Summary

Success or disaster? Developments following the establishment of the statutory right to user-controlled personal assistance (UPA)

The report describes key developments in user-controlled personal assistance (UPA) after the right to UPA was established by law in 2015. UPA is an alternative way of organizing the (conventional) municipal services of practical and personal assistance, and the new legislation meant that some groups with disabilities could now claim the right to have these services organized and delivered as UPA when the need for assistance is comprehensive. We first comment upon overall findings before presenting results for individual questions.

UPA is a small service compared to other services in the health and care sector. Whether UPA is described as a success or disaster depends on who you ask. This report does not include user interviews, but earlier research by Ervik et al. (2017) has shown a high level of user satisfaction. Although user organizations demand a more generous level of spending, from a user perspective UPA contributes importantly towards independent lives and participation in community life.

While the UPA-scheme is contested, neither organizations representing users, nor the municipal sector will unequivocally characterize the scheme as a success or a disaster. The research group behind this report has previously described the statutory right to UPA as a conditional success, and the development in the number of users and allocated hours in recent years indicates a similar conclusion. In addition, it is still the case that variation in allocation practice and in the considerations of appeals, may indicate that regulations are not considered clear enough. UPA-users on average are provided more hours than in comparable health and care services. The data analyzed here document a significant increase in costs, which several municipalities find problematic.

A potential transfer of responsibility for UPA from municipality to state can remedy several challenges with the current scheme but can also lead to new ones. State responsibility is e.g. likely to provide a greater degree of equality and less unequal treatment but can at the same time lead to increased standardization at the expense of individual needs. Different expectations from users and municipalities can probably explain some of the diverging views on how UPA works. Inherent tensions in the UPA scheme have not disappeared as the scheme is becoming more established (Askheim 2019).

In the report, we have used official data registers such as IPLOS and KPR for data on the number of UPA users, hours, diagnoses, etc., and Nestor for the scope and outcome of complaints. In addition, we draw on interviews with informants in selected municipalities, county governors' offices, interest groups, KS (the Norwegian Association of Local and Regional Authorities), the patient and user ombudsman and a trade union. We have also benefited from a survey that KS conducted in 2019 and made available for this project.

The report answers the following questions (in bold):

How has the statutory right affected the number of users and the scope of UPA decisions?

At the beginning of 2014, the number of UPA users was 3014, and by the end of 2019, the number had risen to 3600. A growth of 20 % after the introduction of the statutory right does not represent a clean break with the 19 % growth seen in the five-year period prior to 2015. Although the percentage growth is quite high, the growth of approx. 600 users is significantly below the estimates which were

made in connection with the preparations for the establishment of rights. The growth in the number of hours allocated, on the other hand, shows a sharp rise (47 %) in the period 2014–2018. The average number of hours per week per user has increased steadily from 22.9 hours in 2009 to 36.6 in 2019. A cautious conclusion is that the establishment of rights has not resulted in significant changes in the number of UPA users, but the number of hours allocated to users (on average) has increased significantly following the establishment of statutory rights.

The municipal informants reject that the increase in hours after 2015 is related to the establishment of rights alone. Instead, they point out that the number of hours has increased as users have needed more assistance over time.

The development of UPA-related costs for the municipal sector

The growth in costs in the years 2014–2018 is around 56 %. Costs are largely driven by growth in allocated hours, which increased by 47 % in the period. Depending on the wage costs per hour, costs increased by 1,146 billion kroner in a «low cost scenario» to 1,262 billion kroner in a «high cost scenario».

In this report, the cost development is calculated on the basis of observed increases in hours and on data on hourly labour costs for assistants (including social expenses), which we have obtained from interviews with municipal officers and from a survey conducted by KS in 2019. The large spread in hourly wage rates complicates the cost assessments, as does the fact that some municipalities solely use their own employees for UPA services, other municipalities only use private providers, while yet other municipalities use both private and municipal providers. Municipal hourly wage rates are somewhat lower than the wage rates municipalities negotiate with private providers.

We have found large differences in the average number of hours in the municipalities. Whereas the "most generous" of the largest municipalities provides an average of 2886 hours per user per year, the "most reserved" gives 1566. However, it is not always true that the municipalities that appear to be "reserved" in hours are reserved regarding growth in the number of users. It may well be that municipalities with low average hours more often give UPA to users who do not meet the required number of hours needed for the unconditional right to UPA, while those with high average numbers to a lesser extent give UPA to users who do not meet this criterion.

In any case, these figures can be seen as expressions of different priorities. Generous municipalities can raise the list for what is considered a good and acceptable UPA scheme among existing and potential users of the scheme around the country. The problem with contagion effects is that the municipalities that are perceived as "reserved" assign the right to UPA and deliver hours in accordance with what they perceive the scheme opens up for. The same can be said for municipalities that "raise the list". One of the main challenges with the establishment of a right to UPA, is thus that the perception of what the scheme should entail differs, both among the local authorities that administer the scheme, among politicians locally and nationally, and between users. It is therefore no wonder that users end up with very different expectations, and requirements, for the scheme.

What diagnoses do UPA users have?
Diagnoses in connection with disorders of the nervous system and musculoskeletal system are the most common among the users in the sample. The figures indicate that many users have several, partly serious and complex disorders, which will result in the need for a high number of hours. Close to 40 % of UPA users have comprehensive needs for assistance.

Do the municipalities experience that hours are equally provided to UPA as to comparable health and care services?
The municipal informants claim to strive for the same measurement of hours for UPA users as for users of ordinary services. Nevertheless, they declare that UPA users on average are provided more hours. Their own explanations are partly that UPA users on average are younger than users of ordinary services. Hence, they have a higher level of activity, which in turn results in more hours. Furthermore, UPA users generally have more extensive needs than recipients of ordinary services do, and if the weekly need for assistance is low, it is difficult to find a workable way of organizing UPA. UPA users also appear to be relatively resourceful, and they benefit from interest groups and private UPA suppliers who help them argue for more hours.

The most challenging part of the scheme seems to be ambiguities about what the UPA scheme should cover. Informants find it difficult to gauge UPA hours on equal terms with ordinary services as long as the latter is restricted to providing sound health- and care services while the aim of the UPA scheme is to give users the prospects of more independent lives and to participate in community life.

Does the municipality provide UPA to users who have round-the-clock and care services?
Municipalities in our study have had limited experience of providing UPA to people living in co-located homes with shared staffing. Municipal representatives say they will consider applications from people living in such housing facilities on an equal footing with other users who do not live in an institution. The municipalities envisage problems related to overlapping services and a waste of labour resources.

To what extent is the use of welfare technology an issue when hourly needs are to be assessed?
The use of welfare technology can be included in the assessment of hours and can thus reduce the number of hours allocated. The municipalities in our study seem to have different experiences with the use of welfare technology, so issues related to technology and assessment of hours for UPA vary. Welfare technology so far has limited importance in the assessment of hours.

What is emphasized in the County Governor's assessments when reversing a decision?
For the period 2012–2018, the relative scope of complaints for the BPA scheme (4.5–5.7 %) was higher than the total scope of complaints for health and care services (<1 %). The most common reasons for appeals are lack of allocation or low allocation of hours. The municipalities' decisions are confirmed in most cases. Where the user’s appeal is fully or partially upheld, the offices differ regarding whether the cases are canceled and returned to the municipalities for reprocessing, or whether changes are made to the decision given by the municipality. We find that these judgements have changed within the same office over time. Furthermore, when it comes to what should be included in UPA, e.g. about activity outside the home, there are variations in what different county governors emphasize. To some extent, this may be a result of offices emphasizing different sources of law in their work, and that there is minimal cooperation between them to ensure equal judgement.

The patient and user ombudsman linked the variation between municipalities in the handling of UPA cases to cultural and attitudinal differences. The broad "mandate" for the scheme given by the Storting creates challenges for municipalities with regard to deciding what provides sufficient assistance to ensure equality with non-disabled persons.

All in all, this may indicate that the complaints speak less of the situation in the municipalities and more of unclear regulations that open up for problematic differences.

What will be the consequences of moving the responsibility for UPA from the municipalities to the state, e.g. as a standardized service or an allowance from NAV?
The consequences of giving the responsibility for UPA to the state depend on how the state will organize and administer the scheme. Nevertheless, it is likely that state responsibility will lead to an increased degree of standardization and thus greater equality in the service provision across the country. This is not necessarily to the benefit of the users because standardization would also mean less attention to individual needs. Users who do not meet the requirements, e.g. those who do not meet the minimum requirements for hourly requirements to be entitled to the scheme, may lose out if the UPA scheme is handed over to the state.

Potential benefits of the state taking over the responsibility are that the service content becomes less dependent on where the users live, less focus on healthcare and more on community participation, and fewer conflicts and disputes about the ways in which UPA is practiced. Potentially negative consequences are that the state will not necessarily be more generous in its allocation practice and that state responsibility for UPA may be an incentive to move costs from municipality to state. Furthermore, the state will not have the same ability as the municipalities to see different services in context. The result can be a less flexible scheme.

Regarding costs, the municipality will reduce its expenses if the state takes over the responsibility and the financing. Whether the overall costs will increase depends on several factors, e.g. whether the allocation practice will be significantly different from the current practice.