# **Manual of UPA**

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This is the document dealing with User-controlled Personal Assistance (UPA). The purpose of this document is to be of use to municipal governments, users, institutions of the State and other bodies of services with realizing the development project of UPA. The document is published by the board of the UPA project, as the first step in introducing UPA in Iceland. It is planned to instate UPA in the Icelandic laws in 2014, as one of the main pillars in the services to disabled people, just like the temporary provision IV states in the law nr. 59/1992, regarding matters of disabled people.

The law states that the role of the board of the UPA project is to form a structure of User-controlled Personal Assistance to disabled people. This document may be considered as a suggestion of such structure. The board has contacted many different parties during this work and considered the experience gathered both inside the country and abroad among the Northern countries.

The next step of the project is that the municipalities make their own rules about how to implement UPA in accordance with this document. Such rules are the premise for that the UPA contracts can be made. The municipalities can work together in the making of these rules, within the region of said service. Rules will be published soon as guidance to the municipalities about the making of such rules.

It is important to bear in mind that UPA will not be mandatory by law until the end of 2014. No municipality is therefore forced to give UPA until then. The board of UPA project emphasizes the importance that most of the municipalities take part in this developing program.

This frame which is presented here will possibly change as the developing program progresses and its results come in. This experience will be the foundation of a good legislation. All suggestions of the users, of the municipal governments and others are welcome and much appreciated. More discussion will lead to a better legislation.

Please send suggestions to the board of the program to the email: npa@vel.is

# **UPA** in five steps

The following five steps are a description on how to make a UPA-contract in its simplest form. Before taking these steps, the municipal government presumably has introduced UPA as a choice for the users and has introduced what such service would provide. If the user choices to make a UPA-contract, the following steps are these:

- 1. The user applies for UPA to the municipality.
- 2. An assessment is made on the need for support of the applier. An agreement is made.
- 3. An agreement is made between the user and the municipal government about how many work-hours are put into the assistance based on the assessment. Every work hour includes an amount of money.
- 4. On the basis of the number of hours put into the agreement, the user makes a personal contract with the municipality if he wants to handle the service himself, however if the user wants to outsource the work to a third-party which has made an agreement with the municipality, he can make a contract with that independent party. The payments according to the agreement will start. The search for personal assistants will start.
- 5. The personal assistants have been hired. The UPA-service has been activated.

#### **Contracts**

## **Agreement of work hours**

The agreement is signed by the representative of the municipality. It states the number of work hours required of the assistants to work for the user, according to assessment of the user's need. A certain payment comes with each work hour.

# **Cooperative Contract of UPA-service**

Those independent parties that wish to manage the UPA-service and wish to offer these services are obligated to make a contract about their rights and duties with the municipality or the appropriate authority on the basis of a work permit, like is stated in the law. If these steps are not taken, they cannot provide the UPA-service.

#### **Personal Contract of UPA**

UPA-contract can be of two kinds: A contract between the user and an independent party that has made a cooperative contract with the municipality or between the user and the municipality, if the user wishes to manage the service himself.

### **The Work Contract**

The work contract is made between the manager of the service and the assistant hired to do the work and states the wages, the work arrangements, the rights and obligations of the assistant. The user has to approve the work contract.

## Ten points about UPA

1. Everyone that legally lives in Iceland and the law nr. 59/1992 applies to, can apply for UPA. That law deals with the matters of disable people.

In the second clause of the law that deal with the matters of disabled people, is stated that the law applies to people which has a mental or physical disability and because of those reasons need special services and support. These disabilities include reduced mental growth, mental illnesses, physical disabilities, sight-and hearing disabilities. The disability can furthermore be caused by long-term illnesses or accidents. In this document is assumed that everyone that falls under this definition is able to apply for UPA.

Here it is needed to point that the law regarding matters of the elderly applies to persons age 67 and older. The elderly is offered many kinds of services on the basis of the law, because of various physical and mental restrictions due to their age. It is important to point out that people over the age of 67 must, like any other, fall under the law regarding matters of disabled people to be able to apply for UPA. In order to determine which law applies to that particular person, it is possible to check whether that person fell under the jurisdiction of the law regarding matters of the disabled before the age of 67 or not. If he did it is fairly reasonable that he continue to fall under that jurisdiction in spite of his age.

Those under the age of 18 are not legal adults and therefore their guardian must apply for UPA on their behalf. It is important to keep in mind during the whole application process and during the realization of the service that children are entitled to certain rights, and are individuals independent of their guardian, like it is stated in several clauses in the law of children rights. When the individual reaches the age of 18 and is a legal adult, it is important that the UPA contract be renewed, that way the contract is made with the user, not the guardian.

- 2. Application for UPA should be filled out in a written form and handed over to the social service of the municipality, where the applicant lives. In the 5<sup>th</sup> clause of the law regarding matters of the disabled is stated: "The municipality where a disabled person lives decides about the services to this person according to these laws, unless something else stated or other laws are applicable." This main rule is withheld here and it is assumed that the user, or his guardian on his behalf, will apply for UPA to the social service where the applicant lives.
- 3. After the application has been received, a team of professionals from the municipality or the service area should in cooperation with the applicant and possibly his consultant make an assessment of the need of support, if such an assessment has not already been done.

This is based on the 5<sup>th</sup> clause of the law regarding matters of the disabled. There it is stated that the municipality should operate a team of professionals that evaluates the total need of disabled people for services and how it is appropriate to meet their needs. It is also stated there that the team should operate in full accordance with the individual and that the assessment should be based on official standards. The outcome of the assessment does not involve an actual administrative decision but the municipality at hand should take the decision based on the assessment. The user can either ask for a revised assessment or denounce the decision taken by the municipality, if he feels that his right has been broken.

It is assumed that with applying for UPA and during its assessment the procedure will be similar to the description in the law. It must be emphasised that the teams, mentioned by the law, should include persons well aware of the ideology of independent life that is the basis of UPA-service. In the process of applying, it is important to discuss with the applicant what expectations he has to the services of UPA and how it is possible to meet those needs. It must also be emphasised that there will be a good agreement about the assessment regarding the need of support, which will be used to determine the number of work-hours. At this stage, when no structure of laws regarding UPA exists, it is not possible to start UPA-service unless both parties accept said assessment.

In the assessment it is important to keep in mind, that it is essential in the making of individual contracts of UPA, that the contracts should be realistic and serve the real needs of the user. A contract that does not serve the needs of the user will lead to a double system which is uneconomic. The user will be forced to seek assistance elsewhere, in addition to the assistance he receives via UPA. It is important to approach the assessment as it were a personal assessment of the user.

It is important that the user has access to a third party counselling and assistance during the assessment, this counselling should come from someone that the user trusts and knows. The possibility of such counselling and assistance insures equality, because it is clear that the applicants can be differently abled to participate in the assessment. It is appropriate to point out the law regarding the safety of disabled people's rights in this context, but there it states the right of the disabled to appoint their spokesman.

4. When the assessment of support need is ready, the user and representative of the municipality should make a signed agreement of the number of work-hours of the assistants that the user can hire. The work-hours should be determined for a month time, with an average workload per month, but the user is allowed to move his hours between months within the calendar year.

Now it is time to determine how many hours the user needs in support on the average per month. This number of hours determines the amount of money that the user has to hire people.

It is important to keep in mind that during this process, the assessment of the support need must be the basis of this agreement, not the financial capacity of the municipality. The agreement of work-hours must reflect completely the need of the user for support, in order to be able to live an independent life. It is not an option to offer reduced UPA, compared with the work-hours agreement.

The agreement of work-hours should be signed by both parties. The process cannot continue without this agreement. This number of work-hours which has been appointed to the user is the basic size, which the user can use to take the next steps and begin to hire people. The funding that comes with each work-hour will be paid by the municipality, according to the personal contract of UPA, to the correspondent party that handles payments to the assistants and manages other duties, which will be discussed later.

The agreement states the average number of work-hours per month. The user is allowed to move certain hours within the calendar year, to meet different level of stress in his life.

5. Certain payment comes with each work-hour. 85% of that payment should be the salary of the assistant, 5% should go to the user as compensation for the assistant and 10 % goes into managing. It is recommended that for each hour the payment should be 2800 isk. It is authorized to add to the payment for the cost of a specialist in a personal contract, according to an especial agreement.

In this article will be listed how much money comes with each work-hour and how that money is divided into different categories.

It has been suggested that the total amount should be 2800 isk. per work-hour. This amount is comparable with the daytime salary of a 30 year old worker of the City of Reykjavík which has only completed elementary school and has 3 years of experience, but that salary is 1351 isk. Also added to this sum is 33% evening overtime and 55% night overtime, with 90% holiday overtime. When the added cost of salaries and managing cost has been taken into account, including cost of an assistant, this number goes up to 2800 isk.

85% of the total amount is to be the salary of the assistant or 2394 isk. Included in this sum is all salary-related cost. This is an equalized number, taking into account evening work, night work and work during holidays. It is clear that in some instances the work of the assistant will not involve such diverse work-hours. For example some personal contracts would only involve work during the day. Then this sum would be lowered accordingly.

Then the 5% of the amount or 141 isk. of each work-hour should be a payment to the user to cover his cost of having an assistant. Such cost can be varied, because it is clear that the assistant must follow the user in his everyday life.

Finally the 10% of the amount or 282 isk. of each work-hour will go into managing cost. This managing cost includes paying salary, finding employees, insurance cost, accountancy, making the yearly audit, organizing the work schedule, arranging for substitutes and managing other things related to the workforce. Then this amount should also go into educational instruction for the assistants and the users.

Some users might need the part-time assistance of experts or specialists, so they can lead a normal independent life. An example of such service would be a translator of sign-language. It is authorized in such exceptions to make an especial arrangement of such specialist assistance, which can be categorized into special clauses-section of the agreement of work hours. That particular sum can then be added to the personal contract of UPA to meet expenses that arise from such services.

- 6. The assistant or assistants should now be hired to work for that number of work-hours in question. The user then has two choices:
- a. He can seek an independent party to provide the employees and take care of managing them. The user then will make a personal contract of UPA with that party. The cost managing will then go to that party and the assistants will be paid by them. That independent party must have made a cooperative contract with the municipality or the service area, about managing such service on the basis of work permission.

b. He can himself manage the search for assistants, the process of hiring them and managing their affairs. The personal contract of UPA is then made between the user and the municipality, the managing cost then goes to the user.

The municipality shall always offer counselling during this process, if the user wishes so.

The personal contract of UPA will be valid for 24 months and should be revised when needed.

The payments from the municipality or the independent party that manages the service commence when the personal contract has been signed. Other services with the user will then be cancelled, if UPA replaces those services.

At this stage the personal contract of UPA should be made, the assistants should be hired and the service should commence. Here are two choices available: The user can choose to make an agreement with an independent party that the municipality has made a cooperative contract with, about hiring assistants at the salary already mentioned and for that number of workhours agreed upon and managing the affair. The managing cost then goes to that party and that party is considered the work-provider. Otherwise the user himself can handle the hiring and the management. The managing cost then goes to the user and the user himself is then considered the work-provider.

In both cases the municipality should provide counselling, if so is wished. In the first case, where an independent party is chosen to manage the affair and be the work-provider, the personal contract of UPA should be made between the user and that party where the rights and obligations of each party are defined. In the latter case, where the user himself chooses to be the work-provider and manage the affair, the personal contract of UPA is made between the user and the municipality.

In this document it is recommended that the personal contract of UPA should be valid for up to 24 months, like mentioned in the contract, and those partaking in the contract can ask for a revision when needed.

When the personal contract of UPA has been signed, the payments should commence according to the contract, to the party that handles the affair. It is important to prepare well for this moment. When this stage has been reached, other services of the municipality for the user will be cancelled according to the agreement, if the services of UPA replace said services.

It is important to have a good agreement and understanding between the user and the municipality about how this change in services is done. The user might need some space to adjust to the changes.

If the individual needs a service or if he has enjoyed some services provided by the state, an agreement should be made on the basis of a declaration of will with the State institution or the Ministry in question about making the service part of UPA. It is especially important to reach an agreement about the service of the disabled in their own homes and this refers primarily to home-care. Services offered to the disabled to help with studies in secondary school or university, and on the job-market are also important. Work has begun on making a declaration of will with the State.

7. When the assistants have been found, the manager of the affair makes a hiring contract with the employees, whether it is an independent party or the user himself.

The hiring contracts state the rights and obligations of the assistants, the amount of work, their shift schedule and salary, the notice of termination and other matters which are appropriate to mention in such an agreement, both from the aspect of normal rights and obligations in the work market and also from the personal well-being and needs of the user.

No class-related contracts of assistants exist, but they will surely be made in the future, when the class of assistants has established itself. Until that time the employers need to rely on hiring contracts exclusively and on the class-related contracts of similar working classes. It is clear that in the hiring contract must be taken into account the especial work environment. For example it is likely that assistants must work so-called "sleeping" night shifts, but few other working classes need to do that. Things like that must be included in the hiring contract.

8. The user is always the work manager. No one should be hired as an assistant against the will of the user. No hiring contract is made with an assistant without the agreement of the user or his guardian. If a close relative is hired as an assistant the municipality should make sure that the relative is hired with the full agreement of the user.

In this article some fundamental matters of the UPA are emphasised, that must be always kept in mind. The ideology that is basis of the service is the ideology of independent life. With UPA, the disabled will acquire a tool to govern their own life. While preparing and executing the service this goal must not be forgotten.

Here it is first of all reaffirmed that the user is the work manager. That means that the user himself decides what he wants to do during the day and how he wants to utilize the assistance of the assistants. Although it is clear that some difficult issues might arise. Those individuals that will apply for UPA will without doubt be differently abled to manage this workmanaging role and take independent decisions about their lives. However it is the will of the board of the project that the municipalities will try to interpret this skill in a wide context when deciding whether to offer that individual UPA service. It is clear that some will need support to express their will. Because of those reasons it is stated in the 5<sup>th</sup> clause of this manual that it will be possible to buy such extra services through additional funding, to hire an interpreter of sign language or a physical therapist, for example. Others might need the assistance of their next of kin to express their will and to be able to be work managers. When taking this item into account, the municipalities should at least be open to that the users might have different ways and methods to take care of their work-managing role.

Secondly it is stated here that no one should be hired as an assistant against the will of the user and that no hiring contract should be made with an assistant unless the user, or his guardian, accept that contract, because such an agreement is supposed to meet the needs of the user exclusively.

Thirdly it is considered right to put forward the disclaimer regarding the matter of hiring assistants which are close relatives. If close relatives are hired as assistants, the municipality should make sure the hiring is made with the full agreement of the user. Such an obligation is also transferable to an independent party, and that agreement of transfer should be mentioned in the cooperative contract with the municipality.

9. Assistants and users should complete a short seminar about their obligations and rights.

To make sure that UPA works well, it is important to invite the assistants and the users to attend a seminar. The board of the UPA project will make sure, in cooperation with other parties, that such seminars will be offered. It is also important to educate the staff of the municipalities about the goal and implementation of the UPA service.

10. The manager of the affair should turn in the yearly audit to the municipality, once a year, where among other things it is stated how many work-hours were completed. The municipality should supervise that the UPA service is realized according to the agreement of work-hours.

In order to make sure that the municipality can manage the task supervising, it is necessary that the manager of the affair, whether it is the user himself or an independent party, turn in an audit once a year. In the audit it is important to state how many assistants were hired and how many hours they worked. The municipality should especially make sure that the amount paid into the UPA service, has all gone to pay for those work-hours completed, but not into paying for other unrelated things. More information should be stated in the cooperative contract between the municipality and the independent party about this yearly audit, and also in the personal contract with the municipality, if the user himself prefers to be the manager of the affair.