Summary

Social support: choices of clients and local policy

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Summary

This dissertation examines the three main options available to people with disabilities in the process of choosing social support: (1) whether or not to make use of support; (2) whether to opt for informal or formal support or a combination of the two; and (3) whether to receive support in kind or in the form of a personal budget. These options and choices were investigated in five studies:

Non-use of support

For this study, 14 respondents with severe physical disabilities were interviewed. In a previously held survey they reported to be unable to manage adequately in at least one domain of life (maintaining a household, travelling, meeting other people and/or participating in activities). Previous research indicates that the main reasons for non-use were related to thresholds, such as a lack of information or having difficulty with forms. In this research we found additional reasons such as causes of psychosocial nature, a complex personal situation, ambivalence regarding the need for support and negative previous experiences with applying for facilities. In many cases, a complex combination of reasons was found to lie behind their non-use of support services. Another group of respondents consisted of people who consciously do not apply for services. Their reasons for not applying are related to having a private aid, wanting to remain independent or not desiring to participate anymore in society. Local authorities can benefit from these findings by being aware of the complexity of personal situations, by gaining trust of the persons involved, by identifying the question behind the question and by providing clear information on time.

Choice between informal and formal support

Care and social support in Europe are increasingly being devolved to the local level because local authorities are assumed to organise this more effectively and efficiently. In the Netherlands, local authorities are responsible for offering citizens the social support they need. They have policy discretion to decide how and to what extent they encourage and support the use of informal help. This article explored whether the local policy focus on informal or formal help influences the actual take-up of help in the household. We expected that a stronger policy focus on informal help, would be related to more use of informal help and less use of formal help. Data on 567 people with a physical disability who use informal or formal help in the household were linked to local policy data in 167 municipalities. We performed multilevel multinomial regression analyses. Since we expected that local policy will have more influence on people with slight or moderate disabilities, cohabitees and people aged under 75 than their counterparts, cross-level interaction terms were included between characteristics of local policy and of individuals. The findings reveal differences between local authorities in their policy on support. However, we were unable to establish a relationship between local policy and use of informal or formal help in the household.

Choosing a personal budget to purchase social support

Since the Wmo came into force in the Netherlands, it has been possible to apply for a personal budget to pay for individual provisions such as wheelchairs, transport and home provisions. In the Wmo the personal budget is anchored in the law.

Based on face-to-face interviews with 4,073 applicants for provisions provided under the Wmo (in 81 Dutch municipalities), a study was carried out to determine if applicants chose a personal budget and also whether or not the possibility of a personal budget was discussed during the application. The study then looked at whether the differences found in domestic help (for which it has been possible to obtain a personal budget for around 15 years) are the same as the differences found for individual provisions (for which a personal budget has only been possible since the introduction of the Wmo in 2007). People with severe impairments, people aged up to 54 years and people with a higher education level were found to choose a personal budget more often than people with no more than moderate impairments, people aged over 75 years and people with a lower education level; this echoes findings from earlier research.

Only one difference was found between the types of support involved: people with severe impairments report more often that the possibility of a personal budget had been discussed with them during the application procedure for domestic help than for individual provisions. Interestingly, the presence of (long-term) psychological disorders was found to have no influence on the choice, nor on whether or not a personal budget was offered (for both types of support).

Choosing a personal budget: do differences in local authority policy lead to inequality of access?

Dutch local authorities have a statutory duty to offer people who apply for support a choice between receiving support in kind or in the form of a personal budget, but are free to set their own policy regarding who is offered a personal budget and how attractive the personal budget option is. This policy freedom may manifest itself in how actively local authorities inform applicants about the possibility of a personal budget, the level of personal budget rates and the support local authorities offer in administering the personal budget.

Earlier research has focused mainly on the characteristics of personal budget-holders (the micro-level). The present study not only considers the impact of those individual characteristics, but also investigates what impact differences in the policy on personal budgets between local authorities (the meso-level) has on how well informed people are about personal budgets and on the extent to which this form of support is chosen. In a structured face-to-face interview, we interviewed 1,026 applicants who had been ruled eligible for domestic help. Choosing a personal budget was an option for these applicants. The applicants lived in 70 municipalities for which we also had policy data, and we were therefore able to relate the data across the municipalities. Since we used a clustered sample (first selecting municipalities and then applicants within them), multilevel analyses were performed.

Older persons and people with a sudden onset disability were less often informed about the possibility of a personal budget than younger people and people with a gradually deteriorating disability. Higher educated people were more often informed than low-educated people. Other characteristics at individual and policy level had no influence on the extent to which people were informed about the personal budget. The degree to which people opt for a personal budget is explained mainly by the degree to which applicants were informed about this possibility. The inequality in choosing a personal budget between local authorities could be reduced relatively simply, by ensuring that people are properly informed.

Impact of personal budgets on independence, participation and quality of life

Personal budgets have been introduced in many European countries over recent decades. The assumption is that people with a personal budget are able to purchase care that matches their needs more closely and therefore experience greater independence and improved well-being. The question is whether this assumption is true. Little research has been carried out on this to date, and the research that has been carried out is hampered by methodological limitations.

Propensity score matching with multilevel analysis was used in an observational study to investigate whether people with a personal budget experience better independence, participation in society and quality of life than comparable people using conventionally organised help.

After the matching, no significant effects of the personal budget were found.

There may be several reasons that we did not find any effects. First, there are simply no effects. It may also be possible that, for some recipients, organised help is just as 'customised' as it would be with a personal budget. A personal budget need also not always mean customisation; for example, it is not always possible with a personal budget to find someone who is able to come at precisely the desired times and perform exactly the desired tasks. The study could be expanded methodologically, among other things by also looking at the number of hours' help received and studying more subgroups.

Conclusion and discussion

The studies show that differences in local authority policy have virtually no influence on the choices made by people with disabilities. One exception to this finding is the degree to which local authorities inform applicants for Wmo support about the possibility of a personal budget. We regard the fact that many applicants were not (clearly) informed, that there are systematic differences across local authorities in how well informed applicants are, and that this influences access to support, as an unintended consequence of the Wmo. This is a problem which local authorities could do much to improve.

The fact that personal budgets were found to have no effect on the independence, participation and quality of life of people with disabilities does not alter the fact that in individual situations a personal budget can be of great value.

The strengths of this research are its policy relevance, the combination of a range of analytical methods and techniques, and the linking of policy data to client data. Each of the studies also has limitations, mainly relating to the data collection. The data used were drawn from individual studies of the first and second Wmo evaluations and were not specifically designed to answer the questions addressed in this dissertation.

Future research could focus on the actual interaction between consultants and citizens, something about which little is known in the context of social support. The research on personal budgets could also be expanded to include other forms of support besides household help, since the type of support needed can influence the choice between receiving a personal budget and support in kind. It is also important to investigate which subgroups benefit greatly from the personal budget and to involve sufficient numbers of respondents from these subgroups in the research.

Further research could look in more detail at the precise mechanisms which determine choices or behaviours with regard to support. For example, what (extensive) judgements are made, who makes them and when, and for whom and on which aspects do third parties make decisions on behalf of others? How satisfied are people later found to be with the choices made?

The findings of this dissertation that (differences in) local authority policies have little or no impact on the choices made by people with disabilities throws into question the assumption by policymakers that local authorities are better able to deliver personalised care. More extensive research would of course be needed to be able to answer this question.