My life, my responsibility!

Uloba's experience report on the development of the PA scheme – causes, consequences and solutions

Short version

ULOBA
INDEPENDENT LIVING | NORGE

Foreword

The international Independent Living movement is a liberation movement for disabled people that is fighting for equality all over the world. Personal assistance was created as a necessary tool in our work to promote equality.

Through nearly three decades, Uloba – Independent Living Norway has been on the barricades to establish and develop citizen-controlled personal assistance (PA) as a tool to promote equality for disabled people in Norway. PA is our solution for achieving full participation and equality in education, in working life, in political work, in the family, and in cultural and organisational activities for disabled people.

PA is a revolutionary scheme in Norwegian society because it is a radical model that challenges established power structures. It is radical because it breaks with our traditional understanding of what it means to be disabled. Radical because it empowers people and enables people to take responsibility for their own lives. Radical because it is about giving disabled people the same right as others to take control of their own life.

Through systematic efforts and hard work, we succeeded in having the Norwegian Parliament passing a bill introducing PA as a statutory individual right with effect from 2015. Disabled people would finally be able to contribute to society as citizens and not be degraded to passive users. With PA, we would claim back our right to participate in society – the right that everyone else take for granted. That was what we thought.

Instead, we see that making PA a right under healthcare legislation, administered by municipalities, is wrecking the PA scheme. PA is being turned into traditional healthcare services with standardised requirements for safety and quality, reporting and control, and with limitations in the citizen's control of the assistance. Again, responsibility for our own life is taken away from us disabled people. And again, and still, disabled people are regarded as sick and in need of care, not as people whose lives are limited by discrimination and inequality.

The law that was meant to guarantee disabled people the same rights as other people, that was to help to create a richer, more diverse, inclusive and sustainable society, is failing. Our report explores more than 700 disabled people's experience of their new everyday life. The stories they tell us reveal that making PA a statutory right under the health and care services legislation has ruined the PA scheme. I would like to thank our members and others who have shared their stories with us.

When the bill introducing PA as a statutory individual right was passed, the politicians' clear intention was to give disabled people the right to control their own life. PA was meant to be an investment in people, a tool for creating a non-discriminatory society. Discrimination cannot be stopped with nursing and care that is administered on the basis of discretionary judgement at the mercy of the municipal administration's priority-setting. Only tools that promote real equality can stop discrimination.

Uloba is raising the alarm. We are now demanding a legal basis for PA that guarantees the civil and human rights of disabled people, that does not medicalise disability and does not allow the municipalities to ignore the very intention behind PA.

Vibeke Marøy Melstrøm
Secretary General
Uloba – Independent Living Norge

BPA → responsibility → equality

Citizen-controlled personal assistance (PA) is qualitatively and fundamentally different from traditional home care services. The PA scheme was developed by disabled people themselves as a tool for promoting equality.

PA is based on a completely different model than traditional health and care services. A model that transfers power and responsibility from the public administration to the individual.

PA is practical assistance. When such assistance is available to a disabled person, it is up to the person him/herself, if relevant with the assistance of an acting work leader, to take full responsibility for his/her own life and health – as other people are required and expected to do.

The purpose of PA is to give people the opportunity to live a life without unnecessary scrutiny and control, and it should only be limited by general legislation that regulates the health, safety and working environment of the employees (assistants).

PA requires people in need of assistance, if relevant in cooperation with a person close to them, to be willing and able to take responsibility for their own life and to administer and manage their own assistance. Disabled persons are granted a certain number of PA hours, recruit their own assistants and are assisted when, where and how they need assistance – both at home and in society.

PA = freedom

After decades of systematic work, PA has slowly, but surely become a right for large groups of disabled people that allows us to live with full participation and equality. In 2012, PA was moved from the Social Services Act to the Health and Care Services Act, and three years later, in 2015, PA became a right for disabled persons under the age of 67 who need more than 25 hours of assistance per week.

The preparatory works to the regulation of PA as a statutory right, Proposition No 86 L to the Norwegian Parliament (Bill), reads as follows: 'The government envisions a society where everyone can participate. Most people aim to gain an education and work, and expect to live independent and active lives. (…) The proposal forms part of the Government's work to follow up the intentions underlying the UN Convention on the Rights of Persons with Disabilities.'

The proposition goes on to state that the disabled persons themselves should function as work leaders and take responsibility for the assistance's organisation and content based on their own needs.

Traditionally, a person in need of assistance has been at the mercy of the public administration that has decided the framework conditions, scope and quality of the assistance. The public administration decides which needs are met. In PA, control and responsibility rests with the disabled person. The person in need of assistance goes from being a recipient of others' care to becoming an independent person with the right to take responsibility for him/herself and live an ordinary life.

'I support the PA scheme because I believe that people should be able to decide as much as possible for themselves.' Prime Minister Erna Solberg, 2016

Disabled people’s own experience

Uloba - Independent Living Norway SA has prepared a report based on the experience of the organisation's members and work leaders. More than 700 interviews have been conducted to provide a basis for understanding how the PA scheme functions after PA became a statutory right.

This is an abbreviated version of the report. The full version is available at www.uloba.no in Norwegian.

Our report shows that all too often, the ambitions of and desire for freedom, responsibility and self-determination have become control, regulation and lack of freedom in people’s everyday lives. Although PA has given many disabled people an opportunity to live life on their own terms, far too many disabled people find that the PA scheme is being weakened and is becoming more and more like ordinary nursing and care services. The Norwegian Parliament’s intention of equality for disabled people has not been realised.

In our report, we show how our members perceive the limitations and what it will take to reclaim PA as the crucial tool for liberation and equality it was intended to be.

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A right on paper is not the same as a right in practice

PA becoming a statutory right was a milestone in disabled people's work to promote equality. Unfortunately, it turns out that a right on paper is not the same as a right in practice. Up-to-date figures show that there has been an increase in 223 citizens with PA (Rokkan, December 2017) since PA became a legal right, that it is a long and winding road to be granted PA, and that there are great differences between municipalities.

'Whether or not I am granted BPA and how many hours I get is as random as a lottery.'

Very few enjoy their individual right

When the Norwegian Parliament unanimously decided to make personal assistance a statutory right in Norway in 2015, the Government estimated that 14,500 people would enjoy such rights. Statistics from Statistics Norway showed a total of 3,330 work leaders at the end of 2016 – an increase of 223 since the right to PA entered into force on 1 January 2015. The annual increase in work leaders per year since the right was introduced has been lower than the average annual increase during the period 2002–2014. The fact that 1401 citizens with an individual right to PA had PA at the end of 2016 means that approximately 13,099 disabled citizens had not exercised their right.

The number of municipalities that have not made a single decision to grant PA is about the same today as it was before the right was introduced. Nearly 80 municipalities in Norway still do not have a single resident who receives PA.

There could be several reasons why people are not granted PA. Our survey shows that the road towards PA is strewn with obstacles. Several of our informants tell of a 'secret service' that they have had to fight for. The Norwegian Parliament's intention of ensuring equality for a far greater number of disabled persons has not been fulfilled.

'Nobody told me that I was entitled to PA. It has to be the municipal administration's best-kept secret.'

The road to PA is a hard one

One third of all Norwegian municipalities provide little or no information about PA on their website. Some municipalities provide inadequate or incorrect information, which has serious consequences for any potential PA applicants. Many parents tell us that their children are offered respite care and residential care when what they in fact want is practical assistance in day-to-day life. Some are wrongly told that the PA scheme is not for children.

'The municipality rejects the application for PA with reference to the decision to grant respite care. What we want is to keep Adrian at home with us, with PA – not to send him away.'
Mother of Adrian (14)

Many also tell that they received no information from the municipality, but found out about PA from acquaintances. We have also heard many stories about people who are advised against applying for PA. Aslak (19) told us:

'They advise me not to apply for PA because it's demanding to be a work leader. The municipality believe that I'm living a free and independent life already. I'm not! I'm politically active and a volunteer visitor at an asylum reception centre. It's important for me to contribute to society in any way I can. In my present situation, my opportunity for participation is severely limited because no one can ever assist me in these things.'

'Many municipalities communicate to disabled people that being a work leader is very demanding and not for people like you...'

The Health and Social Services Ombudsmen also shows that municipalities estimate the needs of applicants in such a manner that they fall below the minimum number of hours (25) required to be entitled to PA. Our informants tell similar stories, and the consequences are often serious, such as not being able to study, socialise or get out of the house at all.

Determined by your postal code

Our survey shows that the situation varies considerably depending on where in Norway you live. Persons with the same needs for assistance can get completely different administrative decisions from their municipality. The term 'municipality refugee' has been coined by some work leaders. The situation is particularly hard for young disabled people who wish to move to another municipality to study. We have several examples where the number of PA hours has been cut and this has prevented people from choosing where to study.

'I moved to Trondheim to study. They cut my PA hours by half, and as a result I had to give up my studies.' Johannes (23)

The Health and Social Services Ombudsmen's annual reports paint a worrying picture of developments in the PA scheme. They point out that it is unacceptable that the target group and quality of the PA scheme should differ depending on which municipality a person resides in. The ombudsmen, like Uloba, have seen examples of municipalities attempting to discontinue well-functioning PA arrangements when a work leader has applied for more hours.

Despite considerable variation between municipalities in administrative decisions concerning PA, we find that PA is consistently across Norway administered in a way that makes it more and more similar to ordinary nursing and care services. This means that the challenges are due to fundamental problems with the system, not individual municipalities that are not doing their job properly.

Poorer PA since it became a right

Our review of the whole PA scheme clearly shows that citizen-controlled personal assistance all too often becomes another nursing and care service controlled by the authorities.

Not only is PA more or less inaccessible to many disabled people, but many are not given this right, and what is offered varies greatly from municipality to municipality. The stories about services that have deteriorated since PA was made a statutory right are equally disturbing. These stories tell us that:

- The struggle to be granted enough hours has become tougher
- More people (13% of Uloba members) report that their number of hours has been cut
- Fewer hours are granted for activities and participation in society
- The focus is on basic needs, not on the right to live an equal life
- Many have less self-determination and control over their PA services
- The use of standards are increasing, while individual assessments are decreasing
- The use of control, requirements and reporting is increasing
- Responsibility for the lives of disabled people is being taken over by the municipality
- Many are subject to 'municipality arrest'/travel bans
- Disabled people are institutionalised against their own wishes

It is important to point out that this new practice is in breach of the UN Convention on the Rights of Persons with Disabilities (CRPD), as well as the principles underlying real PA.

Survive, not live

The number of assistance hours is calculated on the basis of the municipality's standard for nursing and care services. This only includes hours for the most necessary activities: eating, personal hygiene etc.

> **'The current norm is that young people are not given enough PA hours to be active citizens.'**
> Marianne (17)

The PA scheme was intended to contribute to a more active life and make it possible to participate in all arenas of life. Realising this goal requires much more than a limited number of hours for attending to only the bare essentials. We see that municipalities apply quality standards that state how much time a person should spend on individual tasks. In reality, the quality standard functions as a minimum standard and does not take into account individual needs. This form of municipal rationing often prevents the independence, participation and freedom that is at the very core of PA and, moreover, it constitutes a violation of the right to individual consideration.

It has become the rule rather than the exception for Uloba work leaders to have to forgo activities that other people take for granted. As Lena said: *'I have been saving up hours for months to be able to go on that trip to the cabin in December.'*

> **'Nikolay, aged 18, is only granted PA for 11 months a year. It is not as if his need for assistance takes a holiday?'**

«

Christian (48) told us:

‘The municipality conducts an annual assessment of my PA decision. This time, I was ordered to receive an “observation visit” in connection with this review of the number of hours granted. The municipality demanded to observe a visit to the toilet, with defecation, transfer from bed to wheelchair, and eating.

My assistant was instructed to assist me as little as possible. I fell off the toilet and choked when I had to swallow crispbread. The visit was so humiliating, and also hazardous to my health. I need round-the-clock PA, which I have had for many years. This PA arrangement has worked well and allowed me to live an active life like any other man in his 40s. I don’t understand why they should suddenly stop believing my need for assistance.’

Willy (53), father of Terje (9) told us:

‘Terje has a great need of assistance – in reality he needs supervision 24 hours a day. However, the municipality has estimated his need for assistance to be 21 hours a week. They don’t believe us when we try to describe his needs. We've applied for PA, and the municipality's response was that PA would not be good for my son or for the family. In the end, we had to accept an offer of respite care. We were so tired of fighting and needed time to recoup. But it is sad – to eat our Friday night taco meal and not have him there with us. He has been sent away.’

Removing responsibility and control

PA is a tool for liberation and equality. It is also an empowerment tool, which makes it easier for the individual to take responsibility for her own life. PA is about taking control of one's own life, which entails both freedom and responsibility. Experience shows that the scheme is often administered in a way that questions the citizens' ability to take on this responsibility, as evidenced by the stories of people being told that 'BPA is not for you'.

Another, equally serious, factor is that the municipalities are overriding the individuals' right to decide who they want to employ as assistants, what the assistant is to do, and where and when the assistant is to provide practical assistance. '*The municipality lists how many hours are allocated to leisure activities, practical assistance, personal assistance etc. Somehow, it is wrong to use them differently.*'

Bjørn (38) told us:
'I'm a wheelchair user with extensive assistance needs. The municipality has cut my assistance from 14 to 8 hours of PA per week, even though my need for assistance has not changed. Now I have to apply to the municipality for leisure activity hours on a case-to-case basis, and what is done and when has to be written on timesheets. This is obviously hopelessly impractical and unpredictable. Instead of being able to control what my assistants do and when, I have to ask permission to go to the cinema or visit a friend, as if I was still a teenager and had to ask mum and dad for permission to do stuff.'

Control and reporting requirements

In connection with the experience of being disempowered, our informants express deep frustration and concern about the municipalities' increasingly strict control and reporting requirements in the wake of PA becoming a statutory right. It is a recurring issue that disabled persons are not allowed to take their assistant on trips out of the municipality. The requirements to report on one's day-to-day activities are becoming more stringent. Such control and reporting requirements clash with the idea of an independent life managed by the individual him/herself. The grounds given for the control include professional standards, service quality, the principle of fairness or rationing.

The sum of our informants' stories paint a picture showing that the introduction of a statutory right has taken PA in the wrong direction. The goal of PA contributing to making people active citizens is being replaced by 'users of municipal services'. People are left with a day-to-day life managed and controlled by municipal employees. People who were promised freedom, independence and equal participation are left with the right to survive, but not to live. Disabled people are left standing cap in hand, while the right to define their own life and what a good life means for them is replaced by life at the mercy of forces that control, override and, at worst, impose sanctions. And again, and still, disabled people are regarded as sick and in need of care, not as people whose lives are limited by discrimination and lacking equality.

The stories described in our report tell of everyday lives that are far from equal, about people who are deprived of their most fundamental rights, such as being with their family.

And more and more people are confirming this picture. Organisations for disabled people are hearing the same stories all over Norway. The Health and Social Services Ombudsmen in every county can describe similar experiences, and they are deeply concerned that PA is losing its importance in municipal management.

Cradle to grave

Wants his assistant back

A small boy had one assistant to relate to during the day. The municipality discontinued the boy's PA arrangement when the parents applied for more hours. The parents cannot see how it is necessary or advisable that a large number of different home nursing service staff assist their son during the day.

Wants to go to confirmation classes without his mum

A teenage boy needs more PA hours to take part in social activities. The municipality rejects his application. The case officer considers it natural for his mother to function as an unpaid assistant in connection with overnight trips and confirmation classes.

Wants to study

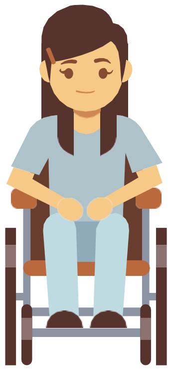
Student applied for PA at night-time to get enough sleep to be able to complete his studies. The municipality rejects his application and grants him home care instead. The man’s health situation does not allow him to receive services from a large number of staff members from the municipalities’ home care services.

Wants to live at home with her husband and newborn baby

A new mother is granted some practical assistance from the municipality, but far less than she requires. The grounds given by the municipality for rejecting her PA application is that her husband can care for the baby and also assist his wife. The municipality’s alternative is for the mother and baby to move into an institution for the elderly.

Wants to continue to work

A man in his 30s receives so little home care services from his municipality that he wears himself out. The municipality and the county governor are of the opinion that he can largely manage on his own, and has therefore rejected his PA applications and appeals for several years. The man has felt forced to go from full-time to part-time work.



Wants to get a home of her own

A young woman is living in a municipal assisted living facility. She wants to buy a home near her family, but is met with resistance. The municipality refuses to amend the existing administrative decision granting her traditional health- and care services to PA.

Wants to continue to be a single father

A single father applies for more PA hours to be able to take care of his daughter. The municipality conducts an overall assessment of the man's assistance needs. The new administrative decision drastically cuts the number of PA hours.

Wants to continue to live at home after the age of 67

A 66 year old man has been in need of assistance for one year. His wife is very tired, since a lot of work now falls on her. The rehabilitation institution recommended 42 PA hours per week, but the municipality rejected the application. The man believes that the municipality is stalling for time since he will soon turn 67, which is the age limit for being entitled to PA.

PA is equality, not healthcare

Why has this situation arisen? We believe that much of the answer is that PA falls under the scope of health and care legislation and is administered by the municipalities as part of their range of nursing and care services.
There are at least four important reasons why PA does not belong in the health and care services legislation:

1. **Disabled = sick:** Health and care legislation perpetuates the erroneous perception of disabled people as sick and in need of nursing, and incapable of taking care of themselves and playing an active part in society. This perception is the greatest obstacle to equality for disabled people and the most important reason why disabled people is the group most discriminated against in all areas of society.
2. **Power and responsibility are taken away from disabled people:** In a classic healthcare way of thinking, disabled people are not allowed to be responsible for their own life. It is the healthcare professionals who know what is best for us and who take responsibility. We see this in the requirement for professional standards, which is a fundamental and often vital principle in healthcare, but one that is not relevant here and destroys the very core of PA. The worst thing you can do is take responsibility away from someone and call it care. By allowing PA to remain part of the health and care services legislation, we are contributing to precisely that.
3. **Control and reporting:** PA is incompatible with the type of requirements, control and regulation that apply in the municipal administration of rights under the health and care services legislation. The individual is the work leader and responsible for his or her own life. If you do not have the right to take responsibility for your own life, you cannot achieve equality.
4. **The basis for comparison:** In the municipal administration, disabled people who are entitled to PA are compared with the ill and the elderly (other groups of 'users'). They are not compared with active, participating citizens. We have plenty of examples of people not being granted enough PA hours or being denied hours for various activities based on an idea of fairness. Why should you be able to travel, attend conferences, go to the cabin etc. when other 'users' do not have the same opportunities?

While PA is based on the same legislation as and is largely understood as one of the health and care services, disabled people are denied the freedom we were promised and the fundamental human rights that Norway and the Norwegian Parliament have undertaken to observe under the UN Convention on the Rights of Persons with Disabilities (CRPD) – and which the minister of health and the prime minister have both clearly expressed that we were to enjoy. PA allows people to take as much responsibility for their own life as possible, which is why we have fought for it, according to Prime Minister Erna Solberg. That responsibility and that freedom is being diluted in our health and care services legislation.

Uloba therefore calls for PA to be moved out of the health and care services legislation. We see that other schemes, such as the functional assistance scheme, function far better in a system where disabled people are primarily motivated to be active participants in society. PA has nothing to do with health – it is a matter of equality. It is my life and my responsibility.

Summary of the main report

The statutory right to PA, which entered into force on 1 January 2015, was intended to guarantee that disabled persons under the age of 67 who need more than 25 hours of assistance per week would be entitled to PA. This group was estimated to include 14,500 people. Making PA a right was intended to be an important contribution to equality and participation in society. The perspective was that PA is crucial to the possibility for labour market participation, education and an active and independent life.

> **‘Norway has undertaken commitments under the UN Convention on the Rights of Persons with Disabilities. Equality is not a guideline, it is an obligation.’**

Uloba’s report sheds light on how PA has been practised by Norwegian municipalities in recent years. This report is a result of interviews/conversations with 704 disabled people who have or want PA.

The result of making PA a statutory right is disheartening. Only 223 more disabled people had been granted PA two years after the right entered into force. It emerges from the interviews that the municipalities stipulate more stringent limitations. Many municipalities are primarily granting hours for basic needs and reject or limit assistance hours for social activities. This is in breach of the statutory right and with the idea of PA.

The interviews we have conducted and our review of the municipalities’ websites show that municipalities provide little and sometimes incorrect information about PA.

Approximately 13 per cent of those who have Uloba’s PA have had their number of hours cut since PA was made a right. In addition, many municipalities apply standards defining how long different activities should take. This constitutes a violation of the right to individual consideration. The consequences for disabled people are that the administrative decisions are not in agreement with their needs and that assistance is only granted for surviving, not for living.

If the municipality does not grant PA, assistance must be provided in the form of traditional services, which are more expensive. One hour of PA costs less than one hour of traditional services, and PA is cost-efficient.

The changes in how Norwegian municipalities practise PA cannot be ascribed to the introduction of a statutory right alone. PA was incorporated into the Health and Care Services Act with pertaining regulations in 2012, after first being regulated by the Social Services Act. We can tell from data from Statistics Norway and the interviews conducted that many of the changes started as early as in 2012. During the two years immediately before the introduction of the Health and Care Services Act, i.e. 2010 and 2011, the number of work leaders increased by 365, more than during the first two years after the right was introduced. Since 2012, we have seen a change for the worse both in the number of persons with PA and in how municipalities practise PA.

Many municipalities choose to refer to the Health and Care Services Act and supplementary acts when introducing restrictions on the use of PA.
Such restrictions involve work leaders not being allowed control over who they want as assistants, what the assistants can do, and when and where the assistants can work. The requirements for professional standards and control stipulated in the health and care services legislation are among the grounds given.

PA is caught in the middle when conflicts arise between the intention behind the statutory right on the one hand and its legal basis in health and care services legislation on the other. The same applies to municipal case officers, who are to base their decisions on two conflicting sets of legislation. The consequence is that PA is diluted and becomes more and more similar to ordinary nursing and care services.

> **There is no such thing as part freedom.**
>
> Nelson Mandela

My life, my responsibility!

The report ‘My life, my responsibility’ is based on interviews/conversations with 704 disabled people who have or want BPA. Their stories are reproduced in anonymous form.

The full report is available in Norwegian at www.uloba.no.

We would like to thank the authors
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