people - with the help of personal assistance.

Personal assistance for relationships

Over 30 years ago I met my wife and after a few years we got married. We made this decision after much deliberation. We had seen many couples in other countries where one of them - often the wife – was the sole caregiver of the other; where both lived in extreme mutual dependence; where none could take a step without the other, tied together like Siamese twins. My wife was familiar with my system of personal assistance. We both wanted to live together but also needed to feel free in a relationship where both, independently from each other, could develop and grow as human beings. We knew this was possible with personal assistance. With the help of my assistants I would continue to take care of myself, and, with the help of my assistants, I would do my part of the household chores. Sharing household responsibilities among partners is cultural norm in Sweden.

Personal assistance for equal partnerships

My wife and I travel in our work and on vacations. She often visits her big family in Germany, goes to international conferences or works abroad. I too get invitations to lecture or work abroad. She often travels by herself and I want to be able to do the same – with the help of my assistants. When we travel together, it is because we choose to do so and not because I need her to come along as my assistant.

Personal assistance for raising a family

Our decision to have a child was also based on personal assistance. At that time, Sweden had passed a law that entitled people in my situation to direct payments for personal assistance. I wanted an active part in raising our child, I wanted to be close to my child. Besides, sharing the responsibilities for children is also the cultural norm in Sweden. I would do my share of the physical work in child raising with the help of my personal assistants. I took our daughter Katharina to the kindergarten in the morning, my wife picked her up after work. I also wanted to be alone with my daughter and do things together – only she and I. So Katharina and I went shopping for groceries every Saturday, visited museums, went fishing. I instructed my assistants to stay behind us and only interfere when I'd ask them to or to prevent an accident. Now, Katharina is an adult. She works as an Occupational Therapist, and lives in a nearby apartment.

Not your diagnosis but the politics of your country make you disabled

There is nothing special about me as a person. Many, many people in my situation could have similar lives under the right conditions. What is special about me is the fact that I have had personal assistance for the last 50 years. That is, sad to say, very special. In most other countries I would not have been able to have such a good life. Without personal assistance I would have been much more disabled.

Without personal assistance I would not be here.

Without personal assistance I probably would have died years ago.

How a disability affects your life is not so much the result of the medical diagnosis; it is the result of the politics of your country.

Let's do something about this.

Muito obrigado