The formal employment of disabled people is not specifically determined by economic factors but by direct technical ones or ultimately by social interests and values. A solution, neutral in economic terms and achievable in technical terms, to the problems hindering the employment of people with disabilities and health conditions would be a realistic technical solution and actual employment, but only if the society making the relevant decisions and aiming for the inclusion of disabled persons. In a period of economic upturn with a huge expansion of the labour force, higher employment rates appear not only among non-disabled persons but also among people with disabilities and health conditions. However, once an economic downturn occurs and the demand for labour falls we see the appearance of groups that ‘cannot be employed in a profitable manner’. These groups include not only people with disabilities and health conditions but also unskilled workers, long-distance commuters, women with no more than secondary school graduation, immigrants, the Roma minority and others, in other words, all groups in a weak social position, to whose detriment it is easier to implement dismissals, or who can safely be blamed for any declining efficiency of company output. As finding a job is increasingly difficult in general so those labour groups that are unable to protect themselves are excluded from the labour market while intensive efforts are made to serve the interests of those who benefit from this exclusion, with the suggestion of some ideology. In this context, the losers in this game are given a label to legitimise the situation or for some ideological purposes. Labels such as ‘lazy’, ‘drifter’, ‘lumpen elements’, or negative perceptions of people with disabilities or health conditions also serve to disguise the fact that unemployment is rooted in macroeconomic and social inequalities lying behind the direct causes. It is obvious that only those in a vulnerable position are excluded from the labour market or are at risk of exclusion. In a period of economic downturn, some of those excluded, revenge is not only a reason, but also a means, to discount a failure in the job market. The same reasoning is applicable to the labour market successes and failures, putting individual excellence or fault to the fore serves to facilitate the exclusion of social groups unable to defend themselves within the labour environment. This upside-down logic is all the more dangerous as many disabled people, and generally all those in a marginalised position, believe that the fault lies with them. The resulting frustration reinforces harmful behaviour such as alcoholism, crime and voluntary dropping out from the labour market. For disabled persons, employment may contribute to a lower public burden in the same way as would their better social inclusion. Arguing for the many-sided necessity of employment, Tegyey summarised his view as follows: ‘In the employment of the disabled with reduced working capacity, it must be ensured to give them the most appropriate job opportunity despite their handicap, that is, such a job where working capacity requirement could be provided to the fullest possible extent, that is, to develop working abilities and fine-tuning those as far as possible, all the disabled persons’ social
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National Personal Assistance Policies
What We Need and How to Work for It?

ENIL Webinar on Personal Assistance, September 14, 2020

We need to work for national personal assistance policies in our countries. What features must they contain in order to empower us, and how can we work for such policies?

First, what do we expect from such a policy? What can personal assistance do for our lives? There are many examples of how assistance users have managed to live with the help of their assistants but here is my story.

In 1961, at the age of 17, I contracted Polio. As a result, I have been using a ventilator, an electric wheelchair, and increasing assistance with the activities of daily living ever since. In 1966, after five years in a hospital, a scholarship enabled me to move from the hospital ward in Munich, Germany to a dormitory room at the University of California in Los Angeles.

The transition from patient to student was made possible by the scholarship that not only covered my expenses as a student but also contained direct payments for personal assistance. With that money, I hired, trained, paid, scheduled, and supervised fellow students as my assistants. I was able to pay them competitive wages, i.e. wages that they would have earned for working on campus at the libraries or cafeterias. They assisted me with everything I needed to concentrate on my studies and to enjoy life as a young adult living by myself for the first time. I had to learn to express my needs, had to learn to be the boss. That was difficult and I made many mistakes. But my mistakes have been valuable lessons.

In 1973, I moved to Sweden to work on my dissertation. Again, I hired people there as personal assistants. With their help, after completing my academic training, I worked as a researcher at the university.

Throughout the years, I must have employed hundreds of students, immigrants, and people between jobs to work for me. They not only enabled me to study and work but also to live the way I wanted, with a rich social life, with many interests, romantic relationships, with travel for work and pleasure. With their help, I became involved in disability work nationally and internationally. I founded several organisations, traveled and lectured widely, was recruited for research positions overseas, and headed international projects.

Personal assistance was also the key for me to getting married. My wife and I were confident that, with the help of my assistants, I not only would take care of myself, independently of my wife, but could also share household chores and work around...
the house, on an equal basis. (That was the plan but it has not always worked out that way, I’m ashamed to admit.) My wife would not be my life-long, unpaid nurse. We wanted a relationship where we both, independently of each other, could develop and grow, pursue our interests, and have a meaningful career. For example, we both traveled in our work to meetings and conferences in Sweden and abroad. When we did travel together it was because we choose to so and not because I needed her as an assistant. The decision to have a child was also based on my personal assistance. My assistants would enable me to have an active part in raising and being close to my child. For instance, as a small child my daughter and I went shopping for groceries or fishing. My assistant would stay behind us and only interfere to prevent an accident.

The Swedish social security system pays me a monthly amount of money for which I employ seven parttime assistants to provide me with 18 hours of personal assistance a day. I can pay competitive wages. With that money, I have been able to live in the community despite my extensive disability. I am a profoundly ordinary person. There is nothing special about me, I have no exceptional gifts or talents. Many, many people in my situation could have equally fulfilling lives. What is special about me is that I have had personal assistance throughout my entire adult life. That is, sad to say, very special. In countries without personal assistance services – that is, in most parts of the world – I would not have had any self-determination. With only help from my family, I would have been very limited. In a residential institution, I probably would have died decades ago.

From my experience with personal assistance since 1966, I conclude that a personal assistance policy that is to enable you to live with the same choices and conditions as your non-disabled brothers and sisters, friends and neighbors must meet three main conditions.

First, we must have control over our personal assistance. The more we can adapt and fine-tune our personal assistance solution to our unique person and life circumstances, the better we learn how to handle this tool, the better will be the quality of our lives. That, in turn, requires that we recruit, employ, train, schedule, and supervise our assistants.

Second, we need direct payments from the government to pay our assistants’ wages, that is, money paid directly to our banking accounts. Without controlling the money, we cannot be the employer and must accept any services that the government selects for us. Without direct payments, we have no choice, are stuck with services we don’t like. Also, without controlling the money, you don’t have the final word in important decisions in recruiting, setting wages or dismissing employees. You will be object, not subject. Your assistants will have a different attitude toward you. If you are not the boss, if you cannot switch service providers you cannot enforce good service quality and you are made to feel dependent on your assistants.

Third, the Direct Payments must cover the cost of all the hours of assistance we require, and enable us to pay competitive wages. Without decent wages people working for us may expect our gratitude. Under these circumstances, we cannot expect prompt, competent and reliable workers. With assistance insufficient in the number of hours and insufficient in quality, you have to rely on family and volunteers. You will be dependent, must make compromises and concessions. Planning activities or larger projects will become very difficult.
How do we work for personal assistance in our countries? How can we convince our governments, members of parliament, the media and, most importantly, the general public of our right to personal assistance?

One argument is in the area of economics. But, please, do not claim that personal assistance is cheaper for the government than residential institutions. That might backfire. Institutions with very few staff and crowded conditions like Third World prisons are definitely cheaper per inmate than personal assistance. Instead, we argue that with the same amount of money that institutions receive from the government for each of their residents, most residents could have better lives living in the community with personal assistance. In most countries, governments pay more for keeping us in an institution than for enabling us to live in the community. In Spain, for example, an institution received €2,400 per month for each resident while someone wanting to leave the institution could count only on €750. (The figures are from 2007 but their relationship is probably still the same today.) We can only speculate about the reasons why owners of institutions are entitled to such generosity from the government. Perhaps it’s simply that they are better organised and have more money than our movement, have a better lobby, and better friends in government.

Institutions are capital intensive – considerable money is tied up in land and buildings. Personal assistance is labor intensive – almost all the costs are wages. Our assistants are low-income earners who use their wages for food and rent. This promotes the domestic demand – an excellent way for lifting a country out of a recession.

In Sweden, personal assistance has become a labor market instrument. Some 50,000 persons work as assistants or 0.5% of the country’s total population. Many of my assistants would have difficulties in finding other work and would have to rely on social welfare payments from the government. Doesn’t it make more sense to use direct payments for enabling us to contribute to the community, for allowing our relatives to work in their chosen field of interest, and, at the same time, for putting our assistants to work? We must make the general public understand that direct payments for personal assistance are not costs but investments – investments in people’s ability to contribute to society.

The other argument for direct payments for personal assistance are health and safety issues in residential institutions and parental homes – the alternatives for assistance users. The media ever so often report about physical and sexual abuse of persons with disabilities in institutions and – to a lesser degree – in families, in particular, where parents as the sole caregivers are over-burdened and burned-out.

There is ample scientific evidence that institutionalization, through lack of stimulation, exclusion from family, friends, class mates, and the community, leads to retarded development and loss of social skills. I lived five years in such a place, from age 17 to 22. It took me nearly a decade to recover from the damage of this most horrible period in my life.

The current Corona pandemic provides further evidence of the dangers of institutionalization. So far, a higher percentage of older persons has died in institutions than in the community. It would not surprise me if this were also true for younger persons with disabilities.

A third argument are our Human Rights. The European Union, as a whole, and all its member states have signed and ratified the United Nations Convention on the
Rights of Persons with Disabilities. According to Article 19 of the CRPD, we have the right to living independently and being included in the community, at conditions equal to others. The General Comment Nr 5 in its operational definitions makes it very clear that residential institutions must be phased out and replaced by personal assistance services.

Sure, we shouldn’t need to enumerate these economic, health and safety, and legal arguments to convince people of our right to personal assistance. In a decent society, all citizens have equal opportunities for living in the community in safety, health, and enjoyment of their innate potential. But, as we know all too well, we don’t live in decent societies, we have to make them decent first.

I suggest the following strategy for working for a decent society.

More accessible housing

Our societies have to become more accessible. To replace residential institutions with personal assistance services, we must have more accessible housing in the community. Otherwise, many persons with disabilities – even with personal assistance – would still be forced into institutions. We need Universal Design in housing. For that, building codes for new construction and grants for housing adaptation of existing buildings must be in place.

Coalition building

In line with the CRPD General Comment Nr 5, residential institutions are to be phased out by redirecting resources into direct payments for personal assistance. To get that far, our movement has to become wider. As Founding Chairperson of ENIL, I’m proud about our organisation and its achievements. But we have to get better at coalition building, particularly at the national level. In many European countries, the disability movement is still divided into organisations for and of persons with disabilities. On top of that, organisations are mostly oriented along medical diagnoses. Thus, we find countries where one organisation, for example the Muscular Dystrophy Organisation, works for personal assistance but not the Spinal Cord Injury Association or any of the other organizations of the country. As if people with Cerebral Palsy, rheumatism, autism, sight impairment, Downs Syndrome, etc. would never need personal assistance! Would not our fight for personal assistance be more successful, if more organisations, more people were pushing the issue?

National organisations for Personal Assistance

I suggest we start ad-hoc one-issue organisations in our countries – national organisations for personal assistance. Anybody who wants to support or work for the goal is highly welcome regardless of their medical diagnosis or affiliation with other organisations.
Coalitions with the organisations of retired and older persons

Having worked for personal assistance for the last 40 years, I realise that we make a big mistake when we do not build coalitions around personal assistance with the organisations of retired and older persons. If our movement could get these often very large, rich and politically influential organisations to support our cause, lawmakers would pay more attention to us. How can we get these organisations on board?

Let us join organisations of retired and older persons

One of the ways is that those of us who are old enough join them and try to climb up in their ranks. We need these organisations to realise that their members are not only old but also prone to become disabled sooner or later, with a high probability of needing assistance by others with the daily activities of living. We have to convince their leadership that to live in the community with personal assistance is a hundred times better than being warehoused in an institution.

Our motto: We are profoundly ordinary people

We must double our efforts in making everybody – most importantly ourselves – understand and identify with our position: Though we may look, walk, or behave different, we are profoundly ordinary people because, like everybody else, we need to be seen for who we are, we need to be respected, we need to be loved. These needs we share with everyone, these needs make us truly human. To meet these needs, we need to live, love, and work among our friends and family in the community – with personal assistance.
The unIceF study continues with a quote from the Lithuania country report of 2002: ‘Policy, law and practice have been linked in Lithuania to make strong progress in mainstreaming children with disabilities in the mid-1990s. However, special schools have generally failed pupils with disabilities and major school reforms are necessary if they can make accurate provision for them.’

This reform must operate at two levels: the academic organisation and curriculum provision of the school, and the professional development of staff. The former requires rethinking the ways in which pupils are grouped for teaching purposes, the arrangements that schools can make for support teaching and the modifications to the mainstream curriculum that teachers can make without qualifications in special education, as well as advice and consultation on all matters related to the education of pupils with disabilities. These resource-centred functions are important in improving the standard of special educational provision regardless of where it is provided. By capitalising on available expertise and establishing a bank of information, guidelines and expertise, this offers a powerful model for making best use of frequently limited resources. In special schools, there have been changes, and recent school reforms have significantly reduced special schools in Lithuania and in other States, for example in the Netherlands. The most important changes required are attitudinal: staff who are ready to use their expertise and act on management-level professional development.

The current deployment of special schools is not necessarily determined by technical factors but by social technical forces, often ultimately at the local, social and cultural level. In a situation where some institutions are already providing mainstreaming, mainstreaming is likely to be seen as a solution and not as a requirement. Yet, it is important that the institutional arrangements and arrangements for mainstreaming should be seen as a process and not a one-off solution. In a process of change with a new emphasis on the local voice, mainstreaming should be seen as a tool to address the needs of all children. Further, in an inclusive education system, the role of special schools needs to be seen as a means of supporting inclusive education, not as an end in itself. Special schools may become resource centres, providing information and advice to local schools, offering support services for parents and contributing to in-service training activities. Designing these functions successfully requires careful changes within special schools, staff. New skills must be developed and new attitudes formed. Training needs to be looked at in the same way as it is for remedial activities, schools of the future. In the end, schools are educational resources, and the demand that schools are comprehensive education systems is an important point for understanding the role of special schools.

In the future, schools need to work cooperatively in whatever new structures may be devised. The question is that special schools of the future could be very different from now. Efforts would move away from educating limited numbers of pupils in relative isolation towards acting as resource centres. The latter could encompass curriculum development, service delivery, role identification, as well as advice and consultation on all matters related to the education of pupils with disabilities. These resource-centred functions are important in improving the standard of special educational provision regardless of where it is provided. By capitalising on available expertise and establishing a bank of information, guidelines and expertise, this offers a powerful model for making best use of frequently limited resources. In special schools, there have been changes, and recent school reforms have significantly reduced special schools in Lithuania and in other States, for example in the Netherlands. The most important changes required are attitudinal: staff who are ready to use their expertise and act on management-level professional development.

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